

Effectiveness of Follow-up Care provided by Stomal Therapy Nurses for Quality of Life among Adolescents and Adults: A Systematic Review

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Abstract

Background

Stomal therapy is a specialized nursing stream. The specialty was formed to promote the well-being of patients with a stoma. In current times of expanding health care costs, the profession needs to justify the benefits they provide to their clientele to retain firstly adequate service provision to its members and also the range of products required to carry out its work. This systematic review was undertaken to evaluate the effectiveness of follow up care provided by stomal therapy nurses.

Objective

The objective of this review is to synthesize the best available evidence of the effectiveness of follow up care provided by stomal therapy nurses to adolescents and adults.

Inclusion Criteria

Participants in the studies were young adolescents of fourteen years of age to older adults. All participants needed to have a stoma for the duration of the research study.

Results

Six quantitative studies were approved for inclusion in this review. Meta analysis was not possible due to heterogeneity of studies.

The benefit of stomal therapy nursing care to patients with a stoma was demonstrated in studies using follow up care at home visits, after stomal therapy input where none had previously been provided and by improvements in quality of life scores after stomal therapy follow up care.

Conclusion

Although significant benefits were demonstrated associated with stomal therapy nurse contact, the study design was often such that cause and effect could not be illustrated. A stoma specific tool was often not used which also affected results. The value of stomal therapy nursing care needs to be investigated in different ways so that a direct causal relationship can be demonstrated.

Chapter 1: Introduction

Context of the Review

The development of Stomal Therapy as a specialist nursing role closely follows the advances made by colo-rectal surgeons in this area of care. From very humble beginnings, it is now a widespread speciality with a worldwide network of practitioners. However, even from its inception, stomal therapy nurses have had to justify the value of their contribution to the patients they assist.¹ Initially this meant that the profession had to struggle to gain recognition of its worth and purpose. The early leaders in this field began to be involved in developing collegial relationships with surgeons, other health care professionals and patients while later, as an established speciality, included negotiating with government officials and ostomy supply manufacturers to achieve the best outcomes for their clients.²

With the increasing interest in how health resources are spent, "access to and ability to spend quality time with the ostomy patient is becoming more difficult" (pg 15).³ These authors also advise that stomal therapy nurses need to demonstrate that outcomes for their patient's care are beneficial. This can only be done effectively by collecting evidenced based data.

From the 1950's, there was an increasing number of stomas being created, growth in industry surrounding stoma care also increased to meet the needs of the ostomate.³ Pouching systems, which were initially reusable rubber devices, have been replaced by a plethora of disposable options. The choices currently available to ostomates not only include numerous pouches but also a range of other accessories such as seals, pastes, skin film barriers and adhesive removers to name just a few. These tools have been developed to improve wear time for ostomates when suboptimal results for appliance management has resulted for any of a number of reasons.³

The increase in resources available to ostomates comes at a cost. Direct financial costs of equipment and accessories to the ostomate can be detrimental as the high price can impact on quality of life and reimbursement for supplies differs greatly from one country to another.⁴ In the United Kingdom for example, a person with an ostomy receives their supplies through the National Health Scheme. Australian ostomates are required to pay a yearly subscription to join the Stoma Appliance Scheme and are then entitled to a certain amount of supplies per month. In Northern America, ostomates need to purchase their own supplies although reimbursement policies assist with their requirements. However, because of the costly nature of these products, justification for their use and their benefit, in stomal therapy practice also needs to be demonstrated.⁵ If this does not occur, cost savings measures may affect the availability of products that people with an ostomy may be offered.

The growing cost of health care also has other ramifications for the Stomal Therapy Nurse. Often healthcare providers are reluctant to employ adequate specialist nursing care to meet the needs of patients.³ This can lead to a reduction in or a narrowing of, service provision. Maintenance of quality of life for people with ostomies requires ongoing contact with their stomal therapy nurse and this can only be attained with adequate staffing levels.³

Review Question

This review therefore seeks to analyse the best available evidence to evaluate the effectiveness of follow up care provided by stomal therapy nurses in terms of impact on quality of life for adolescents and adults. The chosen methodology is quantitative synthesis. For the purpose of examining effectiveness of stomal therapy nursing practice, this methodological basis was imperative so that the evidence could be examined and synthesised. Quantitative data informs evidence of safety and efficacy as well as effectiveness, and is therefore the preferred source of evidence for this review question.⁶

Measurement of stomal therapy nurse benefit and its cause is often difficult to pinpoint especially in cohort studies. Although this "benefit" is often referred to in research, the strength and direction as well as degree of association or causation is difficult to pinpoint.⁶ Therefore, the outcome measures in this review were determined by identifying outcomes important to patients as demonstrated through existing literature in a precursory consideration of the key evidence related to this topic.

The Science of Evidence Synthesis

The sheer volume of published information available to health care professionals makes it impossible to read the enormous amount of literature available on a given topic in order to determine what is relevant and high quality. Often healthcare workers need information on a wide range of issues associated with their specialty, which again makes the task of perusing a vast quantity of published material burdensome and impractical.

Often when evidence from individual studies is gathered on a given topic, the available data can appear unclear and/or contradictory. With a systematic review this evidence is systematically identified, appraised, extracted and synthesised. The review findings are usually presented as a cohesive body of knowledge presented to give a clearer overall picture of the conclusions drawn from the synthesis of information.

Traditional reviews of literature have been published in this topic area, but have proved to be inadequate due to concerns regarding quality, reliability and transparency of methods. Pearson et al write that "a systematic review is essentially an analysis of all the available literature (i.e. evidence) and a judgement of the effectiveness or otherwise of a practice"(pg 211).⁷ They write that a systematic review should contain the following steps:

- Firstly the development of a rigorous proposal or protocol is required. This then predetermines the plan of the review to ensure rigor and minimise potential bias that may occur. Periodic updating of the review may be carried out as necessary and the process includes a peer review prior to commencement of the review.
- The question or hypotheses needs to be clearly stated.
- Identification of the criteria used to choose literature needs to be clearly described.

