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REVIEW

Optimal support systems for patients with stomas – an opinion piece

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Jennie Burch

St Marks Hospital, Surgery, London, UK

Abstract: Coping with a stoma is physically and emotionally difficult. This adaptation process can be hindered by various factors, including complications associated with the stoma, such as appliance leakage, and comorbidities, such as arthritis. There are many ways of learning to live successfully with a stoma, which may be influenced by family, health care professionals, and spiritual support. There is some evidence that a good social support network can result in a positive coping mechanism for people with a newly formed stoma. Difficulty in accepting the stoma has been shown to slow down the adaptation process. This article explores the basic issues related to stomas and the general preoperative and postoperative support that is supplied by health care professionals. There was no optimal support system protocol discovered in the review of the literature. However, some of the published data related to stoma care were extrapolated to enable the reader to understand the important role that support systems can play in the acceptance of the stoma. Health care professionals provide support in a variety of ways, including the provision of telephone advice, clinics, and "open days", to assist the patient to come to terms with their newly formed stoma. Care includes training on the practical aspects of the stoma, supporting empowerment and self-efficacy of people with a stoma (ostomates), and providing assistance when problems arise. Other support systems that are available are support groups, which may be local or national. It can be seen that the adaptation process takes many months or longer, but by utilizing various means of support, people with a stoma can have a good quality of life. The optimal support systems for patients with a stoma are discussed in relation to the literature and the personal experience of the author.

Keywords: colostomy, ileostomy, urostomy

Introduction

There are an estimated 100,000 people with a stoma in the UK.[1] Stomas are commonly encountered by nurses, who may be in a powerful position to positively help ostomates to adapt to life with a stoma. Adaptation to the stoma can be difficult as there is a change to the person's body and thus, their body image.[2] With a stoma, there is a rerouting of the feces and flatus, or urine, which can lead to concerns about regressing back to childhood. There can be fears that the stoma appliance will be noisy or leak. The person with a stoma might also worry about reintegrating aspects of their previous lifestyle, including work and sexual relations.

Correspondence: Jennie Burch
St Marks Hospital, Room 5x006, Watford Road, Harrow, Middlesex, HA1 3UJ, UK
Tel +44 078 2560 6020
Fax +44 020 8235 4001
Email jburch1@nhs.net

Stomas

There are three main types of stoma, also termed ostomy. The types of stoma are the colostomy, ileostomy, and urostomy (the latter is also termed an ileal conduit).[3] The person with a stoma can be termed an ostomate or ostomist.

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Colostomy

A colostomy is formed from the colon and will pass formed feces and flatus. The stomal output is collected and contained in a closed appliance.[4] The closed appliance is generally changed between three times a week and three times a day; this will depend upon a variety of different factors, such as where in the colon the colostomy is formed.

Ileostomy

An ileostomy is formed from the ileum and will pass loose feces and flatus. The stomal output is collected and contained in a drainable appliance. The drainable appliance is usually secured with a Velcro-type fastening. The drainable appliance is generally changed daily or on alternate days. The appliance requires emptying multiple times daily, most commonly between four and six times. The frequency with which the ileostomy appliance is emptied will depend upon a variety of things, including the diet and fluids that were consumed.[5]

Urostomy

A urostomy is most commonly formed from the ileum but can also be formed from a segment of colon; the former is termed an ileal conduit and the latter a colonic conduit. The stomal output will be urine, with a small amount of mucus from the conduit. The stomal output is collected and contained in a drainable appliance. The drainable appliance is usually fastened with a bung or tap, to allow release of the urine. The drainable appliance is often changed on a daily or alternate-daily basis. The appliance needs to be emptied about four to six times in 24 hours, depending on the volumes of fluids consumed. To aid a restful sleep, a nighttime drainage bag can be fastened onto the bottom of the appliance.[4]

