
Portfolio including thesis

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Written Exercise

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Anxiety and depression are so interwoven that it is difficult to view them as separate. Critically argue your position on this statement, illustrating with clinical case examples.

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Traditionally anxiety and depression have been considered as separate and distinct disorders. Descriptions of anxiety and depression in the Diagnostic Statistical Manual (DSM) and the International Classification of Diseases and Related Health Problems (ICD) reflect this, although in more recent editions there does seem to be a move to recognising them as more interwoven. Research has examined the relationship between anxiety and depression in some detail. There are several possible different kinds of links between depression and anxiety. Mullaney (1989) proposed seven possible hypotheses with regards to this link, and this argument continues. His hypotheses are as follows:

- (a) Anxiety and depression are closely interwoven.
- (b) Anxiety and depression are separate disorders.
- (c) Anxiety is a depressive disorder.
- (d) Anxiety and depression are symptomatically distinct but not mutually exclusive.
- (e) Anxiety and depression generally occur together but depression can occur as a separate entity.
- (f) There is a hierarchical arrangement in terms of specific symptoms with specific symptoms further up the hierarchy.
- (g) There are qualitative as well as quantitative differences between anxiety and depression but it is not possible to specify them clearly.

This paper will discuss some of the above hypotheses, using research which has looked at the relationship. Examples of clinical cases from my clinical work will be given to illustrate various points. While it has been decided using ongoing assessment, psychometric tests and supervision that the primary problems in the cases have been *either* anxiety or depression, it has been difficult in my experience to find clients who have just one or the other. There is therefore the possibility that some aspects of the presentation that I will be discussing could be to do with either anxiety or depression. From my direct experience, the exception to this

has been simple phobia, where anxiety has existed in the absence of depression. These findings in themselves may be of significance.

Before a discussion of the extent to which depression and anxiety may be interwoven/inseparable can take place, it is important to explain what we understand depression and anxiety to be. This paper will mainly focus on the cognitive model as a framework for understanding depression and anxiety. The reason for this is that the evidence suggests that Cognitive Therapy is the most effective form of intervention for both depression and anxiety (Roth and Fonagy, 1996). It also seems to be the most common.

The cognitive model states that early learning experiences result in the development of various assumptions/schemata which are used to organize perception and guide and evaluate behaviour and to predict and make sense of experiences. These assumptions/schemas are likely to be rigid, and resistant to change, even in spite of available evidence which may disprove their existing assumptions/schemas. Schemas of depressed people often reflect loss, deprivation, worthlessness and defeat. Examples of assumptions are to do with what they need in order to be happy, such as "if someone disproves of me, then I will not be happy". Assumptions may also be to do with what they must do to be considered to be worthwhile, such as "to be worthwhile I must be good at everything". These schemas can essentially be summarised within a cognitive triad. The cognitive triad consists of negative thoughts about the self, the personal world and the future. When stressful life events occur, schemata are activated which result in negative automatic thoughts which are negative interpretations of current experiences, predictions about the future, and recollections of past events. This may result in emotions such as feeling guilty, low, sad, and depressed. Symptoms will also include a change in behaviour such as decreased activity, taking fewer risks, avoiding social contact and withdrawal.

Motivation will be affected by a loss of interest. They may also suffer from poor concentration, indecisiveness, and the physical affect may be a change in appetite and sleep. These symptoms then reinforce the negative schema that they are deprived, worthless and defeated. This tends to be a vicious cycle, in that as the negative automatic thoughts increase in frequency and intensity, any rational ways of thinking are crowded out, and so the feelings of depression increase.

While the cognitive interpretations depressed people make are to do with perceived loss, deprivation, worthlessness and defeat, in anxiety, interpretations tend to reflect an over-estimation of perceived threat/danger. Schema can again be summarised within the cognitive triad. They view themselves as vulnerable, their view of the world is that it is a threatening place, and their view of the future is that is unpredictable. This results in autonomic arousal, (a preparation for fight or flight), which may include palpitations, sweating, shaking, and light-headedness. Common behaviour will be an avoidance of certain activities, and/or selectively scanning the environment for possible sources of behaviour. Individuals will tend to interpret their physiological symptoms as being, for example, an indication of loss of control or evidence of an impending heart attack. This further increases the anxiety.

There is much research that has found that often anxiety and depression do not occur in isolation from each other, but often can be diagnosed together. Sanderson, Beck and Beck (1990) administered the Structured Clinical Interview for DSM-III-R with principal diagnoses of depressive disorders. They found that at least 66% of individuals had at least one additional diagnosis. They found that 47.6 % of individual's who had been diagnosed with dysthymia also had an anxiety disorder, 27% had social phobia, and 22% had generalised anxiety disorder. With those who had been diagnosed with major depression, 41.6% also had an anxiety disorder, 15% had social phobia, and 20.3% had generalised anxiety disorder. However in earlier versions of the Diagnostic Statistical

Manual (DSM), the presence of major depression could exclude any of the anxiety disorders. For example if an individual was displaying signs of panic attack, this did not require the diagnosis of panic disorder if it was believed that the panic attacks were due to major depression. Until the DSM-III-R, the presence of concurrent disorders was largely ignored.

The highest prevalence of any anxiety disorder was found in the Kessler et al. Report (1997). They found that 93% of individuals with bipolar I depression met criteria for anxiety disorder, and 2/3 of them had a simple phobia. Pini et al (1997) also found high rates of anxiety in a mixed group of bipolar I and II individuals; 79.2% had a diagnosis of an anxiety disorder. However the authors do recognise that the high rates may have been inflated by 'specific help-seeking patterns'.

There is some evidence which suggests that rates of anxiety are higher in bipolar depression than in unipolar depression. Chen and Dilsaver (1985) found comorbidity rates for panic disorder and Obsessive Compulsive Disorder was twice as high in bipolar, compared with unipolar subjects. The explanation for such finding is unclear. One explanation is that in the studies mentioned, interviews were carried out by trained lay interviewers, as opposed to clinicians, and they may have confused subtle bipolar symptoms with anxiety.

These research findings suggest that assigning one diagnosis may be unhelpful. "Prototypic descriptions of patients with specific disorders are often extreme oversimplifications of the multifaceted clinical profile of patients who receive that diagnosis" (Maser and Cloninger, 1990). They are therefore in favour of multiple diagnoses to describe the overall clinical picture.

It is still unclear at this point, to be sure which of Mullaney's hypotheses should be supported. Comorbid data certainly indicates that there is a relationship, however this could be just that two disorders are correlated.

We need to consider similarities and differences to be able to clarify what type of relationship they have.

There is much symptom overlap in anxiety and depression. These symptoms include negative affect, restless sleep, decreased energy, irritability, worry, indecisiveness, and negative self-evaluation (Harrington and Blakeship 2002). Perhaps significantly, there is a 70% item overlap between the Hamilton Rating Scale for Depression, and the Hamilton Rating Scale for Anxiety (Hamilton, 1959, 1967).

Individuals with both anxiety and depression may give unrealistically high probabilities to negative outcomes (Beck, Emery and Greenberg, 1985; Beck, 1989). For example, the anxious person may exaggerate the possibility of personal danger such as receiving a scratch on his or her arm and dwelling on the possibility of it leading to a fatal infection. Steven, who suffers primarily with generalised anxiety disorder interprets heart palpitations as a sign that he will have a heart attack. A negative view of the future is part of the cognitive triad in depression, and also fits into the hopelessness theory of depression. A depressed person may exaggerate the possibility of personal failure. Anna suffers primarily from depression and exaggerates the possibility of failing an exam, and so decides there is little point trying as she perceives negative outcomes as being uncontrollable.

What maintains anxiety and depression is often avoidance. Individuals with agoraphobia, social phobia and other phobias will avoid what makes them anxious. Although in the short term they get a reduction in anxiety, in the long term their anxiety increases, and their difficulties become more severe. Individuals with Obsessive Compulsive Disorder often avoid situations that they expect will trigger obsessional thoughts. Richard suffered primarily from OCD and avoided driving as this would trigger off worrying thoughts that he had knocked someone down. Over time this increased his fears, and he did not learn that if he faced the situation and exposed himself to his troublesome thoughts but do not act on them, the

anxiety would automatically decrease. People with Generalised Anxiety Disorder do not by definition avoid situations in the same way, however their forms of avoidance may be more subtle which maintain their negative beliefs. For example, Steven believed that if he did any DIY it must be perfect, and so put off DIY as he was unsure whether he could get it exactly right. When he fails to get anything done around the house it reinforces his doubts about himself about being unable to do any good DIY. When he fails to produce writing, this reinforces his doubts about himself as being unable to produce outstanding work. Sarah who I worked with was a social phobic and she would avoid talking so as to not expose herself to the possibility of criticism or ridicule. As a result of this avoidance, others found it hard to include her which reinforced her fears that she was not interesting. Individuals with depression may avoid doing the things which they think they will fail at. Anna avoids applying for jobs and as a result, her thoughts that she is worthless and defeated are reinforced. People with depression may also display “cognitive avoidance” as a way of avoiding painful issues.

A similarity between social phobia and depression is that they are both about meeting internal expectations, such as perfectionism, a fear of negative evaluation, sense of failure, and opinion of how others perceive them. Bieling & Alden (1997) examine the consequences of perfectionism for patients with social phobia. They see the key feature of social phobia as negative self-appraisal, or a sense of falling short of what is required in social situations. Sarah believes that if she is to have conversations with people, they should always be intelligent, interesting, humorous and that she should never stutter, repeat herself or lose her chain of thought. Bieling & Alden discuss how their negative self-appraisal arises from perfectionistic personality features. Individuals with Generalised Anxiety Disorder also have perfectionistic thoughts. Steven believes that “if something is not perfect then it is no good at all”, and “I have to be perfectly calm at all times”. Individuals with health anxiety may have thoughts such as “I have to be absolutely certain I am not developing cancer”. A common thought in people with depression may

be “this is not good enough. I should have finished everything I planned to do”. (Hawton et al, 1999). Anna says to herself that unless she can do a job one hundred percent perfectly, there is no point in being one.

Harrington and Blankenship (2002) found that ruminative thoughts are not just unique to depression, but also are common in anxiety. Martin and Tesser (1996) propose a definition of rumination, which is “a class of conscious thoughts that revolve around a common instrumental theme and that recur in the absence of immediate environmental demands requiring the thoughts”.

One of the most distressing symptoms of depression may be frequent intrusive negative thoughts. Beck (1979) proposed that negative thoughts in depression occur automatically and are difficult to stop. Anna often ruminates about everything which she feels she has failed at. Hannah with Post Traumatic Stress Disorder has constantly had ruminative thoughts all through her adulthood and the question that goes on in her mind is, “how could my father have physically abused me as a child?” Anxiety has also been shown to increase as a function of ruminative cognitions. Harrington and Blankenship see this as being significant in that it this may suggest new treatments for both these disorders.

Other studies have compared worrying in individuals with anxiety disorders and individuals with depression. Worrying thoughts are considered to be similar or the same as ruminative thoughts. In a cognitive model of GAD, Wells (1995) proposes that worry is maintained by maladaptive metacognitions, or negative beliefs about worry concerning uncontrollability and danger, and negative appraisal of worrying (meta-worry). The main aims of a study by Wells and Carter (2001) was to compare GAD patients with patients with social phobia, panic disorder, depression and non-patients on measures of negative metacognitions and worry. They found that patients with depression were relatively close to those with GAD on these measures, and these scores

were high. Wells suggests that it may therefore be of value to adapt meta-cognition focussed therapy of GAD to treat chronic rumination in depression.

Suicidal ideation may also be common to both anxiety and depression. Waern et al (2002) found that suicidal thoughts were acknowledged by one fourth of women with a depressive disorder and one fifth of women with an anxiety disorder.

Some research suggests that it is not possible to distinguish between “anxiety-neurotics” and “depressive neurotics”, or what is sometimes referred to as “anxious depressions”, and that any attempt to distinguish between them may be of little value for drug treatment. Johnstone et al (1980) investigated whether anxiety can be separated from depression in an out-patient population, and whether the distinction was relevant to the response to (i) a benzo-diazepine, (ii) a tricyclic antidepressant, (iii) a combination of treatments, (iv) a placebo. They found that ratings of depression and anxiety at the outset of the study did not allow a distinction to be made between individuals with anxiety and those with neurotic depressions. However distinctions have been more easily made when the patients were more severely affected than in this study (Klerman 1974), although Johnstone et al suggest that this is because the patients had learned to think of their symptoms in terms of those under consideration in the trials which influenced the results. The authors also acknowledge that differences have been found when more detailed and sophisticated analyses have been used, however the fact that such detailed analyses is required does put forward the question of is the distinction really so important. The fact that patients improved more with amitriptyline compared to other drugs, regardless of whether they were classified as having depressive or anxiety symptoms, does question whether a distinction is of any value.

So there are many differences between anxiety and depression. These include unrealistically assigning high probabilities to negative outcomes,

avoiding thoughts/feelings/situations which is a maintaining factor, striving towards unrealistic internal expectations, ruminative and worrying thoughts, suicidal ideation, and similar responses to medication.

There are many similarities between anxiety and depression. This would suggest that Mullaney's hypotheses that anxiety and depression are separate disorders, or that anxiety and depression are symptomatically distinct although not mutually exclusive, are questionable. However there is a lot of research which concludes that there are differences between anxiety and depression.

Roth et al (1972) did an important piece of work where they recorded clinical and demographic data from patients diagnosed with depression or anxiety. First they compared the frequencies of symptoms. Severe and persistent depression was found in 65% of depressives and in only 21% of anxiety disorders. Persistent severe tension occurred in 31% in those with anxiety disorders, and 16% of depressives. This suggests that there is an overlap, but also that both anxiety and depression can exist as separate entities. Typical depressive symptoms which also occurred in the anxiety states but more so in depression were morning worsening of depression, early morning wakening, suicidal acts and psychomotor retardation. Typical anxiety symptoms which were also found in the depressives, but significantly less often, were panic attacks, increased vasomotor responses, emotional lability, perceptual disturbances and depersonalisation and derealisation. This suggests that symptoms can sometimes overlap, but that there is still a trend for a certain group of symptoms to belong to anxiety and a certain group of symptoms to belong to depression.

Kerr (1974) used multiple regression analysis to look at the prediction of outcome for the two groups separately. They used uniform assessment and follow-up for all patients and were able to find distinctions between the two groups. They found only one item to be common for both groups, which was 'hysterical features' for the anxiety states and 'hysterical personality traits' for the depressive states. Symptoms most common in

anxiety was agitation, suicidal tendencies, heavy drinking, and more than five symptoms of anxiety. For depression it was physical illness associated with onset, duration of illness, depersonalisation and extraversion.

There is some evidence to suggest that anxiety and depression are symptomatically distinct but are not mutually exclusive. Finlay-Jones and Brown (1981) support the view that the life events which cause the onset of a depressive episode are different to the life events which cause the onset of an anxiety state. Severe loss precipitated the onset of a depressive episode, and severe danger precipitated the onset of an anxiety state. Anna who suffers primarily from depression was “kicked out” of drama school and she felt a great loss of status. Richard whose primary problem is OCD was brought up by his parents to believe that he was clumsy, absentminded and that someday he would cause serious harm to someone. Hannah who suffers primarily from posttraumatic stress disorder was physically abused by her father. Cases of mixed depression/anxiety were more likely to report both a severe loss *as well as* a severe danger before onset. Katie who seemed to suffer equally from anxiety and depression was beaten up and as she became agoraphobic she became depressed as a result of her loss of independence. This supports an argument for recognising a distinct group of mixed disorders. In addition while loss was unrelated to anxiety, danger was related to depression although the danger had disappeared by the time most of them became depressed. By contrast, the danger was still threatening in most of those women who became depressed and anxious after a dangerous event. There may be some problems with this study in that there may be some bias when reporting life events; events which had occurred earlier or after the onset may have been reported as life events preceding the episode. There may also be a tendency to exaggerate the unpleasantness of life events. Although the respondent’s subjective appraisal of the events was ignored, it may still have led to some bias on the part of the rater, perhaps unconsciously. It could still be argued that the themes of loss and threat may not be totally different, as

perhaps a threatened loss can bring about anxiety. Indeed this is the case with Steven when a threat to the loss of his job without actually losing it, triggered his first episode of anxiety. But the results from this study suggest that anxiety and depression follow qualitatively distinct life events. Finlay-Jones et al conclude, "the results suggest that a position between the 'unionists' and the 'separatists' in which anxiety and depression are seen as distinct but not mutually exclusive disorders is more likely to be correct".

Hamilton (1983) concludes that it is "easy" to distinguish typical depression from anxiety. However it is the 'anxious depressions', which are more difficult to distinguish, and these seem to be more common than the "classical syndrome". He suggests that if the symptoms are unhelpful in making a distinction, we should look at background information, which will strongly influence the probabilities on which a diagnosis is made. He suggests we should look at previous personality and the occurrence of previous attacks. First incidents of anxiety will often occur in teens and early twenties, and depression in the forties and fifties. Looking at the family history of depressions or suicides may "clinch" the diagnosis of depression. He acknowledges that there will always be a small number of cases where the diagnosis remains in doubt. As in all branches of medicine it is easier to diagnose the more seriously affected individuals, but that mild cases may be much harder. In these situations, the practitioner may have to use response to treatment as an indication of diagnosis. However an ineffective treatment may be demoralising for the patient, and perhaps in some cases discreditable to the practitioner.

An empirical demonstration of distinguishing between anxiety and depression appears to be a challenging research exercise. Ruth and Mehrotra (2001) acknowledge that distinguishing depression and anxiety is difficult because measures of depression and anxiety correlate so highly. They therefore have developed the Tripartite Model of Affect which explains the overlap by proposing a factor common to anxiety and depression and two factors specific to depression and anxiety respectively. They found that the Mood and Anxiety Symptom

Questionnaire (MASQ) (Watson and Clark, 1991) can discriminate between anxiety and depression better than more commonly used self-report scales. This is achieved by assessing unique symptom clusters of (a) somatic tension and arousal and (b) low positive affect. However non-specific symptoms of general distress are common to both anxiety and depression.

McWilliams et al (2001) examine self-report differentiation of anxiety and depression. They suggest that while previous research has found a considerable overlap between anxiety and depression and that distinguishing between the two is difficult, they can in fact be differentiated when measures of the two disorders are considered at an item level. Previous research has tended to look at the relationship between anxiety and depression scales. They also suggest that there is some evidence that differentiation is easier in individuals experiencing high levels of anxiety and depression. When looking at the two disorders and using Spielberger State Trait Anxiety Inventory (Spielberger et al, 1970) and the Beck Depression Inventory (BDI-II) at an item level, they found that the pattern for depression is more complex than for individuals with anxiety experiencing less severe levels of depression.

Much research aims to identify exact and complex models to distinguish anxiety and depression (Ruth and Mehrotra 2001; Derogatis et al 1972; Foulds and Bedford 1976; Goldberg et al 1987). However there is very poor agreement on such classification systems. Derogatis et al (1972) state, "the development of a definitive system of classification for these conditions represent a complex, multi-determined problem that will demand full utilization of the information and methodology available to contemporary clinical science". This must therefore reflect the fact that individuals with anxiety and depression do not form themselves into natural groupings. How useful then is it to use arbitrary decision rules to distinguish the two disorders?

Another possible hypothesis is that while anxiety and depression generally occurs together, depression can occur as a distinct entity. Anxiety commonly is associated with some degree of depression, and as previously described, anxiety often develops into a depressive disorder. However depression commonly occurs as a distinct anxiety without evidence of anxiety (Zung 1971). When looking at the DSM and ICD classification systems, anxiety is listed as a chief characteristic of all the neuroses including depression, whereas the diagnostic criterion for depression does not include anxiety.

Kendell (1974) found that a large percentage of individuals diagnosed with anxiety, were often re-diagnosed as depression on future episodes. Is this due to confusion in diagnosis, or is there a temporal relationship between anxiety and depression? Stein et al (2001) did a longitudinal study of adolescents and young adults and found that Social Anxiety Disorder (or social phobia) is an important predictor of depressive disorders. This has important implications, as early identification and intervention may reduce the chances of later developing depression.

Hamilton (1983) speculates as to why anxiety with depression is relatively common, and depression without anxiety is rare. He suggests that the reasons are linked to the temporal relationship between anxiety and depression, and that anxiety often precedes depression, as the depression is due to the debilitating effects of the anxiety. However, the picture is fairly complex in that certain anxiety disorders are more likely to show this temporal pattern than others. Sanderson et al found that generalised anxiety disorder and social phobia is more likely to precede depression than other anxiety disorders such as panic disorder with and without agoraphobia, agoraphobia, simple phobia, Obsessive Compulsive Disorder, and Posttraumatic Stress Disorder. The reasons for this are unclear.

Yuan, Zhang and Qin (2002) suggest that when anxiety and depression are both present at a level where on their own, both problems would meet

the criteria for single diagnosis, that there should be a separate diagnosis of 'Comorbid Anxiety and Depression (CAD). They claim that comorbid anxiety and depression (CAD) is associated with more severe symptoms such as increased functional impairment, a more chronic course, poorer outcome and a higher incidence of suicide. They suggest that psychological tests indicate that CAD has common features such as self-contempt, rejection, demoralisation, self-consciousness and affective distress. Therefore perhaps CAD should be considered a new, independent disease unit, separate to simple anxiety disorder and simple depressive disorder. In their 2002 paper, they look at whether CAD patients differ from simple anxiety and simple depressive disorder in respect to their defense mechanisms. They found that CAD patients have significantly higher scores for regression, somatization, undoing and denial and have significantly lower scores for passive aggression, complaining and anticipation. Individuals with depression have significantly higher scores for undoing and affiliation, and significantly lower scores for complaining and humour. However compared with CAD individuals, patients with anxiety have significantly lower scores for humour and significantly higher scores for reaction formation, whereas patients with depression have significantly higher scores for fantasy. These results indicate that the three groups of patients have their particular defense styles. While the three groups of patients display some similar symptoms, it would seem that defense style is independent of symptoms. This strengthens the argument for considering Comorbid Anxiety and Depression as being a new, independent disease unit.

Classifications in the ICD-10 and DSM-IV-R do not acknowledge CAD, although they do include a category called 'Mixed Anxiety and Depressive Disorder' which was not present in earlier publications. It may be used when symptoms of anxiety and depression are both present, but neither set of symptoms considered separately may be enough to justify a single diagnosis of either anxiety or depression. ICD-10 recognises that there may be problems encountered in using this new category, but suggests that it needs to be tested in order that the definition may be improved.

However when both anxiety and depression are both severe, two separate diagnoses should be made. Perhaps, as Yuan et al suggest, there should be a separate diagnosis of 'Comorbid Anxiety and Depression', where both are severe enough to justify a single diagnosis. If only one diagnosis can be made for practical reasons, depression should be given precedence. If both seem to be present, but anxiety is more severe and the depression is less severe, a diagnosis of anxiety disorder should be made.

In conclusion, it would seem that anxiety and depression often do not occur in isolation from each other as many studies show high comorbidity rates. Therefore a single diagnosis may be unhelpful. There may be also much symptom overlap which makes finding a distinction between anxiety and depression a very difficult and subjective exercise. The overlap of symptoms include negative effect, restlessness, decreased energy, irritability, worry, indecisiveness, negative self-evaluation, giving high probabilities to future negative outcomes, avoidance as a maintaining factor, perfectionism, fear of negative evaluation, sense of failure, and a negative opinion of how others perceive them. There may be a particular overlap between individuals with anxiety and individuals with anxious depressions. However there still may be aspects which are unique to anxiety and depression respectively. This includes qualitatively different life events preceding episodes, previous personality, family history of depressions and suicides, differences in somatic tension and arousal, differences in low positive effect. There appears to be less reported differences than similarities. Much research has attempted to identify the definitive distinction between anxiety and depression. The fact that this is such a challenging exercise does pose the question of whether it is a useful purpose trying to make such a distinction when individuals do not naturally fall into such groupings.

When anxiety and depression do occur together individuals tend to have more severe symptoms, have a poorer outcome from medication and therapy, and are more likely to show risky behaviour. This seems a good

argument for changing the way we treat these people, rather than targeting just the anxiety or just the depression.

Returning to Mullaney's hypotheses, and after examining the evidence, it would seem that a combination between the first, fifth and seventh suggestions is a realistic way of describing the relationship between anxiety and depression. There is a considerable overlap between anxiety and depression with many similarities making it difficult to distinguish the two. There do seem to be some qualitative differences between the two, however these cannot often be specified clearly. They generally seem to occur together but can BOTH exist as separate entities, although it is rare to find anxiety on its own with the exception of simple phobias.

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Written Exercise

Year 2

Critically discuss the concepts of challenging behaviour and the role of the Clinical Psychologist in assisting with this.

4,513 words

THE CONCEPT OF CHALLENGING BEHAVIOUR

It is estimated that between 10% and 15% of people who are supported by Learning Disability services either display challenging behaviour, or would do it their behaviour were not managed by the use of controlling measures such as medication, or psychological interventions (Emerson et al, 1998). The sorts of behaviours which this client group often display include aggression, violence, self-injury, destructiveness, overactivity, inappropriate sexual behaviour, and eating inappropriate objects. The term 'challenging' behaviour, replaces terms used in the past such as 'abnormal', 'disturbed', 'dysfunctional', 'maladaptive', and 'problem' behaviour. The first part of this essay will show how some of these descriptions are inaccurate and unhelpful, and how we have come to view these kinds of behaviour in more recent years as 'challenging'. Emerson (2001) believes that by calling the behaviour 'a challenge' rather than 'a problem', this encourages more "productive responses" to how it is approached. The second part of this essay will discuss the role of the Clinical Psychologist in assisting with such challenging behaviours. As will be seen, Clinical Psychologists have much to offer in this field, although the majority use behavioural models, and behavioural approaches to the assessment and intervention of challenging behaviour. Some recommendations will be made as to how the role of the Clinical Psychologist in working with challenging behaviour, could be developed.

Defining what is 'Challenging behaviour' involves a subjective value judgement. It is often used to describe behaviour which is considered to be **undesirable**. However behaviour cannot be considered simply as being either desirable or non-desirable. The same may be true for other adjectives used such as "appropriate" and "acceptable". LaVigna and Donnellan (1986) say that we should be judging the *degree* of appropriateness of a given behaviour. However judging this depends on the standard we choose to measure the behaviour against. LaVigna and Donnellan suggest that we use the standards of **quantity and quality of**

life in order to define the behaviour. For example suicide attempts may threaten quantity of life, and shouting obscenities may interfere with the person's quality of life as it antagonises others. However other standards against which a behaviour is sometimes judged include "social acceptability", "religious acceptability", or "political acceptability".

Emerson (2001) discusses how challenging behaviours **should not be seen as behaviour which is disordered, dysfunctional or maladaptive**. He shows evidence that suggests that challenging behaviour can be 'orderly' in that it can follow a consistent pattern rather than being random. It can also be **adaptive** in that it may be functionally related to what is going on in their environment. He sees many challenging behaviours as being "construed as (at least in the short-term) as coherently organized adaptive responses to 'challenging' situations. For example a person with learning disabilities may like everything to be in a particular order. Although their behaviour may be disruptive for everyone else the person lives with, it may be a way of gaining some control and autonomy over what may seem like a chaotic world.

Emerson also says a behaviour should only be considered as 'challenging' when they put the **safety or health** of themselves or other people in danger, or which may **limit their use of, or deny them access to community settings**, and therefore limits their quality of life. Emerson says that the responses of community carers, care staff, and service agencies may have a bigger impact on quality of life than the immediate physical consequences of the challenging behaviour itself, as their response can lead to abuse, inappropriate treatment, exclusion, deprivation and neglect.

We should not try to change behaviours which may just be “odd” or “unusual”. Behaviours which may put themselves or others safety at risk include physical aggression, destructiveness and self-injury. Behaviours which may put health at risk include smearing faeces over the body, or eating inedible objects. Behaviours which may limit people’s use of community settings include, in addition to some of the behaviours already mentioned, less serious forms of physical and verbal aggression, inappropriate sexual behaviour and other behaviours which may cause other people to avoid them.

By labelling the behaviour as ‘challenging’, we are saying that the behaviour is a **social problem**, or a challenge for the social setting, and may not necessarily be a problem for the individual with the learning disability. Whether a behaviour is seen as challenging in a particular context depends on: what the social rules are with regards to what is seen as appropriate behaviour in that setting; the beliefs of the people in the setting about the nature of learning disabilities and their perception of the causes of the person’s challenging behaviour, and the capacity of the setting to manage the disruption caused by the behaviour. Settings will have different rules and expectations about what appropriate behaviour is. Morris & Midgeley (1990) state that challenging behaviour can only be understood when it is viewed as a ‘social construction’.

Lowe and Felce (1995) examined the assessment of severity of challenging behaviour by carers. They found that how severe carers saw the behaviour, was mainly assessed on how the behaviour had impacted on their daily activities, rather than the effect it may have on the client’s progress and development. Therefore the challenging behaviour may not be a problem within the individual, but may be a problem with the individual’s interaction with their environment.

This is supported by a study by Kiernan and Kiernan (1994) who used discriminant functional analysis to identify factors which distinguish 'more difficult' from 'less difficult' pupils with severe learning disabilities. The first ten factors found in their analysis, in order of significance were: physical aggression with high risk to others; persistent interrupting the activities of others, social disruption such as screaming, regular violence, unpredictable behaviour, breaking windows, fixtures and fittings; aggression towards other pupils; lack of understanding of the emotions of others, and non-compliance. These behaviours are involve a problem with the person's interaction with the environment.

Expectations about what is appropriate behaviour is also dependent on **cultural and religious beliefs**. For example someone who is a Hindu who is asked in his residential home to help cook and then to eat bacon and eggs may start displaying aggressive behaviour as eating bacon goes against the Hindu religion, however he is unable to communicate this to staff. In a Hindu society this kind of behaviour would be likely to be seen as less challenging and inappropriate, as he is being made to do something which goes against his values. In our culture we may see aggression in a woman as being more challenging than aggression in a man.

Displaying challenging behaviour is likely to mean that these people are seen as **'abnormal'**, and as a result there may be an increase in tolerance of the behaviour as they are expected to behave in "unusual" ways. If their challenging behaviour means that people define them as being "learning disabled", or "mentally retarded", then people come to attribute their success on a task as being due to external factors, such as the ease of the task, and failure as being due to the person's cognitive impairments. This means that they are not seen as having any personal control over their behaviour, and are being perceived as being unable to learn. This may include learning to behave in less challenging ways.

There are many **negative implications of challenging behaviour**. Methods of control may be used, that are not actually in the best interests of the client. Rusch, Hall & Griffin (1986) looked at documented instances of abuse in an institution, and found that challenging behaviour was the main predictor of who was likely to be physically abused by staff, for example being hit may be used as a way of stopping someone from self-harming. Other forms of control include medication. Studies have shown that approximately 50% of people with severe learning disabilities who show challenging behaviour are prescribed anti-psychotic medication (Davidson et al, 1994; Kirenan, Reeves & Alborz, 1995; Meador & Osborn, 1992). This is in spite of the fact that there is no evidence that this kind of medication works in reducing challenging behaviour, and that there are many possible serious side-effects. Mechanical restraint is sometimes used for stopping self-injury which can have serious negative physical and psychological consequences.

Other implications of challenging behaviour, include exclusion from services both within residential care settings, but also health and social services. Emotional reactions on staff may include anger, despair, sadness, fear and disgust (Bromley & Emerson, 1995). Challenging behaviour is one of the main predictors of whether parents seek residential placement (Tausig, 1985). Challenging behaviours also means that the person may be limited in developing social relationships (Anderson et al, 1992).

Therefore there is a great need in assisting with people with challenging behaviour. By seeing challenging behaviour as a social construction, this can help Clinical Psychologists to identify many possible approaches to intervention, such as looking at the setting, or ways in which the behaviour is construed by carers.

THE ROLE OF THE CLINICAL PSYCHOLOGIST IN ASSISTING WITH CHALLENGING BEHAVIOUR

Clinical Psychologists have much to contribute to the understanding of people with learning disabilities and to the support of these people. Although other professions work with people with challenging behaviour by applying psychological skills and techniques, what Clinical Psychologists should be able to do is to offer a multi-theoretical base to formulate complex problems, and then to devise an individually tailored strategy to the presenting problem. Clinical Psychologists should be flexible enough to adapt and combine approaches. Most of the work that has been done by Clinical Psychologists with this client group is behavioural. It could be argued that Clinical Psychologists should be developing other approaches based on other theoretical models, in order for us to retain skills and techniques which are unique to us.

Behavioural Models of Assessment – Assessment and Formulation

Much of the work of Clinical Psychologists in this field is to do consultancy work with family members, or care staff. An important part of this consultancy is to help care staff to understand that the patient's challenging behaviour may be a form of communication. For example it could be their way of trying to communicate that they are too hot, too cold, hungry, tired, in pain, frightened, or frustrated. It is also part of our role to help staff to understand that the behaviour may be followed or accompanied by a desirable outcome for the person and so they may repeat the behaviour in order to get that outcome. For example the behaviour may be a way of avoiding doing unpleasant things, or a way of enjoying sensory stimulation. It could be a way of gaining something material or of getting something to happen which is pleasurable. It could also be a way of gaining social contact with other people. In order for any change to happen, it must be identified what the behaviour means.

Functional Analysis

Functional Analysis aims to describe the challenging behaviour, and predict events that typically precede the behaviour (antecedents) and typical consequences following the behaviour. In order to do an analysis of the antecedents it is important to know the settings the behaviour is more or less likely to occur in, with whom the behaviour is more or less likely to occur with, at what times the behaviour is likely to occur and what events, activities and types of interactions increase or decrease the likelihood of the behaviour. To do an analysis of the consequences it is important to learn about the consequences the behaviour has for that person, what consequences the removal of the behaviour would have for the person and for others, the reactions of others to their behaviour, and what attempts have been made to control the behaviour in the past and what the outcomes of these attempts were.

Clinical Psychologists often teach staff how to use ABC charts, which record the antecedent (A), the behaviour (B) and the consequence (C) for each time the challenging behaviour occurs. As Clinical Psychologists can only observe clients for limited amounts of time, it is important that we help care staff to understand the importance of the method so that it can be used at any time the challenging behaviour occurs. The method we teach must be 'user friendly' so that it can be implemented and can be continued over long periods of time.

Once we have the information from the ABC charts we can then do an analysis of the meaning of the behaviour to determine what the individual is trying to communicate to people.

The dominant behavioural approach views challenging behaviour as an example of 'operant behaviour'. Environmental consequences which maintain behaviour are named 'reinforcers'. Two types of relationship between behaviour and reinforcers are important in establishing and maintaining operant behaviour. Positive reinforcement is an increase in

the challenging behaviour as a result of the consequence. Negative reinforcement is the increase in the behaviour as a result of the absence of the reinforcing event.

Individual and environmental influences

When Clinical Psychologists try to understand the meaning of the challenging behaviour, they consider both the individual and the environmental influences. Individual factors may predispose an individual to respond in a certain way. One factor may be psychiatric conditions which can increase the likelihood of the challenging behaviour occurring, however it is difficult to be sure they have a psychiatric problem if they have limited speech and other forms of communication.

Clinical Psychologists are becoming increasingly interested in the context within which the behaviour occurs. Care staff may not always consider these environmental factors, so it is important for us to help them in their understanding. Factors such as temperature, light, noise and the number of people should always be considered. In many residential and community service settings there may be low levels of contact and interaction from staff and other clients, the environment may hold many aversive experiences to escape from, there may be a lack of stimulation, and there may be a controlling environment where there is restricted access to objects and activities that they desire.

As a challenging behaviour may be explained by a number of complex factors from both within the individual and from the environment there needs to be an intervention which is multi-element. All factors considered to contribute to the occurrence of the challenging behaviour should be addressed in the intervention.

Behavioural Interventions for challenging behaviours

Proactive Strategies

Clinical Psychologists have a role in preventing challenging behaviour from developing. The principal purpose of these strategies are to produce change in the future. Here below are some brief descriptions of some proactive strategies.

Ecological Changes

When Clinical Psychologist visit residential homes, it is important to consider the physical, interpersonal and service environment and see if the environment fits the person, rather than if the person fits the environment. If the individual finds noise and crowded environments difficult, this should be avoided. Interactions with the people in the client's environment may have an effect on their behaviour. The Positive Interaction Profile (Burgess, 1991) attempts to define the responses to best suit the individual by using information from the assessment and knowledge of good practice gained from the carers. The service environment should have high levels of social contact, mainly contingent on adaptive behaviour, meaningful activities with a good level of stimulation, and support and assistance instead of demand and control.

Positive Programming

This is the attempt to provide the individual with skills and competencies that will enable them to gain control over their environment. For example, *General Skills Training* involves learning skills such as domestic skills, recreational and community skills. An increase in such behaviours may result in a decrease in challenging behaviours. Such skills may also increase their independence, self-esteem and sense of mastery and mood.

Functionally equivalent skills training teaches the client alternative more adaptive ways to communicate their message such as to go to the fridge when hungry, or leave the room when it is too crowded. Giving clients some choice helps them feel they have more control over their environment and helps make their routines more predictable. Even if the client does not have verbal forms of communication, they can be taught to communicate their choices, such as what they would like for dinner, or what they are going to do that day. It is also important to teach clients coping skills for when they feel criticised, frustrated, or when they experience loss of a staff member or resident, or when they experience failure, such as relaxation.

Reactive strategies

Reactive strategies are what are used when the challenging behaviour occurs. The purpose of such a strategy is to ensure the safety of the client and those around them. Strategies may vary from carers ignoring the behaviour, distraction or diverting the client's attention, active listening, verbal calming, or using a physical intervention where the individual is supported by carers until they are able to take control of their own behaviour. If the strategies described above do not work, sometimes physical intervention is necessary, although this is a very controversial strategy.

Other approaches

Psychotherapies, including psychodynamic approaches systemic and cognitive approaches are rarely used with people with learning disabilities (Dosen, 1993).

Psychodynamic Therapy

In the Psychology literature there are some descriptions of psychodynamic therapies with people with learning disabilities (Berry, 2003; Hollins, Sinason & Thompson, 1994), but very little evaluation of their effectiveness. Psychodynamic therapists do not always require people to have verbal communication, as there are other ways to communicate the expression of emotion, such as through drawings, gestures, and other forms of non-verbal communication. It is therefore possible to form a therapeutic relationship, even if the person has a severe learning disability. Counter transference can actually happen quicker, be more pronounced and primitive compared with people who do not have learning disabilities. The suggestion is that this makes psychotherapy particularly effective for this group of people.

There are very few studies which have looked at the development of the course of challenging behaviour over time. Instead our understanding seems to be about what is current happening in the person's environment. The limited evidence that is available suggests that severely challenging behaviours may develop in early childhood and persist over time (Emerson, 2001; Kiernan et al. 1997). This could provide some argument for applying psychodynamic approaches to people with challenging behaviours.

Berry (2003) describes some case studies using psychodynamic therapy with people with learning disabilities who have challenging behaviour. Using the therapeutic relationship he writes about how he helped a man of 33 with a history of violence and aggression. The man had a complex family structure with many siblings and half-siblings, and grew up in a home environment full of violence and abuse. The experience of living in the care home was a re-enactment of living with his own family. The care workers were often in the role of the tough parent, and the other residents were in the role of his many siblings, where everyone was his enemy.

Through building a relationship with the therapist where he slowly was able to risk experiencing disappointment, and thereby increasing trust, his relationships improved in the home and his aggression decreased.

Systemic Therapy

Rhodes (2003) discusses how challenging behaviour impacts on the family setting, and that families can find it difficult to make lifecycle transitions or respond to other life events and become stuck in patterns of interaction that include the challenging behaviour. He recommends that behaviour and systemic therapy are used to complement each other, as behaviour therapy alone cannot resolve problems in the family such as polarised gender roles, enmeshment and grief. He says that strategies such as collapsing time, amplifying deviations, challenging beliefs from the past, and circular questioning were important for change. Behavioural strategies may then be implemented without resistance from the family. Harris (1982) described different structural deficits in families with someone with a learning disability. For example, the mother may be over-involved with the child with the disability and the father and sibling may be distant. Or the sibling may be parentified alongside the mother with little involvement from the father.

However research into systemic therapy with people with challenging behaviours is scarce. More research would perhaps increase the use of family therapy in what is pre-dominantly a field which is pre-dominated by behavioural theory and therapy.

Cognitive-behavioural therapies

Cognitive-behavioural therapies have not been widely applied and evaluated, although there has been a growing interest in them in more recent years. However there have been some attempts to adapt therapy for people with learning disabilities.

Behavioural approaches may not always be effective, perhaps because they do not consider all the factors which underly the maintenance of behaviour. Verbally formulated rules for responding, both overt and covert, may be big determinants of human behaviour (Lowe and Horne, 1985).

Studies of people with mild/moderate difficulties have shown that people with learning disabilities can reliably self-report their emotions and cognitions (Lindsay et al, 1994). Self-monitoring alone can reduce many challenging behaviours such as self-harm and aggressive behaviour (Pope and Jones, 1996). In addition, there is some evidence that self-management procedures such as anger management, and social problem solving may help many clients to reduce many challenging behaviours (Koegal et al, 1992; Loumidis and Hill, 1997).

It is unclear how self-management techniques may apply to people with severe learning disabilities. However there have been some studies which have demonstrated that self-management among young children with autism may be more applicable to people with severe learning disabilities than had been previously thought (Koegal and Koegal, 1990). This may be an area of development for the role of the Clinical Psychologist.

