

**Narratives of Young People
Living with a Diagnosis of
Chronic Fatigue Syndrome /
Myalgic Encephalomyelitis (CFS/ME)**

Wendy Solomons

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Abstract

CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) is a distressing and potentially debilitating condition. It can also be understood as a contested condition, surrounded by controversy about its nature, causes and treatment. Previous research indicates that those affected experience this climate of contestation as a troubling and discrediting assault, not only on the nature of their condition, but also on their identities. However, little attention has been paid to the voices of young people living with CFS/ME.

This thesis extends a relatively small literature in new directions, focusing a constructionist, discursive narrative lens on the accounts of ten young people (aged 13-18) living with a diagnosis of CFS/ME. Narratives constructed during repeated interviews over a year, and drawing on multimodal materials collected by participants over that period, were analysed for their content, structure and performance, with reference to the local and broader contexts of their production.

This analysis demonstrates that teenagers construct rich, multi-layered narratives with the potential to enhance understanding of their situation and broader features of the social world. As they speak of the onset of illness, attempts to live with enduring, unpredictable symptoms and their psychosocial consequences, and (for some) the possibility of “moving on” from the worst of illness, this analysis throws new light on how young people’s narratives can be understood as simultaneously constructing the condition (“M.E.”) and the identities of those involved (“me” and others), in ways that engage with, reflect and resist prevailing discourses.

It is argued that the discursive contexts of CFS/ME and adolescence raise particular challenges for young people as they try to construct credible narratives that convey the full extent of their difficulties, while resisting stigmatising identities (eg, as “complaining”, “lazy” or otherwise “not normal”). This analysis highlights implications for them, their families and those who work professionally with them; and for the ongoing social construction of CFS/ME in young people.

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**“Stories have to be told or they die, and when they die, we can’t
remember who we are or why we’re here.”**

Sue Monk Kidd, “The Secret Life of Bees” (2001)

**“...I’m just a soul whose intentions are good;
Oh Lord, please don’t let me be misunderstood”**

“Don’t let me be misunderstood”

Benjamin, Caldwell & Marcus / Nina Simone (1964)

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Chapter 1

Introduction

1.1 Locating the project

This research is about young people who are diagnosed with a condition known as Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (or Encephalopathy) (CFS/ME). It arises from a concern with how health and illness come to be understood, experienced and responded to within societies: the forces shaping this, and the multiple implications for those who live with, or work alongside, conditions of bodily distress. In particular, it relates to a concern for those whose embodied experiences are not easily understood within currently-accepted medical frameworks, and ways in this is responded to.

1.1.1 A framework and a lens: Social constructionism

The broader project is located within a theoretical framework of social constructionism, a set of theories of knowledge that consider how we come to “know”, understand and respond to the world around us. Though the work of Berger and Luckmann (1966) forms a landmark, input and development over time from multiple disciplines means that there is no one agreed definition, but a “family resemblance” (Burr, 1995, 2003; Gergen, 1985) of orienting features. These include the adoption of a critical or questioning stance towards “taken-for-granted” knowledge about “the way things are”; questioning assumptions that knowledge is a simply representation of underlying phenomena; viewing knowledge instead as constructed by the social interaction between people and groups within particular historical and cultural contexts; and attending to ways in which constructed knowledge is central in determining further social actions.

The implications of this type of analysis are critical in understanding issues of suffering and social inequality. If our understanding of “how things are” in the world is not simply a

consequence of “what is” (Gergen, 2015), there is room to consider *why* or *how* particular understandings become dominant in different settings; how different constructions impact on different members of society; who this might be dis/advantageous to; and importantly what *could be* - that is, whether alternative constructions might be brought to bear, and how these might create new possibilities for living at personal and societal levels. The current project will explore how contemporary constructions of illness contribute to the suffering of those living with a condition known (among other things) as CFS/ME, and the ways in which this is reflected in the narratives given by young people (YP) living with this diagnosis.

Constructionist approaches attend particularly to the power of language in constructing “knowledge” of the world, such as defining situations or behaviours as “natural” or “deviant”, and how this can act as a form of social control (Fox, Prilleltensky & Austin, 2009). The notion of knowledge as a form of power has focused attention on institutions such as the medical profession, whose preferred constructions are widely disseminated and attended to. Analysis has highlighted implications of these professional discourses for the legitimisation of societal practices (eg, medical interventions, public health policies, legal proceedings) as well as people’s behaviours, subjective embodied experience, and identities (Foucault, 1975, 1977, 1980). However, Foucault also draws attention to ways in which such “power” does not simply emanate from institutions, but circulates through the practices and discourse of everyday social relationships. Reflecting this focus, this project is also influenced by schools of symbolic interactionism in exploring how individuals participate in the construction (or “making sense”) of their own social worlds, including the construction of “self” or identity, through their talk and other social actions (Goffman, 1959, 1963).

1.1.1.1 The social construction of “adolescence”

An example relevant to the current project is our understanding of “adolescence”. This depiction of a period of “growing up” dates back as least as far as Roman times, and is commonly linked to “natural” biological changes associated with puberty. A range of states and behaviours (eg, mood swings or “risk-taking”) are then attributed to this, in everyday social interaction (“it’s his hormones!”), media representations and academic discourse

(eg, endocrine, neurobiological and psychological theories)(Sercombe, 2010). However, consideration of different times, places and cultures shows that “adolescence” has been understood as applying to those as young as 10 and as old as late 30s (ie, beyond physiological puberty), with changes reflecting broader societal pressures (eg, need for workforce or military recruits, birth/death rates). Further, the sanctions or condoning of different behaviours vary in parallel (eg, changes to ages set for criminal responsibility or sexual consent.) As such it can be argued that “adolescence” is a social construction fashioned according to the needs of the mature adult population, with implications for social action (Graham, 2004). Some consequences of contemporary constructions will be considered in this research for YP living with symptoms of CFS/ME.

1.1.1.2 The social construction of illness

Though the project will consider implications of a range of social constructions (eg, gender, “adolescence”), its main focus is on the *social construction of illness*. At first glance, this may appear counter-intuitive: surely illness is simply a consequence of biological disruption - the “brute facts” of the world (Searle, 1995)? One way in to this debate (sometimes understood as a “light” form of social constructionism) has been to distinguish between *disease* (a biological condition) and *illness* (the social meaning of the condition) (Eisenberg, 1977). Even for those who hold that disease is simply a physical reality, it can be seen that different illnesses have particular social and cultural meanings and associated metaphors, ascribed differently at different times. For example, Sontag (1978) notes widespread metaphors of cancer as “evil” or repressive within the US, and subsequent research has tracked the rise of military metaphors in the “fight” against cancer (Reisfield & Wilson, 2004). While these cultural associations can position sufferers as “brave” in their “fight” (alongside the powerful “armaments” provided by doctors and pharmaceutical companies), such metaphors may bring additional burden for those deemed to be “failing” in this fight (*ibid.*). It may also be unhelpful for cancer prevention programmes, since the adoption of behaviours such as reducing smoking or drinking does not fit with cultural concepts of *fighting* cancer (Hauser & Schwarz, 2015).

Relatedly, illnesses differ in the extent to which they are stigmatised (Bird & Conrad, 2010). While some patterns can be discerned in what is stigmatised over time (eg, sexually-

transmitted infections, mental health problems), a constructionist standpoint emphasises that there is nothing inherent about a condition that makes it stigmatising; rather it is the cultural meanings that become attached to the condition and its consequences, or sometimes the individuals most commonly affected (eg, women, minority groups), that lead to a condition becoming stigmatised.

However, while acknowledging that illness has both biomedical and experiential features, the conceptual distinction between what is “real” and what is “constructed” has been criticised (eg, Timmermans & Haas, 2008). There is increasing recognition that medical knowledge itself arises from a particular social context (Conrad & Barker, 2010), so even our understandings of *disease* - what qualifies as biological and is thus labelled - is socially contingent. Consideration of the very real consequences for those diagnosed (Freidson, 1970), particularly where these may perpetuate suffering or reinforce structural inequalities (eg, in denying welfare payments to those without currently-diagnosable medical conditions), has focused attention on how medical research and definitions of health and illness are susceptible to the interests of certain interested parties or groups (Conrad, 2005; Horton, 2015). For example, the development of a new diagnostic category, Attention Deficit Hyperactivity Disorder (ADHD) during the 1990s - and rapidly-expanding levels of diagnosis of the “disorder” in children subsequently - has been questioned by critical psychiatrists. While questioning the evidence-base for such a disorder, they also note that conceptualising certain behaviours as health problems individualises suffering (thereby obscuring and absolving the role of social factors) and creates new markets (for example in the pharmaceutical industry). ADHD, they argue - like other diagnoses - may be better understood as a social construction contextualised by the interests of capitalist society (Timimi, 2005; Timimi, 2010).

1.1.1.3 “Contested” illness

Constructionist perspectives are therefore useful in exploring processes by which certain conditions come to be medicalised (or not) and responded to differently within society. It is argued that this is particularly salient in understanding conditions that are currently contested. *Contested illnesses* are defined as conditions where sufferers and their advocates struggle to have medically-unexplained symptoms recognised in conventional

biomedical terms, meeting resistance from medical researchers, practitioners and institutions (Barker, 2010; Dew, Scott & Kirkman, 2016; Dumit, 2006). Such illnesses may be dismissed as illegitimate, psychosomatic, problematic or even non-existent (Conrad & Stults, 2008). What is “contested” at any one point in history may change. Currently, conditions such as Irritable Bowel Syndrome (IBS), tension headache, multiple chemical sensitivity disorder, Gulf War Syndrome, fibromyalgia, chronic pain syndromes, and CFS/ME all fall under this umbrella. Though differing in many ways, they are united by heated debate regarding aetiology, pathology or even physiological existence, discussion of the identities of those afflicted, and the distress that results.

Importantly for the current project, contested illness can be understood as arising through, and resulting in, *processes* of contestation - or *practices of critical engagement* (Moss & Teghtsoonian, 2008). Examination of medical texts, policy documents, different forms of research, clinical consultations or personal conversations reveal multiple narratives, multiple constructions of the “reality” of contested illness. So if multiple constructions exist - and some perhaps are heard more loudly, or frequently, or from more trusted sources - how are we to make sense of this?

Social constructionism is sometimes critiqued for its insistence on acknowledging the multiple and co-existent forms of “reality” (in opposition to positivist positions of search for “the truth”). Are all constructions equally valid? It is beyond the scope of the current thesis to enter into sustained debate on this (see Edwards, Ashmore & Potter, 1995; Gergen, 2015; Hacking, 1999). Rather, I will consider how this question can be considered somewhat differently, not simply as an academic point, but as an everyday concern. That is, in contexts where multiple constructions are possible - and where much may be at stake - how can individuals or groups *persuade* audiences that *their* own preferred constructions of reality are not only worthy of attention, but potentially *more* valid, “better” in some way, than the alternatives? Relatedly, how can those who traditionally have less relational power - “patients” rather than professionals, for example, or children rather than adults - assert the authority of their voices over others?

1.1.2 Implications of a constructionist approach to research

In pointing to the socially constructed nature of knowledge, it becomes clear that the presentation of research - such as this Doctoral dissertation - is one such constructive process. Scientific research located within positivist paradigms traditionally works to demonstrate the “truth” of its findings: while competing views (or theories) of the world are acknowledged, it is the role of the scientist to test these to determine which is truly the case, citing criteria such as accurate, objective, replicable observation and statistical analysis to back its claims of neutral universality. By contrast, constructionist approaches to research emphasise the multiple interpretations that may validly be made on the topic of their enquiry, each with potential and limits, both scientifically and for societal outcomes (Gergen, 2015). Further, such approaches emphasise the importance of context in the development of understanding, and the impact of the researcher and research process in generating “data” or “knowledge”. As Silverman (2014:246) posits, “contrary to the view of crude empiricists, the facts *never* speak for themselves”.

The multiple implications of these understandings will be explored throughout this thesis, but three related points should briefly be noted here, as a context for what follows.

First, I expect my thesis - my reading of this particular area of study - to be understood as a partial, context-dependent understanding, leaving room for other valid interpretations. However, as I have just noted, in a world of multiple constructions - where *every* perspective is held to be worthy of consideration - there is a danger of drowning in relativity. Why would a reader plough through or put any faith in a lengthy dissertation if the arguments contained there are “just another view”, no more valid than those espoused by (for example) someone who has given the topic no more than a minute’s thought? I too have to meet an interactional concern to engage an audience, and make a persuasive case that my constructions are, while not the only ones possible, at least plausible and worthy of further consideration. I therefore aim to show throughout this thesis the processes by which I have come to my understandings through a process of research, allowing audiences to decide whether they are indeed credible.

Relatedly, my belief in the context-dependent nature of knowledge construction - including the role of myself as researcher in influencing what evolves - leads to a commitment to reflexivity in my work, and a need to “locate the researcher” in the research. Many forms of reflexivity (or “reflexivities”) have been adopted in qualitative work, to different ends (Finlay & Gough, 2003). Further consideration will be given throughout this work to ways in which this was attended to during the development and interpretation of the project. For now, it leads me to give some orientation to my position (below). It should be stressed that this type of positioning is not an end in itself¹, but a starting point for further exploration of impacts on the research process (Finlay, 1998; Guillemin & Gillam, 2004; Spyrou, 2011) aimed at improving the quality of the project (Seale, 1999). By setting out some of the personal contexts informing my engagement with this project, the aim is to invite audiences to consider how these may be influencing my decisions, my interactions, and my interpretations. Nevertheless, my reflections and self-positionings – in action and outlined below – cannot be viewed as “truth”, nor producing any more “objective” an account of the research, but are subject to the same systematic cultural and personal influences as any other accounts.

Finally, and again relatedly, a brief note on the use of language following from this. Constructionist approaches draw attention to the power of language in constructing particular versions of the world, and thus my own use of language is subject to scrutiny. Some choices are already visible: for example, to use the term “CFS/ME” (rather than, say, “M.E.” or “Chronic Immunodeficiency Syndrome”, which are sometimes used) already positions my work in ways that some would challenge, as will be discussed later. More generally, “I” am already visible. Traditional research texts are written in the third person, arguably a rhetorical device that obscures its context and elevates claims to objectivity and universality.² By contrast, inclusion of the first-person at different points - in line with the

¹ Within a constructionist critique of research methods in constructing knowledge, the process and application of “reflexivity” itself is subject to scrutiny (Burr, 1995). A review of the application of “reflexivity” (particularly introspection) suggests that researcher “confessional” has been used within a positivist frame as a way of “coming clean” about sources of potential “bias”. That is, it can appear to lend extra authority to the assertions of the researcher in a world where the scientific model still holds sway.

² Sparkes (2002) wryly suggests that academics traditionally adopt the position advocated for Victorian children: that is, to be seen (in the credits) but not heard (in the text)...

approach to reflexivity outlined - aims to draw attention to my own role in constructing a contingent account, which is subject to the critical gaze of the reader.

1.2 Locating the researcher

I grew up in London within a White, culturally-mixed family where both parents were affected by chronic and potentially life-limiting illness. Despite this, both appeared “healthy” much of the time. The more dramatic incidents, such as the sudden appearance of an ambulance crew in the house after my father’s collapse into a diabetic coma, or periods of hospitalisation for both, soon faded into the background of my childhood. Seeing parents managing medication, blood-testing and (later) transfusions seemed “normal”. Only the occasional puzzled comment from friends reminded me that other families’ fridges did not harbour insulin bottles, needles and other medical equipment alongside the milk and juice. Illness was not talked about much, and I am not sure at what stage I began to worry about the implications of my father’s poor glycaemic control for his health, or the silent fear of watching him eat the foods I knew were dangerous for him.

One memory stands out though: at around 10 years old, being asked by a disapproving-looking neighbour why my father didn’t cut out these foods and lose weight. It didn’t seem like a simple question, but loaded with accusation. Alongside anger and a confusion of emotions, I felt shame and blame - whether for him or myself I was unsure - and what I would only later come to understand as the stigma associated with some forms of illness.

In my younger years, I was less aware of my mother’s health problems. Short periods in hospital appeared unrelated. It was only in my late teens that I was told of the genetic (and at that time largely untreatable) condition affecting both her and her more obviously-ill sister; and of the uncertainty this created for them, and potentially for myself and my generation as genetic carriers. My indignation at not having been told earlier was met with growing awareness of pressure from the generation above (particularly my grandmother) “not to talk about it”; and her perception of shame at passing on a heritable disease - particularly, perhaps, one associated with being part of a minority ethnic group with a history of marginalization.

Thus even before I had the vocabulary to describe such things, there was an early sense of the moral dimensions of illness. An awareness too that not all illness is equivalent in the eyes of society, with implications for how “the ill” are treated by others, and how they learn to respond. However, those heated arguments with my grandmother also alerted me to how such beliefs are subject to change over time. As an undergraduate student of biochemistry in the late 1980s, my own view of the condition was shaped by a genetic conceptualisation that rendered the condition more understandable, less persecutory; and I found it hard to comprehend why my grandmother would feel such shame at a “random”, unpreventable set of biochemical events. Much had changed, I concluded. However, my confidence in this position was then shaken as I reached my mid-twenties and considered having my own children. Suddenly my personal wish to have children was met with questions about responsibility for passing on genetic susceptibility to future generations, and the spectre of accusatory finger-pointing raised its head again. Yes, beliefs about illness change over generations and contexts; but the personal meanings of such beliefs also change for individuals and families through the life-cycle, I realised.

My academic studies, research interests and later professional training as a clinical psychologist brought me into contact with the world of mental health, where I became increasingly focused on the interplay between physical, psychological and social influences, particularly for people living with different forms of illness. The stigma associated with mental health was clear, not only in public discourses of the “mad, bad and sad” (Appignanesi, 2009), but in the talk of those referred to me within NHS services. My work with those living with HIV, sexually-transmitted infections, chronic pain and metabolic conditions (eg, Sickle-Cell Disease, diabetes) further forced the issue of stigmatised conditions - and stigmatised identities - into the spotlight, and prompted concern with the social processes by which children, adults and groups become positioned as (un)deserving of help and compassion. I began to see how clinical decisions apparently made at individual or local levels, could be seen as reflecting - and perpetuating - broader sociocultural stereotypes and structural inequalities. For example, I was struck by differences in medical readiness to prescribe powerful but potentially addictive pain-relieving medication to different patients, and the way that gendered, age-related and racist stereotypes appeared unchallenged in clinical team discussions.

My concern with the impact of “deserving” and “undeserving” discourses was particularly acute as I began to work with children and adults whose physical health conditions had been considered “medically unexplained”, and particularly the ways in which these were sometimes dismissed by medical professionals as “psychological”. To me, the distinction between “physical” and “psychological” simply didn’t make sense. Similarly, the tendency to locate problems within individuals (“she’s got a low pain threshold”; “he’s just depressed”), rather than considering how they are constructed in relationships located in particular sociocultural contexts, seemed equally problematic.

Further, I became increasingly aware that the stories people tell about their lives have different capacities to elicit empathy and support from others, not simply because of *who* tells them (and to whom), or even just because of the *content* of these stories (eg, about difficult life events). For example, working with victims of sexual trauma, I was disturbed to find that accounts that appeared chaotic, fragmented, with omissions, contradictions or lack of a consistent timeline, were quickly judged as “unbelievable” by police officers. This appeared to ignore the highly traumatic and often confusing context in which the incidents took place (eg, in darkness or intoxication), the nature of traumatic memory and recall (Graham, Herlihy & Brewin, 2014), the intimate and stigmatised nature of what victims had to recount, the language and cultural resources available to the narrator, or the good reasons they might have for withholding some aspects from particular audiences. The fact that these stories did not fit an “ideal” (perhaps that would be recognised by a Court), in structure or performance as well as content, appeared to compound a climate of disbelief. The implications of this, legally as well as personally for those needing their traumatic stories to be recognised, was shocking to me, and led me to question the idea of what constitutes a “good” - or believable, or empathy-drawing - story, whether about trauma, illness or other aspects of life experience.

I am undoubtedly influenced by my training and experience as a clinical psychologist, as well as later training in systemic and postmodern narrative therapies. I also carry an uncomfortable awareness of how my own profession is implicated in the construction of many of the problems I am addressing, not least in defining (or tacitly accepting) what constitutes psychological “disorder” and how it should be managed (Maracek & Hare-Mustin, 2009). My current role in training future clinical psychologists at a University-based

Doctoral programme is strongly influenced by critical and constructionist critique that questions much of this *status quo*. Nevertheless, I am conscious that many, not least those diagnosed and referred with “medically-unexplained symptoms”, will be understandably wary of my position as a clinical psychologist. My decision to enrol for a part-time research Doctorate *outside of* the school of psychology has enhanced my appreciation of different positions, and afforded me an opportunity to approach my research topic and participants as a research student rather than primarily as a clinical psychologist. Nevertheless, tensions remain in this positioning, and there has been a need for ongoing reflection (in supervision and other settings) on the ways in which my professional training has impacted on my engagement with this project - a theme that will be attended to throughout this thesis.

My interest in hearing more from children and young people living with illness arose from my clinical work over two decades, particularly hearing their stories told against the more powerful voices of their doctors, parents and teachers. However, I hear their voices now through the filter of having become a parent myself. I began to formulate this project when my own children were very young, engaged with the participants of this study while my children were in primary school, and at the point of writing, both are now teenagers. Thus my engagement with the ten teenagers of this project and their families is inevitably influenced by my “other role” as a mother, and a changing perspective as I review their narratives over time while my own children approach a similar age.

1.3 Mapping the terrain

Chapter 1 has provided an initial orientation to the current research project, locating the project and the researcher within broader frameworks. Chapter 2 continues this orientation, providing a review of existing literature. This considers how powerful and opposing constructions of CFS/ME have developed, and how these provide a context to experiences and narratives provided by those currently diagnosed with the condition. The review highlights gaps in literature, particularly in the relative lack of attention to the voices of children and young people (CYP), and some methodological concerns. These provide an argument for the development of research with YP living with CFS/ME, within a frame of narrative inquiry.

Chapter 3 develops the case for a particular form of discursively-focused narrative inquiry, and approaches to working with YP diagnosed with a contested condition. It addresses questions of ethics and credibility within such research, and provides detail of the study's methods in engaging ten YP, and interpreting narratives constructed in interviews over time.

Chapters 4 & 5 set out explorations of these young people's narratives with a discursively-focused narrative analysis: first (chapter 4) considering each young person's extended narrative separately; and then (chapter 5) bringing their narratives into dialogue. In exploring major storylines for similarities and differences in their content, structure and performance, this draws out discursive resonances and highlights tensions for YP as they attempt to negotiate a complex dialogical territory between their personal and social worlds.

Chapter 6 then draws together and develops the main findings, discussing these with reference to a broader literature, and considering what this study adds to our understanding. It then reviews some of the methodological tensions encountered in the research within a reflexive framework, exploring the value, limitations and implications of different methodological decisions.

Finally, chapter 7 draws together a summary and conclusions from the project, highlighting its contribution and implications for professional practice, methodological implications, and areas for future research.

Chapter 2

Constructions of CFS/ME

2.0 Overview

As set out in the previous chapter, this thesis begins with the position that our understandings of health and illness are socially constructed, and that these constructions have significant implications for those living with or alongside different forms of illness. It is argued that this becomes particularly relevant when an illness condition is “contested”: where different constructions, often set out by different bodies of individuals, clash powerfully. This chapter aims to give an account of the multiple and contested constructions currently contextualising the condition known in the UK as CFS/ME (Chronic Fatigue Syndrome / Myalgic Encephalomyelitis or Encephalopathy), considering how the major positions have developed, how they draw on and challenge each other, and how they influence what it is currently possible for people to say about the condition.

It is argued that these constructions have developed over time as a controversy in which medical and psychological theories have been pitted against each other, reflecting professional and academic divisions and a long history of Cartesian dualism. The review then considers what is added by more recent qualitative research on personal (or first-person) constructions, in which those living with the symptoms of CFS/ME speak of their experience. Finally, it is argued that too little attention has been paid to the voices of children and young people (CYP) living with this condition, identifying a gap in current understandings and a need for further research.

2.1 Evolving constructions of CFS/ME

Where does the story of CFS/ME begin? “The beginning” is not clear when talking about a condition (or possibly a set of conditions) whose very existence is contested. There are

many versions, but over time some have gained prominence - not necessarily because they are more “true”, but perhaps because some make sense in particular historical contexts, some are easier to tell or hear, some are told more powerfully - repeated more often, disseminated more widely, by more powerful voices. Even choosing a “beginning” of a history sets up a particular construction not only of the story, but of the condition itself - for example as a new consequence of 20th century pollution or a newly-mutated virus, rather than continuation of an established entity. In keeping with the constructionist stance of this thesis, the reflexive dilemma of writing is acknowledged: my own writing of any form of “history” is necessarily only one construction, my particular version of reality. It is not possible to give a complete or “correct” history, only perhaps a “plausible history” while acknowledging that other versions remain both possible and plausible (Gilbert & Mulkey, 1984). The purpose of this section is therefore to give a flavour of the main narratives and counter-narratives that have developed over time, to allow consideration of how these provide a context for those affected by and working with CFS/ME now.

In 1955, an outbreak of unexplained illness was reported among over two hundred people at the Royal Free Hospital in London, subsequently affecting over seventy medical staff and closing the hospital for two months. Symptoms appeared to resemble those of poliomyelitis and Central Nervous System (CNS) dysfunction (exhaustion, muscle weakness, headache, visual disturbance), but the usual infective pathology for poliomyelitis could not be detected. Nevertheless, initial theories focused on infectious disease, and a label of *benign myalgic encephalomyelitis* proposed in the UK (Lancet, 1956).

Parallels were quickly drawn with previous outbreaks of mysterious clusters of symptoms, including one at the County Hospital in Los Angeles in 1934 (Acheson, 1959). Sporadic outbreaks of apparently similar symptoms continued to be reported during the 1950s and 1960s, but no clear diagnostic markers were ever established, making it hard to conclude whether these were indeed instances of the same phenomenon. As biological pathology proved elusive, there arose increasing speculation about whether symptoms were better accounted for by psychological disturbance (Patarca-Montero, 2004). Publication of papers in the prominent British Medical Journal (McEvedy & Beard, 1970) suggested that the supposed viral epidemic at the Royal Free was in fact attributable to mass hysteria,

reigniting controversy that further polarised proponents into “organic” or “psychiatric” camps (Wessely, 1991).

Public awareness grew during the 1980s, with reports of increasing numbers of people in the West presenting similar symptoms of profound and chronic fatigue, malaise, muscle pain and a range of other symptoms, often following flu-like illness. As before, viral causes were proposed (this time the recently-identified Epstein-Barr virus associated with “glandular fever”); and as before, testing for infectious conditions proved inconclusive. Nevertheless, the term *postviral fatigue syndrome* (PVFS) took hold alongside *myalgic encephalomyelitis* (M.E.) and *chronic fatigue syndrome* (CFS).

Postulated causes explored internationally could, argues Showalter (1997), be understood as reflecting national medical cultures and obsessions: biomedical (eg, dental amalgam (Scandinavia), viruses (USA, at a time where awareness of HIV/AIDS was growing); environmental (pollution); or sociological (pressures from increasingly-unregulated capitalism, competition and individualism (de Wolfe, 2009)). As previously, psychiatric formulations were also proposed: for example, that symptoms were the physical manifestation of depression, or of personalities preoccupied with unattainable achievement (Rosen, King, Wilkinson et al., 1990).

Some commentators questioned whether CFS should even be considered a distinct syndrome (Straus, 1991; Wessely, Hotopf & Sharpe, 1999); whether there was ever an “epidemic” (rather than an artefact of reporting and reclassification); and whether the condition was new or simply contemporary labelling of conditions previously diagnosed as *neurasthenia* (Ward, 2015; Wessely, 1990, 1991) or hysteria (Showalter, 1997). Ware (1998) notes the periodic surfacing of unexplained fatigue syndromes over time, suggesting that these diagnoses temporarily perform a “legitimizing function” (ie, defining the sufferer as physically rather than mentally ill), until psychiatric critiques of the labels gain prominence. Thus Shorter (1992:12) suggests that “the volume of perceived aches, pains and weariness has probably changed little historically. What changes is people’s readiness to seek medical help for these symptoms, to define them as disease, and to give them fixed attributions.” Nevertheless, widespread reporting of these symptoms and pressure from increasingly active patient groups led to classification of CFS as a distinct syndrome by the

Centres for Disease Control (CDC) in 1988, in what many felt was a legitimisation of patient voices; and after some further wrangling, diagnostic criteria were revised in 1994 into the ones commonly used today (see below).

The power of language in medical construction of the condition is clearly recognised by different groups, who dispute labelling of the syndrome as CFS rather than M.E. or other terms (Ward, 2015). Many UK patient groups advocate the use of M.E., insisting that Chronic Fatigue Syndrome (a term suggested to emphasise the predominant symptom while deliberately not making assumptions about pathology or cause) fails to convey the severity or breadth of symptoms. Conversely, a report by the Royal Colleges of Physicians, Psychiatrists and General Practitioners (1996) explicitly rejects the term M.E. on the grounds that it implies specific, un-evidenced processes of muscular and CNS pathology. Current British adoption of the hybrid “CFS/ME” (CFS/ME Working Group, 2002) may be seen - dependent on one’s perspective - as an attempt at inclusivity and acknowledgment of multiple perspectives, or an unhelpful conflation of two separate conditions (The Nightingale Research Foundation, 2011), or “a surrender of medical authority to consumer demand and popular prejudice” (Fitzpatrick, 2002)³.

The constructive power of language is also relevant to wider depictions of the condition. For example, media headlines citing “outbreaks” or “epidemics” draw on understandings of infectious transmission without having to specify (and be challenged on evidence for) this. Then comes the related depiction of sufferers. Early reports that the condition affected health “professionals of good character” not only highlighted possible exposure to pathogens, but also implied the respectability and credibility of sufferers and hence the condition itself (Wessely, 1991). In contrast, media labelling of “yuppie flu” implied a derogatory link with (over-)aspirational lifestyles (de Wolfe, 2009). Similarly, McEvedy & Beard’s (1970) comments about nurses affected at the Royal Free – women “segregated to a very considerable degree” – were used to support their hypothesis of a hysterical epidemic. This drawing on gendered and class-related discourses of mental health and credibility is still apparent in depictions of CFS/ME as “psychological”, in which women tend

³ Dispute about the deployment of labels extends further, into attacks on the credibility of opposing groups. For example, Fitzpatrick (2002:432) pointedly suggests that “ME activists [...] no doubt [...] enjoy the legitimacy conferred by a polysyllabic Latinate term, even though - perhaps because - it mystifies rather than clarifies the underlying condition”.

to be diagnosed in significantly higher numbers than men (Lian & Bondevik, 2015); and in pejorative, unsubstantiated assertions from physicians regarding the role of mothers in diagnosis of CFS/ME among children (eg, Harris & Taitz, 1989; MacDonald, 1989).

Finally, it is worth noting briefly how debates have gone beyond critique of scientific evidence and arguments, escalating into attacks on the credibility of whole professions and on individuals seen (sometimes caricatured) as representing particular positions (eg, Gosling, 1970; Hooper, 2007). Attacks and frequently-repeated (mis-)representation of individuals or professions now continues within less restrained online forums directing abuse and even death threats towards researchers exploring psychosocial factors (McKie, 21st August 2011)⁴.

Clearly the consideration of different constructions of CFS/ME is not simply an academic exercise. The “facts” that are “...supposed to settle matters of who is sick and what care is appropriate become instead forces deployed by participants in attempts to emplot and counter-emplot each other” (Dumit, 2006:578). Despite calls over time for less dualistic frameworks (David, Wessely & Pelosi, 1988; Gill, 1970; Ward, 2015), the enduring influence of Cartesian separation between mind and body is evident in these constructions and the controversy that has evolved (Horton-Salway, 1998). The intensity with which people will attack or defend different positions is an indication of what is believed to be at stake. It is argued that the echoes of these historical arguments continue to make their presence felt in contemporary debates about CFS/ME, and it is to these that we now turn.

⁴ Simon Wessely, psychiatrist and co-author of much research into biopsychosocial models of CFS/ME was described in *The Times* as “the most hated doctor in Britain” (Marsh, August 6th 2011), compared on the internet with Nazi doctor Josef Mengele, leading him to withdraw from active research in this field (Holgate, Komaroff, Mangan et al., 2011). Similarly, though working from a very different position, Charles Shepherd - medical advisor to the ME Association and supporter of a neuroimmune conceptualisation of M.E - has been the target of attacks: one website claimed he had a psychotic illness, was physically violent, and “a medical failure” (Hawkes, 2011).

2.2 Current professional constructions of CFS/ME

In line with previous discussion, it is not the intention of this review to set out a “correct” contemporary understanding of CFS/ME. However, young people in the UK experiencing symptoms associated with CFS/ME do so within a health system which is influenced by current professional and public discourses, providing an important context for their experience. This section briefly reviews the dominant (predominantly biomedical) constructions available to health professionals through research journals, summaries in professional publications such as the Lancet and the British Medical Journal, and material disseminated by professional bodies such as the Royal College of General Practitioners and the National Institute for Health and Care Excellence (NICE)⁵.

2.2.1 What is CFS/ME? Definitions and diagnoses

Chronic fatigue syndrome (CFS) is the term most commonly used by scientists and clinicians in the UK to label the range of symptoms that are also referred to (particularly by patient groups) as *myalgic encephalomyelitis* or *encephalopathy* (M.E.), or *postviral fatigue syndrome* (PVFS) or *chronic fatigue and immune dysfunction syndrome* (CFIDS) (Prins, van der Meer & Bleijenberg, 2006) – although, as discussed, there is dispute about whether these are simple alternative labels, or whether they refer to different underlying conditions.

Even for “CFS”, different case definitions exist. The most widely used are from the US Centers for Disease Control and Prevention, often referred to as the CDC or Fukuda definition (Fukuda, Straus, Hickie et al., 1994). Here the main feature is considered to be a persistent or relapsing fatigue of at least six months’ duration, of new or definite onset, that is not explained by other somatic or psychiatric illness, and which severely affects normal daily activities. Additionally, patients must report at least four of eight accompanying symptoms.

⁵ Formerly the National Institute for Health and Clinical Excellence.

CDC definition of CFS (Fukuda et al, 1994)

Main criteria (all required)

Persistent or relapsing fatigue of 6 months duration or more
Fatigue is not explained by any current somatic or psychiatric condition
Fatigue is new or definite in onset
Fatigue is not the result of ongoing exertion
Fatigue is not alleviated by rest
Fatigue results in substantial reduction to previous occupational, educational, social & personal activities

Additional criteria (4 or more required)

Impaired memory or concentration
Sore throat
Tender cervical or axillary lymph nodes
Muscle pain
Multi-joint pain
New headaches
Unrefreshing sleep
Post-exertional malaise

Other case definitions contain some significant differences. The insistence on an acute rather than gradual onset is disputed (Prins et al., 2006), but arguably important because infectious triggers of illness would be expected to produce an acute onset. The “Oxford definition” (Sharpe, 1991) accepts symptoms that might indicate psychiatric disorder, while the Canadian definition (Carruthers, Jain, De Meirleir et al., 2003) specifically *excludes* these. It is argued that the latter prevents diagnosis of people whose symptoms are “really” due to psychiatric illness (the symptoms of clinical depression, for example, can include fatigue, pain, problems of memory and concentration). However, exclusion of people with psychiatric illness may be equally problematic since – even if CFS/ME is understood as resulting primarily from physiological pathology - mental health issues may be secondary to, or simply co-morbid with, physical illness.

Jason, Porter, Shelleby et al (2008) note the need for caution when applying criteria developed with adults onto children and young people (CYP), and have developed a further case definition of “ME/CFS” for this population. Adaptations acknowledge that families of CYP may not be able to pinpoint a definite onset, so this criterion is removed; and require unexplained, disabling fatigue for just 3, rather than the usual 6 months prior to diagnosis.

These adaptations, and the broad diagnostic criteria used by the Royal College of Paediatrics and Child Health (2004) and NICE (2007) for their UK clinical guidelines, may be seen as pragmatic responses to clinical challenges - or, conversely, as contributing to the construction of CFS as a “dust-bin” in which to “dump” and inappropriately label people in the absence of more accurate diagnosis (Shepherd, 2008), exacerbating confusion and conflict (Grue, 2013). Of relevance here is the variability in diagnostic and operational criteria (Brurberg, Fønhus, Larun et al., 2014), and lack of clarity about how these decisions are made. Diagnoses are shown to be far from an objective entity, but rather convenient social constructions (Barker, 2010). In the absence of uncontested research and evidence bases (of which more later), it is argued that “the diagnoses at stake here - of CFS and of psychiatric disorder - are literally the construction of committees” (Sharpe, 2005:270).

2.2.1.1 Developing the clinical picture: Impacts and impairment

Adult patients typically report sudden onset of fatigue, often associated with a flu-like illness, against a backdrop of previously good health and physical fitness (Afari & Buchwald, 2003; Salit, 1997). As noted, the situation is less clear for CYP: while many families report childhood onset to be sudden and post-viral (Lievesley, Rimes & Chalder, 2014), up to 25% report a more insidious onset (Bell, 1992; Jordan, Landis, Downey et al., 1998). Otherwise, studies indicate a broadly similar clinical picture for CYP and adults (Farmer, Fowler, Scourfield et al., 2004), though with some differences in presentation such as increased reports of sore throats in younger children, but increased headaches and cognitive symptoms in adolescents (Collin, Nuevo, van de Putte et al., 2015). Two UK studies (Saidi & Haines, 2006; Tucker & Tatum, 2000) report a wide range of symptoms, including: digestive disturbance (irritable bowel, stomach pain, nausea); allergies or sensitivities to foods, chemicals, medications, odours or noise; visual disturbance (sensitivity to light, blurring); pain; dizziness, orthostatic intolerance and palpitations; subjective temperature

sensitivity and night sweats; “brain fog”; and depression, mood swings and anxiety. Tucker & Tatum also note that, while all participants reported significant fatigue, only 14% rated it as their “over-riding, worst symptom”. This is significant in the debate over the naming of the condition, where patient groups contest the label of “chronic fatigue syndrome” as unrepresentative of their symptoms.

Psychological difficulties, poorer quality of life and impaired psychosocial functioning are consistently reported at higher levels for CYP living with CFS/ME compared with other illness (Lievesley et al., 2014; van Geelen, Fuchs, van Geel et al., 2015; Winger, Kvarstein, Wyller et al., 2015). Although there are heated debates about the relationship between physiological and psychosocial aspects of the condition (see below), both can contribute to functional impairment. Levels of disability vary considerably, but over half of YP attending tertiary centres report having been bedbound for significant periods (Rangel, Garralda, Levin et al., 2000). Poor educational attainment and impairment to home-based and social activity are particularly problematic for CYP diagnosed with CFS/ME (Crawley & Sterne, 2009; Garralda & Rangel, 2004; Newton, 2015; Potgieter, Patel, Beasant et al., 2015; Sankey, Hill, Brown et al., 2006).

Further, to understand the impact of illness on CYP, it is important to look beyond the here-and-now and consider potential disruption to future development. For CYP, longer-term disability associated with CFS/ME can be exacerbated by impacts on emotional and social development, including development of autonomy, sense of self, body image, relationships, sexuality and academic development (Vollmer-Conna, 2010), and can exacerbate isolation and anxiety about returning to the peer group (Wright, Partridge & Williams, 2000), creating a vicious cycle interfering with long-term social reintegration even after improvement in physical symptoms.

2.2.1.2 Symptoms or signs: Medical invisibility?

In medicine, *symptoms* are defined as subjective reports of experience (eg, feeling tired) that are otherwise invisible to doctors, while *signs* can be objectively observed – either directly (eg, a rash) or indirectly (eg, through biochemical markers identified in blood tests). Doctors seeing patients who report fatigue and other symptoms use tests to diagnose or

exclude *other* conditions (eg, diabetes or thyroid dysfunction), but diagnosis of CFS/ME is then one of exclusion: despite research and debate in medical and public forums, there are no laboratory tests or signs currently accepted as confirming a diagnosis of CFS/ME (Carruthers, van de Sande, De Meirleir et al., 2011; Holgate et al., 2011; van der Meer & Lloyd, 2012; Werker, Nijhof & van de Putte, 2013).

Instead, practitioners must rely on descriptions from their patients of symptoms and disability, something that runs counter to trends of increasing reliance on biomedical technologies in diagnosis (Casper & Morrison, 2010; Conrad, 2005). The challenge of diagnosis thus becomes a challenge of communication, but this may be problematic. As noted, symptoms are “invisible”. Additionally, symptom intensity is acknowledged to fluctuate even within individuals, so that at times even their *functioning* may appear normal (Bell, 1992). Further difficulties arise because “fatigue” is such a commonly-reported symptom (Bates, Schmitt, Buchwald et al., 1993; Pawlikowska, Chalder, Hirsch et al., 1994): we all (think we) know what it is like to feel tired, and consequently may be inclined to dismiss or trivialise the significance of symptoms (Jason, Taylor, Plioplys et al., 2002). These factors contribute to the difficulties of diagnosis, and highlight the need for good communication between patient and doctor in the consultation. However, as will be explored shortly, an emerging body of literature suggests problems in this process (Nettleton, 2006).

2.2.2 Who is affected? Epidemiology

Given such difficulties with definition and diagnosis, epidemiological estimates are understandably problematic. A recent meta-analysis estimates pooled prevalence from 0.76% (clinical assessment) to 3.28% (self-report assessments) (Johnston, Brenu, Staines et al., 2013), whereas current NICE guidelines quote more conservative estimates of “at least 0.2 – 0.4%” population prevalence (NICE, 2007).

Though earlier reports suggested that CFS mainly affected young, successful, white women (Lloyd, Hickie, Boughton et al., 1990), it is now considered to occur more frequently in people in their 40s and 50s (Gallagher, Thomas, Hamilton et al., 2004; Turnbull, Shaw, Bake et al., 2007). Most studies still indicate that 75% or more of those diagnosed are female

(Prins et al., 2006), but more recent studies challenge the idea that the condition is more prevalent in economically-privileged groups (Johnston et al., 2013). Inequities in healthcare provision, and gendered, cultural and class-related biases, may all contribute to the systematic over- or under-representation of different groups within epidemiological estimates (Afari & Buchwald, 2003; Lian & Bondevik, 2015).

Epidemiology is even harder to establish for children and young people (CYP), partly due to issues of case definition and partly to methodology (eg, use of parent report versus child self-report). Most studies suggest a lower prevalence of CFS/ME among CYP compared with adults, with UK studies suggesting that approximately 0.05 - 0.2% of CYP are affected (Chalder, Goodman, Wessely et al., 2003; Haines, Saidi & Cooke, 2005; Wessely, Chalder, Hirsch et al., 1997). However, differences across the age range of "CYP" are important: a longitudinal UK birth cohort study estimates CFS prevalence of 0.6 - 1.9% in 16 year-olds, based on parental report of symptoms (Collin, Norris, Nuevo et al., 2016); and Farmer, Fowler, Scourfield and Thapar (2004) conclude that, while chronic fatigue is rare in children under 10, the prevalence and presentation in those over 11 is similar to that of adults. Age is also important in considering gender differences. A survey of UK GPs indicates a 50:50 sex distribution of medically-unexplained severe fatigue in children aged 5-9, but with the representation of girls rising to 66% among 10-15 year-olds, and 72% of 16-19 year-olds, bringing them in line with gender distribution reported in adults (Haines et al., 2005).

2.2.3 What causes CFS/ME? Constructions of aetiology & maintenance

Debate about the aetiology and pathology of CFS/ME cuts to the heart of a contested condition. What *is* it? What underlies the picture of symptoms reported? Three decades of research into biomedical and psychological mechanisms have produced thousands of papers, but a lack of consensus or coherent theory (Werker et al., 2013). It is notable that guidelines on clinical diagnosis and management largely avoid this issue (eg, NICE, 2007). It is not possible (or the purpose of this paper) to give a full review of this body of work. However, this section will briefly outline some of the major areas of work to have received attention, insofar as these provide a discursive context to the current experience of CFS/ME as a contested illness.

Much of the reported research attempts to establish disease or pathophysiology associated with the condition, or to go beyond this to establish causal pathological processes in the pathway from aetiology, triggering and maintenance of symptoms. It is however widely acknowledged that, within such a heterogeneous condition, it is likely that no one single cause is likely to be found (Beverley, 2005), and that complex, multi-factorial processes are likely to be at play. Several experts have been particularly critical of the Cartesian dualism inherent in classifying symptoms or their causes as either “physical” or “mental” (Fitzpatrick, 2002), with many arguing that a biopsychosocial framework is needed to understand health and illness (eg, Wessely, 2001). However, at risk of perpetuating this dualism, this section reflects current divisions between research focusing on physiological or psychosocial constructions.

2.2.3.1 Physiological hypotheses

Twin studies indicate a moderate heritability of CFS, although environmental rather than genetic effects still appear predominant, and research into genomic variation is still at an early stage (eg, Sommerfeldt, Portilla, Jacobsen et al., 2011). Given the nature of symptoms, much focus has unsurprisingly been on the Central Nervous System (CNS) and its impact on autonomic/hormonal regulation. Neuroimaging (eg, fMRI) and neuropsychological testing have indicated possible structural and functional alterations (Prochalska, Gressier & Corruble, 2012; Wyller, 2007), but other studies challenge these findings, suggesting that they may not be specific or indicative of a pathogenic pathway in CFS (Cho, Skowera, Cleare et al., 2006). Similarly, focus on the hypothalamic-pituitary-adrenal (HPA) axis of hormonal regulation - particularly its role in response to stress, immunological and auto-immune responses - suggests pathophysiology, including some findings in CYP (Segal, Hindmarsh & Viner, 2005). However, again these are not consistent in all studies (Lievesley et al., 2014); and again there is controversy about causality - whether abnormalities are primary, or secondary to inactivity and excessive rest (Tak, Cleare, Ormel et al., 2011).

Reports of infections prior to the onset of chronic fatigue continue to prompt research into possible infectious agents such as Epstein-Barr Virus, retroviruses, enteroviruses, bacterial

agents, and Lyme disease (Beverley, 2005; Wyller, 2007). However, while some studies demonstrate elevated antibody levels, this is not evidence of causality because some of these conditions are relatively common, and healthy individuals also show elevated antibody levels many years after recovering from infection.

Professional and public interest continues in a search for infectious and pathophysiological causes. However, the contested nature of CFS/ME may perversely be reinforced by patterns of research activity and reporting of “new findings”, frequently followed by heavy critique and refutation. The recent surge of interest in retrovirus XMRV (Lombardi, Ruscetti, Das Gupta et al., 2009) followed by “failure to replicate” from other scientists, partial retraction of the original paper, and conclusion that original findings were the result of laboratory contamination (Moran, 2011), is just one example of this. The emotional consequences of such cycles for those living with the condition - where hopes for “cure” are repeatedly raised and dashed, alongside further public debate about the nature and reality of the condition - may be devastating.

2.2.3.2 Psychiatric, psychological and psychosocial hypotheses

Historically there has been much discussion about whether symptoms of CFS/ME are better understood as somatisation of psychological distress, even attributable to mental (rather than physical) illness. Both professionals and the public have often associated medically unexplained symptoms with dissociative/conversion disorders and functional somatoform disorders (Eminson, 2007; Geist, Weinstein, Walker et al., 2008). As Jordon et al (1998) note, the argument that CFS/ME is of psychological origin arises through three lines of reasoning: first, the absence of conclusively replicable biomedical markers; secondly, the degree of psychological and psychosocial distress seen in sufferers; and thirdly, evidence of improvement in at least some patients following psychological and psychopharmacological treatment. The focus of research has now largely shifted from “either/or” explanations of biological vs psychological aetiology, to exploring how psychosocial processes may contribute to risk, triggers, and maintaining aspects of chronic fatigue. Additionally, the heterogeneity of the diagnosed population is acknowledged, such that different processes are likely to be at play in different individuals.

From a narrative synthesis of seventy-nine studies examining predisposing, precipitating and perpetuating factors in CFS among CYP, Lievesley et al (2014) conclude that there are strong, consistent findings in cross-sectional studies of increased rates of psychiatric comorbidity (particularly anxiety and depression) compared with healthy CYP or those with other illness conditions. Additionally, certain “personality” traits (eg, rigidity, excessive conscientiousness, sensitivity) are reported to be associated with CFS in adults (Prins et al., 2006) and YP (eg, Rangel, Garralda, Hall et al., 2003). This is a contentious area, fraught by methodological and conceptual issues, and studies cannot establish causality and direction of association: emotional disorders or traits may arise secondary to the experience of living with chronic fatigue, disability and/or factors specific to living with a contested condition.

As with physiological research, there is a clear need for large-scale longitudinal research (Bould, Lewis, Emond et al., 2011). Prospective studies are now emerging, suggesting that emotional and behavioural disorders earlier in life do increase risk of later CFS, both for adults and CYP (eg, Rimes, Goodman, Hotopf et al., 2007; ter Wolbeek, van Doornen, Kavelaars et al., 2011); that childhood adversity may be a significant risk factor for later development of CFS/ME (eg, Collin et al., 2016; Kempke, Luyten, Claes et al., 2013); and that children whose mothers (but not fathers) experience anxiety or depression during the child’s first six years of life are then at increased risk of developing “chronic disabling fatigue” in early adolescence (Collin, Tilling, Joinson et al., 2015).

The relationship between CFS/ME and emotional difficulties is likely to be complex, with each contributing to the development and maintenance of each other. Iatrogenic injury is also pertinent, as prolonged uncertainty and inconclusive medical tests can understandably increase health anxiety (Rangel et al., 2000). Increasing attention is now being given to the role of cognitive, behavioural, affective and social factors in the *maintenance* of difficulties within a biopsychosocial model of response to illness (eg, Brooks, Rimes & Chalder, 2011; Cella, White, Sharpe et al., 2012; Lievesley et al., 2014). Though the majority of research on psychosocial moderators has focused on adults, some smaller-scale studies (eg, Garralda & Rangel, 2001; Garralda & Rangel, 2004; Richards, Chaplin, Starkey et al., 2006) suggest similar patterns of beliefs and behaviours among CYP and parents that may be unhelpful in maintenance of their illness (eg, fears about the negative impact of routine activities; excessive rest; underestimation of normal fatigue levels in others, with consequent

overestimation of their own). Additionally come suggestions of parental “over-protection” as a problematic response to CFS in CYP, although findings are mixed (Lievesley et al., 2014) and unsurprisingly contentious.

To conclude: a great deal of research has been aimed at developing understanding of physiological and psychosocial factors influencing the onset and development of CFS/ME. No one model can be considered definitive, and there is good reason to believe that a range of factors are interacting. Research is hampered by methodological issues, including paucity of prospective studies. Some of the factors presently being considered may equally prove to be red herrings, later to be added to the pile of discarded historical constructions. The point of including these here is not to show what is “true”, but the range of discourses circulating around those presenting to health professionals for help. Given the potentially stigmatising nature of some of these, their impact on professionals, sufferers and their families must be considered as part of the ongoing construction not only of CFS/ME itself, but the identities of those affected.

2.2.4 What happens next? Prognosis & interventions

What happens to those diagnosed with CFS/ME? From a systematic review of fourteen studies, Cairns & Hotopf (2005) conclude that diagnosed adults experience a mean illness duration of 3 – 9 years, and that full recovery without treatment occurs in only approximately 5% of cases. However, the outlook for CYP appears more positive, particularly for those diagnosed younger (van Geelen, Bakker, Kuis et al., 2010), although again methodological problems hamper conclusions (Moore, Anderson & Crawley, 2015).

A series of studies (eg, Gill, Dosen & Ziegler, 2004; Patel, Smith, Chalder et al., 2003; Rangel et al., 2000; Sankey et al., 2006; van Geelen et al., 2010) conclude that 25-50% of CYP report “recovery” or “nearly complete improvement” over 2-4 years follow-up; and a 13-year study reports a “satisfactory” outcome in 80% of the YP (Bell, Jordan & Robinson, 2001). Studies from specialist centres, which see the most severely affected CYP, indicate an average duration of illness of 3 to 4 years, although with a significant minority incapacitated for longer (Beverley, 2005; Royal College of Paediatrics and Child Health, 2004). Prompt

diagnosis and advice on symptom management is considered to improve patient outcomes (Burns, 2012), but it is also argued that half of CYP reporting severe fatigue for less than six months will spontaneously recover without intervention over the next six months; and beginning intervention with CYP too early for cases of unexplained fatigue may actually prolong fatigue and school absence (Bakker, van de Putte, Kuis et al., 2009, 2011). Significantly, however, all of these studies indicate significant proportions of CYP reporting no improvement over follow-up periods.

Current guidelines to physicians in the UK (NICE, 2007) are derived mainly from adult-based studies, and it is acknowledged that further study is required to establish the evidence base for CYP. In the first instance, for early or milder cases, GPs are advised to use general management strategies (sometimes referred to as “standard medical care”) focusing on function and quality-of-life: tailored advice on diet (eg, slow-release energy sources, adaptation of meal frequency, fibre and water intake to manage intestinal symptoms); advice on sleep management (eg, sleep hygiene, avoiding daytime sleeping to address sleep reversal); and advice on incorporating rest or relaxation periods into activity schedules, but avoiding excessive rest (NICE, 2007:18-21). Though there is no established pharmacological treatment or cure for CFS/ME, some symptoms may be managed as in usual clinical practice, such as use of mild/moderate analgesics for pain, or melatonin to aid sleep; and for CYP, medication should initially be started by a paediatrician (NICE, 2007:18-19). Physicians are also encouraged to liaise with occupational or school agencies to try to maintain contact and functioning, even if this is on a reduced schedule or with adjustments (eg, mobility aids), since having to stop work or education is considered detrimental to health and wellbeing (NICE, 2007: 21-23).

However, NICE guidelines recommend referral to *specialist services* immediately for those presenting with severe symptoms, and in any case after 6 months of persistent symptoms. These involve three main clusters of intervention, with some overlap: activity management, graded exercise therapy (GET) and cognitive-behavioural therapy (CBT). All are aimed at sustaining or extending the individual’s physical, emotional and cognitive capacity, and managing the physical and emotional impact of symptoms (NICE, 2007:26).

Activity management is a person-centred, goal-directed approach to managing an individual's symptoms through regulating their activity. It draws on principles and techniques particularly associated with occupational therapists (Cox, 2000), but has been incorporated into the work of other professionals and multi-disciplinary programmes. NICE guidelines (2007:31-32) highlights how the approach is goal-directed and uses activity analysis and graded activity to enable people to evaluate, maintain and improve their function and well-being in self-care, work and leisure. Acknowledging that activities have physical, emotional and cognitive components, professionals work closely with sufferers to identify these components (eg, by keeping a diary to record different forms of activity, daytime rest and sleep) and establish baseline levels of activity (a stable and sustainable range of functioning). The approach then seeks to develop a planned activity/exercise strategy, monitoring and gradually increasing activity in line with personal priorities above the baseline while avoiding "boom and bust cycles" of (over-)activity followed by excessive rest when fatigue or other symptoms are exacerbated. This involves careful planning and prioritising of daily activities to allow for a balance and variety of different types of activity, rest and sleep; spreading out demands over the day or week; and where necessary splitting activities into smaller achievable tasks according to the person's level of ability/functioning, followed by gradual increases in the complexity of the tasks. Work also focuses on how to manage set-backs and relapses which are a central feature of CFS/ME (NICE, 2007: 31-32).

Graded Exercise Therapy is underpinned by theories of CFS/ME that assume the syndrome is perpetuated by reversible physiological changes of deconditioning: that is, that initial inactivity (perhaps as a consequence of initial illness such as viral infection) results in physiological deconditioning; that subsequent attempts at activity are then perceived as more effortful and/or resulting in increased fatigue, pain or other symptoms; that further activity is therefore avoided; and that further deconditioning therefore ensues. GET aims to reverse deconditioning, thereby reducing fatigue and disability (White, Goldsmith, Johnson et al., 2011:825).

GET incorporates many of the principles of activity management outlined above, but with a greater focus on *physical* fitness and stamina. According to NICE guidelines, (NICE, 2007: 29-31), intervention again begins with assessment of the individual's current (baseline) level of ability. Intensity and duration of "exercise" should again be led by the goals and

wishes of the individual, and may begin at a very low level (eg, sitting up in bed for 5 minutes, brushing one's own teeth), building very slowly depending on (closely-monitored) progress; and again, attempting to avoid "boom and bust" cycles. However, there is a greater emphasis on aerobic development, with use of heart rate monitors and target heart rates to avoid over-exertion, and NICE (2007) recommends that GET should only be delivered by a qualified therapist (usually a physiotherapist).

Cognitive Behaviour Therapy (CBT) is an evidence-based psychological therapy used in many health settings (eg, cardiac rehabilitation, diabetes) (NICE, 2007:49) by appropriately-trained professionals (usually clinical psychologists or specialist nurse therapists). Based on a biopsychosocial model, its application in CFS/ME assumes that many aspects of the condition or associated disability are reversible; and that cognitive-emotional responses (such as fear of engaging in activity) and behavioural responses (eg, activity avoidance) are linked, and interact with physiological processes to perpetuate fatigue (White et al, 2011). There is clearly some overlap with GET and more general activity management, in terms of the behavioural aspects aimed at gradually increasing activity and engagement in social life. However, there is more focus on cognitive aspects such as identifying and challenging thoughts, beliefs and assumptions which influence behaviour and mood (NICE, 2007:27-29). These may be illness-related (eg, beliefs that pain is an indication of serious disease, and that activity is therefore dangerous), or more general (eg, belief in the personal importance of striving for perfection, so there is no "achievement" in making small changes in activity; or beliefs that other people will not be supportive, so it is safer to avoid them). Techniques aimed at challenging unhelpful cognitions and improving problem-solving then support moves towards gradual increases in physical and social activity; and can also address mood difficulties such as depression or anxiety that often accompanies health problems.

A feature of all these approaches is that, unlike common Western understandings of illness and medicine, they do not focus on the identification of a specific *cause* or pathology underlying symptoms, and do not rely on administration of a pathology-focused medical intervention that is the primary responsibility of the doctor. They require close collaboration between professionals and "patients", which requires sensitive referral to, and timely availability of, specially-trained professionals – something that is often felt to

be lacking for CYP with medically-unexplained symptoms (Hinton & Kirk, 2016). And for families who have spent time focusing on identification of pathology and wish for medical cure, there may be understandable confusion, hesitation and even distress or fear about the rationale for such a shift in focus towards primarily non-medical approaches (eg, that doctors have “given up”, dismissed their problems as trivial or “in the mind”, and perhaps are missing serious physical pathology).

Beyond sensitive management of the referral and rationale for the approach, professionals may lead and support the interventions closely, but a great deal of work is expected of the individual in monitoring and managing symptoms; sometimes making very significant changes to their lives and also tolerating uncertainty about the outcomes. The health professional is not always present when day-to-day, moment-to-moment decisions have to be made about activity (eg, what constitutes “too much”?). Clinicians themselves still question the best ways to manage activity with their patients (eg, with time-contingent or symptom-contingent pacing)⁶ (Van Cauwenbergh, De Kooning, Ickmans et al., 2012) . Add to this the complexities of people’s existing understandings of health and illness, and culturally-bound meanings of activity and inactivity (Pemberton & Cox, 2014), and it is unsurprising then that people living with CFS/ME may have difficulty managing their activity on a day-to-day basis, or engaging with the currently-recommended approaches.

There is now considerable research to compare the outcomes of different intervention approaches. Within the UK, there has been widespread attention to the PACE trial (White, Goldsmith, Johnson et al., 2013; White et al., 2011), which has reinforced previous (NICE) guidelines in supporting the use of GET and CBT (but not Adaptive Pacing Therapy) in addition to standard medical care, to “moderately improve outcomes”. While most research is focused on adults, a recent systematic review of 21 studies relating specifically to CYP (Knight, Scheinberg & Harvey, 2013) similarly supports the existing guidelines, and

⁶ Further difficulties arise from different understandings of common terms. For example, “pacing” is a term often used to describe the “spreading out” of activity over time, within “common-sense” understandings and as in the activity management approaches described above which aim to rationalise but gently extend activity / rehabilitate over time by forward planning. However, it is also used to describe an approach (as in Adaptive Pacing Therapy) underpinned by a different model which contents that CFS/ME is an organic disease process *not* reversible by behaviour, resulting in a finite amount (“envelope”) of energy; therapy therefore encourages patients to identify and then adapt to (live *within*) limits (White, Goldsmith, Johnson et al., 2011), stopping activity *before* triggering any post-exertional fatigue (Goudsmit, Nijs, Jason et al., 2012).

concludes that although much of the research to date is limited by methodological problems, the strongest existing evidence is for specialist CBT programmes (most of which also incorporate graded activity).

However, much of this research and related recommendations has drawn criticism from other researchers and patient groups such as the ME Association (Shepherd, 2016). Critics maintain that findings are not robust enough to justify the use of CBT or GET as a primary intervention; that they rest on flawed models of CFS/ME; that they ignore the heterogeneity of presentations and underlying problems; and that trials ignore other forms of “evidence” (eg, from the ME Association’s patient survey) reporting that that GET can exacerbate symptoms, or that CBT had no impact (ME Association, 2015).

Given the debates outlined previously, it is unsurprising that treatment recommendations too are controversial (Boseley, 18th February, 2011; Holgate et al., 2011). For example, though CBT is widely used to support adjustment to many physical health conditions (Kennedy & Llewellyn, 2006), its established use in mental healthcare may render it inflammatory to those with firm views about the “organic, not psychological” basis of CFS/ME. As before, challenges go beyond academic argument, including legal proceedings involving (in the words of a High Court judge) “unfounded” and “damaging” attacks on health professionals (Dyer, 2009).

Research and systematic review of outcomes continues. Beyond the existing support for activity, exercise and cognitive-behavioural programmes, some medical directions are being pursued, while other approaches appear discredited (Smith, Haney, McDonagh et al., 2015). However, it should also be noted that the ongoing uncertainty about CFS/ME, as well as understandable desire for a “magic bullet” cures, leaves space for a proliferation of alternative therapies. While the potential for innovative approaches should not be ruled out, many are not supported by evidence (Lewith, Stuart, Chalder et al., 2016). Yet the financial gains for those popularising poorly-evidenced interventions (eg, vitamin treatments, “detoxification cures”, Mickel Therapy) - and the financial and emotional costs to vulnerable individuals - add confusion and heat to discourses surrounding intervention and outcomes for those diagnosed with CFS/ME.

2.3 Personal Constructions of CFS/ME: Illness Narratives

Having given a flavour of the way that CFS/ME is considered within professional narratives, it becomes important to recognise what these omit, and what alternative constructions may add. The last three decades have seen a proliferation of interest in first-person illness narratives - the accounts that the people who *live with* illness provide about their own lives - and in qualitative studies of health and illness that can provide a counterpoint to the “grand narratives” of science and medicine (Hydén, 1997; Lawton, 2003).

Over the last 15 years, there has been increased attention to illness narratives of adults living with CFS/ME and related conditions. The majority of these consider accounts elicited within semi-structured interviews or group discussions, and focus on experiential aspects of living with CFS/ME. Working primarily within frameworks influenced by phenomenology (Giorgi, 1985), grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) and interpretative phenomenological analysis (IPA) (Smith, 1996) which stay “close to” the accounts of participants, these provide rich descriptions of distress and debilitation experienced as a result of the condition. Though many of the *topics* of these narratives are similar to professional constructions (eg, symptoms, functional disability, contested theories of causes), they present a very different perspective which enriches our understanding. Then they speak on other topics: most notably, they turn the spotlight back onto the professionals who otherwise hold the authoritative voice, giving accounts of bruising encounters with their doctors and others in positions of power, and highlighting iatrogenic injuries; and they speak of less-easily observable topics, such as experiences of stigma and identities in transition. In this, newer qualitative methodologies that incorporate narrative and discursive analysis offer further possibilities for understanding, and these too will be discussed.

As with quantitative research reviewed in the previous section, there is variability in the quality of this qualitative research, and studies have been omitted where this is considered particularly problematic. The following section reviews approximately forty qualitative projects, including three review papers (Anderson, Jason, Hlavaty et al., 2012; Drachler, Leite, Hooper et al., 2009; Larun & Malterud, 2007), in which adults are asked to talk of their experiences living with CFS/ME. There is much less research of this type with children

and young people, and this will be reviewed separately afterwards. The major themes of these studies are summarised here, although categories inevitably intertwine so act as a guide only.

2.3.1 Living with the symptoms and consequences of CFS/ME

Qualitative studies provide vivid accounts of living with a range of symptoms which can change unpredictably in their nature and intensity. Although the symptoms themselves are, unsurprisingly, largely those listed in professional texts, such first-person accounts lift them off the text book pages and situate them in real lives, worlds that we may (at least to an extent) understand and empathise with. For example, while “fatigue” and “pain” - the terms used professionally - are descriptors that people might feel they recognise, accounts of *“days in bed with constant torture”*⁷, or trying to eat but finding *“I could not lift my arm holding the fork”* (Söderlund, Skoge & Malterud, 2000: 166) graphically depict a world away from normal tiredness or everyday aches and pains. Physical and mental *“fatigue within one’s self”* (Gray & Fossey, 2003), are communicated as an “extreme depletion” of energy (Anderson & Ferrans, 1997), like having an “empty battery or a blown fuse” (Larun & Malterud, 2007) or a limited resource that must be constantly monitored in order to plan for even basic functioning (Arroll & Senior, 2008). However a discourse analysis (Hart & Grace, 2000) notes that diverse and complex constructions of fatigue are articulated predominantly as an “absence”, not easily represented in biomedical terms; and it is argued that this may contribute to sufferers’ difficulties communicating and gaining validation of these symptoms within medical settings.

Pain is frequently described - in muscles, joints, lymph nodes, sore throats and especially headaches - which might last *“for days, even weeks; intense pain 24 hours a day”*, contributing to sleep disruption (Söderlund et al., 2000). A vicious cycle can then be understood, when fatigue exacerbates pain, and pain disrupts sleep, resulting in further

⁷ As part of the commitment to understanding the voices of those living with illness, direct quotes from these contributors are frequently used. These participant quotes are additionally italicised, in order to distinguish them from other forms of quote in the text (ie, the more traditional quoting/extract from professional voices; and also from my inclusion of some words within quote marks to draw attention to their socially constructed and potentially contested nature (eg, “malingering”)).

fatigue. Nausea, dizziness and muscle weakness are described “*like having the flu every morning*” (Larun & Malterud, 2007), along with less common symptoms such as over-sensitivity to light, noise or smell which make it impossible to bear ordinary conversation and social interaction (Söderlund et al., 2000).

The effects of mental fatigue on concentration, short-term memory and communication are highlighted as particularly difficult to live with. Beyond feeling “*too tired to even talk to anybody*” comes the social embarrassment of word-finding difficulties or “*totally forget[ting] what we were talking about*” mid-conversation (Hart & Grace, 2000). Inability to follow conversation, and reduced ability to read or watch television, are also described (Söderlund et al., 2000), contributing to a sense of isolation. The same study highlights potential dangers from mental fatigue, such as forgetting that the kitchen stove had been left on, raising questions for independent living.

Impacts of unpredictable physical, cognitive and communicative impairments on study or employment are also described. Ware (1998) highlights the difficulties of conforming to a work schedule when “*you never know when the illness is going to hit*”. Participants in this and other studies (see meta-synthesis by Anderson et al., 2012) describe a range of strategies used to “live within limits” (Travers & Lawler, 2008), focusing limited energy on priorities such as work, or hiding deficits. Despite this, 50% of Ware’s participants speak of losing their jobs as a direct result of CFS.

Losses are not just financial. Ware locates the loss of employment within broader processes of “role constriction” resulting from chronic illness, which act to marginalise those individuals unable to fulfil valued and expected social functions as employees, parents, partners, friends etc. Relatedly, a subjective experience of “loss of control” is frequently reported among those living with CFS/ME (Anderson & Ferrans, 1997; Clarke & James, 2003; Edwards, Thompson & Blair, 2007). Most speak of having had busy, active lives prior to the onset of their illness (eg, Lovell, 1999; Söderlund & Malterud, 2005), and of the devastation of losing valued relationships and roles as they became unable to plan for or cope with a social life (Åsbring & Närvänen, 2004).