Stoma appliances

The stoma appliance may also be termed a stoma bag. The two types of stoma appliance are a one-piece appliance or a two-piece appliance. As the name suggests, with the one-piece appliance, the adhesive part of the appliance and the collection part are joined. The adhesive part is also known as the flange, baseplate, or faceplate. With a two-piece appliance, the flange and the collection part are separate and must be joined by the ostomate. Older appliances were joined by rings that clipped together; more modern two-piece appliances are joined by adhesive.[4]

Literature search

A literature review was undertaken to establish the optimal support systems for patients with stomas. When examining the Cochrane database with the search terms "stoma" and "ostomy," nothing relevant was discovered. When entering "optimal support system" into a database search, including MEDLINE and CINAHL (Cumulative Index to Nursing and Allied Health Literature), no articles were discovered related to stoma care. When searching the National Institute for Health and Care Excellence (NICE) (http://www.nice.org.uk) for guidelines, no specific guidelines were found related to stoma care. However, there were NICE guidelines discovered for colorectal cancer.[6] These guidelines discuss stomas, suggesting that prior to surgery, stomas need to be discussed with the patient. The guidelines also instruct that a trained stoma professional should give specific information on the care and management of stomas to patients considering surgery that might result in the formation of a stoma. The NICE guidelines on inflammatory bowel disease are currently being developed. Thus it can be seen that there is limited guidance on stoma care available for health professionals who will provide care.

UK stoma care guidance

There are approximately 650 stoma specialist nurses in the UK.[7] There are several documents to guide the stoma care provided in the UK. Three of these were written in the past few years, two that were published on behalf of the Royal College of Nursing and one by the World Council of Enterostomal Therapists UK. These will be briefly explored.

The oldest of the three articles was written for the Royal College of Nursing in 2003. Its conception was the result of a conclusion, following court cases, that it was necessary to guide stoma specialist nurses in relation to documenting the care they provided. Breeze and Cottam were the authors of the document, entitled "Documentation in Colorectal and Stoma Care Nursing."[8] They drew guidance from a number of government documents on the subject. The authors discuss specific documentation that needs to be recorded in the patient's notes (although it should be remembered this was written before electronic records were commonly utilized). They considered that it was essential to include information such as the patient's name and date of birth, and the date and time. Breeze and Cottam also discuss the quality of written documentation, stating that it should be objective and factual but without the use of terminology.[8] Furthermore, they state that telephone calls, as well as face-to-face contacts, should be documented. Finally for documentation, the writing should be in black ink, legible, and signed (more recently, it has also become essential to add the health care worker's surname and status, such as

registered nurse). Breeze and Cottam also provide, as an appendix, additional specific details to be documented, to guide the reader.[8]

In 2008 a group of stoma specialist nurses from the World Council of Enterostomal Therapists UK published a document entitled "Role Descriptives of a Stoma Care Nurse Specialist."[9] This document contains many facets of stoma care, including reasons for stoma-forming surgery and complications associated with stomas. In relation to the role of the stoma specialist nurse, there are several topics developed, including definitions of the role and scope of practice. The latter includes care of problem stomas, stoma siting, and discharge planning. Furthermore, issues such as leadership, evidence-based practice, education, and long-term follow-up are explored. In relation to follow-up, it is anticipated that the nurse should offer education and advice on issues such as treatment options for complications; the authors also address empowerment of patients in their stoma management, provision of psychological support, regular review of stoma patients, and monitoring of clinical activity through the use of audit.

In 2009 the Royal College of Nursing published "Clinical Nurse Specialists − Stoma Care."[10] This document includes basic explanations of stomas and the role of the stoma specialist nurse, describing the need to address issues such as provision of information and support for patients, their caregivers, and relatives. This information provision will include preoperative care for patients having planned and emergency surgery. Furthermore, there will be specialist nursing care during the time in hospital and continuing support. In the provision of care, there will be education and discussion with relevant health care professionals involved in the care of the ostomate − the stoma specialist nurse also needs to be involved in the education of colleagues. Furthermore stoma specialist nurses need to develop detailed discharge plans, working with the relevant health care professionals in the hospital and community. Finally there should be delivery of ongoing support to the patient and family, to provide advice when necessary. To ensure that the quality of care is maintained at a high level, there should be research and audit. To aid the reader, there are examples of how this works in practice, throughout the document.