Understanding carer experiences of challenging behaviour

This area has developed in recent years by Clinical Psychologists and researchers who work in the field. Carers' experiences can help explain the development and maintenance of the behaviours of people with learning disabilities. How staff behave towards people with learning disabilities may be "under the control of contingencies that are related to how they experience the challenging behaviour" (Hastings & Remington 1994). For example when a client self-harms, if staff experience this as aversive they will tend to act to end their unpleasant experience and so will intervene quickly. This then gives the client attention, and the client then stops their self-harming behaviour. Staff behaviour is negatively reinforced by termination of the self-harming behaviour, which then provides reinforcement to the self-harming behaviour of the client.

Carers tend to believe that they have no control over challenging behaviour. By understanding the cognitions of staff, it is possible to use cognitive-behavioural interventions to produce change in their behaviours, thoughts and emotions.

Weiner's attributional model of helping behaviour (1980) can be useful in understanding carer experiences and behaviours. According to Weiner's model, the attribution of controllability (whether the behaviour is under the observed person's control), and stability (whether the cause is the same each time the behaviour occurs), determines the emotional reaction of sympathy or anger in the observer, which then impacts on whether they offer help. A carer may be more sympathetic and more helpful, if they see the cause of the behaviour as being outside the client's control. If they see the behaviour as being within the client's control they are more likely to feel angry and then be less likely to help, as they see them as 'manipulating' the situation.

Dagnan, Trower and Smith (1998) explored the application of Weiner's model to the responses of care staff in residential settings. Forty care

staff were presented with six examples of challenging behaviour, and asked to give a probable cause, rate attributions of stability, internality, globality and controllability, their optimism for change of the behaviour, their evaluation of the behaviour and the person displaying the challenging behaviour, their emotional response to the behaviour and their willingness to put extra effort in to changing the behaviour. Dagnan et al used a path analysis which showed that helping behaviour was best predicted by optimism for change, which was best predicted by negative emotion, which was best predicted by the attribution of controllability. When staff rated behaviour as controllable they reported fewer negative emotions. They conclude that “the application of clear cognitive models of staff response to challenging behaviour of people with learning disability and the exploration of variables that may interact with such responses may aid understanding of the development and maintenance of such behaviours”.

This indicates that it is important for Clinical Psychologists to develop approaches that work with staffs’ attributions and emotional responses as part of their training. Dagnan et al believe that this area deserves “considerable further work”.

Central to the range of approaches to assessment and interventions described is the process of trying to understand why the person acts in these ways in these settings. The client remains in the centre of the intervention process.

Future Developments in the Role of the Clinical Psychologist

There are some areas in which the role of the Clinical Psychologist may be lacking, which could be areas for future development.

Most interventions are implemented by carers, care staff or other professionals. Self-management techniques for people with severe

learning disabilities are not used frequently, and there has been little research to assess their effectiveness of such approaches. However, there have been a few studies which suggest that self-management techniques may be useful for children with autism (Pierce and Schreibman, 1994; Koegal and Koegal, 1990). Emerson (1998) recommends that Clinical Psychologists give more attention to interventions which allow people with severe learning disabilities to have more of an active role in overcoming their challenging behaviour.

This essay has discussed the concept of challenging behaviour, in particular how challenging behaviour is defined by its' impact, how it is a social construction, and how there are many consequences for the individual who displays the behaviour, and for the social setting. It has also discussed the main approaches that Clinical Psychologists have taken to the assessment, formulation and intervention of people with learning disabilities who display challenging behaviour. Most of these approaches have been based on behavioural models. There is currently little research evidence to support the use of approaches based on alternative models. However this may not be because other therapies have been shown to be ineffective, but because the research has not been done. Certainly there is very little available in the published Psychology literature. However an important part of the role of the Clinical Psychologist is to use a multi-theoretical base to formulate problems, and from this then to devise an individually tailored strategy. Other professions are trained in behavioural models such as Social Workers, Nurses and Challenging Behaviour Nurse Practitioners. Perhaps the role of the Clinical psychologists in future years will be to research and develop other approaches in order that we may have a broader theoretical base to draw on. As much of our work involves working with the care staff and other professionals by empowering them with psychological knowledge, it is important that we retain what is unique to us, rather than giving all of our skills and knowledge away. Otherwise our role may become of decreasing importance.

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Small Scale Service Related Project

Year 2

Service Based Development Project Looking at the Informal Needs of Family Carers of Older Adults with Depression and/or Anxiety

4,979 words (not including tables)

ABSTRACT

Aims:

- 1) To identify the numbers of carers of older adults with functional mental health problems which started in their later years, who would welcome a carer's assessment and/or an information sessions about depression and anxiety in old age.
- 2) Pilot an information session about depression and anxiety in old age.
- 3) Pilot an adaptation of the Illness Perception Questionnaire (IPQ) in carers of older people with late-life onset functional mental health problems.

Methods:

Participants were carers of clients from psychiatric outpatient clinics who had an onset of depression and/or anxiety in their later years. Carers accompanying clients when attending the clinic were asked to participate. Those who agreed to participate were then interviewed using the IPQ in the form of guided completion and were invited for a full assessment of their needs, and to attend an information session. At the end of the information session they were asked to complete an evaluation form.

Measures and analysis:

Data was gathered from outpatient clinic lists, questionnaire scores from subscales on the Illness Perception Questionnaire, and evaluation forms completed by attendees following the Information session.

Results:

Over the period of six weeks from 28th January to 11th March, and from 8 clinics, 66 clients were invited for an outpatient appointment with a Psychiatrist. Out of the 66, 16 clients (24%) had depression and/or anxiety which had started in their later years. 10 carers were interviewed, 5 of the 10 carers attended the information session, and 2 requested to have a full assessment of their needs. The evaluation forms from the information session were analysed, and all

attendants found the session to be of some value. An examination of the psychometric properties of the IPQ showed that Cronbach's alpha reliabilities were reasonable, and some inter-item correlations fell into the optimal range whilst others were too weak or strong. There were no statistically significant inter-subscale correlations.

Conclusions:

The results indicate that some carers do see information about depression and anxiety as being relevant to their needs. In addition, only a minority were interested in a full assessment of their needs, which suggests that if the service was to offer full assessments to carers, they may not be overwhelmed with additional work. The IPQ as a tool for measuring perceptions in this population may have some use, although the psychometric properties may improve if some of the scales had more items, and if more carers completed the IPQ.

INTRODUCTION

Carers Assessments

Under the Carers and Disabled Children Act 2000, carers are entitled to an assessment of their own needs (Department of Health, 2001). The assessment should be to determine whether the carer is eligible for support, and to determine their support needs. The act lists the possible positive outcomes from having an assessment. These include:

- Recognition of their role
- Peace of mind from knowing how to make contact in the future
- A chance to talk through the issues and consider their own needs
- Information which can be provided from other support, such as carer groups and local statutory services
- A sense of shared responsibility, particularly where any support offered is on a regular basis
- Increased confidence to take up services.

In addition, in the National Services Framework for Mental Health, (standard 6 – ‘Caring for Carers’), carers who provide regular and substantial care for someone on the Care Programme Approach (CPA), are entitled to an assessment of their own needs, and a care plan (Department of Health, 2001).

However, the Trust Clinical Governance Group have identified that only 5% of files of people on CPA record a Carers Assessment. The Community Mental Health Team is not actively offering assessments or interventions to carers with functional illness, even though there is a dedicated support service for carers of people with dementia. Through informal discussions with staff, the reason for this may be that staff feel they have high work- loads, and are concerned about the extra work this would involve.

Carers of older adults with a recent onset of depression and/or anxiety

Train, Livingston and Manela (2002) looked at the needs of carers of older people with psychiatric illness, mainly depression. They found that although carers represented a saving in social and health costs, and many carers were ill themselves, most were not treated with medication. Those who were more stressed did not receive more services. Train et al suggest that carers need accessible information, as well as joint GPs, integrated services, occupational therapy assessment, and the identification of an appropriate 'educator'.

Scazufca, Menezes and Almeida (2002) found that carers of older people with depression, experience similar burdens of care when compared to carers of older people with dementia. However, there are more resources for carers of older people with dementia.

There are less studies looking at carers of older people with depression and anxiety than carers of older adults with dementia. However a few studies have highlighted the needs of these carers. For example, Billig (1991) concluded that despite their "extensive special needs and burden", they receive relatively little clinical and research attention. Rosenvinge et al (1998) found that these carers experienced "considerable stress" and Goodman et al (2002) found that spouses of older adults with depression were likely to experience similar depressive symptoms.

Carers' Informational needs

There have been studies looking at improving carers' knowledge of dementia and the effect on carers well-being (such as Sullivan & O'Connor 2001). However, there is no easily available research in the literature which has looked at either the information needs, or the effect of information sessions on carers of people of any age with depression/anxiety.

Ballard & Sham (1997) found that carers of relatives with dementia with more information and knowledge had significantly lower rates of depression, although they had higher rates of anxiety. Carers with more knowledge were more likely to feel competent and confident as carers.

There is research in the literature which has looked at the effectiveness of interventions targeted at care-giving spouses with depression, however these are therapeutic interventions aimed specifically at improving the mental health of carers (Murray, Manela, Shuttleworth and Livingston, 1997). There is no easily available literature looking at information interventions aimed at increasing awareness, understanding, and looking at ways of helping the relative.

Aneshensel et al (1995) looked at the experiences of family members caring for relatives with dementia, and found that the need for information was greatest around the start of the illness. This may therefore also be true for relatives caring for relatives in old age who start to have depression or anxiety.

The Illness Perception Questionnaire

Part of the Trust's CPA Carers Assessment looks at the carer's understanding of the diagnosis of the person they care for, including cause, consequence, prognosis and time-line. These dimensions reflect the dimensions of Health Belief models commonly used by Health Psychologists, such as Leventhal's Health Beliefs model (Leventhal, Nerenz and Steel et al, 1984).

The Illness Perception Questionnaire (IPQ) is a method of assessing perceptions about illness. This was a method of assessing cognitive-representation of illness, developed by Weinman, Petrie, Moss-Morris, and Horne (1996). It is derived from the Leventhal Health Beliefs Model. The five key dimensions within this model are: 1) Identity – the symptoms the clients associates with the illness, 2) Cause – aetiology, 3) time-line – the perceived duration of illness, 4) Consequences – expected effects and outcome, and 5) Cure/control – perception of how can control or recover from illness. The IPQ has normally been used to look at personal ideas about perceptions of patients with physical illness.

Barrowclough, Lobban, Hatton and Quinn (2001) developed a modified version of the IPQ to investigate the perceptions in a sample of carers of people with Schizophrenia. There is no other easily available literature which has used the Illness Perception Questionnaire on carers. In its original form the questionnaire

consists of five scales, as described above. The modifications of the IPQ used in this study are here described. The Illness Identity scale was changed to a symptom list which was appropriate to Schizophrenia rather than physical illness. To accommodate the nature of mental illness, a time-line scale to assess carer's perceptions of the episodic nature of the course of mental illness was included in addition to the time-line scale in the original IPQ which focuses on chronicity. To assess carers' perceptions of the consequences of the illness and control/cure of the illness, two additional scales were included (consequences for carer and control/cure by carer). These scales contain parallel items, for example the parallel item for "there is a lot they can do to control their symptoms", is "there is a lot I can do to control their symptoms". As Barrowclough et al were assessing carers' perceptions they also made some changes to the wording of items, for example "my illness" became "their illness". These modifications were not validated prior to this study.

Although the psychometric properties of the questionnaire may be questionable (see the Discussion session of this paper), the authors concluded that the modified IPQ was a reliable measure of carer's perceptions of schizophrenia. In addition, they concluded that there was a relationship between perceptions as measured by the questionnaire, and client functioning, carer functioning, and the client-carer relationship. Therefore, carer's perceptions based on their understanding and information they have about the illness, may have important implications for both client and carer outcomes.

Research questions

1. How many older adults attending a psychiatric outpatient clinic have late onset depression/anxiety?
2. Which family carers attend appointments with their relatives, and how many express an interest in having a full assessment of their needs?
3. How many carers express interest in an information session?

4. Is the IPQ a useful tool for assessing perceptions of carers of older adults with depression/anxiety?

5. If the IPQ is reliable enough, what can we learn from it about the kind of information carers appear to need (as assessed by the modified IPQ)?

6. How many carers attend the information session, and do they find it useful (as assessed by an evaluation form)?

METHODS

Participants

Participants were carers of clients from psychiatric outpatient clinics who had an onset of depression and/or anxiety in their later years. Carers accompanying clients when attending the clinic were asked to participate. They were then interviewed using the IPQ in the form of guided completion and were invited for a full assessment of their needs, and to attend an information session. At the end of the information session attendees were asked to complete an evaluation form to get information on their perception of the usefulness/relevance of the session.

Design and Measures

This is mainly a descriptive study. Data collection methods included, 1) Numbers recorded from outpatient clinic lists; 2) Demographic questionnaire (see appendix 2); 3) Questionnaire scores from the Illness Perception Questionnaire, and 4) Evaluation forms to measure carers' perceptions of the helpfulness of the information session. Psychometric properties of the IPQ were also examined.

Measures used

The modified Illness Perception Questionnaire was used to measure carers' perceptions of the illness (see appendix 3). This was the same modified questionnaire that was used in the Barrowclough study, except that the Illness Identity subscale was excluded as it was not relevant to depression/anxiety. The modified IPQ, as in the original IPQ gives mean scores for six of the seven subscales. It is not appropriate to sum the items of the Cause scale as each item represents a specific causal belief. As in the original IPQ, the items from the four other subscales are rated by the participant on a five point scale ranging from "strongly disagree" to "strongly agree" (scored 1 to 5). Reverse scoring is appropriate on some items, as identified with an asterisk in appendix 3. The higher scores (i.e. the closer to 5), indicate more consequences from the illness for client and carer, the more amenable the illness to control or cure, the more the carers can influence the illness, the more chronic the time-line and the more

episodic the time-line. There is no assumption that the subscales can be combined to give an overall score.

To evaluate the value of the information session, an evaluation measure was used which was an adaptation of a method of group evaluation developed by Cheston, Bender & Byatt(2000), see appendix 6.

Recruitment of Participants and Procedure

Stage 1

At the beginning of each outpatient clinic, the researchers met with the Psychiatrist to look through the case notes of each client due to attend, to determine who would be appropriate for the study, i.e. those clients who have depression and/or anxiety which started in their later years. This therefore did not include those who 'graduated' from adult services into older adult services, or those with any psychotic or organic illness.

Stage 2

If the client came with a carer, during the outpatient appointment the Psychiatrist informed both the service-user and the carer that a researcher would be hoping to meet with the carer.

Stage 3

After the appointment the researcher invited the carer to participate in a short interview. Interviews were conducted separately by two interviewers, who met regularly to promote consistency.

Stage 4

If they agreed to this, the carer then spent approximately twenty minutes with the researcher. Firstly some demographic information was collected (see appendix 2). They were then asked to complete the Illness Perception Questionnaire in the form of guided completion. The researcher then explained the purposes of the full assessment of carers' needs, and gave the opportunity for the carer to request this in order that their details could be passed on to the relevant person, and the assessment could be arranged for another time. The

researcher then explained the purpose of the information session, giving them a flyer, and asked the carer to complete the slip at the bottom of the flyer at home, and to send it to the researcher, identifying whether they wished to attend or not.

Stage 5

Two weeks before the information session, reminder letters were sent to all those interviewed unless they had expressed a strong wish not to attend at the interview.

Stage 6

The information session was delivered. At the end of the session, participants were asked to complete an evaluation form to gain a measure of their perception of the relevance and usefulness of the session.

Table 1. Breakdown of client and carer population

Clients invited for outpatient appointment between 28 th January and 11 th March 2003 (8 clinics)	66
Clients with depression and/or anxiety which had started in their later years	16 (24%)
Clients attending appointment	13 (81%)
Carers attending appointment	13 (9 clients attended with 1 carer, 2 clients attended with 2 carers)
Total number of carers interviewed	10

Data analysis

SPSS was used for checking reliability of the IPQ. Reverse scoring was incorporated by reversing the score on relevant items before the data was input into SPSS.

Ethical considerations

As this is part of assessment and service provision, it was agreed by the Research and Development Director of the Trust that the project did not have to go through the Local Research Ethical Committee. The service user was informed by the psychiatrist that the carer would be invited to take part in the study, but carers are entitled to an assessment of their own need irrespective of the service users willingness for engagement with services. The carer was able to choose whether or not to take part in the interview, as explained on the Information sheet (see appendix 1).

RESULTS

1. How many older adults attending a psychiatric outpatient clinic have late onset depression/anxiety?

66 clients were invited for an outpatient appointment over eight clinics over a six week period. Out of the 66, 16 (24%) had late onset depression and/or anxiety with no accompanying psychotic or organic illness, as established by psychiatric assessment.

2. Which family carers attend outpatients with their relatives and how many express an interest in having a full assessment of their needs?

Of the 16 clients with late onset depression and/or anxiety 13 attended their outpatient clinic appointments. Out of these 13 clients, 9 (81.8%) were accompanied by one relative and 2 (15.38%) were accompanied by 2 relatives. Out of a total of 13 relatives, 10 (77%) were interviewed.

The characteristics of the interviewed carers & clients are shown in tables 2 and 3.

Table 2. Characteristics of interviewed carers

Gender	6 male 4 female
Age	Mean - 70.00 years (SD – 10.13)
Ethnicity	10 White/British
Relationship	5 husbands 2 sisters 1 wife 1 son 1 daughter
Living arrangement	8 live with client 2 live away (1 hour, 25 hours per week contact respectively)
Other people cared for/commitments	7 – none reported 1 – 2 daughters 1 married plus work full-time 1 – part-time voluntary work

Table 3. Characteristics of clients

Gender	5 male 5 female
Age	Mean – 74.6 years (SD – 4.25)
Ethnicity	10 White/British
How long had difficulties for	4.6 years (SD-3.98)

2 out of the 10 interviewed carers expressed a wish in having a full assessment of their needs. Therefore 80% declined the offer of a full assessment. Some of those who declined said that it may be something that they may like to take up in the future, but that they did not wish to pursue this at the current time.

3. How many carers express interest in an information session?

Out of the 10 carers interviewed, 3 said that they were not interested in attending an information session. Although we might see the onset of the depression/anxiety as being fairly recent, for the 3 who were not interested in the session, it felt like they had been managing it for some time, and had arrived at their own ways of dealing with things. At the interview 7 expressed an interest in attending. 1 of the 7 later phoned to say they could not attend, the other 6 later returned a slip in the post to confirm their attendance.

4. Is the IPQ a useful tool for assessing perceptions of carers of older adults with depression and/or anxiety?

The psychometric properties of the IPQ for this population were examined in terms of internal consistency, inter-item correlations within subscales (see table 4), and inter-subscale correlations (see table 5).

Table 4. Illness Perception Questionnaire Subscales, Mean Scores, Cronbach's Alpha Reliabilities and Mean Inter-item Correlations. N=10

IPQ subscale	Mean subscale score (SD)	Mean inter-item correlation	Cronbach's alpha reliabilities
Consequences – client (8 items)	3.54 (0.63)	.28	.76
Consequences – relative (6 items)	3.12 (0.66)	.22	.63
Control/cure of illness (6 items)	3.35 (0.34)	.12	.45
Control/cure by relative (2 items)	3.05 (0.07)	.79	.88
Time-line – chronic (3 items)	3.03 (0.45)	.60	.82
Time-line – episodic (2 items)	3.65 (0.07)	.26	.42

Internal Consistency

Cronbach's alpha reliabilities were generally acceptable for the IPQ subscales, although reliabilities for control/cure of illness and time-line-episodic were relatively low, (.45 and .42). Generally 0.7 & above is considered acceptable. In the future, addition of further items for these two subscales may improve their internal consistency, particularly for the time-line episodic subscale which only had 2 items.

Inter-item Correlations

Biggs and Cheek (1986), considered the optimal range for inter-item correlations to be between .2 to .4. Anything below .2 may be too weak a correlation, and above .4 may be too strong a correlation. Using Briggs & Cheek's optimal range, consequences-relative & consequences-client and time-line episodic have inter-item correlations of appropriate strength. However inter-item correlations for cure / control is too weak. Inter-item correlations for cure / control by relative and timeline-chronic are too strong, possibly because there are very few items in both subscales which increases the likelihood that the correlation is due to chance.

Inter-subscale Correlations

To further examine the psychometric properties of the IPQ, inter-subscale correlations were calculated.

Table 5. Spearman's Intercorrelations Between IPQ Subscales. N=10.

	Consequences – client	Consequences - relative	Control/cure of illness	Control/cure by relative	Timeline - chronic
Consequences – client	1.00				
Consequences – relative	.32	1.00			
Control/cure of illness	-.15	-.08	1.00		
Control/cure by relative	.05	.59	.25	1.00	
Timeline- chronic	.55	.16	-.47	.04	1.00
Timeline- episodic	-.52	.39	-.18	.20	-.32

On SPSS the table of correlations identifies three moderate correlations:

- 1) Control/cure by relative and consequences – relative

correlation co-efficient = .59

sig (2 tailed) = .071

- 2) Time-line episodic and consequences –client

correlation co-efficient = -.52

sig (2 tailed) = .127

- 3) Time-line chronic - and consequences - client

correlation co-efficient = .55

sig (2 tailed) = .1

None of these are at or above the level 0.05 or 0.01. However with such a small sample size the power is small which means that statistical analysis is not possible. It is therefore not possible to conclude from the above that there is independence between the subscales. The strongest associations are; if participants rate more negative consequences for the client, they are more likely to rate the timeline of the illness to be more chronic, and less episodic. If they rate more negative consequences for themselves, they are more likely to rate the illness as being more controllable by themselves.

5. What kinds of information do carers appear to need (as assessed by modified IPQ)?

Subscale Mean Scores

Table 3 gives the mean scores for each subscale. All items had a possible range of 1-5. The higher scores (i.e. the closer to 5), indicate more consequences from the illness for client and carer, the more amenable the illness to control or cure, the more the carers can influence the illness, the more chronic the time-line and the more episodic the time-line.

The IPQ mean scores are all between 3 and 4, where 3 represents 'neither agree nor disagree' and 4 represents 'agree'. Taking mean scores above 3.5 as 'agreeing' and scores below 3.5 as ambivalence or uncertainty, we would conclude that as a group carers tend to agree that depression has an impact on the person with depression, and that the illness is episodic, but they are uncertain as to whether the illness has an impact on themselves, whether the illness is amenable to control or cure, whether they are able to influence the illness, and whether the timeline is chronic. These results suggest that family carers have a different perception of depression to professionals. This has relevance working on the assumption that both the person with depression and their relatives have a large influence on the course of the illness.

The 'Cause' subscale cannot be scored in the same way. The results of this subscale are summarised below:

A germ/virus caused the illness

All 10 disagreed or strongly disagreed

Diet played a major role in causing their illness

1 neither agreed or disagreed

9 disagreed or strongly disagreed

Pollution of the environment caused their illness

1 neither agreed or disagreed

9 disagreed or strongly disagreed

Their illness is hereditary – it runs in the family

1 agreed/strongly agreed

1 neither agreed or disagreed

8 disagreed or strongly disagreed

It was just by chance they became ill

7 agree/strongly agree

3 disagreed or strongly disagreed

Stress was a major factor in causing their illness

7 agreed/strongly agreed

1 neither agreed or disagreed

1 disagreed or strongly disagreed

1 left the question blank

Their illness is largely due to their own behaviour

3 agreed/strongly agreed

1 neither agreed or disagreed

6 disagreed or strongly disagreed

Other people played a large role in causing their illness

4 agreed/strongly agreed

6 disagreed or strongly disagreed

Their illness was caused by poor medical care in the past

2 agreed/strongly agreed

1 neither agreed or disagreed

7 disagreed or strongly disagreed

Their state of mind played a major part in causing their illness

7 agreed/strongly agreed

2 neither agreed or disagreed

1 disagreed or strongly disagreed

This indicated that this group of carers may benefit from some information about the cause of the illness, particularly that depression/anxiety is unlikely to occur by chance, and that generally anxiety and depression is often a result of internal factors such as the ways they see things, and how they behave, rather than events, other people and other things external to the person with depression/anxiety.

6. How many carers attend the information session, and do they find it useful (as assessed by an evaluation form)?

5 out of the 10 interviewed attended the session. 7 out of the 10 had expressed an interest in the session, 6 had returned a slip to confirm their attendance, 1 was unable to attend, 1 did not attend and the reason for this is unknown. Two additional carers were also invited as they were already well known to the Psychology service, one of whom attended the session. Therefore, in total 6 carers attended the information session out of a possible 12. The content of the session is shown in appendix 5.

Table 6. Carers' evaluation of information session

Perceived relevance of the session	0 could not see the point 2 found it of some relevance 4 found it very relevant
How much was learnt from the information session	0 did not learn much 4 learnt some 2 learnt a lot
Level of interest in the session	0 found it boring 1 found it ok 5 found it interesting
Perception of the leader's style	0 did not like the way it was run 1 thought it was run ok 5 liked the leaders style
Appropriateness of speed	0 found it too slow 6 found it the right pace 0 found it too fast
How carers felt in the session	0 felt frustrated/angry/inhibited 1 felt ok 5 felt relaxed
Level of understanding in the information session	0 did not understand it 0 understood some 6 understood it all

Carers were also asked what they found most and least useful, and whether they had any suggestions as to how the session could be improved. 5 out of 6 carers said that listening to other people's problems or sharing their experiences was the most useful part of the session. No comments were given about the least useful aspect of the session. Only one suggestion for improvement was given by one carer, which was "more advanced information may be needed in the future".

DISCUSSION

24% of older adults who attend a psychiatric outpatient clinic may have late onset depression and/or anxiety with no accompanying psychotic or organic illness. Over a six week period we attended 8 outpatient clinics out of a possible 12. If we assume that on average clients will present twice for an appointment a year as the standard period between appointments is 6 months, with some clients presenting less frequently and others attending a clinic more frequently, a crude estimate of how many of these clients that may present at a Psychiatric outpatient clinic over the course of a year may be around 89. Thinking about family members who care for these people is therefore important.

When the results were presented to the team, there was particular interest in how the demands on professionals' workloads may be fairly minimal, and less than feared. It would be interesting to continue to monitor whether the team starts to offer any more carer assessments as a result of these findings.

8 out of the 10 carers interviewed were in their old age. It is common in this age group to find that people under utilise services that are on offer. Yang and Jackson (1998) discuss how older adults significantly under-utilise mental health services relative to their numbers in the population. This may be due to physical, cognitive, emotional and attitudinal issues. They suggest that mental health treatment has a greater stigma for this age cohort, as they may have been taught by their families that negative feelings made someone bad or weak, and to talk about such feeling is shameful. They may also have a lack of education about mental health services. Older adults may strive for independence, particularly as increasingly they may be having to accept help from others. Therefore accepting one more service may be a further loss of independence for carers. Yang and Jackson say that in order to engage these carers, we should consider education about treatment, alternative ways of recruiting clients, use of alternative terminology, and rapport building.

Informational needs may be the greatest at the beginning of the illness, therefore there is a group of clients and carers who may particularly benefit from

information about the illness. As a group, carers may benefit from information on the causes of depression and anxiety, (particularly that it may not be caused by chance or something else outside the person's control), the impact their relative's depression/anxiety has on them, and how in return this may then impact on their relative. They may benefit from information on how depression/anxiety can be controlled or managed, and what they can do to help their relative control it.

50% of the carers interviewed expressed an interest in, and attended an information session. This suggests that it is worthwhile continuing the information session in this service on a regular basis. As many as 45 carers of older adults with recent onset depression and/or anxiety may be interested in attending such a session in a year. However, it is important to bear in mind that the information session was presented as an opportunity to meet other carers in a similar situation, as well as to get information. Therefore we cannot be sure whether it was the prospect of gaining information that was the motivation for attending. Indeed, in the evaluation forms completed after the session, 5 out of the 6 carers said that the most helpful aspect of the session was meeting other carers.

The evaluation forms indicate that most carers who attended the information session found it of some value; most found it to be very relevant, most learnt something, and most found it interesting. None of the carers said that they could not see the point of the session, that they did not learn much, or that they found the session boring. There were no criticisms of the appropriateness of the structure and presentation of the session; most liked the leaders' style, found the speed of the session to be the right pace, felt relaxed in the session and understood it all. This indicates that sessions using a similar format could be continued. However this age group may be less likely to be critical of a service provided to them. Indeed some of the carers at interview, expressed appreciation that they were being taken notice of, and therefore may not have wished to appear critical. However, one attendee stated that he had come to the session with the intention of being hostile to what was on offer, but had been surprised that he had found the session to have been both useful and enjoyable.

The Illness Perception Questionnaire as a tool for measuring perceptions in this population may have some use, although the psychometric properties cannot be properly analysed as the sample size is very small. However, Cronbach's alpha reliabilities were generally acceptable for the IPQ subscales, and may have been better if there were more items in some of the scales in to improve internal consistency. There were a few moderate correlations between subscales, but none statistically significant. However a larger sample size would be needed to determine whether there was independence between the subscales.

The psychometrics are a little better in the Barrowclough study. This may be at least partly because in the Barrowclough study there were 47 carers. In their study, once a single item was removed from four of the scales the alpha reliabilities were generally acceptable. The inter-item correlations generally fell within the acceptable .2-.4 range, and there were 3 significant inter-scale correlations at $p < 0.05$, which were between consequences for the relative and consequences for the client; time-line chronic and consequences for the client, and time-line episodic and time-line chronic.

The study was presented by my supervisor at the European Annual Behavioural and Cognitive Psychotherapies Conference in Prague, September 2003. The other three papers presented in the symposium were on CBT with parents of children with mental health problems, spouses of people with manic depression, and carers of people with schizophrenia. The paper on family carers of people with schizophrenia also used the revised illness perception questionnaire. The fact that there was a symposium on carers, suggests that carers needs and perceptions are becoming of increasing importance.

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APPENDICES

Appendix 1: Lay summary for carers.

Appendix 2: Demographic information sheet.

Appendix 3: The Illness Perception Questionnaire for Carers

Appendix 4: Flyer given to carers interviewed advertising the Information Session

Appendix 5: Hand-out to carers at the Information Session.

Appendix 6: Evaluation form completed by carers at the end of the Information Session.

RELATIVES' SURVEY

Recent changes in the way we work means that we need to be more aware of the needs of relatives who provide support and care for a family member with mental health difficulties.

We would therefore be very grateful if you would agree to spend 20 minutes to meet with ***** , Trainee Clinical Psychologist. This would give us the opportunity to:

- a) Help us gain an initial understanding of your experiences which would help us to develop our services, to help us meet the needs of people in your situation. We will be asking you about your personal views on how your family member's illness has affected your life, and the life of your family member, and how you see the future. We are hoping that by talking to people like yourself, we will be able to see what kinds of help we could offer people in your situation.
- b) Find out whether you would like to have a full assessment, with the view to getting support for yourself. Anyone who, like yourself, provides this kind of care is entitled to an assessment of their needs, and help from our services.
- c) Invite you to an Information Session on depression and anxiety.

As part of a team providing care for the needs of your family member, any information you give us will be kept confidential within the service.

Whether you decide to meet with ***** or not, will not adversely affect any future treatment you or your relative will receive.

If you have any queries please do not hesitate to ask either ***** (Trainee Clinical Psychologist), ***** (Consultant Clinical Psychologist), or ***** (Consultant Psychiatrist), either in person at ***** either in person or on *****.

Thank you very much for your help.

DEMOGRAPHIC INFORMATION

Carer details

Name

Gender

Date of Birth

Ethnicity

Relationship to client

Live with client/live away from client

If live away – how many hours of contact do they have per week

Other responsibilities:

Family responsibilities

Other people cared for

Work commitments

Client details

Age

Gender

Ethnicity

How long has had difficulties for

Who else lives with client

Illness Perception Questionnaire for Carers

We are interested in your own personal views of how you now see your relative's illness. Please indicate how much you agree or disagree with the following statements about the illness, by circling the most appropriate answer.

Rated:

<i>strongly agree</i>	<i>agree</i>	<i>neither agree nor disagree</i>	<i>disagree</i>	<i>strongly disagree</i>
---------------------------	--------------	---	-----------------	------------------------------

1) CAUSE OF THE ILLNESS

- | | | | | |
|----|---|--------------|---|------------------------------|
| 1. | A germ of virus caused their illness | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |
| | | | | |
| 2. | Diet played a major role in causing their illness | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |
| | | | | |
| 3. | Pollution of the environment caused their illness | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |
| | | | | |
| 4. | Their illness is hereditary – it runs in their family | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |
| | | | | |
| 5. | It was just by chance that they became ill | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |
| | | | | |
| 6. | Stress was a major factor in causing their illness | | | |
| | <i>strongly
agree</i> | <i>agree</i> | <i>neither agree
nor
disagree</i> | <i>disagree</i> |
| | | | | <i>strongly
disagree</i> |

7. Their illness is largely due to their own behaviour
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
8. Other people played a large role in causing their illness
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
9. Their illness was caused by poor medical care in the past
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
10. Their state of mind played a major part in causing their illness
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

2) CONSEQUENCES OF THE ILLNESS FOR YOUR RELATIVE

1. Their illness is a serious condition
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
2. Their illness has had major consequences on their life
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
3. Their illness has become easier for them to live with
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
4. Their illness has not had much effect on their life
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

5. Their illness has strongly affected the way others see them
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
6. Their illness has had strong economic and financial consequences for them
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
7. Their illness is disabling
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
8. Their illness has strongly affected the way they see themselves as a person
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

3) THE CONSEQUENCES OF THE ILLNESS FOR YOU

1. Their illness has had major consequences on my life
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
2. Their illness has become easier for me to live with
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
3. Their illness has not had much effect on my life
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

4. Their illness has strongly affected the way others see me
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
5. Their illness has had strong economic and financial consequences for me
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
6. Their illness has strongly affected the way I see myself as a person
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

4) CONTROL OF THEIR ILLNESS

1. Their illness will improve in time
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
2. There is not a lot they can do to control their symptoms
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
3. There is very little that can be done to improve their illness
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
4. Their treatment will be effective in curing their illness
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

5. Recovery from their illness is largely dependent on chance or fate.

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

6. What they do determines whether their illness gets better or worse

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

5) HOW YOU CAN CONTROL THEIR ILLNESS

1. There is a lot I can do to control their symptoms

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

2. What I do determines whether their illness gets better or worse

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

6) DURATION OF THEIR ILLNESS

1. Their illness will last a short time

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

2. Their illness is likely to be permanent rather than temporary

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

3. Their illness will last for a long time

strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

7) CHANGES IN THEIR ILLNESS

1. Their illness may change from time to time
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*
2. There will be periods of illness and periods of improvement
strongly agree *agree* *neither agree nor disagree* *disagree* *strongly disagree*

ARE YOU CARING FOR A RELATIVE WHO HAS DEPRESSION OR ANXIETY?

You are invited to an afternoon workshop for family members who are caring for someone with depression or anxiety.

WHEN IS IT?

Monday 24th March from 1pm to 3 pm.

WHERE IS IT?

Address *****

WHAT WILL HAPPEN?

You will be in a group of about 8-10 people who are in a similar situation to yourself.

WHAT WILL IT COVER?

We will be sharing information with you such as on:

- What sort of things can bring about depression or anxiety
- What you might expect from the future
- Ways of helping your family member cope with it.

TO BOOK YOUR PLACE

Please tear off and complete the slip below and return it to ***** at *****

For the attention of *****

I will/will not be attending the information session on Monday 24th March.

Name:

Address: If you have any queries, please do not hesitate to contact us on *****

Information Session for Relatives:

Understanding Depression and Anxiety

March 24th 2003

WHAT IS THE PURPOSE OF THIS SESSION?

The aim of this session is to give information on depression and anxiety.

We will try to answer the following questions:

- What is it?
- What causes it?
- Will it get better?
- What should I do?
- Who are the people in the Mental Health Service?

This session is limited to general information about depression and anxiety. We will not be able to discuss personal issues relating to your relative during this session, but there may be ideas from this session that you would like to discuss with people in the Mental Health Service looking after your relative.

Please feel free to ask questions throughout the session. We may not be able to give you all the information you want in the time we have together. However if you feel at the end of the session, you still have unanswered questions, please talk to us at the end of the session, and we can arrange to see you on your own on another occasion.

We have also mentioned to you that as someone who provides care for someone with depression and/or anxiety, *you are entitled to full assessment of your needs*. This means that we can look further at what support and care we can provide you. If you would like this now, or at any time in the future, please ask any mental health professional, and this can be arranged for you.

During today's session you may hear personal details of other people and their families. Please do not pass these details on, or discuss other people's personal details with anyone who is not here today. We will not pass on any information that you give us today without discussing this with you first.

WHAT IS DEPRESSION?

Some common symptoms of depression are:

- loss of enjoyment and motivation
- increased irritability and anger
- self-criticism and guilt
- pessimism about themselves, the world and the future
- hopelessness
- reduced activity
- finding it hard to be with people
- difficulty concentrating
- problems remembering things day-to-day.

WHAT CAUSES DEPRESSION?

There are many triggers for depression. Triggers can be physical, or psychological or a combination of the two.

Depression is not caused by a particular germ or virus, but can be triggered in some people by physical conditions e.g.:

- Steroid use
- Stroke
- Hormonal changes (e.g. post-natal, menopausal)
- Lack of light

Psychological triggers are usually related to actual or 'near miss' loss. For example:

- Physical ill-health
- Bereavement, or ill-health in a loved-one
- Redundancy or retirement
- Moving house
- Children moving away

A trigger for one person may not be a trigger for another person. This is because we all see the world in different ways. Our earlier experiences influence how we feel about ourselves, others, and the future.

Some older people may be more prone to depression than others, for example if there has been depression in their families, or if they have had depression earlier in their lives.

Depression is not an inevitable consequence of ageing.

WHAT KEEPS DEPRESSION GOING?

Whatever the trigger, once depression has started, it is self-perpetuating. That is, the symptoms of depression keep the depression going.

It is likely that your relative will have withdrawn from the activities that they used to do and enjoy. When people are depressed, it is hard for them to feel interested in things, and to find the motivation to do things. However, this then further confirms their beliefs that they are “useless”, “that they don’t enjoy life”, “that they never succeed or achieve anything, and perhaps that “life doesn’t have much of a purpose”. This may then make them feel more depressed, and their motivation to do things may decrease even more. This is known as a ‘vicious circle’.

Emotions come from how people think about themselves, their world, and the future. It is their perceptions and interpretations, which keeps their depression going.

WHAT IS ANXIETY?

Signs and symptoms of anxiety include:

- appearing to be overly alert or on edge
- irritability
- tension or nervousness
- reporting sensations in their body such as palpitations, light-headedness, sweating and shaking.
- difficulty relaxing or concentrating.
- seeking reassurance from others
- thinking that the worst is going to happen, for example if someone is late, that they have had an accident.
- avoiding certain situations.

It is very common for people to have a mixture of anxiety and depression.

Sometimes depression is a consequence of anxiety and sometimes anxiety is a consequence of depression.

There are many different kinds of anxiety and depression. We will now look at some of the different kinds of anxiety. It is not unusual for someone to have a mixture, or combination, of these.

WHAT ARE THE DIFFERENT TYPES OF ANXIETY?

You may have heard the Psychiatrist or other professionals refer to the following:

Generalised Anxiety Disorder

This is also known as *worry*. The most common symptom is someone's mind turning anxious thoughts over and over, and feeling unable to relax. They may find it difficult to concentrate, and may often feel that they are confused, that their mind is blurry, and that it is difficult to control their thoughts. Another very common symptom is the fear of losing control.

Health Anxiety

A person may continuously be afraid of developing a serious or fatal illness. For example they may have anxieties about getting cancer. Of course we all have anxieties about this from time to time, however for the person with Health Anxiety, this may mean that leading a normal life is difficult.

Phobia

This is where a person may be afraid of a specific type or object or situation. Common phobias include a fear of heights, (Acrophobia), spiders (Arachnophobia), closed spaces (Claustrophobia), open spaces (Agoraphobia), or social situations (Social Phobia). But in fact you can have a fear of *any* situation or object.

Panic

This is a sudden, intense state of apprehension, fear or terror which is usually accompanied by some of the bodily sensations already described, which feel so severe that the person may believe that they are having a heart attack, or that they are going to faint. In fact they are not, the feelings are symptoms of anxiety. These panic attacks can occur unpredictably, and seemingly "out of the blue".

Obsessive-Compulsive Disorder

The person may experience obsessions, which are a concern that something dangerous will happen. The person may continually doubt whether they have done all they can to ensure their safety, or the safety of others. For example, a person who is concerned that they will accidentally set fire to their home, may doubt that they have done all they can to prevent this happening, such as checking properly that all the electrical appliances are switched off. The person may also have compulsions, which are the things the person does to reduce the doubts. The person in the example above, may check all the plug sockets ten times to reduce their doubt before they can leave the house.

Post-traumatic Stress Disorder

This may follow a series of traumatic events, such as bullying or abuse, or may follow one particular event such as a car accident, or an attack. People may go on to have symptoms such as re-experiencing of the traumatic event(s), numb responses, and/or may seem detached from other people and life in general.

WHAT CAUSES ANXIETY?

Anxiety is usually triggered by the fear that something awful might happen in the near future.

Some people are more prone to anxiety than others. People will be more prone to anxiety if:

- they were exposed to situations of responsibility or danger that they were unprepared for, or too young to cope with.
- they have had past experiences of feeling that things are out of their control or that they have been betrayed or abandoned
- they come from families where other people are anxious, and they learned that the world can be a hostile and fearful place

WHAT KEEPS ANXIETY GOING?

Just as the symptoms of depression are self-perpetuating, similarly the symptoms of anxiety are self-perpetuating.

DO ANXIETY AND DEPRESSION GET BETTER?

Yes. Both anxiety and depression are treatable illnesses.

It can be difficult to predict how long it will take to get better, but a general 'rule of thumb' is that it will take as long for a person to recover as they have had the illness in the first place.

WHAT CAN RELATIVES DO TO HELP?