First-person accounts are particularly powerful in conveying the personal and social impacts of dealing with ranges of symptoms that fluctuate over time without apparent reason: feeling “*overwhelmed*” (Edwards et al., 2007); lost in “*a wilderness and completely drowning in symptoms*” (Arroll & Senior, 2008: 449); “controlled and betrayed by their bodies” (Larun & Malterud, 2007). Depictions of disrupted lives also lead us into picturing the negotiations that must be had with friends, family and colleagues within a wider social context, and the difficulties that can be encountered.

2.3.2 Living with stigma and delegitimation

There is a considerable body of literature on ways in which people living with illness can become, and feel, discredited or stigmatised within society (Goffman, 1963). Attention has now focused on how the socially constituted nature of some illnesses in particular can exacerbate suffering associated with delegitimation: the experience of having one’s perceptions or definitions of illness systematically disconfirmed (eg, Kleinman, 1988; 1992). A number of qualitative studies have drawn attention to first-person accounts of these processes from those diagnosed with CFS/ME.

In an analysis of 50 interviews with chronically fatigued patients, Ware (1992) reports that 90% of these report delegitimising experiences, and highlights two types of encounter in particular that act to construct CFS as “not real”. The first appear related to the apparent insignificance of symptoms, given how common many of them are (aches and pains, feeling tired etc), leading to responses indicating a *trivialisation* of experience: “You’re tired? We’re all tired! So what!” (Ware, 1992:350). Thus the individual is characterised as *not really ill*. The second relates to constructions of CFS as psychosomatic, “hypochondriasis” or “all in your head”, characterising the individual as suffering from an *imaginary or mental illness*. Ware notes the impact of dualistic conceptualisations of “mind and body” on processes of delegitimation, and concludes (p353) that, “of the various forms of suffering that experiences of delegitimation can engender, none was as devastating for this group as the humiliation that resulted from having their subjective perceptions and sensations of illness either trivialized or dismissed as psychosomatic”.

Such devastation is equally audible in the accounts of Swedish women living with CFS/ME and fibromyalgia (a similarly “contested” condition) speaking of social encounters (Åsbring & Närvänen, 2002). These make clear that the apparent questioning of the veracity or physicality of the women’s symptoms is perceived as an assault not just on the credibility of symptoms, but the credibility of the woman herself - her moral character. As one woman puts it:

You see, I’m a super honest and sincere person and have been strictly brought up not to lie not to deceive, not to steal, not to do wrong [...] and then one has to listen to that sort of thing, that one is not believed huh, it is so hard that it is almost the worst thing. It has been worse than the pains, actually

Åsbring & Närvänen (2002:152)

Consideration of the impact of stigma and delegitimation on the self - or identity - will be considered further below. First, though, it is worth noting how the processes of trivialisation and “psychologising” are described in two different sets of social encounters: those with doctors, and those with friends and family.

2.3.2.1 Making sense of CFS/ME, and encounters with health professionals

Within Western societies, the onset of unusual bodily symptoms is met by a number of responses. First comes our own initial interpretation of the sensations: How can these be understood? Do they indicate a problem? Frequently we “make sense of” these from our own experience, with input from family or friends, or perhaps (increasingly) internet sites: a tension headache; the onset of a cold; the effects of over-indulgence. Often these interpretations mean that no action is necessary, or some self-remedy can be taken. However, if symptoms persist or are interpreted as potentially worrying, the usual course of action is to seek help from a health professional.

Participants in qualitative studies of CFS/ME consistently describe the difficulty of making sense of the onset of their symptoms. Fatigue, pain, dizziness, weakness, nausea etc can all be associated with life-threatening pathology (cancer, heart problems, auto-immune conditions, serious infection etc), so having “no idea what was wrong” is unsurprisingly

described as frightening (Blake, 1993). Two separate, though related, pathways became important: making sense of symptoms, and getting a diagnosis - which, in the case of CFS/ME, may take many months, even years, involving a “pilgrimage” of suffering while seeking answers (Bülow, 2008).

Stigmatisation is reported to be greater *before* illness is confirmed by diagnosis (Åsbring & Närvänen, 2002; Dickson, Knussen & Flowers, 2007). This may be understood in a number of ways, including the social processes in recognition and confirmation of suffering (Hydén & Sachs, 1998) and medical legitimisation of need for special care (Parsons, 1951). The importance of diagnostic legitimacy is repeatedly reported by those living with the symptoms of CFS/ME (Drachler et al., 2009; Dumit, 2006), not least to negotiate interactions with family, friends, employers and other health professionals. Diagnosis may then be understood as a way to combat the dual stigmatisation potential of trivialisation (non-recognition) and “psychologisation” noted above. Relatedly, an important feature of the diagnosis is simply that it is *not* a diagnosis of depression, anxiety, or some other mental health problem (Blake, 1993; Horton-Salway, 2004; McCue, 2004).

However, a number of qualitative studies (eg, Ax, Gregg & Jones, 1997; Cooper, 1997; Denz-Penhey & Murdoch, 1993) indicate that, for people experiencing medically-unexplained symptoms, processes of delegitimation may paradoxically be at their most apparent *within* medical encounters. Participants in Cooper’s (1997) study, for example, speak of repeated difficulties in meetings with health professionals, involving power struggles around degree and type of knowledge. They express distress at meeting scepticism; the shame of being judged as “not ill” with a legitimate, somatic condition; and the shock of meeting lack of respect or poor interpersonal skills in their doctors - being described as “malingerers”, “school phobics” or “bored housewives” - leading to a loss of trust in the medical profession.

Further, the diagnosis of CFS/ME does not actually answer the questions of “what *is* CFS/ME?” or “why did I get it?”. It is widely reported that sufferers describe CFS/ME as a *physical* illness with somatic aetiology, speaking particularly about biological agents such as chemicals (particularly for men) or infections (Anderson et al., 2012) as potential triggers. Further, sufferers and their families are sometimes portrayed as “resistant” to

multi-factorial models that include psychosocial factors (eg, Hardwick, 2005). However, while medical discourse and quantitative studies typically promote this perception (Butler, Chalder & Wessely, 2001), qualitative studies suggest more nuanced attributions. For example, though the Swedish women in Söderlund and Malterud's (2005) stress the aetiological significance of biological agents in creating physical vulnerability or triggers to their illness, some also make sense of their illness development with reference to psychosocial stressors, either in the lead-up to the onset of illness (eg, stress reducing immunity to subsequent infection), or as perpetuating factors impacting on their ability to recover or to manage symptoms optimally. One question to be pursued in this work is why such multifactorial reflection is reported only in some studies.

2.3.2.2 Social encounters

Of course, stigmatising encounters do not only occur in medical settings. Dickson et al (2007) focus attention on CFS sufferers' encounters with family and friends, and the distressing consequences of feeling disbelieved or distrusted by those closest to them. While their participants attribute problematic professional encounters to different models of illness (eg, "mind" versus "body" explanations), difficulties with loved ones are mainly attributed to the invisibility of symptoms, as well as general lack of understanding of the condition and a "wearing thin" of patience when sufferers are unable to fulfil social roles over time.

Nevertheless, there is a profound sense of sufferers feeling let down by the people who "should" understand; and that failure to understand patterns of symptoms or behaviours represents a lack of trust, and hence a form of personal rejection leading to feelings of isolation, distress and disillusionment. Again, the assault on the integrity of the character, rather than a simple questioning of behaviour, can be read.

2.3.2.3 Managing stigma? Introducing agency

One further aspect of delegitimation and stigma is important. Rather than simply seeing individuals as passive victims of stigmatising encounters, it should be noted that some report taking active steps to avoid further humiliation. For example, Ware (1992) notes

that some try to hide their difficulties from others, and “pass” as normal rather than expose themselves to the pain of being disbelieved (though with potentially negative consequences for symptom management and support). Other reported actions include developing knowledge with which to counter perceived ignorance about the condition (Åsbring & Närvänen, 2004), and learning how best to explain their condition in social situations, such as highlighting similarities with more familiar infections (“I say, ‘Well it’s kind of like mono. You’ve heard of mono? The Epstein-Barr virus? Well it kind of recurs in people”)(Ware, 1992:355).

Within medical encounters too, participants in Cooper’s (1997) study report learning to take active steps to counter disbelief and the stigma of perceived stereotypes, including “playing the game of the good patient” by not being too “provoking” towards doctors regarding knowledge gained from self-help groups, or taking other steps to gain legitimacy:

One thing also I’ve learnt is psychiatrists and doctors don’t like you in a wheelchair. So my immediate thing I said to him was “Do you mind if I sit in an ordinary chair?” And he looked at me and said “Why?” I said “I feel more normal there”. I didn’t tell him, you know, something I had learnt, you know, what to say to them

“Irene” in Cooper (1997:199)

This highlights that sufferers learn - often through bitter experience - of the ways in which their condition, and their moral characters, may be perceived; and some steps that may be taken in an attempt to manage this in different situations.

Methodological implications

These examples of agency are important for considering the *contexts* in which people give accounts of their experiences, and the interpretation of research findings. Participants will naturally have expectations of the researchers (particularly if working in health / professional settings), or the wider audiences for the research, and what they might conclude about the individual or their condition (eg, are doctors or researchers trying to prove that CFS/ME is a psychological condition?). We should therefore not be surprised if

participants attend to this in their accounts - for example, taking care to counter assumed misperceptions.

The majority of qualitative research reported here adopts research paradigms that adopt a hermeneutic of empathy, seeking to “hear the voice” of participants and take largely at face value their accounts as representation of experience. However, this approach - while laudable in its attempt to raise awareness of marginalised and distressed people whose voices are typically not well understood - may be critiqued for its failure to consider accounts of experience as social *actions*, actively shaped by the contexts of their production, including the need to counter stereotypes or other dominant narratives about CFS/ME. The methodological and wider implications of this critique will be returned to shortly.

2.3.3 CFS/ME and Identity

2.3.3.1 Narrative, illness and identity

The review above highlights several troubling aspects of living with CFS/ME. Loss of control and role constriction arising from disabling, unpredictable and hard-to-explain symptoms clearly impact on people living with a range of chronic illnesses, but the burden of stigma and delegitimation is argued to be particularly acute for those living with contested conditions like CFS/ME. CFS/ME can then be considered to affect not only bodies or practical aspects of living, but people’s sense of “self”, their *identities*.

There are multiple understandings of “identity” and “self”, only some of which can be considered here. At its most basic, this explores questions about who we are, and how others see us. While the personal “sense of self” is often spoken of, most widely-accepted definitions also consider social aspects, understanding the self to be constructed through reflexive interaction with others. The telling of stories about ourselves and our lives can be seen as both constructing and presenting “narrative identity”, our sense of “selfhood” (Murray, 2008): *who* a person (or group) is, or wants to be, or wants to be seen as by others (“what does this story say about me?”) – something arguably of particular importance following critical situations such as diagnosis of serious illness (Giddens, 1991). However,

scholars have different perspectives on just what narrative identities and selves *are*, and how they should be studied (Smith & Sparkes, 2008). Different ontological and epistemological perspectives lead to different foci, for example on the inner world of individuals (assuming a high degree of personal agency, striving towards construction of a relatively stable, coherent self), or alternatively on the social relational world, and the ways in which this constitutes identities (or subject positions) within society (Benwell & Stokoe, 2006).

The impacts of serious illness on the self, and the interplay between the body, biography and self are well-explored (Corbin & Strauss, 1988). Charmaz (1983) proposes that illness brings about a fundamental *loss of self*, noting the relationship between suffering, self and moral status in stories of living with illness. Bury (1982) considers illness as a *biographical disruption*, perturbing expected social structures and roles that in many ways define the self. In this, he stresses the interplay between context and the *meanings* of the illness, both in terms of its consequences (eg, inability to work) and significance to the individual.

The concept of biographical disruption remains influential, but has been critiqued and developed. While the seminal work focused on loss and disruptions to self brought about by the onset of illness in middle age, it is now recognised that this over-simplifies the diversity of experience among those living with chronic illness and disability (Williams, 2000b). Personal and social circumstances, age and nature of the illness, for example, are all considered to impact on variations of the concept, such as biographical continuity (Ong, Jinks & Morden, 2011), biographical reinforcement (Carricaburu & Pierret, 1995), biographical abruption (Locock, Ziebland & Dumelow, 2009) and biographical contingency (Monaghan & Gabe, 2015). Despite this growing awareness of factors like developmental context, biography remains under-examined both empirically and theoretically for CYP living with chronic illness (Bray, Kirk & Callery, 2014).

Additionally, while the earliest studies focused on the loss and disruptions brought about by the onset and burdens of illness, it is now recognised that this is only part of the story. Over time, individuals can be seen as reacting to preserve, reconfigure or reconstruct a valued identity and life story (eg, Frank, 1995; Williams, 1984). Thus the emergent and

unfolding nature of chronic illness make it imperative to consider experience and identity within a temporal framework (Bury, 1991).

Though a range of qualitative methodologies are seen in these studies, it is argued that narrative analysis is particularly well-suited to exploring temporal (re-)construction of illness / biographical narratives. The concepts of “narrative”, and the related “story”, are used and critiqued in various ways (see chapter 3), but can broadly be understood as forms distinguishable from surrounding discourse by their incorporation of temporal aspects into “making sense of” experience and the self within a shared cultural framework. It is argued that constructing stories or narratives is fundamental to the way in which humans (dubbed by Fisher (1984) *homo narrans*) attempt to “imbue life event with a temporal and logical order to demystify them and establish coherence across past, present and as yet unrealised experience” (Ochs & Capps, 2001:2).

There are then many forms of narrative analysis, incorporating realist, postmodern and constructionist strands (Riessman, 2008), and the implications of these different forms will be explored more fully later. For now, it is worth briefly noting that most forms of narrative analysis attend not only to the *content* of talk, but also *how* it is said, particularly in terms of narrative structure.

For example, the influential work of Arthur Frank proposes that people’s illness narratives position both experiences and identities within three main structures (Frank, 1995). *Restitution narratives* are most commonly associated with expectations of common or acute illness, where a previously-healthy life and identity will soon be restored (plot: “yesterday I was well, today I am not, tomorrow I expect to get better”). In contrast, *chaos narratives* are associated with chronic illness in which an “emotional battering” at the hands of unpredictable symptoms, unsympathetic responses, and lack of control preclude a plot or a clear path ahead. Finally, *quest narratives* are argued to portray individuals accepting illness and seeking to make use of it as a challenge and impetus for change, structuring a plot with a trajectory of learning, personal growth and potential way forward.

Analysts then consider movement between the different types of narrative over time, influenced by the nature of the illness/disability and wider factors (Yoshida, 1993).

Importantly, illness narratives form a link between the relating of individual experience and that of others living with similar conditions, and the symbolic meanings associated with different illnesses or groups of people may be seen reflected in narratives (eg, metaphors of “battles with cancer” calling for quest narratives and “heroic” identities (Thomas-MacLean, 2004)).

2.3.3.2 Narrative constructions of CFS/ME and identity

A small body of literature has explored the relationships between CFS/ME and identity constructed in illness narratives. Drawing on interviews with Scottish women, Dickson, Knussen and Flowers (2008) consider CFS as a “dictator” of everyday life, causing change and loss of agency that precipitates a crisis of identity and process of comparison between the currently ill and the “old”/“desired” self. Scepticism and the contested social meanings of the condition in the wider social environment are seen as exacerbating identity crisis, sometimes leading to an “internalising” of the scepticism and a self-questioning (“is this all in my head?”), with the possibility of psychological disorder and the stigma this entails (Ware, 1992). Similar biographical disruption is reported in Åsbring’s (2001) study of 26 Swedish women living with CFS and fibromyalgia. However, both studies suggest that, over time, sufferers undergo a gradual process of “acceptance” as a component of adjustment, involving development of a new illness identity as part of a process of “moving on”. For some (but not all) participants, this is portrayed as involving existential gains such as insight into life priorities beyond work and materialism, or increased compassion for other people’s experiences of hardship.

Challenges and developments to identity over time are explored further in narrative studies of people living with CFS/ME in Australia (Travers & Lawler, 2008), New Zealand (Bell, 2013), Canada (Clarke & James, 2003) and the UK (Whitehead, 2006a), with many parallels. All depict major assault on identities from the dual threats of disruption and invalidation in the early and most acute phase of illness pre-diagnosis, leading to a “disrupted self” (Bell, 2013) or “violated self” (Travers and Lawler, 2008) as adoption of traditional sick roles leads to multiple losses.

All these studies then consider the majority of participant narratives to reflect identity reconstruction, as the “struggling self seeking renewal” (Travers & Lawler, 2008) works to develop a new sense of the normal and their place within altered worlds, speaking of a “new self” or “realigned self” (Bell, 2013). Most studies suggest that the self continues to be viewed as changed, but that this change is now interpreted by participants as positive, with a focus on the wisdom acquired through experience. Nevertheless, oscillation between positions is envisaged, particularly precipitated by relapses in physical symptoms, between times when disability is viewed as all-encompassing, to its becoming incorporated as just part of the total self. It is also noted that that attempts at realignment may be resisted by friends, family or doctors, and interpreted as “invalidism” (Bell, 2013; Travers & Lawler, 2008). Thus there is scope for further exploration of the social as well as the personal conditions that allow or restrict opportunities for such “adjustment”.

Some interesting parallels may be observed in the CFS/ME illness narratives generated by Travers and Lawler (2008) and in Whitehead’s (2006a; 2006b) longitudinal study, as these are interpreted in terms of Frank’s (1995) narrative approach. Both conclude that, for the majority of participants, stories of the onset and early stages of illness follow a typical restitution plot, which then fails as restoration of health does not occur. Chaos narratives then follow. In keeping with Frank’s (1998) observation, the sometimes chaotic and apparently non-logical structure of these narratives accompany expression of anger, isolation, hopelessness and expressed inability to control or predict the future; and it is within these chaos narratives that violated identities are most apparent. For some, re-emergences of restitution plot may occur, although these appear easily interrupted by relapses of symptoms that herald return of chaos narratives. Over time, a majority of participants present quest narratives, arguably paralleling interpretation of “reconstructions of self” (Whitehead 2006a), telling of how life lessons are learned and shared, and new personal qualities are developed.

Despite similarities, there are some differences between these studies. For example, Whitehead discerns greater impact than the “partial identity disruption” reported by Åsbring (2001) in the early stages of illness. Later, Whitehead (2006a) and Åsbring (2001) consider the development of “new selves” to incorporate both elements of old selves and new features; whereas Clarke and James (2003) suggest more drastic change within some

individuals, rejecting old values and identities, and taking on what they characterise as “radicalised selves”. Similarly, not all participants give “quest” narratives of self-development, even after living with illness and disability for some considerable time (Whitehead, 2006b).

It is unclear how these differences should be understood. As noted previously, research in CFS/ME is fraught with methodological difficulties, and the limitations of many of these studies - and their reporting, particularly under the space constraints of journal articles - contributes to difficulties with interpretation. These include differences in (and unclear reporting of) participant characteristics (eg, diagnostic criteria for inclusion, nature and duration of symptoms, age/life stage currently and at onset of illness, cultural background etc); nature of participant recruitment (eg, from community vs specialist sites); and lack of clarity about the interview context, not only in terms of the “interview schedule”, but also the nature of the interaction (the interviewer is rarely included in quotes provided, making it hard to discern the co-construction of narrative). Often analyses of participants are quickly “pooled”, so there is little information about the development of narratives *within* individuals. The reliance on retrospective accounts, and lack of longitudinal design (with the exception of Whitehead’s study), similarly is a limitation. Many questions remain about how and why these different types of narrative evolve; why they appear different for different people; and what implications can be drawn from this.

Further, these studies largely report narratives as simple representation of experiences, albeit developed with retrospective “sense-making”. However, narrative must also be considered as a social form. Frank (1993) reflects on the evolution over time within Western cultures of a “rhetoric formulating the self as a project for change”, and the social expectation that certain events - including illness - will prompt projects of transformation and positive self-change. Thus “quest narratives”, for example, may be understood as rhetorical constructions (alongside familiar forms such as “discovering who I really am” or “discovering a better me”). Is there a cultural pressure on individuals to produce such narratives of self-development? And might some (research or social) contexts set up particular expectations or pressures?

Interestingly, there are hints from other types of qualitative study that this may be a factor. For example, in a brief consideration of the “tone” of narrative accounts, Dickson et al (2008) suggest “a tangible sense of ‘distancing’ and some sense of the participants being removed from their own accounts” in talk about adaptation to illness, suggested by discursive features such as shifts from first-person to third-person narrative, or presenting less personal, “generalised” accounts. (Some similarities may be discerned in accounts reported by Arroll and Howard (2013), who explore the possibility of post-traumatic growth (PTG) among a minority of individuals living with CFS/ME.) The methodological approach of these studies does not focus further on this type of discourse analysis, but these observations suggests that further exploration of the discursive features of narratives - and what they may or may not represent for speakers - would be of value.

The relationship between language, narrative and experience is complex. Frank stresses that awareness and use of rhetorical “technologies of the self” (Foucault, 1988) should not be taken to deny *experience* of self-change; indeed, he notes that they may act as *resources* for self-change (Frank, 1993:50). However, this awareness does suggest the need more careful analytic consideration of how narratives are used, beyond simple presentation of “experience” or “identity” (Benwell & Stokoe, 2006). To what extent are people constrained or enabled by socially-understood forms of narrative or wider discourses? What happens when these do not “fit”, or bring other difficulties (such as stigma)? Might different narrative forms be more or less available to some individuals than others - for example, men compared with women, professionals with “patients”, and - central to the current thesis - for young people compared with adults?

2.3.3.3 Discursive construction of CFS/ME and identity

The rhetorical work and social actions of narrative are explored further in studies informed by discourse analysis, sometimes incorporated within narrative analyses. Though there are variations, Goffman’s (1959) concept of “presentation of the self” often provides a starting point. Narrative, like other talk, is considered as a discursive resource used for different social purposes: not simply to re-present experience, but to educate, entertain, persuade and argue particular constructions of “experience” and identity (Riessman, 2008).

The uncertainties and controversies surrounding CFS/ME, including the often dichotomous positions (mind vs body, physical vs psychological, real vs unreal), have already been considered in terms of their *impact* on sufferers. However, a small but growing literature informed by discursive approaches now explores how people living with CFS/ME *take up positions in relation to* these dichotomies in ways that attend not only to alternative constructions of the illness, but also the identities of those involved, particularly with respect to attribution of blame and accountability. Here illness accounts are not seen as statements of fact, experience or fixed internal beliefs, but as claims (Radley & Billig, 1996) made within specific interactions, working to legitimate particular versions of self or illness, and undermining others.

Thus Bülow (Bülow, 2008; Bülow & Hydén, 2003) considers illness narratives of people living with CFS/ME as “identity performances” (Mishler, 1986, 1999) co-produced by speaker and listener. These approaches problematize the status of illness narratives, considering them as complex social productions (Horton-Salway, 2001b). This should not be considered as treating people’s accounts as motivated by insincerity, but does not assume an equivalence between people’s accounts and their internal experience or cognitive processes. Though not focusing on “experience” in the sense of an inner lifeworld, it can be argued that these approaches offer insight into the ways in which people with CFS/ME experience the social world, and the need to position themselves within it through their talk.

Three related aspects of this discursive work have been considered (Guise, McVittie & McKinlay, 2010; Guise, Widdicombe & McKinlay, 2007): how talk addresses the different constructions of CFS/ME; the warranting of knowledge claims; and dealing with the implication that sufferers may have psychological rather than physical illness.

With respect to the first of these, a number of different “interpretative frameworks” can be seen being employed as sufferers speak either in research interviews, patient groups (Bülow & Hydén, 2003) or in directly-observed discussion with their doctors in medical consultations (Banks & Prior, 2001) - to the extent that Banks and Prior consider these consultations as the sites of “micro political struggle” in which the “true” nature of illness is actively contested.

However, rather than focusing on the possibility of different frameworks or types of knowledge, Horton-Salway (2001a, 2004) argues the need to consider *how* people establish their entitlement to make authoritative claims about CFS/ME - that is, that *their* versions of reality should be accepted over others. Analyses highlight how a number of discursive strategies operate to this end. For example, speakers make relevant their membership of particular categories (eg, health professional with expertise; sufferer with a long history of personal experience) and use discursive positionings of “expertise” or “experience” as forms of knowledge that may “trump” others (Horton-Salway, 2004). Equally, sufferers are heard to position CFS/ME (often with use of medical language) as a condition that *is* known, understood and corroborated by *specialist* doctors; the failure of “ordinary” GPs to recognise and diagnose the condition can then be constructed, by contrast, as due to their relative lack of knowledge (Tucker, 2004), rather than reflecting a problematic construction of the illness. Legitimacy through “corroboration” can also be seen evolving in conversations within a CFS support group, in which consensual views are co-constructed, and later drawn upon by individuals to compare and validate their own personal experience narratives (Bülow, 2004; Bülow & Hydén, 2003).

Finally the *implications* of the questioned legitimacy of CFS/ME - such as the stigmatising notion that sufferers are psychologically disturbed or malingering - can be seen being managed discursively. Some of these threats may be dealt with by addressing the legitimacy of the illness itself, as above. Additionally, Guise et al (2007) identify a range of discursive approaches in operation as women speak within a support group, adding strength to their claims of legitimacy through reported corroboration, membership categories and “active voicing” (Wooffitt, 1992). For example:

I did say to [my husband] ‘look (..) do you think it’s depression or do you think there’s something wrong with me () do you think I’m making it all up’ [...] ‘no’ he says ‘ I live with you to day and (.) I know there is definitely something wrong’

“Liz” in Guise et al (2007:101)

Narrative accounts of the *onset* of illness are often important sites for analysis. It is argued that “attributional stories” that speak of CFS/ME as arising through biological agents such as flu viruses not only construct CFS as a physical illness, but simultaneously attend to implications for the character of sufferers, such as their culpability for becoming unwell. Similarly, potential negative identities as lazy or depressed are addressed in talk about previously happy and active lives. However, this is not an easy task. Horton-Salway (2001b) notes how a face-value reading of this “active lifestyle” narrative may, paradoxically, contribute to alternative discourses where sufferers are positioned as personally culpable for illness because of an over-active or overly-ambitious lifestyle. The cruel paradox - where attempt to avoid one negative positioning may implicate oneself in another - highlights the importance of analyses that sensitively consider the social actions of talk within local and broader discursive contexts.

The discursive context of contested illness is clearly relevant here, but other contexts - for example, the gender and social position of the speakers - are also important. And, crucially, the context of childhood and adolescence brings another dimension to understanding illness narratives of young people, largely unheard at this point. It is to these voices that we now turn.

2.4 Constructions of Young People living with CFS/ME

2.4.1 Marginalised voices?

In contrast to the forty or so papers identified that examine adults’ accounts of living with CFS/ME, there is a paucity of good-quality research focused on the voices of young people. This absence mirrors the situation in paediatric illness research generally. Historically, the emphasis has been on children as the objects (rather than subjects) of research; on child variables rather than children as persons; on child-related outcomes rather than processes; and with the perspective of children as not-yet-adults, rather than persons in their own right (Alderson & Morrow, 2011; Greene & Hill, 2005).

Beyond biomedical studies, much of the research with CYP experiencing chronic illness utilises traditional quantitative paradigms grounded in developmental and socialising

models or models of psychopathology which then highlight deficits from a proposed “norm”. In line with wider discourses of children as innocent and vulnerable (James, 1998), they are then seen as the victims not only of physical ill-health but also psychological ill-health such as anxiety, posttraumatic reactions and dependency (Barakat, Kazak, Gallagher et al., 2000). Often this leads to a situation where young people’s experiences are de-contextualised and heard only through a filter of adult models, failing to see them as “normal people living in abnormal situations” (Eiser, Hill & Vance, 2000), or within the particular social contexts of youth.

More recent social studies of childhood have challenged some of the assumptions underpinning our positioning of CYP within society (Corsaro, 1997; James, Jenks & Prout, 1998; James & Prout, 1997; Nikitina-den Besten, 2009; Prout, 2005). In line with wider social movements (UN Convention on the Rights of the Child, 1989), there have been increased calls to hear the voices of children with chronic illness (McLaughlin, 2015; Sartain, Clarke & Heyman, 2000), and a small but growing body of literature indicating not only the possibility of conducting this type of work, but also the value of doing so. And, while some have criticised the lack of attention given to the youngest members of society, it is also recognised that “adolescents” (or “youth” or “young people”) occupy a particularly difficult position - neither children nor adults - generally and within health services, so further understanding of their situation is needed (Graham, 2004; Kehily, 2007).

2.4.2 Narrative constructions of young people living with CFS/ME

Very few qualitative studies have explored the illness narratives of children or even older young people (YP) living with CFS/ME, and some of these are problematic methodologically. The earliest (Brotherston, 2001) is a retrospective grounded theory study of accounts produced by 4 young women in their early 20s, looking back on their teenage years (and only 3 were under the age of 18 at the onset of symptoms). Thus these are arguably not “voices of young people”, since narratives will be re-presented through the lens of early adulthood. Nevertheless, the study highlights the disruption and distress resulting from missed schooling, lost peer relationships and family tensions around different illness beliefs; and there are suggestions that the anger and isolation following

loss of friendships, coupled with the impact of felt and ascribed stigma, may contribute to longer-term issues in social relationships.

Male and female teenagers' voices are heard more directly in three recent studies based on interpretative phenomenology. Though similar in age (12-18), participants vary somewhat. The 5 interviewed by Jelbert, Stedmon & Stephens (2010) were all considered "recovered", so were giving retrospective (albeit recent) accounts. In contrast, the 11 interviewed by Fisher and Crawley (2013) had only recently been assessed at a specialist CFS clinic; but were selected (in line with the study's focus) for their relatively high levels of social phobia and/or separation anxiety, so do not represent a wider CFS/ME population. Finally, the 17 interviewed in a Norwegian study (Winger, Ekstedt, Wyller et al., 2014) were recruited from a larger study exploring RCT of medication (Wyller, Eriksen & Malterud, 2009). Even within "open" interviews, the different nature of the three studies can be expected to influence not only recruitment, but also the focus and expectations of the interview and analysis. One further study (Williams-Wilson, 2009) is also considered, though with caution: this explores narratives of 8 CYP with a thematic analysis, but the 5 participants under 18 years were interviewed with a parent present, and there is little consideration of this context for what the YP might feel able to say.

Despite this, many similarities appear evident in these studies. As in adult studies, while physical symptoms are described, the social and psychological implications of the condition are even more dominant. All set out stories of loss, as the illness limits participation in normal adolescent life - school, hobbies, social contact - leading to boredom, isolation, "*having to put life on hold*" (Williams-Wilson, 2009) and "*missing out*" (Jelbert et al., 2010) while "*the world goes on without me*" (Winger et al., 2014). Emotionally there is expression of feeling not just "different" but also forgotten by peers. Winger et al (2014) describe the dual process of being "shut in and shut out": initially shut in(side) the home by the need for rest, but also shut out of social groups as they try to return to school, by peers who view them as "different", and teachers unprepared to help with their increased needs.

Like adults, these YP speak of difficulties associated with the unknown and contested nature of their symptoms, particularly prior to diagnosis (a process compounded by diagnostic delay), and feeling that others did not believe them. For some this is described

as leading to self-questioning: “...you’re not bleeding, you’re not ill, you’re faking it... I was just thinking, well what is this, you’re making it all up, you’re going crazy” (Jelbert et al., 2010:271). The majority speak of ongoing fear or actual experiences of judgement from peers, teachers and others, with accusations of laziness and “skiving”.

Additional emotional burden is ascribed to worry about missing school work and being unable to catch up, with great variation in the level of support described from educational providers. Some also describe the challenge of altered family relationships, including feeling guilty about the financial burden when a parent stops work to care for the ill child, and concern about lack of age-appropriate independence. These stresses, alongside physical or mental over-exertion, are then described by some YP as exacerbating their illness (Jelbert et al., 2010), even though the initial cause of illness is maintained to be biological.

As in adult studies, YP consistently describe themselves as having been healthy and active prior to CFS, contributing to sense of loss of the “normal” self, and development of a “vulnerable self” (Fisher & Crawley, 2013). While some suggest that losses and ongoing uncertainty threatens hope for the future, others set out small narratives of positive change and even personal growth, such as closer family relationships, and an enhanced appreciation of themselves, life and compassion for others. Perhaps unsurprisingly, this is particularly noted by Jelbert et al (2010), whose participants were all considered “recovered”. These teenagers are able to speak of getting “back to normal”, with positive shifts in expectations for the future (although accompanied by caution and expressed fear of relapse). However, optimism and personal growth is also heard from the some of the still-unwell young people interviewed by Winger et al (2014) - though not reported in Fisher and Crawley’s study.

As with adult studies, it is unclear why talk about personal growth should be apparent among similarly-aged, similarly-ill participants in Winger et al’s (2014) but not Fisher and Crawley’s (2013) study. One possibility is that the relatively high levels of social anxiety in Fisher and Crawley’s participants is a factor, and the difference is attributable to different participant characteristics (though the reverse causality is also plausible). As before, limitations in methodology and reporting hinder interpretation. For example, while both

studies report use of “open-ended questions”, lack of detail about the interviews limits understanding of the context and co-construction of narratives (eg, encouragement of conversation about particular aspects of living with illness) or the trajectory of narratives *within* individuals.

None of these studies is longitudinal, and none adopts a sustained narrative analysis (ie, consideration of how participants structure their stories over time, attending not just to the *content* of talk, but also *how* it is put together). Equally, they generally treat talk as a fairly straightforward representation of personal experience, with little consideration of the constructive and social actions of language, either in terms of the power of prevailing and dominant discourses (what it is possible to say) or the potential agency of individuals to resist and challenge such constructions. Thus, while these studies highlight that young people - like adults - express concern at the impact of being disbelieved or considered lazy as a consequence of their condition, there is almost no consideration of the steps they may take to address this within the social interaction of their research interview.

An exception comes in a brief observation from Hareide, Finset & Wyller (2011) of what YP may be prepared to say about their “illness beliefs” to whom, and when. This study, like that of Richards et al (2006), interviewed YP (aged 12-19) living with CFS/ME to explore their beliefs (eg, regarding illness causation and treatment approaches). Both studies note parallels with adult studies, in that (in contrast to quantitative surveys in which patients report illness to be purely physical) some participants produce more complex understandings, with a minority suggesting that psychosocial stresses play an additional role as part of a multi-causal understanding. However, Hareide et al additionally note that, within interviews, all their participants *initially* put forward purely somatic models of understanding; and the three (of 9) who volunteered psychosocial factors did so only later in the interview “at a point in the conversation when their somatic understanding had been validated by the interviewer” (Hareide, Finset & Wyller, 2011:2260). Further, they report the words of one participant, talking explicitly about what she will say to whom:

I have made a simple version where I say that I had a virus in the body that triggered it, and so I got sick. I've just sort of said that. I have not really told it

all. If I were to tell everything, I would have started with Dad and it would be very much more complicated

“G2” in Hareide et al (2011:2258)

Significantly, the majority of these CYP reported previous negative encounters with health professionals, stating that they felt doctors had not taken them seriously, or labelled them as either lazy or psychologically disturbed. The authors suggest that experiences of disbelief increase the likelihood that patients will stress physical symptoms when they feel challenged, and be careful who they share all their thoughts with. Unfortunately, the design/reporting of this study does not allow further exploration of this. However, this brief observation does indicate that CYP, like adults, may be understood as understandably active in the presentation of their stories and identities in different settings.

2.4.3 Discursive constructions of young people living with CFS/ME

Only one study has been identified that explores how YP diagnosed with CFS/ME may address such interactional concerns. This single-case study (Crix, Stedmon, Smart et al., 2012) uses a discourse analytic methodology to examine processes by which members of one family define and understand a contested diagnosis through talk-in-interaction, drawing on broader social discourses as they construct their experiences. Close attention to interactional features of talk identifies the scripting of two opposing constructions of CFS/ME - as a “genuine illness”, or as an illness “intentionally used for advantage” - and how these versions function to position family members in relation to the illness and to each other, attending to issues of agency and personal accountability. They show how even younger (teenage) members of the family use discursive techniques (eg, drawing on category entitlements) to lend weight to their own preferred constructions.

Though the single-case design of this study is specialized, it highlights the potential for considering micro-discursive processes of talk in the ongoing construction of illness, identities and relationships within young people’s social worlds. In doing so, young people - like adults - are of interest as “social actors” (Wetherell, Taylor & Yates, 2001), contributing actively to the discursive construction of different understandings of their lives.

2.5 Gaps, concerns, and ways forward

It is perhaps surprising that there is so little health-related research with CYP using discursive approaches. Why this relative absence?

As with adults who are unwell, concerns about the vulnerability of participants are important. Qualitative research that seeks to “give voice” to the previously-marginalised can be argued as justifying the burden on research participants. However, narrative and discursive analyses that consider the rhetorical functions and social actions of talk may be viewed as employing a “hermeneutic of suspicion” (Ricoeur, 1970), problematizing speakers’ voices. Even if (as I would argue) there is no intent to suggest manipulation, or to claim a “truer” understanding of participants’ narratives (Josselson, 2004), the researcher can nevertheless be seen to have different interests from participants. For example, where narrators are wishing to gain audiences for “how it was for me”, researchers may be more interested in the conflicting cultural discourses shaping the presentation (Chase, 1996).

This gives rise to ethical concerns about engaging potentially vulnerable participants in discursively-focused research (Hammersley, 2014). Concern seems particularly pertinent in the case of those living with contested conditions, or those whose immaturity may render them particularly vulnerable. However, I would argue that lack of attention to the complex constructions that YP can produce is also a reflection of ongoing cultural dismissal of their potential roles in society as “social actors”, able to shape - through physical and discursive action - the environment in which they live.

So, while I share ethical concerns about the wellbeing of research participants, I argue that failure to engage fully with the voices of YP - both what they are saying, and *how* they are saying it, to whom, and in what local and broader contexts - does them a disservice, by perpetuating discourses of YP as passive “victims” of illness and society, and underestimating their contributions as embodied actors (Mayall, 1998). Close examination of narratives of YP living with contested illness has the potential to add to our understanding of the ways in which the social contexts of “youth” interact with others such as illness or gender. Further, attention to discursive or performative features allows consideration of the different ways that young people find to negotiate potentially

troubled terrain in accounting for their experience, which in turn may have implications for how they are received, understood and supported by others.

Summary

This chapter has given a brief account of how powerful and opposing constructions of CFS/ME have developed over time, and how these provide an ongoing context to the experiences and narratives provided by those currently diagnosed with the condition. The relative power of some discourses over others can be discerned, as can their potential to position the identities of those affected. However, more recent considerations of personal illness narratives also point to acts of resistance, attempts to discursively reconstruct less stigmatising positions - although with sometimes unpredictable consequences.

There has been very little focus on children and young people, but hints that they too can provide rich and valuable narratives that say much about the complex contexts of their lives, as well as their own potential to manage these. Particular gaps in the literature give rise to the argument that further research is needed, attending closely to what CYP have to say about lives lived with a contested illness, and thus the following research questions:

- How do YP narratively account for lives lived with a diagnosis of a contested condition, and a potentially contested identity?
- What do their narratives tell us about the social contexts in which they must establish themselves as valuable, valued young members of society?

Chapter 3

Methodology

3.0 Overview

The two previous chapters provide some context and rationale for further research into the worlds of young people (YP) living with a diagnosis of CFS/ME, in terms of gaps in current academic and professional understanding. They also set out the epistemological lens through which I view the “knowledge” currently available.

It is argued (Langdrige, 2004; Mason, 2002) that a researcher’s epistemological position should then be central and consistent in influencing the methodological approach taken to that research: not only in selection of methods (procedures, tools and techniques), but also broader aspects such as the relationship between researcher and participant, communication with the audience, approach to demonstrating the quality of the method, and claims made for the interpretation of “findings”.

Within the constructionist position adopted, knowledge is held to be constructed relationally, situated culturally and historically. This problematizes the traditional research goal of unearthing “truth”, promoting respect for multiple positions. Nevertheless, as argued throughout this thesis, audiences should be able to make judgements about the credibility of particular positions argued for.

This chapter therefore aims to set out the process of research undertaken, to provide a context for readers to make judgements about the interpretations and claims that are made for it. I begin by clarifying my position on some key concepts and decisions, providing a rationale for the methodological approach and steps taken to demonstrate credibility of the work. I continue by setting out more detail of the study design and development, attention to ethical commitments, and approach to engaging with young people (YP) and narratives constructed as part of the research encounter. As part of this, I include details

of some of challenges encountered, departures from the apparent “neatness” of research represented in some texts, and attempts to work with - and learn from - these.

3.1 Methodology

3.1.1 Why narrative? Why narrative inquiry?

There are many understandings of what narrative *is*, what it is for, what it does, and what it can tell us about the world; and an accordingly diverse range of approaches to studying it. This is not the place to review all of these, and readers are directed to the many informative texts that consider the ontological, epistemological and methodological implications of different approaches within the “narrative turn(s)” (eg, Andrews, Squire & Tamboukou, 2013; Atkinson, 1997, 2010; Atkinson & Delamont, 2006; Bamberg, 2012; Bamberg & Andrews, 2004; Bruner, 1987, 1991; De Fina & Georgakopoulou, 2008; Mishler, 1986; Murray, 2008; Ochs, 2004; Peterson & Langellier, 2006; Polkinghorne, 1988; Ricoeur, 1984; Riessman, 2008; Sarbin, 1993; Smith & Sparkes, 2008). Here I will limit discussion to developing some ideas touched upon in the previous chapters, setting out how my own position provides a rationale for studying narrative with a particular methodological approach.

As outlined at the start, this project arose from two related concerns. At the broadest level, a concern with how health and illness come to be constructed within society, and the implications for those who live with, or work alongside, conditions of bodily distress. And more specifically, a concern for those - children in particular - whose embodied experiences are not easily understood within accepted medical frameworks, and how they can come to make sense of and manage their situation within contexts that may marginalise their voices. These concerns were prompted by the stories I heard from “patients”, families and clinicians within the health services where I worked. Narrative and “story-telling” (see below) are the primary means by which people communicate in such clinical settings (Mattingly & Garro, 2000), and I became acutely aware of what can be learned by careful attention to these “first-person” accounts of lives, as well as their social importance - what

they say about the worlds we inhabit, the identities of those involved, and what they *do* to us as social beings.

Bruner (1986:11) proposes that, through language, narrative provides a way of “ordering experience, of constructing reality”, and is a fundamental human way of making sense of the world and our place in it. We live in a narrative-saturated and “story-shaped” world (Bruner, 1986; Polkinghorne, 1988), surrounded by folklore, parables, myths, histories, literature, popular culture and political discourse that tell repeatedly of each culture’s values, expectations and “normality”, providing “...libraries of plots [that] help us interpret our own and other people’s experience” (Sarbin, 1993: 59). These can act as templates for individuals or groups to construct stories of their own experiences, linking the personal with the cultural. Then, as we tell our stories to others, their responses recursively shape further understanding⁸. Thus narratives do not simply *relate* or *represent* experience, but – through their construction, communication and responses - actively *shape* people’s experiences of the world.

More broadly, we understand that stories allow listeners to learn something of other people, other lives and experiences they have not personally experienced. Though it is possible to consider stories as simple, more-or-less accurate representations of the “facts” of events, most would follow Bruner (ibid) in arguing that stories construct two landscapes: one of action (what people do); and one of consciousness (what they think, feel or believe), understanding that the “meaning” of stories often relates to the interplay between these. Stories are then (with some provisos) commonly understood as “experience-near”, drawing listeners to infer something about what it feels like to be within that world, while accepting that this will be influenced by the narrator’s personal perspective, and that other people could experience things differently. The approach does not assume objectivity, but privileges positionality and subjectivity (Riessman, 2002a) from the position of narrators and listeners.

⁸ Of course, we also tell stories to ourselves when we are alone. However, it is argued that even this draws on imaginary audiences, and imagined responses drawn from our existing understandings of how these imagined audiences might respond.

Narrative or story? A brief aside

Within social research, a “story” is commonly understood as the depiction of either events or experiences. Often the term suggests a fairly short, temporally-bounded sequence with relatively clear beginning (“how it all began”), middle (“how things progressed”) and end (including demonstrating the “point” of the story - why it was worth telling, perhaps because of its impact on the teller, or its social commentary) (Labov, 1972). Early work on such “storied form” focused on first-person telling of past events. However, broader definitions now extend this, allowing for stories whose temporal strands are hard to follow, third-person stories, talk of imagined or future events and even non-verbal forms.

As individuals (or groups) present sequences of such stories - perhaps interspersed with less obviously “storied” forms of talk or comment - these may then suggest broader narratives (eg, of suffering, or personal triumph over adversity), as in the illness narratives discussed in the last chapter, or the “long stories” of autobiography over a lifetime (Riessman, 1997). Equally (and confusingly) though, these broader first-person narratives are sometimes labelled as “stories” - as in the autobiographical “this is my story”, or the World Health Organisation’s collection of “Stories of Tragedy and Hope” from people living with HIV (www.who.int/features/2003/09/en/). To add to the confusion, narrative can also be understood more broadly still as a cultural form to be drawn on as a template, similar to understandings of “cultural discourses”. These may be quite focused (eg, “the troubled passage through adolescence”) or very broad genres (eg, the “heroic narrative”).

Much has been made of distinctions between “narrative” and “story”, particularly within linguistic and literary traditions. For the most part I find these arguments unimportant for the purposes of my inquiry, and follow Riessman (2008) in using the terms largely interchangeably. I also argue that there is much to be gained from study of “small stories” (Bamberg, 2004; Bamberg, 2006): less-obviously “storied” forms of interactional exchange that can nevertheless contribute to a broader narrative. However, I am intrigued by the interactional force generated by telling first-person “stories”, in their potential to draw listeners into imagining the speaker’s world. For this reason, my analysis considers how more traditional “storied form” is used within broader narratives, and the impacts that these can have alongside non-storied forms.

One final point must be stressed about the term “story”. When I was a child, an account of events or experience was sometimes met by an adult’s response of “*Is that true, or are you telling stories?*”. Though perhaps less commonly-used today, the association of “telling stories” with “fibbing”, “lying” or “making it up” - particularly referring to children - is still discursively present. And, while my approach does emphasise the partial and the socially-oriented aspects of narrative construction, I want to stress strongly that I do not consider “telling stories” as a manipulation of truth.⁹ Importantly, having consulted with young people during the design of this project, none seemed uncomfortable or confused by the term “story”, and all immediately appeared familiar with its currency as an expression of life experience.

3.1.2 Illness and narrative: Evolving positions

Writer Isak Dinesen suggests that “All sorrows can be borne if you put them into a story or tell a story about them” (cited in Arendt, 1958:175). This is perhaps one reason why illness narratives appear so important, why ill people “bleed stories” (Broyard, 1992) and “[wounded] bodies need voices” (Frank, 1995). Chronic illness is uncertain, allowing for multiple interpretations; it is often met with powerful emotional responses that may call for a “confessional” mode of discourse; and it typically threatens valued identities, prompting a need to construct accounts and justifications. Hence there is a strong rationale for analysis of illness narratives (Frank, 1997; Mattingly & Garro, 2000; Miczo, 2003).

Such awareness has contributed to qualitative projects seeking to “give voice” to the stories of people living with illness, traditionally marginalised in comparison to more widely-heard professional (medical) narratives (Kleinman, 1988; Lawton, 2003). This position appeals to my personal and political commitments, and contributed to my early interest in qualitative methodologies. Here some forms of experience-oriented narrative analysis overlap with approaches such as the Interpretative Phenomenological Analyses referred to in Chapter 2 (though narrative analyses are distinguished by their case-centred

⁹ This also being incongruent with a social constructionist rejection of such concrete definition of “truth”.

attention to the sequencing and progression of themes over time, their transformation and resolution (Mishler, 1999; Squire, 2013)). Their commitment to the content of stories - *what* is told - is given primacy, and there is often a great deal to be learned here.

However, other potential insights are lost when narrative content is the only focus. Stories of “personal troubles” are located in particular times and places, and “narratives may reveal as much, if not more, about the norms and dominant meta-narratives of the social, cultural and political context in which they are produced as they do about the narrator themselves” (Atkinson & Rubinelli, 2012:S14). And while experience-centred analyses may draw attention to socio-cultural worlds *depicted* in the content of talk (Mills, 1959), they often rest on naturalist assumptions that narratives, like other language, can be treated simply as a *resource*, a route into another’s interior experience and authentic self. Such “fetishism of words” (Miczo, 2003) has now been heavily critiqued for its inattention to the social aspects of language, and the “extraordinary absence of social context, social action, and social interaction” (Atkinson, 1997: 339) attended to within some narrative analyses, leading to calls for further methodological development.

3.1.3 Constructing my position

3.1.3.1 A discursive narrative approach to analysis

Consistent with a social constructionist epistemological position, I view narratives as accounts of living that are inevitably shaped by the culturally-specific discursive resources available to narrators, and as speech acts produced in response to the perceived requirements of the social setting. “Experiences” and identities are considered to be performative - that is, constructed and enacted in talk (Abell, Stokoe & Billig, 2004). I therefore follow Atkinson and colleagues in arguing that, “if we collect ... accounts of ‘events’ or ‘experiences’, then we need to *analyse* them in terms of the cultural resources people use to construct them, the kinds of interpersonal or organizational functions they fulfil, and the socially distributed forms that they take” (Atkinson, Coffey & Delamont, 2003:117).

My methodological approach follows from this, drawing on a second wave of narrative analysis (Georgakopoulou, 2006) that shifts the focus from narratives-as-text to the study of narratives-in-context, the *doing* of narrative; considering *how* and *why* narrative and identities are constructed within particular local (inter-personal) and broader social contexts; “understanding how we operate dialogically between the personal and the surrounding social worlds that produce, consume, silence and contest us” (Squire, Davis, Esin et al., 2014:111). In doing so, I argue the need to consider not only the clearly-structured “big stories” of biographical experience that are the traditional focus of narrative inquiry, but also “small stories”: “under-represented activities such as tellings of ongoing events, future or hypothetical events, shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell” (Georgakopoulou, 2006:123); and sometimes hard-to-follow narratives marked by “hesitations, unfinished thoughts, interruptions and, often, contradictions” (Ochs & Capps, 2001:56).

I draw strongly on the contextual and dialogic/performative approaches to narrative described by Phoenix (2013) and Riessman (Riessman, 2002b, 2003, 2008), and the narrative-discursive approach set out by Taylor (2006). These in turn build on work within social psychology and social constructionism (Gergen, 1985), discourse analysis (eg, Potter & Wetherell, 1987), discursive psychology (Edley, 2001; Edwards & Potter, 1992) as well as narrative analysis. Several assumptions about the relationship between “personal” narrative and the social world are particularly relevant to methodology.

First, that our understandings of the world, and our place within it (our identities) arise out of the accumulated ideas, images and associations that make up the wider socio-cultural fabric of our lives. These discourses provide *discursive resources* - including interpretative repertoires (Edley, 2001; Potter, 1996), or cultural/canonical narratives (Bruner, 1987, 1991) - for us to construct and speak our own understandings, biographies and identities. Discourse analysis explores how such “common-sense understandings” (Edley & Wetherell, 1995) facilitate but also constrain what can be said, by whom, where and when (Parker, 1992), and the “subject positions” (or identities) (Davies & Harre, 1990) made available (eg, as “patient” rather than “doctor”, with implications regarding expertise).

Foucauldian-inspired discourse analyses typically focus on the relationship between discourse and power, and how discourse constructs subjects, objects and institutions of social practice. This is a concern which I share (for example, in the construction of duality between “mental” and “physical” illness, and the way that individuals are positioned as “ill” or “mad”, and treated accordingly). However, individuals (and groups) do not always simply re-present the status quo, but are active in constructing their personal biographies and identities (Gergen, 1994). “Personal” narratives orient to such social constructions and *perform social actions*: explaining, complaining, entertaining; challenging dis-preferred positions, and providing persuasive accounts of preferred constructions (Riessman, 2008; Schegloff, 1997; Wortham, 2000).

Here the methodological approaches of discursive psychology - drawing from ethnomethodology and conversation analysis - are useful. Analysis can explore how talk is shaped by the immediate interactive context: the turn-by-turn interplay between speakers that shapes the co-construction of accounts and identities within an interview or everyday conversation (Edwards & Potter, 1992). It can also examine how these conversations are themselves socially situated, operating at several levels simultaneously as speakers orient to anticipated or previously-experienced audiences or criticism, doing “rhetorical work” against these (Billig, 1987). Particular attention is given to how speakers manage the risks of having their accounts - or their identities - disbelieved or challenged (Edwards & Potter, 1993). Analyses have identified how different discursive techniques can operate to construct accounts as “factual” or “authentic”, for example; managing concerns about speakers’ credibility and stake, interest or dispositions to say things (Edwards, 2007; Edwards & Potter, 1992); and attending to issues of agency and personal accountability in reports (Horton-Salway, 2001a; Potter, 1996). Here I argue that such issues are particularly salient for those living with contested illnesses, where the credibility of the illness and sufferer may be considered already under attack.

Though discursive psychology and Foucauldian forms of discourse analysis are often contrasted (Willig, 2008), Wetherell (1998) advocates a synthesis - a position drawn upon by Taylor (2006) and which now influences my own approach. It is argued that this discursive approach to narrative analysis is particularly useful in exploring identities in talk,

considering identity work as partly but not wholly determined by broader social meanings, but with each speaker actively taking up and contesting these in particular interactions.

However, Taylor then extends this work further, addressing a concern (eg, Crossley, 2000) often levelled at discourse analysis and discursive psychology: that the postmodern highlighting of the complex, multiple and occasioned nature of identities as people are positioned in (often small stretches of) talk (Antaki & Widdicombe, 1998) understates the coherence and continuity of identity and the narrative structure of normal human experience. Taylor and colleagues re-introduce an extended focus on broader narratives constructed over time, reminding us that, in constructing “life narratives”, speakers do not start afresh with every conversation. Rather, they draw on previous versions - or fragments of tellings - which can be considered as further “discursive resources”, to be adapted to that particular situation. These new versions then become resources for future talk and presentations of identity (Taylor & Littleton, 2006).

Importantly, like other discursive resources, these may enable but also constrain what can then be said. People become “positioned by who they already are”(Taylor, 2005b), indicated not only by context (eg, location), preliminaries to talk (eg, introductions) and appearance (eg, indications of gender, age, health, cultural background, social position); but also by the “cumulative fragments of a lived autobiography” (Davies & Harre, 1990:49). Further, there are social expectations for speakers to be broadly consistent in identity work, and “trouble” when we take up positions which cannot be reconciled with a previous positioning.

Taylor (2005b) argues that the repeated telling of autobiographical stories provides opportunity for reflexive rehearsal of identity work, leading to some continuity across occasions of talk, both in the nature of stories told and subject positions taken up. Analysis should therefore look beyond a single instance of talk, to consider work done across interactions, and this is one rationale for incorporation of a longitudinal element in designing the current study, engaging participants in narration at two points, a year apart.

Questions also remain about how CYP engage in this. Though continuing throughout life, Taylor suggests that narrative identity work may be particularly important for younger

people who have had less opportunity to “construct [themselves] within an autobiographical self-narrative” (Redman, 2005), and this too is a focus of the current study.

I therefore draw on the narrative-discursive approaches used by Taylor (Taylor, 2005a, 2005b, 2006, 2011; Taylor & Littleton, 2006) for their attention to the “doing” of narrative and identity work, but I retain a commitment to the case-centred focus on individual narratives, each analysed as a whole, rather than a quick movement towards seeking generalisations across cases (Riessman, 2002a, 2003, 2008). In doing so, I follow others in a constructionist approach to narrative analysis (Esin, Fathi & Squire, 2013), attempting to apply multiple lenses to the complexity and “messiness” of human meaning-making and reality-construction, and the complex relationships between the personal and the social, represented and representation (Smith & Sparkes, 2006).

3.1.3.2 A case for interviews

One-to-one interviews have become a predominant focus in gathering biographical narratives within the social sciences, valued particularly for talk on “sensitive” topics (Hydén, 2013; Kvale & Brinkmann, 2009). However, critics (particularly those working with ethnomethodologically-informed approaches) compare interviews unfavourably with “naturally-occurring talk” (eg, Schegloff, 1997), noting that participants would not otherwise have talked about the topic (or talked in the ways that they did), so the narratives being explored have been artificially conjured into existence as an artefact of the data collection method.

Such arguments appear to rest on two assumptions: first, that interviews are “unnatural”; and second, that interview-based approaches then treat the narratives elicited as independent ontological entities, ignoring their contextual generation.

With respect to the first argument, while acknowledging that most people have not encountered a *research* interview, interviews are a common form of interaction within contemporary Western culture (the “interview society”), as “natural” as any other (Atkinson & Silverman, 1997). Not only can interviews be viewed as conversation, they

adopt a culturally-rooted and understood format in which meanings are routinely proposed and negotiated between people - including children - within ongoing interaction (Westcott & Littleton, 2005).

With respect to the second argument, I have some sympathy. As I have argued, many of the interview-based studies reviewed in the previous chapter appear to do just this, focusing on the spoken story (what is said) while ignoring the situated, contextual aspects of that talk (eg, what it *does*, how it meets and anticipates the interviewer's demands) within a specific interpersonal (research) encounter. However, I follow Atkinson and Delamont (2006), De Fina (2009) and Tanggaard (2009) in arguing that this should be motivation for different forms of narrative *analysis* that explore the interactional context, rather than abandoning interviews as a valid social form in which to explore narrative. As they point out, analysis of narratives as social action, accomplishing interactional and social goals, also allows researchers to understand how certain kinds of autobiographical talk are accomplished not only through individual creativity, but through the use of social conventions and discursive repertoires - which cannot be fully understood if we abstract the narrative from its context.

It should be emphasised that this type of research does not seek to make simplistic claims about the generalizability of "findings" to different contexts. Indeed, it is a central assumption that another conversation setting (in a doctor's surgery; in playground conversation) *would* lead to the construction of different narratives. However, in line with arguments (Taylor, 2005b) that situated talk may be a new version of what has already been said rather than a wholly original, never-before-expressed innovation, interviews can provide an appropriate context to view the ongoing identity work of the speaker (Bamberg, 2008 Bamberg & Georgakopoulou, 2008; Taylor & Littleton, 2005). It is also argued (Taylor, 2001) that this opportunity to rehearse new versions may be attractive to individuals whose changing or unusual life circumstances precipitate a need for active construction of their evolving identities. Further, there is a rich history of research that engages with individuals interviewed at different points over time, exploring the development of narrative/identities over the lifespan (Josselson, 1996).

Interview research with CYP raises particular methodological and ethical issues (Alderson & Morrow, 2011; Hill, 2005) (see below), but has become established as a valuable format, particularly for work on sensitive subjects and with older YP (Eder & Fingerson, 2001; Westcott & Littleton, 2005). Though less well-developed, there is scope for exploring changing narrative constructions of CYP engaged over time in their rapidly-developing worlds (McNamara, 2013), and this is an area to be considered in the present project.

3.1.3.3 A case for “creative” methods with young people: “Memory boxes”

One criticism levelled at narrative inquiry is that the focus on language potentially ignores other forms of communication, and may disadvantage those (including CYP) who are less linguistically-skilled. It is increasingly recognised that we live in a world where visual media in particular, including the use of online technologies, play a key role in our lives, and in the construction of experience, meaning, knowledge and identities. It is also acknowledged that some experiences - particularly those which are emotionally-charged or traumatic, or relate to bodily experiences - are not easily verbalised. Further, even with use of a minimally-structured interview, there are concerns that a “talk-only” format may perpetuate power imbalances in the researcher-participant relationship, limiting the agency of participants in directing how they express themselves.

These concerns have contributed to the evolution of creative research methods, particularly with CYP, incorporating use of art, photography, video, scrapbooks and diaries (Christensen & James, 2000; Punch, 2002; Thomson, 2009); including a small body of research with young people living with chronic illness (eg, Drew, Duncan & Sawyer, 2010; Hanghøj, Boisen, Schmiegelow et al., 2016). A key principle is that engaging CYP in creative tasks of their choosing enables them to represent their experiences and identities in ways that are meaningful and potentially pleasurable to them (Gallacher & Gallagher, 2008; Leitch, 2009), following the call for research “with” rather than “on” children, engaging them as competent social agents (James & Prout, 1997).

Moving beyond “mono-modal” forms of discourse presents a range of ethical, methodological and analytic challenges (Reavey & Johnson, 2008). Some of these relate to differing assumptions made about the epistemological status of visual or other materials;

for example, that they are somehow more “real”, or allow more privileged access into the emotional experience of individuals than language (Buckingham, 2009; Prosser, 2013). Further issues arise from different approaches to interpreting such material: it is generally considered more ambiguous or polysemic than sequential texts (Frith, Riley, Archer et al., 2005), and the validity of researchers’ interpretations can therefore be particularly open to question (Lynn & Lea, 2005).

There is great potential in the use of creative methodologies, but within the current study, it was decided to explore their potential within a more limited way, in keeping with the primarily discursive form of narrative inquiry outlined above. As noted, the study aimed to use a longitudinal framework, in which the focus of the first interview would be narration of “life so far”, particularly with respect to CFS/ME; and the second, held a year later, would be to focus more on telling “the story of the last year”. It was acknowledged that this might prove initially difficult for YP, not least because of the feats of memory entailed. One initial rationale for the inclusion of creative methods was therefore to facilitate YP’s ability to recall and construct this “story of the last year”. Thus the first interview was designed to have a more traditional monomodal focus, but YP were then given the option of collecting additional material into a “memory box” to bring to the second interview, one year later. Possible options were suggested - photographs, mementoes (eg, of people seen or places visited), extracts from diaries or online blogs/vlogs, music, drawings, links to websites – although YP were encouraged to bring whatever they felt to be helpful. The purpose was set out: to help “jog the memory” at the second interview as YP talked about the previous year; and all materials would remain with the YP. However, given the health issues facing participants and my wish not to over-burden them, and an awareness of the power dynamics inherent in research with CYP, it was stressed that construction of the “memory box” was optional.

In line with the constructionist narrative stance of this project, visual and other modes of discourse are similarly viewed as part of the socially-embedded acts people perform in constructing “reality”, meaning and identities. Consequently, rather than attempting a researcher-led “interpretation” of additional materials per se (as, for example, in psychodynamically-inspired interpretation of artwork aiming to access “deeper meaning”), this analysis focused on how YP might draw on additional material in constructing their

verbal narratives, with reflexive consideration of the contexts in which materials were produced selected and shared, and implications for construction of the broader narrative.

3.1.4 Attending to “quality”: credibility, rigour & trustworthiness

“If it is argued that there is no possibility of direct knowledge of the world, if language does not correspond to a stable external reality, if multiple realities can be constructed by different minds, the imposition of [such] criteria [may be viewed as] no more than an attempt to gain an artificial consensus”

(Seale, 1999:32)

The quality of research within positivist paradigms is judged within well-established criteria of reliability and validity, but these are underpinned by assumptions about the nature of an objectively knowable “reality” that pose problems for constructionist research paradigms. Seale (1999) plays devil’s advocate, but such positions contribute to complex arguments about what (if any) criteria may be used to judge the quality of narrative inquiry - arguments that have not been definitively answered, and are addressed in different ways depending on epistemological and political commitments (Riessman, 2008).

Even within a constructionist framework, I argue that a complete evaluative relativism is unnecessary and unhelpful. The attempt to generate *credible* knowledge lies at the basis of any dialogue. Without the ability to choose between the truth-claims of any statement, we would be reduced to name-calling along the lines of “you would say that, wouldn’t you?” (Silverman, 2014:78).

Further, in situating my work within a framework of social science (rather than, say, journalism or art) - and even as I acknowledge the partial, context-dependent and interpreted nature of such narrative constructions - it is my intention to consider what the narratives of this small, specific group of young people may say, in a theoretical sense, about broader situations¹⁰ (Radley & Chamberlain, 2001). Indeed, Riessman (2008) argues that the relevance or “pragmatic usefulness” or research are hallmarks of its quality and

¹⁰ If readers were to finish this thesis and think, “*Interesting stories but... so what?*”, I would consider the work to be a “failed narrative”, with a failed ethical responsibility to the emotional and time investments of its participants. The challenge of building from narrative research is explored further by Josselson (2006).

credibility. But if readers are to “take forward” my work in academic, professional or personal domains (eg, in how they approach other YP diagnosed with CFS/ME who they encounter in the future), they must have faith in the claims I am making, and the basis on which they have been made.

Thus I aim to demonstrate the quality of this research with reference to the framework for establishing *trustworthiness* in qualitative research set out by Hammersley (1992), drawing on criteria of credibility (whether the interpretations made can be considered plausible and meaningful), rigour (whether the interpretations are supported by systematic interrogation of appropriate data), and relevance or pragmatic usefulness (whether the research can inform clinical practice and the research of others).

Assessment of quality cannot be reduced to a mechanical application of abstract criteria or methodological steps, but rather a consideration of the broader research enterprise (Seale, 1999; Wells, 2011). Nevertheless, I follow Wells (2011) and Riessman (2008) in attempting to provide clarity on the conditions under which narratives are produced, and the consequences of these for interpretation of their meaning, allowing readers to consider whether my interpretations are plausible, persuasive, meaningful and to be trusted (Tracy, 2010).

Thus I include explicit consideration of: the theoretical orientation guiding the study, including its influence on the orienting questions, methodology and analytic processes; how narrative is defined; conditions of narrative production; the linking of narrative text to interpretations; attempts to consider negative cases and alternative interpretations; and the linking of such interpretations to broader contexts, including existing bodies of knowledge. In other words, I aim to demonstrate persuasiveness by documenting my claims for readers who were not present to witness stories as they unfolded, or beside me as I tried to make sense of them (Riessman, cited in Silverman, 2014:76).

Such issues are addressed throughout this work. Further, and as argued previously, *reflexivity* is considered essential in developing and assessing the trustworthiness of claims made (Finlay, 1998, 2003; Finlay & Gough, 2003; Maso, 2003; Nicolson, 2003). Attempts are made throughout to explore how my personal experience and commitments have

shaped my engagement in each element of the research process, from its inception and development, through engagement with research participants, and interpretation of (co-constructed) narratives. These have been facilitated by use of a research journal, professional training and experience, and discussion in supervision with experienced researchers from different personal and professional backgrounds. Supervisors also reviewed transcripts and analyses throughout the project. This is not equivalent to validation through “checking” (which would assume steering towards a “truth”)¹¹, but an invitation to dialogue that enables consideration of “blind spots”, intuitive leaps, and alternative perspectives (Willig, 2008) - a process that will be continued after traditional “completion” of the project, as readers (including my future self) are invited to bring their positioned identities and cultural filters to different readings (Andrews, 2013).

¹¹ More traditional forms of “validation” within qualitative research, such as triangulation and “member checking” of interpretations by participants, are considered incommensurate with a constructionist epistemology, in that they seek verification of a “truth”. Moreover, there may be ethical concerns with the process of member checking, in that participants have reported finding the process ‘objectifying’ and potentially distressing (Wells, 2011).

3.2 Methods

3.2.1 Design: Overview

This project was designed to address the following research questions:

- How do YP narratively account for lives lived with a diagnosis of a contested condition, and a potentially contested identity?
- What do their narratives tell us about the social contexts in which they must establish themselves as valuable, valued young members of society?

The project adopts a qualitative approach based on in-depth exploration of the illness narratives of ten young people (YP) living with diagnosed CFS/ME, drawn from one-to-one loosely-structured interviews. Each YP was interviewed twice, approximately one year apart, introducing a longitudinal element to the design to enable consideration of the changing contexts associated with long-term illness and youth. Additional media (eg, photographs, objects) collected by the YP over the intervening year were used to facilitate construction of their narratives at the later interviews. Interviews were digitally audio-recorded and transcribed in detail.

Interviews are viewed as interactional contexts that shape and are shaped by the construction of narratives. Analysis draws on narrative and discursive approaches to consider both biographical and contextual features of the narratives - ie, both *content* (*what* is told) and *how* this is told - to explore the ways that immediate (interactional) and wider societal contexts contribute to the construction of illness narratives and identities (Phoenix, 2013).

3.2.2 Research with YP: Ethical considerations and project development

Ethical concerns are central to this project. They arise particularly from the age and health concerns of participants, and from the nature of narrative research.