The translation of these documents and other literature into practice will be discussed in the following sections; methods for providing optimal support systems will be drawn from the available literature and, in the absence of specific guidance, from the author's personal experience.

Preoperative support

Prior to planned stoma formation, there should be provision of preoperative information, to prepare the ostomate for the stoma. Part of the preoperative care will include stoma "siting." Stoma siting is the placement, by the stoma specialist nurse, of a mark on the abdomen where the surgeon will form the stoma. This site is placed in a position that the patient can see and reach, but the site also needs to avoid creases and scars. The siting of the stoma is undertaken with participation from the patient. The preoperative siting allows optimal positioning of the stoma by the surgeon,[11] which may reduce the risk of postoperative complications, such as a leaking appliance.[12] Beginning with preoperative stoma care, patients are empowered to become involved in the care of their stoma.

There are practice "change kits" available that the stoma specialist nurse can use with patients preoperatively to commence practical training.[13] Chaudhri et al suggest that a structured preoperative training plan enables a safe and early discharge home from hospital following stoma-forming surgery.[14] Bryan and Dukes found, in their research, that by rearranging patient education to include preoperative stoma training, their patients were safely discharged home within 5 days of surgery.[15] In the preoperative period, nurses are able to positively support patients so that they can begin to mentally adjust to the prospect of having a stoma.

Postoperative support

It is essential to ensure that patients are discharged home from hospital with adequate understanding about the care of their stoma as this has a positive effect on their quality of life.[16] Therefore, it is essential that during the hospital stay, the stoma specialist nurse teaches the ostomate the practical care of the stoma appliance. The basic appliance change technique will include collection of all the necessary equipment, gentle removal of the old appliance, thorough cleaning and drying of the skin around the stoma, and then, application of the new, correctly sized and placed stoma appliance, with appropriate disposal of the rubbish. It is also essential to ensure that the ostomate knows what is normal and who to seek help from if a problem occurs. The postoperative care provided by the multidisciplinary team enables the ostomate to feel supported, aiding the ostomate in the path to accepting the stoma and new body image. This was confirmed by Piwonka and Merino, who used a questionnaire to examine how people with a colostomy adjusted to their stoma.[17] They discovered that adequate instruction on self-care helped people to adjust to their new body image.

With advances in postoperative care, such as enhanced recovery pathways, the length of time spent in hospital is reducing,[18,19] often to a few days.[20] There is UK government support of the enhanced recovery pathway, with the Department of Health being involved in guiding and promoting the Enhanced Recovery Partnership Programme.[21] There is also international support and guidance for this initiative, from the Enhanced Recovery After Surgery (ERAS®) Society, which offers an informative website at http://www.erassociety.org. ERAS consists of a variety of elements that commence preoperatively. Preoperative care includes counseling patients about their surgical experience and includes stoma care training as mentioned before, bowel preparation is no longer routinely used and fasting is not prolonged and patients are given a carbohydrate drink to be completed two hours preoperatively.[22] During the operation the excessive use of sodium and fluid overload is prevented, there is provision of antibiotics and antiemetics, the anesthetics used are short-acting to prevent postoperative drowsiness.[19] In the postoperative period there is no nasogastric tube, eating, drinking and mobility recommence the day of surgery, there is gut stimulation and urinary catheters are removed the day after the operation.[18] Finally there is audit of results to ensure that evidence-based care is being provided. All of this is encouraged; but can vary depending on the patients condition.