(1) Try to be patient

This is easier said than done! You may need to let off steam from time to time, so try to find someone you can talk to, or an activity that helps you to relieve the tension or frustration.

(2) Do spend time with the person – are there some things that you can do in a companionable way?

(3) Try to work out how they see things, from their point of view. This might be different from yours as they have had different life experiences – even if you have lived together for many years.

(4) Let them know things that you appreciate, or value about them.

(5) Try not to blame or criticise them for the depression. Depression is an illness.

(6) Try not to take over all of the tasks that they used to do.

There may be tasks that absolutely have to be done, but if you take over everything, you will not only get exhausted, but it does not leave anything for them to start doing again as the depression begins to lift.

(7) If they suffer from anxiety, they may feel embarrassed doing things as they do not feel in control. You can give them some reassurance that their uncomfortable feelings are not as obvious to them as it is to others. However try not to give them so much reassurance that they come to rely on it, as this will make it difficult to do things for themselves without your reassurance.

(8) Look for opportunities to give genuine praise.

LOOKING AFTER YOURSELF

In order to look after someone else, you must look after yourself.

Relatives caring for someone with depression and/or anxiety often experience a whole range of emotions, such as guilt, frustration, anger, loneliness, fear, envy, despair

Pay attention to your own needs. You can do this by:

(1) Seeking the support of others.

Often people in your situation find that people around them will undermine what they are doing to help, or will make suggestions opposite to what they want to do. So try to seek the support of people who are supportive of your efforts. Maybe then you can talk through your feelings with them, and share the responsibility with them. Try to spend some time away from your relative without feeling guilty.

(2) Try not to give yourself a hard time

There will be times when you feel you have not been able to help. There may be times when you think you may have made them feel worse. It is inevitable that you will sometimes make mistakes, so try not to beat yourself up about it!

We know that there are many pressures on you, and the relationship you have together, and your life as a whole may have changed quite a lot. But we do know that a good understanding of the illness and what can be done about it, can be of some help and support to relatives, even if it does not take the illness away.

SUMMARY

In this session we have looked at some of the questions commonly asked by relatives, such as: “What is depression and anxiety?” “How are depression and anxiety related?” “Will it ever get better?” and “What can I do to help?”

Are there other things you would like to ask?

What would you like to remember from today?

Is there anything you would like to try differently?

Appendix 6

EVALUATION FORM – UNDERSTANDING DEPRESSION AND/OR ANXIETY (RELATIVES)

Please circle the phrase in each question that best describes how you felt about the session.

1.	Interesting	OK	Boring
2.	Did not learn much	Learnt some	Learnt a lot
3.	Frustrating – I felt angry/inhibited	I felt OK	I felt relaxed
4.	Too fast	Right pace	Too slow
5.	Understood it all/almost all	Understood some	Did not understand
6.	Too long	Right length	Too brief/condensed
7.	Could not see the point	It was of some relevance	It seemed very relevant to me
8.	It was almost all new information	About half of it was new information	I had heard the information before
9.	I liked the session leaders style	It was run OK	I did not like the way the session was run

What did you find most useful?

What did you find least useful?

Do you have any suggestions as to how we could improve the session?

Critical Literature Review

Year 2

The Quality of Life of Adolescent Burn Survivors: current research findings and measures.

4,717 words

The Quality of Life of Adolescent Burn Survivors: current research findings and measures.

Background to Burns Research

Due to medical and surgical advances in recent years, more people who suffer from burn injuries are now being kept alive, when previously they would have died. This means that there are more people who have to cope with;

“the trauma of the injurious event; medical treatments which are often painful and frightening; physical changes in their body which are permanent reminders of what has happened to them; reactions of others to their bodies which may be real or imagined, as well as feelings of being rejected, isolated, unworthy and humiliated” (Blakeney et al, 1998).

The decision of whether to keep people alive is a difficult ethical question. Fratianne et al (1992) discusses the difficulty in determining at what point treatment is futile, which may result in the continuation of aggressive therapy for many patients. Physicians tend to err on the side of doing as much as they can to keep their patients alive.

Looking at the quality of life may help to address this ethical question. If it can be shown that burn survivors have a reasonable quality of life, then this would suggest that keeping these people alive is ethical. There is not enough research to date which explores this, and the existing research has methodological limitations, particularly around measurement. However from the little knowledge we do have, it seems that people with burn injuries can lead reasonable lives.

Also to consider in such a complex ethical dilemma is cost-effectiveness. “Burn management is a refined speciality, and its technical success is well documented, however, in the current climate of cost-containment, its costs and cost-effectiveness for the achievement of patient-oriented outcomes are subject to scrutiny” (Daltroy et al, 2000). Therefore the measurement of outcomes should be seen as important.

There is very little research in the burns literature which discusses this kind of decision making.

This review will firstly explore the concept of quality of life as it is defined in the literature, and the problems in defining the concept. This review will be focusing on the quality of life in adolescents. The stage of ‘adolescence’ will be explored a little, and the fact that research in many areas does not consider adolescence as a separate developmental stage. There is very little research on outcomes, and especially quality of life of children and adolescents surviving burn injuries. Some of this existing research will be described with a particular focus on quality of life. This will be followed by a critique of the generic and disease-specific quality of life measures available in the literature for looking at the quality of life of adolescents with burn injuries. It is hoped that this review will highlight the gaps in the current literature and indicate areas for future research.

The Concept of Quality of Life

According to Munster (1999), quality of life of burn survivors is the most relevant aspect of outcome for physicians and other health-care providers. Finding out about self-perceived quality of life helps health-care professionals understand the implications of their work. Changes in interventions should demonstrate that they will lead to an improved quality of life. It is also important for the public to understand the quality

of life of people with disabilities or health problems, as perhaps the public do not recognise how valuable their lives can be (Ubel et al 2003).

Another advantage is that it may be useful for Clinical Psychologists, Psychotherapists and other therapists to understand how these different groups of people see different aspects of their lives. This can then help inform intervention.

It is difficult to define what is meant by 'Quality of life'. From looking at the literature there is no precise meaning of the term. Jonsen et al (1982) see 'quality of life' as being an attempt to place some value on some feature of human experience (Jonsen et al, 1982).

Eiser (2001) describes some of the main approaches to measuring quality of life. The economic approach is concerned with material wealth. The sociological approach is concerned with an individual's assessment of their circumstances, such as how they see their relationships with others and their views about how they are loved by others. The psychological approach looks at an individual's self-esteem, ability to make decisions, whether they are active, happy and fulfilled. The psychological approach has the assumption that the nearer a person is to attaining their life goals, the better their quality of life. The medical approach emerged in response to advances in medical care, and is concerned with a 'feel better' factor.

Several authors see the quality of life as being the subjective sense of well-being of the individual. For children and adolescents with cancer, well-being may reflect "how closely their desires and hopes match with what is actually happening", and their "orientation to their future, both their own and that of others" (Ivan et al, 1994).

According to Drotar (1998), any measure of quality of life should include an assessment of physical function, mental status and social interaction.

The World Health Organisation Quality of Life Group define 'Quality of Life' as an "individuals' perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".

The concept of 'quality of life' has come under some criticism. McDowell and Newell (1987) describe the concept of quality of life as being "a fashionable idea rather than a vigorously defined concept.....there is little agreement over the appropriate content for such indices or over how empirical measurements of quality of life relate to conceptual definitions".

If there could be universal agreement on what exactly "quality of life" is, and what aspects of their lives should be measured, this would make the study of quality of life across a range of client groups more meaningful. It would also help health policy makers to make better informed decisions.

Background to Adolescence

The stage of 'adolescence' is frequently neglected in all areas of research. Research into children often includes adolescents as children, rather than considering them as a separate developmental age. This can also be seen in the quality of life literature and the burn literature.

According to Erikson's theories (1959), adolescents struggle with role confusion and identity formation. Adolescents with scars from burn injuries may have an even greater struggle as they need to deal with a role and an identity that has been forced on them and they are often made to feel different by their peers.

How a person sees their appearance is particularly important to adolescents because during this time the physicality of the body changes which heightens bodily awareness (Bernstein, 1990). Thus for adolescents with burns, their view of their appearance may be even more

prominent. The adolescent's body image may have a significant impact on their quality of life. Fauerbach et al (2000) looked at the effect of early body image dissatisfaction on quality of life in adults, and found that it did have an impact. This has not been researched in adolescents, and this gap in the literature should be addressed.

As well as body changes and higher bodily awareness, adolescence is also associated with changing attitudes to themselves, their families, and their peers (Giljohann (1980). Giljohann interviewed parents of early adolescents aged 12 to 14 who had been burned in childhood. Parents were becoming increasingly aware of their children's desire to look like their peers, and for example might be reluctant to go swimming. Parents were becoming concerned often for the first time, about the reaction of the opposite sex to their appearance and their sexual desirability.

It would be useful for future research to focus on adolescents so we can learn more about the specific issues that affect them.

The Literature on Outcomes for Children and Adolescent Burn Survivors (not specific to quality of life).

There are some positive outcomes for child and adolescent burn survivors that have been found in the literature. Blakeney et al (1998) looked at the "long-term psychosocial adaptation" of 63 children between the ages of 4 and 18 with 80% and above total body surface area burns. They used standardised tests of adjustment, completed by parents, teachers and patients. They found that most of the children are adapting "satisfactorily" without severe psychological or behavioural problems. Those children who reported additional information all seemed to be happy, with some volunteering that they felt happy to be alive.

Robert et al (1998) looked at the impact of scars on adolescent sexual development. 19 adolescents with scars from burns completed a

sexuality survey, and their information was compared to information reported by other investigators who looked at sexual development in adolescents who have not been burned. They found that the adolescents with burn injuries appear to have similar thoughts, feelings and behaviours with regards to sex, and intimate relationships.

Stoddard et al (1989) compared the psychiatric outcome of 30 children between the ages of 7 and 19 who have been burned, with children who have not been burned. They found that according to the DSM-III criteria, the children who had been burned had significantly higher levels of overanxious disorder, phobias, and enuresis, but they had the same rates of depressive disorders.

Other outcome studies have looked at social competence and behavioural problems of children aged six to 18 (Blakeney et al, 1993); self-esteem in forty-nine 5 to 18 year olds (Abdullah et al, 1994), and depression in thirty 7 to 19 year olds. However none of these studies have comparison groups making the results difficult to interpret.

Zeitlin (1997) was critical of studies looking at psychological outcome in children with burns. Some of the criticisms were that there were too few prospective studies and studies with comparisons to children who do not have burns. Other criticisms were that often the sample size is too small and that children were seldom considered separately from adults. Many of these criticisms seem true of the studies described above; the sample sizes are relatively small and few studies make comparisons to a control group. In addition, none of these studies consider adolescents separate to the children.

Quality of Life Studies on Children/Adolescents

There are only two easily available studies in the literature which claim to have specifically looked at the 'quality of life' in pediatric burn survivors.

Of course, with the lack of agreement over a definition of 'quality of life', and the breadth the concept may encompass, it could be argued that the studies described above look at aspects of quality of life. However it seems that the above studies look at quite specific aspects of someone's life, e.g. sexual development, social competence, and behavioural problems. 'Quality of life' seems to be something more global.

Herndon, Le Master and Beard (1986) looked at the 'quality of life' of 12 children who had survived with greater than or equal to 80% total body surface area, or 70% third degree burns. They ranged from 0.08 to 2.8 years post discharge. At the assessment the children were between nine months and seventeen years. Children were assessed during an outpatient clinic by surgeons, physiotherapists, occupational therapists, nurses and psychoanalysts. 'Quality of life' was not objectively defined, and no standardised measure of quality of life was used. In this study 'quality of life' seems to encompass a wide range of physical and psychological aspects. Physical tests included motion measurements of joints, audiometric tests, walking/running exercise, activity questionnaire, test of activities of daily living. Psychological testing involved a child mental status examination, a developmental history, and the Louisville Behaviour Checklist, the Burn Injury Questionnaire (Fisher, 1984) with yes/no questions about problems relating to scarring or activity. They found that 'physical impairment' was approximately 60%. Out of the children old enough to be tested 50% were completely independent in activities of daily living. One third of the children had excessive fear, regression and neurotic and somatic complaints, but all showed "remarkable energy in adapting to their disabilities".

Landolt, Grubenmann and Meuli (2002) did use a standardized measure of quality of life to look at 105 burn survivors aged 5-17 years. The TACQOL is a questionnaire for parents designed to assess their child's quality of life. Landolt et al found that all the norms were within the norms published for healthy children, the only difference being that parents reported less positive emotions in their burned children.

However there are limitations to this study. Firstly, the data from the TACQOL was obtained from the childrens' parents which may only provide selective information. In a separate study, Theunissen et al (1998) evaluated the agreement between child and parent reports on children's health-related quality of life using the TACQOL. It was found that on average the children reported a significantly lower quality of life than their parents on physical complaints, motor functioning, autonomy, cognitive functioning and positive emotion scales.

In both of these studies, we know very little about the child/adolescent's self-perceived quality of life. Also adolescents were not considered to be separate to children.

With such a lack of research on the quality of life of children and adolescents who have been burned, it may be interesting to look at the adult literature. However we cannot draw conclusions from this literature to what the quality of life of adolescents might be.

There has been a little research interest in the quality of life of adults, although this is still an area for development.

Lawrence et al (1997) looked at changes in quality of life ratings of adults over the early course of treatment. Quality of life was measured using the SF-36, a well standardised widely-used generic quality of life measure which has both a physical and a mental domain. They found that as a group they viewed their physical but not mental health as being significantly compromised by their burns. There was no comparison group.

Altier et al (2002), used a matched-control study to compare the quality of life and psychological profile in adults who have been burned, to adults who have not been burned. They found that psychologically the burned adults adjust relatively well, as measured by the Symptom Checklist 90-Revised, and enjoy a quality of life comparable to the controls, as assessed by the SF-36. However some do develop significant psychological disturbances such as somatisation, and phobic anxiety.

Sheridan et al (2002) looked at mainly adult survivors of childhood burns of over 70% total body surface area (TBSA), and measured quality of life again using the SF-36. They found that people who had been burned had similar scores on the SF-36, to the available norms.

However perhaps the little differences found is because the SF-36 is not sensitive enough to the issues of burn survivors.

There is one specific burns quality of life measure for adults, 'The Burn Specific Health Scale' (Munster, Fauerbach & Lawrence, 1978). This is discussed in more detail on page 11. It has been used in a few studies, however as it is burn specific, it is not possible to make comparisons.

(6) Measures of Quality of Life in Children and Adolescents

In recent years there has been a growth in measures assessing health-related quality of life (Jacobs, 2000). While quality of life measures in adults are widely used, there are fewer available measures for clinicians working with children, and none that are widely used. Titman et al (1997) review many of the assessment tools for measuring quality of life in children. They criticise most measures as being adapted from adult models and not considering developmental issues. These measures also do not make adaptations to the construction and language of the questionnaire.

Eiser & Morse (2001) also discuss how the measurement of children's quality of life has received less attention than that given to adult quality of life. They comment on the fact that Quality of Life has been a category in Index Medicus since 1966, and that it was not until the 1980s that any interest was given to children's quality of life.

(i) Generic Quality of Life Measures for in Children/Adolescents

Table1 gives an overview of the most common generic quality of life measures used in children and adolescents. Only the TACQOL has been used in one study in the literature on children with burns. This was the Landolt et al study, previously discussed.

Table 1 Over-view Of Generic Quality of Life Measures

Measure	Respondent	Age range	Domains	Origin	Specific to adolescence? YES/NO	Areas of research (as found in Psych Info and Pub Med)
The Child Health Questionnaire Landgraf et al, (1997) Adapted from SF-36	Self Parent	10-19 4-19	Physical functioning, role/social functioning (physical), general health perceptions, bodily pain, discomfort, general behaviour, mental health, self-esteem, role/social functioning (emotional), parental impact (emotional), parental impact (time), family activities, family cohesion.	UK	No	Epilepsy Cerebral Palsy Sleep-disturbed breathing Sickle Cell ADHD Obesity Diabetes Cystic Fibrosis Sexually abused children Juvenile Rheumatic Disease
Child Health and Illness Profile (Starfield, (1987)	Self	11-17	Achievement, discomfort, disorders, resilience, risks, satisfaction.	USA	Yes	Children in care Adolescents exposed to community violence
Child Quality of Life Questionnaire Graham et al (1997)	Self	9-15	Getting about and using hands, school, out-of-school-activities, friends, family, relationships, discomfort due to bodily symptoms, worries, depression, communication, eating, sleep, appearance.	UK	No	Imperforate Anus

Measure	Respondent	Age range	Domains	Origin	Specific to adolescence? YES/NO	Areas of research (as found in Psych Info and Pub Med)
Functional Status (II) R Stein & Jessop (1990)	Parent	0-16	Communication, mobility, mood, energy, play, eating, toileting	No	No	HIV/AIDS
Generic Health Questionnaire Collier (1997)	Self	6-16	General affect, peer relationships, attainments, relationship with parents, general satisfaction	UK	No	Diabetes Epilepsy Acquired Brain Injury
How Are You? (HAY) Bruil (1999)	Self	7-13	Physical cognitive and social functioning, physical complaints and happiness	Netherlands	No	Asthma
KINDL Ravens-Sieberer et al (1999)	Self	8-16	Psychological well-being, social relationships, everyday life activities	Germany	No	Diabetes Asthma Obesity
Nordiac Quality of Life Questionnaire for Children Lindstrom et al (1991)	Self Parent	12-18 2-18	Global, external, inter-personal, personal	Sweden	No	None found
Pediatric Quality of Life Questionnaire (Peds-QL) Varni et al (1999)	Self Parent	5-18 2-18	Physical, psychological and social and school functioning, well-being	USA	No	Asthma AIDS/HIV
Quality of Life Profile Adolescent version Raphael et al (1996)	Self	14-20	Being (physical, psychological, spiritual) belonging (physical, social and community) becoming (practical, leisure and growth)	Canada	Yes	Headache

Measure	Respondent	Age range	Domains	Origin	Specific to adolescence?	Areas of research (as found in Psych Info and Pub Med)
The Youth Quality of Life Instrument Topolski et al (2002)	Self	12-18	Self, relationships, environment and general quality of life	USA	Yes	Health-risk behaviours
The TACQOL Theunissen et al (1998)	Self Parent	11-15 6-15	Pain and symptoms, basic motor functioning, autonomy, cognitive functioning, social functioning, global positive emotional functioning, and global negative emotional functioning	Netherlands	No	Imperforate Anus Inflammatory Bowel Burns

As can be seen from the table, only three out of the twelve questionnaires are specific to adolescence. These are the Child Health and Illness Profile, Quality of Life Profile (adolescent version), and the Youth Quality of Life Instrument.

The Youth Quality of Life Instrument (YQOL) (Topolski et al, 2002) is a questionnaire that may be useful in looking at quality life of adolescent burn survivors. It is specifically for adolescents aged between 11-18 year olds and claims to incorporate adolescents' perspectives, and language, apply to general and vulnerable populations, and to tap perceptions and feelings. It has a cronbach's alpha value of .70. It has been used with adolescents both with and without disabilities. It has been shown that adolescents with disabilities report lower quality of life than adolescents without disabilities.

Only a few of the above measures were developed in the UK. The issues affecting children and adolescents could vary, depending on cultural differences. Therefore researchers should bear this in mind when using these tools.

The problem in using a quality of life measure for burn survivors, is that as they are quite broad, some of the long-term consequences of burns may be more specific, and may therefore not be picked up by a general measure. Thus a child who might well benefit from psychological input, such as for specific concerns about body image, may score within the normal range on a general quality of life measure. Perhaps the measures are simplistic when compared to the complexity of the concept of quality of life. This argument could also be applied to adult measure of quality of life. These criticisms should be kept in mind when reviewing quality of life research.

The table shows that although these questionnaires have not been widely used, some areas of childhood illness have been explored to a certain extent through the use of generic quality of life measures, particularly in areas such as asthma and diabetes. Therefore the area of burns research could also start to develop in this way.

(ii) Quality of Life Measures Specific to Burns in Children and Adolescence

Research into children's quality of life in childhood cancer, especially Leukemia has received more attention than any other physical illnesses/conditions, such as Mulhern et al (1989). Eiser and Morse (2001) did a review of existing disease-specific quality of life measures for children. They found that the following number of quality life measures for children specific to that disease; cancer (5), epilepsy (4), asthma (3), arthritis (1), chron's disease (1), dermatology (1), diabetes (1), headache (1), otitis media (1), short stature (1), spina bifida (1) and spine deformities (1). They did not report measures for any other types of illness.

There is no standardised and validated quality-of-life instrument for burned children, with the exception of The American Burn Association/Shriners Hospitals Children Burn Outcomes Questionnaire' (Daltroy et al 2000). However it has not been used in any outcome study in the current available literature. The Children Burn Outcomes Questionnaire is completed by the parent, for children between the ages of 5 to 18. Its' purpose is to "evaluate the effectiveness of comprehensive burn management treatments with regard to improved function, physical appearance and other relevant outcomes". It came about as a result of changes in American health care to do with privatisation, disease management, increased accountability for outcomes including results, costs and patient satisfaction.

It may be more applicable following a recent injury rather than long-term outcome, as some of the questions are to do with how the children are coping with dressings, pain, and compliance with burn team's instructions on wearing dressings. These issues do not tend to affect children in the long-term. It is not specific to adolescence so may not pick up on the issues for adolescents.

It is completed by parents of burn survivors, and some studies have shown that parents may portray a picture of their children which may be too optimistic as a result of defence mechanisms during the adjustment process (Loeber et al, 1991; Theunussen et al, 1998). Indeed, parents may often feel they are to blame for their children's burn injuries.

Although it may have limitations and although there is no subsequent literature on this, it is encouraging that an interest is starting to be taken in finding a burn specific outcome measurement for children with burn injuries.

There is a questionnaire specific to burns, which has only been used for adults. The Burn Specific Health Scale (BSHS) is a burn specific quality of life measure that was developed at the Baltimore Regional Burn Centre, originally developed by Munster, Fauerbach and Lawrence in 1978. The original BSHS includes 114 items derived from a larger pool of items by a panel of burn treatment professionals and burn survivors. The abbreviated BSHS includes 80 items which give a global score and 4 domain scores; (1) physical domain (including functional and hand status and role activities; (2) psychological domain (including emotional and body image items; social general, social psychological, mobility/self-care tasks, hand function ability, and role resumption abilities, (3) social domain (including sexual and family/friends relationship status, and (4) general domain (including burn injury related physical symptoms and cognitive/emotional items).

The BSHS is used in clinical practice in some centres in America. However there are only a few research studies which have used the BSHS (Blades et al, 1982; Blalock et al, 1992; Kimmo & Sirpa, 1998; Cromes et al, 2002). These studies have used the questionnaire to further assess its' validity, and to look at what variables predict less favourable BSHS scores.

The BSHS could perhaps be adapted for adolescents. For example some of the questions on sexual behaviour and work could be changed. However this would be utilising an adult model of quality of life which as discussed previously, may be inappropriate. The construction and language of the questionnaire may also be inappropriate. However from my own discussions with the authors of this questionnaire in Baltimore, they are considering a pilot of the questionnaire on adolescents, as they too recognise the importance of addressing this gap in the research literature.

The problem with using a burn specific measure is that it cannot be used to make comparisons with controls and other groups of children or adolescents with other illnesses/physical difficulties.

Conclusions and Summary of Gaps in the Literature

While there has been some published research which has looked at quality of life in adults with burns, less is known about the quality of life of children, and even less about the quality of life of adolescents. However adolescence could be a particularly critical time, as they may become more concerned with body image and intimate sexual relationships. This should therefore be a focus for future research, so that appropriate interventions can be given.

There is no agreement on what 'quality of life' means. If researchers could agree on a definition this would make the study of quality of life across a range of client groups more meaningful. It would also help health policy makers to make more meaningful decisions.

It would be beneficial if research into adolescent burn survivors could make more use the generic quality of life measures available. This would make it possible for researchers to makes comparison to a control group possible, and would also allows comparisons to adolescents with a variety of health-related problems. Although generic questionnaires have not been widely used in studies of child and adolescent quality of life, some research into areas such as asthma and diabetes have made some use of such measures.

There is little known about the quality of life of adolescents who have been burned and how this compares with adolescents who have not been burned. Gleeson and Frith (2003) at the first ever conference of the Centre for Appearance Research, proposed the idea that the experiences of those who are visibly different may not be unlike those whose appearance is not problematised, i.e. those who are not in a clinical population. However there was no research evidence to support this idea. Their criticism of research in this area was that it has traditionally focused on those with visible differences in clinical populations. It would therefore be of value for research to start to look at some of the similarities and differences between the experiences of adolescents who have been burned and those who have not.

The Youth Quality of Life Instrument (YQOL) has been shown to discriminate between adolescents with and without disabilities, and is not based on adult models. However it has not been used on burn survivors in the published literature. It may be useful to use this in a future study with adolescents who have and have not been burned.

However as generic measures can be broad, and may not be sensitive to specific problems that might be experienced by adolescent burn survivors, to compliment this research, a burn specific quality of life measure should be developed. The validity of any generic measures used could be tested by correlating outcomes to the burn specific questionnaire.

With the increasing number of people surviving burn injuries, and a greater emphasis on outcomes and cost-effectiveness in health care systems, the measurement of quality of life, particularly in the neglected area of adolescence, is becoming increasingly important. Even though quality of life is arguably the most relevant aspect of outcome, there is currently no standardised, well validated quality of life instrument for adolescents who have been burned.

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Body image, mood and quality of life in
young people burned in childhood

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ABSTRACT

Little is known about how young people who survived burn injuries as children cope when they reach adolescence. This study looked at the body image, mood and quality of life of a group of young people who had burn injuries as children, and a group of young people who had not had these injuries. It was hypothesised that there would be no difference in outcome between the two groups. The study also looked at the relationship between body image, mood and quality of life. The participants were 32 young burn survivors recruited from hospital records of a regional burns unit, and three burned children's clubs. The control group were 41 young people from a comprehensive school. The overall mean age across both groups was 15.24 years, ranging from 11 to 19 years. The mean size of burn in this study is 21.93% total body surface area, ranging from 1 to 63%. The burn survivors completed the Body Esteem Scale (BES), the Satisfaction With Appearance Scale (SWAP), the Beck Depression Inventory-II (BDI-II), and the Youth Quality of Life Questionnaire (YQOL). The school sample completed all questionnaires with the exception of the SWAP. Burn survivors reported significantly more positive evaluations of how others view their appearance, more positive weight satisfaction and a higher quality of life than the school sample. They reported a similar mood to the school sample. Strong relationships were found between body image, mood and quality of life. The data suggest that young burn survivors may be coping well in comparison to their peers, and in some areas may be coping better, in spite of living with the physical, psychological and social consequences of a burn injury.

INTRODUCTION

Context

In Britain, 250,000 people per year are injured as a result of thermal, electric and chemical burns, 13,000 of whom are hospitalised. The majority of burns are thermal, the biggest sub group being scalding, particularly of children (Coughlan and Clarke, 2002). 50% of children admitted to the Regional Burns Unit involved in the current study are under the age of 3.

There are two bodies of psychological theory that may be applicable in understanding the psychological outcomes for young burn survivors; problems could be conceptualised in terms of post-traumatic reactions, or in terms of body image concerns. There is some evidence that post-traumatic stress disorder can be present in children following traumatic experiences, including burn injuries (Caffo & Belaise, 2003), however Stoddard, Norman and Murphy (1989) found an absence of traumatic reactions in many severely burned children. The current study will concentrate on issues around body image. This introduction will first consider some of the many problems encountered by burn survivors related to their injuries and altered appearance, and the current inconsistencies in psychological service provision. It will then look at some of the psychological theories and concepts around the development of body image in children with disfigurements. This will be followed by a summary of the published research to date on three of the important outcomes for young burn survivors; body image, mood and quality of life. The limitations of the research will be highlighted which will lead onto research questions and hypotheses for this current study.

Problems encountered by burn survivors

Burn injuries can cause long-term scarring as well as changes in skin colour and body contour. Burn survivors can also lose fingers, toes, ears or hair. In addition sometimes donor tissue may be taken from a non-burnt part of the body for reconstructive surgery. Surgical reconstruction can take months or years, and as the child grows and the skin tissue stretches, typically further surgery will need to take place. Medical treatment, plastic surgery and skin camouflage (specialist make-up)

can help make changes in appearance less noticeable, but will often not remove the disfigurement.

However, problems encountered by burn survivors go beyond physical problems. Blakeney, Meyer, Robert, Desai and Wolf (1997) highlight how the physical changes continue to act as a constant reminder of the incident, as well as leading to feelings of being rejected, isolated, unworthy and humiliated.

Survivors of burns then have to deal with not only their own physical and psychological adjustment, but also with the reaction of others. Macgregor (1974) highlights some of the reactions that people with disfigurements encounter.

“in attempts to go about their daily lives, people are subjected to visual and verbal assaults, and a level of familiarity from strangers... (including) naked stares, startled reactions, ‘double takes’, whispering, remarks, furtive looks, curiosity, personal questions, advice, manifestations of pity or aversion, ridicule and outright avoidance” (p.15).

Indeed, in a recent annual conference of the ‘Centre for Appearance Research’, (2003), Partridge referred to a Harris Poll in the States in the early 90s which revealed that of all of the disabilities people fear to meet, facial disfigurement ranked second only to schizophrenia and severe mental illness.

In light of these challenges, it is unsurprising that a number of studies have suggested long-term psychological effects of burn injuries, an area which will be considered in more depth later.

Service provision

In 2001 the National Burn Care Review report (NBCR) published by the British Burn Association described the current state of UK burn services as “disorganised, fragmented, inadequate and inequitable from the patient’s perspective”. It says that although historically Britain has been considered a world leader in the provision of burn care, over the last two decades, British services have not developed in comparison with their counterparts in the USA, Europe and Australia. The review provides standards recommended for all burn services. With regards to psychological

input, it is recommended that the psychological needs of the patients is assessed by a psychologist with a special interest in burns and disfigurement, and that patients and families should have access to therapy. As far as longer-term input is concerned it is recommended that each patient has a key worker who is responsible for their psychosocial rehabilitation following their burn injury, and that therapy services continue as long as deemed to be necessary by the provider of care. Given the financial constraints of the NHS/most health providers, decisions about meeting these types of recommendations are complex. It may therefore be useful for burns services to learn more about the longer-term effects of burns on psychological functioning.

Relevant psychological theory and concepts

The effect of being disfigured by burns is a neglected area in the psychological literature. However the effect of disfigurement more generally has been explored.

Development of body image

Many major theorists such as Freud (1923), Erikson (1959), and Piaget (1950, 1970) hold that body image is a central factor in cognitive and emotional development of children.

Disfigurement in infancy is often assumed to affect the development of appropriate attachment, which may lead to a risk of psychological difficulties in adulthood (Holmes, 1997). Although this has not been directly researched, there is some evidence that children with congenital disfigurements can be at risk of developing anxious attachments. Langlois and Sawin (1989) found that at two days old less attractive babies were held less close by their parents and had less contact than babies who are seen to be more attractive.

McQuaid, Barton and Campbell (2000) describe how infants tend to see their bodies, and the body of their mother as being the same, but by the age of 2 to 3 years children are aware of their bodies, what is inside and outside their bodies, and that they are separate from their mother and other people. It is thought that at this stage in a child's development, the foundations of body image are present. Therefore, if a child is burned before the foundations of body image are present, there is good

reason to believe that they will be able to integrate the burn into their already developing body image. There is some evidence that this may also be true for slightly older children who had already begun body image formation (Stoddard, 1982; Belfer, Harrison & Murray, 1979).

Stoddard (1982) used case studies to look at the different body image concerns experienced by children of different ages with burns covering 10% to 67% of their body surface area. Stoddard argues that a school aged child who has already formed a relatively stable body image who then acquires a burn, experiences a type of mourning for their old body image, and of their 'previous self'. The child may experience negative reactions from their peer group which may make adaptation more difficult.

Disfigurement in adolescence

However, the work of Belfer et al. (1979) and Stoddard (1982) does not tell us how the body image of a child with burns may change as they get older. McQuaid et al. (2000) refer to body image as being 'dynamic' rather than stable, and changing particularly as a child progresses through the developmental stages. Bernstein (1990) argues that body image is particularly important to adolescents because of the physical changes of puberty, and consequent increased focus on the body.

As described in the review by Pope (2004), Erikson (1959) states that adolescents struggle between 'identity formation versus role confusion'. In other words, they are in the process of trying to understand who they are and how they relate and fit into the world at the same time that their bodies are changing dramatically. Children with disfigurements have to deal with the conflict over maintaining valuable identity versus that of "spoiled identity" which has been forced on them (Goffman, 1963). According to Goffman, they may be so consumed with this struggle and their exclusion from the social scene, that they are unable to work out who they should be loyal to, and fall back on disaffected others who will accept them, thus confirming their sense of themselves as being flawed and unworthy.

The effect of parental behaviours

The effect of parental behaviours are also important in psychological theories of how body image develops in children with burns. Couglan and Clarke (2002) estimate that 90% of burn injuries are avoidable, and since most childhood burns occur in the home, parents will often feel great shame and guilt. In particular, they may expect others to think that they are inadequate parents. Couglan and Clarke describe how parents, in order to defend against this shame, may try to shift the blame onto their child ('externalising'), hide the disfigurement from others ('concealment'), pretend that there is nothing wrong with their child ('denial'), or distance themselves from their 'damaged child'. As a result the child is given messages about the social meaning of their burn disfigurement. In addition, when the parent feels responsible, a common consequence is to interact with the child in ways which can be seen as "over-protective", with possible long-term implications for the child's social and psychological development.

The effect of teacher behaviours

In addition the behaviour of teachers may be important. Bull and Rumsey (1988) have observed that in the education system, teachers have lower expectations from children with disfigurement. As a result children may be socially disadvantaged and will need to make extra efforts to get on in the world.

Body image in non-clinical populations

Much of the work on body image in non-clinical populations suggest that body dissatisfaction is very much an issue.

Body image dissatisfaction in adults

Body dissatisfaction may be widespread amongst women, and has been considered as 'the norm' in a number of US studies (for example Rodin, Silberstein & Striegelmoore, 1985; Thompson, Heinberg, Altabe & Tantleff-Dunn, 1999).

Body image dissatisfaction in young people

In a US study, Levine and Smolak (2002) report that 40-70% of adolescent girls are dissatisfied with two or more aspects of their bodies. Between 50-80% of adolescent girls would like to be thinner, and self-reported dieting varies from 20% to 60%. They

describe this as “normative discontentment”. While they do not have statistics for adolescent boys, they do say that many boys are also dissatisfied with their weight and shape, many wanting to gain weight in order to develop bigger upper arms, chest and shoulders.

In another US study by Cusumano and Thompson (2001), it is reported that body dissatisfaction emerges as early as 8 or 10 years of age, with about half of adolescent girls reporting that they were dissatisfied with their appearance.

In a UK survey of almost 1,000 adolescents, Lovegrove found that 75% of 11-13 year-olds had experienced teasing or bullying about their appearance which they found to be distressing. 31% claimed that they did not engage in classroom debate because of their appearance, and 20% of 15 year olds truant because of their appearance.

In addition, Argyle (1994) reported that good looking adolescents are more confident and get more dates. Argyle also reported that attractiveness was almost as important as educational attainment in predicting social mobility in working class women.

Comparing clinical and non-clinical populations

At a conference of the Centre for Appearance Research (2003) held in Bristol, one of the main discussion points was that the experiences of those who are visibly different may not be unlike those whose appearance is not problematised, i.e. those who are not in a clinical population. However Psychologists in this area have traditionally focused on those with visible differences in clinical populations. It would therefore be of value for research to start to look at some of the similarities and differences between the experiences of adolescents who have been burned and those who have not.

Research on body image in adults with burns

In order to look at the existing research of body image in burn survivors, adults will be considered first, followed by children and young people.

Bergamasco, Rossi, Amancio and Carvalho (2002) conducted a retrospective descriptive study of body image changes after burn injury, asking adults to recall their thoughts and feelings in looking at themselves in the mirror for the first time following burn injury, and the moment they realised that their appearance was noticeable to others. Associated with the perceptions of changes in their bodies were reported feelings of fear, rebellion, and shame. However, this study focuses solely on the immediate aftermath of burn injury, and says nothing of the development of the altered body image over time.

Fauerbach, Heinberg, Lawrence, Munster, Palombo et al. (2000) looked at the impact of body image dissatisfaction on quality of life of adult survivors at two months post-discharge. The average total body surface area burned was 17.02%. They used the Satisfaction With Appearance Scale to measure body image dissatisfaction (Lawrence, Heinberg, Roca, Munster, Spence & Fauerbach, 1998), and the Short-Form-36 Health Survey to measure quality of life (Ware & Sherbourne, 1992). The average total body surface area was 13%, ranging from 1% to 77%. After controlling for injury, distress, and pre-burn quality of life, they concluded that body image dissatisfaction does affect quality of life. However again this tells us little about the long-term effects of burns on body image.

There is a debate in the literature about whether it is more difficult to cope with visible or hidden scars. It is feasible to think that the impact on adjustment will be more difficult for people with facial scars as the face is a means for communication in all 'face-to-face' interactions. However, although having hidden scars may be more private, difficulties may arise in the context of more intimate relationships.

There is some evidence that visible scarring is associated with greater distress. Abdullah, Blakeney and Hunt (1994) looked at burn survivors aged 5 to 18 years, for male survivors, as the number of scars increased in socially visible areas (i.e. face,

head and neck), their scores for 'physical appearance' and 'happiness and satisfaction' decreased. However, the same was not found for females. In an adult sample, hand injury was found to be related to greater distress and lower satisfaction with life (Patterson, Ptacek, Cromes, Fauerbach & Engrav, 2000).

Lawrence, Fauerbach, Heinberg and Doctor (2004) looked at the effect of visible and hidden scars on body image in 361 adults in whom the average time since being burned was 18.5 years. Interestingly, they found that the visibility of the scars did not have a strong relationship with body image: scar severity and visibility only accounted for 20% of the variance in predicting body image. Neither did visibility have a strong relationship with social and emotional adjustment, and there was no correlation at all between visible scarring and depression. One possible explanation for this is the suggestion put forward by Pruzinsky and Doctor (1994), that people with hidden scars live with the fear of discovery and the subsequent guilt. Consequently, they argue, if the scarring or disfigurement is hidden, body image revision may be delayed or remain incomplete. Whereas those with visible scars have more opportunity to habituate to the reactions of other people and to learn adaptive coping strategies.

These studies provide some interesting observations, but they also highlight some of the methodological limitations of much work in this field. None of these studies used a control group, and two out of the three studies concentrated on body image relatively soon after the burn. This will also be seen in the studies described in the next section.

Research on body image in children/young people with burns

Although researchers sometimes mention in passing the influence of body image on psychological functioning, few have looked directly at body image in children and adolescents with burns (McQuaid et al., 2000).

Two studies have attempted to evaluate the body image of burned children by observation of their drawings of themselves. Beard, Hemdon and Desai (1989) looked at six children of primary school age who had been burned five years previously, and who had burns covering over 80% of their bodies. Self-image was evaluated by the content of the drawing (which is not explained in the report), and by

the manner in which they approached the task which was judged subjectively. When first asked to draw themselves, all six were judged by the researchers to show 'high levels of anxiety' which was seen to be an indication of incomplete adaptation. However by a second evaluation, three of the six were able to draw themselves 'without observable distress' and all but one were judged to display a 'moderate self-image'.

Similarly Jessee, Strickland, Leeper and Wales (1992) used self-drawings to look at perception of body image in 32 children with burns, aged 6 to 15 years, approximately 5 years post-injury. The size of burns ranged from covering 3% to 95% of the body, with a mean of 48%. Drawings were judged by child development specialists who judged that children with burns tend to have "slightly worse" body image scores than controls, although this was not found to be statistically significant. A more detailed and accurate drawing was seen to indicate an enhanced body image. Those children who gave less detail and who were more likely to draw a 'normal' body, were seen to be resisting change, and to be trying to 'get rid' of their disfigurement. Inter-rater correlation in scoring the drawings was 0.94.

However both these studies have serious methodological limitations including the use of non-validated highly subjective measures which have no norms, and small sample sizes, particularly in the study by Beard et al. (1989).

Orr, Reznikoff and Smith (1989) looked at the effects of burn-related variables (such as age at burn, years since burn, and size of burn), demographics and perceived social support variables on body image, self-esteem, and depression in 121 burn-injured 14 to 27 year olds who had been burned within the last 10 years. The mean percent total body surface area burned was 27.3%. They found that perceived social support is the variable that explained most of the variance on all measures including body image.

The emergence of adult relationships and sexual behaviour in adolescence is an important measure of adolescent adjustment and may be closely linked to concerns around body image. Robert, Blakeney and Meyer (1995) looked at sexual behaviour in 19 13-20 year olds with burns ranging from 7% to 85% (average about a third of

the body surface area). They found that one year after the injury, there was little difference compared with adolescents without burns. However they did not use a control group, instead they compared their findings to the current literature on adolescent sexual behaviour. Although this was a descriptive study, the sample size was small, and there was no control group, it does suggest that if body image concerns do exist, they may not necessarily affect normal sexual development.

From a review of the major databases, there is no research which compares the body image of burned adolescents with the body image of non-burned adolescents. It would seem that relatively little is known about body image in adolescents/young people with burns.

Quantitative self-report measures of body image

As the above suggests, no standardised measures of body image have been developed for use specifically with young burn survivors. The Body Esteem Scale (BES) for Adolescents and Adults (Mendelson, Mendelson & White, 2001) is a generic body image questionnaire with 30 items and three subscales: general feelings about appearance (e.g. "I like what I see when I look in the mirror"); weight satisfaction (e.g. "I really like what I weigh") and attributions to others of positive evaluations regarding one's body or appearance (e.g. "people my own age like my looks"). This measure has been used in one published study on adult burn survivors (Lawrence et al. 2004), described above.