As noted in Chapter 2, CFS/ME is a poorly-understood and stigmatised condition which can lead to social marginalisation. In research too, the voices of those affected - particularly CYP - are poorly represented. It is argued that the qualitative research design of this project, in which participants can significantly influence material brought (rather than, say, having to respond to fixed questions within questionnaires or very structured interviews), respects their agency as social actors and their capacity to contribute meaningfully to research (Mason & Hood, 2011). However, it is clear that such research requires careful ethical consideration and such concerns were addressed from the earliest stages of the project.

Early project development was guided by research literature on ethical practice working qualitatively and with CYP (eg, Alderson & Morrow, 2011; Christensen & Prout, 2002; Duncan, Drew, Hodgson et al., 2009; Hill, 2005; Morrow, 2008; Morrow & Richards, 1996; Punch, 2002; Warin, 2011); academic supervisors at the University of Hertfordshire; health, social and educational practitioners working with CYP and CFS/ME; professional guidelines (British Psychological Society, 2009); and guidelines from the NHS National Research Ethics Service (NRES; now part of the Health Research Authority). It was also shaped significantly by consultation with those who traditionally have less power in such research environments: young people living with illness.

3.2.2.1 Consultation with young people: Working with AYME

It is now understood that public and patient consultation - including meaningful engagement with CYP - is an ethical imperative in health-related research; but also that such engagement can bring significant benefit to the research itself (Alderson & Morrow, 2011; Brady, Davey, Shaw et al., 2012; Kirby, 2004; McLaughlin, 2015; United Nations, 1989; see also invo.org.uk/). This underpinned my decision to consult with the charity AYME (Association of Young People with ME) for guidance from those who are “experts by experience” (McLaughlin, 2009). I was particularly concerned to hear whether members - those who live with the condition and their carers - considered this to be a useful, viable and ethical endeavour in principle, and if so, to hear their proposals for shaping its design and implementation.

Initial discussion with senior members of the charity led to two phases of consultation. Two young adult members (in their early twenties) first reviewed and commented on the draft research proposal. They then acted as a link, inviting younger members through the web-forum to act as consultants. Five YP (teenagers) then contacted me by email and provided useful suggestions that were incorporated into a Participant Information Sheet (PIS), interview topic guide and overall study design. Examples include suggesting that participants might bring music rather than visual materials as part of a “memory box”; adjusting language to avoid suggesting that CFS/ME was necessarily “a bad thing”; and including more prompts for participants to take rest-breaks during interviews.

However, in response to my query about whether interviews might be too upsetting for participants, all consultants were unanimous: as long as the interviewer created a supportive environment in which young people felt genuinely listened to, YP would welcome the opportunity to tell their stories; and though talking might be distressing, this would be because the *condition* and its consequences are themselves upsetting - simply talking about this was unlikely to make it worse.

3.2.2.2 Addressing ethical concerns

The project protocol was reviewed for all areas including research governance at the University of Hertfordshire, and accepted for sponsorship (Appendix 1). As some participants were to be recruited through an NHS service, approval for the study was sought from the National Research Ethics Service (NRES) via a local branch Committee (followed by local Research and Development approvals for the NHS Trust involved), in line with national guidelines. This involved submission of written material followed by questioning at a review panel. After minor clarifications, approval was then given (REC approval reference 10/H0301/4; appendix 2). When the recruitment strategy altered to include participants from a non-NHS source (see below), the Chairs of the NHS REC and departmental REC at the University of Hertfordshire were consulted, and confirmed that the existing ethical NHS REC approval was sufficient. Details of major ethical considerations within the design of the research were addressed within the REC application, but some significant aspects are noted here.

First, the **health** of participants raises ethical issues: CFS/ME can leave sufferers easily fatigued, and may limit concentration or memory. This was a consideration in decisions about the location, timing and nature of data collection, which were made at the request of participants and their parents (eg, meeting at their homes to avoid travel, at times to meet their health/energy levels, and with encouragement to take breaks or end meetings when needed).

The **age** of participants also raises ethical issues. Given life-stage and possibility of illness-related cognitive difficulties, particular attention was paid to ensuring participants' full understanding, both in gaining **informed consent** and throughout interviews. Written material was prepared in line with NRES guidelines for research with YP and reviewed by a reference group of YP for comprehensibility and style. Additional time was made available for YP to read about, discuss and ask questions about the project. The flexible interview schedule, developed with YP from the consultation group, allowed time for me to develop understanding of, and adapt questions/prompts to, the capacity, fluency and style of each individual, drawing also on many years' experience working with CYP.

The age of participants is also relevant in considering **safety, power imbalances, and risk (potential for distress)** (Alderson & Morrow, 2011). Time was taken to gauge whether each participant felt comfortable talking alone with me, and sufficiently in control of the interaction. For all those under 16, a parent was present for the initial, practical stages of the first meeting (see 3.2.5). After this a balance had to be achieved, where the parent left to allow the YP to talk independently (this having been made discussed previously) but with the parent remaining in the home. It was left to parent and child to decide whether (eg) to close the door, balancing confidentiality and safety concerns. YP were encouraged to decide for themselves what topics they wanted to speak of and to what depth, and reminded that they could withdraw at any time. This was considered particularly important given the potentially sensitive topic (Corbin & Morse, 2003; Dickson-Swift, James, Kippen et al., 2006; Hydén, 2013; Renzetti & Lee, 1993), and the possibility that YP, given an interested (and a clinically-trained psychologist) audience, might be tempted to "over-disclose" and later regret this (Thompson & Russo, 2012). Again, the clinical experience of the interviewer was important in managing this balance, and in identifying and containing

any distress. Finally, participants were provided with contact details of myself and other sources of support, should they want this after the interviews.

It is worth noting that, as with most research, much of the initial ethical focus was channelled into issues considered by the REC. These tend to centre on what has been labelled “procedural ethics” at the expense of the ethical tensions that creep into the everyday *practice* (or “micro-ethics”) of qualitative research (Guillemin & Gillam, 2004), where the nature of the research relationship means that much cannot be fully anticipated. It is argued that procedural ethics are no substitute for ongoing “ethical mindfulness” and reflexivity, particularly in ongoing research relationships with CYP (Duncan et al., 2009; Warin, 2011). And while my clinical experience, reflection within a research journal, and discussion with supervisors and peer researchers form important elements in this, it is here that I was acutely aware of my own “novice” status as a researcher. The challenges of managing a young person’s confidentiality, for example, while a guest in their (parents’) home - when the parent (or even the family dog!) left the door ajar - was not something that the REC had prepared me for! Further consideration of such issues, including tensions between clinical and researcher roles, is made throughout this work, particularly in chapter 6.

3.2.3 Sampling

In line with the study’s research aims and intended methodology, a purposive sampling strategy was developed (Silverman, 2014) to identify young people living with CFS/ME. The age range (13-17 at the start of the study) was selected in line with theoretical interest and common definitions of “young people” (usually 12-18). As a longitudinal study designed to run for one year, it was considered preferable for all participants to be within the more homogenous “secondary school age” for the whole of the study. Ideally, a longer period of study would have been of interest to explore changes over time, but the practicalities of this Doctoral study precluded this.

The question of “how many participants” to interview in qualitative research is widely-debated, with no definitive answer, though it is agreed that this depends on the nature of the research aims, sample, quality and richness of data generated, epistemology, model

and quality of analysis, and also practical considerations (Baker & Edwards, 2012). Narrative analyses may be based on a single in-depth case study or much larger numbers of texts (especially if these focus mainly on content) (Riessman, 2008; Wells, 2011), though Wells (2011) argues that a sample of 5 is suitable for detailed analysis of rich data. Considerations for the current sampling included: focus on a specific, relatively homogenous group; intention to generate rich data through extended, flexibly-structured interviews; exploratory nature of the study, meaning that data would be widely explored, rather than quickly cut to explore only theoretically-driven areas of interest; intention to subject data to multi-layered analyses; and use of repeat interviews (generating more data per participant) (Morse, 2000). Additionally, involvement of only one interviewer/analyst within specific timeframes was a factor.

However, I was also repeatedly advised that, in planning a longitudinal study with YP, I should expect “drop-out”, and therefore plan to recruit more participants in order to still have a viable sample at the end. All these considerations led to the decision to aim for 8 - 12 participants at the start of the project.

Inclusion Criteria

1. Current diagnosis of CFS/ME confirmed by a paediatrician.
2. Persistence of symptoms for at least 6 months.
3. Aged 13 - 17 at the time of recruitment.
4. Fluency in English language.

Exclusion Criteria

1. YP where there are safeguarding or other significant concerns about vulnerability.

It is acknowledged that a requirement for “fluency in the English language” potentially excludes other marginalised groups. However, as a novice in narrative research, I felt ill-equipped to conduct a language-based analysis with the additional challenges of working with expressive difficulties or interpreters. This remains an area for a future project. However, review of potential participants within the two sources (a Hertfordshire-based NHS clinic and a charity) indicated that, in this case, no otherwise-suitable participants were excluded on this basis.

3.2.4 Recruitment

Phase 1

In line with my professional experience and expressed interest from a local NHS paediatric outpatient service, I originally intended all (8-12) participants to be recruited from this NHS setting. This is not a national/ specialist site (often featured in CFS/ME research), but more representative of the paediatric NHS care available to most YP presenting with symptoms of CFS/ME in the UK, and therefore considered a suitable site. Early discussion with clinicians (May 2009) suggested that there would be sufficient (“15-25”) YP available within this clinic to provide participants for this study. The study protocol, initial ethical review and R&D processes (Sept 2009 - Feb 2010) reflected this. However, their subsequent review of clinical caseloads after REC approval (March 2010) then identified only 9 YP meeting inclusion criteria¹².

Clinicians were provided with written summaries of the agreed recruitment processes and asked to approach YP already known to them, either during routine appointments or by post (April - July 2010). Clinicians outlined the research project, provided a letter of invitation and Participant Information Sheet and suggested that the YP contact me directly by phone/text or email to discuss further if interested. For all YP under 16, this material was also provided for parents. (See appendix 3 for examples, tailored to YP / adults and different sites).

For YP who expressed interest to their clinician but did not contact me, one “reminder” letter was sent (appendix 4). However, it was stressed that the study was separate from the NHS clinic, participation was entirely voluntary and would have no impact on NHS input to the YP, and no information was shared between the clinic and researchers. Guidance from NRES and the University of Hertfordshire on information governance and good practice were followed throughout.

This process ensured confidentiality and avoided undue pressure on NHS patients to participate. However, it left a great deal resting on busy clinicians. By June, no YP had been

¹² Approximately 20 other YP within the age range were excluded by the team either because they were considered “recovered”, because of doubts about the diagnosis, or with safeguarding concerns.

recruited, prompting a re-evaluation (below). Subsequently (July - August 2010), 4 YP (2 girls, 2 boys) from this clinic contacted me and elected to participate.

Phase 2

Two options to extend recruitment appeared possible. The first was to find another NHS site. However, my experience of NHS research-related bureaucracy¹³ and time-pressures faced by busy clinical departments made me hesitant to embark on this route.

However, by this stage I had experienced a very positive engagement with AYME, and considered for the first time the possibility of recruitment through them. There followed a process of discussion with senior members of AYME (including their Research & Development advisors), advisors at the University of Hertfordshire, and the NHS Research Ethics Committee. Following this, a slightly amended protocol was developed, to allow for recruitment in the South East of England through an advertisement placed by AYME in their monthly newsletter (appendix 5). It was again emphasised that AYME was involved only in circulating information about the study their members: no information about AYME members was available to me unless provided by families themselves, and details of their participation were not fed back to AYME.

12 YP or their parents contacted me following this. Of these, 5 lived too far for me to access in the time available. 1 mother said her daughter was too ill to talk, but offered to speak for her; this was considered unsuitable for the current project. The remaining 6 YP (5 girls, 1 boy) subsequently joined the study.

3.2.4.1 Participants

Summary background details of participants are given below. All participants were White British, living with current symptoms of CFS/ME. All names are pseudonyms, and some details have been altered to protect confidentiality. To help readers, pseudonyms were

¹³ At this point, the new "Integrated Research Application System" (IRAS) and new system of "Research Passports" was supposed to streamline the Ethical Committee (REC), Research & Development (R&D) and other systems to allow for smoother multi-site research within the NHS. However, my experience was that the system was unwieldy and not fully understood/adopted by different NHS sites. I am aware that the brief noting of "ethical and R&D approval" above retrospectively glosses what was, in fact, a very lengthy, difficult and sometimes disheartening process.

deliberately chosen with alphabetic order (A-K) and assigned to reflect participants' ages (ie, Adam is the youngest, Katie the oldest).

Pseudonym	Age at start of study	Age at onset of symptoms	Age at diagnosis	Education at 1 st interview	Parental occupation (Mum/Dad) *	Recruitment route to study
Adam	13	10	10	Part-time, state	Special needs teacher / Emergency services	NHS
Becky	14	12	12	Part-time, state; no longer with ESTMA	Carer (SEN teacher) / Sales	NHS
Callum	14	12	12	Part-time, state; no longer with ESTMA	Carer (professional) / Scientist	NHS
Danni	14	12	12	Out of education for almost 2 years	Carer (child-minder)/ Mechanic	AYME
Evie	15	9	12	Part-time home educated (mother & private tutor)	Carer / IT professional	AYME
Freya	15	13	13	Part-time, state; ESTMA	Teaching assistant / Tradesman	NHS
Grace	16	14	15	Completed y11 (state); not in education	Nurse / Emergency Services	AYME
Harry	16	12	12	Part-time college & home tutor (state)	SEN professional / Lorry driver	AYME
Jess	16	11**	12	Part-time, private school	Secretary / Engineer	AYME
Katie	17	16	17	Part-time, private boarding school	Counsellor / Scientist	AYME

* Where a parent had given up work to care for ill child, former occupation is in brackets.

**Unclear - gradual onset

3.2.5 Engagement

Initial engagement with participants was by phone or email, providing details of the study, ensuring that they had received and read the Participant Information Sheet, and answering questions. All requested interviews at their homes, and time preferences were accommodated. The University of Hertfordshire's Lone Worker Policy was followed.

3.2.5.1 Initial meeting: Practicalities and parental involvement

As discussed beforehand and in the PIS, the first few minutes at participants' homes was to answer any other queries, gain some background information (eg, confirming demographics, diagnosis, professional involvement; see appendix 6), review the plan (including arrangements for audio-recording the next part of the interview and ensuring confidentiality of participant data, and steps to avoid harm and access support where needed), and confirm informed consent. YP were offered the option of later choosing their own pseudonym, but none took up this offer.

For all YP under 16, this meeting included a parent who then completed a Consent form, alongside the YP's Assent form (see appendix 7). Participants over 16 were not required to involve a parent, but were encouraged to do so. Parents left the room for the main part of the interview.

3.2.5.2 "Data Collection": The construction of narratives in interviews

Setting the scene

Interviews were approached as "guided conversations" (Lofland & Lofland, 1984) that provide an interactional context for storytelling, and the (co-)construction of narratives (Mishler, 1986; Riessman, 2008). It is therefore relevant to consider how interviews were set up, "setting the scene" for what can be said, with methodological and ethical implications. For example, CYP in particular may be inclined to assume that any interaction with an adult is (rather like a classroom interaction with a teacher) searching for short,

“correct answers”, or (like meeting a doctor) seeking only certain types of “information”, about symptoms or “facts” (say), rather than longer stories of personal experience.

It was emphasised throughout this project, and particularly at the start of interviews, that there “are no right or wrong things to say - I’m just interested in *your* story, what things have been like *for you*”. Similarly I repeated that, while I had some ideas about areas that might be interesting to talk about (suggested by other YP who live with CFS/ME), I was happy to be led by “whatever seems the most important for *you* to tell me about”. This participant-led focus was mirrored by the informal settings (usually on sofas in the living room, with mugs of drink, often with pets present, with encouragement to take breaks whenever they wished) and care with non-verbal cues such as my posture, tone, leaving aside pen and paper. Participants led seating arrangements and finding a suitable position for the small digital audio-recorder; all appeared very familiar and comfortable with this type of device.

Narrative Interviews

YP then engaged in open-ended, face-to-face loosely-structured interviews aimed at generating narratives of their lives, particularly (though not exclusively) living with CFS/ME. All interviews were digitally audio-recorded. Topic guides (appendix 8), guided by prior literature and consultation with AYME, were used lightly and flexibly to guide main areas of conversation; but YP were encouraged to take the lead, allowing for introduction of unanticipated areas. Major areas covered for all participants included (stories of) the onset of illness, contact with health professionals, impact for school, family, friends, and changes over time.

In line with the narrative focus, open questions were used to encourage long turns of participant-led narrative (eg, “How did you first become aware of...?”; “Can you tell me about when...”; “Can you remember ...”). Follow-up questions and prompts were used facilitate ongoing talk, to clarify or develop areas referred to, and to demonstrate close attention and interest (Rubin & Rubin, 2005). However the focus was on attentive listening rather than questioning (Kvale & Brinkmann, 2009), though sensitive to the individuals involved: though some readily produced extended narrative accounts, others (especially younger participants, and early in the engagement) needed some structure and more

“normal” conversational exchanges to guide their talk. Within the second interviews, participants were encouraged to use any materials they had collected into the “memory box” as they constructed their narratives (eg, as a trigger for storying experiences from the year, or the meanings attached to these). Some more direct questions were introduced conversationally towards the end of each interview (eg, my request for future-orientated hopes, or a “message you’d like to give to the world about what it’s like to live with CFS/ME”), expected to encourage different types of talk (eg, reflection rather than story-telling). The nature of interviewer engagement in co-constructing talk was then considered in the analysis.

All interviews ended with opportunity for participants to reflect on “how this has been today”, to add further comments or to have removed “anything you wish you hadn’t said”; and a reminder that they could contact me later if they had second thoughts about this. (No participant requested this.) The first interviews also ended with discussion of the plan for a second meeting in a year’s time, and for compiling of a “memory box” to help them recall and communicate their experiences (as discussed above). It was suggested that media might include written material (eg, diary/blog accounts), photographs, drawings, music or items (which would be discussed but not handed to me), but that this was entirely at the choice of that particular individual.

At the very end of the interviews, participants were offered a £10 voucher of their choice as thanks for their time and contribution. All asked that I email them occasionally over the year to keep in touch and help them remember to keep their memory box; one, unable to use screens due to light sensitivity, asked me to keep in contact via her mother.

Interviews were planned to last 45-60 minutes, with breaks as requested by participants to accommodate fatigue, get drinks or snacks etc. However, most lasted longer than this, even when I expressed concern about possible fatigue. First interviews lasted 40-80 minutes; second interviews lasted 55-110 minutes.¹⁴ Each YP contributed between 2 and 3 hours of interview, producing a total of 24 hours of recorded material for analysis.

¹⁴ Further details of individual contacts and use of memory boxes are given in chapter 4. Contrary to expectations, all ten YP chose to continue their involvement with the project, returning for second interviews approximately one year later.

3.2.5.3 After the interview

Recording initial impressions

While digital audio-recordings capture a great deal of conversation, they miss context and non-audible features that may be central in co-constructing the interview and its interpretation. Immediately after leaving participants' homes, I began writing notes about what I had just experienced, including observations and initial impressions of the physical setting (eg, type of housing, how the layout of the home affected confidentiality), the nature of the engagement, "tone" of the interview, my own emotional responses and other reflections.

I then listened to each interview in its entirety within 24 hours, giving opportunity to prompt and note further contextual detail while memory was still fresh. The digital timer allowed noting of observations linked to specific portions of speech (eg, when a participant had avoided eye contact or appeared uncomfortable talking about a particular topic; when a strange noise on the recording had been caused by a parent walking past, simultaneous with the YP's abrupt change of subject; holding up of an item from the memory box (and a brief description of this, if not provided elsewhere); or an ironic smile and raised eyebrow accompanying a particular phrase, affecting its interpretation). Additionally, this early "whole interview" listening prompted consideration of its overall impression at the time, including broad shifts at different points: in its social actions (eg, educating, entertaining) and my own responses (eg, feeling different emotional responses, dis/engaged).

Transcribing

The process of transforming audio-recorded material into texts involves many decisions, and hence transcription must be viewed as interpretative, leading to a "partial and selective" portrayal of the interview (Hammersley, 2010; Riessman, 2002a). My decisions about how to transcribe are guided by the assumption that narratives are co-constructed in interaction, and that such interactions go beyond words, constructed with subtle paralinguistic and non-verbal features (Riessman, 2008). Thus transcriptions include myself and participants, and indications of conversational details such as pauses, emphasis, expressive

sounds (eg, sighs, different types of laughter), overlapping, garbled or interrupted speech. A simplified and slightly modified version of the transcription scheme developed by Jefferson (2004) was used for this (appendix 9).

As a novice qualitative researcher, I learned the value of transcribing my own research material, gaining a much greater depth of understanding than I had anticipated from the intensely close listening required. Transcription was facilitated by software that slowed down the digital recordings and allowed for repeated “rewinding” and review of short sections. However, with the limitations of my typing skills, I found this extremely time-consuming. After transcribing all first (10) interviews myself, I made the pragmatic decision to enlist help with the second interviews a year later. The compromise made (Kvale & Brinkmann, 2009) was to employ a professional for initial transcription of conversation (words)¹⁵. These initial texts were then read and corrected where necessary while listening to the initial recording; and I then added all the further discursive features (timed pauses and hesitations, emphases etc) needed for my analysis, and links to other non-verbal observations (eg, YP pointing to an item from the memory box) as before. Even this “second phase” of transcription was detailed and time-consuming, allowing for my immersion in the texts prior to further analysis. All identifying details were changed in written transcripts, and pseudonyms substituted.

All the transcribed texts were then imported into MAXqda 10, a Computer-Assisted Qualitative Data Analysis System (CAQDAS) selected to aid management of complex qualitative data (Silver & Fielding, 2008). Fieldnotes and other observations made soon after interviews were added as “notes” directly onto relevant sections of each interview text (examples of which can be viewed in appendix 11). Digital audio-recordings were imported, and sections of audio “time-stamped” onto corresponding sections of text. This feature allowed easy retrieval of audio data, so later analysis was in fact based on close attention to the audio-recording and other interview observations rather than simply the text itself, allowing for detailed analysis not only of *what* was said, but *how* it was said.

¹⁵ Recordings were anonymised as far as possible and sent using password-protected files. The experienced professional transcriber signed a confidentiality agreement (appendix 10).

3.2.6 Analysis

Although traditionally viewed as a distinct stage in the research process, it should be clear that “analysis” (or a process of interpretation) begins even in interviews, and through note-making and transcription. My analysis then continued more formally, addressing content, structure and contextual/performative elements of narratives. I outline this process here in their separate elements, demonstrating the different “lenses” brought to narratives through processes of analytic bracketing (Gubrium and Holstein 2000). However, in practice the process is not straightforwardly sequential but inevitably iterative, with understandings developing in the interplay between these facets of talk.

Nevertheless, the approach is systematic in that it involves rigorous reading, re-reading/listening, and indexing to ensure that all material is considered. In this, the use of the MAXqda software was invaluable. The system of colour-coded indexing and note-making shows at-a-glance if any areas have been neglected or covered in less depth. It also allows for easy retrieval of evolving analyses, so these could be shared and reflexively examined with supervisors as part of an “audit trail”. A sample of coded transcript and notes, within different features of MAXqda, can be found in appendix 11.

Reading for content

Early readings noted broad and overlapping areas of biographical content (eg school, getting ill, family) - *what* the narrative refers to. Re-readings then noted “themes” within this that began to indicate storylines over longer stretches of material (eg, the shock of incomprehensible illness; confusion over treatment), including expression of emotions (also considered later). Over successive readings, this also suggested consideration of interpretative repertoires (eg, “being a good patient”) explored further later.

Reading for structure

Each participant’s narrative was explored for *how* it was put together, and the implications of this. Sections using tradition “storied form” were noted (though not the only areas considered) and compared with other types of talk (eg, habitual narrative, reflection, quick or extended turns). Further analysis considered how different stories were introduced (including where they were/not prompted by me), ended, returned to and linked, as well

as refusals to tell (eg, changing the subject). Initially this was a simple noting of narrative structure; later this was integrated with consideration of content and performance, exploring evolving plotlines and positioning of characters (eg, of heroic struggle in *trying* to get better).

Reading for context and performance

Each narrative was read with attention to the different contexts - interpersonal, sociocultural, historical, discursive - contributing to its co-construction. Analysis considered *who* talk might be directed to, *when* and *why* (for what purposes) , and *how* this was done - with particular attention to the construction of identities and broader performative struggle over competing meanings (Riessman, 2008). Orienting questions included:

- What kinds of stories do narrators position themselves in?

- How are characters in these stories positioned in relation to each other, themselves (at different times), and the audience(s) - myself, potential readers of the research, or “ghostly audiences” from the speaker’s past, present or future (Minister, 1991)?

- How do narrators respond to me, and I to them? How might this have influenced the development of the narrative and its interpretation?

- How do speakers use language to make claims that they hold to be true beyond the local context? How are discursive resources drawn on and resisted to do rhetorical or identity work, attending to the “trouble” of dispreferred positionings, including use of:
 - interpretive repertoires (Potter, 1996), canonical narratives (Bruner, 1991) and existing personal positionings (Taylor, 2005b)
 - discursive devices such as repetition, rich description, im/personal pronouns, emphasis, hesitation; “active voicing” and corroboration, humour, idiom and irony (eg, Edwards, 2007; Edwards & Potter, 1992; Wooffitt, 1992)

- What counter-narratives (Bamberg & Andrews, 2004) may be discerned?

3.2.6.1 Process in analysis and representation

Individual narratives

In keeping with the case-focused approach to narrative analysis, each participant's narrative was first analysed in its entirety, focusing on its particularities and aiming to preserve sequence and detail across long stretches of talk (Chase, 2011; Riessman, 2008). All material was examined, whether in storied form or not. Detailed notes were made, outlining all major storylines and observations about their contextual and performative construction. All interpretations were closely linked to (quoted) talk, and reflexively examined personally and in supervision. This process was repeated for each participant in turn ¹⁶.

This process was repeated a year later, after the second interviews. An additional element of analysis was added, as narratives generated here were considered in relation to the first (and vice versa) - for example, for continuation, development or deviation from storylines (eg, of chaos or redemption), and positioning of present in relation to "past self" (Taylor, 2005b).

Following this, I drafted an impression of each YP's story. Written in the third person (to remind readers that this too is a construction from my own perspective, rather than the summary that the YP would necessarily produce), and in the present tense to preserve the immediacy of their construction-in-interaction, these draw out key narrative threads for each YP, broadly in the order that they were presented (unless noted otherwise). These draw on participants' own words (*in italics*), interwoven with my own observations, context and impressions drawn from my notes and reflective journal. The ten individual "short stories" comprise chapter 4, presented in order of the age of participants, from the youngest (Adam) to the oldest (Katie).

¹⁶ Inevitably my immersion in narratives sensitised me to particular areas in others, occasionally leading me to revisit an earlier narrative if I realised I had "missed" potentially important meanings. For example, the third YP interviewed talked in detail about feeling "left behind" when an older sibling was "moving on" and leaving home - and I realised that both previous YP had mentioned this issue, though it had not struck me as significant at the time. However, at this stage analyses were predominantly separate.

Bringing narratives into dialogue

There then followed a sustained comparison of narratives across the group of YP. This looked at consistencies and departures in emerging stories, allowing for the construction of broad storylines (eg, “getting ill”; “seeing psychologists”) in which participants might adopt similar or distal positions in terms of content, structure or performance. There was also consideration of “disconfirming instances” - narratives or particular sections not conforming to a broader pattern, allowing attention to how this might be explained within particular contextual frameworks.

Drawing on the metaphor of a patchwork quilt, the aim was to respect the particularities of each individual’s narrative but, by stitching them together, point to discursive resonances between them (Saukko, 2000); and hence to bring voices into an ensemble in which each “begins to sound differently than it would have sounded on its own” (Bakhtin, 1981:412). Storylines are represented in chapter 5, again closely interwoven with participants’ words, and stitched together with my own consideration of the different ways that these YP take up the challenges of accounting for lives and identities living with a diagnosis of CFS/ME.

Chapter 4

Young People living with CFS/ME: Ten Short Stories

4.1 Adam's Story

The youngest participant in this study, Adam was 13 when we first met, living in a village with his mother and younger brother (his parents were separated). Although Adam clearly agreed to talk, his involvement was led by his mother, who had learned of the project through the NHS paediatric team where Adam had been diagnosed with CFS three years previously.

We met in the family living room, surrounded by the paraphernalia of family life (books, toys, laundry). The door was left slightly ajar by his mother as she left the room, but Adam did not show any concern about confidentiality. He proved an engaging narrator, storying his experiences with detail and humour (eg, mimicking his doctors), and it was easy to warm to him. At times I was conscious of feeling somewhat maternal towards him as he spoke, conscious that he was not much older than my own son. His talk mixed child-like and more adult features of content and style (eg, clearly relishing describing his tablets tasting “*like animal faeces*”¹⁷, in contrast with his scathing judgements of “*shocking*” and “*very poor quality*” health professionals), and there was a strong sense of the co-construction of some parts of Adam’s narrative in partnership with the adults in his life.

Adam begins his story “*from when I got M.E.*”, waking on the morning of his tenth birthday, “*just feeling a bit like bad and that so I didn’t go into school that day(1) or the next day(.) or the next day*”. Although noting very briefly a previous “*stomach thingy and chest thingy*”, a feature of Adam’s narrative is that there is almost no talk about experiencing more severe

¹⁷ Quotations in italics are taken directly from participants’ own words. Additional notation (eg, underlining, punctuation or numbers in parenthesis) to convey the nature of talk follows a simplified form of transcription conventions based on Jefferson (1994), as set out in Appendix 9.

or ongoing symptoms, and no attempt to articulate possible causes of this ill-health. Instead the focus is on responses: his bed-rest and considerable time off school, contact with health professionals, and disruption to some aspects of his life. There is also almost no talk of his emotional experience - Adam is disparaging about the contemporary culture of emotional expression in *"TV-show-reflection-strictly-come-dancing hheh sort of thing"*, and speaks of his discomfort on having to speak to a Child and Adolescent Mental Health Service (CAMHS) psychiatrist, *"this woman who I'd met once about(.) like(.) my er inner feelings"*. I took this also as a communication to me, as another woman he had just met once, not to press him on this.

Adam's talk here positions him clearly as a child, in terms of his understanding of, and his agency in, unfolding events. Language includes child-like terms (eg, being given *"pilly things"*) and hesitation over pronunciation of medical terms. Stories of encounters with health professionals are at times confused, and emphasise his relative passivity: he expresses uncertainty about the roles of practitioners consulted by his mother, and their diagnoses and re-referrals (*"I didn't really understand cos I was only like ten"*); and attributes healthcare decisions to his mother (*"so er basically we came out of that and my mum just said to me 'we're never going there again'(.) and we didn't"*).

By contrast, stories about ongoing management of symptoms (such as deciding whether or not to get up for school in the morning) position Adam with more agency (*"I just like won't respond(.) so [Mum] just knows when to leave me(.) alone"*). Similarly, Adam constructs a picture of persisting with activities of importance to him - sport - even when missing school. Talking with a cheeky smile of the first year of his illness, he tells *"I made even less school in Summer(.) but err yeah- I got- I got in for like the big events like sports day erm and blitzed all the medals and won 'em all (2)"*.

However, this illustrates potential trouble arising from Adam's talk. In the absence of detailed description of symptoms, and perhaps the lack of understood cause, it is sometimes unclear how Adam's actions are an inevitable consequence of his illness. When I ask about the decision to miss school the previous day, his response is off-hand: *"I didn't get ↑up (1) that's basically ↑it (2)"*. Unlike other participants, there is no attempt to justify or show sanctioning of this decision, other than saying that he was tired. He lists activities

he does while absent from school - playing computer games, watching DVDs - that might be considered appealing, potential motivators for staying at home - again contrasting with other participants, who either talk of the impossibility of these forms of entertainment due to illness (light sensitivity, poor concentration), or stress how boring they become. Further, Adam is the most open about some benefits of his illness (eg, securing a good secondary school on grounds of special health needs). It is important to stress that this observation is not to question the legitimacy of Adam's illness or responses, or any aspect of his character. Rather, I wish to note how his talk is less oriented than that of the other participants to rhetorically "justifying" his behaviour, and to consider how this style of talk might be responded to in different situations.

Meeting just over a year later, Adam's increased height and lower voice contribute a different tone to his narrative. The overwhelming storyline now is of progress and increasing ability to "do stuff" with increasing energy levels over the year. All the photographs and items he brings depict activity (eg, flying a kite on holiday) and achievements in sport (eg, holding a football trophy), as well as events associated with increased age and identification with the men in his family (eg, going to a music gig with his Dad, and becoming a referee for younger footballers). Interestingly, Adam later tells me that his mother had helped him choose photos to talk about in this second meeting with me, again highlighting the issue of family co-construction of narratives.

Relatedly, a strong storyline is Adam's increasing independence and success in learning to allocate still-limited resources of energy. He now highlights agency in learning to prioritise important activity - school and his preferred sports - by reducing other, less important activity. This extends a thread from the first interview of previously feeling under pressure from adults to participate in many activities, and finding it difficult to say "no" until illness forced the issue. This is now linked to a broader thread of growing up, growing responsibilities, and new challenges. Adam talks of "*high expectations*" from his mother, and times when he might feel unable to meet these. He reflects that "*as like time goes by in the future I'll have less reason to say 'no(.) I can't do that because I'm tired' because I'll be getting better(.) and most of the reasons for me not doing something will be because no I just can't deal with doing that*". Thus Adam concludes this chapter of his story looking to

the future, reflecting that recovery from illness will bring about new challenges in negotiating his role as a young man.

4.2 Becky's Story

Becky was 14 when we first met, living in a village with her parents and younger sister. Research participation was initiated by her mother through the local NHS paediatric team, and although Becky appeared content to engage, she seemed shy at first, and occasionally uncomfortable both physically and emotionally. Meetings were (at her mother's suggestion) in the family living room, where the open-plan layout of the house limited confidentiality. At one point when her mother passed through the room, Becky clearly hesitated and let the topic of conversation drop.

Becky's story begins with a fluent account of the onset of illness soon after the start of her second year in secondary school; there is a sense that this is a familiar story for her to tell. Migraines and "*a bug or something*" are briefly mentioned as she talks of how she "*just became really tired*", constructing her illness as physical and confusing, though possibly understandable within broader medical frameworks. Throughout her interviews, brief descriptions of symptoms are embedded in stories of her life, and also made visible through her embodied communication: her slow, soft voice, and habit of periodically pressing her hand to her forehead with a pained expression on her face. Alongside this picture of suffering, Becky's narrative positions her as valiantly trying to "*keep going*" through the progression of fevers, sleep disturbance, nausea and extreme fatigue until a point in the Christmas holidays when she finally "*just flaked out*", overcome by physical symptoms.

In contrast with this fluently-spoken account, Becky's talk of early encounters with health professionals - of inconclusive test results and re-referrals - is told with more uncertainty and uncomfortable-sounding "*I don't know*"s, and her suggestions that she was too unwell at this time to retain details. Like Adam, her narrative clearly positions her as a child (she was only 11): there is hesitation in using medical terms; recurrent use of the plural ("*we*") indexing her mother's role in consultations; and the power/agency imbalance between doctors and the family is highlighted ("*[the doctor said] she'd refer us*"..."*we ended up at [the paediatrician]*"). Then, talking of early attempts to get well, Becky language again

positions her as relatively passive in relation to adults (“*I was being fed anything that looked green!*”).

Becky’s narrative highlights progressive loss of functioning, where she “*slowly got more tired and more tired and more tired*”. Though a number of health professionals populate the account, they are positioned as of limited value. Like Adam, she is particularly dismissive of a member of the CAMHS team. The content and performance of her talk convey a sense of helplessness and distress that others cannot understand or help with what she is going through.

A turning point in the story comes around eighteen months after the onset of illness, and many months of missed school. A member of the Educational Support team is presented as suggesting she build up her activity very gradually, beginning with simply waking up at a regular time each morning, or reading just one or two sentences before taking a break. In contrast to previous storylines, now there is a shift in narrated agency, as Becky’s own “*hard work*” in this process is repeatedly stressed in a narrative of gradual progress.

This thread continues strongly in Becky’s second interview, again conducted with her mother nearby. There are many stories of work and progress in managing symptoms and education, but also of setbacks (eg, from “*bugs*”) and frustrations. There is particular focus on the difficulties of “*catching up*” within an inflexible educational system and inconsistent support from teachers. Becky tells again of how she “*tried really hard*” with home education, achieving good exam results, but also of the price of success: how she has sometimes pushed herself too hard, resulting in increased nausea and fatigue.

As with Adam, Becky’s mother is visible in co-constructing the narrative to be presented to me. Unlike other participants, Becky did not bring photos or mementoes to illustrate her story. Instead, she explained that she and her mother had printed a summary of the “*main events*” of the year, drawn from a diary that her mother kept at the time. Thus this might be considered, at least in part, “*Mum’s story*”, although Becky talked easily to this script, with a sense that it was incorporated strongly into her own narrative.

After putting aside these notes, Becky's narrative turns more to her increasing ability to "bounce back" from minor infections. In contrast to earlier talk focused entirely on physical constructions of CFS/ME, Becky now introduces more complex considerations of the relationship between physical and emotional aspects. She talks for the first time of how anxiety may show itself in her as physical symptoms, and how recognising the role of emotion has allowed her to respond differently to symptoms and recover more quickly. However, this should not be taken as indicating a smooth path. There is still hesitation and confusion as Becky tries to articulate the "fine line" she is trying to tread in balancing her activity, learning that doing too little will lower her mood and make her feel worse, but doing too much will increase her fatigue. Drawing on established medical and cultural narratives of the need for "balance", she presents a narrative not simply of her achievement so far, but the still uncertain way ahead.

As in her first interview, Becky closes with a reminder that, despite her narrative of progress, she has lost a great deal and changed as a person because of illness. While noting her above-average academic success, she counters this with reflection on her pre-illness "top-set" achievement and expectations that will not now be realised. She positions herself as having learned to adjust her previous striving to be "perfect", drawing repeatedly on the idea that "as long as I've tried my hardest erm(.) whatever I get will be the best I could do (#) so that's fine". This suggests a quest narrative (Frank, 1995) of personal growth through adversity, but these statements are troubled by hesitations and doubt in her voice. I was left with a strong sense that this narrative construction of her "journey" and identity development does not emerge in isolation, but in collaboration with the adults in her life.

4.3 Callum's Story

Callum was 14 at the time of the first interview, living in a pleasant area of a small city with his mother and older sister while his father worked abroad. After hearing of the research through the local NHS paediatric CFS service, Callum's mother contacted me, and then emailed me twice to volunteer context about Callum in advance. She stressed that his positive experience with an extended medical team and supportive school was "not representative of others with M.E.", and also that - now much recovered from illness - he

did not appear to remember or talk about the extent of previous difficulties or disability from the condition. At the pre-interview meeting, she gave her occupation as "carer", saying she had had to give up her career to look after Callum when he became ill two years previously. Callum objected, saying this was "*overstating*" difficulties. There was some tension in the room. Thus the beginnings of an interactional context and narrative of Callum "*playing down*" difficulties / his mother taking the role of articulating them, was established even before the start of the first interview.

Speaking without his mother, Callum constructs a strong narrative of a "*normal*" boy whose problems "*obviously started*" with appendicitis and "*infections*" that left his body "*weak*". Physical symptoms - sore throats, dizziness, fatigue - and "*annoying*" disruptions to school, sports or social life, are noted but quickly dismissed as "*not horribly bad*". His tone is brisk and unemotional, adding to the impression of a boy who is not complaining. Even when short, quickly-spoken accounts hint at more severe past difficulties, they are accompanied by evaluations that downplay their impact: "*it didn't last that long it was only like a couple of months of being like completely(.) almost like(.) er(.) hardly being able to get out of bed then it(.) it all got easier*".

Presentation of a "*normal*" identity is the strongest thread running through Callum's narrative over both interviews. In contrast to other participants, he talks of strong and continuing friendships largely unshaken by his illness, and the importance of this to his life and identity ("*so I didn't feel like completely isolated [...] it made me feel normal*"). He further positions himself as uncomfortable with others needing to treat him differently ("*I don't want people to go out their way[...] it doesn't seem normal*"), in opposition to cultural narratives that position sufferers of CFS/ME as "attention-seeking".

Callum's narrative also orients to (and resists) cultural narratives of CFS/ME as reflecting psychological problems, both in his repeated descriptions of himself as "*normal*" with positive relationships, and in construction of his symptoms and their cause in purely medical terms. Here though he has to do additional work, knowing his mother has already told me that he has seen a clinical psychologist. He does not raise this spontaneously, though responds when I ask directly. Unlike Adam and Becky (who saw psychiatrists and a social worker within NHS CAMHS), Callum presents a more positive story of contact with a

private clinical psychologist - though only after constructing this input too as “normal”: stressing that the paediatrician “*always recommended*” this for his patients; quoting his Dad’s evaluation (it “*can’t hurt*”); and framing it as something that he “*didn’t really need*” since - as the psychologist reportedly confirms - he had always been “*positive*”. Thus Callum is positioned as a “good patient” prepared to work at his recovery, while maintaining a non-stigmatised identity as psychologically healthy.

Another strong feature of Callum’s narrative is of *working* to get better. He focuses particularly on the work he undertakes to rebuild physical strength as a way to resist future illness, in stories that can also be seen as performances of healthy masculinity (eg, commenting that he has just run 6 miles); but also the work of rebuilding concentration and capacity for schoolwork, following a period when he was unable even to read. There are indications of a quest narrative, as Callum talks of a positive thing to have come out of his experience: “*it’s shown me like(.) to(.) just(.) work(.) all(.) work- well I’ve always like worked hard but(.) I’ll work harder and that’s going to benefit me in the future(.) without doubt*”.

The narrative is developed further the following year. Summarising “*a good year*”, Callum’s stronger physique and deeper voice resonate with his portrayal of personal agency in a project of self-development. He outlines the targets he has set himself, and how he has not only achieved but surpassed these, despite setbacks. There are stories of academic success, but it is in the arena of sporting achievement that Callum’s narrative is particularly strong. He gives a vivid account of his struggle to regain his place on the local rugby team after long absence through CFS/ME, and his sense of pride at regaining a prized place in the line-up - only to find himself at the receiving end of a dangerous tackle, resulting in a broken shoulder just a few minutes into the match. Callum’s ruined rugby shirt, cut off by the paramedics as he is treated, is the first item he draws from his “memory box”, providing a graphic illustration of the ups and downs of his year. In addition to a portrayal of strength and masculinity, the performance of the story - told with good humour and wry comment - continues the theme of Callum as emotionally resilient and “not complaining” about his life; and he continues his talk of the year with an account of recovery, illustrated by the handful of medals brought to show his success at his school sports day a few months later. The narrative of resilience is reinforced as Callum brings out further items: a CD featuring

a song about an ex-addict who “felt he had no-one as well in his life” but overcame his adversity; and an “*inspiring*” book about a mountaineer who heroically survives an accident and being left for dead.

Callum’s story challenges many prevailing cultural narratives of “people who have CFS/ME”. He presents an identity of a worker (in contrast to cultural positionings of “shirkers”); of physical and mental resilience (in contrast to positionings as “weak”); of masculinity (in contrast to statistics that highlight female predominance); of “not complaining” (in contrast to discourses of “whinging” and malingering); and of a healthy social identity (in contrast to positionings of psychopathology or wish for “secondary gain”). In many ways Callum’s (counter)narrative may be seen as working to reject identification with a stereotyped “M.E. identity”. This is particularly striking in talk of a recurrence of fatigue shortly before our second meeting: in contrast to all other participants, Callum asserts that he no longer has CFS/ME. Instead he constructs this recent fatigue as the “*burnout*” increasingly reported by athletes. Significantly, he indexes reference to this diagnosis in sports magazines as a consequence of impossible sporting schedules and high standards, and not the weakness of individuals. Thus an emerging narrative can be seen, in which Callum can make sense of any ongoing fatigue through a narrative that fits more easily with his preferred identity as a healthy, sporty young man.



4.4 Danni's Story

Aged 14, Danni was living with her mum, step-dad and younger siblings when we first met. Although the setting initially looked similar to that of several other participants, it was clear even before entering the house that Danni's life was different: a wheelchair ramp had been installed, and a note by the door asked visitors not to ring the door-bell, so as not to disturb Danni who was "having a bad day". The note appeared to have been there for some time.

Inside, Danni lay almost flat and motionless in a hospital-style bed by a baby monitor. Her mother, who had contacted me through AYME, explained that Danni could no longer move, chew or call out, so she carries the receiver to hear if Danni needs help. Danni was pale and the muscles of her limbs appeared severely wasted, but she smiled gently as she whispered hello. I felt very conscious of her vulnerability. This, and my concern that our conversation might be heard by her mother through the monitor, contributed to my feeling that I needed to tread particularly gently in the interview.

Though speaking quietly, Danni was engaged and engaging throughout the interview, smiling and laughing quietly, and giving short but expressive accounts of her experiences. Her first and repeated narrative is of restitution (Frank, 1995): of being previously active and happy until inexplicably struck down by illness two years before, but confident that she will one day return to health and previously-enjoyed sport and play. However, alongside this come quieter, more troubled narratives: of feeling bullied in school and unsupported by teachers before becoming ill; of sadness, annoyance and frustration at estrangement from her biological father; and her "past self" as someone who "*used to get angry about life*" and "*(.) hit my mum .hhh(.) erm but now I've changed*".

In contrast to these short references to an aggressive past self, the now-immobile Danni is positioned passively within the dominant storylines of becoming and being unwell. After telling of getting flu during her first term at secondary school and developing joint pain which then "*escalated*", the narrative is of how she "*just went downhill*" with progressive fatigue, pain and sleep disturbance, while being passed between health professionals with

inconsistent messages and diagnoses. Here Danni also introduces the spectre of disbelief: a suggestion from her aunt that she is “*faking it*”, and peers calling her a “*skiver*”. The narrative continues even after diagnosis of M.E. from a private paediatrician as a descent into disability compounded by iatrogenic injury, as she continues to be passed between eminent professionals and centres of expertise for exhausting and sometimes painful assessments, only to be told that they are unable to help as she is “*too severe*”.

Danni outlines the functional significance of symptoms that leave her “*trapped[.] in my own body*”. Now a “chaos” narrative is infused with incomprehension and disappointment (Frank, 1995), but Danni expresses no anger or even frustration; rather she is positioned passively as a victim of circumstances.

Isolation and loneliness, and discourses of “normal” teenagers, form an ongoing thread. Here Danni orients to a psychosocial narrative attributed to a member of the CAMHS team to which she was referred: that her disability might be caused by an unconscious desire not to grow up. Danni counters, “*if I could rebel I’d love to be able to rebel and be out on the streets[.] starting to pa:rtv*” (although she immediately troubles this: “*well(.) hh I’d love to be but I probably wouldn’t be(.) I’m too shy*”). Danni also draws on cultural narratives of a split between mind and body, both in her portrayals of health professionals who question whether she is depressed, and in her own construction of M.E.: “*it’s not in my head [.] it’s real*”.

Danni’s narrative repeatedly positions her not only as *wanting* to be better, but also as *working* towards this. This is a difficult position for her to maintain, given her immobility. She manages this discursively by framing “*letting my body rest*” as the work that will allow her to recover, and talking of her intention for future work and “*persistence*” (“*tomorrow I’m hoping to start putting more pillows under my head to sit up a bit more*”)¹⁸. Nevertheless there is dissonance between Danni’s expressed hopes for the future (eg, to attend the school prom at the end of the year), her “inspiring” song and mantra (“*Don’t worry, be happy*”), and her current appearance and pace of change. I left the meeting feeling very

¹⁸ But see chapter 6 for discussion of my own role, as well as broader cultural narratives, in this co-construction.

concerned for Danni, although wanting to believe that a multi-professional meeting scheduled soon after might be able to help her.

It was almost 18 months before I saw Danni again. I learned from her mother that Danni had stopped eating or drinking three months after our meeting, resulting in hospitalisation and then transfer to an adolescent inpatient unit specialising in eating disorders, CFS/ME and “pervasive refusal syndrome”. Although Danni was apparently keen to speak to me, it was several months before the clinical team were prepared to facilitate a meeting, with understandable concerns (from myself too) to ensure Danni’s wellbeing and capacity to continue with this project.

I met with Danni in the unit’s living room. Nurses lifted Danni from her wheelchair to a sofa, where she half-lay, supported by cushions. She wore a nasogastric feeding tube, and her hair looked unwashed - I recalled her mother saying that she had refused to let anyone touch or wash her. As we spoke she cuddled a large teddy-bear, relaxing her hold as the conversation progressed. Despite this appearance of vulnerability, Danni smiled as she greeted me, and engaged readily in continuing her story. Though other people could be heard in the corridor, Danni did not appear concerned about confidentiality.

Danni’s first and strongest narrative of the past 18 months is of a chaotic descent into further disability. There is vivid portrayal of withdrawal from the world: of Danni using ear-defenders and an eye mask, communicating only by “puffing”, then “*put in isolation*” in the general hospital, apparently because of her refusal to be washed. As before, the narrative is of Danni being buffeted not only by symptoms, but also by the seemingly dismissive and even punitive responses of professionals who “*didn’t understand or believe us (.) they- they just treated us badly*”. As in the first interview, the repeated use of “we” and “us” (referring to Danni and her mother) and inclusion of phrases that her mother has also used (eg, “*we’ve seen who our real friends are*”) gives a strong sense not only of their joint journey, but also of the co-construction of Danni’s narrative.

A feature of Danni’s story now is the proliferation of diagnoses, and her changing relationship with psychological understandings of her difficulties. She tells of having developed an eating disorder and “*dissociative disorder*”, and - in contrast to the first

interview - now speaks positively of work with a new psychological therapist. Danni initially makes narrative sense of this by stressing that these psychological difficulties have arisen as a *consequence* of M.E. and subsequent treatment: “... *because like people didn't like believe that I had M.E.(.) and then they gave me like false hope and things so(#) I just retreated back ...*”. However, this is troubled by later talk of anger management strategies learned before becoming ill, and presentation of a new narrative that makes sense of her difficulties within a more psychological framework.

Danni speaks positively of her life in the adolescent unit, though noting the strains of separation from her family and pet dog. Now she introduces small stories of progress: having her first hair-wash; growing relationships with carers and the other young people; and beginning some education (“*nice because it's kind of(.) like normality*”), tying in to her broader expressed position of wanting to be “*a normal teenage girl*”. There is also talk of learning how to express anger more positively, and - in the beginnings of a “quest” narrative - becoming a better person as a result of her illness, with dreams of becoming a paediatric nurse.

However, this narrative of progress is tempered by expressed awareness that the adolescent unit is not “*normal life*” or a permanent home, and that there is a difficult journey ahead. Here Danni introduces the idea - attributed to her mother - that, while other teenagers speed towards their destinations in fast cars on the motorway, Danni is in a “*pink Morris Minor [.] going down all the back roads(.) but [.] still gonna get*” to her destination. This is consistent with her previously-expressed position of *wanting* and determinedly *trying* to get better. However, in contrast with her first interview - dominated by a narrative of chaos - now there is a stronger narrative of slow movement, of Danni assuming more agency, and greater awareness of the steps she must take on the long road ahead.

4.5 Evie's Story

Evie was 15 at the time of her first interview, living with her parents and older siblings in a house on a small modern estate (very similar to those of Becky, Danni, Grace and Harry). Other family members were nearby as we met in the main living area, and Evie seemed occasionally conscious of being overheard. From the outset, she had an engaging style of talking, speaking quite fast, smiling and laughing at times in a somewhat self-deprecating way. She came across as open and thoughtful, and keen to tell her story.

Evie story begins aged 9 *“on my sister’s birthday”* with sudden onset of *“really strange stomach pains”*. It then depicts a progression of physical symptoms - pain spreading to muscles and joints, and fatigue - to the point of needing a wheel-chair. Evie speaks briefly of multiple visits to doctors, inconclusive test results, and (mis-)diagnosis with *“like all sorts of viruses and infections and arthritis which I was on hh:medication for(.) which it turns out that I didn’t have hheh”*. This chapter of her story turns with talk of a diagnosis of M.E. and IBS three years later almost by chance - when family relocation resulted in a new GP - and allocation of a CFS nurse who helped her learn to manage her illness and negotiate with school-teachers who *“didn’t really understand”*, or seemed irritated by her inability to do normal activities.

An important feature of Evie’s narrative is its ability to convey a strong sense of her difficulties (both physical symptoms and their psychosocial impact) without appearing to over-dramatise or complain. A number of aspects of her talk contribute to this. In speaking of her treatment by others, Evie does not criticise or mock them (as other participants have) and even uses humour to *“make light”* of this; yet her storied accounts contain enough detail for listeners to draw their own conclusions about how difficult this must have been for a child. She reflectively suggests that it is difficult for other people (particularly peers) to understand; *“balances”* any implied criticism (eg, about her friends’ irritation: *“it’s not very common...they’re very good”*); and immediately follows accounts of unhelpful treatment by positive statements about other people who *did* understand and help her, positioning herself as *“lucky”*. This representation of good people who will help Evie simultaneously reinforces her position as a child who is worthy of the love of friends and

family; narrated support from a specialist CFS nurse further reinforces the credibility of her illness and need for help.

The importance of family is a major thread running through both Evie's interviews. She speaks warmly and with many short stories of her extended family and the support they give, including with home education. Family and their cultural background (non-European Catholic) are presented as the source of her preferred identity, and its impact on her approach to coping with M.E.. Evie repeatedly positions herself as accepting that "*what happens happens for a reason*", even if she may never fully understand this; and as believing that "*there's no point in worrying? because it just makes things worse?*". She positions herself as independent, not wanting "*drama*", and just wanting to get on with things. This ties in with a strong position made by Evie: rather than questioning the cause or meaning of her illness ("why me?"), Evie's narrative is of focusing on the here-and-now, *working* to understand any patterns in her symptom variance so that she can learn to manage them and regain some independence.

While most other participants also draw on the cultural narrative of "hard work", Evie's narrative is perhaps the most detailed about what she has learned about diet, activity, medication etc. She includes psychological aspects: learning how to keep going even when feeling "*very very low(.) depressed or cranky*"; and keeping calm in the face of everyday stresses, because "*worrying doesn't help it makes it worse(.) erm but it's not easy hheh!*". There is a clear depiction of a journey in this, from the initial period of struggling to accept her condition, to the beginnings of a "quest" narrative as Evie begins to reflect on some success in learning to keep things on an "*even keel*".

This narrative is developed further in the second interview a year later. Evie - now looking older, slimmer, wearing a little make-up - is quick to engage and take up the story. The main narrative now is of improving health and achievement over the year, illustrated by the many items collected in her memory box. Her family again feature strongly in her journey, in stories of trips, activities and meals out linked to her increased energy levels. There is a sense of pride as she relates her academic success in GCSEs, showing the long revision timetable developed for her by her sister, illustrating both family support and the

hard work involved. There are also stories of increased social independence as a teenager, in taking on voluntary work.

Accompanying this dominant narrative of progress comes talk of new challenges. Academic success at this time of her life leads to thoughts of leaving the relatively safe environment of home (and home education) to go to University. Stories of meeting her new manager and other volunteering teenagers highlight the challenge of explaining her home education and history of illness to other people, reviving old themes of feeling questioned or positioned as an outsider. Being asked about her illness at a time where she has relatively few symptoms, highlights a further dilemma for Evie in making sense of her relationship with M.E.. On the one hand, she states that she still would still describe herself as having M.E., albeit with symptoms that are *“in the background”*. On the other, her aspirations for University are presented as an opportunity for a new identity. She tries a number of times to articulate this: *“erm (#) it’s not necessarily that I’m ashamed(.) of my illness but there is a certain(.) erm(.) want for(.) I guess a clean slate you know (#) to be able to sort of start new and want the same thing as all the people around me”*. This is a somewhat confused narrative which loops in circles; there is a strong sense of Evie working to make sense of the next phase in her life, looking at the possibility of a more *“normal”* teenage life while acknowledging that her history makes this difficult.

One item Evie shows me seems particularly significant as a communication of her narrative of quest and hope, as well as her preferred identity: a brightly-coloured badge given by her sister, with the title of a song from a popular teenage TV series, it reads: "Don't stop believing".



4.6 Freya's Story

Freya was 15 at our first meeting, living with her family in a suburb north of London. Fashionably dressed and wearing make-up, she looked like many of the teenage girls I had just passed on the street; but she moved slowly and carefully, spoke quietly, and kept the curtains partly closed as we spoke, telling of the light sensitivity she still experiences. At her mother's suggestion, Freya and I talked in her bedroom upstairs, Freya sitting up on her bed. We left the door slightly ajar, but Freya showed no concern about confidentiality. She engaged quickly in telling her story, but her tone was emotionally flat even when talking of distressing events.

Much of Freya's narrative is structured around her illness trajectory, which she suggests is unusual: two distinct episodes of illness, separated by a period of recovery and relative well-being. Rather than telling her story in strict chronological order, episodes from these two periods are presented in contrast to each other (eg, *"even though this time I couldn't walk [...] I still think that other time(.) I felt worse"*).

Freya's narrative is densely populated by other people, who she divides into those who support and *"understand"* her (particularly her parents and brother) and those who do not. Arguably the strongest storyline is Freya's ongoing struggle with people who *"don't understand"*, sometimes directly challenging her version of her illness and her moral credibility. This begins with her story of being sent home from school aged 13 after becoming dizzy, and repeated visits to the GP practice where *"the doctor didn't believe me and they thought that I was just wanting to get off school [...] and I wasn't"*. She tells of headaches, pain and nausea, and how she consequently *"didn't get out of bed for three months"*, *"not doing anything(.) and hheh getting bored"*, while a series of re-referrals and tests *"didn't show anything"*.

Medical uncertainty is described as having profound social and personal consequences for Freya. First she tells of beginning to doubt herself : *"cuz when the doctors told me there was nothing wrong(.) it kind of made me think(.) am I just being stupid? Cuz(.) obviously you always think doctors are right"*. Then - in a storyline that echoes across her narrative - she sets out the responses of her peers: *"they were asking me what was wrong(.) and I said*

'I don't know(.) cuz the doctors don't believe me'(.), and that made them think(.) 'oh(.) if the doctors don't believe you then why should we?'"

Despite hints of ongoing difficulties with peers throughout this first episode of illness and a graded re-introduction to school, the story progresses to a happier (first) resolution, in which Freya - having been diagnosed by a paediatrician and supported by a specialist team - regains function and friendships over the year. However, an important turning point in the narrative comes a few months later, soon after the start of the new school year: having *"thought I was gonna be fine from then"*, she notes *"loads of work[.] and then(.) aha(.) then it happened again"*.

Two aspects of this relapse emerge strongly in the narrative. First, the return of symptoms raises again the spectre of disbelief, and a renewed assault on Freya's moral credibility. She tells that *"this time around [the paediatrician] didn't believe it either(.) cos it shouldn't happen twice or something"*. Though Freya quickly jumps forward in time to tell of how the paediatrician later *"apologised"* when he *"obviously realised that he was wrong"*, practical consequences are highlighted (eg, reduced input from the paediatric physiotherapist). Additionally, Freya tells how *"my friend said 'oh stop faking you're missing too much school (.) erm(.) you just need to get over it(.) and(.) stop lying'(.)"*. The emotional impact of this is emphasised as Freya returns to this story, with its stressed and voiced *"lying"*, several times over the two interviews.

A second significant aspect appears in Freya's account of her own responses. In contrast to the first episode (in which symptoms appear inexplicable, and when she quickly goes to bed for a prolonged period), Freya emphasises that this time *"I knew it was kind of happening cos I recognised it from last time(.) but I thought if I carried on this time instead of just stopping(.) I thought it would just go"*. This account positions Freya as morally responsible, striving to resist giving in to illness and to learn from past experience. The re-emergence of symptoms *despite* her different response increases the sense of inevitability within the narrative: that M.E. will take control despite her best efforts, and she cannot be held responsible.

Nevertheless, Freya ends her first interview suggesting that she has made progress again, and is looking ahead to a time when she can leave school for college. In line with cultural narratives of adolescence, she positions herself as now wanting more independence, particularly when her parents suggest she is not well enough to go out. She even tentatively imagines a future beyond illness, when she may “*put it behind*” her and not “*have to tell anyone about it(.) hheh(.) and that it can just be something that never really happened(.) hheh*”.

15 months later, there are immediately signs that at least some of these wishes have come true. Her stories (and the photos she has brought to illustrate them) are now of achievement and progress: attending the school prom with friends and a (first) boyfriend; learning to drive; going to a pop concert; academic success and starting college. Stories given most prominence are of leaving behind troubled peer relationships and making a very different group of friends, “*more supportive than my old friends ever were*”. This can be seen not only as a story of moving to happier times, but also as providing vindication of Freya as a likeable character, worthy of good friends; not only believed, but *believable* in her need for support. Thus the narrative dilemma of talking of previous peer rejection (and risking a stigmatised identity as “unpopular”) is resolved by this new story.

However, the story highlights that Freya’s other “wish for the future” has not occurred: CFS/ME is still a factor to be reckoned with in her life, personally and socially. It portrays good friends as *noticing* her need for care by the (obvious) visible signs. Importantly, Freya is not complaining (again, countering the narrative CFS/ME sufferers as “attention-seeking”). Her position is reinforced as Freya evaluates their care as “*nice*” but also “*a bit annoying cos(.) I wanted to kind of(.) carry on and just work*”.

Thus this positions Freya as still striving to resist “giving in” to illness, persevering heroically until stopped by caring others. This seems be particularly important in Freya’s ongoing narrative, given the earlier personal attack for missing school. However, this position is potentially troubled. Freya is now 17, expected not only to be more independent but also training for a career where she will be caring for other people. In a culture where adults are expected to take a high degree of personal responsibility for their health, Freya’s positioning as trying to ignore symptoms risks slipping from “heroic” to “irresponsible”. She

appears aware of this dilemma, as her narrative moves to give a more nuanced portrayal of her symptom-monitoring and decision-making, reframing her as “*stubborn*” but also able to make sensible decisions: for example, choosing an entry-level course, despite being academically eligible for a higher-level (but more physically demanding) course (“*because I thought it was safer heheh*”). The narrative is of a life and an identity where she is confounding her detractors, and of a successful “quest” whereby she has learned from her experiences and become a better person as a consequence; yet where the shadow of CFS/ME is never very far away, and there is an ongoing need for Freya, and those around her, to take care.



4.7 Grace's Story

Aged 16 when we first met, Grace was the only participant to have left education. She lived with her family on a small housing estate in the Midlands, and was receiving disability-related state benefit. She welcomed me brightly and appeared to move around the home easily, but explained that she was unable to move far without a wheelchair, and that this had caused her to become overweight. Her parents and pets moved in and out of the room as we spoke, and this influenced the tone of the interview. Grace spoke quickly, lightly and

sometimes ironically, even when talking of distressing events, and this perhaps also contributed to less emotional “connection”.

Unlike other participants, Grace begins her interview chatting about her life generally, initially without direct reference to CFS/ME, painting a picture of a young woman kept busy by her many pets and volunteer-work with an animal welfare charity, church group and AYME. However, amongst this are brief, almost implicit, references to the presence of M.E. in her life (eg, describing one social activity as good because it takes “*almost no effort*”). As her narrative develops there is increasing focus on limitations and consequences of M.E.: needing her parents to wash her hair and make her bed (and feeling frustrated when this help is not forthcoming); wanting but denied part-time work (*they said ‘you have to work from eight till twelve’ and I was like(.) ‘that’s just not possible’*); and moving from being an “A” student to leaving school with just two GCSEs, unable to fulfil her dream of training as a veterinary nurse.

When asked about the onset of her difficulties, Grace briefly notes earlier problems with nausea and tiredness in the mornings, though questions whether she was “*pulling sickies or [...] genuinely really ill*”. Her story then jumps to a Winter holiday to Lapland aged 14, having “*caught something*” and “*didn’t really get over it*”. She speaks fluently, noting unexplained and frightening pains, and months of inconclusive medical tests (eg, querying “*pulmonary embolism*”). She is dismissive of a cardiologist’s suggestion that her palpitations are “*just*” panic attacks (“*he just fobbed me off cos there was nothing on my ECG*”), and quickly follows this with the story of her diagnosis with M.E. by paediatricians. Unusually, she concludes this story with the evaluation that she was “*quite lucky really*” in being diagnosed within around eight months (“*some people are like left for years and years with like no answers*”), and attributes this to the prior knowledge of her mother and herself: “*we knew what we were looking for(.) cos Mum’s best friend’s daughter had M.E. as well(.) erm(.) [...] so we knew what the symptoms were*”. More generally, Grace’s story is infused with the language of medical expertise; her position as an AYME representative, and her mother’s professional nursing background, appear to contextualise the construction of her narrative.

Grace's narrative constructs a somewhat ambivalent relationship with medical expertise. On the one hand, she constructs M.E. as a medical condition that requires professional knowledge, and expresses scorn for people who suggest "alternative" remedies (" *hheh(.)* 'No: you're not a doctor!'""); but also expresses doubt about whether health professionals can help her ("*other than exercise (1) I don't think there is much they can (1) cos there's not enough really known about it*").

In contrast to her evaluation of the diagnosis as "lucky", the label of M.E. is then depicted as provoking less positive responses from others. Grace is overtly critical of teachers who "*didn't seem to care*" about her educational difficulties after diagnosis. Even more distressing are stories of challenges from peers, for example about her use of crutches ("*they used to tell me 'oh you don't need those'*") or who "*don't understand*" her need for rest. Grace initially speaks lightly of this, dismissing it (them) as "*just generally being a teenager*", but later tells more detailed stories of feeling hurt and let down by friends who "*take advantage*" or reject her as she becomes ill. She discursively "*makes sense*" of this by positioning peers as immature, and reframing her difference as maturity: being "*past that bit now hheh(.) done all of that*", preferring to "*hang out with a lot of older people anyway*". She tells of a close relationship with her mother and mother's friends, and with a new friend from AYME ten years older than Grace, positioning them as people with the expert knowledge and maturity to support and value her.

However there remains a sense of distress and confusion. Structurally the narrative jumps back and forward between the past and present. The lack of a clear trajectory contributes to two aspects of her story. First, it leaves open questions of how Grace's life has come to be as it is described (eg, the extent of her functional impairment) - which, when combined with the lack of detail provided about her experience of symptoms or expressed emotion, make it harder to empathise with Grace's story. Secondly, it contributes to the impression that Grace's life is "stuck", without a way forward. This is compounded by an unusual feature of Grace's talk: unlike other participants, she does not position herself as "working" to get better; and there is a general lack of expressed agency, accompanied by more direct complaint about lack of support from parents, teachers and friends that positions Grace as helpless. There is an overall element of a "chaos" narrative (Frank, 1995) with no way forward. As Grace says:

G: I can't imagine myself much older than being sixteen hheh(.) Everything seems so stopped ((sigh))(2)

Grace(1):308¹⁹

In contrast, on my return 14 months later, a small brightly-coloured car, complete with furry seat covers, cuddly toys and a disability badge, is parked on the drive: Grace has learned to drive. Grace too looks different (with hair dyed a vivid pink, multiple facial piercings, and dramatic eye make-up), appears much more confident, and pleased to talk about the last year.

Her main narrative now, accompanied by photographs she shows me on her mobile phone, is of unanticipated change and progress: *"having a social life hehheh(.) it's not something I ever imagined I'd be able to do"*. There are many stories of time spent with a new, older group of friends met through AYME, including a new boyfriend; and developing a new identity within this group of young people who are also "different", not only with health problems but also actively adopting non-mainstream style. This new narrative positions her as embracing difference as a form of resistance to those who have rejected her in the past, and positioning of herself as much happier now. This is accompanied by a more reflective tone and much less direct complaint about others.

Grace's narrative now also engages with possibilities for the future, including a potential college course. She tells of how learning to drive has not only opened social possibilities, but how this has positively affected her health, allowing her to gradually build her activity levels. Fatigue and pain are presented as a backdrop to, rather than inhibitor of, her life - and something that can be accommodated by her new friends, who *"understand"* her limitations. Grace's life with M.E. is now presented as a *"big journey"* which has *"changed"*

¹⁹ Convention for locating the source of longer quotes is as follows: *Name (pseudonym) of participant; "(1) or (2)" indicates an extract from the first or second interview; ": final number" refers to line of talk, and hence an indication of how far into the interview. Each new turn of talk (participant and interviewer) was given a new line number. Additionally, long turns of talk from participants were divided into further lines pragmatically, with new lines being attributed for new "points" made in talk.*

my life and it's changed my life for the better [...] I've found all these new friends and it's definitely worth(.) worth it even if it does hurt(.)” .