- A strategy which will be used to identify all suitable literature must be outlined and an agreed time frame set.
- How the quality of each paper/study will be judged and critically appraised must be clearly established as well as any exclusion criteria. This must be based on considerations of quality of the paper under scrutiny.
- The review also needs to set out clearly how the data will be extracted from the primary research or selected literature.
- Included in the review should also be a plan of how the extracted data will be synthesised.

Pearson et al write that systematic reviews hold the highest position in current hierarchies of evidence.⁷ This is because of the use of a systematic search, identification and summarisation of the available evidence which focuses on a "clinical question with particular attention to the methodological quality of studies or the credibility of opinion and text".⁷ (pg 211) The model is "premised on a pluralistic approach to evidence synthesis" (pg 211) and includes evidence that is produced from quantitative research, qualitative research, opinion and text and also economic analyses.⁷ This review of the effectiveness of follow up care provided by stomal therapy nurses for quality of life to adults and adolescent follows these guidelines.

Definition of Terms

For this systematic review the following definitions are used:

Follow up care in adults with a stoma refers to care given in regard to post-operative education, assistance with ongoing difficulties in stomal management and psychological adjustment for the patient with a stoma.⁸

Specialised stomal therapy nurse is defined as a registered nurse who has completed a nationally approved course in stomal care.¹

The following terms are interchangeable: stomal therapy nurse (Australia), stoma care nurse (England), enterostomal therapy nurse (ET) (USA) and wound, ostomy and continence nurse (WOCN) (USA) depending on country of origin of the nurse.

Ostomy and stoma are interchangeable terms

A colostomy is a stoma formed on the large colon.²

An ileostomy is a stoma formed on the ileal portion of the small bowel.²

A urostomy is a stoma formed for the urinary system and is also known as a urinary diversion or an ileal conduit.²

Stomal irrigation refers to the practice of instilling fluids (usually water) via the colostomy to flush out, and thereby empty, the bowel.² The colostomate is then able to wear a small appliance or covering over the stoma until irrigation is next due.

Chapter 2: The Systematic Review Protocol

Review Question/ Objectives

This review seeks to ascertain the best available evidence regarding the effectiveness of follow up care provided by stomal therapy nurses to adolescents and adults.

Background

In Australia, in 2007, there were 14,234 reported cases of bowel cancer.⁹ Despite advances in the treatment of this disease over the last two decades with the advent of improved surgical techniques and the introduction of pre and post-operative radiotherapy combined with neoadjuvant chemotherapy, it remains a major health problem globally.

Quality of life after surgery for colo-rectal cancer has been a subject of great interest to health professionals for many years since the first publication on this subject by Devlin et al in 1971.¹⁰ In response to this article, colo-rectal surgeons developed the technique whereby the resected colon could be re-anastomosed straight to the rectal remnant and a covering temporary, loop ileostomy formed to protect the healing anastomosis.¹¹ This ileostomy, or small bowel stoma, was then reversed at a suitable time to restore intestinal continuity. Due to poor functional outcomes from the previously described operation, Parc et al modified this technique.¹² The surgeons added the construction of a J-shaped colonic reservoir to the end of the distal bowel and this was then reattached to the rectum or rectal remnant. The addition of this colonic pouch improved outcomes for rectal cancer patients by acting as a storage reservoir for stool, aiding evacuation and subsequently enhancing quality of life.¹³

Issues surrounding this topic revolve around the decisions that colorectal surgeons and their patients have to make in regard to choice of surgical pathway and treatment outcomes. There are generally two options. The first of these is sphincter saving surgery of the rectum accompanied by a temporary diverting loop ileostomy that often results in unwanted consequences. These consequences include, difficulties with the management of a stoma which produces liquid stool and then, on reversal the possibility of the appearance of a cluster of defaecatory symptoms known as Low Anterior Resection Syndrome which includes stool urgency and frequency, as well as fragmentation and imperfect continence. An addition of the previously described colonic pouch, alleviates many of these symptoms, but the pouch is not always possible to form.¹² The alternative choice to this is the formation of a permanent end colostomy which, in itself, although easier for the patient to manage, results in adjustments to body image as well as changes to sexual and psychological functioning that may greatly affect quality of life.¹⁰ This later approach involves either removal and closure of the rectum or alternately a rectal stump is left insitu depending on the position of the tumour in the rectum. With either of these operations, this group of patients have to adapt to life with a permanent stoma.

Care of the individual with a stoma is often carried out by Stomal Therapy Nurses. Monetary resources in the health care setting are sometimes scarce and specialist stomal nursing services are not always provided or resourced. More accurate knowledge of the benefits or otherwise that a stomal

therapy nurse provides should help inform decision making regarding the provision of follow up services and equipment for individuals with a stoma by specialist stoma nurses.

Stomal Characteristics

Ileostomy

An ileostomy is a stoma formed on the portion of the small bowel known as the ileum. This type of stoma produces, on average, around one litre of fluid effluent per day and to manage it, the individual needs to wear a drainable appliance so that they can empty the contents around 4-6 times per day.² If a closed bag were used, the constant renewal of the appliance when full would require such frequent changes that the epidermis of the skin would suffer from the constant removal and reapplication of adhesives. Therefore a drainable bag is considered the best type of appliance for the needs of the ileostomate.

The individual with an ileostomy needs to manage their diet and fluid intake with some attention. Fibrous foods can cause small bowel obstruction and dehydration can be a risk for those individuals who do not consume adequate fluids to replace losses from the stoma.² Patients with an ileostomy are more prone to be troubled by skin maceration, excoriation and leakage due to the liquid nature of the output.²

Colostomy

A colostomy is a stoma formed on the large bowel. The most common sites are the descending and sigmoid colon and occasionally, if required (in the presence of an obstruction) the transverse colon. Faecal output from a stoma located on the descending and sigmoid colon, once established, should be formed stool. A stoma on the transverse colon produces stool of paste consistency and passes a lot of flatus often making this unpleasant for the individual to cope with.²

The management of a colostomy is generally much easier than the ileostomy as effluent is firmer and volume of stool produced is less.² This also means that there are fewer problems with skin irritation and leakage. The appliance is usually changed once a day or when the bowel functions. There are no dietary or fluid restrictions or other precautions to adhere to for proper functioning of the stoma.² Colostomates more often complain about issues such as flatus and odour.