The Satisfaction With Appearance Scale (SWAP) is a 14-item questionnaire assessing both the subjective appraisal and social-behavioural components of body image among burn survivors. Validation of the measure on the 165 adult burn survivors (one week post-discharge) indicated good internal consistency, test-retest reliability, convergent and discriminant validity (Lawrence, Heinberg, Roca, Munster, Spence et al., 1998). The authors conclude that the SWAP is a valid and reliable measure of body image in burn-injured adults, and that it is helpful in identifying and monitoring patients who could benefit from cognitive-behavioural therapy regarding body image.

Lawrence et al. (1998) have found the SWAP to correlate with other standardised and well validated measures including mood and quality of life. It was found that the SWAP had a moderately high positive correlation with the Beck Depression Inventory-II (Beck, Steer & Brown, 1996), and a low positive correlation with the Beck Anxiety Inventory (Beck & Steer, 1990). It has been used in one published study on adult burn survivors (Fauerbach et al., 2000) which has been described above, showing a statistically significant correlation with quality of life, as measured by the Short-form-36 Health Survey.

A standardised measure of body image for young burn survivors may help clinicians to more quickly and easily identify problems and highlight individuals who may benefit from therapeutic interventions. As there is no published data for the BES or the SWAP on young burn survivors, both will be used in the current study.

Research on mood in adults with burns

Depression has frequently been shown to exist in people who have medical conditions (Wharton & Zucker, 1983). In a comprehensive review of the literature on adult burn survivors, Malt (1980) and Patterson, Everett and Bombardier (1993), reported that anxiety and depression were the most prevalent psychological disorders in adults at 1 year post-injury. They reported prevalence rates of combined anxiety and depression as being between 25% and 65%. They also reported that these symptoms would normally subside after 1 year, with the best predictor being pre-morbid psychopathology. Other studies have reported depression in adult burn survivors (Williams & Griffiths, 1991; Fauerbach, Lawrence & Haythornwaite, 1997; Tedstone & Tarrier, 1997; Fukunishi 1999; Maes, Mylle & Delmeire, 2000; Wiechman, Ptacek & Patterson, 2001; Madianos, Papaghelis, Ioannovich, 2001 & Ptacek, Patterson & Heimbach, 2002). However these studies have not used control groups and have not tended to focus on long-term follow-up beyond 2 years.

Research on mood in children/young people with burns

There is much less research looking at mood in adolescents. And as before, there are methodological limitations. None of the studies outlined in this section used a

control group. As described above, Orr et al. (1989) looked at the effects of burn-related variables, demographics and perceived social support on body image, self-esteem, and depression in burn-injured 14 to 27 year olds.

In addition, Stoddard, Stroud and Murphy (1992) looked at depression in 30 children and adolescents (aged 7 to 19 years) with burns ranging from 5% to 95% body surface area at a mean of 9 years post-injury. They used interviews to assess child psychiatric disorders with diagnostic criteria from the Diagnostic Statistical Manual III-R (1987), and found that one child/adolescent had symptoms of major depression and three with symptoms of dysthymic disorder. However eight had a life-time history of major depression. O'Connell (1985), in an unpublished thesis, looked at depression, anxiety and self-image in severely burned adolescents. They found no significant correlations between depression and size of burn, or the area of the burn. They also found that girls reported lower self-esteem after burn injury than boys.

Neither the Orr et al. (1989) or the Stoddard et al. (1992) studies focus specifically on adolescents. Studies that group children and young people together mean that average scores may mask effects specific to adolescence.

Self-report measures of mood

The Beck Depression Inventory-II (BDI-II) (Beck, Steer & Brown, 1996), is the most commonly used measure of depression in psychiatric and general medical populations. It was developed to measure severity of symptoms of depression as defined by changes in mood, a negative self-concept associated with self-devaluation and self-blame, self-punitive wishes, vegetative symptoms and changes in activity level. It is validated on people aged 13 and upwards.

The BDI-II was used in the development of the SWAP study by Lawrence et al. (1998). A moderately high correlation between the SWAP and the BDI-II was reported. The BDI-II was also used to measure mood in the studies by Orr et al. (1989) and O'Connell et al. (1985) described above, as well as many of the studies on adults.

Research on quality of life in burn survivors

As highlighted in the review by Pope (2004), it is thought by Munster (1999) that the quality of life of burn survivors is the most important outcome. Munster says that it helps health-care professionals understand the implications of their work, as well as helping therapists to better understand how they see different aspects of their lives. Also when interventions depend on funding, Munster says changes in interventions must demonstrate that they will lead to an improved quality of life.

Quality of life appears to be a challenge to define. The World Health Organisation Quality of Life Group in WHO (1958), define 'Quality of Life' as an "individuals' perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p.609).

Research on quality of life in adults with burns

There is some work which has looked at the quality of life of adult burn survivors. The review by Patterson et al. (1993) reported that the majority of burn survivors have an "adequate" quality of life. However more recent studies have shown that at discharge and at 6 months, quality of life was lower than in people with no burns (Patterson et al., 2000).

Only a few of these studies looked at outcomes after 6 months. A study by Riis, Anderson and Pederson (1992) reported that psychosocial outcome for 25 adults 7 to 21 years post-burn was "optimistic". However in the absence of a control group, there may be limitations to what can be concluded about quality of life in adult burn survivors. Kimmo, Jyrki, and Sirpa (1998) reported that in adults 9 months to 7 years post-injury, physical function was unaffected by the severity of burn and hand injury, and that sexual functioning and body image was influenced by the depth of the burn. Salvador-Sanz, Sanchez-Paya and Rodriguez-Marin (1999), reported that in adults ranging from 9 months to 21 years post-burn, there were no serious difficulties in physical and personal care, some concerns in social relationships, affect and overall psychological health, and that females report a poorer quality of life than males.

Again, these studies did not use control groups, and there is also a lack of agreement over the definition of quality of life.

However Altier, Malenfant, Forget and Choiniere (2002), did use a control group in order to compare the quality of life and psychological profile in adults who have been burned 2 to 10 years previously, with adults who have not been burned. The average total body surface area burned was 35%. Using the Short-Form-36 to measure quality of life (Ware & Sherbourne, 1992), the study reported comparable quality of life in both groups. Similar findings were reported by Sheridan et al. (2002), who looked at mainly adult survivors of childhood burns of over 70% total body surface area (TBSA), and compared their outcomes to the available norms. For a more detailed review of the study by Sheridan et al., please see the paper by Pope (2004).

Research on quality of life in children/young people with burns

As reported by Landolt, Grubenmann and Meuli (2002), "...although there is some knowledge of psychological adjustment, almost nothing is known about quality of life in paediatric burn survivors" (p.1146). A study by Herndon, Le Master and Beard (1986) is described in more detail in the review by Pope (2004). They looked at the quality of life of 12 children aged 5 to 14 years of age with very severe burns, ranging from 8 months to 2.8 years post injury. A wide range of physical and psychological tests were used in order to determine quality of life, rather than using a standardised quality of life measure. Of the children old enough to be tested, 50% were completely independent in activities of daily living. One third of the children showed "excessive fear, regression and neurotic and somatic complaints", but all showed "remarkable energy in adapting to their disabilities".

The only study which has attempted to measure quality of life in children with burns using a standardized quality of life measure, was the study by Landolt, Grubenmann and Meuli (2002). They studied 105 5 to 17 year-olds, 1 to 13 years post-burn, with burns ranging from 10 to 64% total body surface area, using the TNO-AZL Questionnaire for Children's Health Related Quality of Life (TACQOL) (Theunissen, Vogels, & Koopmann, 1998). This is a generic pediatric quality of life measure with both a child version (for children aged 11 and over), and a parent version for children

of all ages. However in this study, only the parent version was used. The only differences between the norms published for 'healthy' children were that parents reported fewer positive emotions in their burned children. They found that size, depth and location of burn did not have a significant impact on quality of life.

Some criticisms of Landolt et al. (2002) are that parents may be too optimistic in their perception of their child's quality of life, as a result of their own defence mechanisms. Also children, especially adolescents may not wish to confide in their parents about how they really feel. Data from the children as well as teachers may give a more accurate picture. It should also be acknowledged that good quality of life may not have the same meaning for a younger child as it does to an older adolescent, and that patients at 1 or 2 years postburn may not be comparable to those at 12 or 13 years post-burn. The TACQOL is not specifically designed for children/adolescents, and instead is adapted from an adult model of quality of life.

As discussed above, there is no universal agreement amongst researchers about the exact definition of quality of life. The two studies below maintain that their studies in some way address quality of life issues. Myers-Paal, Blakeney, Robert, Murphy and Chinkes (2000) looked at functional outcome as an important aspect of quality of life in 41 young burn survivors (aged 2 to 18) with very large burns. They found that 86% of young people who were aged 10 or over, were independent in activities of daily living. Blakeney, Meyer, Robert, Desai and Wolf (1998) looked at a wide range of outcomes, including behavioural problems, social competence, academic performance, and parental stress in 19 children with burns covering 80% or more of their bodies. They concluded that on all measures, the survivors were within normal limits, and that children with very large burns can achieve positive psychosocial adaptation.

Quality of life measures

Pope (2004) highlights some of the problems associated with attempting to measure quality of life in children/young people. Many researchers and clinicians question whether quality of life measures can tell us anything useful about quality of life, with the overall criticism being that they are too general. One major problem in measuring

quality of life in young people, is that many of the measures are adapted from adult models and do not take into account developmental issues, or adapt the construction or the language of the questionnaire (Titman, Smith, & Graham, 1997). Also, as described above, there is no universal agreement about how quality of life should be defined.

The Youth Quality of Life Instrument (YQOL) (Topolski, Edwards & Patrick, 2002) for 11-18 year olds, claims to incorporate adolescents' perspectives, and language, apply to general and vulnerable populations, and to tap perceptions and feelings. As this questionnaire has not been used on burns survivors, it is not known whether it will be sensitive enough to the relevant issues of adolescent burn survivors. Use of the YQOL in the current study may provide some future guidance to researchers or clinicians who may be considering using a quality of life measure for young people with burns. Components of the questionnaire are summarised below in figure 1.

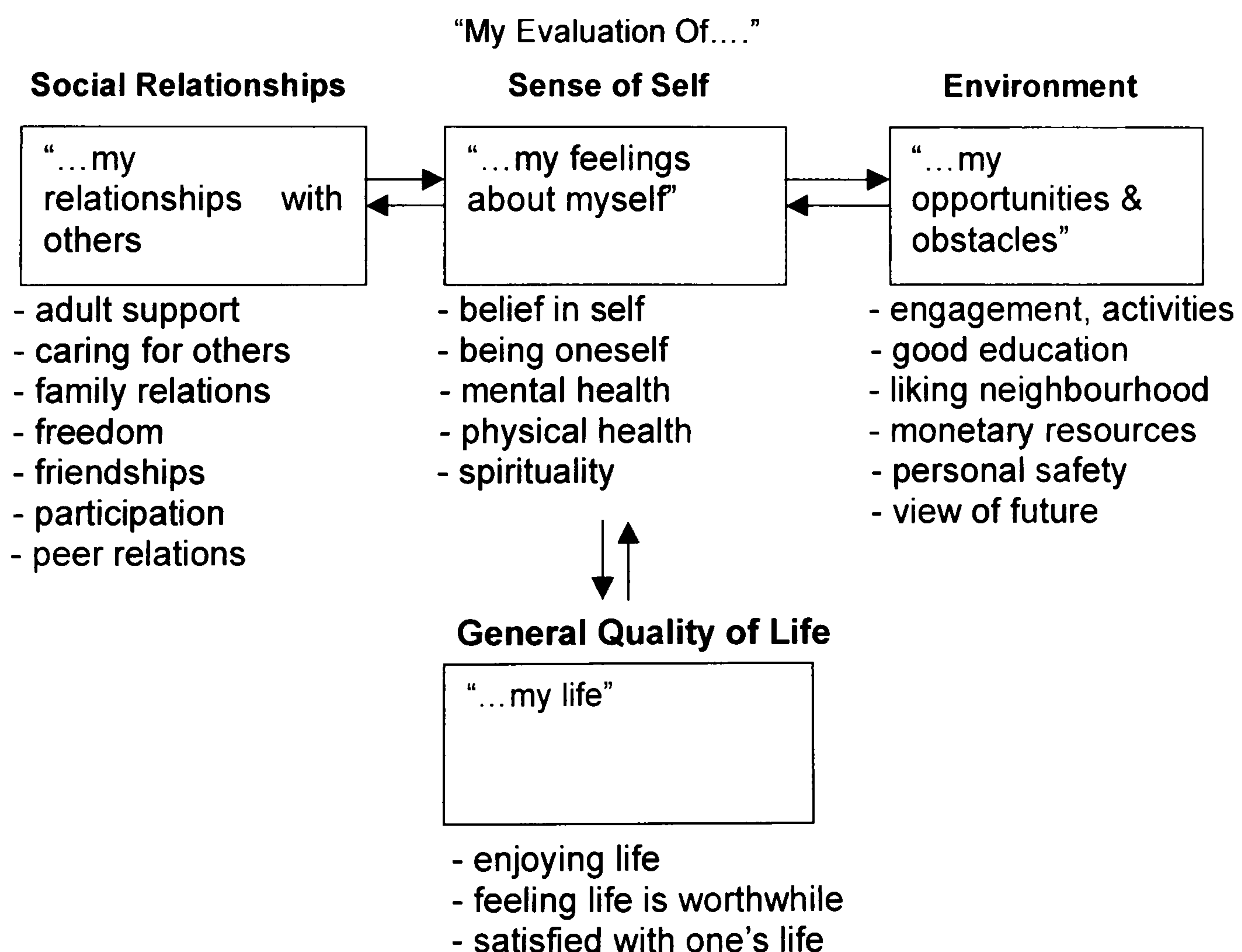


Figure 1. Components of the Youth Quality of Life questionnaire (YQOL)

Therefore, in addition to looking at body image and mood in young burn survivors, it may also be useful to look at associations with quality of life. If a statistically significant relationship is found with body image and quality life, this gives further ideas for directing provision of clinical interventions for young people with burns.

Summary of limitations of current body of knowledge

1. The majority of the published research described above looks at the psychological outcome of burn survivors is focused on adults. Much less is known about outcomes for children and adolescents.

2. The majority of the research has been conducted in the United States, and therefore there may be problems in applying the findings to a British burn-injured population. The most common age a child acquires a burn in the UK is around 18 months whereas in America, few are burned before 5 years. In the Regional Burns Unit that is involved in the current study, 50% of children admitted are under the age of three, with the majority of burns are from scalds where the infant will pull off a pan of boiling water off the cooker, or a kettle. (It has been suggested anecdotally that this may be partly because in the USA less tea is drunk than in the UK!) There may also be cultural differences in response to disfigurement.

3. Studies that group children and young people together mean that average scores may mask effects specific to adolescence.

4. As can be seen from the above, many of the follow-up studies in the literature look at outcomes shortly after the injury, with fewer looking at longer-term outcomes.

5. There is little known about how outcomes for young people who have been burned, compare with young people who have not had this experience. One of the criticisms in Zeitlin's (1997) paper evaluating research into paediatric burn survivors (as outlined in Pope, 2004), is that too few studies have comparison groups. Such comparison studies would enable us to learn more about whether or not there are problems specific to being a young burn survivor.

Research aims and hypotheses

The current study will look at body image, mood and quality of life among young people (often referred to in the literature as adolescents) who were burned as children, and a group of young people who have not had burns. It aims to address some of the gaps in the current literature, which are described above.

It will include young people with all sizes of burns. Issacs (1996) found that even those who had injuries covering less than 1% of their bodies could experience clinically significant levels of psychological difficulty. The study will aim to include young people who have been burned as children under the age of 8, in order to reduce some of the confounding variables concerning development of body image prior to burn.

Main research questions

As discussed above, there is evidence that body image concerns are common in non-clinical populations, and therefore may not be specific to people with disfigurements. It was suggested at the conference for the Centre for Appearance Research (2003), that there would be little differences in body image in people with disfigurements, and those without. In addition, from talking to counselling and psychotherapy clinicians from the Regional Burns Unit involved with this study, their anecdotal evidence suggested that many young burn survivors may be coping well. However research has tended not to make this comparison. Therefore, for research questions 1 to 3, the null hypothesis will be assumed.

Research question 1

How does body image in young burn survivors compare with body image in young people who have not been burned?

Hypothesis

There will be no difference in body image in young burn survivors and young people who have not been burned, as measured by the Body Esteem Scale (BES).

Research question 2

How does mood in young burn survivors compare with mood in young people who have not been burned?

Hypothesis

There will be no difference in mood level in young burn survivors and young people who have not been burned, as measured by the Beck Depression Inventory-II (BDI-II).

Research question 3

How does the quality of life in young burn survivors compare with quality of life in young people who have not been burned?

Hypothesis

There will be no difference in the quality of life in young burn survivors and young people who have not been burned, as measured by the YQOL.

Research question 4

How does body image relate to mood in both groups?

Research question 5

How does body image relate to quality of life in both groups?

Research question 6

How does quality of life relate to mood in both groups?

Additional research questions

Research question 7

How satisfied are young burn survivors with parts of their bodies which are burned, compared to the parts of their parts of their bodies which are not burned?

Hypothesis

Young burn survivors will be no more dissatisfied with the parts of their which are burned, compared to the parts of their body which are not burned.

Research question 8

How do the Body Esteem Scale (BES) outcomes relate to Satisfaction with Appearance Scale (SWAP) outcomes in young burn survivors?

METHOD

Design

A cross-sectional between-groups design was used to test the hypotheses that there will be no difference in the body image, mood and quality of life in young burn survivors and young people who have not been burned. A cross-sectional within-groups design was used to test the hypothesis that young burn survivors will be no more dissatisfied with the parts of their which are burned, compared to the parts of their body which are not burned.

Participants

In total, 32 young burn survivors, and 41 young people from the school participated in the study. Assuming a medium-to-large effect size, 30 participants per group should lead to about 80% power, which is the minimum suggested power for an ordinary study (Cohen, 1992).

Overall across the two groups, 31 respondents (42.5%) were male, and 42 (57.5%) were female. Within the burn survivors sample, 13 (40.6%) were male and 19 (59.4%) were female. Within the school sample, 18 (43.9%) were male, and 23 (56.1%) were female. The overall mean age across both groups was 15.24 years with a range of 11 to 19 years. The mean age for the burn survivor sample was 15.45 years with a range of 11 to 19 years. The mean age for the school group was 15.10 years with a range of 12 to 19 years.

Young burn survivors

Participants were recruited to the study from a Regional Burns Unit, and from four Burned Children's Clubs. Most children who require admission to hospital at the time of burn injury will be admitted to a Regional Burns Unit. A Burned Children's Club is a club for children and young people who have survived burns. They usually provide support to young burn survivors, and activities throughout the year giving opportunities to mix with other burn survivors. Some clubs are voluntary and function independently of a hospital trust, and some are funded by the trust. The clubs included in this study function independently.

Hospital sample

Case notes were first requested for 90 young people between the ages of 12 and 18 who had been admitted to the Regional Burns Unit at the age of 8 and under. Trust Research and Development protocol dictated that all of these case notes had to be retrieved and checked by a member of trust staff for child protection issues, and any cases involving ongoing child protection concerns omitted from the present study. However due to the move of the Regional Burns Unit to its current location five years previously, only 29 sets of notes were available. The hospital only held records of young people who had returned to the unit since the move, for example for ongoing surgery or outpatient appointments. From the 29 sets of case notes, only one young person was excluded because of ongoing child protection issues. Notes then had to be screened by the consultant surgeons responsible for each young person's in order to give their consent for each young person to be contacted.

From the 28 sets of notes, five were then excluded by the consultants: two did not have any scars, two had learning difficulties, and one was excluded due to concerns of the emotional impact of the research on the young person/family. 23 research packs were therefore sent out, and 8 returned completed questionnaires.

Burned Children's Clubs

Due to the problems in recruiting from the hospital, young people were also recruited from Burned Children's Clubs within the UK.

The directors of six clubs were approached, all of whom expressed interest in being included. Four clubs were included in the study. Research packs were sent in the post by camp directors. Club A sent out packs to ten young people, and two chose to participate; Club B sent packs to five young people, and two chose to participate; Club C sent out a pack to one young person, who chose to participate.

In addition the main researcher attended two burns camps (the main annual event of the Burned Children's Clubs). In total, 22 young people were asked by the camp directors whether they would like to participate, and 19 chose to participate. All of those asked to participate came from clubs A and D.

School sample

172 young people from a mixed comprehensive school in Essex aged between 12 and 19 were invited to participate. The Ofsted inspection report in 2003, describes the school as “a very good school serving a socially deprived area”. Compared to all schools nationally G.C.S.E. results are “below average”. However, compared to other similar schools, the results are “above average”. The report describes the attitudes and behaviour of the pupils as “good”, personal development as “very good”, but attendance as “unsatisfactory”.

One class from each of years 8 to 13 were included. The deputy headmistress chose the classes based on those she anticipated we would be more likely to get a response from. 51 returned questionnaires, however only 41 of these had returned the consent form, therefore only 41 could be included.

Measures

Young burn survivors

1. Body Esteem Scale for Adolescents and Adults (BES)
2. Satisfaction With Appearance Scale (SWAP)
3. Beck Depression Inventory-II (BDI-II)
4. Youth Quality of Life Scale (YQOL)
5. Body drawing for scars

Control group

1. Body Esteem Scale for Adolescents and Adults (BES)
2. Beck Depression Inventory-II (BDI-II)
3. Youth Quality of Life Scale (YQOL)
4. Demographic information sheet

The *Body Esteem Scale for Adolescents and Adults* (Mendelson et al, 2001) is a generic measure of body image which is not specific to burn survivors, and can therefore be used to compare both groups. It is a 30 item questionnaire and has three subscales which in the validation study were all found to have high internal consistency. The three scales are: General feelings about appearance, (cronbach's alpha = .92); weight satisfaction, (cronbach's alpha = .94); and evaluations of how

others see their body or appearance, (cronbach's alpha = .81). There is currently no published data which has used the Body Esteem Scale with burn survivors.

The Satisfaction with Appearance Scale (Lawrence et al, 1998) is the only burn-specific body image scale in the published literature. However this is a questionnaire for adults, and there is no published data which has used it with young people. It is a 14 item questionnaire assessing both the subjective appraisal and social-behavioural components of body image among burn survivors. Its authors conclude that it is a valid and reliable measure of body image in the adult burn-injured population (cronbach's alpha = .87), and that it is helpful to identify patients who could benefit from cognitive-behavioural therapy, and to monitor improvement in body image over time. In the current study this questionnaire was completed by young burn survivors only.

The Beck Depression Inventory-II (Beck et al, 1996) is the questionnaire which has been most commonly used to measure depression in both research and clinical practice since its' introduction in 1996. It was developed to measure severity of symptoms of depression as defined by changes in mood, a negative self-concept associated with self-devaluation and self-blame, self-punitive wishes, vegetative symptoms and changes in activity level.

The Youth Quality of Life Instrument (Topolski et al, 2002) for 11-18 year olds claims to incorporate adolescents' perspectives and language, apply to general and vulnerable populations, and to tap perceptions and feelings. The validation study found it to have high internal consistency (cronbach's alpha value = .70. It has been used with young people both with and without disabilities. It has been shown that young people with disabilities report lower quality of life than young people without disabilities. There is no published research which has used this questionnaire on burn survivors. The components of the questionnaire, as described in the introduction, (figure 1) include evaluations of their 'sense of self', 'social relationships', 'environment' and 'general quality of life'. The questionnaire also gives an overall quality of life score.

Body Drawing for Scars

This questionnaire asks burn survivors if they have any scarring currently. If they respond YES they are then asked to either describe where the scars are, or to draw where they are on two blank gender-neutral figures (one for the front of the person.

one for the back of the person). This questionnaire was developed by the research team.

The young people from the Burned Children's Club in addition were asked their age, size of burn (total body surface area), age at injury and cause of injury.

Procedure

Young burn survivors

Hospital sample

23 research packs were sent out addressed to the parent(s)/guardian(s) requesting that they pass the packs on to their son/daughter, as they were all aged 17 and under. The packs consisted of:

- letter of invitation to participate signed by the appropriate consultant on trust headed paper, introducing the main researcher, outlining the project and stating their support of the project.
- two letters from the main researcher on University of Hertfordshire headed paper. One letter was for the parent and one was for the young person. These two letters explained the research, the reasons for the research, and invited them to participate.
- two consent forms; one to be read, signed by parent and young person and returned, and one to be kept for their own information.
- the five questionnaires to be completed and returned.
- a brown pre-paid envelope for the questionnaires and a white pre-paid envelope for the consent form both addressed to the University of Hertfordshire.

Please see appendices for the contents of the research pack.

Young people and parents had the option of emailing or telephoning the main researcher if they felt they needed any help with the questionnaires, to discuss any aspect of the research, or if they were upset by the questionnaires.

The parent(s) then had the decision of whether they passed the research pack onto their son/daughter. It was anticipated that each participant would take between 35 to 45 minutes completing the questionnaires.

Therefore 23 research packs were sent out, and a total of 8 young people chose to participate. All responders had given permission for a staff member of the trust to extract their date of birth, admission date, size of the burn and cause of the burn.

Burned Children's Club sample

Research packs including consent forms were sent out to parents of young people who were under the age of 18, and directly to the young person if they were aged 18 or 19. In total, 17 packs were sent, and 5 young people returned completed questionnaires. The packs were similar to those sent to the hospital sample, with the exception that the letter of introduction to the research was from the club director.

In addition, the main researcher attended two burns camps, and recruited a further 19 young people between the ages of 11 and 18. The main researcher and a member of the camp staff sat with the young people in small groups as they completed the questionnaires. They were able to ask for help with the questionnaires if they wished.

School sample

The main researcher briefed the form tutor of each of the classes and gave them the research packs. The packs were similar to the ones sent to the burn survivors, except that the letter of introduction was from the deputy headmistress on school headed paper, the Satisfaction with Appearance Scale was omitted, and they were asked to give their age and gender on a separate page.

Form tutors then explained the research to their classes. It is not known how many young people did not receive packs, as some were frequently absent from school. From the 172 packs, 51 sets of completed questionnaires were returned. However 10 young people had not completed a consent form, and it was not possible to identify who these young people were to follow this up. Therefore these responses could not be used. The response rates (including completed consent form) was 23.84%.

Ethical Considerations

All data collected in this study was kept confidential and stored in a secure place. Parents were asked in the introductory information letter not to look at their son/daughter's completed questionnaires. The only person who saw the completed questionnaires was the main researcher. No identifying information was written on the questionnaires, which were tracked in a database by the main researcher with an identifying number. Only the main researcher had access to this database. The information letters made it clear that information about an individual would only be shared if there were concern about the safety of that person, or the safety of someone else. However this situation did not arise during the study.

The information letter informed participants that if they found completing the questionnaires upsetting, they could discuss this with the main researcher by telephone or email. If the participant was distressed and in need of any kind of support, the main researcher would discuss this with them in the first instance. Further support could then be arranged if the participant wished this. Parent(s) would then have been advised for those under 18 years of age, after discussion of this with the young person. However no participants notified the researcher of any distress brought on by this study. Parents of the young burn survivors were also informed that if they found any aspect of the study upsetting, they had the option of phoning the Counselling and Psychotherapy Service at the hospital.

For all participants up to and including the age of 17, both the young person and the parent were asked to complete a consent form. For participants of 18 or 19 years, the consent form could be signed by the young person and a witness of their choice. Participants were made aware that they could withdraw their consent at any time, without giving a reason and without affecting services they receive from the NHS or services they would receive in the future.

RESULTS

Sample characteristics

Age

The overall mean age across both groups was 15.24 years (SD = 2.18), with a range of 11 to 19 years. The mean age for the burn survivor sample was 15.45 years (SD = 2.5) with a range of 11 to 19 years. The mean age for the school group was 15.10 years (SD = 2.1), with a range of 12 to 19 years.

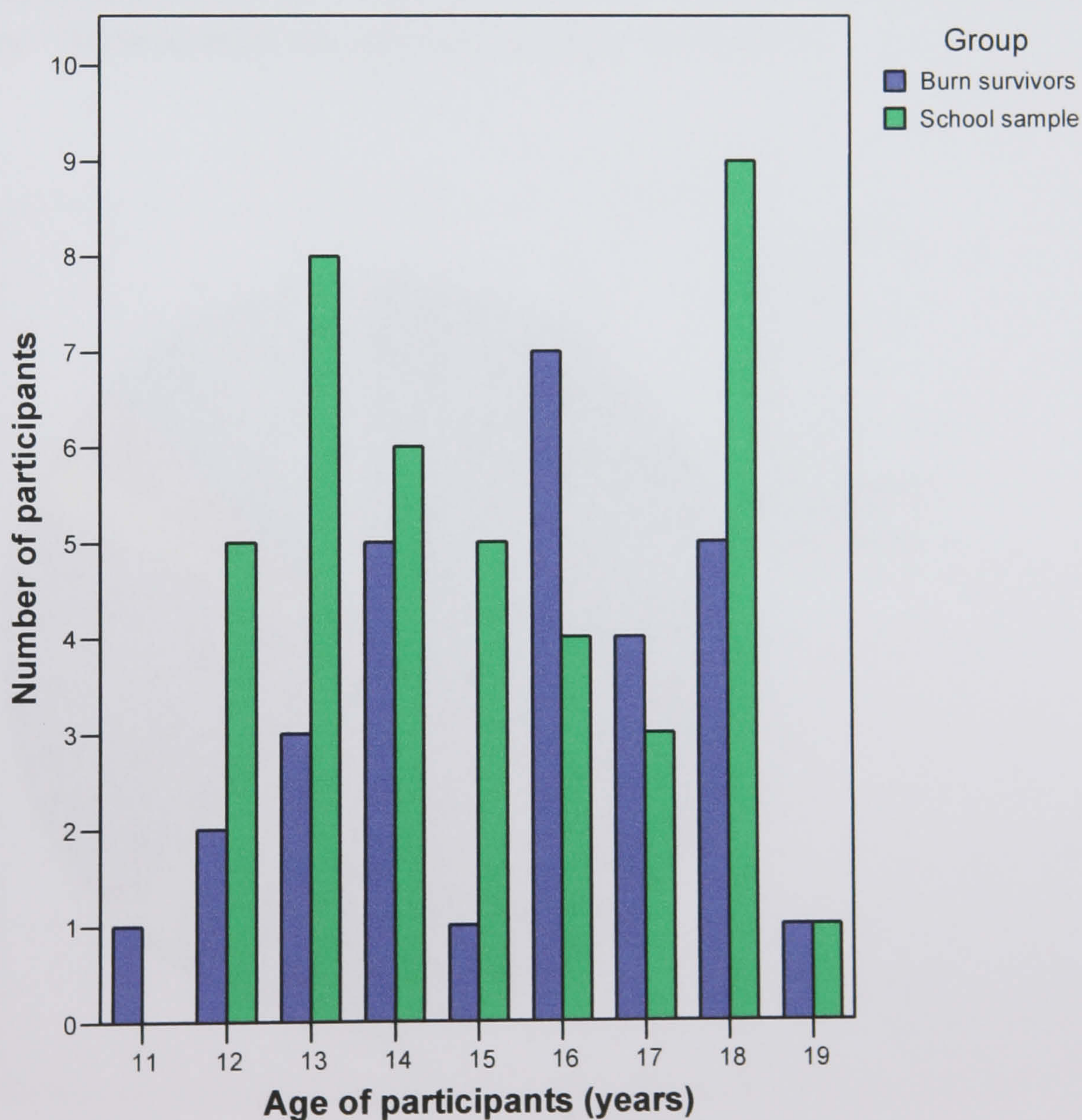


Figure 1. Spread of ages across both groups.

Gender

Overall across the two groups, 31 respondents (42.5%) were male, and 42 (57.5%) were female. Within the burn survivors sample, 13 (40.6%) were male and 19 (59.4%) were female. Within the school sample, 18 (43.9%) were male, and 23 (56.1%) were female.

Cause of burn

The majority of young burn survivors had scalds (18, 56.3%); six (18.8%) had been in house fires; one (3.15%) had a burn from hot fat; one (3.15%) had a contact burn from a radiator; one (3.15%) had a burn from a car fire; one (3.15%) had accidentally set themselves on fire, and one (3.15%) had been deliberately set on fire. This information was missing for three survivors (9.4%).

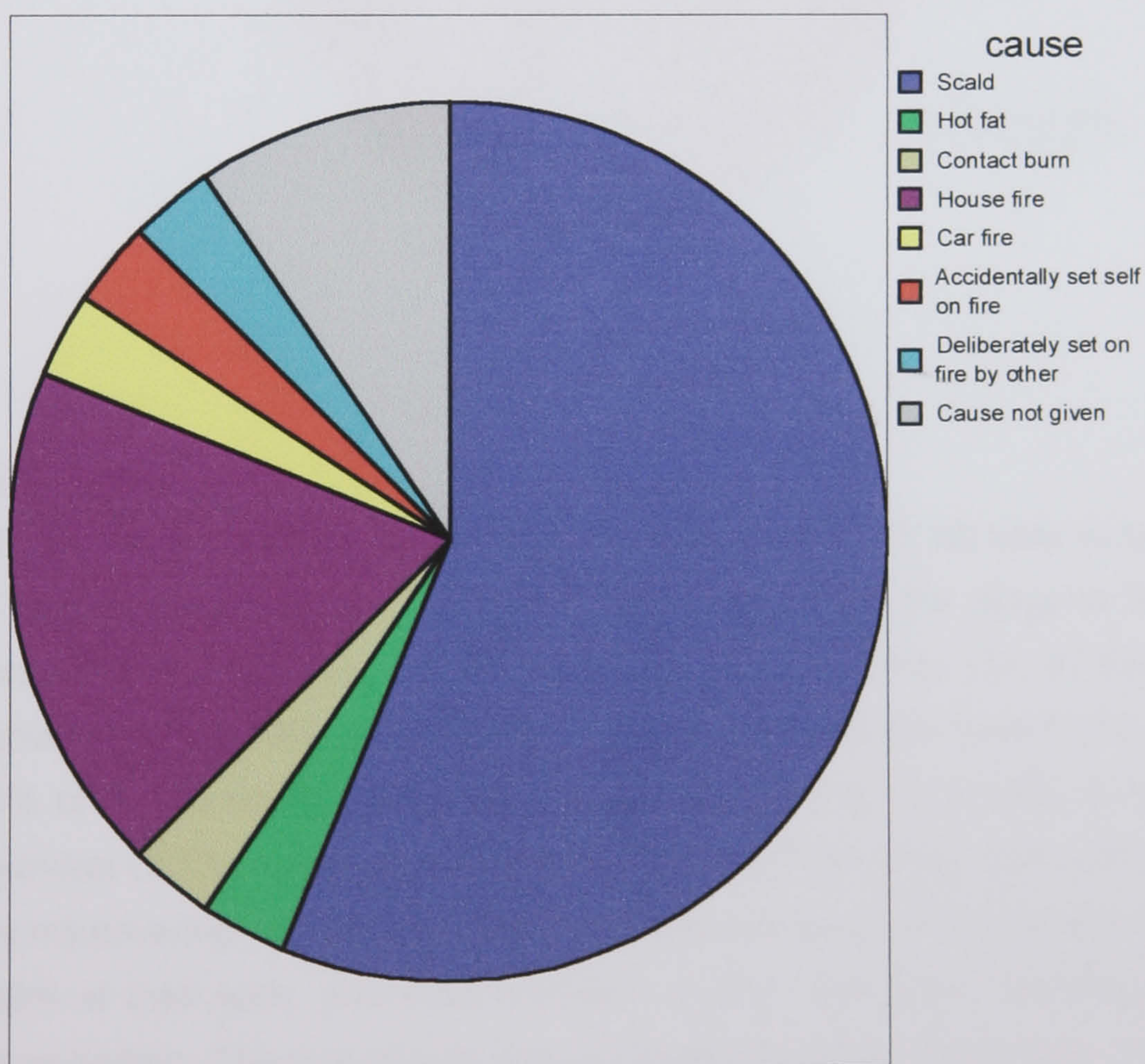


Figure 2. Cause of burn

Age at burn

The majority of young burn survivors were burned at the age of 3 or under (20, 62.5%). Six (18.8%) were burned between the ages of 4 and 7, four were burned between the ages of 12 and 15. The information was missing for two survivors (6.3%).

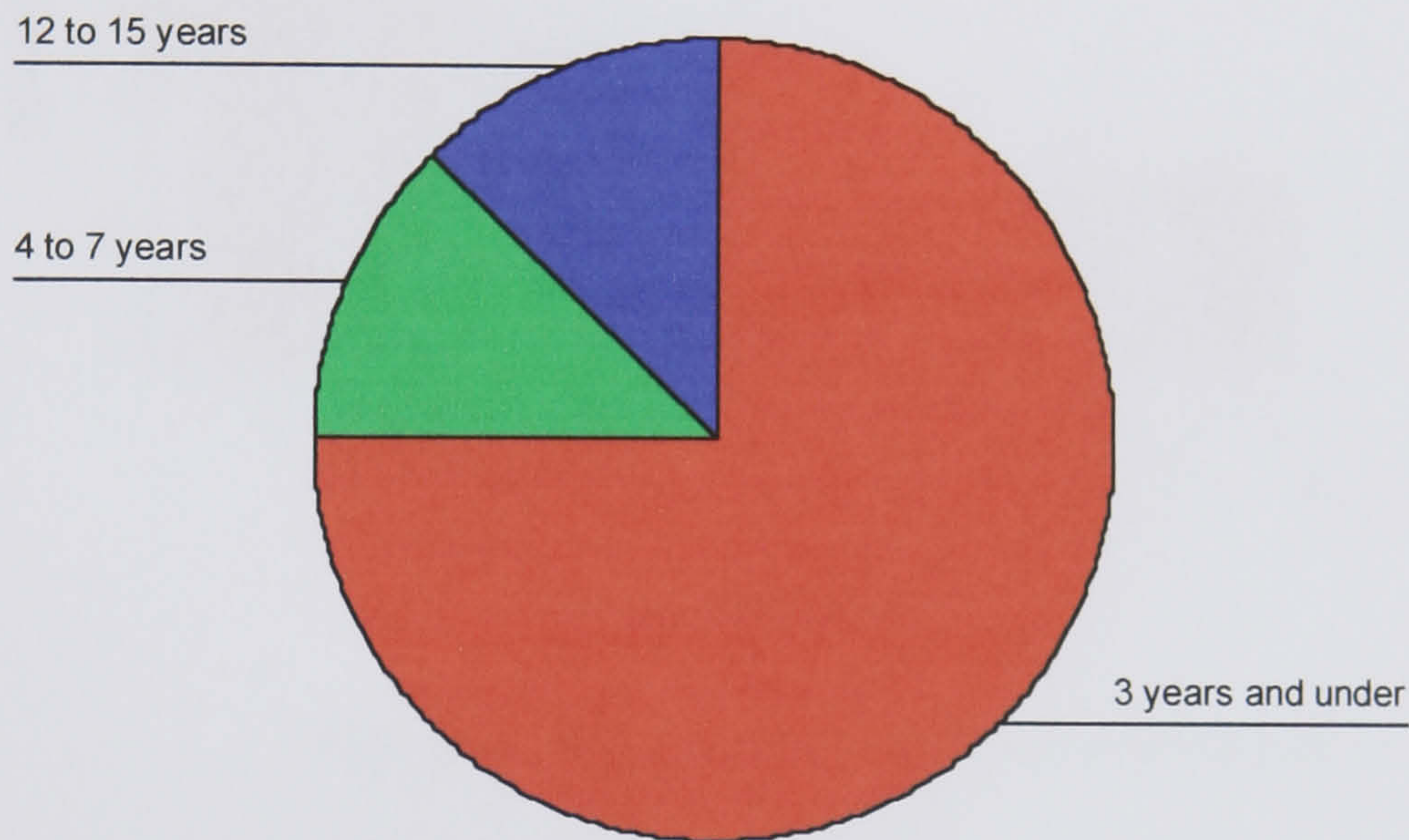


Figure 3. Age at burn

Size of burn

The mean size of burn in this study is 21.93% (SD = 17.13) total body surface area (TBSA), ranging from 1 to 63%. Figure 4 illustrates the range in the size of the childrens' burns. The majority of young burn survivors (12, 37.5%) have burns covering 10 to 19% of their body. Six survivors (18.8%) have burns covering 1 to 9% of their body; five survivors have burns covering 20 to 29% of their body; one survivor (3.1%) has burns covering 30 to 39% of their body; one survivor (3.1%) has burns covering 40 to 49% of their body; one survivor (3.1%) has burn covering 50 to 59% of their body, and three survivors (9.4%) have burns covering 60 to 63% of their bodies. The size of burn was not known for three survivors (9.4%).

