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Traveling with a Stoma. Dr Kate Young, University of Hertfordshire

Abstract

Given the daily challenges that unfamiliar environments, food and culture bring, many ostomists find the prospect of traveling with a stoma stressful. Yet with good advice, international travel can be enjoyed, whether experienced for vacations or work purposes. To practice safely, nurses require knowledge of research evidence, combined with a wealth of practical knowledge, derived from patient experience. This article examines how these types of knowledge can be brought together to ensure that people with stomas are able to anticipate travel in a more positive way.

Key Words

Travel, Stoma, health promotion, nursing, vacation.

Background

Clinical guidelines are written to incorporate best research evidence as well as expert opinion, patient choice and economic considerations (NICE, 2014). It has been argued that nurses should also include information about aesthetics of nursing, organisational aspects of practice and local service variations in their decision making for each patient (Rycroft-Malone, 2004; Chandler et al, 2016). Indeed, Barnwell (2015) writes that stoma care nurses (SCNs) should disseminate “ingenious solutions” to problems developed by people with stoma (PWS) as they engage in stoma self-care. This article will incorporate each type of evidence, discussed by these authors, in examining the issue of travel for PWS.

In one of the first studies in this area, Nugent et al (1999) found that 20% of English stoma care patients reported that their travel was impaired. Since then, stoma appliances have improved, international travel has become more common, and healthcare provision has changed so, though useful, this is now an outdated approximation. More recently, a systematic review, Vonk-Klaassen et al (2015) discovered that travel was still a widespread concern for PWS, replicated across several quantitative studies. Carlsson et al (2010) found that amongst the top ten concerns for PWS six months post-operatively included (ranked highest to lowest): the uncertain nature of disease, depleted energy levels, access to quality medical care and achieving full life-potential. Sun et al (2013) found that it was common for PWS who were surveyed more than 5 years after stoma formation to be concerned about clothing restriction/ comfort, diet and ostomy equipment. They described a constant need to modify or adapt their self-care practices according to everyday situations. Given this, it is easy to understand why travel represents an additional challenge for PWS. However, travel opportunities may be symbolic of a full, independent and healthy approach to life (Steinbach et al, 2011) and is therefore a particularly important element of discussion between PWS and nurses.

In one of the few qualitative studies available, Debirian et al (2010) discovered that all Iranian PWS interviewees (n=14) except one were unconcerned about travel. Although this person mentioned embarking on a long journey of over 20 hours, he made it clear that he felt well-prepared and empowered to deal with this aspect of his life. The study offers a useful perspective on how PWS respond differently in relation to travel, and the potential for stoma nurses to positively influence this. The study is particularly interesting because a person's attitude to travel may possibly be explained by cultural, economic and environmental norms and expectations as with other aspects of psychosocial adjustment to stoma (Fujimori et al, 2007; Simmons et al, 2011).

Further, Simmons et al (2011) warned that unless health care professionals engaged in nuanced cultural adaptations to practice advice, they would be in danger of "falling short" of ensuring best outcomes are achieved for PWS. Black (2009) writes of the need to offer sensitively designed adaptations to stoma care and advice to PWS according to culture and religion. Both of these points are particularly relevant for travel. PWS may need to discuss the implications and choice about whether to travel and this can be affected in three ways. Firstly, for those who travel within this country, who may need to adapt their usual practices to variations in environment, food and infrastructure. Secondly, for those who have exacting religious requirements which are likely to create conflict in travelling itineraries and practices which impact self-care of stoma. Finally (and more commonly), PWS who are considering international travel destinations which are challenging for cultural, religious, nutritional, infrastructure (such as poor provision of water supply, public conveniences or transport links) or environmental reasons (such as different standards in hygiene practices leading to increased risk of food poisoning, infection or viral transmission). Each of these circumstances call for nurses to provide individualised travel information as they support self-care activity with PWS.

Knowles et al (2014) have reported on the process of psychological adjustment which takes place as PWS adapt to their stoma / underlying physical condition. Using complex modelling of different validated psychological scales, their work suggests that the degree to which PWS develop positive or negative perceptions of illness is extremely important as the *precursor* to individual coping ability, which, in turn, affects positive or negative emotional or mental health outcomes. They suggest that PWS may best be helped if they are given good psychological care and information about their illness prior to discussion of lifestyle choices and adaptive coping strategies. Their work indicates that positive, but realistic messages about prognosis and underlying disease are important before attempting any discussions about potential lifestyle choices, not just prior to travel.