While there are many advantages to the enhanced recovery pathway, including less separation from family and a 50% reduction in complications,[22] there are also drawbacks to a shorter period of time in hospital. There is less time during the hospitalization period for the ostomate to learn how to care for their stoma and to become adjusted to it. However, as patients recover more quickly in the immediate postoperative period compared with traditional care, it is possible to start to educate them on their stoma care on the first postoperative day. In addition, preoperative training has proved to be effective and to reduce the duration of postoperative training.[15] Another benefit of the enhanced recovery pathway is that it encourages independence and involvement by patients in their own care, which is consistent with the philosophy of being independently able to manage the practical aspects of stoma care ie, changing the appliance and emptying (if appropriate). Intensive stoma care training, as provided on the enhanced recovery pathway, was found to be acceptable by patients.[15] Anecdotally, self-care with respect to the stoma appliance change is a first hurdle that ostomates need to overcome on the pathway to acceptance of their stoma.

Discharge criteria

It is essential that people with a newly formed stoma are adequately prepared for discharge from hospital.[24] Francis suggests that there are a number of essential criteria that need to be met to enable a safe discharge home.[25] These criteria include mobilization to preoperative levels, tolerable pain on oral analgesia, passage of flatus, and to be apyrexia. It is essential that stoma management be undertaken independently prior to discharge home, to ensure that the ostomate is fully prepared once they are home, where the long-term recovery begins. Stott et al report that a third of patients were not confident in their stoma care at the time of discharge,[26] although interestingly, satisfaction with the stoma care service was high. Conversely, once home, most Chinese patients felt they were able to care for their stoma, with a high level of confidence.[27] Thus it could be presumed that although some ostomates were not confident, they were able to undertake the care of their stoma, suggesting that training on the practical care of the stoma was efficacious. Anecdotally, during the time in hospital, ostomates may not be able to fully focus on issues such as returning to work or other social activities. It is thus important to address these and other topics again at a subsequent date.

Physical issues

If there are problems associated with the stoma, it is more difficult to learn to adjust to life with a stoma than without such complications. Salter undertook a qualitative study related to quality of life, comparing people with a stoma and people with an internal pouch who no longer had a stoma.[28] One issue that six out of seven ostomates identified was that the stoma appliance was noisy and there was gaseous distension of the appliance, which at times led to the appliance leaking. This resulted in concerns that clothing would be soiled and about "regressing back to childhood," and in a low self-esteem. Often patients felt that they could not wear "normal" clothing as they needed to disguise their stoma appliance as it filled. Clothes, including underwear and swimwear, are available that are specifically designed to disguise stoma appliances. Wu et al also reported that ostomates found that gas and odor were embarrassing.[27] It should be noted that Salter undertook her research some time ago, and modern appliances have improved flatus filters that more readily release flatus from the stoma appliance.[28] Furthermore Wu et al undertook research in Hong Kong, where stoma appliances need to be paid for by the ostomate

and thus, may be cheaper and may not be the most up-to-date or appropriate model.[27] The nurse can advise on emptying appliances regularly to prevent overfilling (which can lead to appliances being more visible under clothing and prone to leaking). Erwin-Toth et al reported that quality of life could be improved with effective management of problems such as appliance leakage;[29] which seems logical.

In Hong Kong, when examining the quality of life of people with a stoma, it was established by Wu et al that older patients had less self-efficacy than did younger ones.[27] This could be explained by the fact that older people are likely to have comorbidities, such as reduced manual dexterity. Reassuringly, the authors did report that the majority of their elderly patients with a permanent colostomy were able to care for themselves. In my practice, only patients who are unable to live independently are generally unable to manage their stoma.

When various issues related to quality of life and rectal cancer were examined by Bloemen et al,[30] the researchers found that people with severe postoperative complications had significantly worse physical function affecting their daily activities when compared with patients with no or few complications. This was an expected finding; however, it was unexpected that respondents without a stoma reported more problems with bowel dysfunction, namely, diarrhea and constipation. Theoretically, anal incontinence might result from diarrhea, which may be worse than the worry of a leaking stoma appliance. It is therefore important for health care professionals to provide support and treatment for issues such as stomal complications or bowel dysfunction.