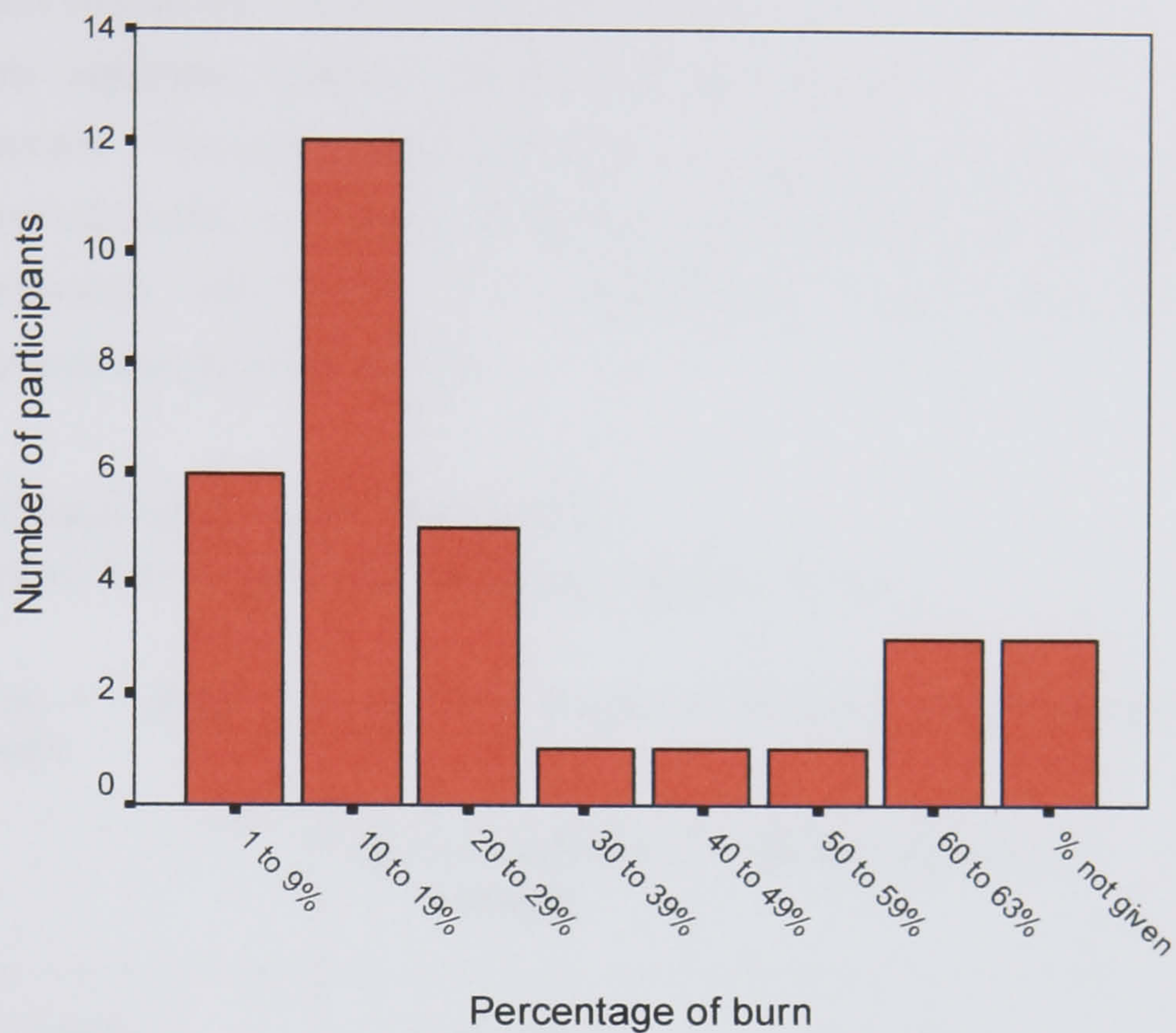


Figure 4. Size of burns in burn survivor sample

Research question 1

How does body image in young burn survivors compare with body image in young people who have not been burned?

On the basis of the evidence reviewed in the introduction, for research questions 1 to 3, the null hypothesis was assumed.

Hypothesis

There will be no difference in body image in young burn survivors and young people who have not been burned, as measured by the Body Esteem Scale (BES).

There are no diagnostic cut-offs for the BES. Respondents rate how much they agree with each statement, with 4 representing the highest possible body satisfaction and 0 representing the lowest.

Given that there are three separate subscales of the BES, with no overall score, three separate between groups two-way ANOVAs were calculated for each subscale. The two grouping factors were burns vs. no burns, and gender. The three subscales are: general feelings about appearance (BE-Appearance), weight satisfaction (BE-Weight), and evaluations of how others see their body or appearance (BE-Attributions).

General feelings about appearance

Data for this measure are reported in tables 1 and 2.

Table 1. Mean, median and range of BE-Appearance scores across the two groups.

	Burn survivors sample	School sample
Mean (SD)	2.42 (1.19)	2.2 (.81)
Median	2.85	2.10
Min – Max	.00 – 4.00	.00 – 3.40

Table 2. Mean BE-Appearance scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	3.077 (.801)	2.390 (.856)
Females	1.970 (1.214)	1.902 (.718)

As can be seen from table 3, a two-way analysis of variance did not reveal a significant effect of group on general feelings about appearance, ($F_{1, 69} = 2.962, p = .090$), although this is just below the significance level. Burn survivors scored marginally higher than the school sample, indicating more positive feelings about their appearance. Analysis of variance revealed a significant effect of gender on general feelings about appearance, ($F_{1, 69} = 13.228, p = .001$), with males in both groups reporting more positive feelings about their appearance. However there was no significant interaction between gender and group ($F_{1, 69} = 1.994, p = .162$).

Table 3. BE-Appearance: ANOVA between group and gender

	Type III Sum of Squares	df	Mean Square	F	Significance
Burns/ No burns	2.491	1	2.491	2.962	.090
Gender	11.122	1	11.122	13.228	.001**
Interaction - group and gender	1.676	1	1.676	1.994	.162

** Significant at the 0.01 level

Weight Satisfaction

Data for this measure are reported in tables 4 and 5.

Table 4. Mean, median and range of BE-Weight scores across the two groups.

	Burn survivors sample	School sample
Mean (SD)	2.77 (.97)	2.02 (.99)
Median	3.00	2.13
Min - Max	0.50 – 4.00	.14 – 3.75

Table 5. Mean BE-Weight scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	3.332 (.520)	2.336 (.876)
Females	1.970 (1.214)	1.902 (.718)

As can be seen from table 6, a two-way analysis of variance revealed a significant effect of group on weight satisfaction, ($F_{1, 69} = 13.256$, $p = .001$), with burn survivors reporting greater satisfaction with their weight than the school sample. It also revealed a significant effect of gender on weight satisfaction, ($F_{1, 69} = 11.826$, $p = .001$), with males in both groups expressing more weight satisfaction than females. However it did not reveal a significant interaction between gender and group ($F_{1, 69} = .803$, $p = .373$).

Table 6. BE-Weight: ANOVA between gender and group

	Type III Sum of Squares	df	Mean Square	F	Significance
Burns/ No burns	11.182	1	11.182	13.256	.001**
Gender	9.997	1	9.997	11.826	.001**
Interaction – group and gender	.677	1	.667	.803	.373

** Significant at the 0.01 level

Box plot (figure 5) illustrates that the burn survivor group reported a higher level of weight satisfaction than the school sample. The box plots in this section show the distribution of scores obtained on each measure for both groups. The horizontal line through the box indicates the median or middle score. The lower boundary of the box is the 25th percentile, whilst the upper boundary is the 75th percentile. The line above and below the box show the largest and smallest scores that are not outliers. Values which are shown as a circle between 1.5 and 3 box-lengths from the 75th percentile, are outliers.

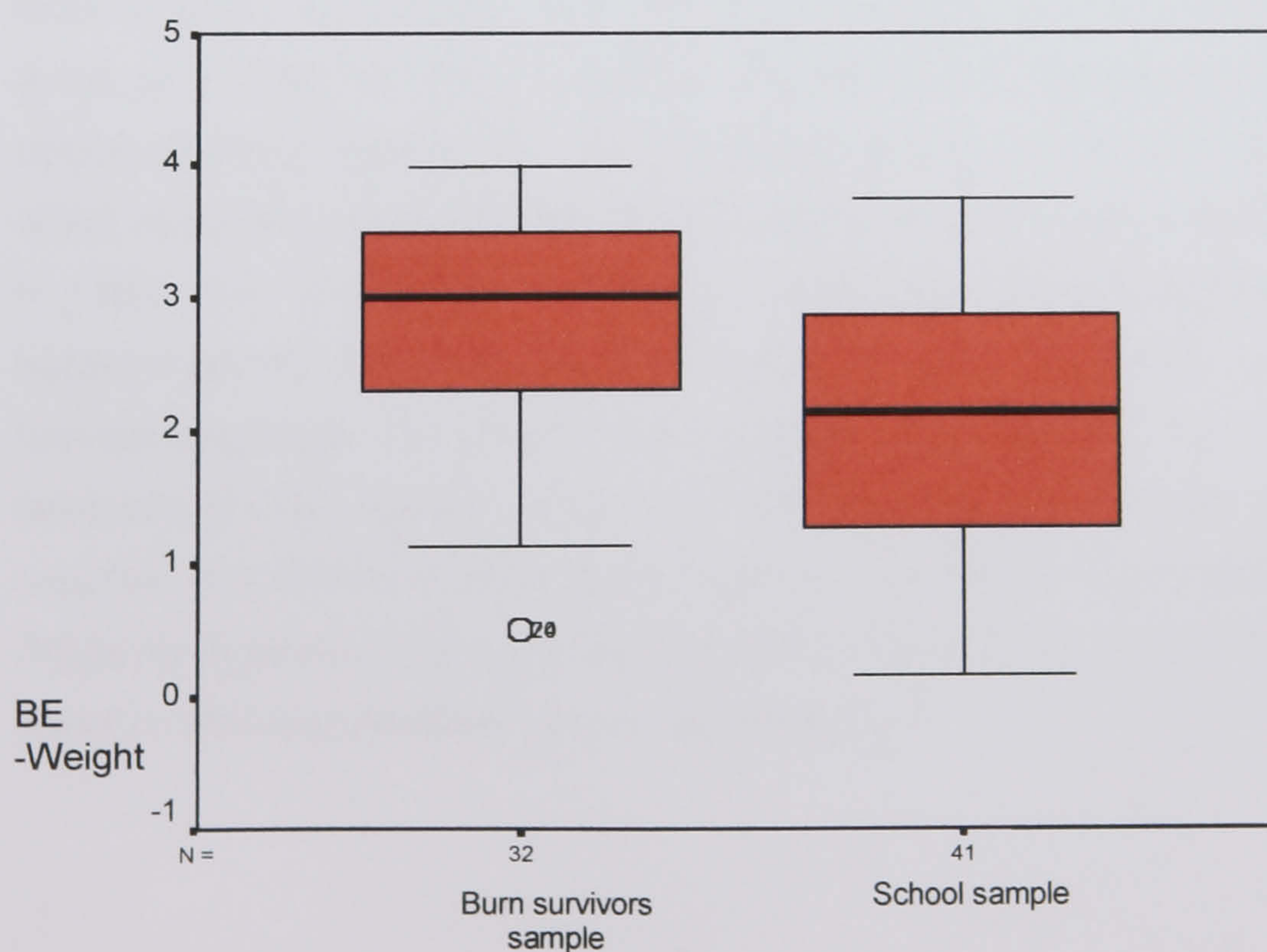


Figure 5. Weight satisfaction across the two groups.

Evaluations of how others see their body or appearance

Data for this measure are reported in tables 7 and 8.

Table 7. Mean, median and range of BE-Attribution scores across the two groups.

	Burn survivors sample	School sample
Mean (SD)	2.01 (.98)	1.64 (1.75)
Median	2.00	1.60
Min - Max	.20 – 4.00	.00 – 3.00

Table 8. Mean BE-Attribution scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	2.486 (.868)	1.545 (.765)
Females	1.677 (.935)	1.720 (.753)

As can be seen from table 9, a two-way analysis of variance revealed a significant effect of group on evaluations of how others see their body or appearance ($F_{1, 69} = 5.151, p = .026$), with burn survivors expressing more positive evaluations of how others see their appearance than the school sample. It did not show a significant effect of gender on evaluations of how others see their body or appearance ($F_{1, 69} = 2.569, p = .114$). The analysis of variance did reveal a significant interaction between gender and group ($F_{1, 69} = 6.188; p = .015$). In the burn survivor sample, females expressed marginally more negative evaluations of how others see their appearance than males. However in the school sample, males expressed more negative evaluations of how others see their appearance than females. Box plot (figure 6) illustrates that male burn survivors reported the most positive evaluations about how others see their body or appearance.

Table 9. BE-Attribution: ANOVA between gender and group

	Type III Sum of Squares	df	Mean Square	F	Significance
Burns/ No burns	3.523	1	3.523	5.151	.026*
Gender	1.757	1	1.757	2.569	.114
Interaction- group and gender	4.233	1	4.233	6.188	.015*

* Significant at the 0.05 level.

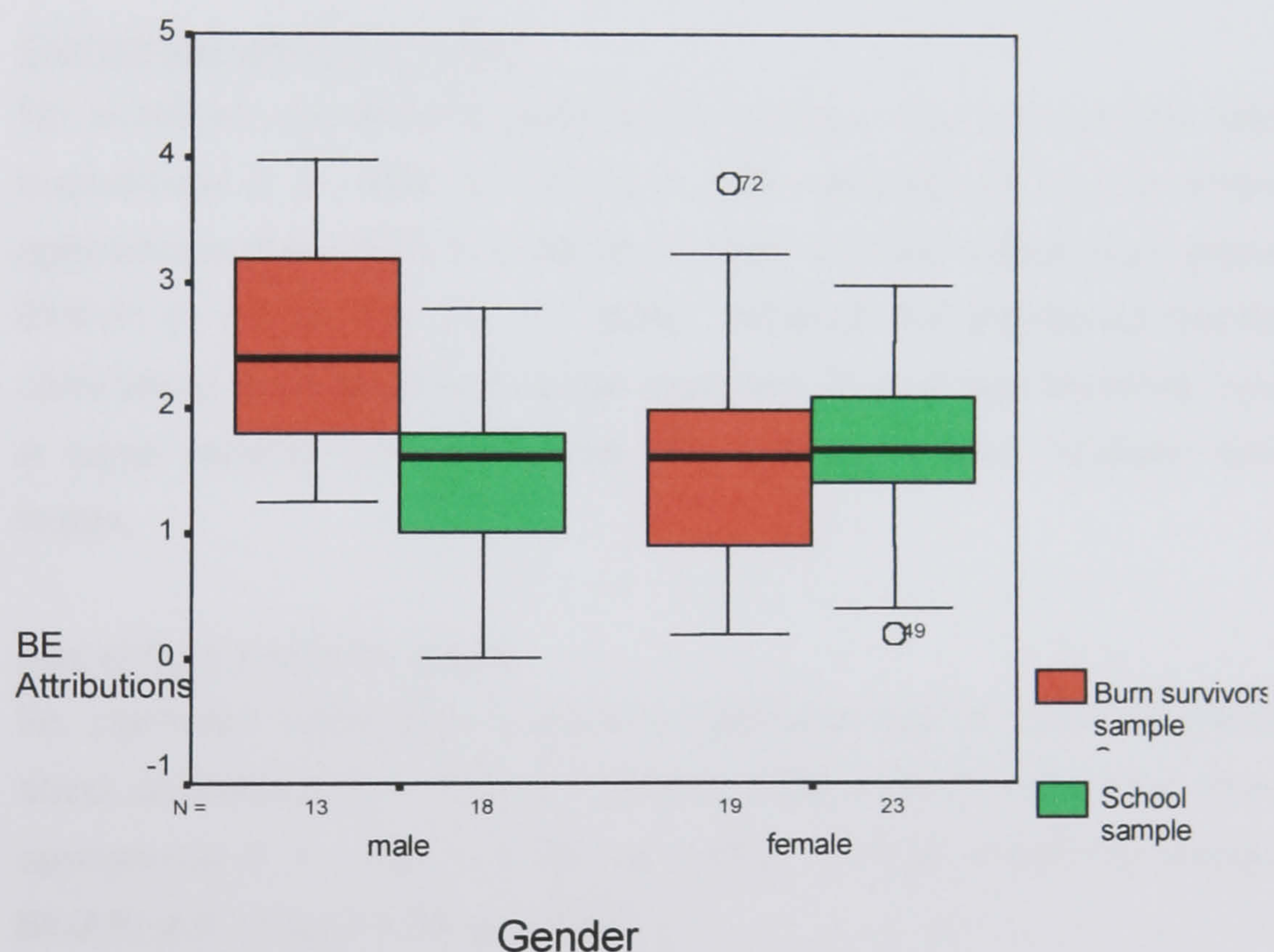


Figure 6. BE-Attribution across both groups and gender.

To summarise, for two of the three subscales from the BES there were statistically significant differences between the two groups. The null hypothesis that there will be no group differences in body image can therefore be rejected.

Size of burn and body image

Correlations were calculated between the size of burn and each of the three subscales of the BES. A significant negative correlation was found between the

size of burn and general feelings about appearance ($r = -.446$; $n = 29$, $p = .015$), indicating that as the size of burn increases, there are more negative general feelings about appearance. Significant correlations were not found between size of burn and weight satisfaction ($r = -.118$; $n = 29$, $p = .541$). The correlation between size of burn and evaluations of how others see their body was found to be just below the significance level ($r = -.318$; $n = 29$, $p = .093$). Also just below the significance level was the correlation between size of burn and body image, as measured by the Satisfaction With Appearance Scale (SWAP) ($r = .364$; $n = 29$, $p = .052$).

Current age and body image

No significant correlations were found between age and general feelings about appearance ($r = -.129$; $n = 29$, $p = .506$); evaluations of how others see their appearance ($r = -.177$; $n = 29$, $p = .528$); or body image (as measured by the SWAP) ($r = .190$, $n = 29$, $p = .324$). Although not statistically significant, these correlations do indicate that as age increases, body image becomes more negative. A larger sample size may reveal stronger associations between age and body image.

Age at burn and body image

No significant correlations were found between age at burn and general feelings about appearance ($r = .134$; $n = 29$, $p = .489$); evaluations of how others see their appearance ($r = -.133$; $n = 29$, $p = .491$), or body image (as measured by the SWAP) ($r = -.123$, $n = 29$, $p = .526$).

Research question 2

How does mood in young burn survivors compare with mood in young people who have not been burned?

Hypothesis

There will be no difference in mood in young burn survivors and young people who have not been burned, as measured by the Beck Depression Inventory-II (BDI-II).

The data for this measure are reported in tables 10 and 11. Mean scores for both groups lie within the 'minimal' range for depression. A score of 14 indicates 'mild' depression. In the burn survivor sample, the mean score for females falls just within the range for mild depression, at 14.32.

Table 10. Mean, median and range of BDI-II scores across the two groups.

	Burn survivors sample	School sample
Mean (SD)	10.97 (11.39)	10.10 (7.92)
Median	8	9
Min - Max	0 - 39	0 - 29

Table 11. Mean BDI-II scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	6.08 (5.82)	6.71 (6.66)
Females	14.32 (13.10)	12.73 (7.94)

As can be seen from table 12, a two-way analysis of variance did not reveal a significant effect of group on mood ($F_{1, 67} = .048, p = .828$), although burn survivors report a marginally lower mood than the school sample. Therefore the null hypothesis that there will be no difference in mood between young burn survivors and young people who have not been burned, cannot be rejected.

Analysis of variance did reveal a significant effect of gender on mood ($F_{1, 67} = 10.535, p = .002$), with females reporting a lower mood than males, across both

groups. Analysis did not reveal a significant interaction between gender and group ($F_{1, 67} = .255, p = .615$).

Table 12. BDI-II: ANOVA between gender and group

	Type III Sum of Squares	df	Mean Square	F	Significance
Burns/ No burns	3.938	1	3.938	.048	.828
Gender	869.660	1	869.660	10.535	.002**
Interaction – group and gender	21.029	1	21.029	.255	.615

** Significant at the 0.01 level

The data can be compared to the student sample used in the validation of the BDI-II. The sample consisted of 120 first years on a psychology degree course in the US. The average age was 19.58 years (SD = 1.84), and the students were predominantly white. The mean score was 12.56 (SD = 9.93). Therefore young people in the current study report a slightly elevated mood in comparison to the norms. In the student sample in the BDI-II validation study, the mean score for females was 14.55 (SD = 10.74), and for males was 10.04 (SD = 8.23). Therefore in the current study, females reported comparable mood, and males reported slightly elevated mood in comparison to norms.

It should be noted that there are differences in terms of age, educational level, socio-economic status and culture between young people in the current study, and the students in the validation study. The other sample used in the validation study included people between the ages of 13 to 86 who were outpatients, mainly being treated for mood disorders, anxiety and adjustment disorders. Therefore comparison to this sample is less helpful.

Table 13 shows mood across the diagnostic categories of the BDI-II. It shows that 25% of the young burn survivors fall into the range for depression, and 30.77% of the school sample fall into the range for depression. Of the burn survivors, 4 (12.5%) reported severe depression, compared to 1 (2.56%) of the school sample. Also of note, 7 (17.95%) of the school sample reported mild depression, compared

to 1 (3.13%) of the burn survivor sample. This indicates that burn survivors may be more at risk of severe depression than mild or moderate depression. The BDI-II norms do not state the percentages of people who fall into the different diagnostic categories.

Table 13. Mood across the BDI-II diagnostic categories across both groups.

	Burn survivors sample Frequency N=32	Burn survivors Percentage	School sample Frequency N=39*	School sample Percentage
Minimal depression (0-13/63)	24	75%	27	69.23%
Mild depression (14-19/63)	1	3.13%	7	17.95%
Moderate depression (20-28/63)	3	9.38%	4	10.26%
Severe depression (29-63/63)	4	12.5%	1	2.56%

* Data missing for 2 young people

Box plot (figure 7) illustrates that the mood was similar for both groups. However there are four outliers for the burns group indicating that of the burn survivors, four reported particularly high levels of depression.

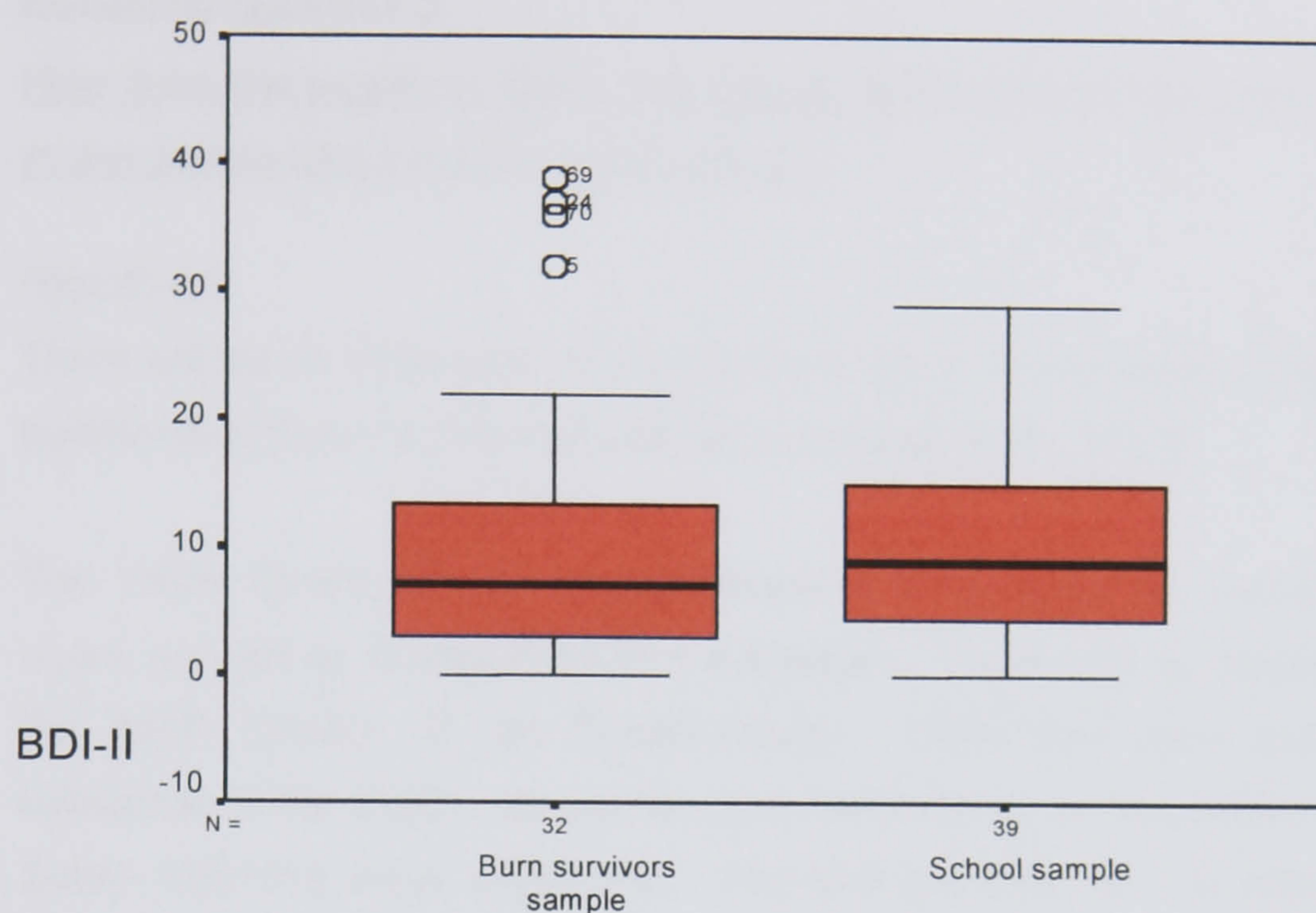


Figure 7. Mood levels in burn survivors and school sample

Size of burn and mood

No significant correlation was found between size of burn and mood ($r = .217$; $n = 29$, $p = .258$). Although not statistically significant, the correlation suggests that as the size of burn increases, young people become more depressed. A larger sample size may reveal stronger associations between size of burn and mood.

Current age and mood

No significant correlation was found between current age and mood ($r = .056$; $n = 29$, $p = .772$).

Age at burn and mood

No significant correlation was found between age at burn and mood ($r = -.171$, $n = 29$, $p = .375$). Although showing only a weak correlation, there may be some indication that as the age at burn increases, mood becomes more negative. However the majority of burn survivors were burned at young ages with only four being burned within the last few years. Therefore a bigger sample size with a greater range for age at burn may reveal a stronger relationship.

Research question 3

How does the quality of life in young burn survivors compare with quality of life in young people who have not been burned?

Hypothesis

There will be no difference in the quality of life in young burn survivors and young people who have not been burned, as measured by the YQOL.

The Youth Quality of Life Questionnaire (YQOL) gives an overall quality of life score, as well as scores from four subscales. There are no diagnostic cut-offs in the Youth Quality Of Life Questionnaire. Given that there are four separate subscales of the YQOL, as well as an overall score, five separate between-groups 2-way ANOVAs were calculated. The two grouping factors were burns vs. no burns, and gender.

Overall quality of life

Data for this measure are reported in tables 14 and 15.

Table 14. Mean, median and range of overall quality of life scores across both groups

	Burn survivors sample	School sample
Mean (SD)	78.16 (14.78)	69.18 (15.38)
Median	82.68	70.00
Min – Max	39.27 – 95.37	32.68 – 95.37

Table 15. Mean scores of overall quality of life across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	87.239 (7.856)	74.507 (13.553)
Females	71.946 (15.316)	65.005 (15.715)

As can be seen from table 16, a two-way analysis of variance revealed a significant effect of group on overall quality of life ($F_{1, 69} = 8.641, p = .004$), with young burn survivors reporting a higher quality of life than the school sample.

Analysis of variance also revealed a significant effect of gender on overall quality of life, ($F_{1, 69} = 13.727, p = .000$), with females reporting a poorer overall quality of life than males, across both groups. However there was no significant interaction between gender and group ($F_{1, 69} = .749, p = .390$).

Tables 16. YQOL Overall: ANOVA between gender and group

	Type III Sum of Squares	df	Mean Square	F	Significance
Burns/ No burns	1693.085	1	1693.085	8.641	.004**
Gender	2689.540	1	2689.540	13.727	.000**
Interaction Burns/Non burns*gender	146.733	1	146.722	.749	.390

Significant at the 0.01 level

Box plot (figure 8) illustrates that the burn survivor sample reported higher overall quality of life, than the school sample.

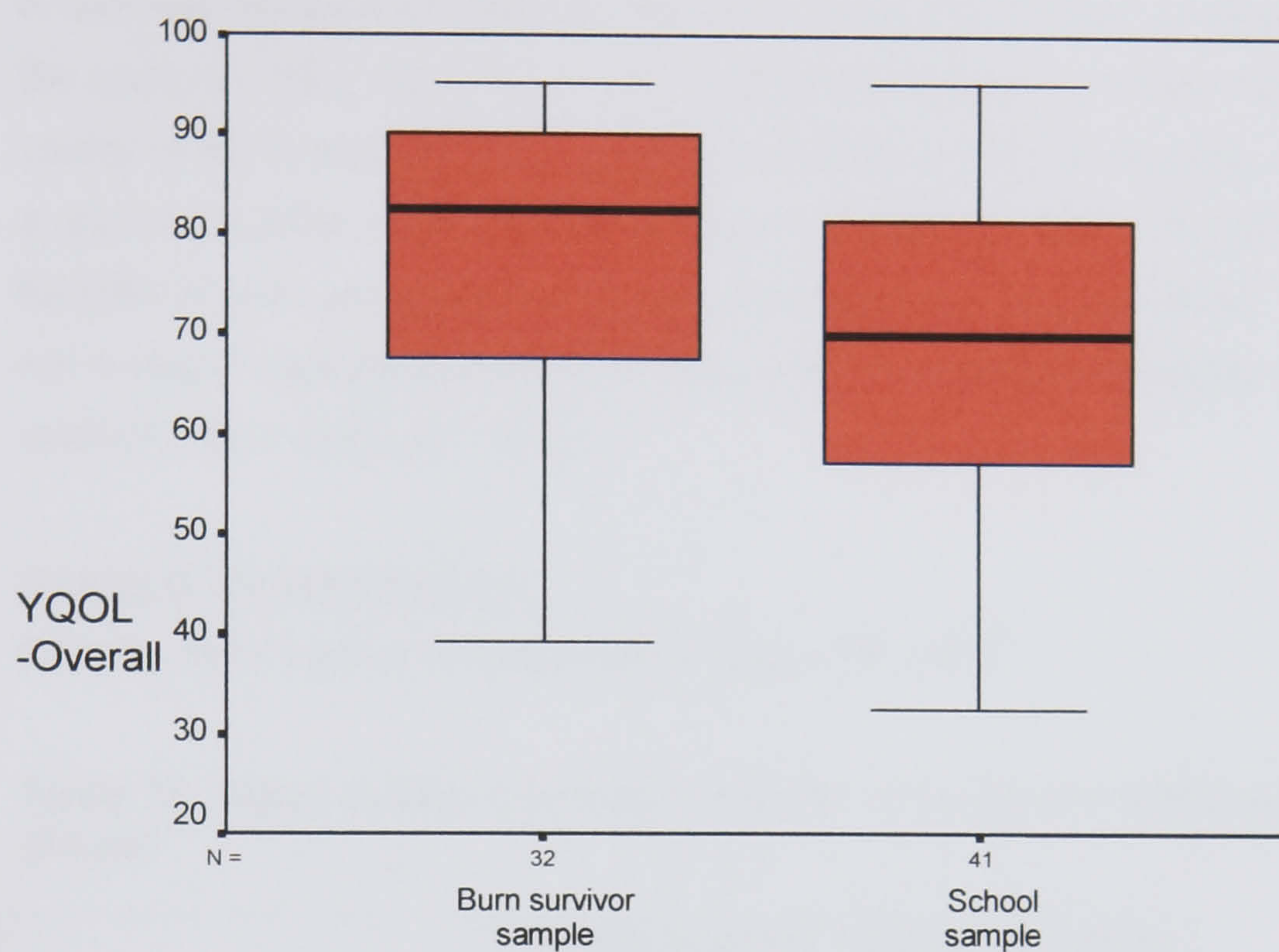


Figure 8. Overall quality of life across both groups.

Quality of life (self)

Data for this measure are reported in tables 17 and 18.

Table 17. Mean, median and range of quality of life (self) across the two groups.

	Burn survivors	School sample
Mean (SD)	74.97 (19.42)	62.74 (15.65)
Median	80.00	60.71
Min – Max	29.29 – 97.86	21.43 – 94.29

Table 18. Mean scores of quality of life (self) across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	85.916 (13.807)	69.207 (14.042)
Females	67.473 (19.398)	57.670 (15.229)

A two-way analysis of variance revealed a significant effect of group on quality of life (self) ($F_{1, 69} = 12.113, p = .001$), with young burn survivors reporting a higher quality of life in terms of their sense of self, than the school sample. It also revealed a significant effect of gender on quality of life (self) ($F_{1, 69} = 15.489, p = .000$), with females in both groups reporting a poorer quality of life than males. However it did not reveal a significant interaction found between gender and group on quality of life (self) ($F_{1, 69} = .822, p = .368$).

Quality of life (relationships)

Data for this measure are reported in tables 19 and 20.

Table 19. Mean, median and range of quality of life (relationships) across the two groups.

	Burn survivors sample	School sample
Mean (SD)	81.38 (13.46)	70.71 (17.89)
Median	86.43	74.29
Min - Max	50.71 – 97.14	31.43 – 96.43

Table 20. Mean scores of quality of life (relationships) across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	89.725 (4.706)	75.119 (15.846)
Females	75.676 (14.580)	67.268 (18.962)

A two-way analysis of variance revealed a significant effect of group on quality of life (relationships) ($F_{1, 69} = 9.825, p = .003$), with burn survivors reporting a higher quality of life in terms of their social relationships. It also revealed a significant effect of gender on quality of life (relationships) ($F_{1, 69} = 8.898, p = .004$), with females in both groups reporting a poorer quality of life in terms of their social relationships. However the analysis did not reveal a significant interaction between group and gender ($F_{1, 69} = .713, p = .401$).

Quality of life (environment)

Data for this measure are reported in tables 21 and 22.

Table 21. Mean, median and range of quality of life (environment) scores across the two groups.

	Burn survivors sample	School sample
Mean (SD)	77.88 (12.85)	74.34 (15.44)
Median	79.00	75.00
Min - Max	47.00 – 98.00	41.00 – 100.00

Table 22. Mean scores of quality of life (environment) scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	84.393 (6.299)	78.611 (14.238)
Females	75.676 (14.580)	71.000 (15.811)

A two-way analysis of variance did not reveal a significant effect of group on quality of life (environment) ($F_{1, 69} = 1.546, p = .218$). However it did reveal a significant effect of gender ($F_{1, 69} = 7.936, p = .006$), with females in both groups reporting a lower quality of life than males in terms of their environment. The analysis did not reveal a significant effect of group and gender on quality of life (environment) ($F_{1, 69} = .260, p = .612$).

Quality of life (general)

Data for this measure are reported in tables 23 and 24.

Table 23. Mean, median and range of quality of life (general) scores across the two samples.

	Burn survivors sample	School sample
Mean (SD)	79.06 (23.38)	75.04 (24.35)
Median	86.67	83.33
Min - Max	6.67 – 100.00	.00 – 100.00

Table 24. Mean scores of quality of life (general) scores across males and females in both groups

	Burn survivors Mean (SD)	School sample Mean (SD)
Males	91.538 (12.810)	83.148 (15.780)
Females	70.527 (25.343)	68.696 (28.100)

A two-way analysis of variance revealed that there is no significant effect of group on general quality of life ($F_{1, 69} = .897, p = .347$), but that there is a significant effect of gender ($F_{1, 69} = 10.805, p = .002$), with females in both groups reporting a poorer general quality of life than males. There is no significant interaction between group and gender on quality of life ($F_{1, 69} = .370, p = .545$).

To summarise, for overall quality of life and two of the four subscales from the YQOL, there were statistically significant differences between the two groups. The null hypothesis that there will be no group differences in quality of life can therefore be rejected.

YQOL Scores and Comparative Data

The YQOL scores can be compared to the data in the YQOL manual (see table 25). Young people were recruited from the Seattle/Washington area of the USA. 236 were recruited from a children's hospital and regional medical, community clinics for treating attention-deficit hyperactivity disorder (ADHD), adolescent health clinics, other health care organisations and advertisements. They were then assigned to three groups, either to the 'ADHD' group, 'Mobility Disability' group or the 'no chronic condition group'. They were pre-dominantly an Anglo-American sample.

The school sample in the current study scored lower than all three conditions of the manual data.

Table 25. YQOL scores and comparative data.

	Group	Mean	Standard error	Confidence Interval	
				Lower	Upper
Self	Burn survivors	74.97	3.43	67.97	81.97
	School sample	62.73	2.44	57.80	67.68
	No condition *	78.77	1.28	76.26	81.29
	ADHD *	72.72	1.65	69.48	75.97
	Disability *	73.33	1.84	69.70	76.86
Relationship	Burn survivors	81.38	2.38	76.53	86.24
	School sample	70.71	2.79	65.07	76.36
	No condition *	80.79	1.43	77.97	83.62
	ADHD *	73.09	1.85	69.44	76.74
	Disability *	73.96	2.07	69.88	78.04
Environment	Burn survivors	77.88	2.27	73.25	82.51
	School sample	74.34	2.41	69.47	79.21
	No condition *	87.56	1.14	85.31	89.81
	ADHD *	80.17	1.48	77.25	83.08
	Disability *	79.21	1.65	75.96	82.47
General QoL	Burn survivors	79.06	4.13	70.64	87.49
	School sample	75.04	3.80	67.36	82.73
	No condition *	86.85	1.58	83.74	89.95
	ADHD *	79.87	2.04	75.86	83.88
	Disability *	77.91	2.28	73.43	82.39
Overall QoL	Burn survivors	78.16	2.61	72.83	83.49
	School sample	69.18	2.40	64.32	74.03
	No condition *	82.20	1.14	79.95	84.45
	ADHD *	75.19	1.48	72.28	78.09
	Disability *	75.31	1.65	72.07	78.56

Data from YQOL manual (Topolski, Edwards and Patrick, 2002).

Size of burn and quality of life

For each subscale, statistically significant negative correlations indicate that as the size of the burn increases, there are lower scores in all but one of the areas of quality of life: size of burn and overall quality of life ($r = -.421$; $n = 29$, $p = .023$); quality of life (self) ($r = -.409$, $n = 29$, $p = .028$); quality of life (relationships) ($r = -.476$, $n = 29$, $p = .009$), and quality of life (general) ($r = -.374$, $n = 29$, $p = .046$). This was not found to be significant between size of burn and quality of life (environment) ($r = -.211$, $n = 29$, $p = .271$), although this is still in the same direction.

This therefore indicates that there may be a relationship between size of burn and quality of life.

Current age and quality of life

No significant correlations were found between current age and overall quality of life ($r = -.102$; $n = 29$, $p = .599$); quality of life (self) ($r = -.165$; $n = 29$, $p = .392$); quality of life (relationships) ($r = -.026$; $n = 29$, $p = .894$); quality of life (environment) ($r = -.003$; $n = 29$, $p = .986$) or quality of life (general) ($r = -.155$; $n = 29$, $p = .422$).

Although not statistically significant, these negative correlations do indicate that for young burn survivors, as current age increases, quality of life becomes poorer. A larger sample size may reveal more significant differences.

Age at burn and quality of life

No significant correlations were found between age at burn and overall quality of life ($r = .146$; $n = 29$, $p = .448$); quality of life (self) ($r = .085$; $n = 29$, $p = .663$), quality of life (relationships) ($r = .237$; $n = 29$, $p = .216$), quality of life (environment) ($r = .116$; $n = 29$, $p = .551$) or quality of life (general) ($r = .095$; $n = 29$, $p = .626$).