Urostomy or Ileal Diversion

These are formed usually for bladder cancer and are less commonly constructed than faecal stomas. The bladder is usually removed from the patient and the ureters implanted into a resected piece of small bowel.² This small bowel segment then has one end oversewn and the other end exteriorised, budded and stitched to the outside of the body on the skin surface and so the stoma is formed. The urinary output is then collected in a stomal appliance which is emptied 4-6 times a day.² Individuals with a urinary stoma occasionally complain of problems with leakage as their output is fluid but generally odour is not a problem.²

Stomal Therapy Care

History of Stomal Therapy Nursing

Reference to stoma creation has been found in biblical times with descriptions of spontaneous fistula formation occurring from trauma or strangulated viscera.³ The beginnings of ostomy surgery were much later than that. One report suggests that the first colostomy was performed in 1750 for an incarcerated hernia, while another source attributes this to a French surgeon, Pilon, in 1776 when he performed the first caecostomy known as the artificial anus.³ Colostomy formation remained a last resort measure until the late 19th century when surgeons began to improve their practice in this area. This became a more commonplace procedure by the early 20th century.³

Historically, ileostomies were performed as a last recourse as their management was seen as problematic.¹⁴ This type of stoma was associated with "severe and painful skin breakdown" due to the practice of exposing the serosa when creating it (pg 8).² On exposure to air, the serosal layer becomes inflamed followed by a gradual necrosis and sloughing off of this layer.² This serositis (inflammation of the bowel outer layer accompanied by stomal wall thickening and oedema) had created difficulties for patients and surgeons as pouching the resulting stoma was more problematic as the peristomal plane was affected by the process. After gradual improvements in surgical techniques, in 1952, a British surgeon (Professor Bryan Brooke) published his surgical procedure for eversion of the stoma. This operation involved turning the bowel back on itself, creating a mucosal covered spout, thereby eliminating many problems associated with the surgery.

Similarly, in 1950, an American surgeon called Dr Eugene Bricker described an operation for the creation of an ileal conduit. This was eventually combined with the budded stoma as described by Brooke to form a functional urinary stoma. Both of these advances in surgical technique resulted in a larger number of patients undergoing stoma formation in the 1950's and their having a better post-operative experience and quality of life.

In spite of these improvements in surgical technique, quality of life for a person living with an ostomy in the 1950's primarily depended on how well they contained and managed the effluent output of the ostomy. Leakage from appliances and skin problems were common as the quality and availability of stoma supplies for them to manage their output was low.³ As there were no stoma nurses at this time, education and advice for people getting discharged to home after stoma surgery was almost non-existent.¹

In 1954 an American woman named Norma N. Gill entered Cleveland Clinic. She was very ill and had to undergo ileostomy surgery which was performed by Dr. Rupert Turnbull.¹⁵ After her rehabilitation, Norma Gill contacted several surgeons offering to assist with patient education of people with ostomies and began, with Dr. Turnbull, to educate these people and also nurses and surgeons about managing stomas.¹⁵ Together, Ms Gill and Dr Turnbull established the first training program for Enterostomal Therapy at the Cleveland Clinic in 1962. At this time the participants were required only to be an ostomate.¹⁵ It was not until 1976 that Enterostomal Therapy became a specialist nursing role in America and required registered nurse licensure for admission to the course.¹

The Enterostomal Therapy nursing scope of practice in the USA was subsequently expanded to include acute and chronic wound management in 1982. It further expanded its speciality to include continence nursing care in 1986.¹ This specialist nursing group had, by this time spread to other parts of the world, such as the United Kingdom and Australia, was well underway with a defined role description and scope of practice in these countries.¹⁴

Stomal Therapy Nursing

Care for the patient with an ostomy is now commonly provided by stomal therapy nurses.⁸ This specialised role has evolved to benefit the patient with a stoma by providing specialist knowledge to the client and to assist with the management of any ongoing difficulties. It has been anecdotally reported that care by specialist stomal therapists as a nursing sub-specialty has a positive effect on patients outcomes and acceptance of the stoma.⁸

Preoperative Care

Boyles outlined the role of the nurse caring for patients with a stoma.⁸ These included "siting" the patient prior to surgery and providing education and skill training and support pre and post operatively. Siting or marking the patient prior to surgery is an important task as a poorly sited stoma can result in poorer functional outcomes for the person with a stoma.¹⁶ The stoma needs to be sited avoiding bony prominences, body creases and folds, scars and the umbilicus. Avoiding the waist line and areas of radiation therapy are also advised.² Colwell and Grey collated the evidence on pre-operative stomal marking and they suggest that there is sparse evidence to suggest that " this may reduce the incidence of postoperative stomal and peristomal complications" (pg 495).¹⁷ However, in spite of the absence of clear evidence, the Stomal Therapy Nurse has an ongoing role in preoperative siting.

Preoperatively another important task for the stomal therapy nurse is to educate the patient regarding life with a stoma and to clarify their expectations after surgery. Colwell et al report that preoperative education should include information pertaining to how the gastrointestinal and urinary system works, stoma appearance, information about stoma function and pouching systems.² It is recommended that preoperative bowel preparation for stoma surgery also be discussed.²

Colwell and Grey also investigated the influence of preoperative teaching on post-operative outcomes.¹⁷ They found that preoperative education by a specialised stoma nurse" improved postoperative outcomes including factors related to health related quality of life , skill acquisition and long term adjustment to a stoma" (pg 495).¹⁷

Prior to stomal surgery, the stomal therapy nurse also needs to assess the individual about to have a stoma. This process is part of the preoperative preparation that the individual needs to go through. Areas included in the assessment are medical and surgical history, diagnosis and education on the surgical procedure to be performed. Support systems, cultural and spiritual issues, hobbies, vision, hearing, dexterity and motor skills skin sensitivities and other physical challenges also need to be addressed and evaluated to ensure optimal care outcomes for the client.²