Psychological issues

It is essential to evaluate how a person with a newly formed stoma is coping psychologically. This may be done through the use of a questionnaire to monitor quality of life, such as described by Baxter et al,[31] or more informally.

There are a variety of studies that discuss how patients cope with a stoma. Wade undertook research on how well patients adjusted to their colostomy formation and reported that 20% had psychological problems.[32] This was also found by White and Hunt, who reported that about a quarter of patients experienced significant psychological symptoms.[33] Krouse et al undertook research to investigate the quality of life for people having surgery for rectal cancer.[34] They suggested that women report a poorer quality of life than men, but both sexes were more likely to be depressed and suicidal than were people without a stoma. Krouse et al reported that twice as many woman as men felt depressed after their stoma-forming surgery.[34] This was also reported by Wu et al, but they argued that men might not readily express feelings and may be more conservative about discussing issues that do not make them look masculine.[27] Notter and Chalmers reported that depression often took months to resolve, and it is therefore important for health care professionals to evaluate depression.[35] Although most nurses are not trained counselors, their general nurse training allows appropriate assessment of their patients. If an ostomate is considered to be depressed or requires support that the nurse cannot offer, a referral can be made to a counselor or psychiatrist. Reassuringly, a Cochrane review by Pachler and Wille-Jorgensen examined quality of life and stomas, and the authors challenged the assumption that people with a stoma fare less well than people without one.[36]

Pittman et al suggested that the presence of a stoma impaired health-related quality of life.[37] They further stated that the impairment is most severe in the immediate postoperative period. Reassuringly, the ostomates' quality of life improves most dramatically during the first 3 months but continues to improve during the first year after stoma formation. This was also reported by Ito et al, who examined quality of life after curative rectal cancer surgery that resulted in a permanent colostomy.[38] The group reported that results from their questionnaire found that at 2 months after surgery, quality of life was at its lowest but had almost returned to preoperative levels by a year after the operation. Recalla et al, in their systematic review, reported that older people adjusted to life with a stoma more quickly than did younger people, taking 6 months and a year respectively.[39]

Pittman et al suggested several factors that contribute to a poor quality of life, namely, complications related to the stoma, poor postoperative sexual function, increased age, and financial issues.[37] They explored the topic and suggested that an intensive follow-up that consists of a monthly review of the ostomate was of greater benefit than was ad hoc standard care to help the ostomates adjust to life with a stoma. Erwin-Toth et al also suggested that regular contact with the stoma specialist nurse improved health-related quality of life.[29] It could be surmised that ostomates require more support in the first 3 to 6 months, to assist them to adapt to their newly formed stoma.

Advice and guidance

O'Connor et al reported that stoma specialist nurses were the most common source of information, and direct conversation was the preferred method to convey this.[40] Unfortunately Kerr

et al reported that many of their respondents were unhappy with the lack of information provided, specifically related to stomal irrigation, chemotherapy, and radiotherapy.[41] This is further supported by the work of Beaver et al that reported ostomates frequently commented that they learned about stoma care through "trial and error."[42] Beaver and colleagues also reported that ostomates felt that follow-up care did not provide sufficient information on topics such as provision of stoma bags.[42] Conversely patients experiencing nurse-led follow-up reported favorably on their outpatient experience in terms of information, support, and knowing what to expect and what was "normal" in their situation. Written information was also perceived to be helpful. Wu et al suggested that health care professionals should ensure that teaching materials are appropriate.[27] Anecdotally, written patient information is reviewed by a variety of people that include patients, but it is not often available in other languages, which puts patients who do not speak English at a disadvantage.