Different psychosocial responses to stoma formation are experienced by PWS according to a wide range of factors, including stoma type, underlying disease, gender, age, personality, religious belief, marital status and occupation (Danielsen et al, 2013). Stoma research is commonly focused on a subset of the population defined by these categories, which makes it difficult to generalise findings to the population as a whole (Danielsen et al, 2013). What is known is that 34% of stoma formation related to colorectal cancer are not seen pre-operatively (Lynch et al, 2008), and that access to quality medical care is a high concern for this group 6 months after surgery (Carlsson et al, 2010). Although PWS evaluate visits to SCNs positively, SCNs are likely to be under considerable pressure in achieving positive psychological outcomes as provision is not yet at recommended levels (Bowles, 2012; RCN, 2009). Knowles et al (2014) suggest that the most efficient way to achieve this is for healthcare professionals to identify strategies which are likely to develop positive illness perceptions and reduce unhelpful illness perceptions. *After this*, facilitation of discussions which emphasise solutions and achievements in self-care, rather than problems, are more likely to be successful (Krouse et al, 2009; Torquato-Lopes & Decesaro, 2014). Better self efficacy and adaptive coping ability in PWS is associated with lessened anxiety and depression (Knowles et al. 2014).

Preparing for travel.

For those PWS who have internet literacy, the Colostomy Association (2012) (www.colostomyassociation.org.uk) contains a wealth of practical advice for those with stomas who are considering travel at home and abroad, as does stomawise (www.stomawise.co.uk). Both organisations are keen to emphasise the importance of planning ahead and preparation before travel as the key to achieving a positive experience and reducing anticipatory anxiety. Maintaining adequate supplies, disposal of used equipment and access to disabled toilets are amongst the main practical concerns listed when travelling. Recommendations to address supply concerns include packing twice as many items for stoma care as usually needed in the time period the PWS is away from home. This will avert shortages since more frequent stoma bag changes might be required due to alterations to diet; leisure activity e.g. swimming; heat perspiration and routine. In the same way that PWS adapt routines when away from home, whilst traveling they may choose to use of flushable liners for stoma bags, drainable bags which can be emptied, or alternatively emptying usual bag (then bagging and sealing used stoma bag in bin provided).

Access to 9000 disabled toilets in the UK may be through use of a RADAR key, which is available through the Colostomy Association for minimal cost.

It is important that PWS have all of the information about equipment product codes and supplier contact numbers in case of urgent need (they will endeavour to supply internationally in emergency) and a travel certificate explaining medical condition in order to ensure that communication with local health services is negotiated smoothly (available in different languages from the Colostomy Association – www.colostomyassociation.org.uk, or from stomawise http://www.stomawise.co.uk/stomawise-store/stomawise-travel-certificate. These require signing by the GP).

Travel insurance is available for PWS when going abroad, but some insurance companies that have arrangements with organisations which exist for PWS. Although most insurances companies will be able to deal with queries, several companies have developed specialised knowledge / a proven track record of dealing with travel issues relating to stoma care. Other advice about insurance is exactly the same as any other person travelling; primarily to declare all existing medical conditions and ensure adequate cover. Certain destinations are cheaper to insure than others, and it is also cheaper when PWS are at least 12 months post-stoma formation.

Ostomists will also need to plan appropriate stoma management before they begin any journey. They will need to consider preparing equipment such as flanges ahead of the journey if they are unable to use scissors whilst being transported (for example during aeroplane travel as these may not be allowed in carry-on luggage or if on a long journey across uneven terrain). The cardboard tube technique for changing or emptying bags may be helpful (Heale, 2013) if turbulence is likely, or if difficult terrain is to be covered for long distances. Here, a pre-cut piece of disposable tubing is placed over the stoma and removed after securing the adhesive wafer to ensure that skin damage to surrounding tissue is prevented.

Plane travel causes concern for reasons of diet and fluid restriction and the effect of pressurised cabins on intestinal gas and production. Williams and Varma (2011) recommend larger or drainable pouches for colostomists for these reasons. These authors recommend that PWS which have been recently formed should not fly (because of increased risk of torn suture lines, bleeding or perforation) and those with partial asymptomatic small or large bowel obstruction should not travel by aeroplane (gas expansion may cause rupture). Liquids required for stoma care must not exceed current aviation security rules, and The

Colostomy Association (2012) recommend that all ostomy supplies are packed in hand luggage, to avoid accidental loss of supplies in other luggage.