Postoperative Care

It is in the postoperative phase that the stomal therapy nurse has the largest time commitment to helping the new ostomate adapt to life with a stoma and all this involves. Postoperatively therefore, the stomal therapy nurse assists in the rehabilitation of the ostomate in many ways. The most pressing activity in the time period immediately after surgery is to teach the patient to manage their own stoma and stomal appliance.² This entails changing the pouch and equipping the patient with information, equipment and skills to complete activities of daily living which they wish to engage in such as swimming, shopping, working, sexual activity etc.² The ostomate requires a pouching system which fits their body contours and provides a leak free system to capture effluent prior to discharge home, and needs to learn how to manage the application and removal of appliances as well as how to use accessories that protect skin integrity.² The knowledge and skills required are not always quickly learned, therefore follow up care by the Stomal Therapy Nurse includes all elements of stoma care that facilitate independent living by the ostomate in order to help them achieve a high standard of self-care and to protect their quality of life.² An outline of the scope of follow up care follows:

Managing Stoma Complications

The stomal therapy nurse also has a role to play in managing the many complications associated with stomal surgery. These include conditions where the stoma is involved such as stomal retraction where the stoma disappears under the level of the skin, herniation where a defect occurs in the fascia and loops of intestine protrude through causing a bulge behind the stoma, often disrupting the integrity of the pouching system and stomal prolapse where the bowel telescopes through the stoma.² Other problems include necrosis of the stoma caused by reduced blood supply to the area resulting in tissue death, stenosis which is a narrowing of the lumen of the stoma and mucocutaneous separation which is when the area between the skin and the stoma separates.² The Stomal Therapy Nurse initiates management and monitors outcomes of these conditions using appropriate pouching systems and accessories, while involving other health professionals as necessary.

Other peristomal conditions where stomal therapy nurses assist with management are problems such as peristomal varices where “large, portosystemic venous collaterals”(pg 314) occur at the site of the stoma often resulting in bleeding and pouching problems². Peristomal candidiasis where an overgrowth of the *Candida* organism results in skin inflammation on the peristomal skin is another condition that Stomal Therapy Nurses treat. Mucosal transplantation, which results in the seeding of viable intestinal mucosa in the peristomal skin along the side the stoma and peristomal dermatitis which is damage caused to the skin around the stoma from a number of irritating agents are also issues for which the Stomal Therapy nurse can assist . Psuedoverrucous lesions, which are wart like growths in the peristomal region, resulting from chronic irritation and exposure of the skin to moisture again need the stomal therapy nurses attention and often an adjustment of pouching system is required. There are numerous other similar conditions for which the stomal therapy nurse supervises patients and manages their care in conjunction with the rest of the multidisciplinary team as necessary.¹⁸

Pouching Problems

One of the more important tasks of the stomal therapy nurse is to assess the patient in order to select the optimal pouching system for them. The success of this depends on close examination of the peristomal skin and the peristomal plane characteristics. Also considered are stoma characteristics, stoma construction and function and also the patient's preferences and requirements of a pouching system. Stomal output volume and consistency of effluent are taken into account as well.²

An inadequate pouching system leads to leakage of effluent under the skin barrier. This in turn causes peristomal skin injury and results in erythema and maceration. In the individual with an ileostomy this could quickly develop into a problem as the skin is affected by the enzymes in the small bowel output, causing denuding of the epidermis, disrupting skin integrity and making effective pouching even more difficult. Pittman et al identify that problems of this nature affect quality of life on individuals with a stoma.¹⁹

Psychological Adjustment

Creation of a stoma has been referred to as mutilating surgery and is associated with stigma.^{20,21} For the individual with a newly fashioned stoma, the event marks the beginning of a period of psychological and social adaptation which has to be cautiously negotiated.²² White and Hunt report that "around one quarter of stoma patients experience clinically significant psychological symptoms postoperatively" (pg 3).²² Stomal therapy nurses include the routine supervision of psychological adjustment of postoperative patients to their stoma as part of their specialist role.

White and Hunt write that "formation of a stoma requires a considerable degree of psychological adjustment" (pg 3).²² They report that patients with a stoma can experience "significant psychological symptoms" the most common being an anxiety disorder or a major depression"(pg 3).²¹ In the immediate postoperative period, patients often do not cope well and "as a result of loss of confidence, independence and dignity may struggle to cope with their new stoma" (pg 693).²² Post-operatively the patient "mourns the loss of the body part and surgery is seen as a physical or sexual assault and an attack on body integrity" (pg 293).²³ These patients also have to cope with managing their new stoma. Problems relating to stoma care that impact on psychological wellbeing include leakage and spillage from the appliance, flatus, odour, noise and dealing with concerns relating to sexual attractiveness and adequacy.²³

Bekkers and co-workers found that self-efficacy played an important role in psychological adjustment.²⁴ Stronger feelings of being able to cope were associated with fewer psychological problems postoperatively. Their study showed that objective medical and socio-demographic factors were poor predictors of postoperative adjustment to life with a stoma.²⁴

Brown and Rundle write that perceived control by patients as well as perceived high levels of support for patients resulted in fewer problems being reported by clients.²⁵ This illustrates the importance of the role of the stomal therapy nurse in support and education of the patient to aid with coping and self management of the ostomy. How well patients adjust to their ostomy affects their quality of life.²⁵

Sexuality

Sexuality is defined as " an individual's self-concept, shaped by their personality and explained as sexual feelings, attitudes, beliefs and behaviour, expressed through a heterosexual, homosexual , bisexual or transsexual orientation" (pg 694).²³ For the person with a stoma it is closely linked to body image.²⁵

Patients who undergo stoma surgery report concerns regarding their sexual function. Williams reports that the most common sexual dysfunction reported by female patients with a stoma is painful intercourse or dyspareunia.²⁶ Pelvic surgery may result in the formation of scar tissue around the vagina creating discomfort on penile penetration. It can also induce a reduction in the amount of natural lubrication in the vagina. As a result of both the tightness and the dryness, friction and pain on sexual intercourse occurs.²⁷ Junkin and Beitz also report that due to these sequelae, or the ostomates psychological outlook, orgasm may be more difficult to achieve.²⁸