Some ostomates prefer to find their own information on the internet.[40] Wu et al have suggested that ostomates with a higher level of education have better coping mechanisms as they were more easily able to access assistance.[27] A higher level of education has also been associated with better postoperative recovery in relation to sexual function.[43] It is thus important, not only to provide information but also, to empower the ostomate to access suitable information and support, such as via official stoma support group websites.

Spiritual issues

Krouse et al reported different ways in which men and women cope and adapt to disease and chronic illness.[34] Women engaged more with coping behaviors and sought social support, such as emotional and spiritual activities, more often than did men. It is interesting that Li et al found people with a strong spiritual well-being coped better with adjusting to their stoma than did people without spirituality.[44] Thus, addressing spirituality is necessary after formation of a stoma, particularly for women.

Economic issues

In America, patients with a stoma reported financial difficulties, even when they had medical insurance.[34] Interestingly, the authors who found this considered that such concerns might be alleviated through supportive interventions, such as counseling. Finances are also an issue in Hong Kong, where ostomates receive subsidized stoma products.[27] Even in the UK, where stoma products are free, it is possible that ostomates may be unable to work, and this may lead to financial difficulties. Notter and Chalmers found, using a questionnaire to investigate living with a colostomy in the UK, that although only a quarter of ostomates had reduced or stopped work, about 15% were adversely affected financially.[35] Interestingly, people in Taiwan who experienced financial difficulties also reported worse psychosocial adjustment to life with a stoma.[44] It is therefore important for nurses to have an understanding of other issues that might affect postoperative recovery.

Resuming activities after stoma forming surgery

There are many activities that the ostomate may feel cautious about resuming after stoma-forming surgery. When discharged home from hospital, for example, it is advised that strenuous activities and certain food types be avoided for a short period of time; this can, anecdotally, result in concerns about how and when to experiment with diet and resume activities in the postoperative period.

Wu et al reported that Chinese patients did not feel confident to resume previous activities[27] such as scrubbing floors and lifting heavy objects. The authors surmised that patients were afraid of damaging their stoma or causing a parastomal hernia. They also suggested that some patients might feel weaker after surgery and thus avoid heavy work. It is therefore important to empower ostomates, helping them to understand when to rest and that activities should be gradually reintroduced into their lifestyle, as appropriate to their recovery. There is research to suggest that use of an abdominal support and undertaking abdominal exercises will assist in the prevention of a parastomal hernia.[45,46]

Krouse et al identified that intimacy was the most affected issue for both men and women.[34] Wu et al also reported that about 30% of ostomates lacked confidence in relation to sexual activities but also, that many did not respond to this topic in the questionnaire.[27] This suggests that even discussing the issue of sexual relations is difficult. Bloemen et al discussed men with rectal cancer but not specifically men with a stoma, and the majority had sexual problems.[30] This is likely to occur in relation to the surgical procedure, where nerve damage that results in sexual dysfunction is common. Ayaz and Kubilay discussed a variety of issues that can affect ostomates psychologically, such as altered body image, anxiety, and embarrassment.[43] Physical issues include a leaking appliance or nerve damage to the sex organs, and all may lead to changes in sexual interest or avoidance of sexual contact. Reassuringly, they reported that over time,

positive feelings replaced negative ones. Ayaz and Kubilay have suggested that as people with a stoma adapt to their altered body image, they experience a decrease in anxiety and more positive feelings, which beneficially affects their sexual life.[43] The authors also suggested that even when there are initial problems in the relationship with their partner after stoma-forming surgery, these can be overcome by discussion, which can resolve negative feelings of loneliness, frustration, anger, and disappointment. The topic of sexual relations and intimacy is often difficult to discuss for both patients and nurses, but it is nonetheless important to discuss this, to provide support and advice.

Support systems

A support system can be seen as a network of facilities and people that can be approached for assistance. In the UK, this can comprise a large range of people, including family, friends, health care professionals, and other ostomates.