Table 26. Pearson's correlations between all scales and subscales in burn survivor sample

Correlations

	BEAPP	BEWT	BEATT	SWAP	BDI	YQOLSELF	YQOLREL	YQOLENV	YQOLGEN	YQOLOVER
BEAPP	Pearson Correlation Sig. (2-tailed) N	1.000 32	.523** 32	.716** 32	-.820** 32	-.828** 32	.901** 32	.744** 32	.595** 32	.817** 32
BEWT	Pearson Correlation Sig. (2-tailed) N	.523** 32	1.000 32	.468** 32	-.655** 32	.600** 32	.522** 32	.702** 32	.614** 32	.651** 32
BEATT	Pearson Correlation Sig. (2-tailed) N	.716** 32	.468** 32	1.000 32	-.521** 32	.675** 32	.345 32	.388* 32	.584** 32	.560** 32
SWAP	Pearson Correlation Sig. (2-tailed) N	-.820** 32	-.657** 32	-.510** 32	1.000 32	-.833** 32	-.724** 32	-.650** 32	-.777** 32	-.827** 32
BDI	Pearson Correlation Sig. (2-tailed) N	-.828** 32	-.655** 32	-.521** 32	1.000 32	-.853** 32	-.673** 32	-.668** 32	-.827** 32	-.830** 32
YQOLSELF	Pearson Correlation Sig. (2-tailed) N	.901** 32	.600** 32	.675** 32	-.853** 32	1.000 32	.797** 32	.771** 32	.912** 32	.912** 32
YQOLREL	Pearson Correlation Sig. (2-tailed) N	.744** 32	.522** 32	.345 32	-.673** 32	.797** 32	1.000 32	.644** 32	.760** 32	.760** 32
YQOLENV	Pearson Correlation Sig. (2-tailed) N	.595** 32	.702** 32	.388* 32	-.650** 32	.771** 32	.644** 32	1.000 32	.801** 32	.801** 32
YQOLGEN	Pearson Correlation Sig. (2-tailed) N	.817** 32	.614** 32	.584** 32	-.777** 32	.912** 32	.760** 32	.801** 32	1.000 32	1.000 32
YQOLOVER	Pearson Correlation Sig. (2-tailed) N	.857** 32	.651** 32	.560** 32	-.827** 32	.966** 32	.893** 32	.851** 32	.932** 32	1.000 32

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

BEAPP – Body Esteem Scale – appearances
 BEWT – Body Esteem Scale – weight satisfaction
 BEATT – Body Esteem Scale – attributions
 SWAP – Satisfaction With Appearance Scale
 BDI-II – Beck Depression Inventory-II

YQOLOVER – Youth Quality of Life Scale – overall quality of life
 YQOLSELF – Youth Quality of Life Scale – feelings about self
 YQOLREL – Youth Quality of Life Scale - relationships with others
 YQOLENV – Youth Quality of Life Scale - environment
 YQOLGEN – Youth Quality of Life Scale - general quality of life

Table 27. Pearson's correlations between all scales and subscales in school sample

Correlations

	BEAPP	BEWT	BEATT	BDI	YQOLSELF	YQOLREL	YQOLENV	YQOLGEN	YQOLOVER
BEAPP	Pearson Correlation Sig. (2-tailed) N	1.000 41	.556** .000 41	.471** .002 41	-.458** .003 39	.666** .000 41	.535** .000 41	.535** .000 41	.607** .000 41
BEWT	Pearson Correlation Sig. (2-tailed) N	.556** .000 41	1.000 .000 41	.207 .194 41	-.309 .055 39	.459** .003 39	.292 .064 41	.292 .064 41	.386* .013 41
BEATT	Pearson Correlation Sig. (2-tailed) N	.471** .002 41	.207 .194 41	1.000 .000 41	-.232 .155 39	.563** .000 39	.356* .022 41	.356* .038 41	.432** .005 41
BDI	Pearson Correlation Sig. (2-tailed) N	-.458** .003 39	-.309 .055 39	-.232 .155 39	1.000 .000 39	-.723** .000 39	-.654** .000 39	-.654** .000 39	-.733** .000 39
YQOLSELF	Pearson Correlation Sig. (2-tailed) N	.666** .000 41	.459** .003 41	.563** .000 41	-.723** .000 41	1.000 .000 41	.787** .000 41	.787** .000 41	.922** .000 41
YQOLREL	Pearson Correlation Sig. (2-tailed) N	.535** .000 41	.292 .064 41	.356* .022 41	-.654** .000 39	.787** .000 41	1.000 .000 41	.767** .000 41	.938** .000 41
YQOLENV	Pearson Correlation Sig. (2-tailed) N	.403** .009 41	.218 .171 41	.227 .153 41	-.604** .000 39	.740** .000 41	.767** .000 41	1.000 .000 41	.881** .000 41
YQOLGEN	Pearson Correlation Sig. (2-tailed) N	.552** .000 41	.487** .001 41	.325* .038 41	-.639** .000 39	.701** .000 41	.692** .000 41	1.000 .000 41	.794** .000 41
YQOLOVER	Pearson Correlation Sig. (2-tailed) N	.607** .000 41	.386* .013 41	.432** .005 41	-.733** .000 39	.922** .000 41	.938** .000 41	.881** .000 41	1.000 .000 41

** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

BEAPP – Body Esteem Scale – appearances
 BEWT – Body Esteem Scale – weight satisfaction
 BEATT – Body Esteem Scale – attributions
 SWAP – Satisfaction With Appearance Scale
 BDI-II – Beck Depression Inventory-II

YQOLOVER – Youth Quality of Life Scale – overall quality of life
 YQOLSELF – Youth Quality of Life Scale – feelings about self
 YQOLREL – Youth Quality of Life Scale - relationships with others
 YQOLENV – Youth Quality of Life Scale - environment
 YQOLGEN – Youth Quality of Life Scale - general quality of life

Research question 4

How does mood relate to body image in the burn survivors sample?

All measures of correlation reported in this study are based on the Pearson's correlation.

Table 26 summarises the strength of the relationships between all the measures for the burn survivors sample. Negative correlations were found between mood and the three aspects of body image, as measured by the BES. This indicates that as mood scores become higher, (indicating lower mood), young burn survivors report a more negative body image. These correlations were all found to be statistically significant: mood and general feelings about appearance ($r = -.828$; $n = 32$, $p = .001$); mood and weight satisfaction ($r = -.655$; $n = 32$, $p = .000$); mood and evaluations of how others see their appearance ($r = -.521$; $n = 32$, $p = .002$).

A significant correlation was also found between mood and body image (as measured by the SWAP), ($r = .846$; $n = 32$, $p = .000$), again indicating that as burn survivors report lower mood, body image becomes more negative.

How does mood relate to body image in the school sample?

Table 27 summarises the strength of the relationships between all the measures for the school sample. As with the burn survivor sample, negative correlations were found between mood and all aspects of body image, as measured by the BES. The correlation between mood and general feelings about appearance was found to be statistically significant ($r = -.458$; $n = 39$, $p = .003$).

Although this correlation is statistically significant, it is noticeably lower than the same correlation calculated between mood and general feelings about appearance in the burn survivor sample. Therefore the two correlations were tested for difference using Fisher's Z, assuming the null hypothesis of equal correlations in the two groups, ($p = .007$). This therefore indicates that the strength of the relationship between mood and general feelings about appearance is significantly stronger in the burn survivor sample, than the school sample.

No statistically significant correlations were found in the school sample between mood and weight satisfaction ($r = -.309$; $n = 39$, $p = .055$), although this is only just below the significance level, or evaluations of how others see their appearance ($r = -.232$; $n = 39$, $p = .155$). This indicates that there may be a strong relationship between mood and general feelings about appearance in a school population, but not between mood and other aspects of body image.

Research question 5

How does quality of life relate to body image in the burn survivors sample?

Positive correlations were found between overall quality of life and the three aspects of body image, as measured by the BES, indicating that as quality of life improves, body image becomes more positive. Statistically significant correlations were found between overall quality of life and general feelings about appearance ($r = .857$; $n = 32$, $p = .000$), weight satisfaction ($r = .651$; $n = 32$, $p = .000$) and evaluations of how others see their appearance ($r = .560$; $n = 32$, $p = .000$).

A negative significant correlation was found between overall quality of life and body image, as measured by the SWAP ($r = -.827$; $n = 32$, $p = .000$). This again indicates that as quality of life improves, body image becomes more positive. Therefore there may be a strong relationship between overall quality of life and body image in young burn survivors.

How does quality of life relate to body image in the school sample?

Positive correlations were also found between overall quality of life and body image in the school sample, as measured by the BES. Statistically significant correlations were found between overall quality of life and general feelings about appearance ($r = .607$; $n = 41$, $p = .000$), weight satisfaction ($r = .386$; $n = 41$, $p = .013$) and evaluations of how others see their appearance ($r = .432$; $n = 41$, $p = .005$).

The strong relationship between quality of life and body image may therefore also exist in young people who have not been burned. However, the strength of the relationship between body image and overall quality of life was stronger for the young burn survivors

than for the school sample across all three subscales of the BES. This difference is particularly noticeable between overall quality of life and general feelings about appearance. Fisher's Z was again used to test for difference, relating to the assumed null hypothesis of equal correlations in the two groups, ($p = .02$). This therefore indicates that the strength of the relationship between overall quality of life and general feelings about appearance is significantly stronger in the burn survivor sample, than the school sample.

Research question 6

How does mood relate to quality of life in the burn survivors sample?

Negative correlations were found between mood and all aspects of quality of life, indicating that as mood scores become higher, (indicating lower mood), young burn survivors report a poorer quality of life. A statistically significant relationship was found between mood and overall quality of life ($r = -.830$; $n = 32$, $p = .000$), quality of life (self) ($r = -.833$; $n = 32$, $p = .000$), quality of life (relationships) ($r = -.724$; $n = 32$, $p = .000$), quality of life (environment) ($r = -.668$; $n = 32$, $p = .000$), and general quality of life ($r = -.827$; $n = 32$, $p = .000$).

How does mood relate to quality of life in the school sample?

Negative correlations were also found between mood and all aspects of quality of life in the school sample. A statistically significant correlation was found between mood and overall quality of life ($r = -.733$; $n = 39$, $p = .000$), quality of life (self) ($r = -.833$; $n = 39$, $p = .000$), quality of life (relationships) ($r = -.654$; $n = 39$, $p = .000$), quality of life (environment) ($r = -.604$; $n = 39$, $p = .000$), and quality of life (general) ($r = -.639$; $n = 39$, $p = .000$).

As can be seen from the above, the strength of the relationship between quality of life and mood was stronger for the young burn survivor sample than the school sample in terms of overall quality of life and the quality of life subscales, with the exception of quality of life (self). This is particularly noticeable between mood and general quality of life, and this was tested using Fisher's Z ($p = .09$). This is just below the level for significance.

Research question 7

How satisfied are young burn survivors with parts of their bodies which are burned, compared to the parts of their parts of their bodies which are not burned?

Hypothesis

Young burn survivors will be no more dissatisfied with the parts of their body which are burned, compared to the parts of their body which are not burned.

The SWAP asks burn survivors how satisfied they are with the appearance of specific parts of their bodies. These parts are the scalp, face, neck, hands, arms, legs, and chest. This was also used to determine how satisfied young burn survivors are with the parts of their bodies that are burned, which was then compared to how satisfied they are with the parts of their bodies that are not burned.

A score of 0 indicates that they 'strongly agree' with the statement that they are satisfied with that part of their body. A score of 1 indicates that they 'agree', 2 indicates that they 'somewhat agree', 3 indicates that they neither agree or disagree, 4 indicates that they 'somewhat disagree', 5 indicates that they 'disagree', and 6 indicates that they 'strongly disagree'.

The overall mean score for satisfaction with burned parts was 2.55 (SD = 1.94), and for the non-burned parts was 1.13 (SD = 1.59). The mean scores therefore indicate that young burn survivors report more dissatisfaction with the burned parts of their body, than non-burned body parts. A paired differences t-test was used to test whether there is a statistically significant difference between the mean value for burned body parts compared to the mean value for non-burned body parts. This indicated that there was a significant difference ($t(30) = 5.637, p = .000$). Box plot (figure 9) illustrates the difference, indicating that young burn survivors were significantly less satisfied with the appearance of the burned parts of their body than they were with the non-burned parts. Therefore the hypothesis that young burn survivors would be no more dissatisfied with burned parts of their body compared to non-burned parts, could be rejected.

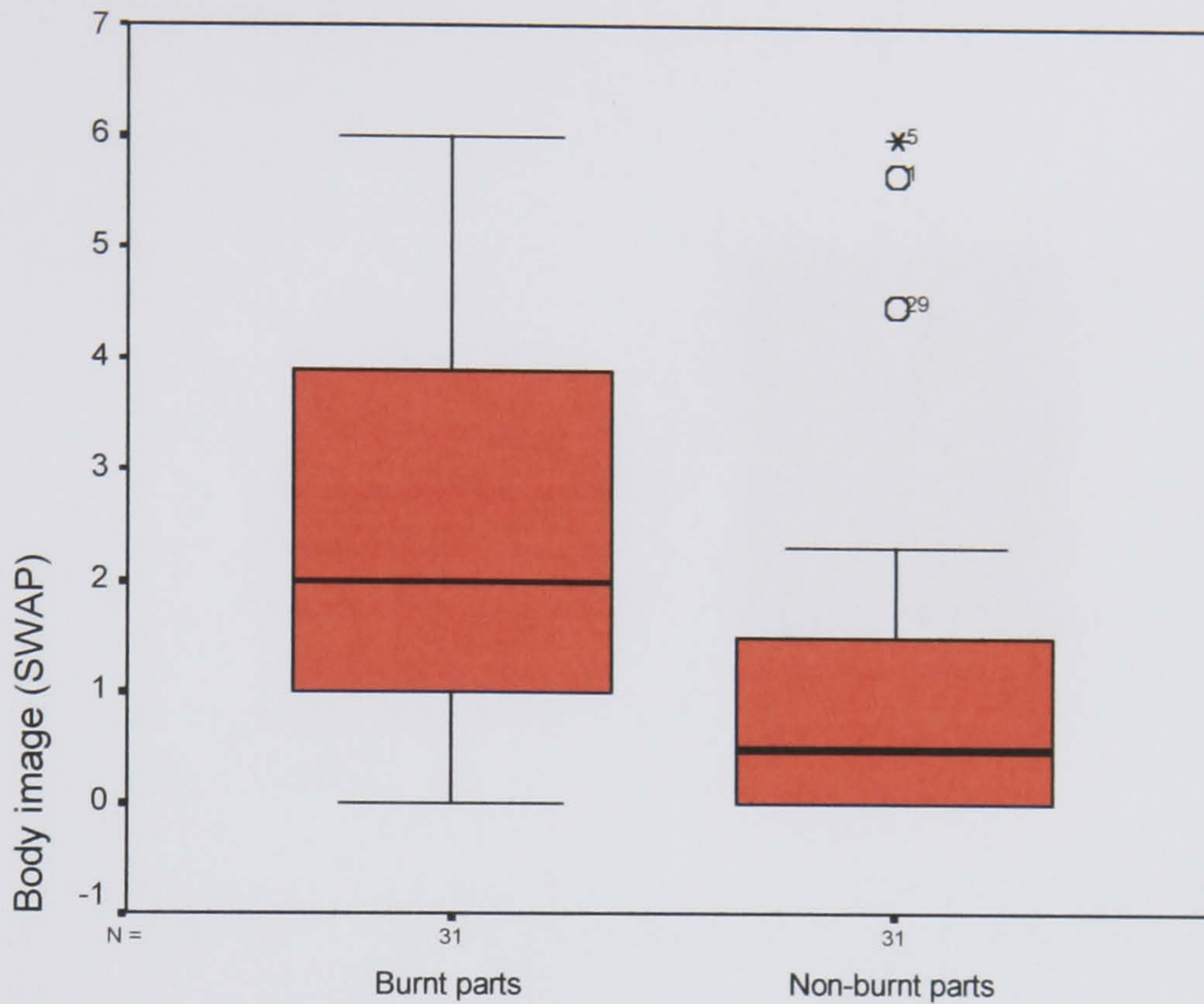


Figure 9. Satisfaction with the appearance of the burned and non-burned body parts in young burn survivors.

20 out of the 32 young burn survivors had both hidden and visible scars. The mean score for satisfaction with visible parts was 2.68 (SD = 2.02), and for hidden parts was 3.05 (SD = 1.92). Therefore burn survivors expressed slightly more dissatisfaction with hidden scars, compared to visible scars. However a paired differences t-test indicated that there was not a significance difference between visible and hidden scars ($t(19) = -1.281, p = .216$). This is illustrated in the box plot in figure 10. These results suggest that young burn survivors may be no more dissatisfied with visible scars than hidden scars.

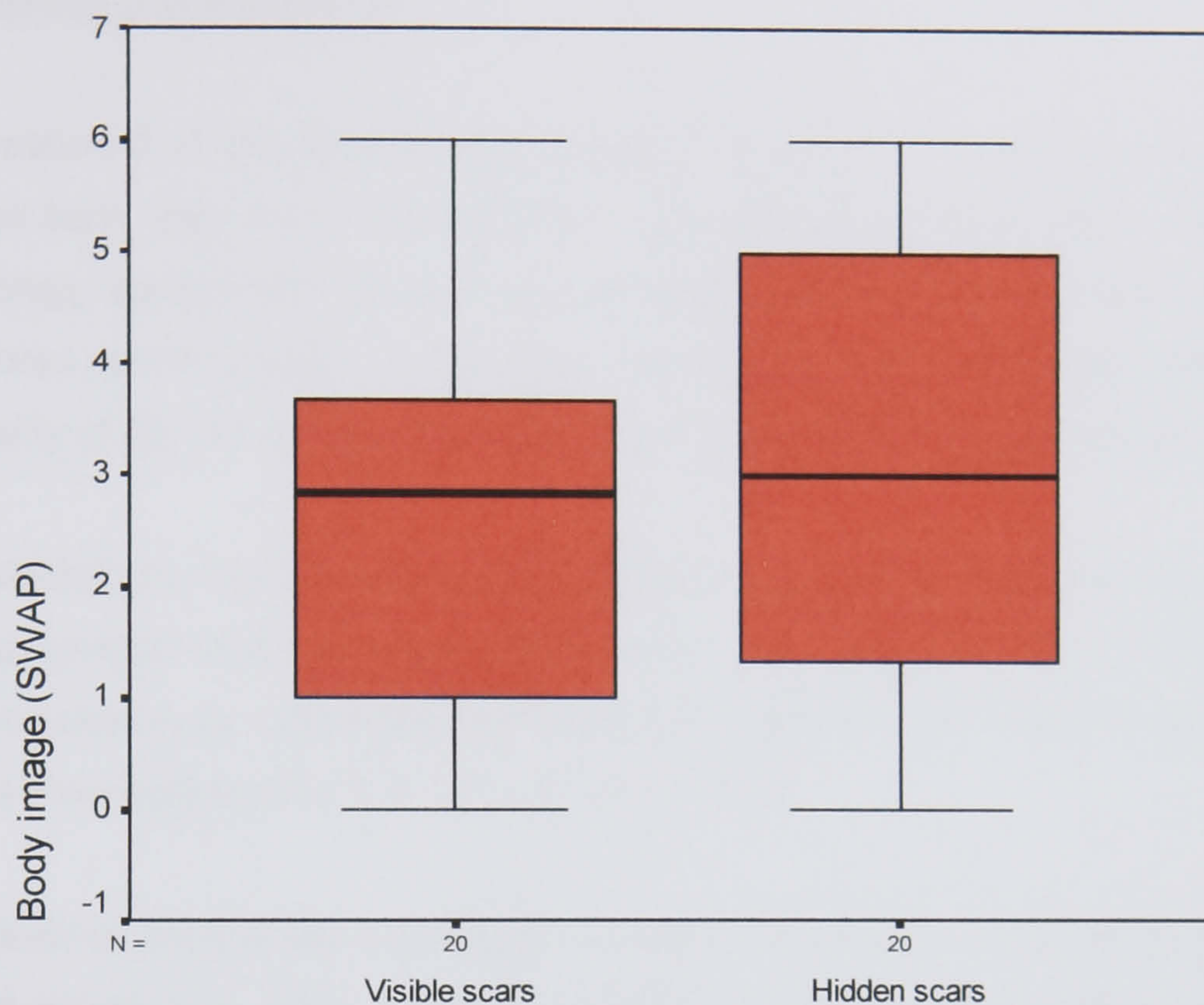


Figure 10. Satisfaction with visible and hidden scars in young burn survivors.

Research question 8

Are the SWAP outcomes related to BES outcomes in young burn survivors?

Negative correlations were found between the three aspects of body image as measured by the BES, and body image as measured by the SWAP. This indicates that as BES scores decrease, SWAP scores increase. A statistically significant relationship was found between body image as measured by the SWAP, and general feelings about appearance ($r = -.820$; $n = 32$, $p = .000$), weight satisfaction ($r = -.567$; $n = 32$, $p = .001$) and evaluations of how others see their appearance ($r = -.51$; $n = 32$, $p = .03$).

As this questionnaire has not been used on young people in the published literature, Pearson's correlation was used to look at how a couple of the questions relate to other measures in this study.

Question 3 of the SWAP

Question 3 of the SWAP asks whether because of changes in appearance caused by their burn, they are uncomfortable in the presence of strangers. 10 out of 32 said they strongly agreed with this, and may therefore be a problem for many young burn survivors. Scores on this question were then correlated to body image (as measured by the BES), quality of life (as measured by the YQOL), and mood (as measured by the BDI-II).

A statistically significant negative correlation was found between question 3 of the SWAP and general feelings about appearance ($r = -.427$; $n = 32$, $p = .002$). No significant correlation was found between question 3 of the SWAP and evaluations of how others see their appearance ($r = .27$; $n = 32$, $p = .129$).

A positive statistically significant correlation was found between question 3 of the SWAP and mood ($r = .537$; $n = 32$, $p = .002$). A significant negative correlation was found between question 3 of the SWAP and overall quality of life ($r = -.458$; $n = 32$, $p = .008$). This indicates that as burn survivors become more uncomfortable in the presence of strangers because of their burn, they report lower mood and a poorer quality of life.

Question 12 of the SWAP

Question 12 of the SWAP asks whether changes in appearance have interfered with their relationships. This question and the relationships subscale of the YQOL had a negative correlation, indicating that as changes in their appearance interfere with their relationships, they report a poorer quality of life in terms of their social relationships. This correlation was found to be statistically significant ($r = -.550$; $n = 32$, $p = .001$).

There is no published research which has used the SWAP in an adolescent population. The above therefore suggests that the measure could be used with young burn survivors aged 11 to 19. However a bigger sample size would be needed to be more certain of its validity.

DISCUSSION

Summary of results

This study investigated the body image, mood and quality of life of young people who were burned in childhood using self-report questionnaires, and made comparisons to young people who have not been burned. The main findings are summarised below, followed by a summary of additional findings. The results are then discussed in relation to the literature according to each of the study's research hypotheses.

Body image

- Young burn survivors reported significantly more positive evaluations of how others view their body or appearance, as well as a significantly increased weight satisfaction.
- Burn survivors did report marginally more positive general feelings about appearance than the school sample, however this was just below the significance level.
- The mean scores for both groups suggest that both groups are either “reasonably satisfied” with their appearance, or are “neither satisfied or dissatisfied” with their appearance.
- Compared with Body Esteem Scale (BES) norms for young people aged 12 to 19, burn survivors scored slightly lower on feelings about appearance, and perceptions of others evaluation of their appearance, and reported a slightly increased weight satisfaction. Interestingly, the school sample scored lower on all three aspects of body image than the norms. The BES is validated on 1334 young people in schools and colleges in Quebec, Canada. The manual does not report anything more about the sample, such as their socio-economic status, making comparison difficult.

Mood

- Young burn survivors and the school sample reported no significant difference in mood, as measured by the Beck Depression Inventory-II (BDI-II). Young people in both groups reported similar mood to the student norms for the BDI-II.
- One of the 32 burn survivors (3.13%) reported mild depression, while seven of 41 (17.95%) of the school sample report mild depression. Also, four burn survivors (12.5%) report severe depression compared to one (2.56%) in the school sample.

Quality of life

- The young burn survivors reported a significantly higher overall quality of life than the young people who had not been burned.
- Young burn survivors reported a significantly higher quality of life in terms of their evaluation of social relationships and their sense of self. However, in terms of their evaluation of environment and evaluation of their general quality of life, they were similar to the school sample.
- Compared to the 'physical disability condition' and the 'no condition group' from the comparative data in the YQOL manual, young burn survivors reported a slightly higher evaluation of their social relationships. Young burn survivors evaluate all other aspects of their quality of life as being slightly lower than the no condition group, and similar to the physical condition group. Young people in the 'no condition group' were reported to have no chronic condition. The literature relating to the measure does not give specific information about the 'no condition group', so it is therefore hard to draw conclusions. It is possible that if they were at least partly recruited through health clinics, they may have had an acute condition.
- The school sample reported a lower quality of life on all dimensions compared to all groups of comparative data in the YQOL manual. The

normative sample were young people recruited from advertisements in local papers and health clinics.

The relationship between body image and mood

- There is a strong relationship between all three aspects of body image (as measured by the BES) and mood in young burn survivors. In the school sample there was also a strong relationship between general feelings about appearance and mood but not between the other aspects of body image and mood. Analysis of these correlations revealed a statistically stronger degree of correlation between general feelings about appearance and mood in the burn survivor sample, than the school sample.

The relationship between body image and quality of life

- There is a strong relationship between all three aspects of quality of life as measured by the BES, and overall quality of life in both samples. The relationship was more closely linked for burn survivors. Analysis of the correlations revealed a statistically stronger degree of correlation between general feelings about appearance and overall quality of life in the burn survivor sample, than the school sample.

The relationship between quality of life and mood

- There was a strong relationship between quality of life and mood in both groups. The relationship was stronger for the burn survivors, although this was not found to be statistically different.

Summary of additional findings

Satisfaction with appearance of burnt and non-burnt parts of the body

Young burn survivors reported significantly more dissatisfaction with burnt parts of their body than non-burnt part of their bodies, as measured by the Satisfaction With Appearance Scale (SWAP).

The relationship between the Body Esteem Scale and Satisfaction with Appearance Scale in young burn survivors

- There was a strong relationship between both measures on all three dimensions of the BES.

Impact of other variables

- Females in both groups reported significantly more dissatisfaction with feelings about appearance and weight than males. They did not report differences in terms of their evaluation of how others view their appearance. Females also reported significantly lower mood and a poorer quality of life than males.
- Current age, age at burn and cause of the burn were not found to have a statistically significant relationship with outcome.
- Location of burn, i.e. whether the burn was visible or hidden, was shown not to have a statistically significant relationship with outcome.
- Size of burn was found to have a statistically significant relationship with general feelings about appearance, overall quality of life, and all dimensions of quality of life with the exception of their evaluation of their environment.

Discussion of the results in relation to relevant literature, psychological theories, and research hypotheses

As discussed in the introduction, it was suggested at the conference for the Centre for Appearance Research (2003), that body image concerns are common in non-clinical populations, rather than being specific to people with disfigurements. They hypothesised that there would be little differences in body image in people with disfigurements, and those without. It was also felt by clinicians from the Counselling and Psychotherapy department from the Regional Burns Unit involved with this study, that many young burn survivors may be coping well. However research to date has made few direct comparisons between those with and without disfigurement. It was therefore

hypothesised that there would be no difference in outcomes in young burn survivors and young people who had not been burned.

The results of the current study supported this impression, however interestingly the results were different to what some people might expect, as some of the outcomes were actually more positive compared to outcomes for the school sample.

Hypothesis 1. Body image in young burn survivors and young people who have not been burned

The current study found that young burn survivors reported a significantly more positive body image in terms of evaluations of how others see their appearance and weight satisfaction. Although a little below the significance level, they also reported more positive general feelings about their own appearance. There is no published literature to compare this finding with, as other studies with young burn survivors have not used a control group. It is interesting to note that Stoddard (1982) said children who are burned at a young age before their body image had fully developed, may more easily learn to integrate their burns into their body image. In the current study, 28 out of the 32 young burn survivors were burned at the age of 7 or below, and of these, 24 were burned at the age of 3 or under.

There were no differences found on any of the measures between the four burn survivors who were burned in the last few years, and those burned at the age of 7 or under. However a bigger sample size with participants with a greater range of ages would be needed to look at this further.

With regards to the statistically significant difference between the two groups in weight satisfaction, it would be helpful to have known the weight of the young people. This would have enabled us to compare their weight satisfaction with their actual weight. However there is no reason to believe that the distribution is not normally distributed in each sample. This finding supports the work of Ben-Tovim and Walker (1995), who found that females aged 13 years suffering from disfiguring physical conditions such as skin conditions and visible blood vessel deformities, worried less about small changes in their weight and shape than comparable controls without such conditions. One hypothesis is that when

someone has a physical disfigurement, other aspects of body image become less important.

There are several hypotheses that could help explain why overall young burn survivors report a positive body image. One hypothesis is that they found it hard to reflect on different aspects of their appearance, and so responded defensively. This hypothesis will be returned to later. Alternatively they may have developed a psychological defence where when they think about their appearance, they focus more on the non-burned parts of their bodies. Family members may have 'compensated' by telling them that the non-burned parts of their body are attractive, such as their eyes, hair and smile. Since these are the parts of their body that they do like more, they may assume that others perceive their appearance in the same way. Family members may have also told the young person that "it is what is on the inside that counts", and they may have therefore learnt that personality is more important than physical appearance.

Hypothesis 2. Mood in young burn survivors and young people who have not been burned

It was hypothesised that there would no difference in mood in young burn survivors and young people who had not been burned. Results from this study support this hypothesis.

There is little to compare this finding with, as the research literature on mood in young burn survivors has tended not to focus on long-term follow-ups beyond two years, and has not used control groups. The studies by Stoddard et al. (1992), Orr et al. (1989) and O'Connell (1985) did find depression in children and young people with burns. However with the absence of control groups, it is not possible to determine whether this was as a result of their burns, or whether this would be found in young people in non-clinical populations. Consistent with the findings of Stoddard et al. (1992), there was no statistically significant association between depression and size of burn.

In the current study, burn survivors were more at risk of severe depression, with four (12.5%) of burn survivors reporting severe depression, compared to one (2.56%) of the school sample. The school sample were more at risk of mild depression, with seven (17.95%) of the school sample reporting mild

depression, compared to one (3.13%) of the burn survivor sample. A bigger sample would be needed to see if this is a statistically significant effect.

Stoddard et al. (1992) reported that 13 (43.33%) of the 30 children with burns they assessed using diagnostic interviews, at some point in their lives had had suicidal thoughts. Four (13.33%) had a history of suicide attempts. In the current study using the self-report measure of the BDI-II, seven (21.88%) of young burn survivors reported that in the last two weeks they had had thoughts about killing themselves, but that they would not carry them out. There was no link between having had these suicidal thoughts and the size of their burn. Within the control group the presence of suicidal thoughts was just slightly higher with eight (19.51%) saying that over the last two weeks they had had thoughts about killing themselves, but that they would not carry them out, and two (4.88%) saying they would like to kill themselves. Therefore 24.39% (nearly a quarter) of the school sample expressed suicidal thoughts over the last two weeks.

This can be compared to studies on suicidal ideation which have suggested the following prevalence rates: in a study on 4,692 high school students in Slovenia, 44% reported suicidal thoughts at some time in their lives, and 10.3% during the recent month (Groleger, Tomori & Kocmur, 2003); in a study on 790 UK adolescents, 22% of 15 year olds currently reported having thoughts about killing themselves, and 17% of 18 years olds currently reported having thoughts about killing themselves (Friedman, 1998).

Hypothesis 3. Quality of life in young burn survivors and young people who have not been burned

It was hypothesised that there would no difference in quality of life in young burn survivors and young people who had not been burned. However, the young burn survivors in this study reported a significantly higher overall quality of life than young people who had not been burned. There is currently no published literature which reports that burn survivors may actually experience a better quality of life.

One hypothesis to account for this is that young burn survivors report having better social relationships, due to interactions with their parents. As a result of

their burn injury they may have become closer to their parents as they have worked through some difficult times. Parents may have had to rub cream into the burn for many years, which may have deepened the bond between parent and child. However, as explored in the Introduction section, Coughlan and Clarke (2002) report that many burn injuries are avoidable, and therefore parents often experience shame and guilt. A common consequence is that they may try to compensate in the way they interact with the child. Although this could be seen as “over-protective”, and in ways unhelpful, children may in ways also benefit from the compensation. It is hypothesised that such interactions may impact on aspects covered in the Youth Quality of Life Questionnaire, such as whether they feel adults treat them fairly, whether they feel they get the right amount of attention from their family, whether they feel useful and important to their family, and whether they feel their family cares about them. Also, many of the young people will have spent a considerable amount of time in hospitals following the accident, and later when returning to hospital for continuing surgery. As a result they may have had more exposure to adults, and may therefore form better relationships with adults.

While young burn survivors may experience teasing and bullying as a result of their altered appearance, alternatively they may have to try harder to succeed in other areas of their life. Giljohann (1980) in a small-scale qualitative study found that adolescent burn survivors were aware of the need to be “accepted”, or the need to succeed well in one area to compensate for their altered appearance. Some described themselves as being leaders, developing a physical skill (for example sport), in order to compensate for their difference in appearance. Young burn survivors may also work harder at their social skills and interactions with peers.

Another hypothesis to explain why burn survivors report a better quality of life, is that as a result of having the experience of coping with the consequences of a burn injury they develop helpful patterns of thinking, feeling and behaving which help them to cope with future difficulties in their lives.

A possible criticism of this study is that the Youth Quality of Life Scale may not be sensitive enough to the needs of adolescent burn survivors. There may be specific issues concerning quality of life that are not included in a generic quality

of life measure that we are currently unaware of. A burn specific quality of life measure is likely to tell us more, although this would not allow comparison with other groups of young people.

As described in review by Pope (2004), the 'American Burn Association/Shriners Hospitals Children Burn Outcomes Questionnaire' (Daltroy, Liaing & Phillips, 2000), claims to be a quality of life questionnaire specific to young burn survivors. However it has not been used in any outcome study in the current available literature, and is more relevant to outcomes shortly after the burn injury rather than longer term follow-up. It does not differentiate between children and young people. In addition parent's perceptions of how their children perceive their quality of life may be different to how young people perceive it.

There is some argument that measuring quality of life generally is too global, and that there is not enough agreement about what 'quality of life' actually is. Meuleners, Lee, Binns and Lower (2003) criticise research into quality of life as being "hampered by a lack of conceptual clarity regarding precisely what quality of life means" (p.283). However the Youth Quality of Life measure is based on the definition of quality of the life from the World Health Organisation, as quoted in the introduction. Their definition locates the concept within the culture and social structure of the individual and focuses on his or her perception of their life.

Hypothesis 4. The relationship between body image and mood

There was a strong relationship between body image and mood, and the relationship was more closely linked for burn survivors. Analysis of these correlations revealed a statistically stronger degree of correlation between general feelings about appearance and mood in the burn survivor sample, than the school sample. One hypothesis for this is that in young burn survivors, satisfaction with appearance may be an even greater contributor to mood than it is for other young people. Satisfaction with appearance may have greater meaning in their lives. An alternative hypothesis is that when young burn survivors experience a drop in mood, this makes them particularly vulnerable to feeling more preoccupied with their appearance. However it is not possible to infer causality from correlations. There may be a third factor which affects body image and mood.

Hypothesis 5. The relationship between body image and quality of life

There was a strong relationship between body image and quality of life, and the relationship was more closely linked for burn survivors. Analysis of the correlations revealed a statistically stronger degree of correlation between general feelings about appearance and overall quality of life in the burn survivor sample, than the school sample. Therefore one hypothesis is that for young burn survivors, satisfaction with appearance may be an even greater contributor to quality of life than it is for other young people. Alternatively, if their quality of life becomes poorer, for example a break up of a relationship, then they become more preoccupied with their appearance than other young people will.

Whilst this study suggests that there is a strong relationship between body image and quality of life, Fauerbach et al. (2000) build on this concept to see if there is a causal relationship, and found that after controlling for injury, distress, and pre-burn quality of life, that body image dissatisfaction affects quality of life in adults two months post-burn.

Hypothesis 6. The relationship between quality of life and mood

There was a strong relationship between all aspects of quality of life and mood, and the relationship was more closely linked for burn survivors, however this did not reveal statistically stronger degree of correlation.

The current study has shown that there is a strong relationship between body image, mood and quality of life, and that the relationship is stronger for burn survivors. However this does not tell us anything about the mechanisms involved, for example, whether poor body image leads to a lower mood, or whether lower mood leads to a poorer body image. Future research could look at the causality, which is likely to be complex.

Hypothesis 7. Satisfaction with burnt and non-burnt parts of the body

It was hypothesised that young burn survivors would be no more dissatisfied with the burned parts of their body than non-burned parts. Results from the study do not support this hypothesis, and suggest that some body image dissatisfaction is present among burn survivors, which was not evident from the results of the BES. This also gives some indication that young burn survivors were responding in an open and honest way to the questionnaires. This

suggests that the earlier hypothesis that young burn survivors are responding in a defensive way to the questions, may not be true.

Hypothesis 8. The relationship between the Body Esteem Scale and Satisfaction with Appearance Scale in young burn survivors

This findings suggest that the SWAP correlates with the other measures used in this study; as well as having a strong relationship with the BES, it also has a strong relationship with mood and quality of life. This indicates that the SWAP has good convergent-discriminant validity.

As well as telling us about what parts of their bodies they are dissatisfied with, the SWAP also assesses the additional aspects of social and behavioural aspects of body image i.e. how their appearance because of their burn impacts on being in the presence of family, friends and strangers, how their appearance has interfered with relationships, thinking that their burn is unattractive to others, and thinking people would not want to touch them. Generic body image measures may not be sensitive enough to such burn-specific related issues.

Some further analysis was done in order to see how items on the SWAP relate to other outcomes. Ten out of 32 said they strongly agreed with the question that they felt uncomfortable in the presence of strangers because of their burn. Analysis showed that feeling uncomfortable about being in the presence of strangers meant that young people were more likely to have fewer positive feelings about their appearance, but perhaps surprisingly this was not related to their evaluations of how others see their appearance. Feeling uncomfortable in the presence of stangers also has a strong relationship with mood and quality of life.

The SWAP asks burn survivors about whether they agreed/disagreed that changes in appearance have interfered with relationships. As anticipated, it was found this had a strong relationship with the relationships subscale of the YQOL.

This is the first study to use the SWAP with adolescents. It has been a useful questionnaire to use in the current study for the reasons described above. It would be helpful if future research attempted to validate it using a larger sample size.

Gender

Females reported significantly more dissatisfaction with feelings about appearance and weight than males. They did not report differences in terms of their evaluations of how others see their appearance. However it was found that there was an interaction between group and gender on evaluations of how others see their appearance, with male burn survivors reporting more positive evaluations of how others view their appearance than female burn survivors and males and females in the control group. Females also reported a lower mood and quality of life, although there were no interactions between gender and group.

There is other evidence to suggest that adolescent girls are more concerned with appearance than adolescent males (Levine & Smolak, 2002; Cusumano & Thompson, 2001; Pruzinsky & Cash, 1990). This would lead us to expect that female adolescents with scars may have more adjustment problems and body image concerns than male adolescents with scars. Orr et al. (1989) found that young female burn survivors reported a more negative body image, lower mood and self-esteem than males. Meyer, Blakeney, Russell, Thomas and Robert (2004) reported that young female adults aged 18 to 28 years overall had more behavioural problems, including withdrawn behaviours, aggressive behaviour, and delinquent behaviour, as measured by the Achenbach's Young Adult Self-Report Scale (Achenbach, 1997). Salvador-Sanz et al. (1999) reported that in adults ranging from 9 months to 21 years post-burn, females report a poorer quality of life than males. Therefore, the current findings are consistent with these studies. However, other studies of adult burn survivors do not report differences in outcome relating to gender, (Altier et al., 2002; Browne, Byrne, Brown, Pennock & Streiner, 1985).

Current Age

Current age was not found to have a statistically significant relationship with body image, mood or quality of life in either of the groups. This is consistent with the work of Landolt et al. (2002) who did not find a relationship between current age and quality of life in burn survivors aged 5 to 17, and the work of Orr et al. (1989) who found no relationship between age and body image, mood and self-esteem in young adults aged 14 to 27 years. However, in the current study there were weak correlations, showing that as age increases, reported body

image, mood and quality of life becomes poorer. A bigger sample size would be more likely to reveal statistically significant differences. However one limitation of the study may be that it is not appropriate to ask the same quality of life questions to young people in early and late adolescence. "Adolescence", spans quite a range of ages, but given the enormous physical, psychological and social changes that occur over this period, what is important in a young person's perception of their quality of life may change.

Age at burn

In the current study, age at burn was not found to have a statistically significant relationship with any of the outcomes. However there were weak correlations showing that as age at burn increases, general feelings about appearance, mood and quality of life become more negative. However, a larger sample size may be more likely to reveal a significant effect. Stoddard (1982) suggested that the older the child is burned, the more stable their body image is, making adaptation to the burn more difficult. Research by Giljohann (1980) suggests that adolescents who were burned at an earlier age may be less distressed by scarring. In addition, Landolt et al. (2002) found that after family, age at burn was the second most important variable in predicting quality of life, with those burned at a younger age reporting a better quality of life at follow-up, 1 to 13 years post-burn.

However as almost all 32 participants in the current study were burned at the age of 7 or under, firm conclusions cannot be made in support of these hypotheses.

Size and location of burn

Many of the studies in the literature suggest that the size and location of the burn does not affect outcome. Landolt et al. (2002) concluded that size, depth and location of burn had no effect on quality of life. O'Connell (1985) found no significant relationship between size and location of burn on mood.

i). Size

In the current study, the size of burn was found to be related to general feelings about appearance, and in terms of quality of life, their evaluations of their sense

of self, relationships, and general quality of life. No statistically significant relationship was found between size of burn and mood.

These findings are consistent with studies by Orr et al. (1989) and O'Connell (1985) who concluded that there was no significant relationship between size of burn and depression. However, Orr et al. also concluded that there was no significant relationship between size of burn and body image, and Landolt et al. (2002) concluded that there was no significant relationship between size of burn and quality of life.

It should also be noted that the size of the burn does not tell us anything about the thickness of the burn. Few studies mention the thickness of the burn, however perhaps this should also be taken into account when considering the severity of the burn. The thickness of the burn may affect mobility, is likely to look more disfiguring, and may be associated with the threat to life at the time of the injury and trauma to the family.

Lawrence et al. (2004) found that the relationship between burn severity and body image depended on how burn severity was measured. They found that objective measures of scar severity such as total body surface area (TBSA), and number of scarred body parts had a non-existent or very small relationship with body image. However a subjective rating of burn severity had a stronger relationship with body image. This suggests that perception of severity of scarring is important, but to date there is no reliable and valid self-report measure of scar severity.

ii). Location

11 of the 32 young burn survivors in the current study had facial burns. The proportion of young people with facial burns in this study is consistent with the overall burn survivor population. This is because of the nature of the majority of burn injuries tend to involve children pulling a kettle or pan of boiling water down onto themselves. In these circumstances the water tends not to hit the face, but instead causes scalds to the chest and below. There was no significant difference found in body image, mood and quality of life between young burn survivors with facial scars and those without.

It was found that they reported no more dissatisfaction with the parts of their body with visible scars (i.e. face, scalp, neck and hands), than the parts of their body with hidden scars (i.e. arms, legs, and chest), as measured by questions on the SWAP. These findings are consistent with those of Lawrence, Fauerbach, Heinberg and Doctor (2004) who looked at the effect of visible and hidden scars on body image in 361 adults. They found that scar severity and visibility only accounted for 20% of the variance in predicting body image. However there are parts of the body which are left out of the SWAP which may be important. Of particular relevance to young people and their sexual development may be genitalia. If as Pruzinsky and Doctor (1994) suggest, people with hidden scars live with the fear of discovery and subsequent guilt, this may be all the more so for young people with burns to the genitalia, and perhaps the abdomen and buttocks.