Destination Concerns

Diet & Nutrition

It is important to note that 79% of PWS say their stoma does not affect enjoyment of their food, although approximately two thirds of people with colostomies and ileostomies (PWCI) report that they avoid certain foods because they affect stoma output (Richbourg, 2012). Beans, garlic, eggs, corn and peas oranges, ice cream, papaya and soft drinks are often said to cause flatulence or odour for many PWS (Palludo et al, 2011). Fulham (2008) points out that there are more foods that may cause problems for ileostomists than for colostomists, but these can be addressed by thorough chewing. Richbourg (2012) found that those most problematic were plant based fibrous foods, especially nuts or pulses. Yet professional advice about diet is often contradictory and this is mirrored in lay organisations. This may reflect the idiosyncratic nature of food intolerance (Richbourg, 2012).

Unfamiliar foodstuffs could become a potential risk to stoma management in terms of changes rates of output, flatulence and odour. Online advice from the Colostomy Association and Stomawise advise PWS to choose cooked foods rather than cold foods (which may have been washed in contaminated water in countries where environmental health standards are poor).

SCNs should offer precautionary dietary guidance, based on the risks to PWS, but more importantly they should emphasise an increased risk of dehydration associated with hot weather and higher output, particularly to those with ileostomy (Williams and Varma, 2011). PWS should keep hydrated by sipping regularly rather than taking on large amounts of fluid in one sitting, and should drink bottled water and avoid ice in drinks unless local supplies are free from contamination (The Colostomy Association, 2014; Stomawise online). Carrying electrolyte replacement medications as a precautionary measure are also recommended by these bodies.

Infrastructure Challenges.

Juul and Preito (2008) conducted a systematic review of papers examining quality of life for those with intestinal stoma, finding that fatigue was a major source of concern. This was primarily thought to be due to the problems that PWS have sleeping, due to leakage and associated anxiety. Jansen et al (2015) found that fatigue and sleep problems were ranked similarly for PWS whether they had the stoma sited for cancer or for other reasons. Pacing activities wisely throughout the day to avoid post-exertional energy depletion may be helpful as with other patients who are prone to fatigue (Barlow et al, 2009). Williams and Varma (2011) indicate that PWS should be able to travel and enjoy their holidays with no ill effect, providing that they plan well and manage their fluid and electrolyte balance appropriately. They give case studies of 3 people who had travelled long distances across the world and the only mention of tiredness came from the person with an ileostomy who had become dehydrated extremely quickly through amoebic dysentery. Increased risk of infection is sometimes a feature of foreign travel, but PWS will need to be more aware of this aspect and its influence on stoma, fluid management, hygiene practices and dietary self-care.

Infection Prevention

Both Stomawise and The Colostomy Association advise that PWS clean their stoma and skin with bottled water as a means of avoiding infection when travelling in countries with poor water quality or hygiene. Williams and Varma (2011) recommend that water used for irrigation can be warmed with a portable water heater for travelling. Food poisoning can be avoided by using the same nutritional guidelines as anyone else in these countries, although PWS should be aware of symptoms (loose stool and stomach cramps – Burch, 2015) and associated dehydration (light headedness, tiredness, headache, dry mouth, reduced stoma output, muscle weakness, pulse abnormalities) in ileostomy or jejunostomy which can occur very quickly, as large amounts of faecal output occuring together with increased perspiration may require swift action (Williams and Varma, 2011). There is an increased risk of infection in countries which have hot weather, and stoma appliances may not adhere normally due to perspiration (Williams and Varma, 2011; Stomawise, online). Adhesion problems may be addressed by applying a barrier spray or protective powder to the skin (Bartle et al, 2013) or skin-sensitive antiperspirant spray. Rudoni and Dennis (2009) found that SCNs would recommend hand cleansing gel for use when travelling to areas without easy access to handwashing facilities or where hygiene is an issue.

Conclusion

Travel is a normal and enjoyable part of life, but it can be a challenging prospect for many PWS. Stoma Care Nurses can play an important role in preparation for travel, giving tailored psychosocial support based on research evidence, expert opinion and patient recommendation. With careful planning, based on information designed to minimise the effects of journeys and maximise adaptation according to destination, PWS can experience travel positively.

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