In the male client, pelvic surgery may cause injury to the nerves that are involved in sexual function.²⁶ This can result in difficulties achieving erection and ejaculation. The extent of the damage depends on the location of the surgical ligation. Pelvic surgery or cystectomy (ie bladder removal in men, which inflicts damage to the pudendal nerves and artery) will result in the inability to have an erection.²⁶ For males undergoing radical cystectomy, the chance of resulting impotence following surgery for bladder cancer are high at around 90%.²⁶ Retrograde ejaculation is also a possibility plus a decrease or inability to have an orgasm may occur.²⁸

Quality of life and sexuality is therefore an issue of concern to many ostomates. Stomal surgery affects not only the sexual and reproductive system it also affects the body image and how the person sees themselves as a sexual being.²⁶ Several strategies have been outlined for nurses to follow when involved in sexual health challenges. Current suggested interventions for nurses include following the PLISSIT model which provides a framework to assist with sexuality self-adjustment. This involves asking Permission, Limited Information, Specific Suggestions and Intensive Therapy prior to embarking on sexual counselling of a client.²⁸ Junkin and Beitz write that nurses should be able to integrate the permission and limited information levels into their practice.²⁸ This means that nurses should be able to suggest to the ostomate that discussing sexual issues in the appropriate setting is allowed and that the nurse should be able to provide some limited information to assist them with their sexual functioning. ²⁸ Specific suggestion and Intensive Therapy would need to be provided by other appropriately qualified health professionals.

Bell suggests that nurses need to firstly "examine their own sexuality and their comfort levels in addressing the sexuality of others" (pg 128) and secondly that they need to be knowledgeable about anatomy and physiology, pathophysiology and psychosexual development and functioning.²⁸ Finally Bell suggests that nurses become proficient in communication skills and function as an educator and counsellor when assisting patients to work through issues of sexuality.²⁸

Body Image

Creation of a stoma results in a change in body image and therefore a change in how individuals perceive themselves.²³ The stoma alters the manner in which wastes are eliminated from the body and this change is commonly perceived as an undesirable with equally undesirable sequelae. These include loss of continence as ostomates no longer have control over the passage of stool or urine and is accompanied by altered sensory phenomena such as odour, sound and the sight and feel of waste on their body.²⁹

The presence of a stoma alters the outward appearance of the individual and impacts on the way the patient sees themselves. Body image is important for healthy physical and psychological functioning, and has been defined as " the perception of physical appearance and physical function individuals have of their body" (pg 76).²⁵ It is an important part of living and our society values the importance of being attractive. ²⁵

Klopp reports various findings in relation to body image and adjustment after formation of a stoma.²⁹ Among them, that individuals with a faecal stoma had a poorer body image than those with a urinary stoma and more concerns regarding sensory phenomena. The concept that the body had been changed in a negative way was also identified through this study. Another finding was that depression after stoma formation was common and even more so among women.²⁹ Black writes that the intensity of emotional reaction to alterations in body image are related less to the severity of body image change than to the value the individual places upon the structure and function of the body part which has been altered or removed.²³ Acceptance of a changed body image after stoma surgery is an intrapersonal experience. How individuals incorporate the changes into their lives depend on their feelings, attitudes and experiences towards their own body.²³ Personal and ethical beliefs, social status and the individual's environment all can be expected to play a part in how the individual adapts to their altered body image.²³ Black suggests that stomal therapists can help patients with stomas adapt to their changed body image by encouraging them to discuss their experiences and anxieties.²³ Borwell writes that patients can be empowered by fully involving them in stoma related concerns and this can assist in helping them to maintain a sense of ownership.³⁰

Quality of Life Measurement

The way in which stoma patients work through acceptance of their new stoma is a matter of interest to those health professionals working among patients with colo-rectal cancer. This adaption is often measured by assessing quality of life and the part the stomal therapy nurse plays in this transition period often also comes under study. The role of the stomal therapy nurse should be crucial in assisting the patient through this difficult time.⁸

Quality of life is a term often used by those in the health professions. Despite this Pittman et al reports that " a clear definition remains elusive" (pg 255).³¹ It has however been broadly defined as "the sum of various life conditions experienced by an individual" (pg 255).³¹ Of recent times, health related quality of life (HRQOL) has become a more useable measure and is defined as "those constructs within the broader domains of quality of life that are specific to an individual's health" (pg 255).³¹ This

provides a more meaningful measure of the effect of disease on the individual than that previously used.

Many studies have been carried out in relation to quality of life for patients with a stoma and there have been many difficulties establishing the attributes of quality of life for this group of patients, particularly in attempting to bring together the literature through a systematic review of the evidence. These difficulties include trying to compare studies that use different measurement tools and different study comparators. For example, some studies compare stoma patients to patients without stomas while others nominate specific types of stomas and again others include only stoma patients with cancer.³² Despite these problems, the general consensus, from three longitudinal studies, is that HRQOL for patients with a stoma "tends to rise steadily during the first postoperative year, especially among younger adults" (pg 259).³¹ The greatest rise in HRQOL is noticed from the immediate post operative period until the third postoperative month. After this time it tends to rise more slowly "possibly reflecting the period of time needed to master the basic skills needed to manage an ostomy and initial adjustment to significant changes in body image imposed by an abdominal stoma" (pg 259).³¹

Several attempts have been made over time to measure the effect that stomal therapy nursing care has on quality of life for individuals with a stoma.^{20,21} This has, however met with limited success. Early researchers used depression and psychological adjustment scales to estimate quality of life on these patients.^{20,33} However, as different psychometric scales and questionnaires were used across initial studies, any comparisons between results was difficult. Also the lack of a stoma specific tool to analyse differences in quality of life for individuals with a stoma impeded research into this area.³³

Over time, several condition specific, valid and reliable instruments for measuring HRQOL for people with a stoma were developed.^{21,34} Pittman et al carried out an integrative literature review in which four of these tools were analysed.³¹ These authors evaluated the Cleveland Clinic Florida ostomy function index, the Stoma Quality of Life tool, the City of Hope Quality of Life Ostomy questionnaire and the Stoma Quality of Life Scale. Their work reports that these instruments are valid and reliable for measuring HRQOL for people with intestinal stomas in the research setting although the Stoma QOL tool was the only instrument reviewed deemed suitable for use in the clinical setting. Unfortunately, most of these tools were developed after the majority of studies in this systematic review of stomal therapy nurse care were complete, however, they will assist to standardise many measures associated with health related quality of life in the future.