One hypothesis to account for this finding in the current study is that adolescents with visible scars learn to take less notice of stigmatisation and learn coping strategies because they cannot hide their scars. Those who have hidden scars may never learn to do this as they have not had the opportunity to do so. In support of this hypothesis, Smart and Wegner (2000) reported that hidden scars in adults can lead to a wish to suppress thinking about scars, and avoidance of behaviours which may lead to revealing scars.

Cause of burn

There were no differences found in the current study as a result of cause of burn. However, a larger sample may be necessary in order to detect such differences. Some children are burned through abuse, which is likely to impact on psychological outcomes. In the study by Stoddard et al. (1992) on depression in children with burns, of the 30 participants aged 7 to 19 years, it was known that two had acquired their injuries through abuse. The role of abuse is not fully known in the sample in the current study, although it is known that one of the participants had been deliberately set on fire.

The consequences of being in a house fire may also impact on outcome, for example losing family members. House fires are sometimes due to arson, for insurance purposes, or sometimes as a racial or targeted attack. The effect of such factors linked with the cause of the burn, are not known.

Further ways in which young burn survivors may be coping

At a recent conference of the Centre for Appearance Research (Bristol, 2003), one of the main discussion points was that the experiences of those who are visibly different may not be unlike those who are not in a clinical population. The findings in the current study support this idea.

One hypothesis to the finding that young burn survivors report a better quality of life, is that they have developed healthy coping mechanisms which enable them to prioritise what is important in life, perhaps more so than young people who have not had burns.

As mentioned above, young burn survivors may also compensate for their altered appearance, by making friends and succeeding at sport, in comparison to young people who may be able to rely on acceptance from others on the basis of their appearance. However, with the exception of the Giljohann study (1980), the literature has not looked at the coping mechanisms of young burn survivors. However the literature on how young survivors of cancer cope, may provide some clues.

Through group therapy sessions, Palmer, Erikson, Shaffer, Loopman, Amylon et al. (2002) gained an understanding of some of the adaptive coping strategies used by adolescent cancer survivors. Active coping strategies included expressing painful emotions, clearly stating their needs, communication with peers, self-determination, living life to the fullest, gaining some control over their lives, and renewing interests. However some young people also used avoidant coping strategies where they would withdraw and as a consequence, avoid addressing stressful events. The authors claim this to be less effective.

Burgess (1996) looked at coping responses in adolescents with cancer. It was found that many of the young people used 'emotion-focussed' coping strategies (where the young person attempts to regulate the emotional consequences of stressful circumstances), and 'problem-focussed' coping strategies (where the young person makes efforts to do something active in order to alleviate part of a stressful situation).

Pruzinsky and Doctor (1994) suggest that adaptation to body image may be influenced by many individual variables such as temperament and pre-burn psychology, as well as social variables such as support networks and socio-economic status of the family. Other studies have emphasised the importance of social support. Landolt et al. (2002) found that quality of life was best predicted by greater family cohesion, higher expressiveness, and less family conflict. In the recent study by Lawrence et al. (2004), they used a new questionnaire they had recently developed called the 'Social Comfort Questionnaire' (manuscript in preparation). This questionnaire aims to measure a sense of comfort in social situations. They found that social comfort had the strongest relationship with body image (as measured by the BES). Therefore perhaps what is important is for interventions for young burn survivors to include a component helping families to build a loving and strong support system. Clarke-Steffen (1997) found that helpful strategies families used in managing childhood cancer included reconstructing reality, strategies of managing the flow of information, reorganizing roles, evaluating and shifting priorities, and assigning meaning to the illness. Some of these strategies may also be useful in families of young burn survivors.

Given the findings in the current study, and the literature on coping strategies and the role of the family, one hypothesis is that the positive impact of a supportive family combined with healthy coping mechanisms, outweighs the negative consequences of having a burn injury.

Clinical implications

The clinical implications of this study are discussed in detail in the critical review paper (Pope, 2005).

Limitations of the study

Sample

24 out of the 32 burn survivors were recruited from the Burned Childrens' Clubs, where children and young people have the opportunity to take part in activities with other burn survivors. The remaining eight were recruited through a hospital

burns unit. It is plausible that those who participate in a burns club may differ in some unknown way from burn survivors at large; they may be more accepting of their scars, or alternatively may have had more problems which led them to seek out a club.

Williams, Reeves, Cox and Call (2004) describe camp as being a place where burn-injured adolescents can “feel normal and accepted”, “acquire insight in regard to self and meaning of life”, “gain confidence, increase self-esteem, and develop empathy”. However it is questionable whether this then generalises to when they are at home when their burns may not be so accepted by others.

Although not statistically significant, the results showed that on all measures, with the exception of evaluations of how others see their appearance, the burn survivors from the clubs did marginally better than those in the hospital sample. A bigger sample size may reveal more significant differences. It should be noted however, some of the eight young people from the hospital sample, may have been involved in another club in the UK without the researchers’ knowledge.

A further possible response bias is that the packs sent in the post from the hospital and the participating clubs, were addressed to the parent/guardian of the young person. If the parent felt their child was not coping well, and that the questionnaires may upset them, they may not have passed the pack on. There is a lack of information regarding non-responders.

The sample in the current study may also not be representative in terms of gender: there were more female participants than male participants. However hospital figures show that of the children admitted to the unit, the number of boys is double that of girls.

However, despite these reservations in terms of sampling biases, the findings still have important significant implications for clinical practice. The current findings show that young burn survivors have the potential to cope well, and this may be both reassuring and motivating to young people, families and professionals working together following a burn injury.

The control group as representing young people in the general population

One hypothesis to account for the findings is that the control group are not representative of young people in the general population. The control group came from one school in Essex which was identified by the local Child and Family Consultation School as being a school they had good links with. The Ofsted report described the school as being “a very good school serving a socially deprived area” (see method). However, a comparison with the student norms from the BDI-II validation study (Beck et al., 1996), revealed similar mood levels, which gives some indication that the control group may be representative of young people in the general population. However some caution should be taken in making this comparison, as the average age in Beck’s student sample was 19, and they were all first year students on a Psychology degree programme in the US.

Sample size

A larger sample size may give greater validity to the findings, and may have detected more group differences.

Generalisation to those with very large burns

Generalisation of the current findings to those with very large burns is unclear as the range was 1% to 63% (mean = 21.93%). However, Landolt et al. (2002) reported that even young people with very large burns, (i.e. above 80%) had a reasonably “normal” quality of life. Sheridan et al.’s 2002 study of adult survivors of childhood burns concluded the same. This therefore suggests that the current findings may be generalised to those with larger burns. However as this study found a significant relationship between size of burn and general feelings about appearance and quality of life, some further research into young people with larger burns is necessary.

Variables specific to population of burn survivors

A difficulty in selecting appropriate control groups in health psychology as a whole, is that each disease or injury, including burns, has idiosyncratic features of its subject population which are impossible to reproduce in a healthy control sample. Therefore burn survivors may be different in a number of ways from other young people.

i) Abuse

There may be a higher rate of experiences of abuse amongst young burn survivors. In Stoddard et al.'s 1992 study on depression in children, five out of the 30 participants aged 7 to 19 years were known to have been abused; two had burns that were the result of abuse, in addition one had been physically and sexually abused, one had been physically abused only, and one had been sexually abused only.

ii) Other family factors which may be precipitants to low mood

In Stoddard's study, most children/young people reported a precipitant other than the burn itself as the cause of low mood, with the most common precipitant being family situation or social problems. They tended to report not getting along with a parent, alcoholism in family members, and/or physical and sexual abuse.

Similarly, Blakeney, Meyer, Robert, Desai, Wolf et al. (1998) found that of children surviving very large burns, there was a high incidence of parental problems including chronic substance abuse, psychiatric diagnoses, and abuse within the family.

iii) Pre-morbid functioning

Young burn survivors may be more likely to have had psychological difficulties prior to their burn, although research has not detailed this. In Stoddard's 1992 study, one adolescent was depressed before the burn injury and another was known to have acquired their burn injury in a suicide attempt. In adult samples, it was concluded that long-term difficulties may be related to pre-morbid difficulties (Andreasen, Norris & Hartford, 1971; Patterson et al., 1993).

iv) Other differences

There may be other issues connected with the burn other than scarring that may impact on body image, mood and quality of life. Distress may be associated with the other consequences of a burn injury, for example young people surviving house fires may have lost family members, and may therefore be bereaved. Other consequences of burn injury can include pain, loss of function,

as well as posttraumatic reactions. Their families may also experience posttraumatic reactions.

This gives us an indication of some of the ways in which young burn survivors will be different to young people in the general population, other than having scars. In the current study there is no information on abuse, family factors, pre-morbid functioning, trauma and other differences. However as the outcomes for young burn survivors in the current study are positive, they may be functioning well in spite of these factors.

Changes in body image, mood and quality of life over time

This study measures outcome at one period in time. It does not capture whether they had struggled more in the past, or whether they will in the future. Stoddard (1992) reported that eight of the 30 young people had a life-time diagnosis of depression. However at the time of interview only one had a diagnosis of major depression, and three had a diagnosis of dysthymic disorder. This highlights the fluctuating course of how mood changes over time. Perhaps an individual's ability to deal with their emotions and social situations varies over time, depending on the occurrence of negative responses and rejection from others.

Similarly, McQuaid et al. (2000) propose that body image is 'dynamic', and that "...we continuously experience things differently and change in our ways of cognitively representing images and perceptions" (p.198). However McQuaid et al. also suggest that changes in body image tends to be slight and gradual.

Suggestions for further research

As generalisation of the current findings to those with very large burns is unclear, a similar study with young people with larger burns would be useful. As it is important to have a control group representative of young people in the general population, it is also suggested that a control group in future studies should include young people from a range of schools in different areas.

A longitudinal study following the same individuals over time from childhood into early adulthood would highlight how body image, mood and quality of life changes over time, as well as helping identify long-term risk factors. There is

likely to be many physical, psychological and social changes over this period. Alternatively a study could look at the differences between groups of burn survivors of different ages.

As this study indicates that overall young burn survivors may be resilient and coping well, it would be of benefit to learn what coping strategies they use in order to counteract the negative consequences of having a burn injury. This could be done either using interviews, either individually or as a group. This could later be incorporated into interventions for those who find it difficult to cope.

Building on the work by Lawrence et al. (2004), further research would benefit from looking at the role of family on outcome, and how interventions can improve family support.

Ideas for future research will be looked at in more detail in the critical review (Pope, 2005).

Conclusions

The results of this study suggest that young people who have survived burns may be coping well in comparison to their peers who have not been burned, in spite of living with the physical, psychological and social consequences of a burn injury. Infact, they actually report more positive evaluations of how others see their appearance, more positive weight satisfaction, and a better quality of life.

Therefore young burn survivors may be coping better than professionals may expect. However a belief held widely by health care professionals is that people with burn injuries will permanently suffer from psychological distress (Patterson et al., 1993). This belief may arise as people can be extremely distressed during the time they are hospitalised, when health care professionals interact most with them. Although there may be some bias in the sample, (for example self-selection inherent in joining a burned children's club), the results clearly show that young burn survivors have the potential to cope well. These results should hopefully be encouraging to healthcare professionals and help them to

understand the implications of their work. A presentation of these findings will be made to health professionals at the annual conference of the British Burn Association in April 2005, and it is hoped that further dissemination will take place at a psychological conference, and through publication in a peer-reviewed journal.

Although young burn survivors may be coping well, it is still important to provide after-care. Inconsistencies remain across the UK in the provision of psychological post-burn care, and adult burn survivors report dissatisfaction with psychological care post-injury (Van Loey, Faber & Taal, 2001).

Further study should be conducted to establish exactly what service provision is wanted by users. However in terms of psychological well-being, this study suggests some likely target areas. The finding of the strong relationship between body image, mood and quality of life in burn survivors, suggests that interventions focusing on these factors are likely to have significant impact on individuals. Further research on coping mechanisms in burn survivors, and on family and social support on psychological well-being, is likely to provide further insight into the most beneficial forms of support for young people living in the aftermath of serious burn injuries.

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APPENDICES

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**Doctor of Clinical Psychology
Training Course**

Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Parent/Guardian,

We hope you don't mind us writing to you and your son/daughter out of the blue like this. We appreciate that it is many years now since your son/daughter was admitted to hospital due to a burn injury. However we are hoping that they can help us with some research, which could benefit young people in the future. We would like to invite your son/daughter to take part in some research which is part of a university course. The study complies with the strict ethical guidelines for research. As part of this study, we would like to ask young people between the ages of 12 and 18 who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay as young children, to complete some questionnaires.

What are the reasons for this study?

Very little research has been done looking at how children who were burned as young children cope when they reach adolescence. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how they view their quality of life. We will also be asking young people who have not had the experience of being burned the same things. It is hoped that any differences revealed between these two groups may give us information about how young people who were burned as young children are coping, and highlight any specific areas for future help.



Version 4, 18th February 2004
Letter/information sheet for parents
HOSPITAL SAMPLE
A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

210

Why has my son/daughter been chosen?

We are asking young people aged between 12 and 18, who were admitted to the St Andrews Centre as young children, to take part in this study. We shall be comparing these findings with another group of young people at a local school, who have never been burned.

What is my son/daughter being asked to do?

If your son/daughter would like to take part we would like them to complete five questionnaires which can be found in the red folder. They should take between 35 to 45 minutes in total to complete. When they have finished filling them out they can be returned in the brown stamped addressed envelope. Two of the questionnaires ask questions about how they see their appearance, one asks questions about their emotions, and one asks questions about how they see aspects of their life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking your son/daughter what the situation is for them. If there are any questions they do not want to answer, they can leave them out.

Does my son/daughter have to take part?

Participation in the study is voluntary. We would be grateful if you would both sign one of the blue consent forms, and return it in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

If your son/daughter agrees to take part, we would like to look at some information that is held about them on a hospital computer. We would like to know their date of birth, what ethnic group they belong to, the date they came to hospital, the size of their burn, and the cause of their burn. However if you or your son/daughter would prefer us not to look at this information, you can tell us on the blue form and we will not look at the hospital computer.

Will their information be kept confidential?

All data collected in this study will be kept confidential and stored in a secure place. The only person who will see the completed questionnaires is the main researcher Selina Pope. Confidentiality is very important, and we would ask that you do not look at your son/daughter's completed questionnaires. Their name and any information that may identify them are not written on the questionnaires, instead they have a number. Selina will enter the answers onto the computer using their number. Only Selina will have access to this computer.

The only time information about an individual young person may have to be shared is if there is concern about their safety, or the safety of someone else.

What if my son/daughter becomes upset?

We hope that your son/daughter will not feel upset by filling out the questionnaires. However if they do become upset they can talk about this with Selina either by telephone or email. If they continue to feel upset Selina can arrange some further support.

What if I become upset?

We appreciate that this invitation for your son/daughter to take part in this research may bring back some upsetting memories for you. If this happens, The Counselling and Psychotherapy Service at the St Andrews Centre for Plastic Surgery and Burns, which is now based at Broomfield Hospital in Chelmsford, will be happy to talk to you. You can telephone them on 01245 516030.

What if I want to make a complaint?

If you wish to complain or have any concerns about any aspect of the way you or your son/daughter have been approached or treated during the course of this study, you may make a complaint through the Patient Advice and Liaison Service. Their telephone number is 01245 514346.

What will happen to the results of the study?

This study is part of a doctoral thesis and the results of this study will be written up in a special report. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. Your son/daughter will be sent a copy of the results in November 2004. ***Their name will not be included in any report or presentation, and there will be no way of identifying them personally.***

Who has reviewed the study?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust.

What happens next?

- 1) We would be grateful if you would pass the red folder on to your son/daughter. This contains a letter to them, as well as the questionnaires and envelopes.

If your son/daughter would like to take part in the research:

- 2) Please could you and your son/daughter read and sign one of the blue consent forms and return it in the white stamped addressed envelope provided. You may keep the other blue form for your information.
- 3) Your son/daughter may complete the questionnaires and return them in the brown stamped addressed envelope.
- 4) If they would like some help with the questionnaires, or if either of you would like more information, you can email Selina at **S.J.Pope@herts.ac.uk** or telephone her on **01245 516030**. There may be someone to take the call during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study. Thank you for taking the time to read this letter.

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Young Person,

We hope you don't mind us writing to you out of the blue like this. However we are hoping that you can help us with some research. This research could benefit young people in the future, who like yourself had a burn injury as young children. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

Very little is known about how young people like yourself are coping, having been burned years ago as young children. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age who have not had the experience of being burned the same things. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different to young people of your age who have never been burned. We hope that the findings will help the healthcare system in the future to provide help for young people who have been burned.



INVESTOR IN PEOPLE



Session 4, 18th February 2004

Leaflet/Information sheet for young people

HOSPITAL SAMPLE

A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993



Why have I been chosen?

We are asking young people aged between 12 and 18, who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay in Essex as young children, to take part in this study. We shall be comparing these findings with another group of young people at a school, who have never been burned.



What am I being asked to do?

If you would like to take part we would like you to fill out five questionnaires which you can find in the red folder. They should take you between 35 to 45 minutes in total to complete. When you have finished filling them out, please return them to us in the brown stamped addressed envelope. Two of the questionnaires ask questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking what the situation is for you. If there are any questions you do not want to answer, you can leave them out.



Do I have to take part?

It is up to you to decide whether or not to join in. If you do decide to take part we would be grateful if you and a parent/guardian could read and sign one of the blue consent forms, and send it back to us in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

If you agree to take part, we would like to look at some information that is held about you on a hospital computer. We would like to know your date of birth, what ethnic group you belong to, the date you came to hospital, the size of your burn, and the cause of your burn. However if you would prefer us not to look at this information, you can tell us on the blue form and we will not look at the hospital computer.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. We will ask your parents not to look at your completed questionnaires. Only the main researcher Selina Pope will see your questionnaires. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer.

The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina by telephone or email. If you still feel upset she can help to arrange some support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research you may make a complaint through the Patient Advice and Liaison Service. Their telephone number is 01245 514346.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results in November 2004. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



Who has said it is okay for us to do this research?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust.



What happens next?

If you would like to take part in the research:

- (1) Please could you and a parent/guardian sign one of the blue consent forms and return it in the white stamped addressed envelope provided. You may keep the other blue form for your own information.
- (2) Please fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (3) If you would like some help with the questionnaires or would like more information, you can email Selina at **S.J.Pope@herts.ac.uk**, or telephone her on **01245 516030**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study, and look forward to hearing from you.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Young Person,

We hope you don't mind us writing to you out of the blue like this. However we are hoping that you can help us with some research. This research could benefit young people in the future, who like yourself had a burn injury as young children. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

Very little is known about how young people like yourself are coping, having been burned years ago as young children. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age who have not had the experience of being burned the same things. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different to young people of your age who have never been burned. We hope that the findings will help the healthcare system in the future to provide help for young people who have been burned.



Why have I been chosen?

We are asking young people aged between 12 and 18, who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay in Essex as young children, to take part in this study. We shall be comparing these findings with another group of young people at a school, who have never been burned.



What am I being asked to do?

If you would like to take part we would like you to fill out five questionnaires which you can find in the red folder. They should take you between 35 to 45 minutes in total to complete. When you have finished filling them out, please return them to us in the brown stamped addressed envelope. Two of the questionnaires ask questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking what the situation is for you. If there are any questions you do not want to answer, you can leave them out.



Do I have to take part?

It is up to you to decide whether or not to join in. If you do decide to take part we would be grateful if you and a witness could read and sign one of the blue consent forms, and send it back to us in the white stamped addressed envelope. A witness can be anyone you know who is aged 18 or over. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

If you agree to take part, we would like to look at some information that is held about you on a hospital computer. We would like to know your date of birth, what ethnic group you belong to, the date you came to hospital, the size of your burn, and the cause of your burn. However if you would prefer us not to look at this information, you can tell us on the blue form and we will not look at the hospital computer.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer.

The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina by telephone or email. If you still feel upset she can help to arrange some support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research you may make a complaint through the Patient Advice and Liaison Service. Their telephone number is 01245 514346.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results in November 2004. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



Who has said it is okay for us to do this research?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust.



What happens next?

If you would like to take part in the research:

- (1) Please could you and a witness sign one of the blue consent forms and return it in the white stamped addressed envelope provided. You may keep the other blue form for your own information.
- (2) Please fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (3) If you would like some help with the questionnaires or would like more information, you can email Selina at S.J.Pope@herts.ac.uk, or telephone her on **01245 516030**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study, and look forward to hearing from you.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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PARTICIPANT CONSENT FORM

***PLEASE FILL OUT THIS FORM AND RETURN IN THE WHITE
STAMPED ADDRESSED ENVELOPE – THANKYOU!***

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.		
Who has written to you and/or spoken to you about this project?		
	Please tick box	
	YES	NO
Do you understand that you may withdraw from the project:		
• at any time		
• without giving a reason		
• without affecting the services you receive from the NHS?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read the letters explaining the research?	<input type="checkbox"/>	<input type="checkbox"/>
Are you happy with the answers given to any questions you have asked about the research? <i>(If applicable)</i>	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you give permission for us to find out from the hospital computer your date of birth, ethnic group, date you came to hospital, the size of your burn, and the cause of your burn?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Participant..... Date.....		
NAME OF PARTICIPANT (IN BLOCK LETTERS)		
Signature of Parent/Guardian..... Date.....		
NAME OF PARENT/GUARDIAN (IN BLOCK CAPITALS)		



version 3



INVESTOR IN PEOPLE



18th February 2004 – Participant consent form - group 1- 225
HOSPITAL SAMPLE

A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

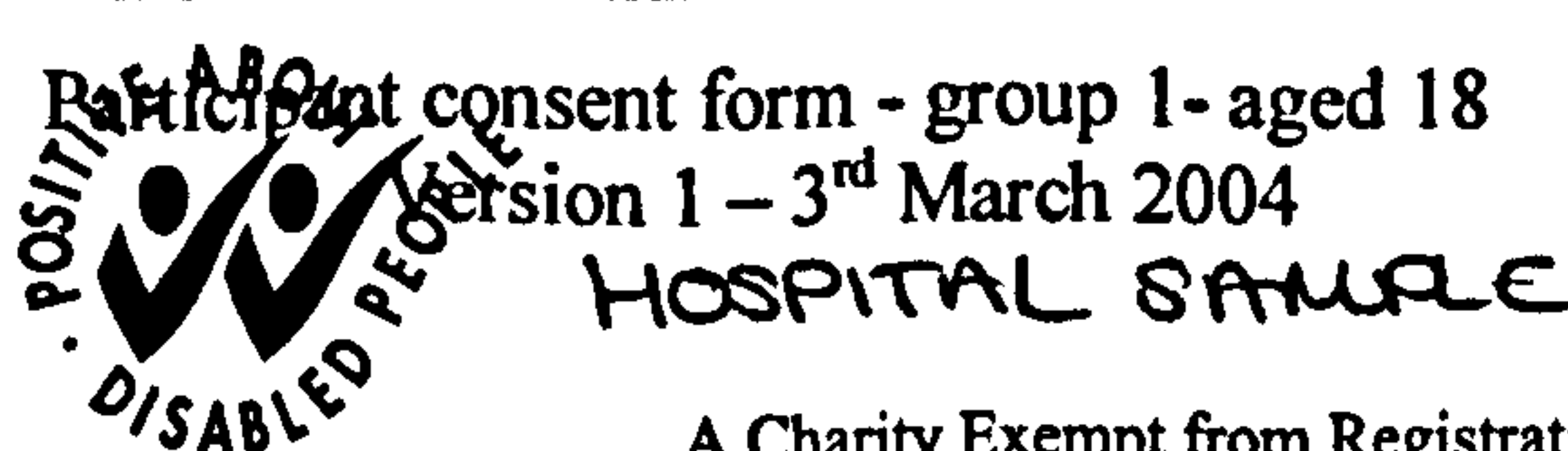


Doctor of Clinical Psychology
Training Course

PARTICIPANT CONSENT FORM

**PLEASE FILL OUT THIS FORM AND RETURN IN THE WHITE
STAMPED ADDRESSED ENVELOPE – THANKYOU!**

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.		
Who has written to you and/or spoken to you about this project?		
	Please tick box	
	YES	NO
Do you understand that you may withdraw from the project:		
• at any time		
• without giving a reason		
• without affecting the services you receive from the NHS?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read the letters explaining the research?	<input type="checkbox"/>	<input type="checkbox"/>
Are you happy with the answers given to any questions you have asked about the research? (<i>If applicable</i>)	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this project?	<input type="checkbox"/>	<input type="checkbox"/>
Do you give permission for us to find out from the hospital computer your date of birth, ethnic group, date you came to hospital, the size of your burn, and the cause of your burn?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Participant..... Date.....		
NAME OF PARTICIPANT (IN BLOCK LETTERS)		
Signature of Witness..... Date.....		
NAME OF WITNESS (IN BLOCK CAPITALS)		





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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Parent/Guardian,

We hope you don't mind us writing to you and your son/daughter out of the blue like this. We appreciate that it is many years now since your son/daughter was admitted to hospital due to a burn injury. However we are hoping that they can help us with some research, which could benefit young people in the future. We would like to invite your son/daughter to take part in some research which is part of a university course. The study complies with the strict ethical guidelines for research. As part of this study, we would like to ask young people between the ages of 12 and 19 to complete some questionnaires.

What are the reasons for this study?

Very little research has been done looking at how children who were burned as young children cope when they reach adolescence. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how they view their quality of life. We will also be asking young people who have not had the experience of being burned the same things. It is hoped that any differences revealed between these two groups may give us information about how young people who were burned as young children are coping, and highlight any specific areas for future help.



Version 4, 18th February 2004
Letter/information sheet for parents
CLUB SAMPLE
A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

Why has my son/daughter been chosen?

Some of the young people we are contacting are involved with the Burned Children's Club, like your son/daughter.

What is my son/daughter being asked to do?

If your son/daughter would like to take part we would like them to complete five questionnaires which can be found in the red folder. They should take between 35 to 45 minutes in total to complete. When they have finished filling them out they can be returned in the brown stamped addressed envelope. Two of the questionnaires ask questions about how they see their appearance, one asks questions about their emotions, and one asks questions about how they see aspects of their life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking your son/daughter what the situation is for them. If there are any questions they do not want to answer, they can leave them out.

Does my son/daughter have to take part?

Participation in the study is voluntary. We would be grateful if you would both sign one of the blue consent forms, and return it in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

Will their information be kept confidential?

All data collected in this study will be kept confidential and stored in a secure place. The only person who will see the completed questionnaires is the main researcher Selina Pope. Confidentiality is very important, and we would ask that you do not look at your son/daughter's completed questionnaires. Their name and any information that may identify them are not written on the questionnaires, instead they have a number. Selina will enter the answers onto the computer using their number. Only Selina will have access to this computer.

The only time information about an individual young person may have to be shared is if there is concern about their safety, or the safety of someone else.

What if my son/daughter becomes upset?

We hope that your son/daughter will not feel upset by filling out the questionnaires. However if they do become upset they can talk about this with Selina either by telephone or email. If they continue to feel upset Selina can arrange some further support.

What if I become upset?

We appreciate that this invitation for your son/daughter to take part in this research may bring back some upsetting memories for you. If this happens, The Counselling and Psychotherapy Service at the St Andrews Centre for Plastic Surgery and Burns, which is now based at Broomfield Hospital in Chelmsford, will be happy to talk to you. You can telephone them on 01245 516030.

What if I want to make a complaint?

If you wish to complain or have any concerns about any aspect of the way you or your son/daughter have been approached or treated during the course of this study, you may make a complaint through Pat Wade on 01268 527796.

What will happen to the results of the study?

This study is part of a doctoral thesis and the results of this study will be written up in a special report. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. Your son/daughter will be sent a copy of the results in November 2004. ***Their name will not be included in any report or presentation, and there will be no way of identifying them personally.***

What happens next?

- 1) We would be grateful if you would pass the red folder on to your son/daughter. This contains a letter to them, as well as the questionnaires and envelopes.

If your son/daughter would like to take part in the research:

- 2) Please could you and your son/daughter read and sign one of the blue consent forms and return it in the white stamped addressed envelope provided. You may keep the other blue form for your information.
- 3) Your son/daughter may complete the questionnaires and return them in the brown stamped addressed envelope.
- 4) If they would like some help with the questionnaires, or if either of you would like more information, you can email Selina at **S.J.Pope@herts.ac.uk** or telephone her on **01245 516030**. There may be someone to take the call during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study. Thank you for taking the time to read this letter.

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Young Person,

We hope you don't mind us writing to you out of the blue like this. However we are hoping that you can help us with some research. This research could benefit young people in the future, who like yourself had a burn injury as young children. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

Very little is known about how young people like yourself are coping, having been burned years ago as young children. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age who have not had the experience of being burned the same things. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different to young people of your age who have never been burned. We hope that the findings will help the healthcare system in the future to provide help for young people who have been burned.



INVESTOR IN PEOPLE



Session 4, 18th February 2004
Information sheet for young people
CLUB SAMPLE
A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993



Why have I been chosen?

Some of the young people we are contacting are involved with the Burned Children's Club, like yourself.



What am I being asked to do?

If you would like to take part we would like you to fill out five questionnaires which you can find in the red folder. They should take you between 35 to 45 minutes in total to complete. When you have finished filling them out, please return them to us in the brown stamped addressed envelope. Two of the questionnaires ask questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking what the situation is for you. If there are any questions you do not want to answer, you can leave them out.



Do I have to take part?

It is up to you to decide whether or not to join in. If you do decide to take part we would be grateful if you and a parent/guardian could read and sign one of the blue consent forms, and send it back to us in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. We will ask your parents not to look at your completed questionnaires. Only the main researcher Selina Pope will see your questionnaires. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer.

The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina by telephone or email. If you still feel upset she can help to arrange some support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research you may contact Pat Wade at the Burned Children's Club 01268 527796.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results in November 2004. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



What happens next?

If you would like to take part in the research:

- (1) Please could you and a parent/guardian sign one of the blue consent forms and return it in the white stamped addressed envelope provided. You may keep the other blue form for your own information.
- (2) Please fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (3) If you would like some help with the questionnaires or would like more information, you can email Selina at **S.J.Pope@herts.ac.uk**, or telephone her on **01245 516030**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study, and look forward to hearing from you.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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Study researchers: Selina Pope
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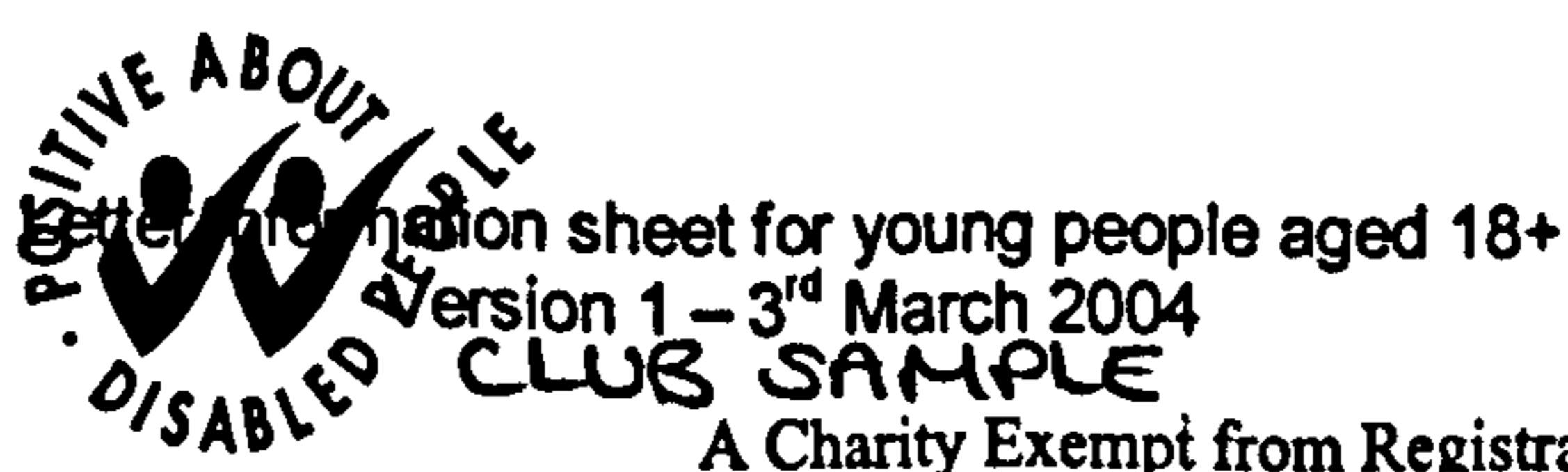
Dear Young Person,

We hope you don't mind us writing to you out of the blue like this. However we are hoping that you can help us with some research. This research could benefit young people in the future, who like yourself had a burn injury as young children. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

Very little is known about how young people like yourself are coping, having been burned years ago as young children. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age who have not had the experience of being burned the same things. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different to young people of your age who have never been burned. We hope that the findings will help the healthcare system in the future to provide help for young people who have been burned.





Why have I been chosen?

Some of the young people we are contacting are involved with the Burned Children's Club, like yourself.



What am I being asked to do?

If you would like to take part we would like you to fill out five questionnaires which you can find in the red folder. They should take you between 35 to 45 minutes in total to complete. When you have finished filling them out, please return them to us in the brown stamped addressed envelope. Two of the questionnaires ask questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. We know that some people will still have scars, others will not, so in the fifth questionnaire we are asking what the situation is for you. If there are any questions you do not want to answer, you can leave them out.



Do I have to take part?

It is up to you to decide whether or not to join in. If you do decide to take part we would be grateful if you and a witness could read and sign one of the blue consent forms, and send it back to us in the white stamped addressed envelope. A witness can be anyone you know who is aged 18 or over. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer.

The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



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What happens next?

If you would like to take part in the research:

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We would greatly appreciate your support in this study, and look forward to hearing from you.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



**Doctor of Clinical Psychology
Training Course**

Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Parent/Guardian,

We appreciate that it is many years now since your son/daughter went to hospital due to a burn injury. However we are hoping that they can help us with some research, which could benefit young people in the future. We would like to invite your son/daughter to take part in some research which is part of a university course. The study complies with the strict ethical guidelines for research. As part of this study, we would like to ask young people between the ages of 12 and 19 to complete some questionnaires.

What are the reasons for this study?

Very little research has been done looking at how children who were burned as young children cope when they reach adolescence. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how they view their quality of life. We will also be asking young people who have not had the experience of being burned the same things. It is hoped that any differences revealed between these two groups may give us information about how young people who were burned as young children are coping, and highlight any specific areas for future help.

Why has my son/daughter been chosen?

Your son/daughter has been chosen, as they are attending camp.

What is my son/daughter being asked to do?

If your son/daughter would like to take part we would like them to complete five questionnaires which can be found in the red folder. They should take between 20 and 30 minutes in total to complete. When they have finished filling them out they can be returned in the brown stamped addressed envelope. Two of the questionnaires ask questions about how they see their appearance, one asks questions about their emotions, and one asks questions about how they see aspects of their life. The fifth questionnaire asks some questions about their burn injury. ***If there are any questions they do not want to answer, they can leave them out.***

Does my son/daughter have to take part?

Participation in the study is voluntary. We would be grateful if you would both sign one of the orange consent forms, and return it in the white stamped addressed envelope. The other orange form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

Will their information be kept confidential?

All data collected in this study will be kept confidential and stored in a secure place. The only person who will see the completed questionnaires is the main researcher Selina Pope. Confidentiality is very important, and we would ask that you do not look at your son/daughter's completed questionnaires. Their name and any information that may identify them are not written on the questionnaires, instead they have a number. Selina will enter the answers onto the computer using their number. Only Selina will have access to this computer.

The only time information about an individual young person may have to be shared is if there is concern about their safety, or the safety of someone else.

What if my son/daughter becomes upset?

We hope that your son/daughter will not feel upset by filling out the questionnaires. However if they do become upset they can talk about this with Selina or any of the helpers at camp, or later with Selina either by telephone or email. If they continue to feel upset Selina can arrange some further support.

What if I want to make a complaint?

If you wish to complain or have any concerns about any aspect of the way you or your son/daughter have been approached or treated during the course of this study, you may make a complaint through Pat Wade on 01268 527796.

What will happen to the results of the study?

This study is part of a doctoral thesis and the results of this study will be written up in a special report. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. Your son/daughter will be sent a copy of the results. ***Their name will not be included in any report or presentation, and there will be no way of identifying them personally.***

What happens next?

If your son/daughter would like to take part in the research:

- (1) Your son/daughter may complete the questionnaires and return them in the brown stamped addressed envelope.
- (2) Please could you and your son/daughter read and sign one of the orange consent forms and return it in the white stamped addressed envelope provided. You may keep the other orange form for your information.

If you or your son/daughter would like to contact Selina after camp, you can email her at **S.J.Pope@herts.ac.uk** or telephone her on **01245 516030**. There may be someone to take the call during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study. Thank you for taking the time to read this letter.

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



DATE AS
POSTMARK

Hatfield Herts
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Doctor of Clinical Psychology
Training Course

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Minicom 01707 284000
Fax 01707 284115
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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Nancy Cohn
Anne Possamai
Wendy Solomons
John Done

Dear Young Person,

We are hoping that you can help us with some research. This research could benefit young people in the future, who like yourself had a burn injury as young children. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

Very little is known about how young people like yourself are coping, having been burned years ago as young children. This study aims to find out about how young people who were burned as young children feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age who have not had the experience of being burned the same things. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different to young people of your age who have never been burned. We hope that the findings will help the healthcare system in the future to provide help for young people who have been burned.



Why have I been chosen?

We are inviting you to join in, as you are attending camp.



What am I being asked to do?

If you would like to take part we would like you to fill out five questionnaires which you can find in the red folder. They should take you between 20 and 30 minutes in total to complete. When you have finished filling them out, please return them to us in the brown stamped addressed envelope. Two of the questionnaires ask questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. The fifth questionnaire asks some questions about your burn injury. ***If there are any questions you do not want to answer, you can leave them out.***



Do I have to take part?

It is up to you to decide whether or not to join in. If you do decide to take part we would be grateful if you and a parent/guardian could read and sign one of the orange consent forms, and send it back to us in the white stamped addressed envelope. The other orange form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. We will ask your parents not to look at your completed questionnaires. Only the main researcher Selina Pope will see your questionnaires. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer.

The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina or any of the helpers at camp, or later with Selina by telephone or email. If you still feel upset she can help to arrange some support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research, you may make a complaint through Pat Wade on 01268 527796.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



What happens next?

If you would like to take part in the research:

- (1) Please fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (2) Please could you and a parent/guardian sign one of the orange consent forms and return it in the white stamped addressed envelope provided. You may keep the other orange form for your own information.

If you would like some to contact Selina after camp you can email her at **S.J.Pope@herts.ac.uk**, or telephone her on **01245 516030**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



PARTICIPANT CONSENT FORM

**PLEASE FILL OUT THIS FORM AND RETURN IT IN THE WHITE STAMPED
ADDRESSED ENVELOPE - THANKYOU!**

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.	
Who has written to you and/or spoken to you about this project?	
	Please tick box
	YES NO
Do you understand that you may withdraw from the project:	
• at any time	
• without giving a reason	
• without affecting the services you receive from the NHS?	<input type="checkbox"/> <input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/> <input type="checkbox"/>
Have you read the letter explaining the research?	<input type="checkbox"/> <input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/> <input type="checkbox"/>
Do you agree to take part in this research?	<input type="checkbox"/> <input type="checkbox"/>
Signature of Participant..... Date.....	
NAME OF PARTICIPANT (IN BLOCK LETTERS)	
Signature of Parent/Guardian..... Date.....	
NAME OF PARENT/GUARDIAN (IN BLOCK CAPITALS)	



group 1



INVESTOR IN PEOPLE



18th February 2004 – Participant consent form - 247
CLUB + CAMP SAMPLE



University of Hertfordshire

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UK

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Fax 01707 284115
www.herts.ac.uk

PARTICIPANT CONSENT FORM

PLEASE FILL OUT THIS FORM AND RETURN IT IN THE WHITE STAMPED ADDRESSED ENVELOPE - THANKYOU!

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.		
Who has written to you and/or spoken to you about this project?		
	Please tick box	
	YES	NO
Do you understand that you may withdraw from the project:		
• at any time		
• without giving a reason		
• without affecting the services you receive from the NHS?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read the letter explaining the research?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this project?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Participant..... Date.....		
NAME OF PARTICIPANT (IN BLOCK LETTERS)		
Signature of Witness..... Date.....		
NAME OF WITNESS (IN BLOCK CAPITALS)		



THE QUEEN'S AWARDS
FOR ENTERPRISE:
INTERNATIONAL TRADE
2004



INVESTOR IN PEOPLE



February 2004 – Participant consent form – group 1 aged 18+ 248

CLUB + CAMP SAMPLE

A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993



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19th April 2004

Doctor of Clinical Psychology
Training Course

Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Anne Possamai
Nancy Cohn
Wendy Solomons
John Done

Dear Parent/Guardian,

We are hoping that your son/daughter can help us with some research, which could benefit young people in the future. We are inviting them to take part in some research which is part of a university course. The study complies with the strict ethical guidelines for research. As part of this study, we are asking other young people from years 8 to 13 at Chalvedon School to take part.

What are the reasons for this study?

This research aims to find out about how young people of your son/daughter's age feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of their age to take part who survived serious burn injuries as young children and now have to live with the scars and the reactions of other people to how they look. We are interested to see what the similarities and differences are between young people at Chalvedon School, and burn survivors of their age. We hope that the findings will help the healthcare system provide better help for young burn survivors. It will also give us information about some of the issues that all young people face. We hope that the findings will contribute greatly to the research body of knowledge on young people.



Session 4, 18th February 2004
Information sheet for parents (controls)

SCHOOL SAMPLE

A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

Why has my son/daughter been chosen?