Amongst an overall “quest” narrative (Frank, 1995), some additional stories are more minimally told – stories that may challenge this preferred position of progress and achievement. Later in the interview are hints of difficulties negotiating her relationship with her “*not quite a boyfriend*”; in gaining a place at college; and in managing fatigue after the demands of her new social life. When asked if she imagines a future without M.E., she expresses ambivalence, suggesting that while it would be good to have “*reduced symptoms*”, a full recovery could be problematic “*because of the person I've become(.) I don't want to lose that and I don't want to lose all my friends*”. Thus Grace's narrative concludes that the quest for a socially-valued identity as a young adult among peers - with acceptance of her limitations - is preferable to a full return to health.

4.8 Harry's Story

At the time of the first interview, Harry was 16 and living with his family on a small housing estate. He appeared comfortable talking, but mostly as a response to my queries with a focus on “facts”, rather than volunteering his experience or evaluation of this. His tone was flat with little expressed emotion. Talk was punctuated with little half-laughs which seemed more habit than expressing humour or other clear emotion, distancing rather than engaging (Marander-Eklund, 2008). Afterwards he commented “*I'm emotionally disconnected, I always have been*”. Alone of the participants, Harry told me that he had never had close friends and didn't mind this. I was left wondering how much of his presentation could be accounted for by the interview context, or by ongoing traits, depressed mood, or simply by the impact of illness.

Harry begins his story with a very brief account of developing aching limbs while on holiday during his first year at secondary school, after playing with his brother. The story moves immediately to state that Harry was “*not really able to do very much at all(.) after that*(.)”; his mother's suggestion, confirmed by a paediatrician, that this was “*chronic fatigue*”; and getting a home tutor and a wheelchair (because “*obviously the walking would tire me out*”).

The story to this point is told sparsely, in just a couple of minutes. The absence of more detailed description of symptoms, events or attempts at understanding, contributes to a confusing narrative: it is not clear at this stage why Harry has a diagnosis of CFS/ME, or the pathway from normal aching legs to significant functional impairment. It is only when I ask specifically for Harry to say more about his symptoms that he talks of stomach aches, headaches, and “*really(.) weird(.) sort of like electric shock feelings*”. He then talks of frightening times when he “*would fall over and things(.) or when I was eating I would start choking(.) cos like the muscles in my throat would like get too tired*”; and illustrates cognitive symptoms with a story of when he “*was cooking some pasta(.) and I was going to sort of like drain out the water(.) and then I just sort of poured it out over the floor(.) I didn’t think of going to the sink with it*”. This detail makes clearer why Harry is, for example, reliant on day care from his grandparents. However this is obviously now a co-constructed narrative, jointly authored by my own prompts. It is unclear if Harry produces this more detailed narrative in other social contexts, with implications for engaging listeners in stories that “make sense” and engender empathy.

Relatedly, Harry’s narrative makes almost no attempt to map out likely causes of his symptoms, or to render them “understandable” to a listener. His observation of similarities with Irritable Bowel Syndrome (IBS), which he had previously been diagnosed with, complicates the narrative of a “sudden unexplained onset” of CFS, but is then largely ignored. Surprisingly, Harry does not even mention the flu predating his illness that his mother has previously told me about, and he dismisses as “*irrelevant*” questions about possible causes:

H: in the end it doesn’t really matter cos(.) I’ve got it there’s nothing I can
 really do about it

Harry(1):54

Instead, Harry focuses in detail on attempts to *manage* symptoms. This is consistent with his more general narrative positioning of himself as a scientist focused on facts and action, rather than reflection or emotion; and as a “good patient” who tries to work systematically on the advice of health professionals. He details a programme of graded activity, presenting

a storyline of a slow progress over four years, though with “*constantly sort of ups and downs*”.

However, the possibility of an upward trajectory is immediately troubled by Harry’s suggestion, here and continuing into the 2nd meeting a year later, that health professionals no longer have much to offer; and a growing sense of frustration as his symptoms persist, flare-up unpredictably, and continually “*set back*” (then defeat) his attempts to return to school after (home-educated) GCSEs. Harry does not complain, and is positioned as stoic, persisting despite limited success. However, at a time of life where other young people are developing their futures, Harry’s is a narrative of chaos (Frank, 1995).

The frustrating unpredictability of symptoms is a strong thread running through both interviews. Harry speaks twice about pressure from other people for him to be “*constantly on the lookout [...] for finding a pattern*” linking his symptoms and activity, but having to conclude that “*there isn’t a pattern(.) it does seem to be just really random*”. He tells of plans for referrals to a gastroenterologist, “*just in case they can find out something else*” and to a Chronic Fatigue service. However, he plays down the significance of these as part of an ongoing tale of not knowing what else to do, “*just(.) running out of ideas so(.) might as well try everything*”. The dominant narrative is of ongoing uncertainty and, as in the first interview, some despondency; not of an active quest for understanding, but a more passive combination of weary hope and scepticism borne of long experience, in which no one is in control, and progress may be suddenly and unpredictably wiped out by sudden relapse.

However, alongside this comes a quieter counternarrative of persistence and personal agency, concluding with Harry’s evaluation that he is “*sort of getting back up again*”, “*getting there*” and intending to take an A’level. He tells of progress in managing some symptoms, sometimes by ignoring them (having learned, for example, that feeling sick does not actually lead to vomiting, or that feeling dizzy does not generally lead him to fall). However, it is notable that, though many characters are portrayed in making decisions (“*we decided it would be best...*”), Harry alone is portrayed as being responsible for success or failure (“*I wasn’t really up to it [...] I wasn’t managing it*”). He makes no attempt to blame others (eg, the failure of an educational system to meet his special needs). This may be

seen as taking a responsible, more adult position of agency; but there is a sense that it leaves him vulnerable to feelings of personal failure when overwhelmed by symptoms.

In addition to the practical challenges of fatigue, there are hints at difficult emotional aspects. Harry talks about his decision not to go on a family holiday, after the "stress" of the last holiday when increased contact with other people highlighted his own limitations - something he is more able to "*sort of forget about*" at home. This parallels Harry's expressed reluctance to talk with me about an imagined future "*because that would just make me really depressed*". Here, Harry is positioned as having worked hard to adapt to his illness, with some success within a fairly restricted world; but aware that further "progress", particularly in social arenas, would force him to confront all that he has lost ("*what I'm missing*"). He orients to cultural narratives of adolescence, and potentially depressing negative comparisons between himself and others of his age. He poignantly notes some wish to "*learn to drive(.) all sort of like the usual stuff*", "*but [.] I mean I don't go anywhere apart from sort of the occasional hospital appointment(.) I have nowhere to drive anyway (1)*". Harry then immediately steers away from this more reflective and potentially emotional line of talk, suggesting that his unpredictable dizziness would in any case make it too dangerous to drive.

Of all the narratives in this study, Harry's is - at the end of the second interview - the least developed as a "trajectory" into the future. Although there are hints at counter-narratives, the predominant narrative is chaos, of Harry continuing to be buffeted by the unpredictable nature of symptoms, and hesitant to risk further steps away from the relative safety of his home.

4.9 Jess's Story

Jess was 16 when we first met, living in a leafy London suburb with her younger sibling, father and her mother, who also had a diagnosis of M.E. Jess engaged quickly in telling detailed stories containing not only description of events but also characterisation with active "voicing" (Wooffitt, 1992), strong expression of emotion, and reflections on "the point" of stories that made it easy to empathise with her.

Asked to “start where you think is the beginning”, Jess begins by briefly noting unexplained stomach aches in primary school that resulted in her mother taking her home early. She gives no elaboration, but quickly jumps forward two years to a time of new unexplained pain, this time in her hip and leg. Symptoms however are barely mentioned; the focus of the story is her distress at the response of friends who “*didn’t believe*” that she needed her crutches. She continues with stories of ongoing peer difficulties after transferring to secondary school and becoming unwell at the end of the first year, missing over two years of school. Again she does not mention symptoms, but focuses on the emotional impact of friends who “*didn’t contact me once [...] it was so hurtful*”. She looks and sounds distressed as she talks, but maintains eye contact and appears reassured by my (mainly non-verbal) responses acknowledging her distress. Only then does she move on to talk (unprompted) about symptoms - pain, sore throats, feeling “*drained*”, and an inability to “*process*” “*work and stuff*”. Her narrative now emphasises physical constructions of illness, drawing on more typical narratives of postviral illness. However, in contrast to other participants in this study, Jess does not put forward a clear time of illness-onset, instead suggesting that “*I’ve always been like ill(.) at some stage – or like I’d always be the one who got the bug(.) or like got the virus or like something(.) and so it all kind of like merges hheh*”. Rather, Jess’s narrative stresses a *history* of vulnerability: to illness that cannot easily be explained; to being questioned and let down by others; and to the distress that this causes.

The sense of being let down by others continues through stories of a slow recovery and attempted re-integration to school and social life. This is joined by another storyline: not only of hard times, but also the “*hard work*” Jess has to undertake to explain herself, to get into school, to catch up missed work (with ongoing “*brain fog*” and word-finding problems that peers laugh at), and to make friends. Jess expresses her frustration (swearing, then quickly apologising) as she speaks of trying to follow unhelpful professional advice that compounds peer problems, the work undertaken by her mother to support her, and tensions within the family when they are not supported by her school.

This section of Jess’s story ends with tearful talk of getting “*quite low quite a lot*” and even contemplating suicide, leading to her mother’s decision to find her another school. This comes as a turning point in the story. From here, Jess’s narrative is of no longer trying to

get back to an old way of life, but working to develop a new one, with new teachers and peers in a private Catholic school who “accept” and support her. Jess now introduces stories of meeting experts in CFS/ME and a psychologist. These are positioned as helping her develop skills to manage her time and emotions, leading to a spiral of academic and social success, which in turn are storied as improving her confidence and ability to engage in more activity. This becomes a “quest” narrative (Frank, 1995) as Jess suggests that, “although M.E. sucks(.) don’t get me wrong(.) I’ve – there’s like positive stuff that’s come out of it”, noting her generally more positive attitude towards life, friends and school, as well as increased appreciation of the importance of hard work.

However, this is not to suggest that all is well. In addition to noting that she is now “more cynical” about people, Jess repeatedly references the fear of relapse: “it’s always like when you get ill it’s like ‘oh no not again’ hehh”. The small laugh mocks but does not mask the apprehension in Jess’s voice, even as her narrative looks towards a more hopeful future.

A year later, Jess’s story resumes by telling how these fears have been realised. She begins by summarising the last year: “as usual with M.E.(.) unpredictable”, with “a horrible Winter” “getting bug after bug”, and missing a lot of school. As before, we hear of the hard work Jess puts into her schoolwork - but that the “big step up” to A’level work and gaps in “basic knowledge” from earlier missed schooling mean that this is no longer successful. Jess conveys the “disheartening” impact of declining results and - more significantly - feeling once again unsupported by some teachers and peers.

Her narrative sets out another downward spiral, in which physical illness and psychosocial factors interact:

J: I felt stupid cos I missed stuff [.] and I really didn’t understand half of it (#) and [.] again I felt like that at [previous school] so it wasn’t(.) so I felt ill anyway and then because I was feeling low then it makes me feel iller?

Jess(2):47

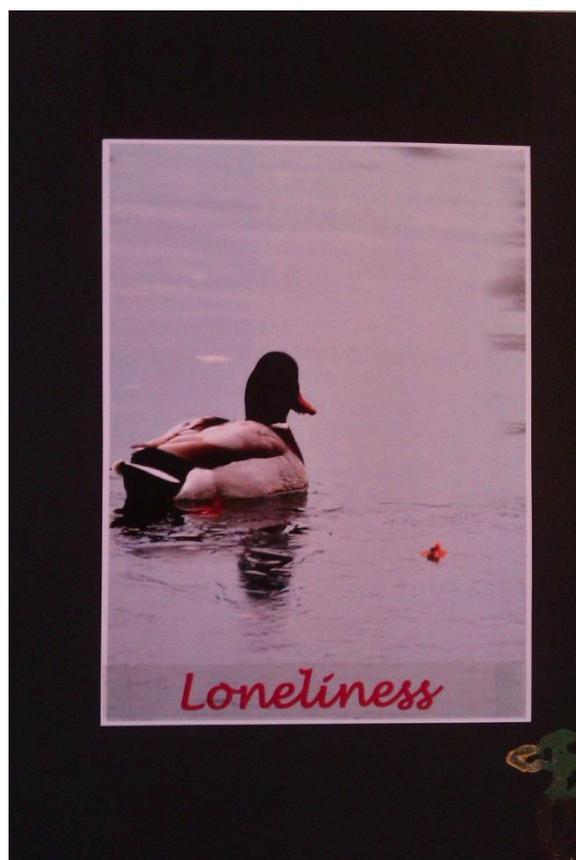
The story progresses to a low point of Jess telling her parents that she “can’t handle it anymore” in school, appealing to them “don’t make me go”. Her words, tone and tears in

the interview clearly convey her distress, positioning her as a child needing the support of her parents. However, as in the first interview, the narrative quickly turns again, presenting this low point as the precipitant for change. Jess describes finally agreeing to return to her doctor, seeing a cognitive-behavioural therapist, and resitting two of her three school subjects. Importantly, given her expressed concerns about *"feeling stupid"*, Jess is now able to tell of success and good results in the third subject as a result of her persistence. Nevertheless, the overall tone of this section of narrative is of disappointment at the turn of events, and the way that *"unpredictable"* M.E. can disrupt even her best efforts.

Jess's narrative continues by focusing on progress and success, illustrated by photographs she has brought, though interspersed with reminders that there are still ongoing challenges to be met. For example, she tells of enjoying a weekend job and the money that gives her a little independence - but needing her mum to argue with teachers who suggest that this might interfere with her homework; and of getting to the stage where she might re-join a sports team - but hesitating at the social challenges, including the fear of not being as successful as her brother or her pre-illness self. Showing me photographs she has taken (one example below), she speaks reflectively of using her A'level studies of art and psychology to make sense of her life with M.E., drawing parallels with cycles of grief and renewal.

Jess also presents a progressive narrative of ongoing identity reconstruction, such that she can now say *"I am me (.) not M.E."* ... *"M.E. is a part of me but it's not everything"* ... *"it's not defining me anymore"*. Despite this, Jess is quick to say that she cannot *"honestly"* imagine a future without M.E. She positions this partly as a result of having had M.E. as *"part of my life for nine years now"*, so she *"just can't remember a time"* without it; and also notes some of the positive things that have come out of it, returning to a narrative of *"quest"* and personal development. However, she also tentatively introduces a more risky suggestion (2:358): that a future without M.E. *"would be nice but it would be weird because [.] in a really weird way it's become like a bit of a crutch?"*. Here she suggests that, *"if I don't want to meet up with someone or something hehheh(.)"* then illness provides an accepted set of excuses that she can give people: *"you know(.) 'I have to be careful'(.)' 'I don't want to get too tired' and things"*.

Her hushed tone, hesitations and qualifiers indicate Jess's awareness that this is a troubled narrative, which could all-too-easily be used by others to dismiss the ongoing label of M.E. as motivated by secondary gain. However, it may also be seen as a reflection of a young woman who, though acutely aware of the powerful reductionist narratives that can be used to position her, is nevertheless struggling to put forward counter-narratives that enable more nuanced constructions of her experience.



4.10 Katie's Story

Seventeen at the time of our first meeting, Katie was the oldest participant in this study but had lived with the symptoms of CFS/ME for the shortest period (only nine months). She had started boarding school the previous year for A'level study, and was currently living there part-time. We met during the Summer holidays at her family home in an affluent rural neighbourhood. Katie was articulate and engaged readily, giving detailed,

entertaining accounts of her experience, enhanced by actively "voicing" (and sometimes caricaturing) the characters in her stories.

Katie begins her story "*at the end of the Christmas holidays*" the previous year, after a "*really really busy first term*" at her new boarding school. She quickly develops the plot, explaining that she had kept herself busy doing "*loads of stuff*" on the advice of "*everyone*" to avoid feeling homesick. Her story then jumps forward to New Year's Day, telling how she "*got(.) a cold*" and "*went back [to school] feeling really rough*", getting "*a temperature*" and returning home; "*starting feeling a bit better(.) from the virus*", but then "*just woke up and felt really really really really tired(.) like it was so sudden*". The content and storyline conforms clearly to one of postviral illness, constructing her illness as physical but with indirect reference to psychosocial factors (eg, "overdoing it"). Importantly though, it positions Katie as not responsible for the outcome: while over-activity might have been a factor, she is acting on the advice of others, positioned as a child doing as she is told. Her depiction of a previously-energetic girl provides contrast to the current picture of fatigue. The message appears that this is a sudden, unprovoked assault, bringing about a dramatically different life.

Katie then paints a detailed picture of the troubled process of seeking help. A homeopath is credited with the suggestion that her symptoms are "*postviral fatigue*", with Katie consequently agreeing she "*had all the symptoms*" of M.E., but receiving a dismissive response from a "*local, random*" GP: "*the doctor said 'ooh no:(.) don't be silly... that's ridiculous' [...] 'you'll be fine!'*". Thus begins a strong storyline of people who simply don't "*get it*". The focus is on doctors, teachers and other adults who either question the diagnosis, trivialise symptoms or give unsolicited advice:

K: lots and lots of people have said 'Oh(.) try this tonic!' or 'Give her zinc!' or 'She needs some grapefruit(.) then she'll be fine!' and all this kind of thing(.)

Katie (1): 48

Katie's mimicry of characters who voice such simplistic or dismissive solutions (adopting ironic exaggeration of tone, posture and facial expression to suggest pomposity or

stupidity) is engaging and works to discredit their authority, but masks other emotions that she speaks of only later. Orienting to established social conventions of age/power, she reflects then on the difficulty that these situations pose for her: feeling frustrated and unable to challenge her elders who *“think [...] they know everything(.) and they haven't(.) but because they're my teacher I can't really say(.) 'you've got it all wrong”*.

Katie's narrative gives more graphic depictions of her symptoms than any other participant, and positions her as an astute observer of her life. An entry in her diary describes pains in her leg *“like someone was squeezing it between two giant metal fingers [...] waves like electric shocks going up and down”*; and feeling *“like someone has scooped out my brain and poured lead into my skull instead which is pressing outwards and weighing me down and making me feel sick”*. Later in the interview (1:126), she suggests an interplay of physical and emotional effects, where the *“actual symptoms”* lead to isolation, loneliness and feeling *“grumpy and(.) sort of depressed(.) and that sort of doesn't(.) help my symptoms so it's a bit of a- a vicious circle I think(.)”*.

Perhaps unsurprisingly given the short duration of her illness, the main trajectory of Katie's narrative in the first interview is of her sudden decline, and trying to make sense of - and live with - symptoms.

In contrast, her narrative when we meet again a year later is of a trajectory of progress in building up school attendance gradually - and Katie smiles broadly as she tells of her excellent A'level results. But this is a story not just of success but of struggle, and a vindication of Katie's insistence on combining part-time schooling with self-directed learning, against the advice of adults (doctors and her father) to spend more time in school, and the initial scepticism of teachers who *“didn't believe it would work”*.

Katie selects items brought from her memory box to construct a coherent chronological narrative of the year. She begins with a pair of pyjamas and a pillow, *“my constant companion”* during the early part of the school year while *“glued to the sofa”*, too unwell even to dress. Notably absent in the first interview, she then introduces stories of times with a small, *“really close”* group of school-friends who *“know what I can do and what I can't do”*. Small stories of developing friendships are illustrated by photographs and a large

framed photo-collage made by these girls for her 18th birthday, which Katie appreciates has taken a lot of effort - *"my best birthday present [...] kind of a labour of love hheh(.)"*.

She brings cake wrappers, souvenirs of a trip to visit a friend in Europe. The story of this trip (involving the first time Katie would take a flight alone) illustrates some important aspects of her developing narrative. She describes *"agonising"* over whether or not to go, initially framing this in terms of managing her M.E. and schoolwork. However, as the interview progresses, she talks more about her longstanding reticence to take risks or meet new people (*"that's just my personality"*), and it becomes clear that *"progress"* with her health and functioning brings heightened expectations and challenges to her development as an adult. There are also stories of more public recognition of her achievement (eg, being awarded the school prize *"for courage and determination"*). Thus Katie is positioned as holding fears for her unpredictable future, but determined to face these fears and overcome challenges.

However, among this progressive narrative comes a cautionary tale. Katie talks movingly of a brief but sudden and seemingly inexplicable deterioration in her health just before Easter, in which symptoms (pain, fatigue, nausea) intensified to *"worse than I'd ever felt"*, resulting in a *"scary"* two weeks back at home, questioning *"am I now going to be like this forever?"*. She then outlines an equally-rapid, equally-inexplicable recovery. An observer might question the significance of this brief episode, yet Katie's message is the ongoing uncertainty she must live with: she cannot understand *"what triggered it"*, leaving her unsure whether she can influence this, and fearful of implications for her future.

A further feature of Katie's second interview is her shifting narrative identity with respect to CFS/ME. Bringing out an AYME magazine, she speaks her changing relationship with the organisation and its members. While this is partly attributed to her improved health and being *"more busy"*, *"less lonely"*, Katie also refers to *"controversy"* and *"a lot of anger"* expressed on the members' forum about a widely-publicised clinical trial, which had backed recommendations for graded exercise treatment programmes. Katie positions herself as more rational about the research, later suggesting that she has become *"more distant from AYME"* because she *"feel[s] like quite a lot of [members] take a passive approach to their illness [...] a position I feel really hard to identify with because I don't like the idea of*

continuing to have M.E. in the future". She orients directly to (and blames) inaccurate media reporting on public perceptions of people with CFS/ME as "*lazy or something*", saying that she has consequently begun to hide her own diagnosis from new acquaintances; and similarly keeps quiet about her tendencies to being "*a worrier*", lest people assume that her M.E is "*psychological*".

She now positions herself within a strong restitution narrative (Frank, 1995), speaking of her decision to pursue referral to a specialist NHS CFS clinic. She concludes, "*they keep saying 'it's not a magic cure(.) don't expect big things to happen'(.) but I do(.) well hheh secretly I'd like to be completely better*". Thus Katie here orients to and rejects for herself a construction of "*passive*" people who accept their illness identity, and - reinforcing the pattern already set out in other areas of her narrative - positions herself as trying to take control of the situation, taking responsibility as a young adult for her future.

Chapter 5

Young People living with CFS/ME: Narratives in Dialogue

5.0 Introduction

The previous chapter considered each participant's story in turn, aiming to give a more holistic impression of each one's particular characteristics. However, simply by bringing them alongside each other, we may begin discern the beginnings of an ensemble, as well as dissonance. Within this chapter, my aim is to bring stories more closely into dialogue, exploring how different storylines and other features speak to and against each other, preserving particularity but also tracing discursive resonances that may have relevance beyond this particular context. Here I build on case-centred work to explore patterns in the content, structure and performance of narratives, and different ways to understand these, in order to address this project's research questions:

- How do YP narratively account for lives lived with a diagnosis of a contested condition, and a potentially contested identity?
- What do their narratives tell us about the social contexts in which they must establish themselves as valuable, valued young members of society?

The analysis is framed by four main areas of narratives: the "start" of illness; descent into serious illness; living with CFS/ME (the largest focus of narratives); and possibilities and challenges for "moving on". These reflect chronology in *how* participants structured their narratives chronologically within and across the two interviews, as well as *what* is represented (events over time). Where there are individual departures from such chronological presentation, these are noted, as are ways in which the interview context may have shaped this structuring.

Within this broad structure, differences in storylines and performance are attended to in detail to explore the complexity and “messiness” of narratives: the different ways that these construct the nature of the illness, experience and the identities of people involved. While conscious that this “messiness” can feel confusing to different audiences, I have deliberately avoided premature “tidying up” that might preclude readers from considering their own interpretations. As the analysis continues, I consider tensions and dilemmas that appear to arise for YP as they attempt to account for lives lived with a diagnosis of CFS/ME. These will then be drawn together further, and discussed in relation to other literature, in chapter 6.

5.1 “How did it all start?”: Constructing the beginning

In learning how to tell stories, children are taught to “begin at the beginning” (Riessman, 2008). However, “the beginning” of a sequence of events is not always clear, even in retrospect. By medical definition, CFS/ME cannot be diagnosed until symptoms have persisted for some months, leaving a question for sufferers and their families: when did symptoms that might originally be attributed to common conditions like ‘flu, “become” CFS/ME? And so, where does the story of CFS/ME begin?

Riessman (1993:18) argues that “where one chooses to begin and end a narrative can profoundly alter its shape and meaning”. Discursive approaches therefore consider this in terms of the interactive business that it performs (Horton-Salway, 2001b). Though interviews were set up as “*a chance for you to tell your story*”, most of the young people expressed some uncertainty about where to begin. Given options to say “*something about you, or your life generally*”, or to focus on CFS/ME, almost all chose the latter, in a framework perhaps more similar to those they had encountered previously in visits to health professionals. All were then prompted with an open question along the lines of “*how did you become aware that something was wrong?*”.

5.1.1 Setting the scene: Constructing “ordinary” childhoods

W: How did it all start? I mean(.) how did you become aware that something was going on(.) that there was something wrong?

C: Er(.) I remember it was the day I got back from a rugby match with my friend erm(.) like after the first week of school(.) and I just felt horrible the next day (.) you know all dizzy and everything(.) and I could barely stand up and(.).oof(.)

well - it obviously started like back in um January 2008 em(.) getting my appendix out and a few infections on that(.) a:nd then we kind of knew(.) we just assumed my body was a bit weak after it(.) then(.)

W: °Ri:ght°

C: we didn't know I was actually quite that weak(.) but(.) er:m(.) so that's pretty much how it started.

Callum (1):9-13

Like Callum, all but one of the participants in this study “set the scene” (Labov, 1972) for their stories with a clear point in time (eg, “*my sister's birthday*” (Evie); “*at the end of the Christmas holidays*” (Katie)), and usually a place (eg, in school; at home with family; on holiday). Narratives that are formed with details of time and place generally enhance the verisimilitude of accounts and credibility of narrators (White, 1987): they suggest that we are hearing stories of *actual* events which the narrator can recall in detail.

Additionally, these scenes of childhood will be familiar to listeners from a similar Western background, and easy to identify with. Relatedly, they begin to construct certain features of participants' pre-illness lives and identities. It is notable that all but one (Jess, to be discussed shortly) construct scenes of healthy, happy, active childhoods that provide a sharp contrast with the stories to come, and challenge stereotypes of people who become ill with CFS/ME (eg, as “troubled”, socially anxious or overly-pressured). Interestingly, these scenes are presented at the start of interviews even by YP who later complicate this early picture (eg, with stories of bullying predating CFS/ME) - an observation discussed later.

One further aspect of scene-setting may be relevant to construction of the CFS/ME story. Of the nine participants who identify a clear onset to their symptoms, eight locate this between mid-September and January - the time of year most commonly associated with Winter viruses. Grace further notes a Winter holiday to Lapland, extending the link to cold and possibilities for having "*caught something*". Thus details of time and place also begin to provide context for constructing the nature of the illness, beginning the "attributional stories" of CFS/ME (Horton-Salway, 2001), that will be considered further below.

5.1.2 The onset of illness: First symptoms

In storying the onset of illness, it is hardly unexpected for participants to tell of their first symptoms. What is noticeable here is the range of symptoms described, the very different ways that these are described - and indications that this is not a simple task.

5.1.2.1 "*Out of the blue*": Tales of the unexpected

Callum's story above (1:9-13) illustrates features common to many participants. The initial description is quite vague ("*I just felt horrible the next day*"). He immediately attempts a clarification ("*you know all dizzy and everything*"), appealing also to an assumed common understanding with the interviewer to fill in the gaps ("*you know*"; "*and everything*"). "Dizziness" is a descriptor recognisable within a medical framework, acknowledged as an accompanying symptom for some sufferers of CFS/ME. Yet there is indication here that neither "*dizzy*" nor "*horrible*" adequately convey all Callum needs them to. Further discursive work is then done to communicate the *magnitude* of the problem in terms of the *impact* on his functioning ("*I could barely stand up*"). Already we may begin to see the challenges of articulating complex experiences, where vocabulary may not feel adequate.

Finally Callum changes tack, narratively stepping back in time to make relevant (Edwards & Potter, 1992) his earlier medical history of appendectomy, with its associated repertoire of post-operative infections and physical weakness. His firm tone of voice broaches no challenge as he sets out this construction of how "*it obviously started*", using the plural "*we*" to imply corroboration from unspecified other(s). Callum's message is clear: his symptoms are to be understood within a medical framework (a formulation reinforced

repeatedly throughout his later narrative). However, even within this framework of post-operative susceptibility, he expresses uncertainty about why the more extreme symptoms developed unexpectedly some months after the appendectomy:

C: (.) it was just a complete shock(.) that's what I mean it was just out of the blue(.) er I just started to feel all of a sudden I have no idea how it happened

Callum (1): 57

Freya also refers to dizziness as a primary symptom:

W: [...] how(.) how did you come to be aware that something was wrong?

F: Well(.) oh well I think it was in 2007 I got pushed over at school I got knocked out for a bit hheh(.) and then like the April of 2008 I just- I was at school I just stood up and I was like I couldn't see or anything(.) so my friends took me to the office and I got sent home(.) and then I went to the doctor's (.) because I just couldn't(.) well I was so dizzy and(.) hhh:I just felt really ill really suddenly(.)

Freya (1):56-58

Like Callum, she also sets out a very sudden onset of symptoms on a particular school-day, and combines a broader descriptor of “*just [feeling] really ill really suddenly*” with the more specific reference to being dizzy. Again there is the invitation for the listener to draw on taken-for-granted knowledge (“*or anything*”) to fill in gaps in the picture, and again an indication of the magnitude of symptoms, both with intensifying adverbs (“*so*”, “*really*” ill) and extreme formulations (“*I couldn't see*”).

Additionally, Freya's scene-setting - beginning her story with reference to being “*knocked out*” previously - can be seen as relevant. Unlike, Callum, she does not make any obvious attribution for her symptoms at this stage, and it is not immediately clear why Freya is mentioning this. However, in doing so she makes relevant a medical repertoire of head injury in which dizziness may be understood as indicating more serious conditions. Thus this may be seen as an indirect form of attributional story, potentially adding credibility to

her account. The relevance of this positioning becomes clearer later in Freya's narrative, foreshadowing stories about social challenges to her credibility.

Pain is the first symptom described by two young people, Danni and Evie. Again, both set out a sudden onset that they can date.

W: How did you first become aware that something was wrong?

D: Erm(.) well I had the flu at the end of December 2008(.) and then(.) in January 2009 I just got pain in my wrist and then I just got(.) all the pain escalated into all my other joints(.)

Danni (1):28-29

Danni's very brief account contains features common to others. First, she makes relevant an episode of flu, often cited in popular literature as a trigger for postviral fatigue (PVF) and CFS/ME. While no direct attribution is made, this again sets the scene for a medical construction of symptoms. The tone here (and in Danni's longer narrative) follows this medical script, focusing almost exclusively on physical symptoms (rather than personal perspectives or feelings) and using language (such as an "*escalation*" of symptoms) more commonly expected from health professionals than 14 year-old girls. There is a sense that Danni, like other participants, has had to tell this story many times before; and is here relating to me as she might expect to do with a doctor, in a co-construction that draws on the language she has learned from adults in these settings.

In contrast, Evie emphasises her personal experience and evaluation of her pain (as "*really strange*", and something she felt unable to "*cope with*"). The strange and confusing nature of personal experience is similarly stressed in Becky's story:

B: (2) erm well in September(.) I felt(.) really funny cos I had a migraine(.) and I was all funny and I thought something's not right(.) and I just kept going(.) and then I got to like November(.) and I was just exhausted(.) it's kind of a bit of a blur(.) because(.) I don't think I was hheh quite hhwith it

Becky (1):57

Though referencing migraines around this time, she quickly indicates that her symptoms go beyond this, and one minute later refers to “a bug or something” predating development of fatigue (again raising the repertoire of PVF). While stressing how “exhausted” she became at this point, the picture is otherwise of a “blur”. There is a sense of confusion, which may be attributed partly to difficulties of recalling events some years ago when she was unwell and not “with it”, but also drawing on a “common-sense” understanding of illness whereby someone can legitimately know that “something’s not right” without being able to be more medically specific.

Initial symptoms are also described only vaguely - or even not at all - in two other narratives. Harry’s account of “how it started” says only that, following some apparently harmless running around with his brother on holiday, the next day his “legs were aching and [he] was not really able to do very much at all(.) after that”. Similarly:

A: Um(.) so: [...] it was my(.) tenth birthday (1) yeah er and er I’d woken up(.) er- before that er I had this like stomach thingy and chest thingy(.) and so I woke up on [the date] – erm(.) err just feeling a bit like bad and that so I didn’t go into school that day (1) or the next day(.) or the next day(.)

Adam (1): 7

While Adam briefly references stomach and chest symptoms, this is vague and not developed as an attributional story. Harry does not mention any prior medical context at this stage. For both boys, there is swift movement into talk of the functional impact of symptoms (ie, what they could not do), to be discussed in the next section. At this stage, it may simply be seen that the “story of onset” may leave many questions for the listener, in terms of *what* (in detail) was experienced, *why* this might have happened, and *how* this led to longer-term consequences.

5.1.2.2 “I just took their advice!”: Actions and accountability

All the above narratives construct illness symptoms as arising suddenly and unexpectedly. One feature of “out-of-the-blue” formulations is that they leave little room to consider

events or actions that might have caused the illness, and for which someone might be considered responsible. Katie's story, however, presents a more complex picture:

K: Well(.) at the end of the Christmas holidays(.) I'd had like a really really busy first term [at a new boarding school] cos everyone said(.) y'know(.) "don't feel homesick(.) so just do loads of stuff"(.). so I just took their advice! hheh and did about four different things every day(.) after all the school stuff(.) And then(.) just before I went back [to school] I think it was New Year's Day I got(.) a cold(.) a:nd I went back feeling really rough(.) and(.) I think after(.) the second day back(.) erm I got a temperature and I just felt really awful(.) [...]

So [two days later] I went home and then(.) I got – I started feeling a bit better(.) from the virus(.) and stopped having a temperature and everything(.)

and then the next morning(.) I think about three days after the cold thing started(.) I just woke up and(.) felt really really really really tired(.) like(.) it was so(.) sudden(.)

Katie (1):26-34

Her story differs from others by including psychosocial aspects from the outset - particularly around school - that might be considered relevant to the development of symptoms. While Katie stresses the medical aspect of "*the virus*" and having a fever, her account also makes relevant aspects of her behaviour. This adds richness, and constructs a narrative that positions Katie as a detailed and thoughtful observer of her life. However, its inclusion is potentially risky for Katie, raising questions about whether she may be considered at least partly responsible for the onset of illness.

"Overdoing it" is a common feature in discursive repertoires of CFS/ME, drawn on by doctors and adult patients alike in attributing reasons for onset of symptoms. However, while adults have been noted to address this construct (eg, Horton-Salway, 2001b), Katie is the only YP here to introduce it. Her developmental context may be relevant: as the oldest participant in the study (17 at the time), living away from her parents at boarding school, she might be expected to show increased responsibility for her health. Equally

though, she speaks in a cultural context where young people are encouraged to develop social relationships and take advantage of life's opportunities, be sociable, not allow oneself to become "homesick" or otherwise psychosocially vulnerable. Within the discursive context of CFS/ME where anxiety, depression and school-anxiety have all been considered as "causes" of the condition (Lievesley et al., 2014), this takes on additional importance.

Katie attends to these interactional concerns by stressing that her activity was at the advice of "everyone", and with good reason (to avoid homesickness). Additionally, reference to Winter virus and description of physical symptoms of fever (enriched soon after by talk of heavy snowfall and power cuts) quickly brings the narrative back into the domain of postviral fatigue, where a body may be "run down" and more vulnerable to illness, but the main cause of ("so sudden") problems is a virus, for which no one can be held responsible. Thus Katie's narrative negotiates the delicate task of addressing multiple concerns about the nature of CFS/ME and her identity as a socially active but thoughtful and responsible young person.

5.1.2.3 A different story: "*It all kind of like merges*"

While Katie's story introduces the possibility that over-activity increases vulnerability, the focus on all the above participants' narratives is on an unexpected illness affecting a previously healthy, happy child. The exception to this comes from Jess.

Jess begins her interview volunteering a history of two previous episodes of unexplained pain during primary school, which resolved but left her with a legacy of distress at the psychosocial injury of not feeling believed, and losing friendships. Her story of the onset of new symptoms (subsequently diagnosed as CFS/ME) around the start of secondary school is then primarily a tale of distress at having to go through a similar process *again*. Relatedly, her story diverges markedly from all the others by its early introduction of talk about her emotions, accompanied by her tears and visible emotion in the interview. It is only after this aspect of her story - and her distress - have been acknowledged, that she gives details about her physical symptoms.

Additionally, and unlike the others, Jess is less clear about the timing of the onset of symptoms of CFS/ME. Although talking initially of difficulties during her first year of secondary school, she later talk appears to contradict this, and also speaks directly about the difficulty of pin-pointing the start of difficulties:

W: Can you remember when you first became aware [.] that something just wasn't right?

J: Phhhh (2) I dunno to be honest – I can't re – it was just cos I'd been – oh- I've always been like(.) as far as I remember I've always been like ill(.) at some stage – or like I'd always be the one who got the bug(.) or like got the virus or like something(.) and so it all kind of like merges hheh.

Jess (1):31-34

Here Jess is positioned as physically vulnerable (“*always [.] the one*” to pick up infections), and this is also used to explain why a clear onset of CFS/ME is difficult to identify, and perhaps is less relevant as a concept²⁰. While the emphasis of the narrative is on the distress caused by *another* episode of prolonged and unexplained illness, her symptoms are still articulated clearly as physical (“*stomach aches, pain, sore throats*”) or cognitively related to fatigue (problems concentrating and “*processing*” schoolwork), in line with major diagnostic criteria. Additionally, while making no direct attribution, she makes relevant the repertoire of infections. The impact is to construct CFS/ME as a medical condition, where psychosocial distress can be a significant consequence. Further consideration of the construction of physical and psychosocial aspects of the condition within these narratives will continue shortly.

²⁰ While the Fukuda et al (1994) criteria for diagnosis of CFS/ME in adults require symptoms to be of new and definite onset, adaptations made for diagnosis and management of children and young people (eg, Royal College of Paediatrics and Child Health (2004) and NICE (2007)) removed this criterion, reflecting the reported observation that families may not be able to pinpoint a definite onset for children.

Summary

Accounts of the onset of illness can be understood as part of the “contingent narratives” that typically form an important aspect of illness narratives, addressing how one can make sense of the emergence of symptoms, and immediate effects on the self and others (Bury, 2001). YP set out a range of physical symptoms with which to date the onset of illness, both specific (pain, dizziness) and non-specific (feeling “not right” or “bad”). Interestingly, fatigue - despite its prominence in the illness label and public perception of CFS/ME - is barely mentioned at this point. However there is also a sense of confusion and unanswered questions in most of these early stories. And with the exception of Callum, suggestions about the cause of symptoms are made only indirectly, contributing further to a sense of unanswered questions about *what* exactly is wrong, and *why*.

All but Jess narrate symptoms as intruding suddenly into previously unremarkable, healthy lives - even when later talk (or talk with parents) makes clear that there have been previous illnesses. Similarly, there is almost no talk of social or psychological difficulties at this stage (again excepting Jess). This, in conjunction with references to medical repertoires of infection or neurological injury, adds to the construction of illness as both physical and unpredictable; and, with the possible exception of Katie, there is no indication in these early narratives that sufferers could have done anything to bring on or prevent their illness.

5.2 “That’s why we realised that it was something a bit different”: Narrating the descent into serious illness

Many of the initial symptoms reported by participants in the previous section are relatively common, at least as temporary events (eg, stomach pain, muscle aches after activity, or more general feeling “not right”). In order for these accounts to be identifiable as stories of serious illness, speakers must demonstrate how symptoms experienced are in fact “out of the ordinary” and (eventually) warranting the diagnosis. The following section explores participants’ narratives about the period of time after initial onset of symptoms and up to the point of a diagnosis of CFS or M.E.

5.2.1 Constructing symptoms as out-of-the-ordinary

5.2.1.1 “I just went downhill”: The escalation and persistence of symptoms

Some narratives incorporate a trajectory of decline from the outset. For example, having already noted the onset of pain in her wrist one month after an episode of flu that “escalated into all my other joints”, Danni is prompted to continue:

W: Ri:ight(.) OK (2) And what happened then?

D: (1) Errrm(.) I got told it was(.) tendonitis(.) juvenile arthritis(.) or that I had the flu still in me and it was waiting to come out (#) and then(.) I got more symptoms bu:hht I can’t remember hhh(.)

Danni (1):30-31

Shortly afterwards, she refers to a family holiday in which she “had to start using the wheelchair”. This indicates a significant decline, but the lack of narrative detail about her symptoms makes it difficult to understand the process. My confusion is apparent in my questioning:

W: Mhm right(.) okay. I was just thinking of(.) from(.) January when you first went to the-the GP with flu and pain in your joints(.) to July(#) sometime between [.] January and July(.) you must have got(.) pretty bad that you ended up in a wheelchair(#) when – how did that happen?

- D: I started go- I started going on a reduced timetable in May(#) and then(.) I just g- I just went downhill(.) like each like each month I- I've gone downhill(#)
- W: Mm.(.) and what does "downhill" mean to – to=
- D: =get poorlier
- W: °Yeah(.) so what – what sort of things were you noticing?
- D: I was getting fati::gued I was getting lots of pai:n(.) err my sleep pattern was being disturbed(.) Err (1) lots of symptoms (hh)I can't reme(hh)mber them all hh

Danni (1):66-71

My (arguably ill-advised) attempt to make sense of Danni's narrative leads her to frame a "downhill" process, eventually noting some symptoms, but with little detail. She gives up with a laugh, assuring me of "lots" of symptoms despite her expressed inability to remember them - her narrative will not so easily be forced by my pressure. However, there is again indication of the challenge for YP of trying to convey credibly a progression of illness when details are not easy to articulate or form into a socially-expected coherence.

Depictions of deterioration feature in other participants' stories too: sometimes (like Danni) through noting new or more severe symptoms; but also by the unusual *persistence* of symptoms that would otherwise be expected to resolve. For example, Becky's narrative (1:57, in section 5.1.2.1) notes early symptoms in September progressing to "November(.) [.] just exhausted", then continuing:

- B: and then(.) when it got to Christmas [..]
I was trying to keep going and [.] we had all our family round(.) and I don't – I couldn't even understand what they were saying? It was like I wasn't there? [...]
I was really tired(.) for the next few days(.) I kept going [.] and I had like(.) kept having temperatures(.) and things [.]
and then I just flaked out(.) yeah yeah then I just flaked (hh)out

Becky (1):72-76

Talk about Christmas evokes a readily-understandable family scene, but also emphasises the passage of time, in which symptoms persist and eventually overcome Becky. Similar storylines are heard from Katie (“I just kept(.) like that(.) and just not getting better”), Evie (“I remember getting really really bad joint pains(.) and they weren’t doing anything about it [.] it was getting worse and worse”) and Grace (“I just got worse and worse and worse”). Within these narratives of deterioration, the persistence of symptoms is intertwined with narratives of the YP valiantly struggling to keep going against the odds. Thus they begin to construct a rationale for why these hard-to-describe symptoms are “out-of-the-ordinary”, strange and unwelcome.

“I don’t remember”: Gaps and uncertainties

C: um I remember going down(.) I don’t actually remember all that much about it cos as I said(.) it just felt kind of normal(.) but it wasn’t

W: °umm°

C: so it was(.) it was odd

Callum (1):76

While accounts of deteriorating health may seem an obvious part of an illness narrative, there are indications that this approach can be problematic. There are gaps and uncertainties in many accounts, areas that appear sketched only briefly, if at all. Most participants say that they *don’t remember* details of their symptoms or events at this time. Some (eg, Harry, Callum) are unclear in their timelines of events, or give somewhat contradicting statements.

Of course, most of these participants are talking of a time at least two years prior to their interview, so gaps in memory are understandable. Additionally, symptoms of CFS/ME (including fatigue and cognitive difficulties) mean that both encoding and retrieval of memories are likely to be compromised. Beyond this, however, the discursive use of “*I don’t remember*” - like the equally frequent “*I don’t know*” - may serve a number of functions (eg, deflecting questions about a topic considered to be difficult or irrelevant (Hutchby, 2002) or an “epistemic hedge” (Weatherall, 2011) that reduces the speaker’s commitment to what follows). Whatever the reason, however, lack of clarity in accounts of

illness symptoms may leave listeners with a sense of confusion or that the story is somehow lacking - with implications that will also be explored later.

Not complaining?

While the potential difficulties of recalling or articulating past symptoms are pertinent, participants' talk later in their interviews indicates that the initial lack of symptom-talk has more complex roots. For example, Harry initially volunteers almost no detail about his symptoms but, when prompted very directly by me, produces a much more detailed picture:

W: Mm (1) Can you tell me a bit about how they symptoms were affecting you at the start? Cos- cos chronic fatigue affects different people in different ways doesn't it

H: Yeah(.) I had quite a lot of(.) sort of stomach aches(.) [...] and then sort of after I'd done an activity I(.) the muscles would ache[.] and I generally felt tired and sort of(.) run down(.) and I'd get headaches and(.) occasionally I'd just sort of get really(.) weird(.) sort of like electric shock feelings(.) just sort of quite random things really

W: All over your body or?

H: Yeah sort of anywhere at any time hehheh(2) which was a bit weird at the beginning but(.) you sort of get used to it(.) hheh(.) just sort of ignore it

Harry (1):26-29

Harry continues with brief stories of time when muscle fatigue caused him to fall over or even choke, but repeatedly down-plays this ("you sort of get used to it(.) hheh(.) just sort of ignore it"). This "down-playing" parallels what is perhaps the most central feature of Callum's narrative, even when symptom-talk is requested:

- W: And your Mum talked about a time when she:: remembers that you could hardly walk(.)
- C: mmm. °just a couple of months°
- W: Do you remember that?
- C: Slightly(.) yeah(.) but again it wasn't actually so bad(.) erm I was still um f-s-(.) no(.)
[changes the subject]

Callum (1):122-125

For Callum, this can be understood as part of a broader narrative that resists identification with a potentially stigmatised illness identity (see section 4.3); but for both boys, there are indications of the importance of being seen as “not complaining”. More traditional psychological analyses would consider such “minimising” of symptoms as a form of coping that “allows feelings of being different from others to be pushed backstage” (Kelleher, 1988:41). However, a performative reading considers how “not complaining” - or “moaning” or “whinging” (Edwards, 2005) - is important in discursive construction of the self, managing the dilemmatic where illness-talk carries the risk that one might be seen as a potential malingerer or even a habitual complainer’ (Radley & Billig, 1996).

Further, these conversations are taking place within the first 30 minutes of a new relationship with a stranger, when establishing oneself in a positive light might be considered especially important. While gender (and the importance of appearing “strong”) may be particularly salient for the boys, similar indications of a wish not to be seen as complaining - by the interviewer or other people - become evident later in the narratives of Katie, Evie and Jess. Further exploration of the possibility - and consequences - of “not complaining” will be made later.

5.2.1.2 “Not able to do much”: Constructing the functional impact of illness

- H: [.] I was not really able to do very much at all(.) after that(.)
 and that's why we realised that (.) it was something a bit different

Harry (1):12-13

Not all participants set out an obvious trajectory of “going downhill”. As noted, both Adam and Harry initially include almost no detail about the nature of their difficulties. Instead they simply note the functional impact: taking a lot of time off school (Adam) or not being “able to do very much at all” (Harry). Again, there may be a number of reasons for this “omission” (eg, memory, prioritising presentation of valued identities as “not a complainer”). However, this shift into talk of the functional impacts of illness may *in itself* be considered a way of conveying the severity and “out-of-the-ordinary” nature of symptoms: after all, while most people sometimes wake “feeling a bit like bad” (Adam), or experience aching muscles the day after running (Harry), these symptoms would not generally lead to prolonged time off normal activity.

However, this is potentially problematic. As noted in Chapter 2, the invisibility of CFS/ME symptoms has led to public discourses questioning the validity of sufferers’ claims to need time off work or school, and the description of the diagnosis as charter for “malingering” (Sicherman, 1977). Without further detail about symptoms which can engender understanding, or medical confirmation of pathology, questions may remain for listeners about the link between barely-described, invisible symptoms and responses: Did the muscle aching briefly mentioned by Harry *need* to result in the family not being able to do much for the rest of the holiday (as he goes on to say)? Did Adam *need* to take this time off school, a listener might wonder?

Authoritative corroboration (1): Constructing the “obviousness” of symptoms

The use of “we” by Harry in the extract above (“we realised that(.) it was something a bit different”), referring to his family, is significant in addressing this interactional concern. Harry and Adam are both children (aged 12 and 10 respectively at this stage in their stories). Within this developmental and social context, decisions about whether or not to engage in activities or attend school are assumed to be mediated by parents and other adults. As with Freya’s account of her first symptoms in school and being “sent home” by “the school office” (1:57), children who speak of needing to withdraw from normal activities draw on powerful membership categories (Sacks, 1992) and “taken-for-granted” repertoires of adult-child relationships and responsibilities. There is an implication that people more powerful or knowledgeable than themselves have recognised (and hence corroborate) the

factual reality or “obviousness” of their symptoms (Potter, 1996) before sanctioning subsequent decisions - something that takes on particular importance for YP whose voices are traditionally dismissed, and particularly when making claims that are hard to verify.

This role for adults (particularly parents) is also relevant to the interview situation. As part of the process of ensuring informed consent for under-16s, each child’s mother²¹ joined us for a few minutes at the start of the first meeting. Although not requested by me, they often said something about their child’s symptoms (eg, Callum’s mother mentioning that he had been unable to stand and needed carrying). Thus it can be argued that, when young people are aware that their parents have already described illness symptoms, their “obviousness” has already been established, leaving less need for direct complaint.

Further consideration of this narrative and discursive co-construction, along with the potential social impact of “omissions” or “not complaining” about symptoms in different contexts, will be discussed later. For now, we move to examining narratives that speak further about how young people and those around them *respond* to the progression of their illness.

5.2.2 First responding

In all these narratives, the reported responses to early symptoms by YP and others are important in constructing the nature of CFS/ME, and in positioning different characters.

5.2.2.1 On “trying to make sense” of initial symptoms

The onset of any illness symptoms will almost inevitably lead to questions about what these *mean*, with associated emotions and implications. (For example, is this chest pain just a bit of indigestion, or a heart attack?). Perhaps surprisingly, there is very little spontaneous talk among these young people about their early thoughts or fears about symptoms. With direct prompting, (“what did you think was going on?” or “what did you think was wrong?”), a range of responses ensue.

²¹ The research request was for consent from any parent or guardian in the case of under-16s; however, in all cases a mother made herself available on the day for this discussion and consent-giving.

Understandable, normal physical illness

The two younger boys both imply that they had always attributed symptoms to understandable physical illness: appendicitis (Callum) or (less directly) infections (Adam). Their talk and tone is in line with early restitution narratives (Whitehead, 2006b), resisting positionings as “ill” with any unusual condition, and emphasising their otherwise healthy, sporty identities. Other participants also structure their understanding of their symptoms in terms of a trajectory, whereby initial thoughts were of “normal” illness such as a cold, or minor sports injury, changing understandings only after the persistence or worsening of symptoms, or the interjection of authoritative adults.

Not making sense

The strongest theme then is of confusion, uncertainty and an inability to make sense of symptoms as they persist and challenge earlier attributions of common infection or injury.

W: So what did you think was happening?

B: Well I don't know hh(.) what I thought back then (1)
all I knew was something wasn't right (2) no-nobody was sure

Becky (1):79-81

W: Wha- what did you think was wrong with you?

D: The- the day I got my wrist pain(.) the day before I'd done badminton at school(.) so I thought maybe that's it but then it escalated and I wasn't really sure what was going on (1)

Danni (1):40-41

Thus the YP is positioned as not “jumping to conclusions” or over-reacting, but being understandably perplexed - a position that, as Becky suggests, is shared by adults: it is not simply that a *child* is confused, but that the *situation* is confusing.

*“Well I thought I was having a heart attack hheh!”:
On fears and not over-reacting*

However, with a gentle prompt, Danni goes on to acknowledge worry about the lack of understanding, and three other girls similarly elaborate on their fears.

W: When it first started happening(.) what- what did you think was going on?

F: I didn't know(.) I was really scared(.) cuz(.) cuz obviously I couldn't see or anything – that was just right at the beginning and I just got up from form(.) and I(.) I just - I pretty much just fell over hheh(.) and it just scared me(.) I thought that it was probably going to be something really serious but(#)

W: Like?

F: Like something wrong with my brain! h-heh(.) but - obviously it's not that serious

Freya (1):78-81

As Freya has already spoken of an earlier head injury and investigatory MRI scan, reference to her *brain* is understandable within an understandably-frightening repertoire of neuropathology. However, explicitly making this attribution might position Freya as “a worrier” or disposed to “make too much of things” (Edwards, 2007) - particularly risky in the context of CFS/ME, where powerful discourses posit that symptoms are “in the mind” and the consequence of anxiety (Garralda & Chalder, 2005). Under such circumstances, might a sufferer be well-advised to keep quiet about health anxieties?

However, to keep silent would be to deny a potentially important aspect of YP's stories, and the serious nature of CFS/ME. Instead, Freya manages this dilemma through her somewhat self-mocking laugh and tone at the end of this extract (Jefferson, 1984). She quickly reinforces this playing down of early worries, telling of how she then tried to dismiss symptoms as “*just a cold or something*” (1:92).

A similar expression of fears followed immediately by a laughing dismissal is heard from Grace (1:122) as she talks of initial chest pain (“*well I thought I was having a heart attack hheh!*”), and also from Katie (1:56), who plays down her initial worries by smilingly dismissing herself as “*a bit of a hypochondriac*”. Discourses of hypochondriasis have long

been linked pejoratively to CFS/ME (Ware, 1992), so introducing it seems risky: by labelling herself thus, will listeners dismiss Katie as in-credible?

However, this may equally be viewed discursively as a form of stake inoculation in the management of subjectivity and accountability as a narrator (Edwards & Potter, 1993). Through use of laughter (Edwards, 2005) and self-mocking depiction of past examples of over-reaction, these girls position themselves as self-aware and able to monitor any tendency to over-reaction; and hence, paradoxically, as more credible narrators of their current, serious, difficulties.

Authoritative corroboration (2): Displacing the concern

As noted briefly above, another way that YP may convey the seriousness of their initial symptoms is to introduce other characters - mainly adults - and their reactions. Parents, grand-parents and teachers are depicted as noticing and responding to their symptoms, but also trying to make sense of them.

The most common narrative is of parents systematically considering different diagnoses, beginning with the commonplace (“Mum thought ‘oh it’s probably a chest infection’(.)” (Grace (1):122)) and moving on to more serious physical conditions (eg, Evie (1):22) - “my Mum said [...] it could’ve been my appendix [...] but it wasn’t [...] and she was worried cos it could be something to do with my kidneys or whatever”). Freya, Evie and Katie also introduce the notion of maternal and family worry. Katie articulates this in a short story:

K: at one point Mum thought I had diabetes because(.) I was drinking loads(.)
 and she didn’t tell me(.) but we were going to the doctor the next day(.)
 and she said(.) “Plee:ase do a urine test!” (.) and afterwards she said(.) “I
 had such a sleepless night”(.)

Katie (1):62

The additional detail and active voicing (Wooffitt, 1992) of her mother (complete with portrayal of a worried tone of voice and facial expression) constructs a vivid picture of concern that is understandable within a recognisable medical repertoire of serious illness,

and also perhaps lay narratives of “maternal instinct”. The worry is narratively displaced from Katie to her mother - an adult, whose voice is arguably harder to dismiss than that of a child. As before, YP may thus convey the potential seriousness of a situation without being positioned as “a worrier” or a complainer. However, there is a danger that the adult - particularly a mother - may then be cast negatively, feeding into a professional and wider cultural discourse of over-reacting or over-anxious mothers.

Freya provides a further perspective:

W: Yeah – what did you think it was?

F: Um(.) I just thought it was some virus that I was over-reacting about really (1) and then I looked it up on the internet and realised that maybe I wasn't over-reacting because(.) I know there's like(.) so much people worse that I am(.) cus I've seen(.) there was a girl that died(.) and there was proof in her spinal cord that it wasn't - that it was a disease(.) and it wasn't fake and stuff(.)

Freya (1):108

Here Freya pre-empts and counters potential accusations that she might be “*over-reacting*” by introducing an alternative source of authority: “*the internet*”. Drawing on medical repertoires of “*disease*” and “*proof in her spinal cord*”, the implication is that anyone who does some research should understand that this is not “*fake*”, and hence that sufferers like Freya are not over-reacting.

However, this strategy may be problematic. While the growing use of the internet as a source of medical information is welcomed by some, others cite concern about misinformation and also the dangers of “*cyberchondria*”: health anxiety exacerbated by searches for medical information on the web (Lewis, 2006). Thus appeals to the authority of “*the internet*” may not only be dismissible on the grounds of poor information, but also risk reinforcing unhelpful stereotypes about health anxiety.

5.2.2.2 On what we did next

On persistence and the inevitability of being overcome by illness

The narrative of a valiant struggle, but eventually being overcome by powerful illness, has already been heard from Becky (sections 5.1.2 and 5.2.1.1), but also comes from all the girls except Grace. Here Freya tells of trying to “*keep going*” over Christmas, until:

F: [...] New Year’s Day um(.) I like collapsed on the stairs(.) and(.) er(.) then I just started shaking(.) and couldn’t see again [..] I just(.) couldn’t(.) I was just really dizzy(.) and I just couldn’t do anything [.] I really couldn’t(.)

Freya (1):140

Strong images such as “collapsing” construct a physical state. Similar language is heard from Evie (1:30) and Jess (1:33) in scenes depicting how they “*couldn’t physically*” engage in activity such as going into school or Church. The tone is of the inevitability of being overpowered by symptoms.

In contrast, the boys’ narratives contain no such construction of struggle against early symptoms. Consideration of YP’s broader narratives is arguably important. These girls all speak of a culture of disbelief over time, whereas the boys do not. Thus it may be considered that the girls’ talk in interviews does discursive work on issues of credibility, as though they have learned through experience that audiences cannot be assumed to be sympathetic. Narratives of struggle to resist illness strengthen constructions of CFS/ME as a powerful illness, and sufferers as not ill by choice. Further, within a cultural framework where “physical” and “mental” are frequently constructed as a duality, such statements also call forth notions that need for rest cannot be overcome by “mental strength”. The implications of *not* following this approach will be considered later, in attending to Grace’s narrative.

On other people’s reactions: family support - and first doubts

Some early responses from other people have already been noted, particularly parents recognising symptoms and sanctioning time off school. At this early stage in narratives, family members feature almost universally as supporters who love and care for the YP.

Significantly, they are positioned as believing and supporting the YP even when others do not: as Freya (1:69) puts it, “*they all cared a lot*” - the vocal stress emphasising the contrast between her close family and (sceptical) others.

The only suggestion of family dissent at this stage comes from Danni, speaking of a family holiday just prior to her diagnosis:

D: [.]I had to start using the wheelchair(.) and I I was able to go round the theme-parks but I wasn't able to go on all the rides(.) and then in the evenings when it would hit me like tiredness and the pain(.) er my auntie used to make comments about how I was able to manage the theme-parks but then it would all hit me(.) but that's how it works with me

W: Mhm(.) what do you think she meant?

D: That maybe I was faking it

Danni (1):49-53

Danni quickly counters this (1:57) - “*b-but now she understands*” - implying that it is only an early lack of understanding that results in her Aunt's initial doubts; yet the inclusion of this short story early in Danni's interview foreshadows the difficulties to follow.

5.2.3 Seeking understanding: Encounters with health professionals

The strongest narrative of family involvement at this stage is in searching for a remedy, and negotiating contact with health professionals.

5.2.3.1 Entering the system

Early encounters, “not knowing” and re-referral

NICE guidelines (2007) recommend that all diagnoses of CFS/ME in CYP are made by a paediatrician, and this was an inclusion criterion for participants in this study. All therefore had to negotiate the healthcare pathway to diagnosis within the UK system, and this forms an important part of all their narratives, though in quite different ways.

Only two of the younger participants (Becky and Callum) required any prompting to speak of this in the interview; all the others spontaneously interwove stories of contact with doctors early in their interviews, into broader narratives of trying to understand or manage physical symptoms, and a need for help.

E: I was having some really strange stomach pains
and then on [sister's] birthday(.) I(.) couldn't cope with it any more
so my Mom called the(.) you know the helpline? NHS helpline(.) and she
talked to them a little bit about it and they said "we:ell we're not really
sure about this maybe you should go to over to [local] hospital"

Evie (1):14-16

Evie's story highlights some common features. First, her mother appears as an agent in this story from the outset. Mothers feature in all participants' narratives of negotiating contact with the healthcare system, sometimes directly and sometimes implicitly (by use of "we" in accounts). This is unsurprising given participants' ages, but narratively emphasises their positioning and lack of agency as children within the system. As noted previously, this also reinforces the credibility of the children's self-reported illness, by showing how they are taken seriously by their mothers.

Secondly, Evie's reference to the "*NHS helpline*" positions her contact at the beginning of the NHS pathway. At this time, the NHS was widely discussed as under strain, and people encouraged to consult this helpline for advice to prevent unnecessary use of GPs or Emergency services. Evie's mother is therefore positioned as acting responsibly and not "over-reacting". "*The helpline*" is made responsible for the decision to take Evie to hospital, supporting the construction of symptoms as potentially serious according to trained authorities.

Thirdly, the reference to non-specialist NHS staff being "*not really sure*" forms a unifying theme for all these narratives - often referring to GPs, as in Becky's story:

B: [.] we went to the GP(.) and there was a really nice lady there(.) [.] but erm she didn't know and she had a few ideas(.) and she said that she'd refer us cos she couldn't find anything and I went and had a blood test and they couldn't find anything cos she thought it might be some virus or something(.) she wasn't sure(.) and then we ended up at Dr [paediatrician]

Becky (1):83

Thus the hierarchy of the healthcare pathway, and processes of referral on toward specialists, forms a central narrative thread as part of the search for medical understanding by YP and their parents.

5.2.3.2 Processed through the system: The search for medical understanding

Tests, confusion, and diagnosis by elimination

While all participants speak of referral to paediatricians, their accounts present very different experiences. Callum, already under the care of a paediatrician following appendicitis, is the only one to present his diagnosis as uncomplicated, “*obviously*” related to infection. All others speak of multiple tests giving negative or inconclusive results. Standard blood tests (eg, for anaemia) progress to more complex investigations, often as part of the series of referrals to different specialists (eg, Freya to ENT, Grace to a cardiologist, Danni and Evie to rheumatologists).

Paradoxically, although understandably given the lack of uncontested biological markers of CFS/ME, the process of receiving negative (normal) test results is then presented by some YP as *supporting* the diagnosis of CFS/ME. Thus Grace's long story about hospital admissions and tests (including x-rays and ECGs) for serious illness concludes that she had “*had every single blood test they could do(.) which I think helped with getting a diagnosis(.)*”(1:127).

Nevertheless, frequent hesitations and repeated “*I don't know*”s again signal a sense of confusion and lack of agency, not only as patients but also as children.

W: What did you think was wrong?

H: I didn't know really[.] my Mum was- sort of suggested that it was chronic fatigue(.) and so we went to the(.) paediatrician at [hospital](.) and (1) did some blood tests I think(.) and the blood tests didn't find anything (#) so (#) somehow that suggested that it was chronic fatigue (2)

Harry (1):17-18

D: [the paediatrician] moved all my limbs and really hurt me(.) so I wouldn't let him touch me after that (2)

W: What was he trying to do?

D: Erm(.) like(.) I don't really know

Danni (1):35-37

Beyond confusion comes indications of greater problems. Evie's story is of a much longer period of misdiagnosis and inappropriate treatment of her pain:

E: I don't really remember what- what they did they gave me a lot of pain-killers and they did a lot of tests and everything(.) but they couldn't like find anything specific?

Erm and then I was - over the next three years I was diagnosed with all sorts of things like all sorts of viruses and infections and arthritis which I was on hh:medication for(.) which it turns out that I didn't have hheh! So
((laughs))

Evie (1):24-25

In keeping with Evie's broader narrative style, she keeps her tone light with humour, and does not obviously complain strongly about her treatment. However, the evident passing of time ("*three years*") presents a clear indication of her difficulties and lack of professional support.

Delegitimation at the doctor's clinic: Disbelief, "psychologisation" & trivialisation

For other participants, the process of consultation with doctors is presented as even more problematic. Here the narrative is not simply that GPs "don't know" how to diagnose or approach the symptoms, but of a broader failure to appreciate the significance of difficulties, leading to delegitimation of experience.

F: [...] the doctor didn't believe me and they thought that I was just wanting to get off school(.) having arguments with my friends and stuff and I wasn't(.) I'm quite happy at school I like it(.) and(.) they – we went back though about three times for three weeks hh so it was really annoying(.) and um they just wouldn't believe me(.) and then we saw one doctor who did believe me(.) and they sent me to the hospital(.) which was where I saw Dr [paediatrician]

Freya (1):58

For Freya, this account comes as just one of a sequence depicting bruising encounters with people who appear to challenge her assertions of illness, and indeed the credibility of her character. It is notable that Freya's story not only presents GPs as disbelieving her, but also links this to the implication that her symptoms link to psychosocial problems - something that she repeatedly tries to counter in her narrative. Here, the impact of "psychologisation" as a form of delegitimation identified by Ware (1992), is first heard.

A second form of delegitimation referred to by Ware - trivialisation - is made particularly vivid in Katie's account of consultations with doctors. After providing a description of her exhaustion following "a virus", Katie continues unprompted:

K: And the:en(.) I think(.) the next week I went to a doctor(.) who wasn't my sch- cos my GP's at school(.) I had to go to just local(.) random one(.) [...] so I said to the doctor - well Mum said(.) "Katie is a bit worried it might be ↑ M.E. because all her symptoms are exactly the same"(.) and the doctor said "ooh no:(.) don't be silly why are you worrying about that? Oh that's ridiculous!"(.) you know(#)

and I said I'd got really bad headache and it was(.) really bad(.) and she said(.)
"oh we:ll(.) it's- it's not getting worse(.) you don't have a brain tumour so
that's fine"(.). you know(.) "you'll be fine!"(.). And then I just(.) wasn't(.)[...]

so then [after moving house] we tried this one(.) the surgery local to here(.)
and the doctor there had to look up M.E. in his book hheh(.) one of those
medical books(.) and I think we actually knew more than he did(.) so I was
quite annoyed and he said(.) "Oh my brother's been feeling off colour since
Christmas too"(.). which was really(.) a bit offensive because(.) you know(.)
it was completely(.) dictating my life

Katie (1):36/42

Narratives of delegitimation within social encounters are related by all the girls in this study. They are clearly important to tell, but also carry risk. In the discursive context of CFS/ME as a little-understood or contested illness, beliefs that symptoms *are* trivial (and exaggerated), or that they *are* manifestations of psychosocial problems, may be held not only by the characters in these stories, but also by listeners (including the interviewer). Stories of challenges - particularly from doctors, viewed as more authoritative than a YP - to the young people may even reinforce listeners' beliefs that their illness claims are *not* legitimate, increasing delegitimation in the telling. And if the listener is a researcher with the power (imagined or otherwise) to disseminate particular understandings of CFS/ME, there may be a great deal at stake for narrators.

There is evidence that YP orient to this interactional concern, working to establish the authority of their own positions and undermine opposing ones within their narratives. The difficulty of doing so should not be under-estimated, but a number of discursive features can be considered.