Prieto and Juul suggest that " a combination of generic quality of life tool such as the Short Form 36 also be used in conjunction with a stoma specific tool" (pg 168).³³ In this way information on both health status and problems specific to people with stomas will be captured.

Reason for stoma

Reasons for undergoing stoma formation are many and this may impact on quality of life in varying ways. For example, if a stoma is formed due to intractable inflammatory bowel disease, the individual may have increased quality of life as shown by a study by Camilleri-Brennan and Steele.³⁵ Permanent

ileostomy for these people may be preferable to frequent defaecation, especially when coupled with the anxiety of constantly needing to go to and/or find a toilet.

A patient that undergoes stoma formation due to incontinence may similarly feel that their life is improved. Craven and Etchells conducted a study involving individuals who had a stoma formed after spinal cord injury for continence problems.³⁶ They found that bowel and bladder management were greatly improved in many cases resulting in improved QOL. These researchers also noted other positive psychological effects from stoma formation including improved lifestyle evidenced by such events as returning to work, becoming involved in sporting activities and social outings.³⁶

In contrast, an individual who requires a stoma after trauma has damaged their bowel or bladder may view the scenario in a totally different way. They have awakened from surgery to find themselves with altered bowel or bladder functioning and this change in elimination may be very difficult for the patient to accept. The emergency patient has the added disadvantage of not being marked preoperatively for stoma siting. Bass et al found that preoperative marking and education by the Stomal Therapy Nurse reduced that rate of adverse outcomes.¹⁶ Adverse outcomes can make for difficulties in stoma management which in turn can affect quality of life.¹⁷

The most common reason from stoma construction is, of course, bladder or bowel cancer. In these patients, the disease process is intertwined with stoma acceptance and quality of life.

Type of Stoma

Some studies include people with all types of stomas and other studies only include those with faecal stomas. The problem with this is that individuals will have differing issues arising from different stomas, causing variation in psychological adjustment and therefore QOL measurement. The quality of life is dependent on stoma type, and hence strategies may need to vary for individuals. Klopp reports that individuals with faecal stomas have a poorer body image than individuals with a urinary stoma and also more concerns for sensory phenomena associated with their stoma.²⁹

Individuals with a urinary stoma do not have problems with odour and gas unlike people with a faecal stoma. The reported issues for patients following cystectomy with urinary diversion remain significant however, and include urine leakage, bowel problems, sexual dysfunction, impaired body image, decreased social activities, anxiety and depression.³⁷ The length of time that the individual may have a stoma also varies and some stomas are temporary and again some studies have included these patients in the same analysis as patients with a long-term stoma.

Disease Stage

Faecal stomas are most often formed for bowel cancer.² Cancer stage, at time of detection of the invading tumour, varies and therefore the ensuing treatment is also dependent upon staging. Options for people with bowel cancer could include radiotherapy either pre or postoperatively, chemotherapy either alone or in conjunction with radiotherapy or surgery alone or in conjunction with these other previously mentioned treatment modalities. Some individuals may be offered only palliative treatments such as stenting or defunctioning the bowel to allow faecal material to escape from the body

unhindered by the tumour.² The end result is that the individual with a stoma could be undergoing different treatment options depending upon the stage of their disease and its course. It would seem that individuals undergoing prolonged cancer treatment such as radiotherapy and chemotherapy may have their quality of life affected to a greater extent than those individuals who have been treated with surgery alone, this necessarily has an impact on quality of life that may influence attempts to objectively measure HRQOL related to an ostomy.²

Length of Time since Surgery

QOL undergoes rapid changes postoperatively. The period up to two months after surgery is known as the recovery phase.³³ In this time frame the patient must learn skills to master stoma care. This is followed by the adaption phase in which the patient begins to deal with matters relating to body image and psychological adjustment. Juul and Prieto write that it is customary to "exclude these newly operated patients and only include patients in a more stable condition" when researching QOL in clinical studies of ostomy products (pg 168).³³ In contrast to this, most studies on QOL and follow up care by stomal therapy nurses are conducted in the period of time shortly after surgery when HRQOL is rapidly changing. This may affect results.

QOL differences due to Country/Religion

The presence of a permanent colostomy has been shown to have a negative effect on QOL for patients living in southern Europe as well as for patients of Arabic origin (p 34).³³ This was demonstrated by the Marquis Study.²¹ It is uncertain why this is so however, it is proposed that simple climatic reasons could be the cause.³³ Warmer weather, for example in Southern Europe, results in less clothing being worn. There is therefore more difficulty in hiding the pouch. Appliance adhesives may also be adversely affected by the warmer weather, providing less security and adhesion to the skin resulting in leakage issues for the ostomate.

Certain religions are also thought to affect quality of life with a stoma. The Muslim faith for example has strict guidelines relating to hygiene and prayer. The presence of a stoma causes some difficulties in relation to following these rules and thereby has an impact on quality of life.³³

Gender

The issue of gender has been studied in relation to QOL after stoma surgery and differences have been identified.³⁸ Grant et al report that studies have shown that women with stomas "consistently scored lower than men with ostomies for overall quality of life, as well as the four HRQOL domains of physical, psychological, social, and spiritual well being"(pg 588).³⁸ Women were also reported to more often suffer from depression and suicidal ideation. They also scored lower on spiritual well-being and family distress than men with ostomies.³⁸

Financial Schemes in different countries

Appliances worn by people with ostomies to collect effluent are expensive. Countries have different ways of dealing with this health expense. Governments in some countries such as Australia have an appliance scheme which allows a person with an ostomy a certain quota of ostomy appliances per

month after they join a scheme. Other countries such as the United Kingdom supply equipment through the National Health Scheme via a prescription from their General Practitioner. Yet again in other regions such as Northern America people with an ostomy are required to purchase their own stoma supplies.