Coping mechanisms

There are a number of ways that people cope, and these will briefly be examined. Coping mechanisms include adaptive, behavioral, and cognitive mechanisms through which people change how they think or behave. Some people act aggressively or avoid potentially difficult situations. Examples of the latter can include avoiding going out to dinner or visiting new places, due to lack of toilets.

Family and friends

In general family, significant others, and friends can be an immense source of support. Notter and Chalmers reported that in a UK survey of people with a colostomy, 40% of ostomates restricted social activities with friends and family.[35] Nichols and Reimer examined ostomates within 2 years of their stoma formation and suggested that a negative life satisfaction with their stoma also affected their quality of life.[47] Furthermore, there was a negative effect on the ostomates' sexual life, social life, family life, and leisure time.

However, research by Salter showed that married ostomates reported a supportive partner helped them to adapt to their changed body image;[28] although young males did not consider that friends and family played an active role in their recovery. Krouse et al did not find that a supportive partner was indicative of an improved quality of life.[34] However, Piwonka and Merino reported that positive adjustment was associated with acceptance from family and friends;[17] Krouse et al also recognized the importance of social support, with women potentially more concerned with issues such as isolation than men.[34]

Thus it can be surmised that acceptance of the stoma by family and friends can help the ostomate to positively adjust to their new stoma. The nurse can facilitate this by involving the family (as appropriate) in discussions.

Health care professional support

There are also more formal sources of support, such as health care professionals, specifically, the stoma specialist nurse. Nurses can provide support in a variety of ways, such as via a telephone clinic, an outpatient clinic, or home visits.

Health care professionals can assist people with a stoma to cope, using a variety of methods. Wu et al suggested that a comprehensive assessment of each patient will enable the health care professional to be able to identify the patient's needs, specifically, how the stoma will impact social life and sexual function, and how to cope with various situations.[27] They further suggested that a positive attitude toward life with a stoma, achieved through open communication, leads to increased levels of confidence. Krouse et al considered that early evaluation of the ostomate's psychological state and long-term follow-up in relation to the ostomate's social well-being and spiritual activities should be encouraged, to assist adaptation to the stoma.[34] Health care professionals can provide teaching, counseling, and reassurance, and offer information, to enable patients to be independent with their stoma care.

Despite ostomates feeling that they were coping with their stoma, it was also found that they considered that society did not accept stomas and that ostomates were "different."[28] Wu et al have suggested that in the public health arena, educating the public may also help to reduce prejudices, discrimination, and patient embarrassment resulting from perceived or actual stigma associated with having a stoma.[27]

Many UK stoma specialist nurses undertake home visits in the immediate postoperative period. At this visit, the nurse will see patients in their own home, to establish that they are coping adequately. However, due to financial constraints, this service is not available in all areas. In remote parts, it can be difficult for nurses to make journeys to geographically diverse areas. Although home visits are one method of assessing ostomates after they are discharged home from hospital, it is not the only one. Telephone or clinic appointments are also undertaken.

In other patient groups, there have been reviews of patients' needs after discharge home; Harrison et al established that the greatest number of unmet needs were encountered within the first week but persisted for up to

6 months.[48] The authors suggested that an early telephone follow-up call might help to reduce unplanned health care professional contacts. Follow-up telephone calls have been well received by women with breast cancer and have prevented unnecessary travel into hospital for clinic follow-up visits.[49] Gray et al concluded that telephone calls are both cost effective and acceptable to patients.[50] Lawlor et al reported that telephone follow-up provided education and was effective in reducing readmissions into hospitals for patients with respiratory problems.[51] It was also shown, by Mistiaen and Poot, that early complications can be recognized through the use of telephone follow-up and that this practice is safe.[52] Zhang et al considered nurse-led telephone follow-up to be necessary to enable any unmet needs of the ostomate to be resolved once ostomates are home.[53] When reviewing the needs of patients after colorectal surgery that included ostomates, it was surmised by Burch and Taylor that minor postoperative complications damaged patients' self-efficacy in the "vulnerable period" within the first month at home;[54] this was also established by Salter.[28] Thus to provide support to ostomates in the immediate postoperative period, a telephone call may be effective.