One strategy is simply to state an opposing construction, as in Freya's statement: "[*the doctor*] *thought that* [I was having problems at school] [but] *I wasn't (.)*". Katie's doctor's apparent dismissal of her concerns is similarly met with a contradictory formulation of "facts": "[she said] '*you'll be fine!*'(.). *and then I just(.) wasn't*". Proposing a different formulation also comes in Grace's account of tests with a cardiologist:

G: [...] I went on to keep getting palpitations and tight chest and breathlessness(.) so I had a twenty-four hour heart monitor thing (1) erm although the cardiologist said “It’s just a panic attack” (2) it – I think it might have been some sort of infection around the heart(.) which sometimes happens after you get(.) like a virus or something(.) which can cause palpitations(.) and it did get better when I was on antibiotics for different things(.)

Grace(1):129

However, this may be problematic when talking about medical symptoms. Given the disparity in power and authority between child and doctor, a simple setting out of opposing positions may be insufficient. Is Grace really more authoritative about palpitations than a cardiologist? Who should listeners believe?

Narratives can then work rhetorically to establish or undermine the authority of different characters to make their claims (Horton-Salway, 2001b). For example, Katie’s account is made vivid by detail and her vocal mimicry of the first two GPs’ dismissive voices telling her not to *be “silly”* with her *“ridiculous”* worries, or framing her symptoms as *“feeling off colour”* and needing her only to *“think positively”* to get better. Grace similarly speaks dismissively of the cardiologist, with a term frequently used by patient groups, suggesting he *“just fobbed me off”* because his tests were inconclusive. Both content and performance work to undermine the professional and personal authority of these doctors, positioning them either as ignorant (*“[he] had to look up M.E. in his book hheh”*) or patronising and unprofessional.

Further, these *“random”* doctors are then contrasted with others. Katie’s *“real”* GP is later heard not only to be *“more sympathetic”* but also to facilitate the process of her diagnosis with M.E. and referral to a specialist. Freya’s and Grace’s accounts conclude similarly, where the authoritative corroboration of more senior paediatricians who diagnose CFS/ME works to undermine the knowledge claims and credibility of earlier doubters, reinforcing constructions of CFS/ME as a legitimate, medically-understandable condition, and of the girls as credible in their depictions of illness.

It should be noted again, though, that considering the discursive actions of talk should not detract from an empathic appreciation of what it might be like for a YP with unexplained symptoms, to have to negotiate other people's responses. Rather, it suggests that processes of delegitimation are considered by YP to be an ongoing risk, to be attended to not only in encounters with health professionals, but in the social contexts in which narratives are later given.

Getting a diagnosis of CFS/ME

Perhaps surprisingly, and in contrast to research with adults (eg, Drachler et al., 2009), there is relatively little talk from these YP about receiving the diagnosis of CFS/ME. None volunteers any emotional reaction or much by way of evaluation (eg, of relief or concern). Evie alone comments that her diagnosis (after three years of ineffective treatment for other (mis)diagnoses) is positive, in facilitating allocation of a specialist nurse who can explain the condition and support her.

This may be partly understandable in two respects. First, for all except Evie, the diagnosis occurs relatively quickly in comparison to the "pilgrimages" often reported by adults (Ware, 1992), perhaps lessening its status in the broader narrative. Secondly, the giving of a diagnosis appears not always as a discrete, "certain" event. For example:

- W: And how did you first get a diagnosis from [the paediatrician]? [...]
- F: (.) I don't actually know what happened there(.) I think he(.) he's a children's specialist I think(.) and he just talked to me(.) and then came up with that(.) and said(.) erm (.) it's not definite that(.) cus you haven't had it long enough yet(.) but then when I went back the next time he – he definitely - definitely knew

Freya (1):101-104

However, again the context of each individual's narrative may be important. Freya's stressing of the "definitely" mirrors Grace's (1:165) statement and tone as she actively voices a paediatrician telling her, "*I'm going to give you a diagnosis of(.) M.E.(.) cos that's*

what I'm(.) sure it is". Given that both these girls speak repeatedly of delegitimising challenges from doctors and peers, this can be understood as working to counter any uncertainty in listeners. Thus the value of a diagnosis appears more implicitly, as potential legitimisation of a recognisable condition - though one whose implications are far from clear.

Summary

All these YP narrate recognisable trajectories into serious and potentially chronic illness, with reference to the nature, severity, or persistence of symptoms and their functional impact; and, relatedly, to the responses of themselves and those around them. Narratives continue to construct the *physical* nature of the condition but, for most, difficulties in "making sense" of their symptoms personally or with others. Here, stories of searching for understanding and medical legitimation provide troubling early indications of the problematic position of patients within health systems, and children compared with adults.

However, narratives are marked by hesitations, uncertainties and absences of detail that, while potentially understandable in terms of failures of memory, understanding or attempts to maintain valued identities (eg, not a "complainer" or "worrier"), may lead to difficulties. Speaking within social contexts where there are culturally-established expectations about what constitutes a "good-enough" story of getting seriously ill (eg, with a certain level of detail and specificity, and some coherence in timelines), difficulties may arise when these are not met (Hyvärinen, Hydén & Tamboukou, 2010). Listeners may be left feeling confused by apparent gaps and inconsistencies, with questions about what type of illness is being referred to, and what (or who) has caused it. On the one hand, this may add to the construction of this illness as out-of-the-ordinary; but on the other, it may lead listeners to question the legitimacy of illness claims, with implications for sympathy and support made available.

5.3 Living with a diagnosis of CFS/ME

The previous two sections focused on YP's narratives of their early encounters with the condition they would come to know as CFS/ME. With some provisos, all construct a recognisable trajectory of "becoming seriously ill", culminating in medical diagnosis. By contrast, "being ill" post-diagnosis - particularly as talked about from the position of (still) living with ongoing chronic illness - is harder to structure with a traditional plot-line. There is no overall "beginning, middle and end"; stories are still evolving, still "in the middle" (or the "muddle", as Emerson and Frosh (2009) aptly label it). Instead, the focus is on smaller stories: of living with and trying to make sense of symptoms; of social, personal and educational impacts; and of the long and confusing process of trying to get better. The majority of these are taken from the later stages of the first interviews, as YP construct understandings not only of CFS/ME itself, but also the identities of the people - including themselves - who live with or alongside the condition.

5.3.1 Living with symptoms

All these YP speak of the physical symptoms associated with their illness post-diagnosis, and the ways that these changed over time, either in their nature or severity. However, again there is less spontaneous talk about symptoms than might be anticipated, with most coming only after my direct inquiry. Additionally, there is little talk of the emotional impact of the symptoms themselves, and very little obvious "complaint". This raises again the question of how or whether these young people would talk of their symptoms, to me or to others in their lives, unasked; why this might be; and what implications this might carry for how others will make sense of their situation.

5.3.1.1 Constructing illness: what is M.E. anyway?

W: Can you recall what those symptoms were(.) what that felt like at the time?

G: at the time(.) I think it was(.) muscle weakness(.) fatigue(.) nausea(.)and
brain fog (1) I think they were my symptoms to start with(.)

W: °What was that like?°

G: Frustrating? Cos like(.) noone particularly understands it(.) so they didn't really believe me (3)

Grace (1):135-138

In talk about her journey to diagnosis just prior to this extract, Grace has focused on atypical symptoms such as palpitations. My question reflects my confusion about why CFS/ME is the diagnosis. Her tone now is brisk as she presents a list of typical (and medically-labelled) symptoms²² of CFS/ME. Her assured, expert tone (she is a representative of AYME) suggests a justification of both her diagnosis and her authority to this knowledge claim: this is *obviously* CFS/ME.

In contrast, Becky provides less technical, more personal accounts, including depiction of:

B: hands always cold and feet always cold hh.(.) no matter how many pairs of socks I wear - I could wear like ten million of socks and have my feet like that big have it by a heater(.) they always remain cold(.) Just – he said it's just one of those things(.) but yeah.

Becky (1):100

Becky's non-medical language and inclusion of non-typical symptoms evoke a graphic picture. However, she appears aware of the difficulties this may present for understandings of a condition like CFS/ME: her closing comment (*"he said it's just one of those things"*) refers to her paediatrician. Thus even her more confusing symptoms are given a degree of medical sanctioning, though it is not clear whether this implies that they are "part of" CFS/ME or not.

This question of "what counts" as CFS/ME arises for others too. For example, Harry (2:15) later expresses uncertainty about ongoing stomach aches *"which(.) could just be(.) chronic fatigue but could be something else"*. And while most participants tell of repeated infections, they differ in how this is constructed in relation to CFS/ME. For example, Callum cites susceptibility to infection as a core feature of CFS/ME:

²² *"Brain fog"* is the term used particularly by CFS/ME organisations to describe cognitive difficulties. My own role in shaping this narrative is discussed in section 6.3.2

C: it's pretty basic(.) you're gonna be tired(.) you're gonna pick up illnesses
easy(.)

Callum (1):110

In contrast, while Jess also speaks of susceptibility to infections, these are described differently:

J: I mean like(.) the annoying thing is like some people might have like say a virus but it doesn't like affect them badly? whereas like I'll like go around and they might like have a cold and then I get a cold but then my M.E. flares up?

Jess (1):129

J: yeah(.) and then the problem is when you get ill you also get your own symptoms as well as the(.) like virus(#)

Jess (2):47

Thus common infections are described as just the *trigger* to flare-ups of Jess's "*own symptoms*" - "*my M.E*" - that she describes as tiredness, cognitive problems and "*headaches and stuff*". These symptoms, rather than the infections, are thus set out as the core features of CFS/ME for Jess, constructing her illness as different from the more common human experience of *bugs* and viruses.

This talk is not "storied", and takes on a more educative tone as it shifts between first- and impersonal (2nd person plural) pronouns ("I" and "you"). This has the effect of linking the personal with broader patient narratives, implying a corroboration of understanding of "what M.E. is" (Bülow & Hydén, 2003). More generally, for all these YP there is again indication of the difficulty of presenting the nature of this contested illness in ways that construct symptoms as invisible but serious, physical and real; sometimes confusing and idiosyncratic but medically-understandable and not just a personal problem.

5.3.1.2 Constructing the impact of symptoms on life

As noted previously, fatigue was rarely referred to these YP's accounts of early symptoms. In contrast, all participants' narratives of lives *post-diagnosis* feature fatigue or lack of energy as an organising presence, often accompanied by muscle weakness or pain, and cognitive difficulties with memory, concentration and speech. Fatigue itself is mostly referred to simply as being "tired", although usually with an additional intensifying adverb (*constantly, more, so, really*) to present a more extreme formulation (Pomerantz, 1986). Some participants use particular terms (eg, Becky repeatedly refers to being "*exhausted*"; Danni uses the unusual but expressive "*slacked*") which - accompanied by emphasis in intonation - also suggest more extreme formulations, beyond normal fatigue.

However, most talk of fatigue and other symptoms is in *functional* terms: what they lead to or prevent the young person doing on an ongoing basis. The most extreme examples come from Danni, bed-bound at home. Speaking softly in her first interview, as if even talking is using precious resources, small stories of her day-to-day existence set out implications of even the most basic bodily functions:

W: [...] what did you do yesterday?

D: Er(.) yesterday (#) I had a carer from twelve till two (1) erm (1) and hh I only open my bowels twice a week cos(.) we have to get out of bed to do that(.) and afterwards I have a massive tumble? Ah- we call these things my tumbles cos(.) I have tumbles cos I can't(.) speak?(.) I can't even nod or shake my head?(.) I can't move at all(.) and my eyes are closed and I'm like(.) trapped as such in my own body(.) and I was like that for two hours yesterday (#) then I had my tea(.) well my sister fed me my tea[.]

W: What's it like to be(.) trapped =in a tumble?

D: = horrible(.) cos I can't even say if I'm in pain?(.) or that I'm too hot or too cold or anything (1) cos I can just(.) I can hear people talking around me(.) and I can't do anything (1)

Danni (1):373-6

Over-sensitivity to normal stimuli - light, noise, touch - is also spoken of by some. Danni again gives the most extreme examples, in which this leads to her effective isolation from the world, wearing eye-mask and ear defenders. However, less extreme examples are also seen as having an enduring impact. For example, Harry (1: 25) suggests that, while his inability to walk far might be overcome with a wheelchair, it is his inability to tolerate “*the hustle and bustle [...] the noise and things*” that prevents him leaving the house often.

All participants describe problems with cognitive function, particularly concentration, with pervasive, everyday impact. Harry’s account (1:32) of attempting to cook pasta and “*going to sort of like drain out the water(.) and then I just sort of poured it out over the floor(.) I didn’t think of going to the sink with it(.)*” hints at potential dangers from these symptoms. However, impact on normal activity is mostly linked to boredom and frustration:

C: I couldn’t really read(.) I couldn’t really get up(.) so um – as I’d never like read the Harry Potter books I got those on the um(.) DV- on the CDs and um listened to them quite a bit(.) uh um(.) bit boring though(.) didn’t like ‘em(.)

Callum (1):125

Depictions of boredom similarly weave through narratives from Evie, Freya, Harry and Katie. Within stigmatising cultural narratives of “malingering” and “secondary gain”, narratives that highlight the downside of time off school also reinforce the message: this is not a *choice* (who would want such boredom?), but an unavoidable and unwanted consequence of illness.

Invisibility and other problems of communication

K: The first time I went to a doctor I forgot to tell her that I kept forgetting things (#) she thought it was really funny..

Katie (1):251

Cognitive problems - particularly with memory and word-finding - are also depicted as inhibiting good communication with others, particularly doctors or teachers, further

limiting their capacity to understand. Katie's short story, told at the end of the first interview in response to my final prompt ("*anything [else] that you think is important for(.) for me to understand about your life?*"), may also be heard as a communication to me as the researcher: don't assume that you have heard everything, or that you totally understand.

Similarly, "*I can't remember*" is a common phrase from participants. As noted previously, this may perform many discursive functions, including a culturally polite way of declining to speak on a topic requested by the interviewer. However, it also hints that there may be more detail not communicated - and therefore that descriptions are likely to under-play the lived experience. Relatedly, "*I don't remember*" may be seen as an in-the-moment performance of cognitive difficulties, making visible a set of symptoms that, like others of CFS/ME, are usually invisible.

The "making visible" of symptoms is clearly a challenge. Possible exceptions occur in the most extreme cases, such as Danni's visible muscle wasting and immobility in a hospital-style bed, or with the use of mobility aids (seven of the YP reported having used wheelchairs or crutches). For the other symptoms of CFS/ME, the limitations of words can for most participants be only partly mitigated by visual demonstrations (eg, Freya's very slow movements while leading me upstairs for our first meeting, and careful closing of the curtains while noting her inability to tolerate bright light; Becky's pained facial expression and gestures, pressing her hand to her forehead to accompany talk of feeling exhausted).

Generally though there is relatively little description or "complaint" about symptoms, and little emotion expressed in accounts of symptoms or losses. In contrast to adults speaking about CFS/ME, there is little use of extreme formulation (Guise et al., 2007) or metaphor (Bowditch, 2006) to draw listeners into imagining experience. One exception comes in a short but powerful reflection from Katie:

K: I feel very heavy the whole time so it's like(.) you know those ball pits for children? If you're lying under them and you have to try and get up(.) it's like that the whole time(.) and I find that it's really (1) frustrating because I can sort of remember what it feels like to feel sort of light and bouncy(.)

and I see everyone else feeling like that(.) and I feel like I'm carrying around about(.) six tons(.) the whole time(.) so (1) that's quite(.) depressing (2)

Katie (1):127

Katie's age (she is the oldest participant), gender and personal context may all be relevant to why her narrative diverges from that of the other participants (she is particularly articulate, and her mother is a psychotherapist, potentially affecting emotional and linguistic resources available to her). However, even here Katie's expression of emotion appears only partly related to a purely physical state of heaviness: immediately prior to this, she has been speaking of her loneliness, and can also be seen to make social comparisons with others and her past self. Thus emotion is tied to narratives of the *social* consequences of illness - something we will turn to shortly.

5.3.1.3 "Making sense of" symptom variability

The *variability* of symptoms over time is a recurring feature of these narratives, particularly woven into stories about being disbelieved by others (discussed further shortly). It is notable then that descriptions of symptom variability are often accompanied by evaluations that "make sense of" this.

Diurnal variation: not just "being a teenager"

Sometimes patterns are suggested, such as fatigue in the morning and evenings separated by increased energy in the middle of the day. Here Evie talks about needing to get up for Church with her family on Sunday mornings:

E: it is a bit(.) hard sometimes because you have to get up really early – erm(.) I get up at(.) six thirty or something and you have to leave at seven(.) and erm there are times when I feel I physically cannot move(.) and I don't think that's from being a teenager I hh:honestly think that's from M.E. hheh [.] sometimes I can't go because I'm so tired and everything especially if I've done something on the Saturday? but my- my- my Mom understands you know(.) she's like "yeh yeah that's fine" (#) erm(.)

This short story contains features common to many participants in its orientation to an anticipated reaction from the audience(s) - perhaps learned from experience - that variable fatigue might be “convenient”, allowing them to *choose* not to engage in certain activities. Three aspects work to counter this. First, Evie’s emphasis in tone and language that she “*physically cannot move*” provides an extreme image of immobility that may or may not be taken at face value, but contrasts with formulations of psychological or social barriers that imply choice. Second, it anticipates - and resists - a cultural narrative of teenagers as bad at getting up in the mornings. Finally, it brings in the authoritative voice of her mother (strengthened by active voicing), corroborating and sanctioning Evie’s need to stay in bed.

Becky similarly speaks repeated of struggles with energy in the morning.

B: what we used to say was um(.) if the day started at 12 o’clock I’d be OK(.)
 because it used to be that I was really ill in the morning then I was okay and
 I was ill in the evening(.) so if the day started at twelve I might have
 managed!

This again ties in with a popular cultural narrative (widely publicised in media at the time) that sleep issues for teenagers are linked to puberty-related biological changes, creating a natural shift in the body clock. The suggestion that teenagers should begin school later in the day has been attributed in the media to both scientists and school heads (eg, Why do teenagers sleep late? <http://news.bbc.co.uk/go/pr/fr/-/1/hi/magazine/7932950.stm> published 09/03/2009). This raises questions about the social construction and management of fatigue in YP generally. However, reference by Becky and other participants to “sleep reversal” and the medical management of their sleep problems (with “sleeping pills”, amitriptyline and melatonin) works to construct *their* difficulties as different from those of “normal” teenagers, and part of a medically-understood condition.

“Overdoing it”: constructions of energy and limited capacity

Constructions of energy and limited capacity appear in all these participants’ narratives. Most often this comes in short stories about particularly busy periods, such as attempting work experience or school exams. Grace tells of a period when she missed sleep to nurse her pet rabbit:

G: (.) so I got worse after that(.)

W: And what - worse(.) what was it like?

G: Physically because I wasn’t sleeping well (1) everything was hurting and - I slipped down the scale a little bit so I was(.) all my symptoms were a little bit worse (#) erm (#) cognitively everything was worse because I wasn’t sleeping (#) so everything was all(.) mushed up in my head (#) so sentences weren’t coming out properly(.) which was kind of difficult(.)

Grace (2):65-67

While stress or loss of sleep may be considered an obvious trigger for later fatigue, symptoms are constructed as beyond the usual range, strengthened by use of more medical language (“*cognitively*”; “*the scale*” - a quantitative measure of symptoms advocated by ME associations). Other participants story consequences of even “everyday” activities such as walking upstairs or (Danni) trying to use a toilet, triggering a flare-up of symptoms. As with adults (Larun & Malterud, 2007; Travers & Lawler, 2008), a common message is of limited resources of energy that are easily depleted, and how sufferers must therefore take care not to overstretch these resources with (over)-activity.

Not making sense

However, participants also note the *unpredictability* of symptom variability, troubling simple notions of a limited capacity:

K: It’s a bit random(.) sometimes I expect something to leave me feeling awful the next day(.) and it doesn’t(.) and (hhh)sometimes I do something really small(.) and I come back and feel like I’ve done something a lot bigger(.)

which makes no sense(.) so(.) like I try not to have sort of a going out thing
two days in a row(.) whatever(.) in case I feel bad from the day before(.)
but it's a bit hard to judge(.)

Katie (1):82

This again hints at the struggle and the *work* expected of young people in trying to make sense of, and then manage, their condition (a theme returned to in section 5.3.3). More broadly, talk about the unpredictability of symptoms contributes not only to construction of CFS/ME as enigmatic (as noted by Guise et al, 2007), but also to a sense of chaos, inability to establish a coherent narrative that makes sense of the situation, and unanswerable questions about the future:

G: With M.E. you've got all that uncertainty of "am I ever gonna get better?
When am I gonna get better? How better am I going to get? Am I going to
get worse?"

Grace (1):338

5.3.2 Living with others: Constructing M.E. & the world around me

5.3.2.1 Life, disrupted

For all these YP, talk of disrupted social lives forms arguably the most powerful storylines within their illness narratives.

"I just couldn't...": The inevitability of disruption to education

Stories of disruption to the world of education and schooling form, unprompted, a central part of all the young people's narratives.

H: (#) after that [diagnosis, aged 12] I think we sort of – cos I'd missed quite a
lot of school by then already (#) we sort of contacted the school and had
sort of a meeting with them(.) and that's when we started the home
tutoring (2) and (3) we sort of (#)

I can't remember how it started heheh but the tutor just came and the school were sending home work(.) eventually hheh(.)
but it took quite a while for them to(.) sort of- especially for some subjects
(2) they just sort of didn't(.) send anything for a while(.) whether it – quite
a lot of the teachers were changing and things[.] which doesn't help (1) so
(6)

[..] sometimes I would manage to go into school (#) at the beginning we
tried for sort of – but [.] we were just wasting time really because I –
because I'd missed all the lessons before [.] the teacher would be saying
like(.) “look at what you did in the lesson before” and obviously because I
wasn't there I hadn't done it(.) so they'd end up saying “go and read a book
in the corner” or something(.) which was ending up wasting time(.)
and on top of that I'd be catching sort of colds and things which again that'd
keep setting me back(.) .hh so that was when we decided not to go to
school at all and just have them send home the work(.)

Harry (1):22-27

Harry's narrative contains many features common to the other participants. It depicts repeated attempts to stay in education, initially within school, but being thwarted both by inevitable exacerbation of symptoms (“*setbacks*”) and by the inability of school to meet health or learning needs. The use of “*we*”, alongside frequent hesitations and some confusion in his storyline, reminds us of Harry's position as a child, and the role of parents in negotiating (and sanctioning) decisions about education. There is a sense of frustration at the lack of response from teachers, although Harry - like most of the YP - quickly tempers complaint, avoiding overt criticism of teachers.

He is positioned as trying hard to remain in education, despite the difficulties of trying to “*catch up*” and re-join classes after missed time. This is a strong storyline for all participants, and makes clear the need for personalised tuition. However, while all the young people here had home tuition at some stage in their illness course, all position this as necessary rather than desirable, and speak of a wish to get back into mainstream education - resisting

cultural narratives of people with CFS/ME as workshy, or using their illness as an “excuse” to be away from school or peers.

C: with GCSEs(.) you know(.) these are the things that shape your life(.)

Callum (2):342

YP also comment on the particular educational challenges for teenagers approaching GCSEs or A’Levels - both in terms of increased workload, and also the potential consequences of failure. Evie, Freya, Jess and Katie in particular refer to the “*stress*” of workload at these times, and being unable to keep up due to illness. All the YP speak of cognitive symptoms affecting their education. However, while the boys present this in a “matter-of-fact” way, all the girls express emotional consequences of “*embarrassing*” and “*awkward*” times (Jess 1:58), feeling “*really stupid*” (Katie 1:157) around difficulties with word-finding or comprehension, and how other people are reacting.

This talk creates potential trouble, since it is consistent with formulations that illness symptoms or school absence are “really” due to psychological factors (eg, anxiety or depression) precipitated by inability to tolerate stressors such as schoolwork. These girls all appear to orient to and manage this discursively. In particular - in as in Harry’s account above - there are strong narratives of persistence, *trying* to work (either at school or at home); and also repeated talk of *wanting* to be in school.

Being different and falling behind: Disrupted biographies, disrupted identities

F: I just wish they’d treat me normally [.] they treat me completely different since it’s all happened

Freya(1): 126

Stories of unwanted disruption to “normal” life and identities are densely woven through the narratives of all these YP. Additionally, all draw on cultural discourses of “*normal teenagers*”, suggesting particular challenges to social identity at this life stage:

K: [...] my Mum will(.) wake me up in the morning or help me get up or wash my hair for me or something like that which a normal teenager just would think was quite(.) peculiar

Katie(1):218

E: Last week(.) I wasn't very well I had some very very bad er (.) pains in my legs and that and er(.) I had to- I went out with my family went out for lunch and I had to use my crutches? and(.) I know that it helps but I suppose when you're fifteen and you don't really want to be attracting that much attention hheh and everyone's always like(.) staring at you and (.) asking you what's wrong and it's just like really intense

Evie(1): 97-98

Discourses of the *trajectory* of adolescence are also drawn on:

K: I think- obviously it's difficult whenever you get [ill] but (2) it might be harder [in your teens] feeling(.) that everyone else is moving forward the whole time(.) because when you're a teenager there are so many markers(.) like exams and things(.)

Katie (1):175

Beyond educational achievement, Katie's words draw on social and developmental expectations of teenagers, painting a picture of herself standing still while her peers are "*moving forward the whole time*", leaving her behind. Grace's softly-spoken comment at the end of her first interview similarly hints poignantly at this:

W: In five years' time(.) can you imagine what your world will be like?

G: I can't imagine myself much older than being sixteen hheh(.) everything seems so stopped ((sigh))(2)

Grace (1):307-308

“Out of the loop”: Disruption to peer relationships

B: [...] I couldn't quite get things like they were joking around(.) and I wasn't(.) concentrating enough or (1) like erm (1) awake enough to know what they were actually going on about(.)

Becky (1):137

A narrative of being “left behind” is also relevant in the many stories of disrupted peer relationships. Becky here sets out how, even when her friends are present, her illness blocks her engagement; she later accounts for losing touch with some friends as they continue their active lives, while she “*wasn't up to it [...] couldn't do it*”. This parallels comments from Freya and Grace, who speak of the *impossibility* of managing fatigue on their girlfriends' social shopping trips or “hanging out” in the local park. As with education, disruption to relationships is clearly positioned, at least initially, as an inevitable consequence of illness, not a choice.

Disruption to peer relationships is also accounted for narratively with reference to life stage. YP report becoming ill soon after joining new schools, with consequences:

H: because I'd only started at the school I didn't really have any(.) loads of close friends anyway(.) because it was(.) when I first started at secondary school that I got it

Harry (1):60

K: it's really hard because I'd only been there a term(.) so I'd made friends but (2) not (1) that many because I just hadn't had time yet or(.) you know(.) there were people I was friendly with but then it just sort of halts because I'm out of the loop(.) so every time I go in I don't know what's going on(.)

Katie (1):110

J: [...] cos year seven is when like you'd all like eat lunch together(.) and then year eight you start splitting off into separate groups? So I would come into

school and like (1) it was so stressful I didn't know - cos everybody had got their groups? And I hadn't – I wasn't there when they split? into groups? so I didn't(.) have any kind of(.) social(.) standing(.) ish – thing – if that makes sense?

Jess (1):29

Narratives also suggest that part-time timetables (often recommended by professionals for management of symptoms) compound the ongoing sense of being different and “*out of the loop*”, perpetuating a sense of isolation even when physically present:

F: I kind of feel out of the crowd cos I miss so much of what's going on [..] they'll be laughing about something and I would have just got there cos I'm in part-time(.) and I'll say “oh what's happened?” and she'll say “oh don't worry(.) you weren't there you wouldn't know” (#) which kind of just makes me feel(.) like(.) harder to fit in really

Freya (1):194

While these short stories convey a sense of frustration and distress at social disruption and threats to social identity (Jess's “*social standing*”), they construct peer difficulties an obvious consequence of illness and simply “not being there” at critical times. As previously, discursive work is done by YP to position themselves as having had friends and been educationally successful prior to illness; personal qualities of the individual are not the cause of difficulties. Additionally, the stories above do not apportion any blame towards peers or teachers for their responses. However, for the majority of YP in this study, this is not the whole story.

5.3.2.2 “They just don't get it”: Constructing failures of understanding

For all the girls, there emerge indications that social problems are attributable to more than the illness or being “out of the loop”, and there are frequent references by all of them to other people “not understanding” - or “not *being* understanding”. Here the multiple meanings of the term “understanding” are drawn on, often overlapping: a failure to understand what CFS/ME *is*; how it might limit what the young person can be expected to

do; or what this might feel like physically, socially or emotionally for the sufferer (ie, an empathic understanding).

“Just generally being a teenager”: Accounting for “normal” peer insensitivity

K: (1) it's just hard cos [my friends] don't really understand(.) and- it's just too difficult for them to(.) imagine cos it's such a long way from what they're doing(.) and (2) it's quite hard to really put it into words [..] because you say “I'm tired”(.) but – it's kind of a different type of tired from the tiredness you usually feel (2) then - it confuses people cos they think it's the same thing [..] cos like – you need a different sort of vocabulary(.) different words

Katie (1):118

Generally, Katie makes little complaint about her peers. As with other participants, her reflection here avoids a complaint by “explaining” peers' lack of understanding, both in terms of the lack of vocabulary available to describe a difficult situation, and also with reference to departures from normal teenage life (“*such a long way from what they're doing*”) or healthy bodily functioning.

Other cultural narratives of “*being a teenager*” are drawn on to position peers' lack of understanding in terms of a lack of maturity, or a culturally-understood self-absorption: being “*wrapped up in(.) all their plans*” (Katie (1):104); and “*that's just generally being a teenager hheh!*” (Grace (1):52).

Further work at explaining peer - and wider public - responses arises in talk about the invisibility and variability of symptoms, exacerbated by the fact that peers only see the YP at times when they are relatively well. In a tearful, extended narrative of feeling abandoned by former friends, Jess stresses:

J: They didn't get it ?(.) and just – and trying to explain M.E. to people is such as hard thing(.) .hh It's like if you have cancer or something you say “it's cancer” and every- people know(.) or if you have a broken leg it's obvious(.)

whereas M.E.(.) they only saw me on my good days? And they never saw me on my bad days? when I like couldn't get out of bed or I wasn't like (2)
I just I just kind of gave up a bit hhehh

Jess (1):48

Jess clearly has good reason for complaint, but the issue of “complaining”, as previously noted, present dilemmas for these YP. If they do not complain, listeners may assume that there are no problems; however, if they complain too obviously, listeners may dismiss their talk as “whinging” (Edwards, 2005). Additionally, positioning peers too quickly as unsympathetic could lead listeners to question whether peers might have other, more stigmatising, reasons to respond in this way (eg, that narrators' experience or behaviour simply does *not* make sense, or that they are simply unpopular). By positioning friends' lack of understanding as “understandable” in plausible ways, participants are able to tell of problems while mitigating this risk.

Additionally, there is repeated comment that at least some friends do *try* to understand and accommodate the young person's needs, and locating accounts of difficulties within broader narratives of friendship.

F: [.] yeah I think they've just helped by trying to understand – they admit that they don't understand(.) but they try

Freya (1):123-124

E: erm most of the time my friends are okay, they do get you know a bit annoyed sometimes(.) erm but most of the time they're okay if I just need to sit down and rest or whatever so I'm lucky in that way

Evie (1):103

These short comments simultaneously position speakers as having, appreciating and being worthy of friends, while maintaining a message that even good friends cannot fully understand. Evie's expression of “*being lucky*” draws an implied comparison with other sufferers. As reported in adult narratives of CFS/ME (Bülow, 2004; Bülow & Hydén, 2003), this locates a personal account within broader patient narratives of being misunderstood

or let down by peers, providing validation through corroboration, and presenting peer difficulties as a common experience rather than personal failing.

Who “gets it”?: Constructing support and understanding within the family

F: my Mum and my Dad and my brother are really good(.) they help me all the time

Freya (1):39

Given the functional impact of CFS/ME and suddenly-extended periods at home, it is perhaps surprising that there is little talk about disruption to family life. Any mention of debate with parents about wanting to “do more”, or minor tensions with siblings (eg, about noise or allocation of household chores) is offset by talk of positive relationships. When I probe further, Harry suggests that his brother “*probably gets a bit frustrated(.) that we can’t do things that sort of normal families can do*”; and Danni and Jess briefly speak of feeling “*guilty*” at the additional demands placed on their mothers. However, the main narrative is of unproblematic family adjustment, and of understanding and support from those closest to them.

Interestingly, my brief contacts with participants’ mothers suggests that they would give very different narratives of family disruption (eg, three mothers said they had had to give up their careers to care for their child), more in line with previous research into financial and psychological impacts of childhood CFS/ME on mothers and families (Haig-Ferguson, 2014; Missen, Hollingworth, Eaton et al., 2012). It is of course possible that YP - particularly when ill - are simply more focused on their own concerns than those of their parents. However, a narrative/discursive reading also draws attention to ways in which family responses are positioned *in contrast* to those outside the family: as helpful even when others aren’t, as accepting of the YP even when others question them. Thus, rather than assuming that YP are unaware or dismissive of impacts on their families, narratives of supportive families can be understood as important in reminding listeners that these young people are accepted (and acceptable) by those who know them best - something that is particularly important in the face of narratives telling of more problematic assaults on identity from other people.

Any familial lack of support is attributed either to more distant relatives, or to fathers. Within a generally positive family narrative, Jess suggests that her father's attempts to push her to attend more school indicate that - in comparison with her Mum - "*Dad(.) d-didn't kind of get it as much?*" (1:33). She quickly works to account for this in two ways: first, that his work pattern means that he does not see her at her worst times of the day; and second, that his concerns about her mother (who also has a diagnosis of CFS/ME) makes him not *want* Jess to be ill (ie, his behaviour has an understandable emotional motivation).

Grace also speaks about her father:

W: [.] your Mum and your Dad(.) do they(.) both understand(.) do they get it?

G: Mu:um does(.) Dad's(#) sometimes I don't know what planet Dad's on (2) I don't think he quite understands that(.) when he's tired I'm double tired (1) mm (1) I think he just assumes I'll do normal things(.) like like yesterday [*details how he refused to help her with a household chore*] so I had to wait until eleven o'clock until Mum got in(1) to sort it out for me(.) er and he comes home and he tells me lots and lots and lots of things(.) all in a very small space of time and expects me to do them all (2) whereas I've forgotten half the things he's said by the time he's said them (3)
I dunno (1) he's a man(.) hheh(.)

Grace (1): 231-234

Within repeated short stories about household chores and how "Dad doesn't get it", we hear much more detailed and direct complaint from Grace, both in her words and her tone of voice. There is a risk here: given that her father may be considered to know a great deal about her - and in the context of prevalent cultural narratives about teenagers (not) helping in the home, as well as the contested nature of CFS/ME - will listeners wonder whether her father is correct, and that Grace should be doing more herself?

Grace appears to orient to this in two ways. First, she contrasts her Dad with her mother, with the implication that Mum (a nurse) would understand that she needs more support. Further, she draws on a cultural narrative of gender: that men are less empathic. The local context of this production seems relevant here. Grace's words, accompanied by direct eye

contact, raised eyebrow and wry smile, work to engage me as another female who might perhaps share this understanding of men, strengthening her claim of her Dad's behaviour as wrong but understandable as "typical", rather than a more serious attack on her father personally.

Constructing failures of understanding from teachers

Narratives of *teachers* who "don't get it" are heard from every YP. All report that their schools had been given information about their condition through letters from a doctor, nurse and/or parents, with the implication that teachers *should* know of their limitations and how to manage these - but that this does not prevent problems. Even the two younger boys, whose narratives are notable in their general avoidance of "complaint", note "annoying" times when teachers "were just a bit confused" (Callum(1):8). All the older children speak directly, often movingly, of frustrations when teachers "don't understand". However, it is notable that all preface their complaints with portrayals of other teachers who have been "really good". This positions the YP as someone who is not simply "a complainer", but also invites the comparison and the question: if some teachers can be helpful, why can't others?

Evie also speaks positively about support from some teachers before continuing:

E: I had erm a teacher(.) and this person was always trying to make me do home-work and I was saying "I can't do it" you know "I'm not supposed to be doing it" or(.) if I needed to miss a lesson(.) erm the teacher would get really really angry with me? Erm even though they knew that I had a note and that I had to miss it because it was(.) it was important for me(.) and there were a lot of incidents where I'd say something and they'd you know brush it off saying "oh you're being so over-dramatic" "you're being silly" and whatever (1) which got me very very angry hhehheh ((laughs)) but erm my nurse wrote a letter to the school(.) °she was brutal °! Hehheh(.) and er you know she was explaining that it was very important for me to keep to my schedule and everything like that(.) and eventually

after constantly saying these things it sort of you know smoothed out a little bit but(.) it was very difficult(.) at first(.) so(.) hhh(.) Yeah(.)

Evie (1): 101-102

Interestingly, this short story hints at difficulties that may go beyond a teacher “not understanding” and into the realm of “not believing” or being more overtly dismissive. At this point, Evie discursively manages this threat to her credibility by drawing on the “*brutal*” authoritative voice of her specialist CFS/ME nurse to corroborate her request for special treatment, quashing suggestion that her need for a reduced timetable is in any way “*silly*” or “*over-dramatic*”.

Nevertheless, the relative powerlessness of the child in comparison to an adult - particularly a teacher - is implicit. The potentially serious implications of this dynamic are apparent in many narratives, including Jess’s emotional account of trying to complete her GCSE exams:

J: in the actual exam (1) erm (#) I get a break? I get a ten minute break in-between and I have extra time[.] to just eat some chocolate and get my blood sugars up and stuff(.) and (#) I put my hand up for my break and I said to the teacher(.) “Can I have my break now?”(.) and she goes(.) “You get a break?” (#) and I was like(.) hheh "oh my god::"hheh(.)
I was like “Yeah(.)” and she goes “Oh why?”(.) and I’m standing in the middle of the exam which isn’t going very well anyway cos I missed loads before and she’s asking me why I have a break and I’m just standing there like [.]
oh god::(.)

Jess(2):30

How can they understand? Responsibility and authority

These stories also orient to an implicit question: if teachers (or others) don’t understand, whose responsibility is it to make, or help, them understand? Significantly, this issue appears most apparent in stories told by the older participants. For the younger ones, the task is clearly located as the work of parents, but the changing developmental context is

highlighted even by Adam (the youngest), drawing comparisons between primary school, where “you have one teacher and one class so everyone knows what is happening”, and secondary school, where “the teachers they teach like three hundred other students a day so .hhh I’m not expecting them to know(.) every(.) detail(.) myeah (5)”(1:112).

However, Adam is the only YP to suggest explicitly that teachers cannot all be expected to hold in mind his health needs. (His mother’s occupation, working in schools, may contextualise this “understanding”). A very different perspective is provided by Grace, as she continues her narrative of feeling let down by others:

G: I really didn’t get on with my teacher (1) we hadn’t got on since year 7 so (1)[...] like I’d miss a couple of days and she’d be talking about something and I’d say “I don’t understand” and she says “well that’s your fault”(#) it’s not really my fault it’s your fault as a teacher for not explaining it to me(#) not giving me(.) the work and things(#) it’s like(.) I used to ask people to email me the work and I’d never get an email hh(#)I think my RE teacher used to email me (2) but that was it (.) the others didn’t (#)

W: Did you try to explain to them what was wrong with you?

G: Yeah(.)

W: How did - can you remember a time when you tried to do that?

G: We sent in lots of – we sent in like a DVD and lots of paperwork and things all about it and (1) I don’t think I ever directly explained things to the teachers themselves but we sent in a lot of things that were meant for the teachers(.)

Grace (1): 278-282

In content, much of Grace’s story about educational difficulties and unsupportive teachers mirrors those of other participants. Given her difficulties, her complaint is understandable. However, while most express frustration at their teachers’ responses, Grace - in keeping with broader narrative tone - is the strongest in her complaint, immediately countering her teacher’s voice with an accusation of her own: “it’s not really my fault it’s your fault as a teacher”. And while empathising with Grace’s situation, my response (“did you try to

explain to them ...?") can be viewed as challenging her complaint and taking up the discourse of responsibility for managing social aspects of illness²³.

While all those living with contested illnesses arguably face similar challenges, there may be particular difficulties for YP who, like Grace, are nearly - but not quite - adult. My response suggests that I am expecting her to demonstrate more adult-like agency in managing her health needs, but simultaneously uncomfortable with the directly-expressed criticism of a teacher *by a child*. Grace immediately orients to my challenge: her account of communicating with the school shifts from the first-person singular to plural ("we"), drawing her parent(s) back into the story with a list of communicative actions, and returning her to the position of a child with limited responsibility.

Katie, unprompted as part of a much longer narrative of managing school demands, provides a more direct commentary on such dilemmas for YP in dealing with adults, particularly teachers:

K: [.] one teacher kept telling me to take vitamins(.) hhh the whole time hh
 (1) but some of them just think(.) they've got it(.) and they know
 everything(.) and they haven't(.) but because they're my teacher I can't
 really say(.) "you've got it all wrong"

Katie (1): 157

Thus Katie orients to a ghostly audience (Minister, 1991) or imagined question ("why don't you tell them they've got it all wrong?") with reference to established power hierarchies. Though her wider narrative identity is of an informed and motivated teenager who is active in trying to understand and manage her condition, even she, she reminds us, is constrained by powerful cultural imperatives on how YP are expected to behave in relation to adults. Responsibility for making adults understand the challenges of CFS/ME cannot reside with a young person.

²³ Further discussion of my role in co-constructing this narrative - and particularly my background as a clinical psychologist - can be found in chapter 6.

5.3.2.3 Beyond understanding: Disbelief and social rejection

D [.]° I just got lower and lower°

W: ° mmhm[.] what were the kids like [at school]?

D .hh they used to call me “skiver”(.) and things (3)

Danni (1):143-145

While narratives in the previous section speak of painful social difficulties, they largely avoid complaint by working to explain other people’s reactions in terms of potentially-understandable failures of comprehension. However, not all social difficulties can be “explained” in this way.

All the older girls give powerful accounts of being challenged about their claims to illness, even after a medical diagnosis.

G: [.] like at school they were really understanding to start with(.) and then they just seemed to sort of – once I had a diagnosis they didn’t seem to care (2)

and then(.) ugh(.) just teenagers at school are awful anyway (2) erm

cos I used to go with my with crutches to start with(.) and they used to tell me “oh you don’t need those”(.) erm and then when I started going in with my wheel-chair(.) they were like – they’d just stare(.)

some of them were like really nice erm and helped like push me up the ramps and push me to the toilets and things(.) but (1) not since

Grace (1):139-141

For Freya, Grace and Jess in particular, stories of “not being believed” and social rejection by peers are arguably the most painful to tell (and to hear), reverberating throughout their narratives over time. Jess is clearly distressed in both interviews as she speaks of her peers’ reactions to her absence from school. She speaks of asking one girl why others appeared to withdraw their friendship:

J: [...] and she said “they don’t believe that you’re ill .hh and that you’re just faking it”(##)
And I came home and I just slammed the door and I cried(.) and my brother and Mum were like woahh(.)

Jess (1):155

Being accused of “*faking*” is a crucial aspect of Freya’s narrative, raised right at the start of her first interview, and returned to many times:

F: [...] I have really good friends and they- the first time round they were really good(.) cause it happened a-bout two years ago(?) and then [more recently] I knew that I wasn’t well and I just didn’t tell anyone cuz I thought if I didn’t then(.) I would get better(.) and(.) it didn’t(.) and then one time my friend said “oh stop faking you’re missing too much school(.) erm(.) you just need to get over it(.) and(.) stop lying”(.) so like that(.)

Freya (1):30

The accusation of “*faking*” is not simply challenging the nature of the illness, but the credibility of the narrator, her moral identity (Åsbring & Närvänen, 2002). Such attacks, and their emotional and social consequences, are clearly important for these young people to narrate. However, once again there are social risks in telling stories in which the YP is positioned as either morally questionable (in-credible) or socially attacked. Arguably, the situation is particularly sensitive for teenagers, for whom the establishment of positive peer group relationships is considered central (Taylor, Gibson & Franck, 2008). Thus a dilemma arises again: to talk about character attacks and peer rejection, and risk the audience drawing stigmatising conclusions about the young person’s character or social desirability; or to avoid talk of these situations, and risk audiences failing to appreciate and empathise with their difficulties.

Narratives can be seen to orient to such interactional concerns. For example, Freya’s foregrounding statement (“I have really good friends”) initially seems at odds with what follows: surely “*good friends*” don’t accuse people of faking their symptoms? However, her next phrase (“the first time round they were really good”) works to contextualise their later

responses, as if there is something particular about a “second time” that makes their responses more understandable (pre-empting later talk (1:80) of response from her paediatrician to a relapse: “[he] didn’t believe it either(.) cuz it shouldn’t happen twice or something”). Thus, despite the disturbing picture of being challenged by peers, Freya’s narrative positions her as a girl who is still a member of a peer group, with friends worthy of defending; and to explain peer behaviour (as previously) as understandable given the hard-to-understand nature of the illness.

However, this type of “making sense” of peer reactions arguably becomes harder as time continues, and for friends who *have* been told about the condition. At this stage, the “failure to believe” starts to look less like “failure to understand” and more obviously questioning the moral credibility of the narrator. An awareness of this threat can be discerned as Freya continues:

W: So what did your Mum tell [these peers][about your illness]?

F: I don’t know really(.) they never told me(.) but I think that she just said(.) em(.) “if you know her you’d know that she wouldn’t fake something like that”(.)

Freya (1):87-88

Thus work is done to defend Freya’s identity: according to her mother (who really ought to know), she is *not the sort of person* who would “fake”.

(Re-)locating the problem (1): Cultural icons and myths about CFS/ME

As narratives of painful peer rejection continue, Freya also later suggests broader reasons for disbelief.

F: [...] there’s a really cruel joke about [CFS/ME] from Ricky Gervais(.) he – erm(.) I can’t really remember what it was but there’s a video on YouTube(.) and he just laughs about it and my friends have all seen that(.) so they just find it really funny[.] cuz he makes – Ricky Gervais is just horrible(.) I don’t like him(.) he just makes fun of it(.)

Freya (1):114

The “joke” refers to part of a sketch by international comedian Ricky Gervais, widely-circulated on DVD and youtube.com, and subsequently criticised for “perpetuating the myth that M.E. is a choice” (<http://ciaramaclaverty.blogspot.co.uk/2007/01/ricky-gervais-and-ignorance.html>). In this, Gervais introduces M.E.:

Gervais: [...] - not MS - not the crippling wasting disease. No, the thing that makes you say *((adopts facial expression of mock lethargy and whining, self-pitying tone))* “I don’t wanna go to work today”

Thus Freya suggests that peers will understandably be influenced by powerful cultural figures, again positioning their actions as a consequence of ignorance rather than a personal attack - though now pointing out that ignorance is not an inevitable consequence of the hard-to-understand nature of the illness, but perpetuated by unhelpful, even malicious, media narratives. Her personal account of difficulty can then be seen as part of a wider narrative of attack and discrimination facing all those with a diagnosis of M.E., drawing on the corroborating power of group narratives (Bülow, 2008) and lessening the risk that she personally could be held accountable for (and socially discredited by) her treatment at the hands of peers.

Re-locating the problem (2): The personal failings of (some) peers

Particular difficulties are apparent in accounting for lack of support or belief from “best” friends who clearly *do* know about the condition, and could be considered a good judge of narrators’ characters. After stories of challenge from peers in school (dealt with narratively by positioning these teenagers as immature or ignorant), Grace then speaks in more subdued tones about one particular girl in this group: Rose, a friend for many years, who herself had previously been diagnosed with M.E.

G: ↑ Yeah (1) it was quite – it was hurtful because it was(.) Rose(.) she was – cos I’d introduced her once she’d got better(.) she had no friends(.) cos (.) she’d got ill in primary school and everyone’d gone off to secondary school and she couldn’t(.)

so I introduced her to ↑my group of friends(.) so she ↑could have friends(#)

and then she was one of the ones that told me that they didn't want to be my friend any more(.) so that was quite hurtful cos we'd been best friends for eight years since we were like six (2)

but she's changed a lot now and I – I don't(2) can't sit with her and talk to her any more cos she's(.) just not the Rose that I knew (1) she's a different person (2) but ↑everyone changes (2)

Grace (1): 203-205

The first part of this story follows a classic narrative genre, in which the hero (Grace) helps someone in need, only to be betrayed when she herself needs help. In the context of school relationships, it also can be heard as an account of bullying and social rejection. But while the *hurt* of this betrayal can be heard, the story raises difficult questions. Why has Rose behaved this way? Does Rose - who clearly knows about CFS/ME, and knows Grace very well - doubt Grace's own claims to illness?

Accounting for peer rejection in terms of the personal qualities of the former friend appears to be a "last resort" in all these narratives. This is understandable for many reasons, not least the danger that such "blaming" may be discounted as merely a product of self-interest such as spite (Edwards & Potter, 1993). Additionally, without an "explanation" of peer behaviour, Grace appears more obviously a victim of bullying, with the social stigma that this entails (Thornberg, 2011).

Positioning former friends as personally unreasonable must therefore be done carefully. Here Grace manages this discursively by drawing on a narrative of how *people change*. The implication is that Rose was, but is no longer a nice person, and this explains her behaviour; and this change in character is understandable as "one of those things" that Grace has learned about the world through painful experience. Further, the switch from detailed first-person narrative to use of idiomatic expression ("*everyone changes*") has been observed to occur particularly in situations where the speaker is complaining, but support from the listener is not obviously forthcoming (Drew & Holt, 1988). Such a situation might be evaluated at the end of line 204, when Grace's pause is not met by a clearly sympathetic

intervention from me. The shift to the idiomatic “everyone changes” narrative can be understood both as a move to close down the topic, and powerful in resisting potential challenge: its figurative, formulaic character is hard to undermine.

A more common approach is to accompany complaint about particular peers with social comparisons, as with positioning of school-teachers or family members noted above. Here, the “bad behaviour” of some individuals is contrasted with accounts of others who *have* been believing, accepting, supportive. For example, after speaking twice of the humiliating peer laughter resulting from discussion of the Ricky Gervais sketch, Freya (1:116) immediately moves to tell of another friend who “*never thought I was faking it*”.

Related storylines comes in talk about making *new* friends, heard further in section 5.4. While in the worst phases of their illness, there are clearly fewer opportunities for CYP to do this, but one exception comes in talk about groups such as AYME (the Association of Young People with M.E.). Though some (particularly the boys) distance themselves from association with support groups, and others position them primarily as sources of information or more general support, Danni and Grace²⁴ speak of AYME as somewhere they have found friends who understand them. For Danni, support from “*loads of friends*” (1:218) is visible in the scores of greeting cards pinned to the wall, and she (1:384) explicitly compares AYME members with others: “*we’ve seen who our real friends are*”

For both girls, the implication is that these friends, who naturally have a better understanding of CFS/ME, are not only alternative but *better* friends. Thus the initial peer rejection must be understood as a failure of those individuals, rather than of the narrator. Additionally we may discern the beginnings of a “quest” narrative (Frank, 1995), in which the “journey” of illness - including painful experience - is presented as having provided opportunity for transformative learning about the self and the world. However, while important for the narrative identity of these YP, such narratives of learning and “understanding” do not take away a sense of the emotional pain experienced at the initial failures of others in accepting and supporting them throughout their illness.

²⁴ To recap: Danni, Evie, Grace, Harry, Katie and Jess volunteered to participate in this study after seeing adverts placed by AYME in their monthly newsletter and on their website

Summary

All these YP give powerful narratives of living with living with a diagnosis of CFS/ME, facing disruption to their lives, relationships and valued identities as teenagers as they attempt to negotiate a hard-to-understand condition within the fast-moving social and educational contexts of youth. The contested nature of CFS/ME is heard in challenges from others, questioning not only the nature of their illness, but their credibility and moral character.

In terms of their content, these narratives mirror those heard in other studies from both adults and peers. However, further discursive analysis here highlights potential dilemmas for YP in relating and accounting for their social and emotional difficulties, and ways in which they orient to these dialogically. In particular, narratives indicate challenges of conveying the full extent of difficulties arising from discreditation and “not being believed”, while avoiding constructions of symptoms as un-believable or “all in the mind”, or the self as in-credible; and resisting being positioned within stigmatised teen identities as psychologically vulnerable or socially rejected, or otherwise “not normal”.

5.3.3 Trying to get better

When people become unwell, there are strong social imperatives on “appropriate” personal responses. Within contemporary Western cultures, diagnosis with a chronic illness creates expectations that people work not necessarily towards a “cure”, but at least to manage symptoms and minimise their impact (Frank, 1997).

NICE guidelines (2007) on CFS/ME focus on symptom management and strategies for maintaining and gradually increasing levels of activity, avoiding either excessive rest or over-activity that produce “boom and bust” cycles. This can include Graded Exercise Therapy (GET) and Cognitive-Behaviour Therapy (CBT) in collaboration with professionals. However, as described in Chapter 2, such guidelines are contested. Within this context, how do YP’s narratives address the idea of “trying to get better” post-diagnosis?

5.3.3.1 The early stages: The informed patient?

Shilling (2003) highlights the “information work” expected of adult who become unwell, to inform themselves about their condition and how to manage it. For CYP, the picture is less clear. When asked, all of these YP note the role of their paediatricians in providing information post-diagnosis, and the work of mothers (not fathers) in seeking out other sources through the internet or networks such as AYME. Within the early stages, YP are not positioned as actively seeking information about CFS/ME.

Becky (1:245) orients to questions of responsibility for researching her illness (*“I wasn’t reading [books on M.E.] cos I wasn’t able to... wasn’t really up to it”*). Later, the age of the YP appears relevant: while Adam, Becky and Callum (the youngest) position their mothers as doing this initial work, the older ones (Grace, Harry and Katie) frequently use the plural “we” to construct a joint exercise of learning between themselves and their mothers.

5.3.3.2 Taking (and rejecting) expert advice - but who is the expert?

In line with cultural expectations, all the narratives refer to consultation with doctors as a potential source of help in trying to get better. However, although Callum (in keeping with

his medical construction of illness) mentions antibiotics, and three participants note temporary use of sleeping-pills, there is little talk of medical intervention. Instead, there is (though only when I ask) talk of advice and some support in a long process of trying to manage symptoms through regulation of activity: in negotiating reduced schoolwork (eg, doctors or specialist teams communicating with schools to amend timetables); seeking to identify patterns (ie, what activity or other factors exacerbate or alleviate symptoms); and, for most participants, later attempting to increase activity.

All participants are positioned, at least initially, as trying to “do what the doctor orders”. All speak positively about at least one professional, often a physiotherapist supporting management of graded physical exercise programme. And, as will be discussed later, almost all participants carefully point out areas of improvement in their condition over time.

However, all the narratives trouble a traditional “good patient” model of illness management (Jadad, Rizo & Enkin, 2003) in which the patient complies with expert advice and makes progress; and all account for this departure at some stage (though to different degrees) with a questioning of the expertise or input of the “experts”.

*“There’s nothing else really that they can suggest”:
Learning through experience & constructing the limits of medical understanding*

Identifying relationships between activity and symptoms, and using this to build manageable levels of activity, is at the heart of current professional approaches to CFS/ME management. However, Harry questions this:

H: I think it was the physio (.) suggested that I sort of kept a diary of what I did (.) and I did that for a while (.)
[gives examples of monitoring activity, conditions and symptoms]
but there wasn’t really any patterns at all (.) it was just seemed to be so random [..] you think you’ve thought of a reason or a cause for something and then something else comes and sort of invalidates it

Harry(1):110-111

Similarly both Harry and Grace set out the limits of professional expertise regarding intervention programmes, basing their knowledge claims on experience of having *tried* these, with little improvement:

G: [Doctors] just told me to do(.) graded exercise(.) and physio and things(.) I've not really had anything suggested other than(.) exercise (1) I don't think there is much they can (1) cos there's not enough really known about it (2)

Grace (1): 180

H: now that we know about that I need to do graded activity and the sort of things that I've said, now that we're doing that there's nothing else really that they can suggest

Harry (1): 108

Some suggest that the professional help they need is not forthcoming. Danni stories encounters with increasingly high-profile professionals, ending with two internationally-recognised hospitals saying they are unable to help her as condition is "*too severe*". Freya suggests that one consultant actively instructed the team's physiotherapist not to continue seeing her because he "*didn't believe*" her need; and Grace complains of being discharged from physiotherapy after one missed appointment.

Other narratives go further, suggesting that professional advice is not only inadequate, but actually harmful. Danni (1:119) states her doctors' advice "*to push myself and get back into school [...] didn't work and made me poorer*" (a common complaint on M.E. patient websites). Older participants all suggest that doctors' advice to increase school activity gradually is over-simplistic and naïve to the realities of life, compounding both physical health problems and social difficulties, as peers and teachers are sceptical about why YP do some, but not other activities.

A common thread in these narratives is of young people having *tried* to follow professional advice, but *learned* that it is inadequate. This provides a counternarrative to those

suggesting that sufferers simply do not *want* to get better (as in the Gervais sketch), attending to issues of accountability and agency. Failure to “get better” is not a consequence of poor patient motivation, this narrative stresses, but the inadequacies of current professional understanding and service provision: a claim made on the basis of expertise developed through personal experience that can challenge the traditional expertise of the doctor (Horton-Salway, 2004).

“You get sort of things recommended”: Considering alternative approaches

However, in the absence of medical solutions, narratives also suggest that sufferers are expected to pursue alternatives. A brief internet search reveals a myriad of “miracle cures”; and almost all participants speak of encounters with unsolicited advice. How do CYP with this diagnosis negotiate this challenge?

W: So what has helped?

F: Umm(.) probably mainly my friends and family(.)
and I had(.) um(.) some detox programme that said I had like(.)
everyone gets chemicals in their body(.) but my body just can't get them
away(.) just can't rid of them like everybody else's(.) and so I had to drink
this green slimy goo for like two months which was horrible! um and I had
to(.) I couldn't eat meat and there was some other stuff that I couldn't eat
and(.) just for two months(.) and(.)
I-I think that probably helped a bit(.) like(.) gave me some energy(.) that's
what my Mum thinks(.) I don't really think it helped [...]
Er(.) well I've tried er(.) special tea to help me get to sleep which didn't
work(.) lavender oil which didn't work(.) er (1) I tried two sets of sleeping
pills like natural ones(.) but they didn't work(.) an(.) mm. I don't think there
was anything else(.) we just tried like all stuff off the hheh internet just to
try and help(.) hheh(.) nothing seemed to work

Freya (1): 149-157

Freya's narrative illustrates features common to many when talking about “alternative” therapies. The long list of approaches construct evidence of her willingness to persist in

trying for a solution, but that experience has taught that this is useless. Additionally, alternative therapies are presented largely as her mother's suggestion (a common pattern among this group). Thus Freya is positioned as a "good girl", following adult advice; motivated to get better, and open-minded; but looking for evidence. Equally, talk of the non-effectiveness of these natural remedies reinforces constructions of CFS/ME as a serious medical condition, not easily shaken off.

There appears to be a balance to be achieved, of being seen as persisting in *trying* to find remedies, while being justified in turning down others. In the case of non-mainstream treatments, this can be achieved by positioning the approach as unscientific, and advocates as ill-informed. For example, in talking about online advertisements for the trademarked Lightning Process, Harry describes researching this, commenting on the cost and the lack of information:

H: so(.) we couldn't really say if it was sort of a scam or just luck really (2) and you get sort of things recommended - sort of weird things – sort of crystals and things that you see which(.) heheh!(.) obviously some people think they work but I personally don't think it's – there's no- there's no sort of scientific reason why that could help(.) and I think when people say that it has helped them it could – they could just have naturally recovered and it's just coincidence I guess (2)

Harry (1): 115

G: people like telling me(.) things like the Lightning Process or(.) like drinking things(.) I'm like(.) if it'd work like that they'd prescribe me something (1) everyone thinks they know better than the doctors do (3) [.] so they just assume they know best(.) but they don't(.)

Grace (1): 178

Harry positions himself (in keeping with his broader narrative) as a scientist making informed decisions - a position also advocated within contemporary "expert patient" discourses. The interview context may be significant here, as Harry engages with me as part of a research project, aligned to a University, with its attendant associations of "science"

or “evidence”. Grace here defers instead to the higher authority of medical professionals. In both instances, this works discursively to justify decisions not to pursue every option, without being positioned as lacking motivation to get well.

“I’m not like(.) mentally unstable”: Constructing mental health referrals

Some parallels may be observed in construction of interventions from mental health professionals. Seven of these ten YP were referred to see mental health professionals following their diagnosis of CFS/ME, but most did not elaborate in the interview until prompted²⁵.

All seven express ambivalence about these referrals, and what might be implied by them. Adam is the most forthright. Talking of various referrals made by his paediatrician, he suggests a rationale for seeing a dietician and physiotherapist, but:

A: but the psychiatrist I mean(.) what? I’m not like(.) mentally unstable or anything (2) er I didn’t understand that

Adam (1): 74

Callum, who later describes positive encounters with a clinical psychologist, nevertheless speaks of initial doubt, and awareness of associated stigma:

W: mmhm.(.) when somebody first mentioned seeing a psychologist(.) what did you think?

C: Re:ally? hh I don’t want to like – I just im- instantly thought like(.) straightjackets and padded cells hheh I just thought um(.) re- I’ve sss I’ve(.) was a bit embarrassed about I er I had – still to this day I haven’t told anyone erm of my friends about it

Callum (1): 161-162

²⁵ For all the younger participants, this was reported to me by their mothers in the pre-interview meeting (with their children present). It is impossible to know whether YP would otherwise have raised this. It is also unclear how many knew of my own mental health professional background. Callum’s mother knew this prior to giving consent; and Jess told me at her second interview that she had Googled me, so knew of my professional training by this second meeting.

Narratives therefore construct mental health referrals as implying an “*embarrassing*” identity as “*mentally unstable*”; and also implying a construction of CFS/ME as either psychological (rather than physical) illness, or relatedly as “not real”:

W: If there was (2) something that you thought(.) you really wanted to send a message to the world about(.) M.E. – what would that be?

D: It’s not in our head it’s real(.) cos my paediatricians(.) every time we’ve seen her(.) she’s just gone on about CAMHS(.) CAMHS(.) CAMHS (#) and I believe she doesn’t properly believe in M.E.

Danni (1): 327-328

And from “*not real*”, it is a short step back to positioning the sufferer as not simply psychologically unwell, but - to quote Freya and Danni - “*faking*”, and personally responsible for failure to get better.

W: What’s the most important thing for [your doctors] to understand about(.) you?

D: I’m not faking it and that it is – it is real (1) and that I’d love to get better(.) and I can’t wait to get better.

Danni (1): 340

There appears a dilemma: acceptance of a referral to mental health professionals may suggest acceptance of non-preferred constructions both of the self and of the illness. However, refusal to follow a paediatrician’s advice and NICE-recommended intervention may be construed as being a “bad patient”, showing insufficient motivation to *try* to get better - or even, paradoxically, a defensiveness indicating psychological problems (Hardwick, 2005).

Participants address this narratively in different ways. Discursive work is done to position the young person as “not mad”. Adam (1:74) simply states this directly. Danni (1:330) introduces this as a professionally-sanctioned corroboration, describing a CAMHS psychologist visiting her and actively voicing her conclusion (“*you’re not depressed or*

anything”). More broadly, as already observed, participants’ narratives - particularly in the earlier stages of interviews - repeatedly position them as previously happy, sociable and successful (even when later narratives contradict this.)

Then work is done to discredit the input of mental health professionals. Two participants who largely reject the role of mental health practitioners, Adam and Becky, are able to give narratives of doing so *after* having tried it. While Adam (above) stories a quick rejection of the “*shocking*” psychiatrist, Becky (1:187) narrates a long process where she “*kept going, every single week*” to see a CAMHS social worker despite feeling too ill to concentrate, and a process that left her feeling “*disheartened*”. Thus when Becky concludes in her second interview that this work is not helpful, she can do so from a position of a girl who has given it a good try, and whose experience can legitimately challenge professional advice (Bamberg & Andrews, 2004).

Adam and Becky also draw on corroborating voices of adult family members in discrediting the CAMHS professionals, indirectly through use of “*we*” in stories of feeling confused or annoyed by the clinician, or directly in the conclusion to Adam’s story (“*my mum just said to me “we’re never going there again”*”)(1:78). Thus giving up on this intervention is sanctioned, not the sole responsibility of the young person; and is associated with discrediting the intervention or clinician.

Other participants give narratives of more positive encounters with mental health professionals, but still with attention to the implications of this for constructions of illness and identity. For example:

W: And how did you get to see [clinical psychologist]?

C: (.) I don’t know I think Dad said um ksss I(.)

I wasn’t a hundred per cent sure I needed it cos I’ve always been pos- er positive like that and er then she said the same thing(.)

but er [paediatrician] recommended it(.) um(.) that he sent all his people with M.E. he always recommended them(.)

so we thought(.) oh it can’t hurt um(.) so we tried it and it was(.) it was good like(.) the things she talked over with me(.) it was pretty much just

reflecting positive things that I'd done – well[.] um I didn't need any like coaching to keep my brain(.) you know(.) to keep er me upbeat and everything cos(.) to be fair I didn't really need it

Callum (1): 156-157

Adult voices are drawn on to corroborate Callum's position as psychologically strong and "not really needing" a psychologist: his Dad (talked of repeatedly as a no-nonsense, hard-working man); the psychologist herself; and even the paediatrician, in that the referral to a psychologist is framed as part of a standard package of care for CFS/ME. This narrative positions Callum as a good patient, motivated and striving to work with professionally recommendations, even if they are unnecessary.

The nature of the psychological work is also set out as task-focused: either on learning to managing activity, or on the *consequences* (rather than causes) of illness. Where mental health issues such as anxiety or depression are named as a focus for work (eg, by Harry, Evie and Jess), they are similarly spoken of as an obvious consequence of physical illness and disrupted lives. These constructions of psychological interventions again allow YP to be positioned as actively engaging in the process of trying to get better, while avoiding stigmatised identities associated with psychopathology.

The exception is Katie, who speaks of beginning work with a psychotherapist on more general issues including anxiety and perfectionism pre-dating illness. Katie shows acute awareness of the risk of talking about this, particularly of constructing her M.E. as a consequence of these psychological traits rather than a virus. Countering this, she attributes the idea for psychotherapy to her mother who is "*a counsellor so obviously(.) she thinks (hh)everyone should have therapy of some sort probably*" (1:132). She constructs a distinction between "background" psychological work and CFS/ME, reinforced in her narrative a year later when she suggests that the psychotherapy has been generally helpful with "stress", but had no impact on her M.E.

Thus it may be seen that YP have to achieve a delicate balance in speaking of referrals to mental health professionals, in order to resist stigmatising constructions of either their illness or their identities, while also establishing themselves as active in the process of

trying to get better. It may then be understood why young people may not always volunteer this information, or (as some comment) do not tell even close friends about having seen a psychologist.

5.3.3.3 “In the end it’s up to you”: Constructing personal agency & a work ethic

As has been seen, a strong narrative emerging for all these YP is of developing personal expertise through their own experience. Additionally, for all but one (Grace) come intertwined narratives of the persistence and *hard work* required in the long process of learning to understand and manage symptoms - and relatedly, of the type of person who is able to do this.

In contrast to stories of the early stages of illness, in which illness management is located as the work of parents or professionals, narratives increasingly position the YP as active agents as time goes on. At times there is direct comment (“I kept trying”), but the broader narrative emerges mainly in the ongoing introduction of new stories about having to meet different challenges over time, told across both interviews.

Narratives of the physical and emotional work required to re-build activity while avoiding flare-ups are particularly strong. For example, Becky sets out a journey of painstaking efforts to resume education, first addressing disrupted sleep patterns, then getting out to meetings with the education support team, even “*like[.] ten minutes or even just turned up because that was better than just(.) lying at home hh(.)*”(1:69).