The effect that this has on Quality of life has been examined. Krouse demonstrated a "significant association between paying for ostomy supplies and overall HRQOL for veterans with intestinal stomas" (pg 4669).⁴ A decrease in quality of life was demonstrated.⁴ Further findings are that financial affairs remain a concern for people with a stoma even when insured which affects QOL for those clients who need to purchase their supplies.

Age

Increasing age is positively associated with quality of life with a stoma. Pittman found that that younger participants tended to have more severe skin irritation, leakage problems and greater difficulty adjusting to their stoma than older participants.¹⁹ Wilson and Alexander also found that being less than 65 years of age was associated with poorer HRQOL.³⁹

Summary

From the above it can be seen that there are many factors and influences on quality of life with a stoma. While individual studies have sought to identify, describe and evaluate aspects of health related to quality of life, there have not been robust attempts to systematically identify, appraise, synthesise and report on the impact of specialist stoma care nurses. What this dissertation reports is the effectiveness of such care as measured by these tools.

Inclusion Criteria for considering Studies

Types of Studies

This review considered both experimental and epidemiological study designs including randomised control trials, non randomised controlled trials, quasi-experimental, before and after tests, prospective and retrospective cohort studies, case control studies and analytical cross sectional studies. This review also considered descriptive epidemiological study designs including case series and descriptive cross sectional studies for inclusion.

Types of participants

This review has considered studies that include adolescents and adults from 14 years to 90 years with a stoma. The individual was required to have a stoma for the duration of their involvement in the study, from the immediate post-operative period onwards. All types of stomas i.e. urostomy, ileostomy and colostomy have been considered.

Types of Interventions

This review has examined studies that evaluate follow up care provided by specialist stomal therapy nurses as compared to non specialist nurses regardless of the nature of how the specialist care was delivered (face to face, telephone etc).

Types of outcome measures

The outcome measure of interest was quality of life. As previously mentioned some of the studies predate formulation of quality of life measurement therefore the range of instruments included in the analysis is broad; tools that have been used include, but are not limited to:

Medical Outcomes Study (SF 36) Quality of Life Scale

Present State Examination

Hawthorne's Index of Social isolation

Medical Outcomes Study, Social Support Survey

Life Satisfaction Scale

Stoma Quality of Life Index (SQLI)

Digestive Disease Questionnaire (DDU- 15)

Gazi University Stomatherapy Questionnaire (GUSQ)

Researcher developed tools

All tools used in studies are reliable and validated.

Review Methods

Search strategy

The search strategy aimed to find published and unpublished studies. A three step search strategy was utilised in this review. An initial limited search of MEDLINE and CINAHL was undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. A second, comprehensive and exhaustive search using all identified keywords and index terms was undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in the English language only were considered for this review. Studies published 1971-2011 were considered for inclusion as prior to this date the role of the "specialist stoma nurse " did not exist.¹

The databases searched using database specific search strategies included:

CINAHL

EMBASE

PUBMED

Cochrane Central Trial Register

ANZ Trials Register

Current Controlled Trials

Clinicaltrials.org

The search for unpublished trials included:

Mednar

Proquest Dissertations and Thesis

Three further articles were located by hand searching and these were included in the review. One of the articles was excluded on methodological grounds after critical analysis. The overview of studies identified, retrieved, and included or excluded is included in Figure 1.

Assessment of methodological Quality

Papers selected for retrieval were assessed by two independent reviewers for methodological quality prior to inclusion in the review using standardised critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (Appendix I). Any disagreements that arose between reviewers were to be resolved through discussion, or with a third reviewer, however, a third reviewer was not required as there was no significant differences to be resolved.

Data Extraction

Once critical appraisal had been completed and the studies to be included finalised based on quality assessment, the data relevant to the a-priori stated review methods and outcomes was extracted. Data extracted from papers included in the review using the standardised data extraction tool from JBI-MAStARI (Appendix II). The data extracted included specific details about interventions, populations, study method and outcomes of significance to the review question and specific outcomes.

Data Synthesis

The quantitative data was synthesised as a narrative summary. Because of the differing methods and variation in the type of data collected, a meta-analysis was unable to be performed. The data has been grouped for narrative summary using text and tables to report on findings related to the review outcomes. The results chapter has been structured to give a detailed review of included study methodological quality, then to report the findings. The approach taken is informed by evidence hierarchy tables that situates experimental research as being at less risk of bias, therefore the results are presented in sequence by study design.

Chapter 3: Results

Description of studies

As illustrated in Figure 1, the search strategy identified 1,505 studies that were potentially relevant. Of these sixty-one were retrieved for examination and after perusal of the abstract forty seven further studies were excluded leaving fourteen papers for detailed examination. A further three papers were found by manual examination of the reference lists of identified studies bringing the total to seventeen papers. Ten studies were then excluded from the study as they did not provide any quantitative research data leaving seven papers which were then assessed for methodological quality. A further paper was excluded after critical appraisal as the results were spuriously obtained and unable to be verified through the report due to poor reporting and lack of an audit trail for data collection.⁴⁰ In this study, participants answers were dependent on patient recall which was not accurate and the researcher herself was unable to draw any conclusions regarding specialised nurse input due to this occurrence. This left six studies for inclusion in the review. Refer to Figure 1 for an overview of the pathway for study selection and decision points throughout the review process. A table of included studies is reported in Appendix V; while a table of excluded studies and the accompanying rationale for exclusion are reported in Appendix VI. The studies were conducted in Europe, England, America Spain and Turkey.