We are asking young people aged between 12 and 18 at Chalvedon to join in this research. We are also asking young people who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay in Essex as young children, to take part in this study.

What is my son/daughter being asked to do?

If your son/daughter would like to take part we would like them to complete three questionnaires which can be found in the red folder. They should take about 35 minutes in total to complete. One of the questionnaires asks questions about how they see their appearance, one asks questions about their emotions, and one asks questions about how they see aspects of their life. If there are any questions they do not want to answer, they can leave them out.

Does my son/daughter have to take part?

Participation in the study is voluntary. If your son/daughter would like to take part please could you both sign one of the blue consent forms, and return it in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.

Will their information be kept confidential?

All data collected in this study will be kept confidential and stored in a secure place. The only person who will see the completed questionnaires is the main researcher Selina Pope. Confidentiality is very important, and we would ask that you do not look at your son/daughter's completed questionnaires. Their name and any information that may identify them are not written on the questionnaires, instead they have a number. Selina will enter their answers onto the computer using their number. Only Selina will have access to this computer. The only time information about an individual young person may have to be shared is if there is concern about their safety, or the safety of someone else.

What if my son/daughter becomes upset?

We hope that your son/daughter will not feel upset by filling out the questionnaires. However if they do become upset they can talk about this with Selina by telephone or email. If they continue to feel upset Selina can arrange extra support.

What if I want to make a complaint?

If you wish to complain or have any concerns about any aspect of the way you or your son/daughter have been approached or treated during the course of this study, you may make a complaint through the National Health Service by contacting the Patient Advice and Liaison Service. Their telephone number is 01245 514346.

What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. Your son/daughter will be given a summary of the results in November 2004. ***Your son/daughter's name will not be included in any report or presentation, and there will be no way of identifying them personally.***

Who has reviewed the study?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust. Chalvedon school have also approved the research.

What happens next?

If your son/daughter would like to take part in the research:

- (1) Please could you and your son/daughter sign one of the enclosed blue consent forms and return it in the white stamped addressed envelope. You may keep the other blue form for your own information.
- (2) Your son/daughter may complete the questionnaires and return them in the brown stamped addressed envelope.
- (3) If they would like some help with the questionnaires, or if either of you would like more information, you can email Selina at **S.J.Pope@herts.ac.uk** or telephone her on **01268 366700**. There may be someone to take the call during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study. Thank you for taking the time to read this information sheet.

Yours sincerely

Selina Pope
Trainee Clinical Psychologist



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19th April 2004

Doctor of Clinical Psychology
Training Course

Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Anne Possamai
Nancy Cohn
Wendy Solomons
John Done

Dear Young Person,

We are hoping that you can help us with some research. This research could benefit young people in the future. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

This research aims to find out about how young people of your age feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age to take part who survived serious burn injuries as young children, and who now have to live with the scars and the reactions of other people to how they look. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different. We hope that the findings will help the healthcare system provide better help for young burn survivors, as well as giving us information about some of the issues that all young people face. We hope that this study will greatly contribute to knowledge about young people.



Session 4, 18th February 2004
Extra information sheet for young people (controls)
SCHOOL SAMPLE
A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

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Why have I been chosen?

We are asking young people at Chalvedon School aged between 12 and 18 to join in this research. We are also asking young people who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay in Essex as young children, to take part in this study.



What am I being asked to do?

If you would like to take part we would like you to fill out three questionnaires which are in the red folder. They should take about 35 minutes in total to complete. One of the questionnaires asks questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. If there are any questions you do not want to answer, you can leave them out. Your teachers will not be able to see your completed questionnaires. We will also ask your parents not to look at your questionnaires once they are complete. You don't have to show these questionnaires to anyone else unless you want to.



Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to join in please could both you and a parent/guardian sign one of the blue consent forms, and return it in the white stamped addressed envelope. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. Only the main researcher Selina Pope will see your questionnaires. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer. The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina either by telephone or email. If you still feel upset she can help to arrange extra support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research you may make a complaint through the National Health Service by contacting the Patient Advice and Liaison Service. Their telephone number is 01245 514346.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results in November 2004. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



Who has said it is okay for us to do this research?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust.

Chalvedon School have also said that it is okay for us to do this research.



What happens next?

If you would like to take part in the research:

- (1) Please could you and a parent/guardian sign one of the enclosed blue forms and return it in the white stamped addressed envelope. Please keep the other blue form for your own information.
- (2) You may then fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (3) If you would like some help with the questionnaires or would like more information, you can email Selina at S.J.Pope@herts.ac.uk, or telephone her on **01268 366700**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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19th April 2004

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Study on: 'Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.'

Study researchers: Selina Pope
Anne Possamai
Nancy Cohn
Wendy Solomons
John Done

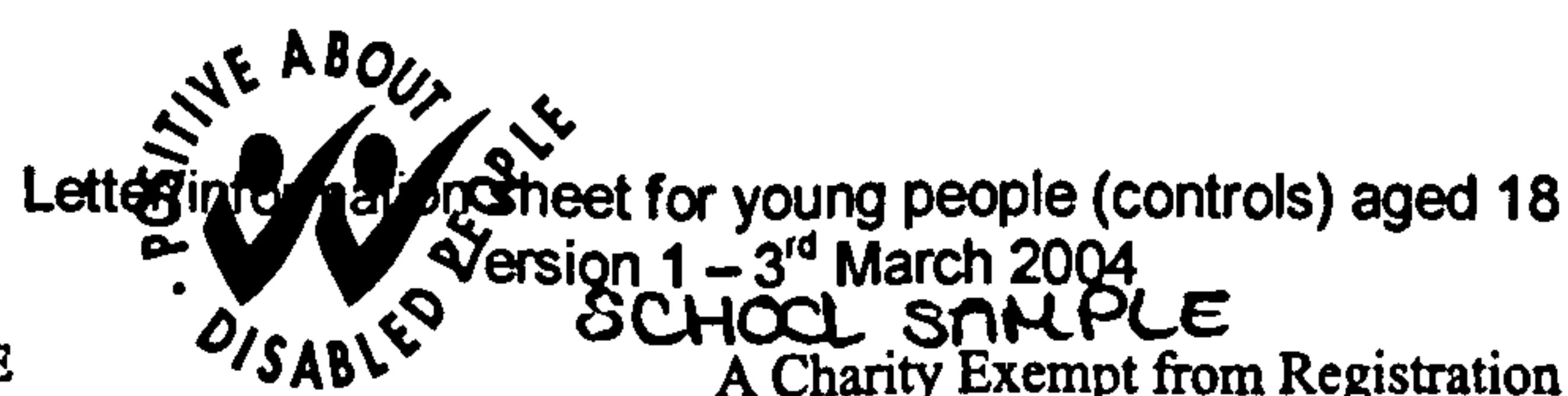
Dear Young Person,

We are hoping that you can help us with some research. This research could benefit young people in the future. The research you are being invited to join in with is part of a university course. It is important for you to understand why this study is being done and what it will involve. Please take time to read the following information carefully and talk about it with others if you wish. Feel free to ask us if there is anything that is not clear or if you would like more information. **Thank you for reading this!**



What is the reason for this research?

This research aims to find out about how young people of your age feel about their appearance, how they feel emotionally, and how life is going for them. We will also be asking people of your age to take part who survived serious burn injuries as young children and now have to live with the scars and the reactions of other people to how they look. We are interested to see what are some of the ways in which you are similar, and what are some of the ways in which you are different. We hope that the findings will help the healthcare system provide better help for young burn survivors, as well as giving us information about some of the issues that all young people face. We hope that this study will greatly contribute to knowledge about young people.





Why have I been chosen?

We are asking young people at Chalvedon School aged between 12 and 18 to join in this research. We are also asking young people who were admitted to the St Andrews Centre for Plastic Surgery and Burns at Billericay in Essex as young children, to take part in this study.



What am I being asked to do?

If you would like to take part we would like you to fill out three questionnaires which can be found in the red folder. They should take about 35 minutes in total to complete. One of the questionnaires asks questions about how you see your appearance, one asks questions about your emotions, and one asks questions about how you see aspects of your life. If there are any questions you do not want to answer, you can leave them out.



Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to join in please could you and a witness sign one of the blue consent forms, and return it in the white stamped addressed envelope. A witness can be anyone you know aged 18 and over. The other blue form is for you to keep for your own information. This form tells us that you agree to take part, that you feel you have had enough information on the study, that you understand what it is about, and that you know you can leave the study at any time without giving a reason. It also tells us that you know that if you don't take part, this will not affect any care you receive from the NHS either now or in the future.



Will my taking part in the study be kept private?

All information, which is collected, about you during the study will be kept private and locked away. Your teachers will not be able to see your completed questionnaires. Only the main researcher Selina Pope will see your questionnaires. Your name and any information that may identify you are not written on the questionnaires, instead you have a number. Selina will enter your answers onto the computer using your number. Only Selina will have access to this computer. The only type of information we would have to pass on about any person is if we were worried about their safety, or the safety of someone else.



What happens if I feel upset?

We hope that you will not feel upset by filling out the questionnaires. However if you do become upset you can talk about this with Selina either by telephone or email. If you still feel upset she can help to arrange extra support for you.



What happens if I want to make a complaint?

If you have any complaints you want to make about the research you may make a complaint through the National Health Service by contacting the Patient Advice and Liaison Service. Their telephone number is 01245 514346.



What will happen to the results of the study?

This study is part of a university course and the results of this study will be written up as a special project. The results will also be presented to health care professionals through a talk or an article in a journal to help increase knowledge. You will be sent a summary of the results in November 2004. ***Your name will not be included in any report or presentation, and there will be no way of identifying you personally.***



Who has said it is okay for us to do this research?

The 'North and Mid Essex Local Research Ethics Committee' have reviewed this study. The 'ethics committee' decide whether research is fair and not harmful. It has also been reviewed by Dr Sandip Pal, Director of Research at Mid Essex Hospital Services NHS Trust.

Chalvedon School have also said that it is okay for us to do this research.



What happens next?

If you would like to take part in the research:

- (1) Please could you and a witness sign one of the enclosed blue forms and return it in the white stamped addressed envelope. You may keep the other blue form for your own information.
- (2) You may then fill out the questionnaires found in the red folder and return them in the brown stamped addressed envelope.
- (3) If you would like some help with the questionnaires or would like more information, you can email Selina at S.J.Pope@herts.ac.uk, or telephone her on **01268 366700**. There may be someone there during Monday to Friday 9 am to 5 pm. However you can leave a message at any time, and if you leave your name and number Selina will phone you back.

We would greatly appreciate your support in this study.

Thank you for reading this letter. 😊

Yours sincerely,

Selina Pope
Trainee Clinical Psychologist



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Training Course

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www.herts.ac.uk

PARTICIPANT CONSENT FORM

Please fill out this form and return it with the questionnaires in the stamped addressed envelope – THANKYOU!

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.		
Who has written to you and/or spoken to you about this project?		
	Please tick box	
	YES	NO
Do you understand that you may withdraw from the project:		
• at any time		
• without giving a reason		
• without affecting the services you receive from the NHS?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read the letters explaining the research?	<input type="checkbox"/>	<input type="checkbox"/>
Are you happy with the answers given to any questions you have asked about the research? <i>(If applicable)</i>	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this project?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Participant..... Date.....		
NAME OF PARTICIPANT (IN BLOCK LETTERS)		
Signature of Parent/Guardian..... Date.....		
NAME OF PARENT/GUARDIAN (IN BLOCK CAPITALS)		



group 2

INVESTOR IN PEOPLE



18th February 2004 – Participant consent form - 261
SCHOOL SAMPLE

A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993



Doctor of Clinical Psychology
Training Course

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PARTICIPANT CONSENT FORM

Please fill out this form and return it with the questionnaires in the stamped addressed envelope – THANKYOU!

PROJECT NAME: Body Image, Mood and Quality of Life in Young People Who Were Burned As Young Children: A comparison study with young people who have not been burned.		
Who has written to you and/or spoken to you about this project?		
	Please tick box YES NO	
Do you understand that you may withdraw from the project:		
• at any time		
• without giving a reason		
• without affecting the services you receive from the NHS?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you may choose not to answer any question without giving a reason?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read the letters explaining the research?	<input type="checkbox"/>	<input type="checkbox"/>
Are you happy with the answers given to any questions you have asked about the research? (<i>If applicable</i>)	<input type="checkbox"/>	<input type="checkbox"/>
Have you had enough information?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to take part in this project?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of Participant..... Date.....		
NAME OF PARTICIPANT (IN BLOCK LETTERS)		
Signature of Witness..... Date.....		
NAME OF WITNESS (IN BLOCK CAPITALS)		



INVESTOR IN PEOPLE



Participant consent form – group 2 – aged 18
Version 1 – 3rd March 2004
SCHOOL SAMPLE
A Charity Exempt from Registration under the Second Schedule to the Charities Act 1993

BODY ESTEEM SCALE FOR ADOLESCENTS AND ADULTS

Indicate how often you agree with the following statements ranging from “never”(0) to “always” (4).

Circle the most appropriate response

	Never	Seldom	Sometimes	Often	Always
1. I like what I look like in pictures	0	1	2	3	4
2. Other people consider me good looking	0	1	2	3	4
3. I'm proud of my body	0	1	2	3	4
4. I am preoccupied with trying to change my body weight	0	1	2	3	4
5. I think my appearance would help me to get a job	0	1	2	3	4
6. I like what I see when I look in the mirror	0	1	2	3	4
7. There are lots of things I'd change about my looks if I could	0	1	2	3	4
8. I am satisfied with my weight	0	1	2	3	4
9. I wish I looked better	0	1	2	3	4
10. I really like what I weigh	0	1	2	3	4
11. I wish I looked like someone else	0	1	2	3	4
12. People my own age like my looks	0	1	2	3	4
13. My looks upset me	0	1	2	3	4
14. I'm as nice looking as most people	0	1	2	3	4
15. I'm pretty happy about the way I look	0	1	2	3	4
16. I feel I weigh the right amount for my height	0	1	2	3	4
17. I feel ashamed of how I look	0	1	2	3	4
18. Weighing myself depresses me	0	1	2	3	4
19. My weight makes me unhappy	0	1	2	3	4
20. My looks help me to get dates	0	1	2	3	4
21. I worry about the way I look	0	1	2	3	4
22. I think I have a good body	0	1	2	3	4
23. I'm looking as nice as I'd like to	0	1	2	3	4

SATISFACTION WITH APPEARANCE SCALE

In each of the following statements please circle the most correct response.

	Strongly Disagree	Disagree	Somewhat disagree	Neither Agree or Disagree	Somewhat Agree	Agree	Strongly Agree
Because of changes in my appearance caused by my burns, I am uncomfortable in the presence of my family	1	2	3	4	5	6	7
Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of my friends	1	2	3	4	5	6	7
Because of changes in my appearance caused by my burn, I am uncomfortable in the presence of strangers	1	2	3	4	5	6	7
I am satisfied with my overall appearance	1	2	3	4	5	6	7
I am satisfied with the appearance of my scalp	1	2	3	4	5	6	7
I am satisfied with the appearance of my face	1	2	3	4	5	6	7
I am satisfied with the appearance of my neck	1	2	3	4	5	6	7
I am satisfied with the appearance of my hands	1	2	3	4	5	6	7
I am satisfied with the appearance of my arms	1	2	3	4	5	6	7
I am satisfied with the appearance of my legs	1	2	3	4	5	6	7
I am satisfied with the appearance of my chest	1	2	3	4	5	6	7
Changes in my appearance have interfered with my relationships	1	2	3	4	5	6	7
I feel that my burn is unattractive to others	1	2	3	4	5	6	7
I don't think people would want to touch me	1	2	3	4	5	6	7

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6. Punishment Feelings

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike

- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness

- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying

- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

P.T.O. →

Subtotal Page 1

Continued on Back

11. Agitation

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

13. Indecisiveness

- 0 I make decisions about as well as ever.
- 1 I find it more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

15. Loss of Energy

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0 I have not experienced any change in my sleeping pattern.

- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.

- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.

- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

18. Changes in Appetite

- 0 I have not experienced any change in my appetite.

- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.

- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.

- 3a I have no appetite at all.
- 3b I crave food all the time.

19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

NOTICE: This form is printed with both blue and black ink. If your copy does not appear this way, it has been photocopied in violation of copyright laws.

Subtotal Page 2

Subtotal Page 1

Total Score

Evaluating Your Life

Following are some statements that you might make about yourself. Please circle the number on the scale that best describes how closely the statement applies to you IN GENERAL. There are no right or wrong answers, we are only interested in how you feel about your life.

1. I keep trying, even if at first I don't succeed (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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2. I can handle most difficulties that come my way (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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3. I am able to do most things as well as I want (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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4. I feel good about myself (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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5. I feel I am important to others (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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6. I feel comfortable with my sexual feelings and behaviors (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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7. I have enough energy to do the things I want to do (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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8. I am pleased with how I look (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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9. I feel comfortable with the amount of stress in my life (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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10. I feel it is okay if I make mistakes (*please circle the number*)

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
11. I feel my life has meaning <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
12. My personal beliefs give me strength <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
13. I feel adults treat me fairly <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
14. I feel I am getting the right amount of attention from my family <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
15. I feel understood by my parents or guardians <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
16. I feel useful and important to my family <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
17. I feel my family cares about me <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
18. My family encourages me to do my best <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
19. I feel I am getting along with my parents or guardians <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
20. I feel my parents or guardians allow me to participate in important decisions which affect me <i>(please circle the number)</i>												
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
21. I feel alone in my life <i>(please circle the number)</i>												

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

22. I try to be a role model for others *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

23. I can tell my friends how I really feel *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

24. I am happy with the friends I have *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

25. I am satisfied with my social life *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

26. I feel I can take part in the same activities as others my age *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

27. People my age treat me with respect *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | COMPLETELY

28. I feel left out because of who I am *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

29. I feel my life is full of interesting things to do *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

30. I like trying new things *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

31. I like my neighborhood *(please circle the number)*

NOT AT ALL | 0 1 2 3 4 5 6 7 8 9 10 | A GREAT DEAL

32. I look forward to the future *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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33. My family has enough money to live a decent life *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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34. I feel safe when I am at home *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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35. I feel I am getting a good education *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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36. I know how to get the information that I need *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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37. I enjoy learning new things *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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38. I feel safe when I am at school *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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39. I enjoy life *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL
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40. I am satisfied with the way my life is now *(please circle the number)*

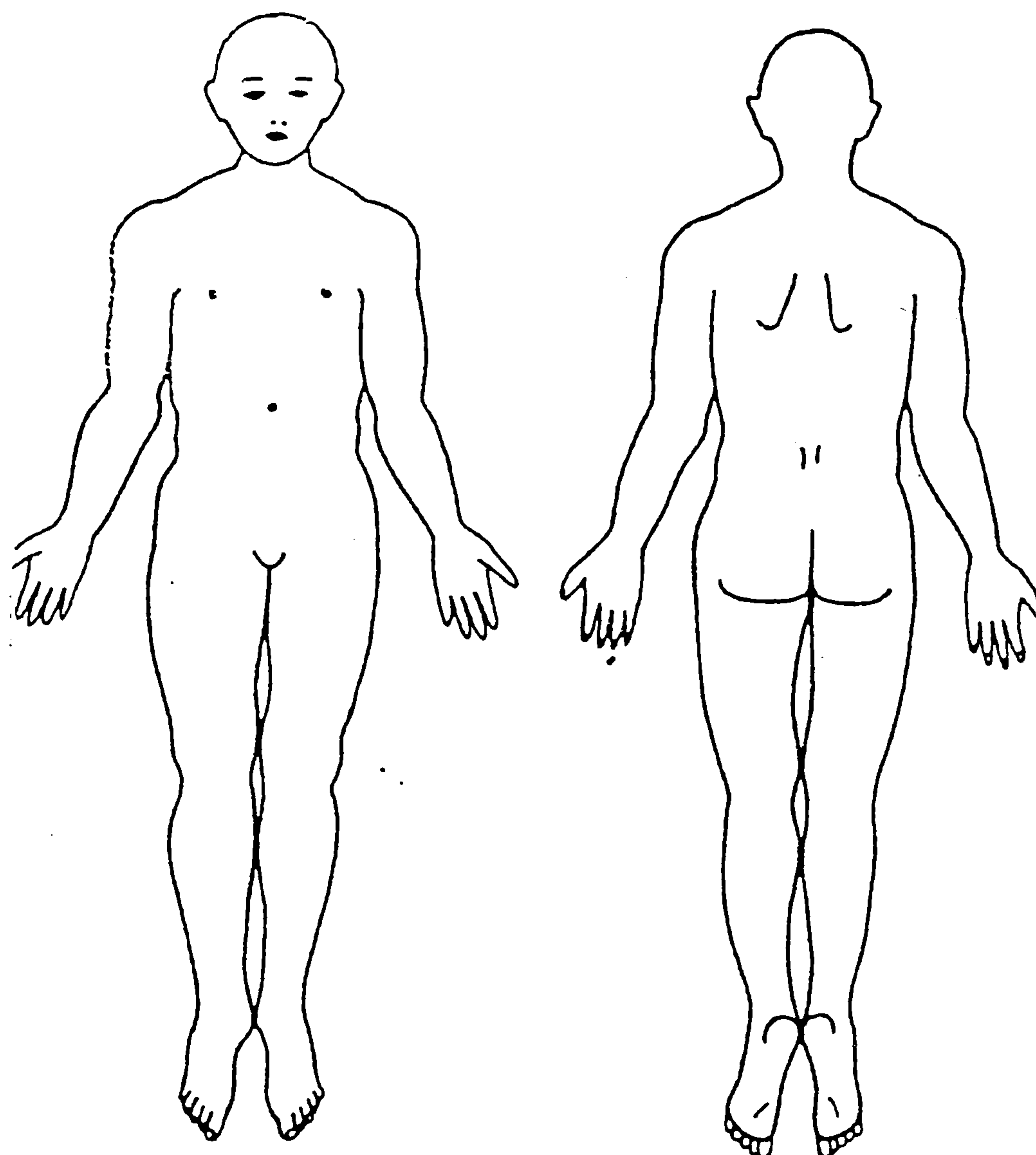
NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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41. I feel life is worthwhile *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	COMPLETELY
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PLEASE ANSWER THE FOLLOWING QUESTIONS

1. Do you have any scars NOW from your burn injury?
2. If YES where are they? Please either describe or draw where they are on the picture below.





North & Mid Essex Local Research Ethics
Committee
2nd Floor
8 Collingwood Road
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Essex
CM8 2TT
Tel: 01376 302224
Fax: 01376 302119

Our Ref: MH 542 – 12-03
Your Ref:

Ms Selina Pope
201B Albion Road
Stoke Newington
LONDON
N16 9JT

3 February 2004

Dear Ms Pope

Re: MH542 - 12-03: Body Image, Mood and Quality of Life in Young People who were burned as young children: A comparison study with young people who have not been burned.

Thank you for your letter dated 24 January 2004 enclosing further documentation. Following further review by the Chair, we are satisfied that your resubmitted application conforms to the requirements of the committee. This study is now given Local Research Ethics Committee approval to proceed. Please ensure that any future correspondence includes our reference number.

You will no doubt realise that even when the LREC has given approval for your project on ethical grounds, it is still necessary for you to obtain approval, *if you have not already done so*, from the Trust in which the work will be carried out. Please contact:

Dr Phillip Smith, Research and Development Co-ordinator, Mid Essex Hospital NHS Trust, Court Road, Broomfield, Chelmsford, CM1 7ET

- It is a condition of the approval that the Committee is advised of research progress annually (a form is enclosed for your use) and that a final report is submitted within three months of completion of the study.
- If the research is terminated prematurely a report is required within 15 days of the termination date giving details of the reason for the early finish.
- Any deviation from, or changes to, the protocol must be submitted to the Research Ethics Committee in writing for consideration *prior* to being implemented.
- The Committee must be advised of any unusual or unexpected results that raise questions about the safety of the research.
- If the research has not started within two years of the date of this letter Local Research Ethics approval will be withdrawn and it is essential that the application be resubmitted.

I wish you every success with your project.

Yours sincerely



MARTIN HARRISON

Chair

North & Mid Essex Local Research Ethics Committee

Email: nmelrec@essexsha.nhs.uk

cc Dr Phillip Smith, Research and Development Co-ordinator, Mid Essex Hospital NHS Trust, Court Road, Broomfield, Chelmsford, CM1 7ET



North and Mid Essex Local Research Ethics Committee

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Tel: 01376 302224

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Our Ref: MH542-12-03

Your Ref:

Ms Selina Pope
201B Albion Road
Stoke Newington
LONDON
N16 9JT

9 March 2004

Dear Ms Pope

Re: MH 542-12-03: Body Image, Mood and Quality of Life in Young People who were burned as Young Children: A comparison study with young people who have not been burned

Thank you for your letter of 3 March and enclosed amendments. I am happy to confirm that this presents no problems on ethical grounds and your study is approved to continue. We wish you every success with your project.

Yours sincerely

MH Martin Harrison
Chairman

North & Mid Essex Local Research Ethics Committee

Email: nmelrec@essexsha.nhs.uk

CRITICAL REVIEW

Body Image, Mood and Quality of Life in Young People Burned in Childhood

Research questions

This study looks at the field of body image, mood and quality of life of young burn survivors. It specifically aimed to address the research questions below.

Main research questions: How does body image, mood and quality of life in young burn survivors compare with body image, mood and quality of life in young people who have not been burned? How are body image, mood and quality of life related in both young burn survivors, and young people who have not been burned?

Additional research questions: How satisfied are young burn survivors with parts of their bodies which are burned, compared to the parts of their parts of their bodies which are not burned? Are the Body Esteem Scale outcomes related to Satisfaction with Appearance Scale outcomes in young burn survivors?

Design

A cross-sectional between-groups design was used to test the hypotheses regarding the differences in body image, mood and quality of life in young burn survivors, and young people who have not been burned. In addition a cross-sectional within-groups design was used to test the hypothesis regarding the satisfaction of young burn survivors with parts of their body which are burned, compared to parts which are not burned.

Setting

Young burn survivors were recruited from admission records at a Regional Burns Unit, and through Burned Children's Clubs in the UK. Most children who require admission to hospital at the time of burn injury will be admitted to a Regional Burns Unit. A Burned Children's Club is a club for children and young people who have survived burns. They usually provide support to young burn survivors, and activities throughout the year giving opportunities to mix with

other burn survivors. The control group were recruited from a mixed comprehensive school.

Participants

32 young burn survivors and 41 young people from the school took part in this study. The mean age for the burn survivor sample was 15.45 years, with a range of 11 to 19 years. The mean age for the school group was 15.10 years, with a range of 12 to 19 years. Within the burn survivors sample, 13 (40.6%) were male and 19 (59.4%) were female. Within the school sample, 18 (43.9%) were male, and 23 (56.1%) were female. The majority of young burn survivors had scalds (18, 56.3%); six (18.8%) had been in house fires; one (3.15%) had a burn from hot fat; one (3.15%) had a contact burn from a radiator; one (3.15%) had a burn from a car fire; one (3.15%) had accidentally set themselves on fire, and one (3.15%) had been deliberately set on fire. This information was missing for three survivors (9.4%). The majority of young burn survivors were burned at the age of 3 or under (20, 62.5%). Six (18.8%) were burned between the ages of 4 and 7, four were burned between the ages of 12 and 15. The information was missing for two survivors (6.3%).

Measures

Young burn survivors

1. Body Esteem Scale for Adolescents and Adults (BES) (Mendelson, Mendelson & White, 2001). This is a generic measure of body image. It measures general feelings about appearance, weight satisfaction, and evaluations of how others see their body or appearance. It has been used in one published study on adult burn survivors (Lawrence, Fauerbach, Heinberg & Doctor, 2004).
2. Satisfaction With Appearance Scale (SWAP) (Lawrence, Heinberg, Roca, Munster, Spence et al., 1998). This is the only burn-specific body image scale in the published literature. However this is a questionnaire for adults, and there is no published data which has used it with young people. It assesses both the subjective appraisal and social-behavioural components of body image among burn survivors.

3. Beck Depression Inventory-II (BDI-II) (Beck, Steer & Brown, 1996). This was developed to measure severity of symptoms of depression as defined by alterations in mood, a negative self-concept associated with self-devaluation and self-blame, self-punitive wishes, vegetative symptoms and alterations in activity level. It is frequently used in psychiatric and general medical populations.
4. The Youth Quality of Life Instrument (Topolski, Edwards & Patrick, 2002) claims to incorporate adolescents' perspectives and language, apply to general and vulnerable populations, and to tap perceptions and feelings. The components of the questionnaire include evaluations of their 'sense of self', 'social relationships', 'environment' and 'general quality of life'. The questionnaire also gives an overall quality of life score.
5. Body Drawing for Scars. This questionnaire asks burn survivors if they have any scarring currently. If they respond YES they are then asked to either describe where the scars are, or to draw where they are on two blank gender-neutral figures (one for the front of the person, one for the back of the person). This questionnaire was developed by the research team.

Control group (school sample)

Participants in the school sample completed the BES, the BDI-II and the YQOL.

Procedure

Hospital participants: Research packs were sent in the post addressed to the parent(s)/guardian(s) requesting that they pass the packs on to their son/daughter. Young people were asked to complete the questionnaires and return them in the post. Participants were asked on the consent form to give permission for their date of birth, admission date, size of the burn and cause of the burn to be extracted from the database. Eight out of the 23 young people returned completed questionnaires.

Burned children's club participants: 17 research packs were sent out by the clubs addressed to the parents, and 5 young people returned completed questionnaires. In addition, participants were asked to give their date of birth, admission date, size of the burn and cause of the burn. In addition, the main

researcher attended two burns camps, 22 young people were asked by the camp directors whether they would like to participate, and 19 chose to participate

Control group: Form tutors distributed research packs. From the 172 packs, 41 sets of completed questionnaires were returned.

Main Results

Body Image

Burn survivors reported significantly more positive evaluations of how others view their body or appearance and weight satisfaction than the school sample. No statistically significant differences were reported in terms of general feelings about appearance. However burn survivors did report marginally more positive feelings about appearance than the school sample.

Mood

Young burn survivors and the school sample reported no significant difference in mood. Mean scores for both groups lie within the 'minimal' range for depression.

Quality of Life

Young burn survivors reported a significantly higher overall quality of life than the young people who had not been burned. They reported a significantly higher quality of life in terms of their evaluation of social relationships and their sense of self. However, in terms of their evaluation of environment and evaluation of their general quality of life, they were similar to the school sample.

Relationship between body image, mood and quality of life

Strong relationships were found between body image, mood and quality of life. Analysis of these correlations revealed a statistically stronger degree of correlation between general feelings about appearance and mood in the burn survivor sample, than the school sample. A statistically stronger degree of correlation was also found between general feelings about appearance and overall quality of life in the burn survivor sample, than the school sample.

Additional results

Young burn survivors reported significantly more dissatisfaction with burned parts of their body than non-burned part of their bodies.

Conclusions

The results of this study suggest that young people who have survived burns appear to be coping well in comparison to their peers who have not been burned, in spite of living with the physical, psychological and social consequences of a burn injury.

Implications for clinical practice

As discussed by Pope (2005), the findings of the current study suggest that young burn survivors may be coping better than some health professionals might expect. Although there may be some biases in the sample, as discussed by Pope (2005), such as self-selection inherent in joining a burned children's club, the results clearly show that young burn survivors have the potential to cope well. This may be both reassuring and motivating to young people, families and professionals. The results may help professionals, such as plastic surgeons and nursing staff, to understand the implications of their work, particularly at the point when people are at the acute stage of the injury. It therefore seems important for health professionals to read the results either in a journal article, or at a conference or presentation.

This study also has implications for information given to parents at the time of injury. As discussed in Pope (2005), parents often experience extreme guilt at the time their children are injured, and may worry about how their children will cope as they get older. Perhaps if future studies also show that many young burn survivors are coping well, this could be incorporated into an information leaflet given to parents at the time of injury. Parents may find this reassuring, which could lessen their feelings of guilt to a degree. Pope discusses how when parents feel guilt, this can impact on interactions with the child, and the child may pick up messages about the social meaning of their disfigurement. This is likely to have long-term consequences for their social and psychological development.

The finding of the strong relationship between body image, mood and quality of life in burn survivors, is likely to have implications for interventions for young burn survivors who are finding it difficult to cope. The findings suggest that interventions focusing on these factors are likely to have significant impact on individuals.

Implications for future research

A particular challenge, which became apparent doing this research, was getting approval from the NHS Trust's Research & Development department. Research with children generally raises a number of issues.

The British Paediatric Association (1992) raise some of the potential problems associated with doing research with children. These include the vulnerability of children, their relative lack of voice, the difficulty of obtaining informed consent, and the possibility that the benefits and harm from research may last many years.

The Medical Research Council (1991) advises that research should only involve children if the same knowledge cannot be gained from research into adults. They also advise that therapeutic studies, (where there may be immediate benefit to the child), should be seen more favourably than non-therapeutic studies where direct benefit is unlikely.

Anxieties surrounding research with children at the moment may be more salient following the tragic incidents at Alder Hey hospital in Liverpool, where organs of children were retained without parental consent and even with forged consent forms, and Bristol Children's hospital where many babies died during or after heart surgery. In the case of the present study, this is compounded by the fact that young burn survivors are viewed as potentially vulnerable children.

McQuaid, Barton and Campbell (2000) highlight one of the difficulties in doing research into body image in a young burn injured population.

“...although body image is a popular concept, it is an uncomfortable personal and political issue and therefore may suffer from the problems of similar discussions of physical appearance and attractiveness of patients with injuries or disfigurement. This is perhaps why few

researchers have looked specifically at body image in children and adolescents with burns” (p.194).

The Research and Development department had many reservations about approving the study, at one point the entire proposal was turned down as they had too many concerns about it, even though the study had already been approved by the Local Research Ethics Committee. This decision was subsequently over-turned, but a number of restrictions were imposed, as described below.

1. The issue was raised of whether young people should be contacted, if they had ongoing child protection issues. Given the nature of the client group, it is possible that some children had acquired their burns through abuse. Therefore case notes had to be checked for any child protection issues by a senior member of trust staff. Then the case notes had to be passed on to the appropriate consultants with the case notes, for their approval. This therefore gave a potential sample bias and meant that those who were more troubled, may potentially be excluded from the study. However, only one young person was excluded because of child protection issues, and one because the surgeon was concerned about the emotional impact the research would have on the family/young person. Researchers should consider these issues, as they may be a potential barrier to doing this kind of work.

This process severely delayed the research as it relied on busy trust staff who were understandably too busy to spend much time on these time-consuming tasks. It also meant that as only about a third of the full case notes were available due to administrative problems at the hospital, an alternative source of young people were required. The research was then extended in order to include young people from Burned Children’s Clubs.

2. Another issue was around the questionnaires being sent in the post, as young people may become upset by the questionnaires, and the difficulty following up any of the issues raised for the young person. They were particularly concerned by a question on the Beck Depression Inventory-II, which asks young people whether they have had any suicidal thoughts or wishes in the last two weeks. The fear was that this question may cause a young person to consider suicide. At the same time, Research and Development did not feel it

was appropriate to phone the young people to help them with any questions, (if they had opted into this on the consent form), which would have given an opportunity to follow up such issues.

There were also concerns about the risk associated with sending sensitive information in the post, should it go missing, and the fear that without a member of the research team present, people may not fully understand what they were consenting to. Young people and parents were given an email address (in addition to a phone number) as a way of contacting the main researcher to ask questions of express concerns. However, the secure nature of the emails was questioned.

3. One issue that regularly arises in research, is that young people should not feel coerced into participating in research. As a result it was stipulated that young people should not be sent a reminder letter about the research. However, this has implications for the response rate.

These difficulties are not uncommon. A recent paper by Stalker, Carpenter, Connors and Phillips (2004) describes the difficulties encountered when the authors sought access to children in hospital in order to explore the experiences of children who spent prolonged periods in health care settings. They discuss the unexpected delays they encountered in gaining access to the children. They relate these difficulties to the role of the MREC and LREC in screening research proposals, recently implemented legislation about data protection, heightened concerns in the NHS about confidentiality and consent, and increased awareness of the risk of child abuse in health care settings. They also suggest ways in which to facilitate the process.

It may be helpful for researchers who would like to build on this research, ethics committees and Research and Development departments to learn that young burn survivors may actually be coping well. It may also be useful for them to know that there were no reports of distress as a result of the questionnaires. Sitting with the young people at camp as they completed the questionnaires meant that their reactions to the research could be observed. Some of the young people voiced that they found the research interesting, and appeared to appreciate the interest that was being taken in them. This suggests that young burn survivors, if asked to participate in research may welcome the opportunity.

While it cannot be claimed that no young person experienced distress because of the questions, none reported feeling distressed, or appeared distressed. Although it is not clear how those who chose not to respond to the questionnaires in the post felt, there were no reports or complaints from parents who had the option of contacting us.

There was concern that questionnaires would be difficult to understand, and that questionnaires would be completed incorrectly, or that parts of questionnaires would be left incomplete. However questionnaires from both samples were almost always completed in full. At camp young people did not appear to find the questionnaires difficult, and all were able to focus on the task without becoming distracted. Therefore, it seems that young people may be more able to complete these types of questionnaires than anticipated.

The current study used the Youth Quality of Life Questionnaire, the Body Esteem Scale and the Satisfaction with Appearance Scale for the first time on adolescent burn survivors. All the measures have been shown to relate to each other, suggesting that they have good convergent-discriminant validity. This may therefore be useful guidance for researchers and clinicians who may be considering using these measures for young people with burns.

In spite of the concern about the question in the BDI-II asking about suicidal thoughts and wishes, no problems were reported. There was also some concern about a question on the BDI-II which asks about changes in interest in sex. There were no complaints about this, however a few of the younger participants left the question blank.

There was a concern that response rate would be low. However out of 23 questionnaires sent from the hospital, 8 young people returned questionnaires, giving a response rate of 34.78%. Also 5 of the 23 research packs were returned by Royal Mail as undeliverable. Most of the young people who were invited to participate at camp, did choose to participate. As the response rate was reasonable, this may highlight an unmet need and a possible lack of service provision for this group.

The need for protection, consent and confidentiality is very important. Also important is the ongoing challenge of ensuring that there is a balance between

ensuring that standards are high, while also ensuring that no excessive restrictions are used as barriers to potentially worthwhile studies. The Department of Health (2001) says that under Research and Clinical Governance, research is “essential to the successful promotion of health and well-being” (p.32).

It is recommended that researchers should build in more time and resources for securing access to young burn survivors, and children generally in research, as this is likely to be time-consuming.

Future Research

It would be useful for a similar study to be conducted in the future, but with some modifications. In the current study, the majority of young people were recruited from Burned Children’s Clubs. Future research should aim to recruit more young people from hospital records who are not known to a Burned Children’s Club. As discussed in Pope (2005), young people who participate in a club may differ in some respect from burn survivors as a whole. Although not statistically significant, the results showed that on all measures, with the exception of evaluations of how others see their appearance, club participants reported marginally more positive outcomes than those in the hospital sample.

As it is important to have a control group who are representative of young people in the general population, it would be helpful if future research used young people from a number of schools from a number of different areas. Perhaps also 16 to 18 year olds could be recruited from work places, as many young people in the general population leave school at 16.

Although the BDI-II was successfully completed by most of the young people in the current study, and was found to be related to other measures, the main disadvantage was that comparison could only be made to student norms where the average age was 19, and all were first year students on a Psychology degree programme in the US. Therefore another questionnaire could be used. The Beck Depression Inventory for Youth (Beck, Beck & Jolly, 2001) is not appropriate for this age group, as it is only validated for children aged between 7 and 14. A better option may be the Center for Epidemiologic Studies Depression Scale for Children (CES-DC) (Fendrich, Weissman & Warner,

1990). This is validated for young people aged 12 to 18. This was not used in the current study, as it is less widely used, and has less of a research-base.

Pope (2005) suggests that further research should look at the coping strategies young burn survivors and their families use in order to counteract the negative consequences of having a burn injury. Studies using longitudinal and qualitative methods may foster greater understanding of these processes. This could later be incorporated into interventions for those who are finding it difficult to cope.

There is little literature on how young people with disfigurements cope, and about interventions. Changing Faces is a UK charity committed to promoting quality of life and well-being for people of all appearances. Partridge (1997) describes the key components of their intervention as teaching practical communication skills that enable people to deal with the reactions of others, and ways of reducing the anticipatory anxiety that leads to avoidance. The main emphasis of their work is helping people to develop their social skills. However other components include helping people to challenge unhelpful beliefs about their appearance, for example that all people are hostile, and encouraging people to work out their own solutions on a trial and error basis. These may be skills that many of the young burn survivors in the current study use. Robinson, Rumsey and Partridge (1996) evaluated this workshop, and found that at 6 month follow-up, adult participants were less anxious, avoided situations less and became less distressed by them, and reported feeling more confident in the company of strangers. They also do similar workshops for young people.

However, this may only give a limited understanding of how young burn survivors cope. A review of the literature on interventions for people with disfigurements by Thompson and Kent (2001), criticises current studies as being uninformed by psychological theory, and tending to concentrate on social skills. They conclude that more needs to be known about the psychological and emotional processes involved in adjusting to disfiguring conditions. Therefore, although social skills may help young burn survivors, more needs to be done to discover further processes involved.

It is planned that this research will be written up as a paper in a peer-reviewed journal. It is likely that the findings will be of relevance to health professionals, as well as psychologists. Therefore the research will be submitted to a

psychological journal, as well as to a more medical journal for health professionals such as 'Burns', or the 'Journal of Burn Care and Rehabilitation'. Further dissemination of the findings will be made to health professionals at the annual conference of the British Burn Association in April 2005, and it is hoped that study will also be presented at a psychological conference.

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