B: It was hard work and erm ((*coughs*)) I remember erm (.) feeling really tired cos I tried really hard(.) cos erm(.) after I did a lesson or something I was exhausted hheh(.) but slowly(.) you’re tired(.) but you keep going(.) [...] I couldn’t read at one point so I had to try and read again so I was reading like two sentences(.) having a break and then later in the day reading two more sentences(.) really hard

Becky (1): 163-164

Here the switching between “I” and “you” suggests the interplay of Becky’s personal story and professional narratives of “what is supposed to work”. While Becky suggests that effort does eventually pay off (a narrative explored further shortly), all participants highlight disruption and disheartening effects of repeated setbacks. These include exacerbation of symptoms attributed either to viruses or “overdoing it”, or lack of support socially, particularly from peers or teachers in the reintroduction to school. Here too, though, the narrative is of persistence:

- F: the first time I went back to school [peers] didn’t talk to me for the whole lunchtime(.) and that made me feel a little bit – it just made it harder for me to go back in every day [...]
all of them(.) I don’t really(.) it was just a few weeks [...]
they just didn’t really speak to me
- W: That sounds hard.
- F: Yeah(.) it was hard but(.) I eventually got back into it
- W: How did you manage that?
- F: I just carried on(.) cos I told my Mum(.) and she said(.) “just keep going in(.) and trying”

Freya (1): 194-200

The prevalence of such narratives of work and personal agency will be discussed further, particularly in relation to broader cultural narratives. However, one caution should be raised. A reflexive consideration of my own (interviewer’s) role reminds me that I too am immersed in such discourses, and this can directly affect co-construction of participants’ narratives. It is uncomfortably clear towards the end of my first meeting with Danni:

- D: [...] I’d love to get better(.) and I can’t wait to get better
- W: Mmhm. What do you think’s going to move you to getting better?
- D: I know that I need some doctors’ input about my like my paralysis(.) but I believe I’m making myself get better because I’m letting my body rest and do what it wants to do at its own pace

- W: Mmhm. And it that what's gonna – is resting is what's gonna be the thing that makes you (.) get better?
- D: And persistence(.) and I am pushing myself a bit(.) this – the end of the week – tomorrow I'm hoping to start putting more pillows under my head to sit up a bit more(1)
- W: °Mmhm.(2) right (2) right° (.) okay(.) so that's going to be one step for you
- D: =yes
- W: =getting your head a bit up(.) who helps you to know what the next steps would be?
- D: Noone(.) my mum just lets me do it at my own pace
- W: °Right°
(6)
[changes topic]

Danni(1): 340-349

This conversation is contextualised by my professional background (discussed further in chapter 6), my concern at the severity of Danni's symptoms, the narrated lack of a professional plan, and her statement that she hopes to attend the school prom in a few months. My questions here persistently reflect a professional narrative of "steps towards" Danni's expressed desire to "*get better*", and implication that she has a role to play in this (rather than, for example, awaiting a miracle medical cure). Danni can then be seen orienting to this: first reframing her bed-rest as a deliberate strategy to "make" herself get better, and then introducing a more active self-positioning of "*persistence*" and "pushing myself". My long pause at the end reflects my awareness that I have slipped into a different (and inappropriate) role, potentially altering the nature of our relationship and Danni's narrative. Though this appears an unusually "obvious" example, it highlights again the way that all narratives must be understood as co-constructed by interviewers immersed in particular cultural, personal and professional contexts.

In contrast to *increasing* activity comes the work of *limiting* (over-)activity in line with professional advice, to avoid cycles of "boom and bust". Many of these YP refer to this as problematic:

J: I have to say I would ignore like my symptoms? Like when it I would get too much I would just ignore it and carry on cos I was having fun? And it was nice like feeling like (.) normal?

Jess(1): 56

While acknowledging that her approach goes against recommendations, Jess's rationale - wanting to feel "normal" - is easy to empathise with and, importantly, resists the alternative (arguably more stigmatising) positioning of being lazy or socially avoidant.

A further aspect of the "work" comes in talk about trying to maintain hope and a positive attitude. As heard from Callum (1:157) in the previous section, a positioning of the self as "positive" and "upbeat" may counter stigmatising constructions of CFS/ME as "psychological". Where depression or other psychological difficulties are brought in to narratives, they are repeatedly positioned as an understandable *consequence* of illness, but also the work of trying to get well, and doubts in maintaining professionally-recommended courses of action. Well-meaning advice to "be positive" is then reported as frustrating, as if this is another burden, another thing YP are failing in: not only failing to get better, but also not fulfilling societal expectations to "be positive".

Such strong portrayals of *trying* to get better provide ongoing counternarratives to stereotypes such as promoted in the Gervais sketch. Interestingly, some of these YP draw directly on such stereotypes themselves in portraying *other people* with CFS/ME. For example, Harry mentions an adult neighbour with the same diagnosis:

H: (.) I mean I think she's actually - I mean it's hard to tell but I think (.) I don't think she's quite as(.) ill as me(.) but she tends to sort of deal with it in a slightly different way(.) sort of (.) hehheh she (#) I mean like she doesn't get up until sort of like eleven o'clock (#) and she just sort of lies around in her dressing gown and then she'll go out occasionally (.) like to the library or something(.) so I mean it sort of seems like she can do more than me(.) but she actually does less than me (#)

Harry(2):192

And Evie, speaking of a recently-diagnosed friend:

E: she hasn't got it as bad as me but (.) she doesn't- at the same time she doesn't really want to be bothered with trying to make herself better?

Evie(1):92

In all of these presentations of "other people with CFS/ME", the YP quickly go on to position themselves as different: some times more "severe" (Danni), and always as refusing to accept the status quo, as striving to change things, countering stereotypes.

The exception is Grace. Her narrative in the first interview is different, in that there is almost no talk about her as an agent in trying to get well. She suggests that she has no idea what she can do, since professionals and circumstances are not helping her. At one level, her expressions of hopelessness are understandable. Yet this lack of expressed agency - especially as she (aged 17) approaches adulthood - risks challenging social expectations. Grace's narrative of social rejection and bullying in this first interview also suggests that others may experience difficulty empathising with her. It is of course impossible to draw conclusions on such limited data, but - given the clear narratives of "work" from other participants - we may question the social implications for sufferers of chronic illness whose narratives do not conform to this pattern.

And in the case of a condition like CFS/ME where there is no clear medical or professional cure, even YP can be seen orienting narratively to the expectation that they must do what they can to help themselves:

C: I knew it was down to me so I've just gotta get on with it (.)

Callum (2:91)

E: if there was hheh [a cure] that pops up I'm gonna run straight to my hospital and you know get it(.) but erm(.) I think it'll probably be a while though won't it(.) so I'm not sure if there's much help for me(.) yeah(.) I think in the end it's just all about(.) you know(.) doing it for yourself

Evie (1): 171

Summary

Narratives of *trying* to get better are significant in their persistent presence (and occasional absence). They take up vexed issues about the contested nature of CFS/ME and how it should be managed, and the identities of those affected. Relatedly, they orient to complex discourses of power relationships, agency and responsibility - of patients in relation to professionals, and of YP in relation to adults - in ways that will be taken up again as narratives progress, and in chapter 6.

5.4 “A big journey”: Moving on?

Unlike acute illness, chronic illness does not carry assumptions of resolution. A significant proportion of CYP diagnosed with CFS/ME report prolonged symptoms (Royal College of Paediatrics and Child Health, 2004), so it was not assumed that participants in this study would speak of improvements in their condition over time. However, the project set out to explore longitudinal aspects of living with CFS/ME, and how young people account for these narratively - not just in terms of symptoms, but as life progresses more generally.

The following section draws on narratives provided in the second interview, approximately one year after the first, which began with my invitation to tell me “*the story of your life over the last year*”. All except Danni and Harry illustrated their narratives with items gathered into their “memory box”. An ongoing question is how the introduction of these items (often photographs) structured the narratives: not only through preparation, but also because some stories may be easier than others to represent in this way. Additionally, three participants (Adam, Becky and Freya) mentioned input from their mothers in selecting photographs to bring, or (Becky) in providing a written “timeline of events” with which to structure the narrative. Thus the co-construction of narratives is particularly evident, and will also be considered in chapter 6.

5.4.1 Negotiating a difficult road

5.4.1.1 Progressing along the road

E: Oh(.) the last year of my life I guess has been (1) I guess probably the best(.)
that I can remember (#)

Evie(2):12

Even within the first interview, all participants spoke of some improvements over time. This is perhaps unsurprising given that YP or their parents are unlikely to volunteer participation into a research interview when at their *most* unwell, but also arguably contextualised by cultural imperatives to be seen as a “good patient”, and “trying ones best” rather than “complaining”. However, for most, there was little sense in the first interview of a clear trajectory of progress that could be expected.

In contrast, the strongest narratives of the second interviews for all but one participant (Harry), are of progress along a difficult road towards a better life. All these are given a chronological structure, from the time of our last meeting through personally significant times to the present, often reinforced and “made visible” by items from the memory box. For example, Katie’s first items shown are a pair of pyjamas and pillow, her “*constant companion*” while ill at home at the start of the year; moving through items (tickets, a birthday present, paper napkin from a restaurant visited abroad) illustrating stories of developing friendships and activity as she regains strength; a ticket to her school prom at which she is given an award “*for courage and determination*”; and finally a referral letter to an NHS Chronic Fatigue Service that she presents as a symbol of her determination to continue fighting to manage remaining symptoms over the next year in preparation for University.

For Danni, having undergone hospitalisation following significant deterioration in her condition, “progress” might seem a problematic concept. Nevertheless, many aspects of her story are presented in this genre:

W: Have there been any particular turning points in your time here?

D: When I first spoke(.) that was (#)

I remember I spoke to Mum(.) “I love you(.) Mum(.)” [...]

all the different stages I suppose(.) being able to see²⁶(.) being able to move(.) having my hair washed(.) going in the bath(.)

Danni(2): 281-284

For most of the others, return to school and social lives forms a central storyline, both in terms of increasing attendance and academic achievement. While all speak of at least some periods of “*feeling a bit better*” from symptoms of fatigue and pain, as before these symptoms are not the main focus of the narratives. Instead, they focus on the pleasure and pride taken from a gradual building of activity, often *despite* ongoing physical symptoms. As before, stories are often entwined with threads about the *work* and persistence - the

²⁶ Danni had previously worn an eye-mask and ear-defenders and refused to be touched or washed, complaining of extreme over-sensitivity to light, sound and touch.

“long struggle” (Danni (2):422) - required to achieve this, and hence a sense of *achievement* in success that builds confidence.

Becky draws on the analogy of a *“snowball”* to suggest that small early steps provide the basis for progressively larger gains, and similar stories are heard from other participants. For example, Grace speaks of the impact of turning 17 and learning to drive through a Disability Mobility scheme. She suggests that, paradoxically, use of a car has encouraged her to walk more, since she feels more confident going out without a wheelchair; and that this has helped her develop friendships that have further encouraged activity and built stamina. Similarly, Freya and Callum suggest that, having made small gains in strength, their parents have let them *“do more”*, and this has further facilitated stamina, friendships and feeling more *“normal”*.

The achievement (and labelling) of *“normal”* things is prominent in all these narratives, particularly in terms of (re-)establishing social lives. For the younger participants, this is storied as a return to previously-enjoyed activities, like Becky (2:80) going sledging with friends (*“I hadn’t done that for years!”*) or Adam (2:19) - illustrated by his photograph of an active family holiday - smilingly describing a return to being *“able to do stuff there like (.) yeah(.) proper stuff(.) like not just like sit around the pool and whatnot”*.

Callum speaks with great pride about the significance of regaining a place in a club rugby team (*“which I thought I’d never return to”*) after a slow process of rebuilding his fitness:

C: it was just a really nice erm time to be in the changing rooms with your friends just feeling you know *“yeah I’m back”* erm(.) and it was such it was such an emotional moment but it(.) it meant so much

Callum(2):62

Callum’s *“I’m back”* may be understood not only as a statement of his physical presence, but as a reassertion of his previous, highly-valued identity as a sporty boy with a place among his peers, in contrast to the *“weak”* (1:11 and 1:23) boy of the previous year.

Older participants focus particularly on new activities that may be considered “rites of passage” and “*normal stuff*” (Jess (2):104) for Western teenagers in developing valued identities: strengthening ties with peers, travelling further from home, going to hear live music, staying out late, having a boyfriend, learning to drive or taking part-time work. These contrast with the narratives of “falling behind” heard in the first interview, and are made visible in items (eg, tickets) and photos brought to illustrate stories of activities and friendship groups that, the narratives stress, even a year before would not have been considered possible.

Most suggest that increased time in school has enabled peer relationships to develop. Freya in particular, having entered college, speaks at length about “*a new group*” of “*really understanding*” new friends (and a boyfriend), presenting a stark contrast with her previous narrative. However it is Grace, not in education, who presents the strongest narrative of developing her social life and a valued identity. Talk of a new group of friends, evolving from AYME contacts, dominates. In contrast to previous talk of social rejection, she now constructs a strong and positive identity within a group who encourage her to embrace being “*different*”, made visible in her blue (sometimes pink) hair and new body piercings.

G: I'd never have imagined that this time last year(.) that I'd be doing this(.)
I'd never have imagine that I'd be going out and(.) having a social life
hehheh(.) it's not something I ever imagined I'd be able to do(.)

Grace(2): 78

These stories of achieving valued teenage relationships and experiences are arguably central in repairing troubled identities, strengthening rhetorical arguments that earlier peer rejection was not a reflection of the YP's own character, and that non-participation in “normal” activity was forced by illness, not a choice. However, despite talk of the work they have put in and pride at achievements, all also express *surprise* at these developments. Thus another thread weaves through the narrative fabric: that this achievement is not normal, but has required a degree of work and strength of character that is not always recognised. Positive outcomes, we are reminded, were not to be expected - and future progress should not be assumed.

5.4.1.2 Setbacks, struggle and an unpredictable journey

W: [.] So how(.) how are things for you at the moment?

B: (.) much better(.) at the moment(.) but erm (#) it's been up and down all
year

Becky(2): 10-11

W: [.] let's just think about then I guess the story of the last year for you(.) and
you can=

J: =oh god(.) a lot(.) as with usual M.E.(.) unpredictable(.)

Jess(2):15-16

Even in narratives of progress, talk of struggle and setbacks provide a counterpoint from the outset of the second interview. This appears in talk and also occasionally visible depictions. Freya brings a photo of herself asleep on the sofa on Christmas Day wearing a gold paper crown from a cracker, that she narrates as representing her inability to celebrate when overcome by symptoms.

As previously, all speak of periods in which symptoms get worse, almost always attributed to infections or to “overdoing it”. And as before, the social and emotional consequences are apparent - for example, for Jess after a period of relative health, speaking of catching “*bug after bug*”, missing more school, then becoming seriously distressed as she feels that peers and teachers are once again critical of her and “*it's happening again*”. And Callum, as always giving an emotionally-understated performance, nevertheless conveys the fears brought on by a sudden return of symptoms at the end of a busy school year, not only practically but for his identity:

C: you know I didn't like that feeling again and that feeling scared me (.) um
(.) like I was saying um thinking I was not normal again (.)

Callum(2): 201

Almost all cite school pressures as the triggers for worsening symptoms. Significantly, where “overdoing it” is constructed as causing set-backs, this is always in terms of an

activity which is *required* of them - that they "had to" do, rather than a frivolous choice; and all immediately go on to speak (as before) of the work they then do to try to recover. Thus again there is an orientation to discourses of responsibility and agency in getting ill and recovering.

Additionally, narratives again reference the work - and the implied strength of character - needed to overcome inevitable doubts or despondency after setbacks. One example is Callum's rugby injury sustained just minutes into his first club game after the long struggle to regain fitness after earlier CFS/ME; another is Katie's "horrible" exacerbation of symptoms after taking advice from an eminent Professor. Both briefly gloss their initial emotional reactions: "*I was like [...] 'I ca:n't do this'*" (Katie 2:17); "*my confidence was a bit rocked erm [...] I kind of went a little bit into my shell again*" (Callum 2:117). Yet both immediately follow this "admission" with a "*but*", and go on to report actions they took to overcome this. And after showing me his cut-up rugby shirt, Callum brings out a different symbol of his year: an "*inspiring*" book, read while off school unwell, about a mountaineer given up for dead after falling into a crevasse, who survives against the odds. Narratives of heroic struggle over adversity are thus restored.

It may also be seen that although most narratives "make sense of" setbacks (eg, as the consequence of "overdoing it"), this is not always presented as clear-cut. Within her overall narrative of recovery, Katie (2:139) suddenly introduces a cautionary tale of "*a really strange time*": a brief but worrying relapse to "*the worst I've ever felt*". Though she then tells of resuming her graded approach to activity, and improving "*a lot in a really short space of time*", the "point" of her story (as she repeats three times) is that she does not understand "*what triggered it*", or "*what was going to make it better or worse*", challenging all she feels she has learnt over the year about managing her condition. Thus hers is not a simple story of heroic struggle and triumph over setbacks, because she cannot predict future relapse, or her ability to manage this.

However, the strongest narrative of unpredictability comes from Harry. Alone of all the participants, his narrative at the second interview is not one of progress or "moving on". He begins by talking of the start of the year, as a period in which he "*was starting to get*

quite a bit better”; but immediately continues to talk of feeling much worse during a family holiday:

H: [it] sort of set me back a bit [.] and then it took quite a while to sort of recover from that[.] I haven’t really got any(.) I’ve got a bit better since that but I’m still nowhere near how I was sort of at the beginning of the year

Harry(2):35

Although he considers possible triggers such as the “*general stress*” of the journey, he quickly returns to the narrative set out previously: that, with the exceptions of catching “a *virus or something*” or major “overdoing it”, “*there isn’t a pattern(.) it does seem to be just really random*”. This contributes to a narrative that, although containing elements of persistence and personal agency in “*getting there*” (2:85), learning “*more sort of strategies for coping with it*” (2:142) and “*sort of getting back up again*” (2:233), is chaotic (Frank, 1995); positioning Harry as at the mercy of a relentless and unpredictable condition. Even if progress is made, Harry and Katie caution, the future is uncertain.

5.4.2 Negotiating changing terrain

A: like I’d done like ninety-five percent of the term(.) so basically my teacher hadn’t even noticed that I’d got M.E. and that(.) well sort of they did know[.] but(.) um(.) yeah(.) they sort of didn’t realise it was affecting me as much as it did

Adam(2):433

As heard in adult narratives of chronic illness, improved management of symptoms (even if not a full “recovery”) can bring its own challenges. For adults, there may be pressures to return to work, reinforced by financial considerations as welfare payments are withdrawn. Financial considerations are understandably less apparent in these YP’s narratives (though mentioned by Grace, expressing concern at the removal of her Disability Living Allowance and Mobility-scheme car). However, other aspects of these narratives parallel those heard from adults, particularly the increasing pressures to “return to normal” at a time when other support appears less forthcoming, socially and professionally, as health precipitates

discharge from medical and other professional services. Additionally, there are hints that the invisibility of the condition (always an issue) increases as symptoms are managed better, further reducing support.

5.4.2.1 Constructing the additional challenges of “getting better”

C: I know people say “who wants normal?” but you do (.) you really do(.)
erm(.) no it’s a very important thing

Callum(2): 246

Living with CFS/ME requires ongoing monitoring of symptoms and pacing of activity to avoid flare-ups. However, we now hear that “progress” increasingly challenges this for teenagers. Improving social lives bring increased expectations to fit in with peers in staying out late, disrupting learned sleep schedules; and inflexible school expectations to take particular exams at particular times appear to reflect wider cultural narratives about CYP “fitting in” with their peer cohorts, stepping back onto the “age-appropriate” conveyor belt.

However, the desire for “*normal*” teenage identities expressed so frequently by these YP, is now more haltingly troubled by some. In particular, cultural expectations for teenagers to take on more responsibility and become more independent are, later in the interviews, presented as something of a double-edged sword.

This applies even to the youngest of the participants. In his narrative of recovery, Adam highlights the increasing responsibility he is being given. At times he speaks of this with pride: being asked to train and qualify as a junior referee, responsible (and paid) for weekend club football matches (“*you’ve got to control fourteen 9 year-olds!*”). However, Adam also gives more hesitant stories of struggling to meet his mother’s increasing expectations of him, including not feeling “*quite ready*” for some of this. He reflects that increasing expectations are due to his “*getting better*”:

A: but then when I do that people think that I can just do all this stuff and then
be fine(.) so like they sort of just like keep keeping the things I need to do

coming and(.) yeah[.] will just expect you to be able to keep doing it and that so:: (#)

W: So that's one kind of downside of getting better is that they might expect more and more and more?

A: Yeah [...]

I imagine as I(.) as like time goes by in the future I'll have less reason to say "no(.) I can't do that because I'm tired" cause I'll be getting better(.) and most of the reasons for me not to be doing something will be because no I just can't deal with doing that or whatever it is(.)

Adam(2):303-5/313

Thus Adam positions himself as aware that increasing freedom from illness, though largely positive, will bring additional challenges as he must learn to negotiate responsibilities (and refusals) without recourse to the "reason" that he is unwell.

Some parallel challenges are suggested by Jess and Katie, who both reflect towards the end of the second interview on times when increasing expectations to participate in "normal" peer activities raise anxieties not entirely related to illness. Here Jess talks of a school trip, in which plans were changed on the day, and a visit to an adventure park quickly arranged:

J: I don't know why(.) I think I was just shattered 'cos I hadn't slept well the night before because I was worried about it(.) but I I like had(.) I don't know what happened [..]

I get a bit (2) freaked out when something isn't planned(.) like if that makes sense(.) I like having a bit of structure to things hehheh(.) and so it just(.) it kind of threw me off a bit [.] so I was a bit like(.) "oh god no"(.)

and I don't(.) I just phoned mum(.) "I'm at [adventure park](.) come down and pick me up"(.)"No"(.) and I'm like "oh god" (*laughs*)

because it just(.) I don't know(.) it's just that change in plan really on that day just(.) really threw me(.) it was weird(.)

I just think I was tired and I was(.)

like new people as well it's always a bit nerve-wracking really(.)

Jess(2):256-261

Jess can be heard accounting twice for becoming “*freaked out*” with reference to her fatigue, but also picks up on an aside she has made earlier (2:67) about previous “*anxiety issues*”. Significantly, all Jess’s talk in the first interview about “*stress*” attributes it wholly to the consequences of illness. Now though, in the context of a more developed relationship with the interviewer and a narrative in which Jess is positioned as having made great progress in many ways, she puts forward the possibility that some *earlier* psychological issues are re-emerging as her contact with a less predictable social world increases.

Similarly, Katie talks much more in her second interview about a pattern she has begun to notice, in which self-acknowledged personal traits (“*I am kind of an anxious stressy person*”, 2:181) may account for her reluctance to stretch herself (eg, travel to visit a friend) just as much as her pain or fatigue. However, Katie and Jess take care to point out that these psychological issues are not the *cause* of their illness; rather, that emergence from the most severe physical incapacity creates situations in which anxiety is another challenge they will have to manage.

5.4.2.2 Widening horizons: When increasing “normality” highlights “difference”

One related challenge is articulated clearly (though briefly) by only three participants, but may be discerned whispering in the wings for almost all. While improving health and widening social horizons are generally narrated as progress and moves towards “*normality*”, there are hints that they may, paradoxically, serve to highlight difference. Stories of celebrating milestones such as a 16th birthday or end-of-school prom are bitter-sweet, suggesting pride and happiness in achievements, but tinged with awareness that these events might be very different if the YP had not been ill. Similarly, Evie’s new Saturday job with other teenagers - spoken of with pride - is storied as leading her to reflect on how different their worlds of school and Saturday-night parties are from her own.

Harry tells a particularly poignant story, of recovering enough to go on a family holiday:

H: from where the cottage was that we were staying in you could sort of like(.)
all views round and things(.)
but it actually(.) meant(.) that I could sort of see people cycling and they
were like getting all their sort of normal holidays(.) so it was actually
making me think(.) “oh I could be doing all this(.) but actually I can’t”(.)
because I think(.) when I’m at home I tend to sort of(.) because I don’t go
anywhere(.) and I can’t go anywhere(.) I tend to just sort of let myself sort
of forget about what I could be doing(.) and what I’m missing(.) so it’s sort
of like as a coping strategy I suppose(.) which does work(.) but it means
that when you then do start to see people doing other things it then sort
of reminds you again “oh(.) I could be doing that”(.) sort of thing(.)

Harry(2):43-45

Thus YP narrate an ongoing challenge, where increased contact with a wider social world may actually heighten a sense of what has been lost, and ongoing difference that may not be repaired. Outward appearance of increasing “normality” is not necessarily matched by the sense of self - an issue discussed further below.

5.4.2.3 Constructing plans for the future: Moving on but taking care

All participants except Harry speak readily in the second interview of their hopes for the future, including education, career plans and even the possibility of having their own children. Even Danni (2:353) constructs her “*journey*” as movement along a road towards a brighter future, albeit at a slower pace than peers. In line with broader societal narratives of teenagers (Kehily, 2007), there are understandably reflections of the competing pulls for the relative safety of childhood and home, and the opportunities that may lie ahead. However, for these YP additional “pulls” are expressed with regard to illness and related identities.

The act of planning for the future is in itself spoken of as a symbol of progress: a change from the earlier state of having to take “*each day as it comes*” (a phrase used by Becky, Harry and Jess) while at their most unwell, to a position more akin to that of healthy peers. Narratively it appears as part of the move from “chaos” narratives into those of

“restitution” or (more commonly) “quest” (Whitehead, 2006a). A significant item brought out by Evie towards the end of her second interview is a photo and newspaper article about a prestigious University:

E: you know I'd love to go to university [...] obviously a massive goal of mine(.)
I - I - to be honest with you erm I'd love to get in anywhere(.) but [name of University]'s(.) you know(.) it's a massive(.) incredible city(.) amazing education - and it's like right round the corner so I can come home for dinner! hehheh!
erm (.) and my dad cut that out for me(.) I keep it(.) on my wall(2) I think it's nice to see that(.) I have a goal(.) as opposed to just sort of (#) um(.) you know(.) just sort of - I I like taking each day as it comes but I also like thinking about what's coming next

Evie(2):264-5

Alongside expression of high hopes can be heard Evie's more muted noting of the city's proximity to home, echoing other (understandable) hesitations in her narrative. A similar theme is heard from all these YP, as voiced also by Freya speaking of the child-care course she has always wanted to do, and her success in GCSEs:

F: I got enough [grades] to do the higher course? but I didn't want to do that because it's more(.) work and more days and I didn't think I'm ready so I'm going to go on to that next year
[...] I thought it was safer hehheh ((laughs))

Freya(2):65-69

Here there are narratives of progress & achievement, and of young people striving to build on this for a more “normal” future, but where CFS/ME cannot be discounted. However, rather than allowing a narrative where illness dictates lives (which would be one possible interpretation of selecting “*safer*” courses or locations), Freya and the others are positioned with some agency, taking responsibility for managing their health and safety, making sensible decisions - itself in keeping with cultural demands for progress and development of more autonomous identities in the transition to adulthood.

5.4.3 M.E. and me

Throughout this work, there has been consideration of how participants' narratives construct not only their experience of CFS/ME, but also their identities - as YP who are (say) overcome by, or fight the condition; innocently, bravely, chaotically or with purpose, for example. Mostly this is interpreted from the way they are positioned within stories of experience, but at times participants step away from story-telling into a more direct commentary on topics like "what sort of a person I am", "what I've learned", "how I've changed". At points in the interviews (always towards the end) I have directly asked for this, and where this is the case I have indicated this. At other times some (particularly the older girls) make these reflective asides without prompt, and these appear to be an important part of constructing the "message" for audiences. Of particular interest now are constructions of the *changing* relationship between YP, their illness and identities over time and into an imagined future.

5.4.3.1 "A big journey"

W: Overall (1) overall how would you say you've changed as a person(.) from having M.E.?

D: I've- I've- I understand pe- I understand how people feel more?
Erm (1) I- we've seen who our real friends are(.) erm(.) I've- I've learnt that life(.) you should enjoy it and embrace life(#) er(.) yes.

Danni(1): 364-366

W: So how do you think you would be different if you- at this stage in your life, if you'd never had M.E.?

E: I don't think I would've been as(.) good a person? I'm very(.) err(.) it sounds a bit boastful but I'm very considerate of other people's feelings(.) erm I treat people the way I would want to be treated(.) so(.) I think I would be a bit(.) not mean but I don't think I'd be as nice in a weird way(.)

Evie(1):120-5

In both prompted and unprompted articulations, almost all these YP offer elements of what Frank (1995) considers a “quest” narrative: that, despite all the difficulties of CFS/ME, struggle with the condition has led in some ways to evolution of better lives, or enhanced personal attributes and identities. Most commonly noted are increased sensitivity (empathy) towards other people, and enhanced appreciation for life: not taking things for granted. Broader cultural narratives of adolescence are drawn on, in terms of having “grown up” more quickly and having a more mature outlook on life than their peers.

Unprompted quest narratives occur particularly in the second interview. As part of a broader reflection on the last year, and coming to terms with a condition for which there are “no answers” (2:111), Grace continues:

G: (#) I mean it’s a big journey for me(.) I mean it’s been a big learning curve and I’m glad that I have(.) got M.E. because I’ve got all these new friends from it(.) and I’d never have met any of the people that I have done if I didn’t have M.E.(.) so it’s definitely changed my life and it’s changed my life for the better [..] it’s definitely worth(.) worth it even if it does hurt(.) yeah(.) if I hadn’t got sick I’d have still been(.) trying to work out where I wanted to go in life and(.) and being with the wrong crowd of people and things so it’s definitely a good thing that it’s happened to me(.)

Grace (2): 113-114

Underlining her point, and drawing on a powerful cultural narrative of troubled adolescence, she continues by speaking of a teenage girl in her old crowd who is now a single mother, and the direction that her own life might have taken: “*I have no doubt that if I hadn’t got sick I’d have been the pregnant one*” (2:115).

Jess also spontaneously and repeatedly talks of how aspects of her life and character are better as a consequence of her illness. She too draws on less appealing cultural narratives (or stereotypes) of teenagers in positioning herself as different: for example, having developed a close relationship with her mother (contrasting with talk of peers who complain about their parents); learning about “*real friends*” (2:356), in contrast with peers who focus on more superficial relationships; and having moved past the “*teenagery*” self-

absorption of an old friend, “*still at that stage where it’s all about her(.) and because of my M.E. I’ve grown up quicker*” (2:78).

There are two exceptions to this narrative of self-development. In keeping with his broader style, Adam mockingly resists the call for such “*TV show responses*” (2:447) and focuses instead on the change in his ability to manage his illness, as well as other positive changes attributed to his condition (eg, gaining him access to a better school, and forcing his separated parents “*to communicate more*” over managing his care) - although he does briefly suggest that it has helped him to “*put life into perspective hheh*”.

However, once again it is Harry who provides the main exception. Although it appears that YP do not need to be free from their symptoms to give “quest” or “journey”-type narratives, Harry - whose second interview revolves around relapse and deterioration - strongly resists a narrative of personal growth (“*I have changed a bit because I have sort of grown up but not changed a lot(.) no*”) (2:179-180). His narrative, and narrative identity, remain in “chaos” (Frank, 1995). The implications of (not) providing “quest” narratives within particular cultural settings is discussed further in chapter 6.

5.4.3.2 Imagining a future without M.E.

Though research indicates that the prognosis for YP diagnosed early with CFS/ME is relatively promising, and YP here present narratives of progress in *managing* illness, there is very little spontaneous talk from them about the possibility of a future *without* illness. Close to the end of the second interview, I ask specifically about this - and there are indications that this is a difficult subject.

W: Yeah... Do you think there will ever come a time where (.) you don't consider yourself to have M.E.?

A: Uh::: ((sighs)) (1) U::hhh:: (2) um ye-ah(.) I think so hope so (#) probably actually (1) when (#) I dunno(.) quite (#) I can imagine not(.) you know(.) in a time not too far from here actually I- I think(.) probably (1) by this time next year I reckon I'll be(.) I'll be fine(.)

W: Ri::ght=so

A: =Well not fine but(.) as fine as(.) you probably get without (#) being er normal(.) er sort of just er(.) going back to what I was doing and stuff before I had M.E.(.)

[...]

(.) but like it'll always sort of be there I think(.) as much as I understand it(.) but erm it's just one of those things isn't it? You can't do anything about it so::

Adam(2):207-210/218

Adam's reflections here initially seem confused, marked by hesitations and false starts. The conjunction of "*fine*" with "*not normal*", "*better*" while simultaneously "*not better*" then appears to draw on a construction of CFS/ME as a condition that can never fully disappear even if there are no obvious symptoms. This construction is audible to a lesser extent from other participants, although ironically it is Harry - struggling to chart a way forward with his unpredictable symptoms - who challenges this. While maintaining (2:190) that there is "*no way of telling*" whether M.E. will always be a part of his own life, he comments that he has learned from personal stories in the AYME magazine that "*people do get sort of better from it or they grow out of it*".

This contrasting of knowledge about what has been reported for others, and expectations for oneself, is also heard from Jess:

W: Yeah(.) do you think there would ever come a time when you would be able to say(.) "I don't have M.E."?

J: Honestly? no hehheh(.) I just personally- like(.) cos I know it's a really good (#) erm percentage(.) like at least people get like 80(.) 90% or even 100% recovery if you're under 18 and you have M.E. (1) personally (2) I don't think(.) it'll ever go away completely I - hopefully I'll get to like 90s but I don't think it'll just(.) not be there(.)

Jess(2):342-343

However, further readings suggest that hesitation in thinking about a future without M.E. is not simply a reflection of medical prognosis or uncertainty, but may also reflect resisting the temptation to imagine a different future - "*looking too far*" (Jess (2):373) - lest this lead to future disappointment.

G: I try not to think about (#) that I might get better(.) I try to accept that this is probably going to be part of my life(.) ↑and if I get better then that's brilliant(.) but if I don't(.) I don't want to get my expectations up too high - I don't want to [.] be like in ten years' time be really upset because I'm not(.) better like I wanted to be

Grace(2):151

Many - Evie and Jess in particular - comment that CFS/ME has been part of their lives for so long that it is almost impossible to imagine life without it, and this forms another "rationale" for hesitations in embracing the topic of imagined futures. Jess, in her extended "quest" narrative of self-development, then touches briefly on a more complex reflection:

J: [...] so I don't know how to see myself without M.E. because I don't feel I've been without it if that makes sense (.) I just can't remember a time when I haven't had it (.)

W: Right (.) so it'd be stepping into something quite new?

J: Yeah(.) it would be nice but it would be weird because it's like in a way(.) in a really weird way it's become like a bit of a crutch?(.)
cos like say(.) if(.) hhehh(.)° I know it sounds really weird°
but like say(.) if I don't want to meet up with someone or something
hehheh(.) then "I can't(.) you know"(.)
"I have to be careful"(.) "I don't want to get too tired" and things(.)
so it's like (1) hh (#) yeah(.) I don't know(.) it'd be weird(.)
but it would be nice(.) but weird hhehh(.)
I think I just think because it feels like it's been my life(.) and everythi- it -
cos - you know(.) most things revolve around hheh it(.) so it would be weird
but it'd be nice(.) hehheh

Jess(2):356-363

Here Jess ventures into potentially difficult territory. Like Adam (who has already spoken of a potentially negative consequence of “getting better”, in that he will have less “*reason*” to turn down adult demands to take on more responsibilities), Jess’s comments could - if expressed in some settings - expose her to accusations of “not wanting to get better” and “secondary gain”.

The context of her talk is relevant. Here, speaking almost 100 minutes into her second interview, such interactional concerns are mitigated by the relationship context. Given my visible responses to her over both interviews and email correspondence between, Jess can reasonably expect that I will not be dismissive of her narrative or her character in such a way. Even so, her narrative manages any residual risk, both by the repeated juxtaposition of costs and benefits (“*weird but [.] nice*”), and (it can be argued) of simply *taking* this risk: ie, continued presentation of a disposition to honest self-reflection, which counters potential challenge of deceit (Edwards, 2007). There are indications that, even for an articulate 17 year-old in this setting, this remains difficult discursive territory.

5.4.3.3 Imagining *me* without M.E.?

Jess’s reflection also draws us to consider the changing relationship with M.E., not only as a condition that “*most things revolve around*”, but that has “*been my life*”. Hesitations in participants’ imaginings of the future may be understood not only as doubts about the nature of the illness or even fears about new challenges ahead, but also in terms of challenges to identities as fundamental as those occasioned by becoming ill in the first place.

As noted, most of the participants construct “quest” narratives of personal growth and positive identity development as a consequence of illness. These are now drawn on by all of the older girls, but particularly Grace and Jess, to “make sense of” hesitations about wanting a future entirely without M.E.

W: would it be a totally good thing if one year you thought(.) “actually I’ve had no symptoms at all for the last year(.) I am better”=

G:

= I don't know if

it'd be a good thing (2) obviously it'd be brilliant because I wouldn't hurt anymore and I'd be able to sleep properly and I wouldn't be constantly tired and I'd be able to do things without worrying about(.) what's going to happen(.)

but because of the person I've become(.) I don't want to lose that and I don't want to lose all my friends and(1) I want to still be able to understand them - because when you - when you're ill you understand people but when you lose that illness(.) you don't quite(.) you can't quite sympathise anymore with them

Grace(2):156-159

Callum's narrative provides sharp contrast. While speaking of significant gains in health and activity where "everything was back to normal" (2:182), his mother has already reported a recent return of some symptoms at the end of a busy school year. Although Callum's narrative through both interviews has worked to position him as a previously, and now increasingly, healthy and sporty young man resisting identification with others diagnosed with CFS/ME, his comments here came as a surprise to me:

W: If I'd asked you at that time (1) do you – would you still say(.) that you still have(.) CFS/ME(.) what would you have said?

C: Oh no I wouldn't – I'd've said "no I don't" I – I would still say that(.) erm:(.) what happened at the end of oh – what happened at the end of this year (1)

erm I was told it was mental burn-out(.) which doesn't surprise me cos I think the example I've heard of(.) is erm yeah people coming up to play rugby in England(.) which is a much much longer season they just get me- they get mentally out of it um(.) I've been doing(.) you know over twice(.) as much school as I done before so [.]

I don't think that's M.E. and nor does my Dad(.) er noone does they just think(.) just mentally out of it by the end of the year(.) but no I think – I think it had gone

Callum(2):183-185

Callum's narrative resistance of the "M.E. identity" here is complete. Even as he speaks of symptoms identical to those previously diagnosed as CFS/ME, he reframes them as the "burn-out" described in athletes who, like him, are forced to work particularly hard. This construction continues as he goes on to note a need to "*watch out for*" "*overdo[ing]*" work in future. Thus the possibility of symptoms may require ongoing guarding against unrealistic demands, but the threat to his sporty, masculine identity by identification with CFS/ME is narratively overcome.

5.4.3.4 "I am *me* not M.E.": Constructing a changing relationship

Though Callum is the only participant to present this narrative identity of "me without M.E.", resistance to being identified as "a person with M.E." is now spoken about explicitly by some of the older girls, constructing a changing relationship with the condition.

Throughout this analysis of lives interrupted by and lived with CFS/ME, there has been attention to the complex ways in which young people's narratives manage the potential for a spoiled or stigmatised identity - for example, in positionings of the self as "normal", hard-working and striving to get better, resisting cultural discourses of people with CFS/ME as psychologically-unwell, lazy or motivated by desire to avoid the outside world. Consideration of the illness identity is, however, particularly highlighted in talk of encounters with others: what is told (or not) about the illness, with view to how others may perceive and challenge the young person's identity. Though the issue of "what to tell" is an ongoing thread, it can be seen that, during the early and worst stages of illness, something at least needs to be said to teachers, peers and others in order to account for absence from usual activity. However, for those YP experiencing considerable recovery - where physical symptoms and their impact on activity are increasingly minor or invisible - new possibilities and a question arise: "Do I want others to see me as 'a person with CFS/ME'?"

While Grace, Danni and the younger participants are surrounded by peers who know about their CFS/ME, the older ones speak of widening social groups who may not. Freya speaks in her first interview of a wish to move on and leave behind the problems of her schooldays: to enter college and "*put it behind me(.) and I don't have to tell anyone about it(.) hheh(.)*

and that it can just be something that never really happened(.) hheh" (1:226). However, a year later she tells of being "advised at the college to tell someone(.) in my class just in case I needed(.) help" (2:81). Again the issue of safety first - "just in case" - is raised, now attributed to an adult voice of authority, and as a rationale for Freya's decision not to try to "pass" (Goffman, 1963) with an unspoiled identity.

Evie also draws attention to this dilemma, speaking of her entry into part-time voluntary work where she is asked to account for her home-schooling. Within these stories she is positioned as reluctant to do so, and then comments:

E: It's not necessarily that I'm ashamed(.) of my illness but there is a certain(.) erm(.) want for(.) I guess a clean slate you know (#) to be able to sort of start new

Evie(2):66

E: i-it's just if someone (#) meets me and they immediately find out it becomes who you are as opposed to(.) an element of who you are(.) you know(.)°yeah(.) I don't know hheh°(.)

Evie(2):126

Three intertwined threads are particularly audible here and, to differing degrees, for almost all the YP over time: the expressed wish for a future in which one can be (and be seen as) less "different"; recognition of potential for "shame" in "my illness"; but also suggestion that it is acceptable to retain the illness identity as "an element of who you are" - just not the totality of "who you are".

These threads are evident as Katie speaks further about deciding not to tell new people in her life about her diagnosis, with reference to public narratives of CFS/ME following newspaper reporting of the PACE trial:

K: [...] everyone who read that article thought(#) will now think people with M.E. are kind of being lazy and should just go to the gym(#) [W:°mmm°] which – that that was the thing that made me quite angry because I just thought(.) more negative press is really hheh(.) not necessary or helpful[.]

I think people that know me really well it doesn't affect them because(1) they sort of know my personality and things they know I make an effort and I'm trying to do things and(.) all that stuff but(.) I suppose it's more(.) people(.) I don't know well or people I've met if I've said to them(.) "I have M.E." (1) erm and I've actually- I sometimes don't tell people any more(#) like I haven't told the people I'm working for doing childcare (1) which I feel a bit bad about but I thought(.) if they've heard something negative(.) it could just give them a negative impression(.)[..] you know that you're lazy or something (#)

Katie(2):74-80

Though the impact of such public discourses have been discernible throughout these YP's narratives, Katie is the most explicit in stating how these will - now that it is an option - lead her to hide her diagnosis from those who don't already know her.

The third thread is also heard from those whose "quest" narratives stress the positive aspects of identity development through the experience of CFS/ME. In contrast to Harry's narrative of ongoing chaos and unpredictability, and Callum's rejection of M.E., the others reflect more complex shifts in the troubled relationship between "M.E. and me". Here an ongoing struggle is heard: both to accept *and* marginalise the impact of M.E. on "me". Evie's consideration of M.E. as just "*an element of who you are*" forms an important element of all these narratives - at least at this point in their journeys - as echoed here by Jess in a section of the journal she has kept over the year, and shared with me in our second meeting:

J: yeah(.) I wrote "I am me not M.E."
 so (#) hehheh it's like it's got to the point where I just(.)
 M.E. is a part of me but it's not everything(.) if that makes sense(.)

 whereas before it felt it was everything(.) like when(.) you know(.)
 it's like "the girl with M.E." instead of like "Jess"(.)

Jess(2):163-5

Summary

Meeting again a year later, these YP take up narratives of ongoing struggle but - for most - journeys of achievement and progress along a bumpy road. Though all cite some improvements in their symptoms, again these are not the focus. Instead, most conform to a “quest” narrative (Frank, 1995) in which the journey is of self-development and insight. Aided by items brought in “memory boxes”, stories of success and new relationships address earlier questions about social identities (eg, as psychosocially abnormal, or not trying hard enough).

These are not simple narratives of triumph over adversity though. Talk of setbacks and uncertainties reinforce constructions of CFS/ME as a serious and unpredictable adversary whose presence is likely to be felt into the future. The contours of contestation can still be traced as YP note new challenges and changing relationships between child and adult, personal and social, illness and self: M.E. and me.

Chapter 6

Discussion

6.0 Introduction

The previous chapter explored what may be understood from a discursively-focused narrative analysis of young people's accounts of living with CFS/ME over time. From the detail and complexity of these narratives, I now aim to draw together some of the main threads, discussing them in relation to existing literature, and considering what this study contributes to wider understanding.

I will then reflect on methodological tensions encountered within this project. In keeping with the constructionist framework, I aim to reflexively consider some of the forces shaping research decisions, and their implications for the development, "doing", interpretation and representation of the research. Such discussion inevitably provokes questions about what conclusions can be drawn, what might have been done differently, and what remains to be explored in future. Such questions will be taken up in chapter 7, which will also consider the *implications* of the research for professionals and others working with young people.

6.1 (Re-)Locating the project

This project arose from a wish to understand more about young people's experience of living with a condition that can be understood as "contested" (Barker, 2010). It was contextualised by my clinical experience and interest in how health and illness are constructed and contested within society; and how this influences how people respond - with care and compassion, for example, or with fear or disregard or suspicion - contributing to the suffering of those affected. It arose too from a particular interest in young people and how they negotiate complex and rapidly-changing worlds; and an awareness that their voices are not well-represented or well-understood in the research literature, but have much to contribute.

This thesis builds on a very small body of qualitative research focused on young people (YP) in their teenage years living with a diagnosis of CFS/ME (Fisher & Crawley, 2013; Jelbert et al., 2010; Winger et al., 2014). However, while these earlier studies are based on interpretative phenomenology, the current analysis adopts a different epistemological and analytic framework. This discursive narrative analysis problematizes the status of talk as a simple representation of lived “experience”, understanding illness narratives as more complex productions that orient to local and broader social contexts: drawing on and resisting existing narratives or discursive repertoires, and actively constructing events, experiences and identities for their audience(s).

Analysis therefore focuses not only on the content of narratives, but on *how* they are constructed, and the interactional and rhetorical work that is done through this. This in turn allows further consideration of the social and discursive contexts in which speakers and audiences are situated, and the way that speakers may navigate these in accounting for themselves. This project therefore extends the limited body of qualitative research with YP living with CFS/ME, considering how they actively negotiate not only their lives, but the challenges of constructing and communicating their experiences and their identities for different audiences. In doing so, it draws on and in turn adds to a broader literature on the social construction of health, illness, disability and identities, and our understanding of young people as active social agents within this.

This analysis shows that even young teenagers diagnosed with CFS/ME can produce rich and complex narratives. Each is unique: there are patterns and areas of overlap, but exceptions to almost every rule. In narrative *content*, there are clear parallels with recent interpretative phenomenological analyses conducted with YP (Fisher & Crawley, 2013; Jelbert et al., 2010; Winger et al., 2014). They speak movingly of the difficulties of living with hard-to-understand and sometimes disabling symptoms that change unpredictably over time, yet illness symptoms are not the main focus of these narratives. Instead, they foreground the biographical disruption (Bury, 1982) to expected social and educational activity and achievement; the difficulties (for most) of having their symptoms understood or even believed by doctors and others; and the ongoing pain of discreditation, feeling “different”, judged, marginalised and left behind as peers move on with their busy lives.

Yet this project differs from previous ones in a number of ways. Narratives are drawn from YP at different stages in their illness - rather than all “recovered” as in Jelbert et al (2010) or in the initial stages of contact with a specialist service, as with Fisher & Crawley (2013) and Winger et al (2014). This, and incorporation of a longitudinal dimension (interviewing participants again a year later), allows consideration of other angles - such as the passage of time, “stage” in the illness journey, and changing social and developmental contexts on the narratives that can be told (an issue of relevance to interpreting narrative in other contexts, and discussed further in section 6.2.3).

The present research is also enriched through incorporation of creative methodologies, in which YP were given opportunities to construct multimodal “memory boxes” and build these into their later narratives. Analyses demonstrate the value of allowing different forms of narrative and identity construction in YP, with exploration of what can(not) be easily “said” in words or in pictures, and the role of other people in such co-construction – an issue with implications for wider research, discussed further in sections 6.3.2.1 and 6.3.3.

However, it is in the analytical attention to the *construction* of narratives and their dialogical, interactional features that this research contributes most. As these YP speak of the onset of disturbing symptoms, the descent into serious illness, the long months or even years of living with disabling, unpredictable illness and distressing social consequences, and then, for some, the possibility (and challenges) of “moving on” from the worst of illness, narratives can be seen as simultaneously constructing the condition (“M.E.”) and the identities of those involved (“me” and others) in ways that reflect - and resist - prevailing social and cultural narratives, attending to the different audiences that may be encountered.

In this thesis I argue that troubling tensions and dilemmas can be discerned as YP attempt to account for their illness and its consequences while maintaining culturally acceptable constructions of the self as a young person; and that particular challenges arise from the discursive contexts of “adolescence” and of CFS/ME as a contested condition. I argue too that young people’s narratives attempt to manage these tensions in different ways, some of which appear influenced by the age and gender of their speakers; that these different

narrative/discursive approaches resolve dilemmas to different extents. Further, I argue that this has profound personal and social implications for YP and their families, for those who work alongside and try to understand them, and for the ongoing social construction of CFS/ME in YP. If we are to understand the lives of YP living with contested conditions, I argue, we must think more carefully about YP's narratives than is the case in much previous research; understanding their talk beyond a representation of "experience", but significantly constrained by competing socio-cultural pressures on what it is possible to say.

There are many aspects to this. Within the space constraints here, it becomes necessary to narrow the focus of discussion, concentrating on a limited number of these narrative tensions, while acknowledging that other areas remain relatively unexplored (some of which are flagged up shortly as avenues for future research). Here, I draw on broader literature – from diverse fields including medical sociology, disability studies, social studies of childhood, as well as existing research in CFS/ME and other contested illness – to explore three inter-related tensions that appear particularly salient as these YP attempt to account for their lives; all of which are woven through with a common thread of addressing what it means to be accepted as a "normal" or valued teenager:

1. Constructing a full, credible and convincing account of the serious nature of CFS/ME and its impact, while resisting stigmatised identities as a "complainer" or hypochondriac
2. Relatedly, but more specifically, conveying the extent of social and emotional difficulties - including those arising from disbelief and discreditation - while resisting constructions of difficulties as un-believable (in-credible), and stigmatised teenage identities as psychologically vulnerable or socially rejected
3. Conveying motivation and agency in wanting and trying to be healthy and "normal" - "a striver not a slacker" - while resisting constructions that position sufferers as responsible for becoming ill or failing to get better, or of CFS/ME as trivial or "psychological". And relatedly, meeting an expectation to provide narratives of heroism and success, while maintaining a position of ongoing struggle and need for understanding, to "take care".

6.2 Telling Their Story: 3 Tensions for YP living with CFS/ME

6.2.1. The problem with problem-talk: Credible complaints and credible complainers

The first tension explored is how YP can construct a full, credible and convincing account of the serious nature of CFS/ME and its impact, while resisting stigmatised identities as a “complainer” or hypochondriac.

Like others, this challenge applies in everyday life and in the interview itself. In order to negotiate their social worlds - be recognised and “understood”, and elicit the support and care they need - individuals must find ways of articulating and accounting for their situation, to family, peers, teachers, health professionals, and sometimes researchers. While some of this is common to all those living with chronic illness, particular difficulties arise for those without a clearly-understood and medically-legitimised condition. Existing research shows that adults living with CFS/ME report great difficulty in conveying the serious nature and impact of their symptoms (eg, Arroll & Senior, 2008; Dickson et al., 2007; Edwards et al., 2007), even with professionals (Cooper, 1997). It is argued that the largely invisible nature of symptoms in CFS/ME and the relative absence of words to describe them may contribute to communicative problems (Hart & Grace, 2000), particularly since language superficially appears to describe relatively common feelings, leading to a trivialisation of experience (“we’re all tired”)(Ware, 1992). Additionally, the sheer number of symptoms considered (but not always widely understood) under the diagnostic criteria for CFS/ME raises questions: how many of these, if experienced, should be detailed in different situations? Will they be understood as indicative of serious illness anyway?

Some of these challenges may be understood within the much broader interactional issue of problem-talk or “troubles-talk” (Buttny, 2004), where one is complaining about a situation (Edwards, 2005). Problem-talk is a regular feature of everyday social interaction, whether on relatively mundane matters or more serious ones, and Bruner (1990) notes that problems tend to drive story-telling. However, problem-talk entails delicate work, including “gauging” (Goffman, 1967) and modifying one’s position depending on the audience, since talk constructs not only the nature of a problem, but the identities of the

speaker and others. On the one hand, problems are potentially significant matters that must be formulated and communicated carefully if they are to be taken seriously. On the other, if they appear as constructed *too* seriously, then speakers may appear not only as “abnormal” (discussed further below), but as over-reacting, self-absorbed or over-sensitive (Edwards, 2005; Korobov & Thorne, 2007).

The social consequences of such identification are significant. Being considered a “whinger” is stigmatising in itself, but also carries the risk that further complaints may – like the boy who cried wolf – be dismissed by listeners as not serious, “just moaning” (Edwards, 2005). Edwards suggests that people making complaints attend to such interactional concerns in two related ways: first, by working to build the “objectivity” of the case (eg, stating its evidential basis and highlighting corroborating information); and secondly, by attending directly to possible (accusations of) subjectivity (eg, the speaker’s disposition to moan). As argued previously, such concerns appear particularly salient for those speaking of contested conditions (Werner, Isaksen & Malterud, 2004) because powerful discursive contexts mean that the nature of the problems and the disposition of speakers may already be in question, increasing the chance of a discrediting negative hearing or challenge from listeners. Others have explored how adults living with a diagnosis of CFS/ME have discursively managed such concerns in different settings (eg, Bülow, 2008; Guise et al., 2010; Guise et al., 2007; Horton-Salway, 2007; Tucker, 2004), but the present study shows how YP also appear sensitive and responsive to such interactional concerns.

One early observation of these YP’s narratives was that their depictions of illness included reference to physical – not psychological – symptoms such as pain, dizziness and (later) fatigue, but that these were relatively brief, not the “rich descriptions” reported in adult studies (eg, Arroll & Senior, 2008; Edwards et al., 2007; Söderlund et al., 2000). The difficulty of verbalising CFS/ME symptoms has already been noted by others (Hart & Grace, 2000), and it would be easy to conclude that younger people with less developed language skills might be further hampered in this respect. However, the discursively-focused narrative analysis within the present study, allowing further attention not only to what was (and was *not*) said – but also *how* and *when* – indicated a more complex situation.

For example, when prompted further, and later in the course of interviews, most of the YP produced more detailed, complex and personal accounts, suggesting that the earlier relative lack of “problem-talk” may be better understood in terms of the contextual, interactional concerns of speakers. In the early stage of interviews, YP have little way of “gauging” (Goffman, 1967) how I, an unknown woman – older, not obviously ill, perhaps associated in their minds with worlds of teachers or doctors - might receive their communications. The relatively brief descriptors of physical symptoms are in keeping with the familiar discursive terrain of an initial meeting with a doctor. It is only after some relationship has become established (eg, they can see from my questions and responses, verbal and non-verbal, that I am still interested, encouraging and not challenging their accounts) that narratives can develop further.

These YP’s narratives then demonstrate some of the discursive patterns previously noted in adults (but not CYP) in constructing the serious but enigmatic nature of CFS/ME, while simultaneously working to construct the objectivity of the account and manage subjective positionings (Guise et al., 2007). For example, in reporting symptoms, participants (particularly older ones, and early in interviews) use listing devices, medical terminology or terms cited in literature from CFS/ME support groups, and movement between personal (“I”) and impersonal (2nd person plural “you”) pronouns. Spoken with little expressed emotion, these allow listeners to infer a picture of an extensive range of physical problems that similarly affect many other people diagnosed with CFS/ME, with symptoms being “obvious”, legitimate and medically knowable in this context, rather than being an idiosyncratic or personal problem. The lack of expressed emotion at this stage reinforces construction of an impression that they are presenting facts, but not “complaining”. Further, YP’s comments that they “can’t remember everything” then suggest that symptoms could go beyond even what is told, but without the need for more detailed accounts that could be seen as “making too much of things” (Edwards, 2005) - always a social concern but particularly pertinent for talk about a contested condition that has been notably dismissed as “hypochondria” (Ware, 1992).

Rather than dwelling on personal suffering, narratives at this stage focus more on what the symptoms prevented the YP from *doing*, contrasting mundane activities such as walking or reading with the assessment of difficulty in completing these, and highlighting the

unpredictable fluctuations in impact. As in previous analyses with adults (Guise et al., 2007), this reinforces constructions of CFS/ME as “*weird*” and fundamentally different from trivial “normal tiredness”. It also deflects the potential charge that symptoms were the consequence of *excessive* activity or targets set by high achievers, managing issues of accountability for illness – again, reported previously in adults (Guise et al., 2007; Horton-Salway, 2001), but not explored before in CYP.

However, challenges remain for CYP. Discursive approaches such as impersonal listing of common symptoms or using medical discourse appeared to sit uneasily with the younger participants in particular, the adult language - punctuated by hesitations, re-starts and difficulties with pronunciation - out-of-key with other aspects of their talk. Further, such devices draw their power from the positioning of the speaker as expert in this realm - a discursive position that is understood as requiring delicate negotiation even for adults (Martin, 2014), and arguably harder still for young people to pull off.

Similar considerations of power relationships and claims to authority appear pertinent in discursive strategies that *are* available to YP to legitimise their claims of hard-to-establish symptoms and need for special care. As noted in previous research (Bülow, 2008; Cooper, 1997; Guise et al., 2007), even adults living with contested symptoms back their claims to have legitimate concerns by citing corroboration from others. For YP, challenged not only by peers but also doctors, teachers and others, it is perhaps unsurprising that they draw particularly on membership categories (Sacks, 1992; Potter, 1996) of those with recognised hierarchical authority - adults - for this. These include institutional categorisations such as “*the school office [who] sent me home*” or the specialist doctor (rather than initial GP) who recognised symptoms; but most frequently drawing on the taken-for-granted authority of their mothers, who “*know me... know I wouldn’t lie about something like that*”.

And unlike adults, the YP who visit doctors, or who do not attend usual activities, are understood to do so under the authority of their parents (a construction reinforced by the frequent use of “*we*” in stories of seeking diagnosis or making decisions about education). Thus comes the strong implication from all the young people in this group, that the most important adult - mum - recognises and legitimises the seriousness of the complaint. This

further allows the YP to be understood as suffering, but without the need to complain (or moan), allowing for face-saving and even heroic presentations of identity.

The position of YP compared with adults may also be relevant to understanding the relative lack of direct “attributional stories”: that is, stories that account for *how* and *why* they became ill. Previous research has demonstrated that adult illness narratives commonly attribute the illness to particular circumstances (eg, catching a virus at a swimming-pool), which construct illness in particular ways (eg, as physical rather than psychological) and also manage positions of accountability (eg, Horton-Salway, 2001b; Tucker, 2004). Such attributional stories are arguably problematic even for adults in the context of a contested illness; the position of YP - traditionally discouraged from positions of “expertise” - potentially adds another layer to the tricky manoeuvre. Instead, indirect references in YPs’ stories make relevant, but do not explicitly attribute illness to, factors like viruses, bad weather or head injury. The current analysis suggests that for YP, this may be an effective way to construct preferred positions of physical, unprovoked illness within narratives, while mitigating the chance of direct challenge that could result from more strongly-claimed presentations. However, while these approaches can be seen as constructing the “facts” of CFS/ME in a particular way, gaps and hesitations may leave listeners unclear about the nature and impact of illness, still far from imagining - and empathising with - YP’s worlds and positions. This is an area not previously researched, and which would benefit from further attention.

It can be seen that the contested nature of CFS/ME creates challenges for sufferers in conveying the serious, non-trivial nature of their condition, while resisting stigmatised identities as “whingers”. Though not a focus of the present study, it is interesting to note that there was particularly little “complaint” from the three boys. Gendered discourses may be relevant here, both in the higher proportion of women diagnosed with CFS/ME, and discourses about whether females or males are considered more likely (or permitted) to “complain” about symptoms to different audiences (eg, Seymour-Smith, Wetherell & Phoenix, 2002; Werner et al., 2004), and the intersection of gendered identities and disability in the transition to adulthood (Gibson, Mistry, Smith et al., 2014). The small sample here - and the presence of a female interviewer, and also the conflation of age and

gender, given that two of the three boys were among the youngest interviewed - clearly limits any conclusions, but this would be an interesting area for future research.

It may also be queried whether YP are particularly at risk of being challenged in this way. Popular cultural narratives of “whining, unappreciative, lazy teens”, prevalent on online forums and in self-help parenting literature, constructs this both as a “normal stage” of adolescence and an aspect of behaviour and identity to be challenged (eg, <http://www.radicalparenting.com/2011/07/28/whining-unappreciative-lazy-teens/>).

Complaint about health, or a focus on one’s limitations and abnormality, appears particularly stigmatised for YP (Ferguson & Walker, 2014; Taylor et al., 2008) - a discourse taken up directly by one participant in the present research, as she accounts for *not* talking about her symptoms to peers, for fear that she will “*bore people*” and sound like “*an old person*”. As she notes herself, though, her reluctance to talk means that they do not understand so cannot support her - and may even see her as *more “weird”*, seeing her non-participation in normal life without clear explanation.

Particular challenges for YP in *how* to achieve the delicate balance between expressing their difficulties (and need for support), while avoiding being characterised as either “weird” or “whinging”, remains an important area for further research. However, this analysis shows that YP have good reasons to be cautious about “complaining” about their symptoms. Consequently, those who live alongside them (peers, teachers, health professionals) should be aware that the lack of a clear picture may arise from complex, competing pressures on YP; and an absence of clear description of symptoms or other problems should not be confused with an absence of legitimate cause for complaint.

6.2.2. Social discreditation and social credibility

Depiction of symptoms and their direct impact on activity is clearly important, but forms only part of the story. Social and emotional difficulties arising as a consequence of CFS/ME form an important narrative thread, albeit in different ways and to different extents for each YP. Some of these are touched on in previous studies of YP living with CFS/ME (eg,

Fisher & Crawley, 2013; Winger et al., 2014), but drawn out more fully here. However, this study's consideration of the construction and *performance* of such narrative over time suggests tensions for YP in conveying the extent of social and emotional difficulties - including those arising from disbelief and discreditation - while resisting constructions of difficulties as un-believable or in-credible; or stigmatised teenage identities as psychologically vulnerable or socially rejected.

For example, it is notable that, in the earliest stages of their conversations with me, almost all these YP construct narratives of happy and unremarkable childhoods prior to illness, of social activity and time spent with friends, and no hint of psychological difficulties. Only *after* the physical nature of CFS/ME has been established and acknowledged by me, their audience, do they speak of troubling social difficulties - initially depicted entirely as a consequence of illness. There are parallels here with the brief observation of Hareide, Finset & Wyller (2011) from their study of "illness beliefs" in YP living with CFS/ME, who noted that while all YP initially proposed purely somatic models of understanding, the minority who volunteered psychosocial factors did so only later in the interview, "at a point in the conversation when their somatic understanding had been validated by the interviewer". Such observations about timing are rarely discussed in the literature on contested illness in YP, but can again be understood as part of a YP's need to establish the parameters of the narrative first, "gauging" their audience response (Goffman, 1967). The strengthening of this observation within the present study has clear implications for researchers, professionals and others talking to YP living with contested conditions, and will be discussed further shortly.

The structuring of narratives in the present study therefore works *from the outset* to establish these YP as having valued social identities, "not the sort of person" who one might expect to have problems. This simultaneously works against constructions of CFS/ME as "really" a psychosocial problem (ie, depression, anxiety or school avoidance). The ubiquity of this - introduced by YP early, without my prompt, enhanced with details of particular peers or events and even with direct statement ("*I have really good friends"; "I always have friends to see") - gives an early indication of the importance of this aspect of the narrative construction of self.*

As narratives continue, though, they draw out stories of psychosocial pain. These are most marked in the girls, but even the boys set out stories of loss as illness restricts social contact. At their most basic, they relate directly to the limitations imposed by symptoms: feeling “*different*” in being unable to do what would usually be expected of a teenager; physically “*weak*” (particularly for the boys), or “*stupid*” as a consequence of cognitive symptoms and reactions from peers. In all but the youngest, there come increasingly detailed stories reflecting themes heard in other qualitative studies (particularly Winger et al., 2014) of being left behind while peers get on with their lives: of the boredom and isolation of being “shut in” to the home during the worst of illness, but then “shut out” as they attempt to retain or later regain social and educational lives, prevented from doing so by the reluctance of peers and teachers to accommodate their part-time involvement and increased needs; sometimes physically present, but still isolated on the social margins.

A focus on the construction and interpersonal context of such narratives adds a further dimension. Often spoken more quietly, with less eye contact and sometimes visible signs of distress, there is a sense that these are particularly troubling stories to tell. Notably, all these YP initially accompany stories of failing friendships by rationalising peers’ actions, drawing on cultural discourses of normal teenage behaviour: peers naturally being too “*busy*” to have time to visit or wait for a YP who cannot *do* the usual things like sport or shopping; the natural formation of friendship groups at particular periods (eg, the start of secondary school), creating difficulties for any YP absent at these critical times; “not understanding” simply because illness is so remote from their own experience, or perhaps attributable to “normal” teenage immaturity or self-centredness. These “rationalisations” can be understood (as previously) as mitigating against charges of undue complaining, presenting narrators as thoughtful and reasonable. Further though, the positioning of peer rejection as *understandable* within developmental contexts deflects questions about whether peers might have other reasons for not wanting to be friends with the narrator - for example, that they are not popular, interesting, fun enough, or simply too *different* - an altogether more stigmatising position, particularly for YP, to be considered shortly.

However, the most distressing accounts come in stories - told by most of the girls but, interestingly, not the boys - of being disbelieved, challenged, discredited, sometimes directly accused of “*faking*”, “*lying*”, being a “*skiver*”. Similar behaviour (labelled as

bullying) is reported by half the YP in Fisher and Crawley's (2013) study. However, the extended narrative focus of this study shows that, even here, there are some attempts to "explain" others' attacks, drawing again on cultural narratives of adolescence ("*teenagers are horrible anyway*") and the pervasive misrepresentation of CFS/ME within popular media, understandably driving people's scepticism.

Other cultural narratives of youth, "age-appropriate behaviour" and hierarchy infuse stories of discrediting encounters with adults (eg, teachers). While the adults are often actively voiced ("*why do you need a break?*"; "*Do it yourself!*"), the YP are positioned passively, rarely heard attempting to argue back. Mainly it appears taken-for-granted that this would be unacceptable, but one YP spells it out for me: "*they're my teacher I can't really say 'you've got it all wrong'*". Here there is indication of particular challenges for older teenagers: increasingly expected to show more autonomy in managing their illness and social encounters with teachers and others, yet simultaneously constrained by social expectations limiting how much they can legitimately challenge adult authority figures. Even in stories of peer challenge, though, these girls are positioned clearly as the *victims* of such discreditation and marginalisation, unable to fight back. Their pain is easy to infer even when not stated directly.

To hear that at least some YP diagnosed with CFS/ME report social difficulties and even social rejection is distressing but perhaps not expected, given previous research outlined above (eg, Fisher & Crawley, 2013; Winger et al, 2014). However, the present research focus on *how* and *when* YP construct such narratives is important, because the action of *telling* such stories (to researchers or others) can itself have social consequences for YP – something that is generally overlooked in other CFS/ME research. Stories of discreditation and rejection in social encounters have the potential to cut deep into the construction of valued social identities (Gilbert, 1997). They clearly must be told if audiences are to understand what it is like to live under such conditions, yet they run risks: that listeners may interpret such discreditation (particularly from those who know these YP well or are in positions of authority) as evidence that the YP are simply *not* credible, that their stories of illness *do not make sense*.

More broadly, stories of social rejection are stigmatising (Goffman, 1963), indicating that peers have judged the YP as deviant (Teräsahjo & Salmivalli, 2003). In the context of a contested illness, where there are already questions about the psychosocial status of sufferers - even whether this is the cause rather than the consequence of complaints - this takes on an added dimension. Further, once positioned as “weird”, others within a social group tend not to want to commit the “social suicide” of associating with those at the bottom of the social hierarchy (Hamarus & Kaikkonen, 2008; Kless, 1992). By telling of such rejection, then, speakers risk further psychosocial injury, as listeners may judge them harshly and join the chorus of rejection –something argued to contribute to the culture of secrecy around YP who are bullied in school (Thornberg, 2011). Thus it would not be surprising, perhaps, if YP diagnosed with CFS/ME - aware of this social risk - were hesitant to speak of social difficulties in all circumstances, or might gloss over their significance. Or alternatively, that YP living with CFS/ME who *do* speak more openly about their difficulties find themselves paradoxically reinforcing cultural stereotypes about “the sort of (psychosocially vulnerable) person” who complains of medically-unexplained symptoms.