In many centers, a telephone call is made to patients to allow issues to be discussed. Telephone follow-up for ostomates can include topics such as diet, exercise, and work concerns. For issues such as sore skin assessment, the telephone will be of less benefit. It is difficult to assess the extent of the problem and to plan treatment without physically seeing the patient. In addition, therapy can often be initiated in the stoma clinic that would not be possible over the telephone. Potentially, videoconference follow-up might be useful for ostomates who live in remote areas without easy access to health care professionals. However, it is also possible that as many of the patients are older, they will not have this type of technology.

There is emerging evidence that telephone follow-up calls might already be utilized with ostomates in other situations. Patients who had a stoma formation for colorectal cancer and who have a low risk of recurrence may have cancer follow-up by telephone.[55] Furthermore, patients with inflammatory bowel disease may use telephone Help lines to manage their chronic disease and thus may also find telephone follow-up for their stoma care to be satisfactory and appropriate.

Assistance from a specialist nurse can help to prevent issues such as stoma appliance leakage, and regular contact was found to improve quality of life compared with no or infrequent nurse visits.[29] There is evidence that patients do not always recognize that they have sore skin.[56] Thus it could be assumed that yearly follow-up by a health care professional is ideal to ensure that the patient is coping well with their stoma, as suggested by Krouse et al.[34] It is also essential to ensure that ostomates do not encounter adverse issues with their stoma and to review stoma product usage. However, there are no UK standards for follow-up, possibly due to cost implications.

There is also a place for "open days," during which ostomates can meet other ostomates and see new stoma products. Open days can also provide an opportunity to renew links with their stoma specialist nurse.

Furthermore, there are examples where patient education in small groups has been effective in providing information and support, discussing topics of common concern including diet.[57] Danielsen et al found, in Denmark, that ostomates wanted group sessions, after discharge home from hospital, to learn from each other and to help them become self-empowered.[58] Group work is not commonly undertaken in the UK, but anecdotally, it works well when utilized.

Support groups

There are a number of national and local support groups for ostomates. In the UK, there are national support groups for the three main types of stoma. People with a colostomy can join and become involved with the Colostomy Association (the website is available at http://www.colostomyassociation.org.uk). People with an ileostomy or internal pouch can become members of *ia*, the Ileostomy and Internal Pouch Support Group (their website is http://www.iasupport.org). People with a urostomy can belong to the Urostomy Association; their website is http://www.urostomyassociation.org.uk.

Support groups, such as these examples and others, aim to assist people to return to a normal life. Support groups can also help, if needed, with employers, travel, family, and friends. These groups may also be involved in research to improve the quality of life for people with a stoma. Interestingly, Furukawa et al reported that in Japan, participation in a support group was linked with lower pain scores compared with nonparticipation in a support group.[59]

Conclusion

It can be seen that ostomates require various support systems to help them cope with their newly formed stoma. These may include health care professionals, their social network, as well as spiritual support. Learning to live with a stoma needs adjustment to the changed body image and the new way in which the ostomy now eliminates waste products. There is evidence to show that a good support system can

aid the adaptation process, whereas complications, either preoperatively or with the stoma, can result in delays in the ostomate adjusting to their new stoma.

There are many roles for the nurse in the process of adaptation for the person with a newly formed stoma. They can provide support in a variety of ways, including training on the practical care of the stoma, advice on skin care, and advice on how to adapt to life with a stoma. Research shows that adapting psychologically to a stoma takes time and that positive intervention from health care professionals is necessary, particularly in the first few months to a year. However, no optimal support system protocols were discovered in the literature to guide nurses in giving the best standard of care; thus, more research is needed in this area.

Disclosure

The author reports no conflict of interest in this work.

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