Given the opportunity to engage in longer conversation, though, it can be seen that YP orient to and manage such risks in a variety of ways. As noted, early narratives work to construct the pre-ill self as socially “normal”, successful and valued, and this is in line with wider observation of YP (Martino & Palotta-Chiarolli, 2005), including those living with chronic illness (Taylor et al., 2008; Williams, 2000a). And later, even stories of worrying social rejection are intertwined with reference to love and acceptance from others - family members and those who know them the best, their “*real friends*”. The opportunity for detailed story-telling also allows YP to do some status management of their own. For example, the adult teachers or doctors who perhaps could not be directly challenged can at least be more subtly discredited through parody in the narration, with active voicing (Wooffitt, 1992) and mimicry of “stupid” or pompous presentations. And finally, the longitudinal aspect of this project allows more opportunity for at least some YP to narrate moving into different social settings, in which new educators and “*better*”, “*more mature*” peers are storied as showing acceptance of the YP, even with the limitations and difference still imposed by residual symptoms and need to “take care”. Again, this contrast with the behaviour of other individuals serves to position earlier rejection as a consequence of the

ignorance and failings of younger peers, rather than the inherent qualities or social non-acceptability of the narrators themselves.

Overall, this analysis indicates the importance for these YP of being seen as psychosocially “normal” and acceptable, and the challenges this presents for them in narrating important social aspects of living with CFS/ME. However, it also highlights – in a way not demonstrated by previous research with this group – ways in which some teenagers are able to take up such challenges, addressing them discursively with skill and sophistication if they are given the opportunities of time and an attentive listener.

Yet many questions remain. As before, gender appears relevant, in that the three boys narrate much less social difficulty than the girls. It is possible (and impossible to know from this study) that they simply experienced less social challenge than the girls; peer-group relations are often observed to be different in girls compared with boys (Nayak & Kehily, 2013). Equally, though, gendered discourses about the nature and importance of social acceptance, and more general acceptability of “problem-talk” regarding relationships, are likely to have a bearing on what is narrated in different contexts (Frosh, Phoenix & Pattman, 2002). And again, the age of narrators - from those still early in their teens, to those soon to be considered adults – may be relevant both in their peer relationships (eg, with more “mature” peers) and their constructions of this, speaking to an adult (female) interviewer.

All these are areas worthy of further research. Even with such questions remaining though, this analysis is relevant for those studying, living and working with YP diagnosed with CFS/ME, leading us to consider: What impact might the desire for socially acceptable identities have on YP as they go about their lives? What might it lead them to hide / not tell to others? What aspects of their stories may be missing? And how might this limit the understanding and support available to them from families, peers, teachers and the other professionals tasked with considering not only their physical health, but also their psychosocial wellbeing and mental health?

6.2.3. A striver not a skiver

People living with chronic illness frequently stress the difficulty of not being able to *do* activities expected in daily life, such as work or even basic self-care. It is argued that this is a profound source of suffering, particularly within societies focused on autonomy and productivity (Hay, 2010; Kleinman, Das & Lock, 1997). Beyond the loss of productivity, suffering arises from complex inter-relating notions of personal agency and moral accountability. Where agency is understood as “the intentional and motivated capacity to act” (Hay, 2010), suffering can arise for those ill or dis-abled when their *intentions* and *motivations*, as well as their capacity, are called into question (Kleinman et al., 1997; Patrick, 2011)²⁷.

This is brought into sharp focus in discourse about those claiming disability, those deemed (un-)deserving of support, and the moral compass of those who fail to meet societal expectations. Political rhetoric, taken up in media and public debate, questions these individuals: it is implied that those who are not working, not productive, may be taking more from society than is warranted, cheating their fellow (“hard-working”, “tax-paying”) citizens, making a “lifestyle choice” of dependency on state welfare (Osborne, 2010), “sitting on their sofas waiting for the benefits to arrive” (Cameron, 2010). Thus has evolved binary discourses of workers and shirkers, strivers and skivers (Cooper, Gormally & Hughes, 2015; Toynbee & Walker, 2015; Williams, 2013) that arguably contribute to the cultural shaming of people who live with chronic illness (Caron, 2008).

Hay (2010) argues that people who seem to manage their illness with a minimum of disruption to their productivity, “working through” and not “allowing” it to control them, are hailed as cultural heroes. She observes that adults living with autoimmune disease construct narratives that orient to such discourses, informed by a “John Wayne Model”: “a purposeful indexing of the image of disease as something to be wrestled into submission”

²⁷ Clearly the concept of “agency” is open to critique. Often assumed to be a positive, personal competence, it is better understood as a more complex, multidimensional concept (Valentine, 2011), bounded by intergenerational relations (of particular relevance for CYP), as well as wider socioeconomic contexts and bodily, social and material resources (Tisdall & Punch, 2012). Nevertheless, the more “individual-focused” concepts of agency and personal autonomy remain culturally powerful.

(2010:260). However, while some adults position themselves within such a model, others - unable to live by it - are forced to construct a position of suffering. Hay argues that while those who articulate this “suffering response” while visibly ill may evoke pity, those with invisible illness are more likely to be labelled as “lazy” – a position argued to be particularly salient for those living with a contested condition (Hareide et al., 2011; Ware, 1992). Additionally, gender, generation and economic concerns are likely to shape such narratives and their reception.

This is not an area that has been explored well with young people. However, a recurring theme is that YP living with chronic illness speak repeatedly of wanting to appear “normal”; and while there are variations (some of which appear gender-related), many report downplaying or even hiding their illness and treatment regimens where possible if these conflict with valued social identities (Taylor et al., 2008; Williams, 2000a). Thus the “John Wayne Model” may have currency for YP too.

Interestingly, while previous adult studies have highlighted the “struggle” in some aspects of the CFS/ME journey (eg, a “struggle for authorship” (Horton-Salway, 1998), “struggle for legitimisation” (Cohn, 1999), and “struggling self seeking renewal” (Travers & Lawler, 2008)), much less has been written about personal struggles to *manage* symptoms – to “wrestle them into submission” in Hay’s (2010) terms - and this is almost entirely absent in the small qualitative literature on YP living with CFS/ME (Fisher & Crawley, 2013; Jelbert et al., 2010; Winger et al., 2014). Even YP judged “recovered” appear only to have spoken about the external factors that had been helpful (eg, supportive relationships), and not *their own* role - or agency - in struggles to manage their health.

In contrast, YP’s narratives within the current study can be seen to highlight not just the physical and psychosocial assaults brought about by CFS/ME, but also – crucially - the *work* that is required of them: first to (try to) resist it, and later to try to manage it; even (for some) to contain it sufficiently to “move on” with their lives. However, this analysis also points to narrative tensions for these YP: to convey motivation and agency in wanting and trying to be healthy and “normal” - “a striver not a skiver” - while simultaneously resisting constructions that position sufferers as responsible for becoming ill, or for failure to get better; or of CFS/ME as trivial or “psychological”, something that could be overcome if only

the YP tried hard enough. Relatedly, there appears a tension for YP in meeting expectations to provide narratives of heroism and success, while maintaining a position of ongoing struggle, need for understanding, to “take care”.

Discourses of “workers and shirkers” are drawn on and resisted repeatedly - a position not highlighted in previous studies of YP living with other chronic illness (Taylor et al., 2008). Sometimes this is referenced explicitly: in stories of being unfairly accused of “skiving”; in self-positioning (“I’ve always worked hard”); or through items brought (eg, Callum’s “*inspirational*” book about a mountaineer’s heroic struggle). Beyond this, almost all these narratives construct these YP as people who are not *inclined* to be ill and do not *want* it: either through depictions of their previously active and happy lifestyles, or actively resisting acceptance of the illness and “illness identity” (eg, “I don’t want people to treat me differently...it’s not normal”; “I just want to do stuff”). This is apparent in narratives of the earliest period of illness (“I just kept going”; “I would ignore it”), and later in multiple stories of the “hard work” of trying to minimise its impact: in trying to meet normal expectations (eg, persisting in trying to go to school, even when this exacerbates symptoms or brings social distress); trying to follow advice from health professionals, even when this appears ineffective; and trying to pick themselves up after set-backs or flare-ups of symptoms, again and again and again. All these resist stereotypes of people who simply give in to illness too easily, “skive” or “shirk” their responsibilities, or make a “lifestyle choice” in embracing disability.

It is perhaps surprising to discern such clear discourse of agency and productivity within narratives of young people. After all, within this culture they are not expected to be economically productive, and unlikely to be claiming welfare benefits - so not the obvious target of political rhetoric. However, the culture of targets, goals, productivity and achievement surrounds children and young people from an early age, within the education system and more broadly as YP are constructed as “adults-to-be”, to be prepared for the workplace and other challenges of adult life (Graham, 2004). Additionally, older teenagers in this study make clear their awareness of how CFS/ME sufferers are portrayed as “lazy” within the media - with some very explicit positioning of the self as different.

However, there are challenges here, not least in constructing the “work” in ways that will be recognised. Work is often recognised only by its productive outcomes, but the usual markers of teenage achievement (eg, school attendance, sporting or exam performance, increasing independence) are compromised by CFS/ME. (It was notable how YP in this study spoke with pride during their second interviews if they were able to tell me of culturally-valued achievements such as public exam results; and also how those unable to do so (eg, because of disrupted education) would point out their pre-illness achievements (eg, “*top-set*” status), and what might have been achieved were it not for the barriers of illness.) The relevance of such developmental markers for young people’s identities should not be under-estimated.

YP who wish to maintain culturally-acceptable positions as working and successful must therefore reframe both concepts. Unlike previous research, narratives in the present study highlight how the focus of effort shifts from pre-illness targets onto the day-to-day struggles to manage symptoms. Sometimes the work itself needs reframing (eg, “*I’m making myself get better because I’m letting my body rest and do what it wants to do at its own pace*”), as do the markers of progress (eg, to wash one’s own hair, or “*to go to Tesco or something*”). However, these appear easily contested: this analysis indicates that tensions arise for YP speaking about symptom management, relating to the contested nature of treatment guidelines, and in turn contextualised by arguments about the nature and aetiology of CFS/ME.

There are now many guidelines and resources for those living with CFS/ME that aim to promote symptom management, functioning and general wellbeing (eg, NICE (2007); BACME, 2015; Pemberton & Berry, 2013; Rimes & Chalder, 2015). Though widely used, they are nevertheless often reported by patients to be confusing and have been publicly contested (Holgate et al., 2011; ME Association, 2015). Such reports highlight how dispute about treatment links to dispute about the “biological vs psychological” aetiology of CFS/ME, and whether recommendations for particular non-medical interventions – such as increased activity or CBT - reflect an implicit denial of serious underlying physiological disease. As noted previously, there are no medicines or procedures that are the undisputed responsibility of the health professional. Instead, guidelines (eg, National Institute for Health and Clinical Excellence, 2007) stress partnership and “shared decision-making”

between health professionals and YP and their families, in attempts to improve capacity and the impact of symptoms. The currently-recommended approaches (eg, activity management, CBT, GET) rely on close collaboration and considerable effort from the YP, but families of YP living with medically-unexplained symptoms express ambivalence and dissatisfaction with current healthcare provision (Hinton & Kirk, 2016).

Such themes can be heard in the narratives of the YP in this study. All talked of referrals to different professionals, and all expressed concerns with the process. Like others before them, these YP expressed particular reservations about the rationale for being referred to Child & Adolescent Mental Health Services (CAMHS) or for CBT (*"I'm not like(.) mentally unstable"*), even when these were later narrated as positive encounters (*"to be fair I didn't really need it"*). Equally, while the YP expressed less resistance to working with physiotherapists on graded activity or other recommended programmes, there nevertheless appeared confusion and a lack of clear rationale for such referrals (*"there's nothing else really that they can suggest"*).

This research goes beyond previous similar reports of dissatisfaction and confusion, by exploring a dilemma that appears for these YP: to demonstrate a wish to getting well and work to achieve this (and hence a culturally-valued identity as a *worker not a shirker*), when engagement in professionally-recommended programmes could be seen as endorsing equally stigmatising constructions of CFS/ME (eg, as psychological or not serious) and those who are diagnosed with it (eg, as psychologically-disturbed or lazy).

YP in this study demonstrated a range of discursive devices that worked to question the judgement of professionals and others suggesting non-preferred approaches. As seen previously in adults (eg, Horton-Salway, 2004), these YP were able to make claims to legitimate decisions on the basis of personal experience of their own condition, and of having worked hard in *trying* to engage with and evaluate a range of approaches, some of which could then be dismissed as *"useless"*. Equally, some YP were able to provide legitimation for engagement in professionally-recommended programmes while mitigating potential stigma at possible associations: for example, the sporty young man noting that his GET was run by a rugby-playing male physiotherapist; reports of CBT emphasising targets and behavioural achievements rather than emotional difficulties, or positioning

engagement as something that his father thought “*couldn’t hurt*” even though he “*didn’t really need it*”. It may be significant that this YP, who narrated most success after a CBT / activity-based programme, was able to frame his referral to a psychologist as something that his paediatrician “*always recommended*” to all his patients, with a clearer rationale of support as part of a multi-disciplinary programme including medication for some infections. While care is required in reading too much into one narrative construction, this may carry a significant implication to physicians in “*setting up*” referrals in a way that does not imply stigmatising and dismissive constructions of CFS/ME or their patients – an implication that is considered again in chapter 7.

Furthermore, the work within such programmes is difficult and not always clear at a “*micro*” level. Sufferers have to learn to distinguish between (and avoid) both too much and too little exertion; and though the overall plan may be agreed with professionals, there are countless judgements to be made on a daily basis. Is accepting a peer’s request to meet for a coffee a step towards increasing activity and beneficial psychosocial care, or reckless over-exertion and poor prioritising of demands? And refusing to do more homework: a sensible precaution in light of self-monitored symptoms and a planned programme of care, or laziness and “*secondary gain*”?

While younger children may rely on the judgement of their parents, older teenagers are increasingly called on to be responsible for their own decisions. Despite the move towards self-management interventions for YP living with chronic illness, it is notable (Sattoe, Bal, Roelofs et al., 2015) that these often neglect psychosocial challenges for young people; and the YP in this study highlighted these. Beyond the inevitable doubt and uncertainty raised by day-to-day decisions and the climate of contestation (Bülow, 2008) that questions even adult sufferers, these YP note their lack of power in an adult world and a heightened struggle for agency as their actions – their attempts at *work* to manage their condition - are questioned by adults (eg, teachers) in positions of authority. As previously, some are able to draw discursively on the voices of supportive health professionals (eg, the “*brutal*” specialist CFS nurse narrated as quashing a disbelieving teacher’s call for more homework); but not all YP have access to such specialist resources, and this again has implications for the professional management of YP diagnosed with CFS/ME.

And demonstration of striving and working towards self-management or “to get better” brings other dilemmas, relating at least partly to the contested status of CFS/ME. While “setbacks” and symptom fluctuations are considered a feature of the condition, there is ongoing debate about the extent to which it can be overcome altogether (Mackenzie & Wray, 2013). So will a failure to get better then be seen as the responsibility - and failure - of that YP? Conversely, if the YP is able to demonstrate striving and success in managing their condition with, say, CBT or GET, does this mean that there never really was a serious illness - that there could have been more “mind over matter” or more mastery at an earlier stage?

And yet there is indication of a societal desire for stories of success and mastery, even in very young (18-22 year-old) adults (Thorne & McLean, 2003). This may be understood as listeners’ disinclination to being unduly emotionally-burdened, but also in line with broader cultural expectations (Polanyi, 1989). Within Frank’s (1993; 1995) typology of illness narratives, listeners are considered to be most comfortable with restitution narratives, in which there is a clear movement towards restored health; but in cases where this is not possible (chronic illness), he suggests, some chronology of chaos and quest narratives may be called for. Chaos narratives, characterised by the narrator’s physical and emotional suffering in the face of unrelenting or unpredictable illness, are emotionally hard to hear. Quest narratives - in which illness is depicted as accepted (inevitable) but also the precipitant of self-learning, bringing some meaning and value to the suffering endured - are in keeping with Western expectations of self-development and arguably less burdening to listeners (Korobov & Thorne, 2007). There may therefore be inherent expectations to “rhetorically deploy” such narratives over time (Frank, 1993). However, it is also suggested that such narratives may elicit resistance in listeners if they appear too quickly, because of our need “to believe in a restitution that the teller has had to work to give up” (Frank, 1998:205), or even a battle through the chaos of illness.

While such trajectories have been noted in narratives of adults living with CFS/ME (Travers & Lawler, 2008; Whitehead, 2006a; Whitehead, 2006b), this is the first study to consider this for YP living with the condition. Though not the main focus of the present study, I argue that even quite young teenagers appear to draw on such narrative frames, and that this may have consequences for how other people respond to them. For example, the lack of

“work” as part of any restitution narrative appears relevant for the potential of Grace’s narrative to draw empathy; and her quest narrative (*“it’s changed my life for the better”*) is easier to accept in her second interview, in which she is able to demonstrate clearer success in at least some aspects of her life. Yet narratives of heroic struggle, success and self-development raise difficulties for those living with ongoing illness, particularly YP facing rapidly-changing environments and expectations. If absent, the YP risks being stigmatised; but if too strong, too successful, risks that listeners will not recognise the ongoing struggle required, the continuing need to “take care” and to be cared for.

And, once again, there is a need to consider gender in how YP engage with – and how listeners “hear” – different narrative types. Recent study (Ahlsen, Bondevik, Mengshoel et al., 2014) of adult men and women narrating life with chronic pain suggests that cultural expectations of masculinity and femininity play a significant role in how men and women construct their stories (eg, with more tendency to construct “quest” narratives in women, and more emphasis on “restitution” narratives in men) – and that health professionals need to be aware of this in understanding their patients’ communications. Further exploration of such gendering in younger people is clearly warranted.

Longer stretches of engagement with an appreciative audience, and the longitudinal nature of the present study in which YP could give extended narratives over time, allows discursive management of some of these dilemmas. Most obviously, there is opportunity for the “small steps” storyline. Here, very small achievements can be recognised as demonstrating persistence and success - the “hard work” needed to achieve what would ordinarily be taken-for-granted and overlooked - while highlighting that the eventual appearance of some apparent normality is not, and may never be, “normal”, but requiring enormous strength of character. Repeated stories of setbacks also remind listeners that progress is never to be taken for granted; this is an unpredictable condition, there is still a challenging road ahead, and future illness should not be understood as a failure of motivation or agency. Thus these YP can take their place aligned with the “workers, not shirkers”, even if their achievements are not recognised by everyone.

However, it must be remembered that everyday life does not always bring such narrative opportunities. Medical appointments tend to be very brief, and there is limited scope for

busy teachers to have extended conversations with pupils about their difficulties. People encountered now will not have seen the past effort required to get to this point; and societal pressures to present narratives of progress and success may obscure ongoing need for support. Once again there are indications that cultural imperatives for YP to maintain acceptable identities - not only striving but at least partly successful in “wrestling illness into submission” (Hay, 2010) or finding meaning through their quest - may silence other aspects of their narratives. This in turn perpetuates the continuing failure of people encountered in everyday life (in social situations, in medical settings, in education and later in the workplace) - and perhaps also researchers who focus only on the content of questionnaires or brief, focused interviews - to recognise the extent of their ongoing struggles, and difficulties that will not easily be overcome.

6.3 Telling my story: Tensions in the research process

Within this project, I set out to explore the construction of a contested condition, by the YP living with it and by wider professional and cultural narratives. I have attempted to do this within a reflexive framework, drawing attention also to the constructed nature of the research itself. I now wish to extend this, considering not only the traditional “strengths and weakness” of the research, but also tensions in research decisions made, some forces shaping this, and potential implications. As part of the power relations shaping the research, I return to considering my own role as researcher, and the impact of the multiple subjectivities I bring. These include positions as an adult, a woman, and a mother; as White, British, educated and not obviously ill; as a novice qualitative researcher and Doctoral student; and - a particular focus now - as a clinical psychologist. This can be seen to influence every aspect of the research, including decisions about its focus and development, interactions with participants, interpretation and representation of (co-constructed) narratives.

6.3.1 In developing the project

As noted previously, my professional experience shaped my belief that YP can make eloquent commentary on their lives, but also that their voices are often marginalised. This

underpinned my turn to qualitative and narrative forms of inquiry (see below), and also a commitment to meaningful engagement with YP in directing the research itself. Engagement with AYME (Association of Young People with ME) began as my search for a research advisory group, but subsequently shaped this project in unexpected ways. Given the tense history between CFS/ME advocacy groups and the “psy” professions, I was nervous about the reception I might receive, but the support I received was emotionally-reassuring as the project began to take shape. It was also unexpectedly important to me as a novice researcher when I later faced hostile questioning at a REC about whether it was ethically-acceptable to expose vulnerable YP to potential emotional distress. Engagement with AYME, and the diversity of views expressed there, also kept me mindful of the multiple audiences that my “findings” might later encounter; treading a careful path between respectfully attending to YP’s voices, while not objectifying or reifying them.

My NHS background led my initial decision to identify participants from a NHS setting, facilitating access and negotiation with clinical teams and getting the research journey underway. However, research journeys are rarely smooth, and here prior engagement with AYME proved fortuitous. Hearing of my recruitment difficulties in the NHS, their willingness to advertise the study to their members allowed for a change in recruitment strategy, eventually bringing over half the participants. Though unplanned, I now believe that this brought further depth to the project. There are clearly insufficient numbers for much comparison, but it is notable that the two most “unwell” YP came to the study via AYME; and one older participant was in the process of transition to an adult service. Even if I had approached clinical teams in their geographical regions, I question whether professionals would have considered them too “vulnerable” or otherwise problematic to recommend for the research. This raises questions for studies recruiting only from NHS services, balancing ethical “protection” with further marginalising the most vulnerable voices.

My professional “label” has been a tension throughout. While it aided access to some NHS settings, I was wary that positioning myself as a clinical psychologist might “scare off” other potential participants, and/or dictate the tone of interactions²⁸. Beyond this, I was keen to

²⁸ All staff within NHS, AYME, and the REC / R&D teams were aware of my professional background as a clinical psychologist, with experience working with CYP and in health settings.

pursue research and perhaps career avenues outside professional confines, to make the most of an opportunity to step away from expectations of professional “expertise” or allegiances, and to embrace curiosity, learning and “not knowing” as a novice qualitative researcher. There appeared ethical as well as methodological implications of both alternatives (eg, misleading by omission²⁹, or creating an unfounded expectation of a more therapeutic encounter). Discussion with supervisors, peers, clinicians and members of AYME informed my decision to privilege my research student role within information about the study (eg, PIS), though being transparent about my professional background if asked³⁰. And though I was attentive to how YP positioned to me during interviews, further research might usefully explore the implications of participants’ knowledge about professional backgrounds for the co-construction of narratives.

6.3.2 In co-construction of narratives within interviews

This project follows many others in working with face-to-face interviews as the site of narrative construction. Such focus is sometimes critiqued, but it may also be noted that my clinical experience - in which face-to-face encounters form a central part of therapeutic practice - drew me to this methodology. There are key differences between therapeutic and research interviews, but also significant areas of overlap in required skills that make the approach attractive to clinicians: sensitive questioning, curiosity and active listening, following feedback, unpacking meanings, entertaining multiple and sometimes contradictory perspectives, with a focus on reflexive working (Wren, 2012). Further, my experience left me confident in my ability to engage YP sensitively when talking about potentially distressing topics.

²⁹ I now perceive an interesting parallel in comments made by YP in this study, regarding ambivalence about labels and their potential to identify a person even before anything else is known about them. To paraphrase Evie, I might say, “*it’s just if someone (#) meets me and they immediately find out it becomes who you are as opposed to(.) an element of who you are(.)*”.

³⁰ In the event, one parent did ask, and quickly consented to her son’s participation after discussion of my professional experience. It is impossible to know whether other YP knew this (although, in the age of Google, this would be easy to establish - and one YP told me at her 2nd interview that she had looked me up). Another YP asked about this after the end of the study, when we discussed a summary of my findings. She did not express any concern about this background, or that she had not known of it at the time of our meetings.

The rich narratives arising from these research interviews - and the fact that all ten YP chose to return for a further meeting a year later - leads me to conclude that this method was a strength of the study. Nevertheless, any decision precludes others. Further work exploring co-construction of narratives within families (Crix et al., 2012) or following research with adults in groups (Bülow, 2008), or online (Guise et al., 2007), remain exciting areas for the future. Further, despite my commitment to working with YP as active participants in research, I accept that my inexperience as a qualitative researcher made me baulk at the challenge of more fully-developed participation, such as training YP to interview others, and/or to participate in the analysis (McLaughlin, 2015). Such approaches would undoubtedly elicit different narratives and meanings, and also remains an area for future work with YP living with CFS/ME.

One critical difference between research and clinical interviews is the (non-)focus on *change*, such as alleviation of symptoms or distress (Squire et al., 2014). Thus a challenge for clinicians is to maintain vigilance to, and step away from, ingrained interviewing habits that usually operate to this end. For example, contrary to beliefs that stories are characterised by a beginning, middle and end, it can be seen that many are more aptly described at best as having a “beginning, muddle and end” (Emerson & Frosh, 2009). While listeners generally wish to “make sense of” speakers’ stories, a clinical assessment interview is particularly prone to this, as clinicians attempt to quickly understand sequences of events and experiences prior to formulating a focus for intervention.

While conscious of a desire to avoid this, there were nevertheless points at which I struggled with the “muddle” - the gaps and inconsistencies - in participants’ accounts, stepping into asking more “clarifying” questioning. This is particularly noticeable following Grace’s description of unusual pains which would not usually be understood as CFS/ME, noting a cardiologist’s suggestion that they were “panic attacks”, before immediately moving to say that a paediatrician “*diagnosed me [with M.E.](.) I think(.)*”. My confusion about the chain of events, and why the diagnosis of CFS/ME had been given, prompted my question, “Can you recall what those symptoms were(.) what that felt like at the time?”. Not a particularly strange question, but Grace’s response - a sudden departure from talk about her unusual symptoms, and immediate production of a list of “classic” CFS/ME symptoms (“*muscle weakness (.) fatigue (.) nausea (.)and brain fog*”) - suggests that my

question was received more as a challenge in the context of a contested illness, leading to performance of a co-constructed, less contest-able narrative.

Similarly, the usual clinical focus on *change* can lead to a search within interviews for agency (discussed further below) and steps towards “realistic goals”. As noted in section 5.3.3.3, this was particularly clear in my questioning towards the end of Danni’s first interview (340-349). Seeing her lying immobile and reliant on carers even to feed and wash her, told that medical professionals were unable to help as she was “*too severe*”, I was struck and worried by the apparent lack of a treatment plan (or at least, Danni’s awareness of this). This precipitated an “escape” of my clinical questioning, as I tried to draw out a framework of agency and steps forward: “what’s gonna be the thing that makes you get better?”; “who helps you to know what the next steps would be?”.

Danni can be seen orienting to my discourse, developing a narrative of more agency (including “*persistence*” and “*pushing myself*”). Danni would almost certainly be familiar with such clinical pressures, having seen many health professionals (including a psychologist). I quickly realised that I had slipped into an inappropriate role that could affect the nature of our engagement and Danni’s narrative, pausing and ending this line of conversation. Awareness of this incident led me to question whether there might be other instances of a work-related “change agenda” influencing the narratives produced, and scrutinised transcripts for this. I have not been able to find other such obvious instances, but it is certainly possible that more subtle communications such as smiles or nods of approval at talk about personal agency - part of a clinician’s remit, although also (as I have argued) a broader cultural narrative - crept into interactions, shaping the narratives co-constructed there.

Finally, my concern with wanting *not* to interview “as a psychologist” may have had rather different consequences. As noted, all the boys produced strong narratives of “not complaining”, and gendered, stereotypically masculine identities as not wanting to be overly introspective. This included specific content (eg, Harry’s “*I tend to be emotionally detached from things*”; Adam’s mocking dismissal of “*TV-show reflection*”), matter-of-fact or emotionally-flat tone of voice, and direct reference to female (over-)interest in emotions (including girls’ “*annoying*” “*sympathy*” (Callum), or Adam’s exasperation with a female

psychiatrist). In this, I felt positioned as a woman, and potentially someone who might be trying to intrude emotionally on these boys. In a clinical setting, and over a longer period of time, I would be inclined to explore and perhaps question such dismissals of emotional consequences. However, without the mandate to do this in a research setting, and mindful of the danger of over-interpreting within a brief research encounter (Frosh & Emerson, 2005), I took these comments as a warning to “back off” pushing them on emotional issues. Listening back to audio-recordings, I note that my tone of voice is also more “upbeat” with these boys than with some of the girls who are more clearly distressed. Such matching of tone is a normal feature of empathic communication, so not an unusual response to the boys (and one with which they are probably familiar within a gendered cultural context). Nevertheless, the possibility remains that my “backing off” in tone and content of “emotion-talk” then contributed to the ongoing shaping of their narratives, potentially perpetuating the stereotype of masculine narratives (and men) as less emotionally-expressive.

Broader features of the interview format are also relevant in constructing certain types of narrative, such as forcing an unnatural narrative coherence (Hyvärinen et al., 2010). For example, my early prompt to ask all participants how they “*became aware* that something was wrong” can be seen as an injunction to “begin at the beginning”. The fact that most YP’s narratives then follow a basically chronological structure (though with some exceptions noted in chapters 4 and 5) may be understood at least partly in light of this.

Similarly, while I believe that the use of second interview one year later is a strength of the research, a call to narrate “how things have been over the last year” may be taken as a prompt to produce stories of *change*, constructing both content and structure that might not otherwise have been seen. Relatedly, there was some indication that YP might be more inclined to speak of problems only in the past, after some progress had been made in resolving them. Longitudinal qualitative approaches have much potential for research with YP (Morrow & Crivello, 2015), not least in opportunity to develop a stronger interpersonal relationship. It is notable that many of the more “troubled” narratives (such as of psychosocial difficulties, or fears about getting better) emerge later in the second interview, when YP had had time to gauge how I might receive such information - whether

I could be trusted with it. However, many areas - particularly in the depiction of time within narrative (Mauthner, 2015; Thomson & McLeod, 2015) - remain theoretically and methodologically underexplored, and a focus for future research into illness narratives.

6.3.2.1 Incorporating creative methods into narrative inquiry

This project also dipped a methodological toe into the waters of “creative methods” in narrative research. YP were encouraged to bring additional media within a “memory box” to their second interviews, to trigger memories and story-telling, and help construct a narrative of the year. These approaches potentially have much to offer when engaging CYP in research (Punch, 2002; Thomson, 2009), including the exploration of identities in adolescents living with chronic illness (Hanghøj et al., 2016). However, there is also potential for ethical, methodological and epistemological naivety in their use (eg, Gallacher & Gallagher, 2008; Lomax, 2012; Spyrou, 2011). In particular, they are often seen as means to enable YP to “express themselves” or “tell their own stories” more authentically, ignoring the contexts in which such media are produced, and whose voices they represent (Buckingham, 2009; Gallacher & Gallagher, 2008).

A number of personal, professional and methodological factors are relevant to my own, somewhat cautious, incorporation of creative methods into this project. In keeping with a commitment to research “with, not on” CYP (Alderson & Morrow, 2011), I was keen to engage YP in communications of interest to them. However, my clinical practice had taught me that working with alternative media “fits” for some CYP but not others – indeed, that some find it threatening (perhaps reminiscent of pressure to “produce” creative work in school). Relatedly, I was conscious of the power imbalance between young participants and myself as an adult researcher, and also of their potential vulnerability to fatigue and other difficulties that might be exacerbated by research demands. Consequently, I was keen to stress that this work was optional. Methodologically, it was not considered problematic if participants chose not to bring additional materials, since the focus of the interviews was on language-based construction of narrative - and indeed, the differential take-up of “creative methods” would provide opportunity for some exploration of how such media might influence the sorts of narratives that could be told.

Compared with previous studies engaging YP in research to explore their experience of illness (eg, photo-elicitation used by Drew et al., 2010; Hanghøj et al., 2016), instructions on use of memory boxes were relatively loose. In the event, 8 of the 10 participants brought material to help construct their second narratives, but in quite different ways. Perhaps unsurprisingly, the two (Danni and Harry) who did not bring items were also the most disabled over the year (discussed further below). One young participant (Becky) brought only excerpts from her mother's diary about her illness, which then structured a section of narrative that revolved around symptoms and functioning, what "*I could do more of*" over the chronology of the year. Most brought photographs taken over the year, not specifically taken for the study though of course *selected* in preparation for the interview to illustrate a preferred narrative. Most (Callum, Evie, Freya, Jess and Katie) also brought items representing particular events in their year.

The relatively common use of photographs is not unexpected (all these YP had access to cameras on their mobile phones), and photographs are often used in qualitative research (Marshall & Rossman, 2016). In contrast to more focused methodologies (eg, where participants in hospital are asked to photograph objects or spaces over 24 hours; Radley & Taylor, 2003), this less directive approach appeared to encourage drawing on photographs taken as part of ongoing cultural life, rather than specifically for research. However, this runs into our culturally-engrained habits of using photos to generate images of celebrations and positive images (Chalfen, 1987; Guillemin & Drew, 2010), and it was notable that the majority of photos in memory boxes depicted scenes of celebration and success. This potentially constrains the narratives that can be told, so the role of photographs in influencing the narratives of "progress" and "moving on" in achievement and social lives must therefore be considered.

By contrast, it is notable that no YP took photographs of, say, "the view from my bed" or "staring at the ceiling". And despite claims that visual media may have a role in portraying bodily experience (Reavey & Johnson, 2008), only one photograph – of Freya, crashed out on the sofa at Christmas (taken and apparently selected by her mother) - depicts fatigue or other physical symptoms, or even their correlates (eg, a wheelchair). The absence of photographs or other material brought by Danni or Harry may then be understood, not simply as indicating that they were too unwell to use a camera, but also because they were

less likely to attend the sorts of events where photography is traditional. (Danni commented, for example, that even her 16th birthday was very low-key, with just her immediate family visiting her in hospital – not the large (and photogenic) party she had once envisaged.) Thus a cultural expectation to produce certain sorts of photograph, if not explicitly countered by researcher directions, may limit some participants' engagement in such methods, again potentially influencing their narratives and recognition from others.

Methodologically it seems noteworthy that, although many of the tangible items brought by participants similarly depicted progress and increasingly successful social lives (eg, tickets to pop concerns, souvenirs of holidays with friends), some of these also triggered more distressing stories (eg, Katie's pyjamas and pillow depicting her inability to dress herself; Callum's ripped rugby shirt prompting narration of further setbacks through injury; Jess's art project on cycles of grief and loneliness). Although these too could also be seen as part of longer narratives of struggle and success over adversity, the rich stories they triggered suggests that this form of "memory box item", rather than just photographs, may be valuable to researchers.

Finally, it must be noted again that materials brought by at least three participants (Adam, Becky and Freya) were significantly guided by their mothers, as they discussed what the YP would say in the upcoming interview, or (in Freya's case) what "*would be good to show*". If parents have been directly involved in selection of photos other material to bring - or even if materials are collected over the year with parental prompts (Drew et al., 2010) - further influences on the co-construction of narratives are apparent (Mannay, 2013), and future research could usefully explore this. The particular time/cultural context is also important: as media such as Facebook, Instagram, Tumblr and Snapchat move in and out of use for (some but not all) YP, the changing (and possibly gendered) use of photographs in identity presentation must be considered. This is not necessarily a barrier to the use of such creative methods - indeed, I see them as a useful addition - but it does require that, as with verbal narrative, there must be sustained critical consideration of contexts and power relationships in their construction and interpretation.

6.3.3 In interpretation and re-presentation of narratives

As a clinical psychologist, much of my training and focus has been on the personal *experience* of individuals referred: on life events and how these have been responded to, personal meaning-making (thoughts or “cognition” or narrative), and emotional reactions; and the ways in which these aspects of experience feed into each other, with personal and social consequences. Attention to the “lifeworld” is key in many forms of therapy, and it is unsurprising that many clinicians are then drawn to qualitative research that privileges phenomenological approaches (Barker, Pistrang & Elliott, 2016). Even when working within constructionist frames of therapy, “experience” (however constructed) is ever-present for therapists, since alleviation of distress is often a primary motivator. Constructionist *research* explicitly moves away from a focus on internal (cognitive or emotional) states, questioning the naturalist approaches that assume equivalence between talk and such internal states or “experience”. This is a research commitment that I embrace; but, as stated at the outset, my research interest *stems from* a concern with (experience of) human suffering. A focus on discourse or rhetorical positioning does not mean that I am no longer concerned by personal distress.

Further, the project began when there was an almost total absence of literature available to either academics or professionals that attended to the voices of YP living with contested conditions. I was drawn to the need to “hear the voices of” - or even “give voice to” - marginalised individuals, even as I questioned the concept of an individual, authentic “voice” (Mazzei & Jackson, 2012; Sartain et al., 2000). And I was aware throughout this project that the YP who gave so generously of their time did so because *they wanted their stories to be heard*, not simply scrutinised for their discursive practices or the sociocultural discourses that shape them, raising ethical as well as methodological and practical concerns (Hammersley, 2014). These YP took their places alongside the other “ghostly audiences” (including academics, professionals, AYME representatives) to my narrative, as a “fear of offending” (Hoskins & Stoltz, 2005) also shaped my interpretations and representations.

Such tensions have pervaded my immersion in this project. My choice of analytic strategy - a constructionist form of narrative analysis that attempts to look at the content *and* the form of stories, attending to local (interactive) *and* broader social contexts of their

production and rhetorical action, unique to the individual *and* with broader resonances - may be seen as my wanting to “have it all”, do it all. And while I believe in the value of analyses that embrace complexity, contradiction and multiple layers of meaning, this - and the absence of any instruction manual (Chase, 2011) - has at times felt overwhelming.

The willingness of these YP to produce rich, extended narratives, and the continuing engagement of all ten, also left me with a larger-than-anticipated “data set”. The exploratory nature of this early research meant that I was unwilling to focus in too quickly on a particular area or sections of narrative for analysis. Added to this, the part-time nature of my research Doctorate (taking place alongside employment and family commitments) meant that, even with a good CAQDAS programme, it was challenging to keep track of the complexity of emerging threads of inquiry, let alone weave them back into a more coherent narrative fabric.

Beyond analytic focus, a tension in my narrative representation - which perhaps mirrors that for participants - has been to present detail and complexity that invites audiences into imagining experiences and interpretations, lending verisimilitude and “credibility” to depictions of this journey, while not drowning them in detail, losing their interest before concluding the “points” I wish to be drawn. But there is a limit to what any one researcher (or reader) can retain, and a danger of losing ability to see the wood for the trees. The deeply uncomfortable process of narrowing the focus of inquiry, and areas to represent in a thesis, inevitably leaves other avenues unexplored, unvoiced (Mauthner & Doucet, 1998; Simons, Lathlean & Squire, 2008) (some of which are highlighted as targets for future research throughout the text and in chapter 7).

This focus is inevitably influenced by professional interests. Wren (2012) notes that researchers who are clinicians often focus analysis on aspects of narratives that, in clinical settings, are important to therapeutic processes of change, such as a sense of agency and motivation, reflexivity, coherence and ability to engage others. Such foci are evident in my own analysis, in ways that non-clinicians would not necessarily have taken up. Similarly, my existing interest in YP’s social relationships, and the social construction of health and illness - and particularly the Cartesian dualism between mental and physical health and related stigma - may be discerned in my attention to such themes within the analysis.

The tension between the personal and social, voice and discourse, is particularly acute in choices about re-presentation of narratives. This is not only an issue for clinicians, of course. Working within a feminist framework, Saukko (2000:299-300) highlights the “philosophical contradiction between research interested in subjugated groups and scholarship investigating social discourses that shape our voices and selves”. But such tension can mirror that of learning from the individuals seen in clinical practice: between wanting to focus on and do justice to individual stories, while also considering patterns across the wider corpus of narratives collected; privileging the unique, but also wanting to go beyond this (Josselson, 2006). I feel that one of my attempted “solutions” - to present two separate chapters of narrative analysis, attending first to each individual’s story before exploring resonances and departures - adds a layer of understanding to the project. However it is a luxury of space and time within a Doctorate dissertation that could not occur within the confines of, say, an academic journal submission.

More broadly, there is a tension in positioning my own “researcher’s” voice in representation of narratives: as authoritative, supportive or interactive in relation to participants’ voices (Chase, 2005). Various postmodern projects have sought to destabilise the traditional authorial voice of the researcher (Adams St Pierre, 2013), although sometimes at the expense of problematizing participants’ voices (Saukko, 2000). Within this work, I have been influenced by metaphors of patchwork quilting (Deleuze & Guattari, 1987) taken up by Saukko (ibid). This aims to be sensitive to the texture and nuance of personal stories (or patches) and, by stitching them together, points to discursive resonances between them. Saukko highlights the importance of making visible the researcher’s authorial “stitches”, and although there are departures between her choices in how to do this and my own³¹, this is a concern that I have tried to attend to also.

³¹ These choices too are influenced by particularities of the researcher and the research. For example, Saukko worked with just 5 participants, making it easier for readers to “hold in mind” these stories simultaneously, and requiring less explicit authorship from the researcher. Additionally, Saukko worked explicitly with friends and acquaintances as an “insider researcher” (positioning herself, like her participants, as “anorexic”), with a clearer rationale for juxtaposing participant voices with her personal reflections on resonances and departures from her own experience.

One aspect of this re-presentation is the use of quotations from participants. This is commonplace in qualitative research, ostensibly for “making visible” their contributions - and indeed is considered essential in establishing the credibility and persuasiveness of such research, demonstrating that the researcher’s claims follow these. However, the use and implications of quotations is complex and potentially misleading. Quotations may appear to “represent” a speaker or category of speakers and even the overall claims of the research, obscuring the complex and time-specific contexts of their production, and the researcher’s decisions in selecting particular quotes (Taylor, 2012). And though I have tried to demonstrate attention to “even-handedness” in this (eg, representing all ten YP, presenting disconfirming voices, working reflexively and under supervision to review selection and representation of these), some partiality is inevitable.

Narrative analyses often address one potential difficulty by trying not to take quotes “out of context” of their interactional (conversational) and biographical production. However, the need to show longer stretches of narrative brings further challenges of time and space. Further, not all speakers lend themselves equally to such representation³². On reviewing an earlier draft, I became aware that one YP (Evie) was less represented in quotations, despite being an articulate speaker. Further scrutiny suggested that her open, chatty style of talk - while excellent for engaging and giving extended narratives in conversation - proved problematic in the ruthless process of trying to find relatively succinct quotations to include in the text.

A similar tension occurs in representing multimodal material brought by YP in their memory boxes. As stated, the focus of this study was participants’ *verbal* narratives, with additional material treated primarily as a prompt for YP’s story-telling rather than for separate, researcher-led interpretation. Nevertheless, I felt these materials to be powerful in shaping their narratives, and wished to represent them (with participants’ consent) more clearly within the thesis. Yet some of these materials lend themselves to such depiction more

³² One critique of some narratives analyses, which focus entirely on “story-telling” (representation of first-person, past events with a relatively coherent chronological form) is that some speakers tend to speak like this more than others; and that some already-marginalised groups in particular (eg, by age or cultural background, or histories of trauma) may be disproportionately affected. My inclusion of non-storied talk - considering this too as part of YPs’ broader narratives - was an attempt to avoid further marginalisation of this type.

easily than others, and this again may have implications for how readers interpret participants' narratives.

Two participants spoke about songs that they found inspirational, and I chose to weave their talk into written narratives rather than attempt the logistical challenges of incorporating (copyright) audio-material into a thesis. Many of the photographs brought were of people (again in keeping with cultural conventions), presenting challenges to anonymity of participants and others; and this led my decision not to print some photos into a document that will be easily-accessible online (eg, of Freya exhausted at Christmas, or - later in the year's narrative – dressed up with a group of friends and her new boyfriend, ready for a party). Though techniques such as pixellation of faces can be employed in such cases, these raise different ethical and representational issues (eg, are culturally associated with media portrayals of criminals or people considered vulnerable) (Sparrman, 2005). Additionally, obscuring a face often seemed to take away a significant aspect of the photo (eg, the look of pride on Adam's face in a photo showing him holding up a sports trophy).

Other objects brought were photographed (with participant consent) by me at the end of the interview. Some of these could be included, but others raised other challenges to participants' anonymity (eg, the names of schools on sporting trophies or a Prom ticket). Some of my photographs did not do justice to the objects (eg, the enormous size of Katie's cushion), so were omitted. Beyond this, some memory box items appeared significant, not as individual items, but in their *relationship* to others brought: for example, the sheer *volume* of material brought by Evie to illustrate her craft projects done while at home with her sister; or the clearly thought-out *progression* of items brought by Katie, out one by one, to accompany her narrative of change and recovery over the year. These would have required me to put together much larger collages of pictures (some of which were problematic in terms of anonymity), raising logistical and representational challenges I felt to be beyond the remit of the current project. So, while I endeavoured to ensure that all materials brought were attended to and represented through the verbal narrative, there is a tension in that readers of this thesis can see visual material from only some participants, and it is unclear how this may affect readers' interpretations of participant narratives.

The range of tensions outlined here have not only affected the development of this thesis, but also other dissemination of the work. The struggle to “wrestle into submission” my analysis has taken longer than anticipated, creating issues in providing feedback to participants. Though all had expressed interest in receiving a summary after the research was concluded, and all were aware that this would take some time, over two years had passed before I felt able to give a clear summary. This presented practical challenges (some contact details were out-of-date), but also ethical ones, since I was conscious that YP would have “moved on” in different ways, and some might not even wish to think about this particular period in their lives.³³ It is testament to their patience that, even after this time, all those in contact still said that they had found taking part to be a positive experience, and none expressed any disquiet with either the process or my summary feedback. Similarly, feedback to the CEO at AYME was met very positively, and further dissemination is planned.

Within this work, I have studied the narratives of ten YP for their content but also for the ways in which their construction works rhetorically to address particular interactional concerns. Further, I have considered whether the resources available to them create particular challenges in constructing credible, persuasive accounts of their lives and identities as valuable, valued members of society. While aiming to do justice to their stories, I have a somewhat different story to tell in constructing a thesis, and different interactional concerns. But, like them, I have to persuade readers of my credibility as a narrator; and that this is a “good enough” story, worth attending to right until the end, with a reasonable “point” to be made. Like them, I - and other researchers - “struggle to do the best we can with the limited resources we have at hand” (Scheper-Hughes, 1992:28). I too will not know how successful or persuasive I have been until I receive reaction from different listeners, all of whom bring their own filters, their own understandings to bear. And, just as these participants’ stories can easily be reified by being “frozen in time” - and

³³ I therefore opted for a “graded” attempt to give feedback, sensitive to the wishes of each. I initially sent a brief email greeting, letting them know that I would be happy to give some feedback if they would like this, and asking them to reply if they wished. Four of the ten emails were no longer reachable. Of the remaining 6, four asked for feedback (a written summary is attached in appendix 12), and one wanted a longer discussion on the phone.

they would surely tell somewhat different versions now, filtered through their young adult understandings - I too will probably be drawn to them differently in future. My “future self” will want to tell a different story about them, as I revisit them with different life experience and understandings. As Andrews (2013) argues, this story is “never the last word”.

With this in mind, I turn now to the (current) “ending” of this particular narrative, summarising my understanding, drawing out implications of the research, and looking forward to how other understandings might be constructed through further research in future.

Chapter 7

Conclusions

7.0 Summary

This research set out to enhance understanding of the lives of young people living with a diagnosis of CFS/ME. Working within a constructionist framework, it asked:

- How do young people narratively account for lives lived with a contested condition and a potentially contested identity?
- What do their narratives tell us about the social contexts in which they must establish themselves as valuable, valued young members of society?

This research has clearly demonstrated that young people (YP) living with a diagnosis of CFS/ME can produce rich, multi-layered narratives which simultaneously construct nuanced understandings of their condition (“M.E.”) and identities (“me” and others) in ways that reflect and resist prevailing sociocultural narratives, attending to the different audiences that may be encountered. This is the first time that a discursive narrative lens has been used to explore their voices in detail. This research throws new light on ways in which YP actively engage with powerful debates relevant to their condition, demonstrating agency and development over time in constructing their narratives and their lives. In doing so, this research demonstrates the value of attending to these young voices, not simply for what they say about their own “personal troubles”, but about the wider socio-cultural and political contexts in which they are constructed - which in turn have potential implications for much wider groups of YP living with contested illness and other forms of illness or disability, and for professionals and others who work alongside them.

YP within this research speak powerfully of the onset of disturbing symptoms; descent into serious, disruptive illness; long months or even years of living with disabling, unpredictable

illness and distressing social consequences; and then (for some) the possibility of “moving on” from the worst of illness, but facing new struggles on the road ahead. In this, there are parallels with a small, recent body of literature based on interpretative phenomenology, exploring experiences of YP living with CFS/ME. However, the new application of a discursive narrative analysis within *this* study reaches beyond this content, allowing focus on discursive tensions and dilemmas as YP attempt to account for the serious and troubling nature of the condition and its consequences, while maintaining culturally acceptable constructions of the self. I have argued that particular challenges arise from the discursive contexts of “adolescence” and of CFS/ME as a contested condition. I have argued too that YP’s narratives address these tensions in different ways, some of which appear influenced by the age and gender of their speakers; and that these different narrative/discursive approaches resolve dilemmas to different extents, with personal and social implications for young people and their families, and for the ongoing social construction of CFS/ME in YP.

More specifically, I have argued that three inter-related tensions appear particularly salient as these YP attempt to account for their lives, woven through with a common thread of addressing what it means to be accepted as a “normal” or valued teenager:

1. Constructing a full, credible and convincing account of the serious nature of CFS/ME and its impact, while resisting stigmatised identities as a “complainer” or hypochondriac
2. Relatedly, but more specifically, conveying the extent of social and emotional difficulties - including those arising from disbelief and discreditation - while resisting constructions of difficulties as un-believable (in-credible), and stigmatised teenage identities as psychologically vulnerable or socially rejected
3. Conveying motivation and agency in wanting and trying to be healthy and “normal” - “a striver not a slacker” - while resisting constructions that position sufferers as responsible for becoming ill or failure to get better, or of CFS/ME as trivial or “psychological”. And relatedly, meeting an expectation to provide narratives of heroism and success, while maintaining a position of ongoing struggle and need for understanding, to “take care”.

7.1 Implications of the research

7.1.1 Implications for professionals working with young people

As argued throughout this work, the relationship between narratives and the worlds depicted within them is complex. The research outlined here is a form of case-based inquiry that emphasises the particularity and context-dependence of knowledge construction. As noted previously, along with other constructionist methodologies, it eschews traditional (positivist) notions about generalizability of “findings” to wider populations, problematizing the process of drawing out the “wider implications” of the research (Potter & Wetherell, 1987).

However, this does not mean that case-centred research, and situated interpretations, cannot speak to wider spheres. Indeed, the research enterprise would be ethically questionable if this were held to be true. As noted previously, Riessman (2008) goes further, arguing that the relevance or “pragmatic usefulness” of research are hallmarks of its quality and credibility. Although there are challenges in building from narrative projects (Josselson, 2006), such case-centred research has a rich history of contributing to developments in natural and social sciences, and to professional practice including medicine, teaching, psychotherapy and social work. Further, analytic focus of the present study means that “narratives may reveal as much, if not more, about the norms and dominant meta-narratives of the social, cultural and political context in which they are produced as they do about the narrator themselves” (Atkinson & Rubinelli, 2012:S14); and hence analyses have relevance to considering others living within such contexts.

Thus, as argued previously, this analysis may form the basis for generalization through theoretical propositions which encourage practitioners and teachers to think again about their own work (Radley & Chamberlain, 2001), including relationships between YP’s talk and the meanings attributed to these. There is no implication that, say, a concern with “not complaining” or being seen as “psychologically normal” will be evident in all, or even a particular proportion of, YP living with CFS/ME. However, this research can offer a means to sensitise professionals to such possibilities, inviting them to consider resonances for the particular YP they are working with. Further, professionals in a position of power may

consider more generally their relationships to such discourses (eg, their constructions of what constitutes “real illness” or problems worthy of complaint; powerful but potentially unhelpful distinctions between “physical” and “psychological”; or expectations of agency and responsibility), how these are reflected and perpetuated within their professional practice, and implications of this.

Wells (2011:134) suggests that, “ultimately, the significance of a narrative inquiry depends on the investigator’s ability to help the readers to understand the nonobvious meanings of the narratives studied as well as their larger significance”. My aim is not to give final, definitive descriptions, but to unsettle taken-for-granted assumptions (Frank, 2005), and invite professionals to consider implications for their own work. However, I suggest some areas for particular consideration:

1. The symptoms of CFS/ME are often barely visible, and their changing impact on YP’s functioning is hard for others to understand. Professionals and others may call on YP to give an account of themselves, the “reality” of their symptoms and their claims to need special treatment (“*why can’t you go into school??*”). But YP’s accounts of their difficulties can “fall short”: symptoms are not always clearly-described; there may be gaps and inconsistencies; and the absence of clear medical explanations hampers understanding. However, this analysis shows that YP also have good reasons to be cautious about “complaining” about their symptoms or difficulties, particularly if they wish to preserve valued social identities. Those who live alongside them (peers, teachers, health professionals) should be aware that the lack of a clear picture is understandable in the context of complex, competing pressures on YP; and an absence of clear description should not be confused with an absence of legitimate cause for complaint or need for support.
2. YP living with a diagnosis of CFS/ME face many social and emotional challenges, including those that arise from disbelief and discreditation at the hands of professionals and peers. Many (health professionals, teachers, parents, peers) will wish to support them with this. However, for YP simply *telling* others about these difficulties presents further challenges, as they risk a further questioning of the physical reality of their illness, as well as stigmatised identities as psychologically

vulnerable or socially rejected. This research demonstrates that YP have good reasons to be cautious in telling their stories of social and emotional difficulties; and that they are acutely sensitive to this risk, and can construct their stories to attempt to mitigate it (eg, glossing over the emotional impact of social difficulties, and only talking about them in the context of trusting relationships, after they are sure that their audiences acknowledge the serious physical nature of their illness.) Professionals and others should be aware that absence or muted nature of such talk does not mean that YP are either lacking in emotional insight into their difficulties, or that their social / emotional needs can be ignored.

3. Current guidelines recommend programmes of activity management (eg, Graded Exercise Therapy or Cognitive Behaviour Therapy), that require considerable engagement and effort from YP. However, in the context of contested understandings of CFS/ME (eg, as trivial, or “really” due to laziness or psychological problems), the rationale for such programmes – and the absence of medical (eg, drug) interventions - can appear confusing and stigmatising to YP. Professionals recommending such programmes need to provide a clear, non-stigmatising rationale for these to YP. Otherwise they can easily be taken to imply that their symptoms (and failure to get better) are believed to be simply due to insufficient “work”, poor psychological functioning or other stigmatising personal characteristics - and hence even implying that the condition was never “real” or physical in the first place. In the absence of clear rationales, trusting relationships with professionals, and belief that physicians are taking seriously their physical symptoms, it is unsurprising that YP might be reluctant to (say) see a psychologist. Professionals must remain alert to the complex and sometimes conflicting messages that are sent about agency and responsibility for getting ill and getting better, as well as the nature of CFS/ME itself; and not assume that resistance to such interventions is due to lack of motivation to get well.
4. There are powerful cultural pressures on YP living with CFS/ME to demonstrate that they are not “lazy”, and are doing everything possible to try to improve their situation - and ideally, that they are successful in making progress over time, suggesting a path either back towards health or towards other “personal growth”

and learning. Though this applies to many living with illness, it is particularly salient in the context of cultural pressures for YP to demonstrate increasing levels of autonomy and self-mastery. Professionals should be conscious of their own wish (and pressure) for YP to produce such narratives of progress; and that this may silence other important stories, including those of ongoing problems and a need for continuing support.

Thus I suggest areas for further professional reflection, and an invitation to further dialogue.

7.1.2 Methodological implications

Narrative inquiry is still an evolving field (Chase, 2011). This research draws together different interpretive approaches, showing the value of constructionist, discursively-oriented narrative inquiry with YP in a way that has been little-explored with this age group. In doing so, it highlights possibilities for extending understanding of the unique ways that young people in particular “operate dialogically between the personal and the surrounding social worlds that produce, consume, silence and contest” them (Squire et al., 2014:111). As such, this project can be seen as a step in doing research that is politically, personally and socially useful to understanding the construction of health, illness and identities for those diagnosed with contested conditions, and particular challenges facing young people.

Though discursively-focused approaches often argue the need to examine talk in more “natural” contexts, this research shows there is continuing value in exploring narratives constructed with extended individual interviews - and particularly repeated interviews conducted over longer periods of time, allowing development of closer relationships between interviewer and participant. This research particularly highlights the importance of time in establishing trusting relationships within research on contested conditions (and potentially other sensitive areas), strengthening the earlier observation by Hareide et al (2011) that YP may only speak about troubled topics like psychosocial difficulties *after* the physical nature of their difficulties has been established and acknowledged by the researcher. This finding has implications for how we make sense of research based on

surveys or briefer contacts, which have sometimes reached different conclusions (ie, that YP do not acknowledge psychosocial aspects of CFS/ME). More broadly, a longitudinal aspect appears particularly appropriate for research with YP, as an approach that can attend to the passage and construction of time within narratives.

The research also develops the use of “creative methods” with YP, showing that the use of “memory boxes” can be a potentially useful addition to methods for teenagers to develop their narrative and identity presentation. It suggests that multimodal materials (eg, encouraging YP to bring tangible objects as well as the photographs increasingly used in visual research) brings additional value - potentially increasing the range of narratives that can be told, and countering our culturally-engrained habits of photographing celebratory events. However, it also highlights the need for researchers to remain vigilant to the ethical and interpretive challenges that such multimodal research brings, including influence of other people (eg, parents, research instructions), culturally-established and gendered practices in the selection of items and the co-construction of narratives that result.

7.2 Areas for future research

Though I argue that this project contributes to academic and professional understanding, many questions remain. This analysis is just one step in a much longer journey to develop understanding of what it means to live with a diagnosis of CFS/ME as a young person, and broader understandings of health and well-being.

One consideration is that all the participants here are from White, British and largely “middle-class” backgrounds. Further, all were articulate and, at least until the onset of illness, reporting above-average educational attainment. It is clearly important to explore narratives of YP from different backgrounds, particularly if research is to avoid perpetuating marginalisation of under-represented voices. Further, these may draw differently on repertoires of health and illness, physical and mental, success and productivity that appear relevant in the current group, and hence extend our understanding.

Potentially important issues also relate to diversity in the population studied. One set relates to gender. As noted, there were indications of gendered constructions of health, activity and identities, and that boys' narratives differed from girls' in some aspects of content and performance. There is a small literature exploring gendered narrative constructions of disability in adults (eg, Ahlsen et al., 2014; Ahlsen, Mengshoel & Solbrække, 2012), and the intersection of gendered identities and disability in the transition to adulthood (Gibson, Mistry, Smith et al., 2014), but very little on how this is constructed in younger people. Within this small group (including only 3 boys) – interviewed by one female researcher - there was very limited scope to explore or draw conclusions, but indication that this would be an area worthy of further research.

Similarly, there was some indication that the age of participants within this group (ie, between early and late teens) was relevant, not only in content but construction and performance of narratives. This is a complex area: younger participants have different stories to tell as well as potentially different narrative/rhetorical skills and relationships with an adult interviewer. Further, important features become clear only in their retrospective gloss (eg, the longer-term social impact of missing the start of secondary school). However, this research enhances to the limited literature in pointing to how some themes (such as construction of agency, autonomy and responsibility) take on different meanings across even this short (5-year) age range. This project has considered how life as a young person (rather than an adult) diagnosed with CFS/ME may be constructed; but the small group means that further understanding of change *within* this critical period remains to be explored.

As noted, narrative inquiry draws on many interdisciplinary traditions. In exploring the narratives here, I have been repeatedly drawn to different frames of analysis, expanding my understanding of what other traditions can bring. Attention to the relationship between “micro” and “macro” features of talk and discourse has been particularly illuminating for me. However, the multiplicity of academic and professional disciplines that have useful contributions to make - and my lack of specialist background training or immersion in these - means that I am unable to do justice to them.

For example, I have been struck by a need for further understanding about broader use of narrative and rhetorical devices expected in this age group. Exploring wider literature, I have come across fascinating work (eg, observations that the phrase “I don’t know” - seen repeatedly in these narratives - increases in teenage girls, contextualised by gendered social pressures on them to mask and disown their relational knowledge (Brown & Gilligan, 1992)). In this, as other cases, I have thoroughly enjoyed forays into internet and database resources, following trails into feminist, social psychological and linguistic arenas. Opening and peering through different disciplinary doors is, of course, an important part of doctoral study. But there are just SO MANY interesting doors, and so little time! This thesis must be just one of many others that could potentially be written from interpretation of these narratives. My aim now is to form links with scholars from other disciplines, and potentially to re-analyse these narratives through different (particularly feminist and socio-linguistic) lenses in collaboration with others.

There is clearly scope to examine further the co-construction of narratives in different contexts, in line with adult-focused studies, such as YP talking to health professionals, online (Guise et al., 2007), within peer support groups (Bülow & Hydén, 2003); or further consideration of YP within their families (following the single-case study by Crix et al., 2012). Relatedly, there is now scope to explore how different discursive approaches observed in interviews (eg, construction of agency, or “complaining”) are *responded to* by others, either individually (eg, doctors listening to young patients) or within broader (eg, classroom) settings.

Within my own analysis, I have touched on the issue of co-construction of YP’s narratives with their mothers. As part of this, I briefly considered the work that mothers may do in presenting symptoms and problems to others, narratively “owning” the anxiety and (perhaps) allowing their children to present more heroic narratives of “coping” and “not complaining”. I began this project with a strong sense of the “hidden voices” of CYP. Entering family homes of the younger participants, many mothers appeared keen to engage with me and tell their own stories, sometimes even sending me copies of their correspondence with schools and hospitals, or excerpts from their person diaries.

My initial reaction was to shy away from this, concerned that it would negatively impact on opportunities for hearing their children tell their own stories. Mindful too of the project's research questions and ethical approvals, I did not analyse these materials. However, while I retain commitment to attending to YP's narratives, I also now have more sense of the marginalisation of parents' voices - particularly mothers of children with contested conditions. My literature review noted briefly the ways in which professional narratives may position mothers in particular ways (eg, as responsible for their children's difficulties), but this project has drawn me to consider ways in which mothers can take up positions in relation to these, and face narrative and discursive dilemmas of their own. This then is an area that I would be keen to pursue in further research.

7.3 Ending

This research set out to enhance understanding of the lives of YP living with a diagnosis of CFS/ME: to explore how they narratively account for lives lived with a contested condition and a potentially contested identity within contemporary society. It sought to depart from much of the earlier research "on" YP, instead embracing a commitment to respectful research "with" them, and an appreciation of YP as competent narrators of their own lives. This project therefore took as its point of departure a small number of recent studies which engaged YP in in-depth interviews in which they could tell their stories; but extended the scope and methods of those studies in a number of ways.

First, it incorporated a longitudinal aspect, in which repeated interviews with each participant over a year allowed consideration of ways in which their stories are shaped over time and by their changing health, developmental and social contexts. Then it extended narrative methodology by encouraging participants to gather multimodal materials into a "memory box" over a year, and to use these to construct their later narratives in different ways.

However, this research also had wider aims, and differed significantly from previous studies in its epistemological and analytic position. Situated explicitly within a framework of social constructionism, it arose from a broader concern with how health, illness, knowledge, lives and identities come to be understood, experienced and responded to within societies: the

complex forces shaping this, and the many implications for those who live with or alongside conditions of bodily distress – particularly those that are not easily understood or recognised within dominant medical or cultural discourses. Contextualised by a wider concern with suffering and social inequality, it was underpinned by a belief in the political importance of attending closely to “personal” narratives, understanding that analysis “... can help us understand what is hidden, unnoticed, unrecorded, often seen as just “personal”, in mainstream history, and to analyse how networks of power position some narratives as dominant while marginalising others” (Squire et al., 2014: 111).

Thus this research approached the narratives produced by these YP as accounts that are inevitably shaped by the culturally-specific contexts and discursive resources available to narrators; and also as speech acts produced in response to the perceived requirements of the social setting. Following from this, its methodological approach departed significantly from previous studies with YP living with CFS/ME, moving beyond phenomenological or content-based focus on *what* was said, onto a parallel focus on the *doing* of narrative: considering *how* and *why* narrative and identities are constructed within particular local (inter-personal) and broader social contexts.

This research is the first to apply a constructionist, discursive narrative lens to the narratives of a group of YP living with a diagnosis of CFS/ME. (Indeed, there is remarkably little use of discursive narrative approaches with YP in other situations.) In doing so, it has clearly demonstrated that these YP can produce rich, multi-layered narratives which simultaneously construct nuanced understandings of their condition (“M.E.”) and identities (“me” and others), in ways that reflect but also *resist* prevailing sociocultural narratives, attending to the different audiences that may be encountered.

The research makes a significant contribution in throwing new light on ways in which YP actively engage with powerful debates relevant to their condition, demonstrating agency and development over time in constructing their narratives and their lives. However, it also highlights troubling tensions – and at times near-impossible positions – for YP to negotiate as they attempt to account for the extent and severity of their illness and its consequences, while maintaining culturally acceptable constructions of the self as a young person. The research shows how particular challenges arise from the discursive contexts of

“adolescence” and of CFS/ME as a contested condition, but also broader discourses related to illness, disability and what it means to be a valued, valuable member of contemporary society.

This analysis demonstrates for the first time how young people’s narratives manage these tensions in different ways, some of which appear influenced by the age and gender of their speakers; and that these different narrative/discursive approaches resolve dilemmas to different extents. It argues that this can have profound personal and social implications for YP and their families and the support they receive, for the way that professionals and others respond to them, and for the ongoing social construction of CFS/ME in YP.

In doing so, this research demonstrates the importance of attending to these young voices, not simply for what they say about their own “personal troubles”, but about the wider socio-cultural and political contexts in which they are constructed. If we are to understand the lives of YP living with contested (or other) conditions, I argue, we must think more carefully about their narratives than is the case in much previous research or popular cultural discourse. That is, we must understand YP’s talk not simply as a representation of “experience”, but as significantly constrained by competing socio-cultural pressures on what it is possible or acceptable for a young person to say; and understand that this in turn has significant implications for the ongoing social construction of health and wellbeing of young people within contemporary society.

Narratives are sometimes characterised as having a “beginning, middle and end”, although I have questioned the apparent neatness of such a concept. As previously noted, narratives are heard, taken up and transformed differently by different audiences at different times, never entirely giving “the last word”. My aim now is for the narratives set out here – those of the ten young people who contributed so fully, and my own narrative woven around these - to be taken up and developed further by others, with the hope of enabling new ways of understanding and responding to those who are suffering.

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Appendices

Appendix 1: University Confirmation of Sponsorship

John M Senior
BSc MSc DSc PGCE CEng FIET FRSA FHEA
Professor of Communications Networks
Pro Vice-Chancellor (Research)
and Dean of Faculty

Ms Wendy Solomons
1F417
School of Psychology
Health and Human Sciences Research Institute
University of Hertfordshire
College Lane
Hatfield
Herts AL10 9AB

University of Hertfordshire
Hatfield, Hertfordshire
AL10 9AB
UK

Switchboard 01707 284000
Fax 01707 284115
www.herts.ac.uk

5 January 2010

Dear Ms Solomons

PROJECT TITLE: Experiences of Young People Living with CFS/ME
Project No. (R1): N/A NHS REC no. 10/H0301/4
CHIEF INVESTIGATOR: Ms Wendy Solomons
SUPERVISORS: Professor Fiona Brooks

This letter is to confirm that the above project complies with the University of Hertfordshire's research governance criteria. On this basis the University is willing to act as sponsor.

The project is not a clinical trial according to the criteria laid out by UM Association Ltd insurers and therefore indemnity can be given. A copy of the letter of indemnity is attached.

Any changes to the duration of the project, investigators, or deviations from the protocol may negate this cover and sponsorship arrangements. Should such a change be made then the Chief Investigator should be advised that the UH Research Office and the awarding ethics committee will need to be notified and advice sought about whether the sponsorship agreement still stands.

Yours sincerely

Professor John Senior
Pro Vice-Chancellor (Research)

Tel: 01707 284300
Fax: 01707 284781
Email: j.m.senior@herts.ac.uk



Appendix 2: Ethical Approval



National Research Ethics Service

Essex 1 Research Ethics Committee

East of England REC Office 3
Level 9
Terminus House
Harlow
Essex
CM20 1XA

Telephone: 01279 413136
Facsimile: 01279 451546

11 March 2010

Ms Wendy Solomons
Clinical Psychologist
University of Hertfordshire
DClinPsy, Health Research Building
University of Hertfordshire
College Lane, Hatfield
AL10 9AB

Dear Ms Solomons

Study Title: Narratives of Young People (aged 13-18) living with
Chronic Fatigue Syndrome / Myalgic Encephalomyelitis
(CFS/ME)
REC reference number: 10/H0301/4
Protocol number: 1

Thank you for your letter of 22 February 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Appendix 3: Material for Participants and Parents
Invitation Letters and Participant Information Sheets

1F418, Health Research Building
University of Hertfordshire
College Lane
Hatfield
Herts AL10 9AB

May 2010

Hi,

My name is Wendy Solomons, and I work at the University of Hertfordshire. I am doing some research to improve people's understanding of what it's like for young people (teenagers) to live with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME). I hope that this will improve people's ability to help and support young people with this condition.

Since you are a young person living with CFS/ME, I'm hoping that you would be interested in taking part in this research. This would involve talking to me about your experiences of living with this condition - telling me what things have been like *for you*. We think that your views are important in helping adults understand this condition better.

This research is supported by West Hertfordshire Hospitals NHS Trust, and by Dr Anthony Cohn, (Consultant Paediatrician) and his colleagues who work with young people with CFS/ME within the Trust. The research is also supported by the University of Hertfordshire.

(Please note: you may have been contacted before about a separate small research project, which was looking at the services provided for young people in Hertfordshire with CFS/ME. This is NOT the same research! This new research is aimed at understanding wider issues facing young people with CFS/ME, not just things to do with healthcare services. It doesn't matter if you took part in this earlier project or not - you are still eligible for this new research.)

Attached is an Information Sheet for you, giving more details about the research. (There is also a copy for your parent/guardian). Please read this, talk it over with your parent, and then feel free to ask any questions - either by talking to Dr Cohn or your usual contact in the CFS team, or by contacting me. My contact details are on the information sheets - including email and mobile phone - and I would be very pleased to hear from you and/or your parent.

If you think that you might be interested in taking part, please could you or your parent contact me within the next few days. You can of course change your mind at any time without giving a reason, and your decision will not affect the health care you receive from the professionals within the Trust.

Thanks for your time. I hope that this seems interesting to you, and hope to hear from you soon.

With best wishes,

Wendy Solomons
Clinical Lecturer
University of Hertfordshire
w.solomons@herts.ac.uk

1F418, Health Research Building
University of Hertfordshire
College Lane
Hatfield
Herts AL10 9AB

May 2010

Dear Parent,

My name is Wendy Solomons, and I work at the University of Hertfordshire. I am carrying out research as part of my Doctorate into the experience of young people who are living with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME), which I hope will improve people's understanding – and their ability to help – young people with this condition.

This research is supported by West Hertfordshire Hospitals NHS Trust, and by Dr Anthony Cohn, (Consultant Paediatrician) and his colleagues who work with young people with CFS/ME within the Trust. The research is also supported by the University of Hertfordshire.

(Please note: you may have been contacted before about a separate small research project, which was looking at the services provided for young people in Hertfordshire with CFS/ME. This is NOT the same research! This new research is aimed at understanding wider issues facing young people with CFS/ME, not just things to do with healthcare services. It doesn't matter if you took part in this earlier project or not – you are still eligible for this new research.)

We are hoping that your child would be interested in taking part in this new research, which would involve talking to me about their experiences of living with this condition. Attached is an Information Sheet for you, giving more details about the research, and a similar version for your child to read. After reading this, please do feel free to ask any questions – either by talking to Dr Cohn or your usual clinical practitioner in the CFS team, or by contacting me. My contact details are on the information sheets – email and mobile phone – and I would be very pleased to hear from you and/or your child.

If you think that you and your child might be interested in taking part, please contact me within the next few days. You can of course change your mind at any time without giving a reason, and your decision will not affect the health care you receive from the professionals within the Trust.

Thank you for your time. I hope that this is of interest to you and your child, and hope to hear from you soon.

With best wishes,

Wendy Solomons
Clinical Lecturer
University of Hertfordshire
w.solomons@herts.ac.uk

Experiences of Young People Living with Chronic Fatigue Syndrome (CFS/ME)



A research project that you might want to take part in

I'm asking if you would like to talk to me, to help people understand more about what it's like for young people like you to live with chronic fatigue syndrome (CFS/ME). Before you decide if you want to take part, it's important to understand what it will involve for you. So please read this leaflet carefully, think about it, and talk to your family or friends about it if you want.

Why am I doing this research?

There has already been some research done with adults, about what life is like for older people living with CFS/ME. But life for younger people may be quite different! So it's important to know more about what it's like for young people to live with CFS/ME, and how this changes over time. This should help people provide better support for young people with CFS/ME in future.

Why have I been asked to take part?

Because you are aged 13-17 and have been diagnosed with CFS/ME - and your views are important. In total, I hope that about 12 young people like you will take part.

Do I have to take part? What will happen to me if I take part?

No, it's up to you. Even if you decide to take part, you are free to stop at any time without giving a reason. Deciding to take part or not won't affect the care that you are receiving.

I will arrange to meet with you, at a time & place to suit you (eg, your home). I will answer any questions you or your parents have. I will then ask you to sign a consent form, saying that you are happy to take part in the research. If you are under 16, your parent will also need to sign a form giving consent for you to take part (ie, we need consent from both of you).

I will then talk with you about your experiences of living with CFS/ME. You can say whatever you like - there are no right or wrong things to say! Because I am interested in what things are like from *your* point of view, we'll need to speak on our own, without family or friends in the room. The meeting will last about 1 hour, but we can stop or take breaks whenever you want.

Then, if you're still happy to be involved, I'll contact you again about a year later for a similar meeting, to see how things have gone over that year. If you want, you can also bring along any items that you have gathered over the year, that help you communicate more about your memories and experiences: eg, photos, diary/ blog entries, music... it's up to you. After we've talked about these things, you would take them back with you - I don't need to keep them.

I will need to audiotape our conversations to make sure I remember them properly. Later I will write down what we have said, but I will remove any names and any information that might identify you or other people you speak about. Members of the research team at the University will check that everything has been written down and reported properly. At the end of the study, I will erase all tapes.

If you need to travel to our meetings, keep your receipts, and I will refund this cost. At the end of our meetings, you'll be offered a £10 voucher for a shop of your choice as a "thank you" for your time.

What are the risks of taking part?

There are no known risks. However, we will be talking about how CFS/ME has affected your life, and it may be that thinking about these things makes you feel upset. If this happens, you can talk to me, or if you want I can put you in touch with a psychologist or group for ongoing support. We have had training to support people with upsetting feelings, and who live with illnesses like CFS/ME.

What if there is a problem?

If you want to talk about anything to do with the research you can speak to me, to your parents, or your health carer. Independent information & advice is available from PALS (Patient Advice and Liaison Service) on 01923 217198. If you want to complain about the study or how you have been treated, you or your parents can contact PALS (as above),

or the Independent Complaints Advocacy Service (ICAS) for Bedfordshire & Hertfordshire at Pohwer ICAS, Hertlands House, Primett Road, Stevenage, Herts, SG1 3EE. (Tel: 0845 456 1082).

What are the benefits of taking part?

Taking part in this study will give you a chance to speak openly about your views and experiences, and you may find this a positive experience. Your contribution should help us gain a better understanding of what it is like for young people to live with CFS/ME. The aim is for this to lead to better treatment of young people with CFS/ME in the future.

Will anyone else know I'm doing this?

If you agree to take part in the study, we will keep your information in confidence, stored in a safe locked location. The only people who could see this would be members of the research team, and people who monitor research to check that it is being done properly. The results of the project will be written up in a report. This may include quotes from your interview, but all names and identifying details will be changed, so no-one will be able to tell who you are from it - what you say is confidential.

The ONLY time I would ever break this confidentiality is if I thought that you or someone else was at serious risk of harm, and I needed to speak to someone to make sure that you/they were safe.

Who is organizing & funding this research?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. It is supported by West Hertfordshire Hospitals NHSTrust.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee (REC). They make sure that the research is fair and useful. This project has been checked by the Essex REC.

If you are interested in taking part, or if you have any questions, please contact me:

Wendy Solomons
Clinical Lecturer
1F417, Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

by email: w.solomons@herts.ac.uk
or TEXT: 079xx xxxxxx

Or if you have any other questions, you can contact:

Dr Anthony Cohn, Consultant Paediatrician, West Hertfordshire Hospitals NHS Trust
Watford General Hospital, Vicarage Road, Watford WD18 0HB

Experiences of Young People Living with CFS/ME: A research project that you might want to take part in



Are you 13 - 17 years old? Have you been diagnosed with CFS or ME?

Do you live in the South-East of England?

If so, I'm asking if you would like to talk to me as part of a research project designed to help people understand more about what it's like for young people to live with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME). Before you decide if you want to take part, it's important to understand what it will involve for you. So please read this leaflet carefully, think about it, and talk to your family or friends about it if you want.

Why do this research?

There has already been some research with adults, about what life is like for older people living with CFS/ME. But life for younger people may be quite different! It's important to know more about what it's like for young people like you to live with CFS/ME, and how this changes over time, so people can provide better support for young people with CFS/ME in future.

Why have I been asked to take part? Do I have to take part?

You're being asked because you are aged 13-17 and have been diagnosed with CFS/ME - and your views are important. In total, I hope that about 12 young people like you will

take part. But it's up to you - you don't have to take part. Even if you decide to take part, you are free to stop at any time without giving a reason.

What will happen to me if I take part?

I will arrange to meet with you, at a time & place to suit you (eg, your home). I will answer any questions you or your parents have. I will then ask you to sign a consent form, saying that you are happy to take part in the research. If you are under 16, your parent will also need to sign a form giving consent for you to take part (ie, we need consent from both of you). I will then talk with you about your experiences of living with CFS/ME. You can say whatever you like - there are no right or wrong things to say! Because I am interested in what things are like from your point of view, we'll need to speak on our own, without family or friends in the room. The meeting will last about 1 hour, but we can stop or take breaks whenever you want.

Then, if you're still happy to be involved, I'll contact you again about a year later for a similar meeting, to see how things have gone over that year. If you want, you can also bring along any items that you have gathered over the year, that help you communicate more about your memories and experiences: eg, photos, diary/ blog entries, music... it's up to you. After we've talked about these things, you would take them back with you - I don't need to keep them.

I will need to audiotape our conversations to make sure I remember them properly. Later I will write down what we have said, but I will remove any names and any information that might identify you or other people you speak about. At the end of the study, I will erase all tapes.

If you need to travel to our meetings, keep your receipts, and I will refund this cost. At the end of our meetings, you'll be offered a £10 voucher for a shop of your choice as a "thank you" for your time.

What are the risks of taking part? What if there is a problem?

There are no known risks. However, we will be talking about how CFS/ME has affected your life, and it may be that thinking about these things makes you feel upset.

If this happens, you can talk to me, or if you want I can put you in touch with a psychologist or group for ongoing support. We have had training to support people with upsetting feelings, and who live with illnesses like CFS/ME. If you're unhappy about anything to do with the research, you can contact the project supervisor, Professor Fiona Brooks, at the University of Hertfordshire (f.m.brooks@herts.ac.uk).

What are the benefits of taking part?

Taking part in this study will give you a chance to speak openly about your views and experiences, and many people find this a positive experience. Your contribution also should help us gain a better understanding of what it is like for young people to live with

CFS/ME. The aim is for this to lead to better treatment of young people with CFS/ME in the future.

Will anyone else know I'm doing this?

If you agree to take part in the study, we will keep your information in confidence, stored in a safe locked location. The only people who could see this would be members of the research team, and people who monitor research to check that it is being done properly.

The results of the project will be written up in a report. This may include quotes from your interview, but all names and identifying details will be changed, so no-one will be able to tell who you are from it - what you say is confidential. The ONLY time I would ever break this confidentiality is if I thought that you or someone else was at serious risk of harm, and I needed to speak to someone to make sure that you/they were safe.

Who is organizing & funding this research? Who has reviewed it?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. Before any project like this goes ahead, it has to be checked by a Research Ethics Committee (REC). They make sure that the research is fair and useful. This project has been checked by the Essex REC and the University of Hertfordshire.

If you are interested in taking part, or if you or your parents have any questions, please contact me:

Wendy Solomons

Clinical Lecturer

1F417, Health Research Building by email: w.solomons@herts.ac.uk

University of Hertfordshire

College Lane or TEXT: 07963 xxxxxx

Hatfield

AL10 9AB

Information Sheet for Parents

Experiences of Young People Living with Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME)

Information about the research

Your child is being invited to take part in a research study. Before deciding whether to take part, it is important for you and your child to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like your son or daughter to take part.

What is the purpose of the research?

As you are aware, Chronic Fatigue Syndrome / Myalgic Encephalomyelitis (CFS/ME) can have a big impact on life. There has already been some research done about the ways in which CFS/ME can affect adults. However, there has been much less research with children and young people, so we have much less understanding of how CFS/ME affects them. This research aims to increase understanding of what it is like for young people to live with CFS/ME from their perspective, and how this changes over time. This should help people (eg, health care providers, teachers and others) provide better support for young people with CFS/ME in future.

Why has my child been chosen?

Your child has been chosen to participate because s/he is aged 13-17 and has been diagnosed with CFS/ME. It is hoped that approximately 12 young people in West Hertfordshire will take part in this research.

Does my child have to take part?

No, it is up to you and your child to decide whether or not to take part. If your child does want to take part, AND you agree, you will both be asked to sign consent forms to show your agreement. (Children under 16 can only take part if *both child and parent* give consent.) However, your child is still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.

What will happen to my child if they take part? What will they have to do?

I will arrange to meet with you and your child at a time & place to suit you (eg, your home). At the start, I will answer any questions you or your child has, and then will ask you both to sign consent forms, saying that you are happy to take part in the research.

I will then talk with your child about their experiences of living with CFS/ME. There are no right or wrong things to say - I am simply interested in what things are like from their point of view. For this reason, I will need to speak to your child alone, without any family or friends in the room – although it would of course be helpful if you are nearby, if your child would like this. The meeting will last about 1 hour, but we will stop or take breaks whenever your child wants. If we meet away from your home (eg, at the University of Hertfordshire) I can provide refreshments for your child.

Then, if you are still happy to be involved, I will contact you again about a year later to arrange a similar meeting with your child, to see how things have gone over that year. Your child can also bring along any items that they have gathered over the year, that help them communicate more about their life: photos, diary/ blog entries, music... or anything else they think of that feels important to them. After we have talked, your child would keep these items – they do not need to be left with me.

I will need to audiotape conversations with your child, to make sure I remember them accurately, but will erase the tapes at the end of the study. I will transcribe (write down in detail) everything that we have talked about, but when doing this I will remove names and any information that might identify your child or other people spoken about. Members of the research team at the University of Hertfordshire will check that everything has been transcribed and reported properly.

If you or your child need to travel to these meetings, keep your receipts, and I will refund this cost. At the end of our meetings, your child will be offered a £10 voucher for a shop of their choice as a “thank you” for their time.

What are the possible risks of taking part?

There are no known risks. However, we will be talking about how CFS/ME has affected your child's life, and it may be that thinking about these things could be distressing to them. If this happens, they can talk to me, or - if they want - I can put them in contact with a local clinical psychologist or support group for ongoing support. We have had special training to support people with upsetting feelings or emotions, and who live with illnesses like CFS/ME.

What are the benefits of taking part?

Taking part in this study will give your child a chance to speak openly about their views and experiences, and many young people find this a positive experience. Their contribution should help us gain a better understanding of what it is like for young people to live with CFS/ME. The aim is for this to lead to better treatment of young people with this condition in the future. Your child may also feel good to know that they are contributing in this way.

Will my child's part in this study be kept confidential?

All information which is collected will be kept strictly confidential. Any information about your child will be anonymised (ie, have their name and other identifying details) removed so that they cannot be recognised from it. Information will be stored in a locked filing cabinet and will only be able to be accessed by the researcher and others directly involved in the research. Additionally, relevant sections of data collected during the study may be looked at by authorised individuals from West Hertfordshire Hospitals NHS Trust Research & Development team or regulatory authorities, who monitor the quality of all research to ensure that it is being conducted properly. The research team have a duty of confidentiality to your child as a research participant.

The results of the research will be written up in a report, and this may contain quotes from the young people who have taken part – but all names and other identifying details will be removed, so they cannot be recognized from this.

Your child's paediatrician will know that your child is taking part in the study. However, he will not know any details of what your child discusses in the interview. Disclosure of any personal information from the interview would only occur in exceptional circumstances, if your child revealed information that may indicate a risk to themselves or others.

If the researcher is worried about your child (for example, if they became very distressed when taking part in the interview), she will discuss it with them in the first instance. For some concerns (eg, if she felt your child was very low or depressed), she would contact you to discuss this. In exceptional circumstances (eg, if she is concerned that your child might harm themselves or other people, or is worried that someone else might be harming your child), she might have to talk to other professionals about these issues.

What will happen to the results of the research study?

The results of the research will be written up as part of my Doctorate in Health Research. All information will be carefully anonymised, so that none of the young people can be identified. A copy of the research will be kept in the University of Hertfordshire library. It is intended that the research will be submitted for publication in peer-reviewed journals and conferences, so that health professionals (and others involved in the care of young people with CFS/ME) can learn from this.

The written transcript of your child's anonymised interview will be kept in a secure location for five years, in line with University of Hertfordshire guidelines. After this time, it will be destroyed securely.

If you or your child would like a summary of the results, please let me know.

What if there is a problem?

If you want to talk about anything to do with the research, you or your child can speak to me, Wendy Solomons, or your health carer. Independent information & advice is available from PALS (Patient Advice and Liaison Service) on 01923 217198.

The normal NHS complaints mechanism is available to you if you wish to complain about any aspect of the way you are approached or treated during the course of this study. Formal complaints should be addressed to: PALS Office, Watford General Hospital, Vicarage Road, Watford, Hertfordshire, WD1 8HB. Should you require independent advice about making a complaint, you may wish to contact the Independent Complaints Advocacy Service (ICAS) for Bedfordshire & Hertfordshire at Pohwer ICAS, Hertlands House, Primett Road, Stevenage, Herts, SG1 3EE (Tel: 0845 456 1082)

Who is organizing & funding this research?

This research is being conducted as part of my Doctorate study, sponsored by the University of Hertfordshire. It is supported by West Hertfordshire Hospitals NHSTrust. The researcher has undergone all the usual checks (eg, CRB) required by health professionals.

Who has reviewed the study?

Before any project like this goes ahead, it has to be checked by a Research Ethics Committee. They make sure that the research is fair and useful. This project has been checked by the Essex Research Ethics Committee.

If you and your child are interested in taking part, or if you have any questions, please contact me:

Wendy Solomons
Clinical Lecturer
1F417, Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB
by email: w.solomons@herts.ac.uk or TEXT: 07963 xxxxxx

Or if you have any other questions, you can contact:
Dr Anthony Cohn, Consultant Paediatrician
West Hertfordshire Hospitals NHS Trust
Watford General Hospital, Vicarage Road, Watford WD18 0HB

This information sheet is for you to keep. A similar information sheet is provided for your child. If your child wishes to participate in the study, you will have a copy of the consent form to keep as well.

Thank you for time.

Appendix 4: Clinician Reminder Letter for Potential Participants

[Trust Heading / Localised to Hospital Site]

[address]

[date]

Dear

You'll remember that, about a week ago, I gave you some information about a research study being carried out at the University of Hertfordshire, about the experiences of young people living with CFS/ME.

This letter is just a reminder that, if you are interested in taking part in this research - or just finding out more - you should contact Wendy Solomons (Clinical Lecturer at the University of Hertfordshire) *within the next 7 days*. Wendy's contact details are below.

As explained, it is entirely your decision whether to take part in this research or not. Your decision will not affect the professional care you receive from myself or my colleagues.

I hope that, if you decide to take part, you find this an interesting and worthwhile experience!

With best wishes,

[name]

[professional title]

Paediatric CFS Service

If you are interested in taking part, or if you have any questions, please contact:

Wendy Solomons
Clinical Lecturer
1F417, Health Research Building
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

by email: w.solomons@herts.ac.uk or TEXT: 07963 xxxxxx

Appendix 5: Advertisement for AYME Newsletter

Experiences of Young People Living with CFS/ME: A research project you might want to take part in



**Are you 13-17 years old? Have you been diagnosed with CFS or ME?
Do you live in the South-East of England?**

If so, you could make an important contribution to research being done at the University of Hertfordshire to help people understand more about living with CFS/ME.

Why do this research?

There is already some research about what life is like for adults living with CFS/ME. But life for younger people may be quite different! It's important to know more about what it's like for young people like you to live with CFS/ME, so people can provide better support for young people with CFS/ME in future. To do this, we need to hear from people like YOU!

What would this involve?

I would arrange to meet with you, at a time & place to suit you (eg, your home) to talk with you about your experiences of living with CFS/ME. You can say whatever you like - there are no right or wrong things to say! We would usually talk for about 1 hour, but we can stop or take breaks whenever you want. Then, if you're still happy to be involved, I would contact you again about a year later for a similar meeting, to see how things have gone over that year.

If you need to travel to our meetings, I can refund this cost. At the end of our meetings, you'll be offered a £10 voucher for a shop of your choice as a "thank you" for your time.

For more information, you or your parents can contact me, Wendy Solomons:

Clinical Lecturer
1F417, Health Research Building
University of Hertfordshire
Hatfield AL10 9AB

by email: w.solomons@herts.ac.uk
or TEXT: 07963 xxxxxx

Appendix 6: Background Information Sheet

**Young People Living with CFS/ME
Background Information Sheet**

Date: _____

Participant's Name: _____

Participant ID: _____

Address: _____

Phone / mobile: _____

Email(s): _____

Date of Birth: _____ Age: _____ Male / Female

Nationality: _____ Ethnic background _____

Parent(s) occupation(s): _____

GP / Paediatrician: _____

diagnosis by who / when _____ / (date) _____

Other professionals involved? _____

Welfare/ benefits: _____

Current education provision: _____

Prior education provision (if different) _____

Any other relevant info?

Appendix 7: Consent Forms

CONSENT FORM FOR YOUNG PERSON OVER 16

Title of Project: Experiences of Young People Living with CFS / ME

Name of Researcher: Wendy Solomons (University of Hertfordshire)

Participant Identification Number:

Please initial boxes

1. I confirm that I have read and understand the information sheet dated February 2010 (Version 2) for the above study. I have had opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that my interview will be audio taped.
4. I understand that when a report is written and published about the study, quotes from my interview may be used, but all identifying information will be removed. I give permission for publication of these anonymised quotes.
5. I understand that relevant sections of data collected during the study may be looked at by authorised individuals from West Hertfordshire Hospitals NHS Trust or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
6. I give my agreement to take part in the above study.

Name of Patient

Date

Signature

Researcher

Date

Signature

When completed: 1 copy for participant; 1 copy for researcher

ASSENT FORM FOR YOUNG PEOPLE UNDER 16

Title of Project: Experiences of Young People Living with CFS / ME

Name of Researcher: Wendy Solomons (University of Hertfordshire)

Participant Identification Number:

If "Yes", put your initials in each box

- | | |
|---|------------------------------|
| Have you read (or had read to you) about this project? | <input type="checkbox"/> |
| Has somebody else explained this project to you? | <input type="checkbox"/> |
| Do you understand what this project is about? | <input type="checkbox"/> |
| Have you asked all the questions you want? | <input type="checkbox"/> |
| Have you had your questions answered in a way you understand? | <input type="checkbox"/> |
|
 |
<input type="checkbox"/> |
| Do you understand it's OK to stop taking part at any time? | <input type="checkbox"/> |
| Do you understand that you will be audio taped as part of the study? | <input type="checkbox"/> |
| Do you understand that we may use quotes of what you say in the final
published write-up, & these will be anonymised (names will be removed) | <input type="checkbox"/> |
| Are you happy to take part? | <input type="checkbox"/> |

If any answers are "no" or you don't want to take part, don't sign your name!

If all your answers are "yes" and you do want to take part, write your name below:

Your name _____

Date _____

The researcher who explained this project to you needs to sign too:

Print Name _____

Sign _____

Date _____

When completed: 1 copy for participant; 1 copy for researcher

Appendix 8: Interview Topic Guides

Young people living with CFS/ME: Interview Guide - First Interview (2010)

Main areas	Prompts (<i>use only if needed</i>)	Domains
General background	As I said before, I'm hoping to hear from you what it's like for you to live with CFS/ME*; but before we talk about CFS/ME, it would be good to hear a bit about you as a person, more generally... who you live with, what you like doing.... That sort of thing.	Family & "important others" How would you describe yourself? likes / dislikes etc
Living with CFS/ME Onset	<p>Can we talk now about CFS/ME, & how it has affected you? <u>How did you become aware that that something was wrong?</u></p> <p>What did you notice? Can you describe to me what happened? Who else noticed? How did they react? What happened then?</p> <p>Making sense What did you think was happening to you? / How did you make sense of it? (at the time) Who helped you with [understanding] this? How?</p> <p>Experiences with other people / Seeking help Who did you turn to for help? What happened? - what sort of help were you wanting (from different people)?</p> <p>Who else needed to be told? How & What did you tell them / What happened?</p> <p>How did people <u>respond</u> to the changes in you / yr life? What happened? What was that like?</p>	<p>Physical symptoms Emotional aspects Behaviour / activity Social aspects</p> <p>Sources of understanding: Family Friends Support group / charity Media / internet / other</p> <p>Health professionals First? Then? (referrals) Diagnosis? (what did they call it?)</p> <p>Family members Friends School Others</p>
Changes over time / turning points How things are now	<p>How have things changed for you since then? (ups & downs) Have there been any particular "turning points"?</p> <p>Tell me a bit about your life now (general) How do you <u>experience CFS/ME now</u>?</p> <p>Are there ups and downs? Can you tell me about some of these? What has helped? Made things worse?</p> <p>Other people How has your CFS/ME <u>affected other people</u>? How has your CFS/ME been affected by other people?</p>	<p>Physical, Emotional Social reactions (local, wider culture)</p> <p>Managing symptoms Supporting more generally</p> <p>Practicalities Worrying etc</p> <p>Parents / Family Friends / peers (old friends? New?) School / health professionals Indirect contacts (eg, soc networking)</p>

		"Society" (& media)
Contexts	<p>Age(if not already covered)</p> <p>How do you think your life (with CFS/ME) differs from lives of other teenagers, who don't have this condition?</p> <p>How do you think life with CFS/ME might be different for teenagers with CFS/ME now, compared with:</p> <ul style="list-style-type: none"> ▪ adults with CFS/ME? ▪ younger children with CFS/ME? ▪ Teenagers with CFS/ME 10 years ago? <p>What is <u>NOT</u> affected by CFS/ME?</p> <p>How do you think your life with CFS/ME is affected by you being a girl / boy?</p> <p>How do you think your life with CFS/ME is (or is not) affected by... [culture](only if raised by YP)</p>	<p>Social networking / electronic comm / use of technology</p> <p>Autonomy</p> <p>Going out / socialising</p> <p>Dating / boyfriends / girlfriends</p> <p>Eg, Religion / faith</p>
Thinking about the future	<p>Do you think about the future?</p> <ul style="list-style-type: none"> • How do you <i>think things will be</i> for you, a year from now? • What do you <i>want</i> from your life... your future? 	
Reflections / identity	<p>Overall, how would you say you have changed, as a person, from your experiences living with CFS/ME?</p> <p>Are there any positive things that have happened / that you've learned, as a result of your experiences with CFS/ME?</p> <p>If you could give a message to the world, what would you tell them about CFS/ME?</p>	
Memory box	Thinking ahead to next time... Suggestions	
Ending	<p>How has it been, talking to me today?</p> <p>Are there any other things that you think it is important for me – or other people – to understand about you, and your experiences with CFS/ME?</p> <p>Any things that you want to say more about?</p> <p>Any things that you're feeling uncomfortable about having said? (Any things that you don't want to be included in your account?)</p>	

Closing up... reminder of what happens next:

- *WS contact details in case participant needs to get in touch etc.*
- *Agree whether ongoing contact (email? Text?)*
- *provisional plans for next year.*

NB – REALLY WANT TO SEE YOU AGAIN, WHATEVER HAPPENS OVER THE YEAR – eg, whether life has changed or seems just the same... if you're ill or better... whatever!

THANK YOU!! - ARRANGEMENTS FOR GIVING / EMAILING VOUCHER OF CHOICE

Young people living with CFS/ME: Second Interview (2011-12)

Main areas	Prompts (<i>only where needed</i>)	Domains
General background	As I said before, I'm hoping to hear from you what it's been like for you to live with CFS/ME* over the last year (Do you still consider yourself to have CFS/ME?)	
The last year (main focus) Memory box/ items to help	Imagine you're telling me the "story" of the last year of your life, since we last met in [month] What does that represent for you? What memories does that bring back? Tell me (more) about that (time) ***LANDSCAPE OF ACTION *** ***LANDSCAPE OF UNDERSTANDING *** High points / Low points / Turning points Your life NOW (recent) <i>(later)</i> How did you decide what to put in memory box? Were there memories you felt unsure about sharing/ chose not to include? Why?	Physical symptoms Behaviour / activity Social aspects Emotional aspects People: Parents / Family Friends / peers (old friends? New?) School Health professionals Other people with CFS/ME Indirect contacts (eg, social networking), "Society" (& media) Important events / markers: Holidays Birthday School / trips Making decisions (eg, options)
As narratives are given, consider prompting further exploration of...	Exploring dilemmas emerging in first interviews - Expressing emotion / distress at past (and present) events* - Telling others (or not) - & why - Telling of problems / "not complaining" - Being "believable" while telling of "not being believed" - "Physical & real" vs "psychological" Family scripts - Being ill / coping with illness - "giving in / giving 100%", competitiveness - Education / career trajectory (& cf siblings) - Emotional expression (incl anger)*	*Especially anger / frustration examples of times over the last year when they have experienced this, or "strong emotions" If not, why not? (felt / expressed) what is felt to be acceptable? Cf seeing psych/therapist

<p>Contexts <i>(if not already covered)</i></p>	<p>Age</p> <ul style="list-style-type: none"> ▪ How do you think your life (with CFS/ME) over the last year has differed from lives of other teenagers, who don't have this condition? <i>(or – from teenagers with more severe CFS/ME)</i> ▪ How do you think your life (with CFS/ME) over the last year has been different as a result of being [age], rather than [age last year]? <p>Gender School/college/post-education Social group Religious / cultural beliefs <i>(if raised by YP)</i></p>	<p>Social networking / electronic comm / use of technology</p> <p>Autonomy</p> <p>Going out / socialising</p> <p>Dating / boyfriends / girlfriends</p> <p>faith</p>
<p>Thinking about the future</p>	<p>Do you think about the future?</p> <ul style="list-style-type: none"> • How do you <i>think things will be</i> for you, a year from now? • What do you <i>want</i> from your life... your future? 	
<p>OR: Trajectory</p>	<p>How has the trajectory / path of your life changed over the last year</p> <p>How to you see it continuing – or changing – in the future?</p>	
<p>Reflections / identity</p>	<p>Overall, how would you say you have changed, as a person, from your experiences over the last year living with CFS/ME?</p> <p>How would you describe yourself now?</p>	
<p>Ending</p>	<ul style="list-style-type: none"> ▪ How has it been, talking to me today? And last time? ▪ Do you think that talking to me, last time, affected how you think about, or live with CFS/ME? <p>Are there any other things that you think it is important for me – or other people – to understand about you, and your experiences with CFS/ME?</p> <p>Any things that you want to say more about?</p> <p>Any things that you're feeling uncomfortable about having said?</p> <p>Any things that you don't want to be included in your account?</p>	

Closing up... reminder of what happens next:

- *WS contact details in case participant needs to get in touch etc.*
- *Agree whether wanting feedback / ongoing contact (email? Text?)*
- *Likely timescale for feeding back*

THANK YOU!! - ARRANGEMENTS FOR GIVING / EMAILING VOUCHER OF CHOICE

Appendix 9: Transcription Symbols

□

Transcription symbols used (simplified and adapted from Jefferson, 2004)

<i>Transcription symbols</i>	Example	
[square brackets]	A: then [I said] B: [yeah] exactly	Represent overlapping speech
= equals sign	A: then I said= B: =yeah exactly	Represent 'latching' where there is no perceptible gap between the end of one person's speech and the beginning of another's.
(2) (.), (#)	A: It was like this (#) he came out (.) and (.) then (2)	Numbers in brackets represent pauses in seconds. (.) represents a brief pause of 0.1 seconds, like a catch between words. (#) represents a pause longer than (.), but less than 1 second
Hyph-	A: She wa- no she di-did it	A hyphen indicates a broken off utterance or a stutter.
: colon	A: she was so::: wrong!	One or more colons indicate an extension of the preceding sound.
<u>Underline</u>	A: I couldn't <u>believe</u> it, HOW COULD SHE? I °trusted °her	Underlining indicates an emphasis on the word or part of the word.
CAPITALS		Capital letters indicate words spoken louder than surrounding talk.
°degree°		Degree symbols (°) around words indicates they are spoken quieter than surrounding talk.
↑↓		Shift to especially high or low pitch
.hh	A: and .hh I just thought	A full stop preceding a word indicates an intake of breath. .hh indicates inbreath.
hh		Hh indicates outbreath. Number of h's indicate length of breath.
hheh		Hheh indicates outbreath/short laugh sound. Hehheh indicates more obvious laughter.
.?!,	A: What was it then?	Punctuation marks indicate intonation rather than grammar
"speech marks"	A: She just said "yeah"	Speech marks indicate the speaker imitating another person
(xxx)	A: Yeah *I *could (xxx)	Indicates inaudible speech

((double brackets))	A: Hahaha! ((laughs))	A non-speech element such as laughter or a descriptor
[square brackets]	A: [Name] was going to	Square brackets indicate deliberately omitted text, for example names, for confidentiality purposes.
Adam (1):344		A citation following a quote indicates its location within the text. This includes the speaker's name, (location in 1 st or 2 nd interview): and line number

Appendix 10: Confidentiality Agreement with Transcriber

University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:

Wendy Solomons ('the discloser')

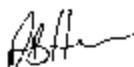
and

Adele Herson ("*The Typing Works*") ('the recipient')

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.



Signed:.....

Name:..... Adele Herson.....

Date:..... 20th December 2011.....



Appendix 11: Example of Analytic Coding and Notes within MAXqda

This section gives examples of how MAXqda was used to facilitate the process of analysing narratives.

Screens A and B show an extract (lines 24-44) from early in Katie's first interview as marked up using MAXqda.

Coloured "codes" (term used loosely, not in the more specific sense from eg, grounded theory) along the left of the screen show initial marking up of the text: reading for content, structure and performance (although structure and performance, as well as broader storylines, are not fully visible in small extracts like this, but emerge from consideration of the broader narrative.)

Marked sections in **GREEN** show very broad areas of content (eg, symptoms) that were among the first to be noted, mainly as ways to reference areas for further analysis.

Sections in **BLUE** also refer to content, though at a somewhat deeper level (eg, trying to make sense of symptoms, delegitimation of symptoms, or persistence with symptoms).

Sections in **ORANGE** mark some narrative (storied) structure. Initial analysis simply noted the presence of such structure; later, these were re-coded in terms of the type of story eg, stories about how friends have helped (or not!) or broader storylines (eg, onset of illness). However, other structural elements of narrative are not easily marked on short sections of transcript, since they refer to much longer stretches. For example, sections of talk about *persistence* and *trying* to live with symptoms might be noted in blue (as noted above), but are better understood as part of the progression of many short stories, across both interviews, all of which show elements of *persistence*, thus building an impression of work *over time*. Hence my definition of a "narrative" beyond "story".

Sections in **RED** note performative / discursive features. Although it may be argued that ALL talk is performative, this refers to particular features: eg, active voicing and/or mimicry that acts to disparage characters; switching between tense or 1st/2nd person pronouns; use of terms such as "I don't know" or "you know". Initial analysis sometimes simply noted a broad "Discursive Device?", highlighting areas for later consideration; later analysis drew together patterns across narratives, though many are not easily categorised, and are better understood in the context of broader narrative performance across longer stretches of talk, or the context of the YP's overall style.

Not visible in this particular extract, **PURPLE** highlighting was used to indicate areas of expressed emotion (eg, crying) and areas relating to the YP's engagement with me (eg, using expressions like "I don't know if you can understand this but..").

Also visible here are the yellow "sticky notes" symbols (also visible on the left of the "split screen" shot on screen C). These are added throughout analysis. They are attached to the document folders for each young person and each interview (field notes), to each "code" (noting, for examples, early hesitations about whether an idea is worth pursuing, and areas of overlap with other codes), and - attached throughout each transcript - note some of my initial and evolving thoughts. Within the MAXqda program, these are easily viewed by hovering the cursor over them - not something easy to

show on paper! As an indication, I have pasted notes from Katie's section of transcript, as well as my field notes from her first interview, onto the following pages.

Screen C is a screen shot of the full split screen, showing how retrieved sections (lower right screen) - in this example, of "disparaging" voicing, visible by the red code on the lower left screen - are easily shown in their context within a participant's broader narrative (upper right screen). This is important for case-focused narrative analysis, to avoid abstracting "themes" from their context.

This lower right screen also brings together all examples of a selected theme or storyline, bringing different participants' voices closely together to help comparisons. This is also possible on charts generated by MAXqda. An extract of one of these is shown in **Screen D**. These were used more sparingly, but to help give an overview of whether particular features of talk were being noted by some YP more than others, and to help provide a check that all YP's narratives were being attended to equally.

Screen A

The screenshot shows a software application window titled "C:\Users\psyqws\Desktop\Documents\DHRes\MAXQDA\YP-CFSME.mx4 - MAXQDA 10 R240113". The interface includes a menu bar (Project, Edit, Documents, Codes, Memos, Variables, Analysis, Mixed methods, Visual tools, Windows, MAXQDICTIO, Language, Toolbars) and a toolbar. Below the menu is a "Document Browser: P3 Int 1 - Katie" window. The main area is split into two panes. The left pane displays a vertical timeline with various colored lines and markers representing different categories: ..voices, ..positioning, making sense of CFS, responses, symptoms, ..disparaging/ discrediting, ..alternative med technology, ..finding out about M.E., and ..voices. The right pane shows a transcript of a conversation between W and K, with line numbers 24 through 36. The transcript text is as follows:

(5)
 25 W: So (.) in terms of the M.E. (.) how did you become awa:re that (.) something was (.) something was wrong?
 26 K: Well (.) at the end of the Christmas holidays (.) I'd had like a really really busy first term (.) cos everyone said (.) y'know (.)
 "don't feel homesick (.) so just do loads of stuff" (.) so I just took their advice! hheh and did about four different things every
 day (.) after all the school stuff (.)
 27 And then (.) just before I went back I think it was New Year's Day I got (.) a cold (.) a:nd I went back feeling really rough (.)
 28 and (.) I think after (.) the second day back (.) erm I got a temperature and I just felt really awful (.)
 29 And it was (.) it was when it was snowing (.) and I was saying to Mum and Dad on the phone "ohh: I want you to come and
 pick me up" and they were saying "no (.) no" (.)
 30 and then the next day we had a power cut at the school (.) so then "okay we'll come and pick you up then" (.) cos don't want
 to be ill and have a power cut
 31 So I went home and then (.) I got – I started feeling a bit better (.)
 32 from the virus (.)
 33 and stopped having a temperature and everything (.)
 34 and then the next morning (.) I think about three days after the cold thing started (.) I just woke up and (.) felt really really
 really really tired (.) like (.) it was so (.) sudden (.) and I went downstairs to have breakfast (.) sat down at the table (.) and then
 went and lay down on the sofa again hheh (.)
 35 And I was supposed to be going back to school that day (.) but I didn't (.)
 36 And the:en (.) I think (.) the next week I went to a doctor (.) who wasn't my sch- cos my GP's at school (.) I had to go to just
 local (.) random one (.) Aa:nd (1) she said (1) I think someone else had said to us (.) maybe(1) cos I sort of have a homeopath
 (1) um (.) but I only see her about once a year (.) she said (.) "oh maybe it's post-viral fatigue" (.) and I looked that up on the
 internet with my Mum and it all came up with the same stuff M.E. (.) and I had all the symptoms (.) so I said to the doctor-

The bottom of the screen shows a Windows taskbar with various application icons and a system tray displaying the time 12:45 and date 04/03/2016.

Screen B

The screenshot shows a software application window titled "Document Browser: P3 Int 1 - Katie". The window is divided into two main sections. On the left is a vertical timeline with various colored lines and markers representing annotations. On the right is a text area displaying a transcript of a conversation.

Annotations (Left Panel):

- ..voices
- disbelief&deligitmation
- ..worry/scared/anx
- making sense of CFS
- ..disparaging/ discrediting
- responses
- other illness
- DD?
- NOT getting better
- symptoms
- getting better
- keep trying/working
- ..assessment/ diagnosis/ coming to an
- professional system
- .."annoying"
- ..disparaging/ discrediting
- ..voices
- ..impact on me
- being positive
- (can they) understand?

Transcript (Right Panel):

well Mum said (.) "Katie is a bit worried it might be ↑M.E. because all her symptoms are exactly the same (.) and the doctor said "Ooh no: (.) don't be silly why are you worrying about that? Oh that's ridiculous!" (.) you know (.) And I said I'd got really bad headache and it was (.) really bad (.) and she said (.) "Oh we:ll (.) it's- it's not getting worse (.) you don't have a brain tumour so that's fine" (.) you know (.) "you'll be fine!". And then I just (.)wasn't (.) I just kept (.) like that (.) and just not getting better(.) And I think (.) I went back to school (.) for two nights (.) thinking "I'll just build it up" (.) erm (.) cos I thought at that point I'd just get better (.) it's just – it's just (.) post-viral fatigue (.) And (.) I went for two nights and then I came home (.) I was just completely shattered (.)and then just sort of carried on like that (?)

37 W: Mmm.

38 K: Erm (.) And after a while I just kept going back to different doctors

39 W: At the same GP surgery?

40 K: Well – in between that we moved here

41 W: Of course

42 K: So then we tried this one (.) the surgery local to here (.) and the doctor there had to look up M.E. in his book hh (.) one of those medical books (.) And I think we actually knew more than he did (.) so I was quite annoyed and he said (.) "Oh my brother's been feeling off colour since Christmas too"(.) Which was really (.) a bit offensive because (.) you know (.) it was completely (.) dictating my life (WS: mmm) and I couldn't go to school and I couldn't do this couldn't do that - and he was just like "O:h he's feeling off colour too (.) you'll be fine" "Think positively and you'll feel better" (.) hh which is (.) (hh)not the best attitude I think hh (.) Erm (.) ° so I didn't see him again° (.) And then since then I've really seen just my GP at school (.) cos she's a bit more (.) ° understanding°

43 W: Okay (.) Is that the doctor that you talked about before?

44 K: Yeah (.) Errm (.) yeah so that was how it started.

Examples of notes made for Katie (1st interview) to support reflexive analysis

“Field notes” made immediately after 1st interview

First person recruited through AYME.

17, but looks younger. Amazing house and garden, very different from others - quite an intimidating environment for me to go into in some ways.

Dad* has just left very high-powered post as Chief Exec of xxxxxxxxxxxx, Mum is a counsellor. Private boarding school; private homeopath and psychotherapist, and referral to [internationally-renowned] Professor xxxx at [prestigious hospital] through a family friend... Feels quite different from others I've met or spoken to - not sure how this affected by engagement with K.

Interview went OK although again a bit frustrating – I feel we're just skimming the surface, with little emotional depth - is this just because I'm used to clinical interviews focused on psychological thinking?? Also (perhaps interesting) it seemed at times hard to get K to give personal narrative in any conventional sense. She preferred to talk in generalities, abstract, third person. Or is this just my memory? Need to listen to recording... Long interview though – well over an hour - she seemed very willing to talk.

Another concern is that she didn't seem very unwell (or that she'd ever been) compared with others. I know that this is always going to be an issue with “invisible illness”, but the recruitment (through AYME rather than NHS team) means that I have no way of verifying the diagnosis. (I have the names of the doctors involved, but obviously can't contact them). Maybe I'm also influenced by the fact that K told me she'd had IBS since she was 18 months old (I've never heard of this being diagnosed so young, especially since I understand it to be a “diagnosis of exclusion”), was prescribed amitriptyline by her (boarding-school) GP within a couple of months of feeling unwell, and is seeing a psychotherapist – all these lead me to question the applicability of the diagnosis... but of course, that's the point of a contested illness! Why am I falling into this trap?

*Dad was around but on the phone, and didn't seem very interested – a bit dismissive of the research / me.

Notes on emerging analysis

Line 26: **positioning - responsibility?**

Creation date 23/05/2011 15:44:29

"I just took their advice"

K's account sets up the busy term / over-activity as the precursor to the onset of her ME (although she doesn't directly say "this is what causes it"). Her commentary "I just took their advice" works to counter potential accusations that she is to blame for her illness. Note that "everyone said..." she should do loads... this strengthens her claim to a lack of culpability, but also avoids laying the blame on any one person in particular (cf other areas of "not being critical")

Line 29(a) : **child-parent: accountability**

Creation date 23/05/2011 16:16:18

reciprocal roles are talked up here, highlighting issues of power and responsibility. K is positioned as at the mercy of her parents, who do not initially respond.

Line 29(b): **tragic**

Creation date 23/05/2011 16:56:15

"ooh i want you to come and pick me up" - said in (self-)mocking, "tragic" voice

Line 32: **making a "virus" relevant**

Creation date 23/05/2011 16:18:10

although "the virus" is not explicitly cited as the "cause" of the subsequent ME (and indeed is separated off from it - she recovered from the (ordinary) VIRUS, but then became much more ill), talk about its proximity to talk about the later fatigue "makes relevant" theories about post-viral fatigue (and in fact K later talks about post-viral fatigue)

Line 36a: **homeopath diagnosis**

Creation date 23/05/2011 16:51:00

note how adult voice (direct quotes) used to give the diagnosis of post-viral fatigue BEFORE F talks about using the internet for corroboration. Is this important? Because she's not an adult herself? Not "looking for" (wanting?) this diagnosis? But at other times she seems a bit dismissive of the homeopath (Given her Dad's profession, I wonder if HE is disparaging about homeopathy?!)

Line 36(b): **"and I had ALL the symptoms"**

Creation date 23/05/2011 16:59:03

this seems really significant to K's understanding - and possibly the course - of her illness. Although K later makes some distinction between post-viral fatigue and ME, here this is not clear - but a diagnosis of ME would not be applicable at this stage, when she had only had the symptoms for a few weeks.

So... "retrospective smoothing"? sense-making? For herself, or for me - make sure I'm not in any doubt??

Line 36(c): **imitating and mocking**

Creation date 23/05/2011 16:54:16

Said in mocking "imitating" of doctor's voice (Doctor being dismissive... but implying that he is stupid)

consider how this strategy of discrediting may be viewed as in response to the doctor's responses, which are received as disbelief/delegitimizing.

do others use this strategy in this way?

What other types of responses can be seen in response to (talk of situations where there is perceived) disbelief/deligitimation?

Different for interactions with doctors / teachers / peers / Ricky Gervais(!)??

Different for older / younger children?

Line 36(d): P3 - **"getting a diagnosis"**

Creation date 24/05/2011 10:07:14

Although labelled "getting a diagnosis", this account shows a close interplay of describing symptoms, responses (her own, her mother's, the homeopath's and the the doctors') over time.

This "works" for me - it is convincing to me. Much more so than when participants give a list of symptoms, for example. Why else might this be? There is also some emotive language "shattered" (but not too much)... and (like Freya and Becky) the use of "kept" (persistence over time)

Line 42(a) **P3's DDs to discredit doctor**

Creation date 24/05/2011 10:16:22

Questioning his level of knowledge (professional competence):- "he had to look it up in a book" / "We knew more than he did"

Questioning the "appropriateness" of his disclosure (irrelevant, trivialising)

Questioning his ability to understand (empathy and professional understanding)

Questioning his attitude

Mimicking (direct speech, in "stupid" voice), and using a cliched, much-ridiculed phrase ("think positively!"), with laughter (engaging audience?) (ie, "isn't he stupid?!). It's quite effective!

Contrasting him with another (better) GP (ie, not all doctor HAVE to be like this - it's just this one who's rubbish)

Line 42(b) **"think positively!"**

Creation date 26/05/2011 11:49:13

"Think positively and you'll feel better!"

Said in mocking, ironic voice.

Not entirely clear if she is directly imitating this doctor, or indicating his general manner / associating this with more general narrative that she is portraying as stupid

Screen C

The screenshot displays a software application window titled "C:\Users\psyqws\Desktop\Documents\DHRes\MAXQDA\YP-CFSME.mx4 - MAXQDA 10 R240113". The interface includes a menu bar (Project, Edit, Documents, Codes, Memos, Variables, Analysis, Mixed methods, Visual tools, Windows, MAXQDctio, Language, Toolbars) and a toolbar with various icons. The main workspace is divided into several panes:

- Document Browser:** Located on the left, it shows a tree view of documents. The selected document is "P3 Int 1 - Katie" (335). Other documents include "P3 Int 2 - Katie" (231), "P2 Int 2 - Callum" (245), "P1 Int 2 - Freya" (168), "P10 Int 1 - Jess" (280), "P9 Int 1 - Harry" (160), "P8 Int 1 - Adam" (196), "P7 Int 1 - Evie" (223), "P6 Int 1 - Grace" (235), "P5 Int 1 - Becky" (197), and "P4 Int 1 - Danni" (243).
- Timeline:** A central pane showing a vertical timeline of responses. The timeline is color-coded and includes labels such as "responses", "disparaging/ discrediting", "voices", "alternative", "finding out", "technology", "making sense", "worry/scared/a", "disparaging/", "disbelief&deligitmat", "NOT getting better", "DD?", "other illness", "getting better", "symptoms", and "keep trying/working".
- Text View:** On the right, the text of the selected document is displayed. It contains a dialogue between a patient (K) and a doctor (W). The text includes phrases like "it was so sudden", "I went downstairs to have breakfast", "sat down at the table", "and then went and lay down on the sofa again", "And I was supposed to be going back to school that day", "but I didn't", "And then:en I think the next week I went to a doctor who wasn't my sch- cos my GP's at school I had to go to just local random one", "Aa:nd (1) she said (1) I think someone else had said to us (1) maybe(1) cos I sort of have a homeopath (1) um (1) but I only see her about once a year", "she said (1) 'oh maybe it's post-viral fatigue'", "and I looked that up on the internet with my Mum and it all came up with the same stuff M.E. (1) and I had all the symptoms (1) so I said to the doctor- well Mum said (1) 'Katie is a bit worried it might be M.E. because all her symptoms are exactly the same (1) and the doctor said 'Ooh no: (1) don't be silly why are you worrying about that? Oh that's ridiculous!' (1) you know (1) And I said I'd got really bad headache and it was (1) really bad (1) and she said (1) 'Oh we:ll (1) it's- it's not getting worse (1) you don't have a brain tumour so that's fine' (1) you know (1) 'you'll be fine!'. And then I just (1)wasn't (1) I just kept (1) like that (1) and just not getting better (1) And I think (1) I went back to school (1) for two nights (1) thinking 'I'll just build it up' (1) erm (1) cos I thought at that point I'd just get better (1) it's just - it's just (1) post-viral fatigue (1) And (1) I went for two nights and then I came home (1) I was just completely shattered (1), and then just sort of carried on like that (?)", "Mmm.", "Erm (1) And after a while I just kept going back to different doctors", "At the same GP surgery?", "Well - in between that we moved here", "Of course", and "So then we tried this one (1) the surgery local to here (1) and the doctor there had to look up M.E. in his book hh (1) one of those medical books (1) And".
- Retrieved Segments:** A pane at the bottom showing segments retrieved from the document. The selected segment is "Ooh no: (1) don't be silly why are you worrying about that? Oh that's ridiculous! (1) you know". Other segments include "So then we tried this one (1) the surgery local to here (1) and the doctor there had to look up M.E. in his book hh (1) one of those medical books (1) And I think we actually knew more than he did (1) so I was quite annoyed and he said (1) 'Oh my brother's been feeling off colour since Christmas too' (1) Which was really (1) a bit offensive because (1) you know (1) it was completely (1) dictating my life (WS: mmm) and I couldn't go to school and I couldn't do this couldn't do that - and he was just like 'O:h he's feeling off colour too (1) you'll be fine' 'Think positively and you'll feel better' (1) hh which is (1) (hh)not the best attitude I think hh (1) Erm (1) ' so I didn't see him again' (1) And then since then I've really seen just my GP at school (1) cos she's a bit more (1) ° understanding?", and "so she put me on some homeopathic tablets (1) which didn't do anything. Cos lots and lots of people have said 'Oh (1) try this tonic! ' or 'Give her zinc!' or 'She needs some".

The bottom of the window shows a taskbar with various application icons and a system tray displaying the time "12:55" and date "04/03/2016".

Screen D

Coded segments

Code: DD?\disparaging/ discrediting 39 codings from 12 documents and 0 document groups

And there was one teacher who actually got ill at the beginning of Summer term (.) and he wasn't there for a couple of weeks and I said to one of my friends "Oh where's Mr S" (.) and she said "Oh he's got M.E. like you" (1) And he hadn't (.) he'd just got (.) a bit of (.) fatigue or something (.) and he came back a few weeks later and he was absolutely fine (.) and when he saw me he was like "Oh so are you better now?" (1) As if (.) because he didn't have M.E. then I didn't either or something (.) and I must be completely better because he was.

Document	Code	Begin	End	Preview	Author	Creation date	Text seg...	Coverage %
P1 Int 1 - Freya	DD?\disparaging/ discrediting	86	86	And I said – em – so I like found (.) em (.) I-I got my mum to	psyqws	21/11/2012 ...	<input checked="" type="checkbox"/>	1.01
P1 Int 1 - Freya	DD?\disparaging/ discrediting	108	108	and there was proof in her spinal cord that it wasn't - that it	psyqws	21/11/2012 ...	<input checked="" type="checkbox"/>	0.49
P10 Int 1 - Jess	DD?\disparaging/ discrediting	35	35	I just remember going to .hh see Doctor W [GP] (.) and then (.)	psyqws	10/11/2011 ...	<input checked="" type="checkbox"/>	0.00
P10 Int 1 - Jess	DD?\disparaging/ discrediting	50	50	"oh I've gotta go home now I'm too tired"	psyqws	12/11/2011 ...	<input checked="" type="checkbox"/>	0.00
P3 Int 1 - Katie	DD?\disparaging/ discrediting	36	36	the next week I went to a doctor (.) who wasn't my sch- cos my	psyqws	23/05/2011 ...	<input checked="" type="checkbox"/>	0.22
P3 Int 1 - Katie	DD?\disparaging/ discrediting	36	36	"Ooh no: (.) don't be silly why are you worrying about that? Oh	psyqws	23/05/2011 ...	<input checked="" type="checkbox"/>	0.17
P3 Int 1 - Katie	DD?\disparaging/ discrediting	42	42	:So then we tried this one (.) the surgery local to here (.)	psyqws	24/05/2011 ...	<input checked="" type="checkbox"/>	1.41
P3 Int 1 - Katie	DD?\disparaging/ discrediting	48	48	so she put me on some homeopathic tablets (.) which didn't do	psyqws	24/05/2011 ...	<input checked="" type="checkbox"/>	0.42
P3 Int 1 - Katie	DD?\disparaging/ discrediting	67	67	So he said (.) "Ohh I think" – it was just before the end of	psyqws	25/05/2011 ...	<input checked="" type="checkbox"/>	0.45
P3 Int 1 - Katie	DD?\disparaging/ discrediting	67	67	But I'm not very convinced it's going to work (2) Because I'm	psyqws	25/05/2011 ...	<input checked="" type="checkbox"/>	0.31
P3 Int 1 - Katie	DD?\disparaging/ discrediting	73	74	I do: on't really know I mean – I definitely think it's a	psyqws	25/05/2011 ...	<input checked="" type="checkbox"/>	0.93
P3 Int 1 - Katie	DD?\disparaging/ discrediting	158	158	And there was one teacher who actually got ill at the beginning	psyqws	26/05/2011 ...	<input checked="" type="checkbox"/>	0.95
P3 Int 1 - Katie	DD?\disparaging/ discrediting	206	206	And also I had (.) whooping cough (.) when I was (.) ff:i fteen	psyqws	26/05/2011 ...	<input checked="" type="checkbox"/>	0.29
P3 Int 2 - Katie	DD?\disparaging/ discrediting	86	86	And I'd said to this man - I didn't really like him anyway so	psyqws	21/04/2012 ...	<input checked="" type="checkbox"/>	0.00
P3 Int 2 - Katie	DD?\disparaging/ discrediting	230	234	he would never say "in my opinion" (.) you know (.)	psyqws	23/04/2012 ...	<input checked="" type="checkbox"/>	0.00
P5 Int 1 - Becky	DD?\disparaging/ discrediting	73	73	and then (.) when it got to Christmas (1) they were going "Oh	psyqws	21/07/2011 ...	<input checked="" type="checkbox"/>	0.00
P5 Int 1 - Becky	DD?\disparaging/ discrediting	187	188	(2) well I didn't really like (.) [social worker] (.) I didn't	psyqws	21/07/2011 ...	<input checked="" type="checkbox"/>	1.11
P5 Int 1 - Becky	DD?\disparaging/ discrediting	190	190	L:And erm (.) we kept going and (.) it was just – we didn't	psyqws	21/07/2011 ...	<input checked="" type="checkbox"/>	1.80
P5 Int 1 - Becky	DD?\disparaging/ discrediting	194	197	L:mm occasionally, we had a family session hh. W:Hh what was	psyqws	21/07/2011 ...	<input checked="" type="checkbox"/>	0.80
P5 Int 2 - Becky	DD?\disparaging/ discrediting	46	46	so that's the controlled assessment. My teacher was my Head of	psyqws	17/04/2012 ...	<input checked="" type="checkbox"/>	0.00
P5 Int 2 - Becky	DD?\disparaging/ discrediting	47	52	Oh and when we had the (#) erm parents evening (.) my science	psyqws	17/04/2012 ...	<input checked="" type="checkbox"/>	0.00
P5 Int 2 - Becky	DD?\disparaging/ discrediting	60	60	and my Physics teacher isn't very good (.) and erm I wasn't	psyqws	17/04/2012 ...	<input checked="" type="checkbox"/>	0.00
P6 Int 1 - Grace	DD?\disparaging/ discrediting	129	131	(1) To start with I just believed what they said and it – the	psyqws	14/08/2011 ...	<input checked="" type="checkbox"/>	0.00
P6 Int 1 - Grace	DD?\disparaging/ discrediting	141	141	And then (.) ugh (.) just teenagers at school are awful anyway	psyqws	24/08/2011 ...	<input checked="" type="checkbox"/>	0.00
P6 Int 1 - Grace	DD?\disparaging/ discrediting	141	141	they used to tell me "oh you don't need those" (.)	psyqws	25/08/2011 ...	<input checked="" type="checkbox"/>	0.00
P6 Int 1 - Grace	DD?\disparaging/ discrediting	225	225	But like Lucy's just moved to the other side of [city] (.) she	psyqws	07/09/2011 ...	<input checked="" type="checkbox"/>	0.20
P6 Int 1 - Grace	DD?\disparaging/ discrediting	240	240	I eat a lot of that too (.) "It's your animal, you clean it	psyqws	07/09/2011 ...	<input checked="" type="checkbox"/>	0.67

Windows taskbar: 12:57 04/03/2016

Appendix 12: Summary for Participants (sent after completion of the study)

Narratives of Young People Living with a Diagnosis of CFS/ME

Some of you have asked me why I decided to do this research, so I'll start with this.

I decided to do this research largely as a result of my work as a clinical psychologist over many years, working with both children and adults who live with a range of physical health conditions (eg, HIV, diabetes) and also my own family history of parents living with chronic health problems. I became very interested with the way that people “make sense of” health and illness, and how this happens - and how we all respond to this (eg, how we behave towards each other, how this makes us feel).

Some of my work was with people whose health - pain, fatigue and other symptoms - was not understood. Sometimes they were diagnosed with “chronic pain”, sometimes other things, including CFS or ME. I began to understand how difficult their lives could be - not only because of the horrible symptoms they were living with, but also because of the way that other people would sometimes treat them. I read research (all done with adults) and found that many people diagnosed with CFS/ME or similar conditions also reported feeling marginalised, disrespected, disbelieved. Not only was their illness “contested” (ie, questioned - especially whether it is “really psychological” or “not real”) - but *they personally* (their character) felt under attack (they were treated as if they were “mad” or making it all up). I also looked at wider talk about CFS/ME (like in newspaper reporting, or online) and saw how polarised and often nasty the comments were.

A lot of my work has been with young people, and I've always been really interested in hearing what teenagers have to say about life. I was also very aware how life as a teenager is quite different from life as an adult, and living with illness is very difficult at this time of life. At the time, there was some research looking at possible causes of CFS/ME in young people, but no research in which they were able to voice their own experiences, tell their own stories. I felt that this was a real gap.

I also spoke to professionals working in CFS/ME services for young people, and to adults and young people working with the charity AYME (Association of Young People living with ME). They all agreed that this project was important, and helped me design it. The project was also supported by the University of Hertfordshire, and approved by a Research Ethics Committee.

What I did

I met with ten young people (7 girls, 3 boys), all aged 13-17 at the start of the project, all diagnosed with CFS/ME. Some came through an NHS service, some through AYME, after reading information about the project. I planned to meet with everyone twice, a year apart, to get more idea of how their stories tell of the passing of time, living with CFS/ME while “growing up”.

Although I had ideas about broad areas that I wanted to hear about - like getting ill, living with illness, responses from family, schools and friends over time - I kept an open mind about what I might hear. I was especially aware that you might not want to tell me - a stranger! - your private stuff, especially when you might be feeling ill, and when that stuff might be upsetting or hard to explain.

So I was deeply impressed and moved by the way 10 young people engaged with the project, painting rich pictures of lives lived with a difficult and sometimes confusing condition over time. And although this was clearly hard for some to tell, I was amazed that all 10 of you opted to return a year later to tell the next chapter of your stories, often accompanied by photos, objects and diary entries that you’d collected over the year. (Everyone else involved in setting up the project - health professionals, University professors etc - told me that many you wouldn’t still be interested a year later... I think they underestimated you!)

So what did I hear?

Of course, everyone’s story was different - but there were a lot of common themes too.

Most people told of a really sudden onset of illness, coming “*out of the blue*”^{*}, affecting previously happy, healthy, active children. Although none of you said this explicitly, I heard mention of viruses and other things (eg, a knock on the head) as you tried to “make sense” of this in your stories. I then heard of the strange period of time when (most of) you expected the symptoms to go away (just like flu), but when they persisted, and sometimes got worse or spread to other areas of your body. I heard of a wide range of symptoms - not just fatigue but also pain, dizziness, problems with memory and concentration, digestive problems, sensitivity to light, problems walking, and “*weird*” things that you weren’t always sure were part of CFS/ME, or just “*random*”.

One thing really struck me though. Most of you did not go into a lot of detail about your symptoms, and some only did so when prompted more than once. At first, I wondered if they are just too hard to explain... but later (thinking about other situations you described, talking to other people about your illness) I wondered if you were also cautious about saying too much about them, in case you came across as “complaining” or “*moaning*” (an accusation that has sometimes been levelled at people with unexplained illness). In fact, some of you said quite clearly that you were worried about this - like you didn’t want to “*bore*” people, or act “*like an old person*”. I think that’s important, because it shows the

^{*} When words are in italics, they are direct quotes from what participants said to me

delicate balance that young people have to maintain: saying enough that others can (maybe) understand what it's like for you, but needing to maintain a good identity, and not just be seen as "*an ill person*", as "*not normal*". I wonder how easy it is to get that balance right...

I then heard many stories about how CFS/ME has affected your lives, particularly disrupting school and friendships. All of you (particularly the older ones) described how hard it was to manage education: because of missed schooling and the problems of trying to "*catch up*", because of ongoing problems with things like concentration, and also (for most of you) because of teachers or schools that did not seem able to provide the flexibility or support that you needed. As for peer relationships... while all of you spoke of some changes and disruption, the girls in particular spoke of some very difficult times. Sometimes these were about feeling "*hurt*" and "*left behind*" as friends got on with their lives while you weren't able to participate; that peers "*couldn't understand*" what you were going through; sometimes feeling "*different*" and "*out of the loop*" even when you tried to return, but had missed so much or were only around part-time. But worse than this, most of you spoke of times when peers were actively challenging: laughing openly at a Ricky Gervais comedy sketch on YouTube, suggesting that ME is "*made up*"; suggesting that you "*don't need*" your walking aids; using words like "*skiver*", and even accusing you of "*faking it*". They weren't just questioning CFS/ME (although that was definitely part of it), they were accusing YOU of lying. There was some similarity here with stories told by most of you about struggles with doctors, who "*didn't believe*" initially in your symptoms.

These stories were clearly painful to tell, and to hear. One thing that struck me was how much time you took to try to understand and explain why people might be behaving this way (eg, they were just too young, or CFS/ME IS just hard to understand, or there is so much mis-information about). You also spoke clearly about the exceptions: health professionals who (eventually) *did* help as much as they could; peers who *tried* really hard to "*get it*" (even if they couldn't!); and - especially in the second meetings - of new relationships with new people - often older, that you met later in your lives - who were "*really good*", supportive and accepting of who you are. And you expressed clearly that, while the pain of these things sometimes made some of you feel very low or worried, "*anxiety*" or "*depression*" were an understandable *consequence* - not the cause - of your illness. What came across was that, while it is hugely painful to experience such accusations and rejections, it is not because YOU are impossible to be around, or un-believable. (This seems obvious because some people (older, wiser, more experienced, kinder people - and also people in your families who know you best) could clearly see this, believe you and want to be around you.) Also, as you told your stories, it was apparent that you weren't simply complaining - you came across as thoughtful and reflective, and trying to learn from your experiences.

One other thing that stands out in your stories (perhaps because I met with you a year later), and doesn't seem so obvious in other research, is the *hard work* you put in to trying to manage your CFS/ME and your lives; and also the possibility for almost all of you of "*moving on*" with your lives in different ways. Almost all your stories speak of how you repeatedly tried to "*keep going*" until overcome by illness, how you worked painstakingly to look for patterns in your symptoms (ie, things that made them better or worse) and to get more understanding, and then worked to re-build your activity bit by bit, and again and again (eg, after colds or over-exertion - or unexplainable things - set you back). I think this is important because some of the more unhelpful talk around CFS/ME (like on the YouTube sketch, and examples that some of you gave) is the idea that sufferers are simply "*lazy*" or don't want to get

better. In contrast, your stories show you as hard-working, keen to try to minimise your symptoms (even if this isn't always possible). Also, your stories in your second interviews all referred to your successes and achievements - maybe not what you would have expected if you'd never been ill, and often a long way from where you eventually want to be - but signs that you are on a journey where you "*keep trying*", keep learning from your experiences, to make the most of your lives.

I could go on and on... but I meant this to be a quick summary for you, and it is getting very long! Your stories are so interesting, and there are many things that I just don't have room to cover. The main thing I want to get across to people - what I see in your stories - is how difficult it can be for young people to live with a diagnosis of CFS/ME, and particularly some dilemmas that arise in talking to other people about it: how to give them a picture of difficulties, while avoiding stereotypes of people with CFS/ME as "moaning", "not normal", "lazy" or with underlying psychological or social problems. Looking at them all highlights the different challenges that come with time as teenagers become adults, but also the increased skill and awareness that develops in managing these.

I hope that this makes sense to you, and that it has been useful to you. Please do feel free to drop me a line if you'd like to discuss any of it. I am HUGELY grateful to all of you for giving your time and energy to this project. As I said, I'm just finishing the PhD manuscript, but hope afterwards to produce some shorter papers for a wider audience - especially those working in healthcare and education with young people living with CFS/ME. I've also given some feedback to AYME already, but hope to do some more.

With thanks and respect for all you have done - and all good wishes for the future.

Wendy