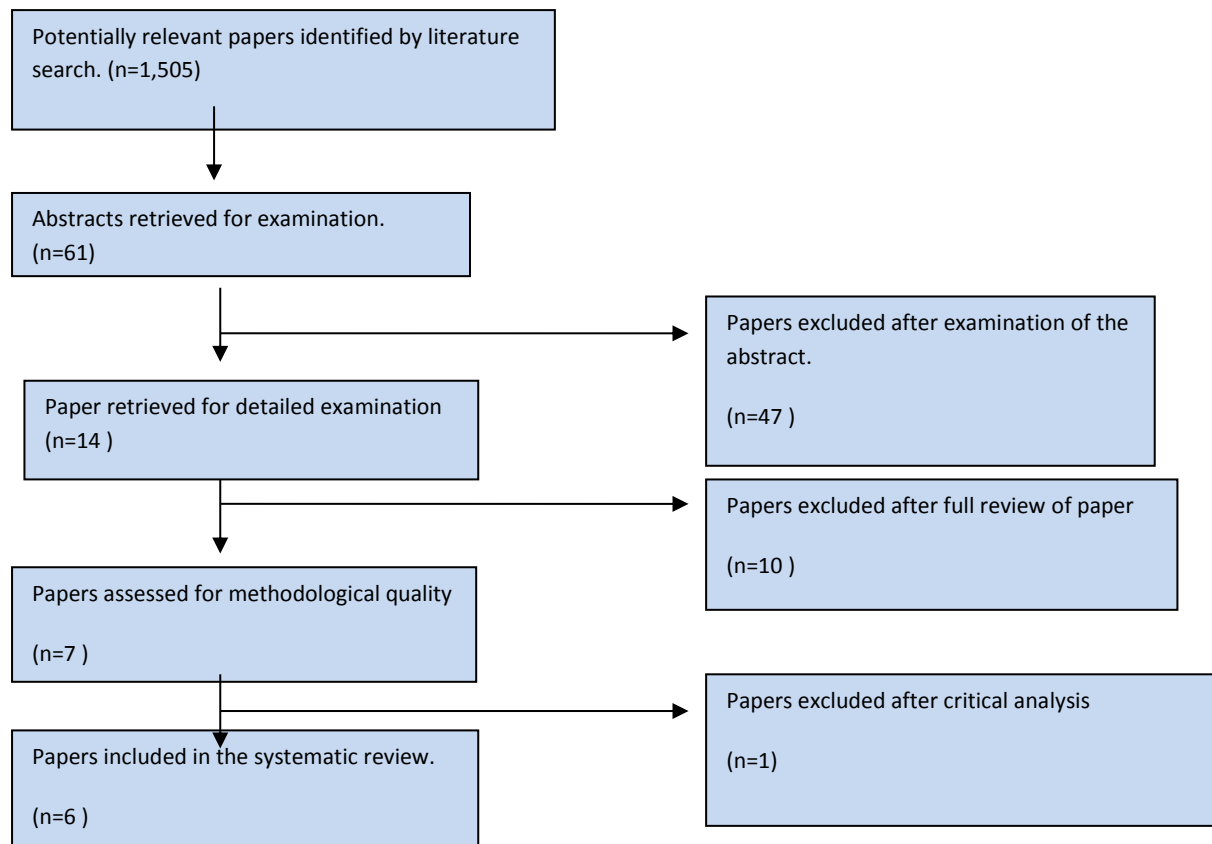


Figure 1: Illustration of the sequence for identifying, screening, appraisal and inclusion of studies for this systematic review.

As Table 1 illustrates, there was a total of 1,505 studies identified through the databases and by hand searching for research papers based on the inclusion criteria for this systematic review. Of these papers, 17 were subject to detailed reading in order to establish goodness of fit with the inclusion criteria. As per Table 2, six studies were included in the review and eleven of the studies were excluded after full reading of the paper.

Table 1: Number of studies found and retrieved

Number of studies found	Number selected for retrieval
1505	61

Methodological quality

Table 2: Number of studies included and excluded

Number of studies included	Number of studies excluded
6	11

Table 3: Randomised Control Trial / Pseudo-randomised Trial

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Addis, 2003	U	Y	U	Y	N	Y	Y	Y	Y	Y
%	0.00	100.00	0.00	100.00	0.00	100.00	100.00	100.00	100.00	100.00

Table 4: Comparable Cohort / Case Control Studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Karadag, Bulent Menten,	U	Y	Y	Y	Y	Y	Y	Y	Y

Uner, Irkorucu, Ayaz & Ozkan, 2003									
Jimenez, Pastor Juan, Prados Herrero, Perez Lopez, Fuentes, de Mena Casaseca, Romaguera, Tejido Valenti, Garcia-Alamino & Espirac., 2010	Y	U	U	Y	Y	U	U	Y	Y
%	50.00	50.00	50.00	100.00	100.00	50.00	50.00	100.00	100.00

Table 5: Descriptive / Case Series Studies

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9
Marquis, MD; Marrel; & Jambon, MS, 2003	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nichols, 2011	U	Y	U	Y	Y	N/A	Y	Y	Y
Wade, 1990	Y	Y	Y	Y	Y	Y	Y	Y	Y
%	66.67	100.00	66.67	100.00	100.00	100.00	100.00	100.00	100.00

Tables 3,4 and 5 are the results of the critical appraisal process which was undertaken on articles selected for inclusion in this review. The results of the appraisal of the Table 3 show that the study achieved agreement in most of the areas of the quality criteria in the appraisal instrument. The results illustrated in table 4 indicate a higher level of uncertainty over reporting of the quality indicators in those papers, however, as per table 5, the descriptive studies series overall scored well in terms of critical appraisal.

The following results from the studies are presented based upon the types of studies, with the experimental research papers findings being reported first, followed by the findings from observational and then descriptive studies. There was no deviation from the a-priori protocol with regard to the inclusion criteria, searching, critical appraisal, data extraction or data synthesis in this review report.

Quasi Experimental

The study by Addis compared two randomly divided groups of patients with newly formed bowel stomas.⁴¹ While still in hospital, the researcher interviewed all participants and collected questionnaire information plus the SF(36). The patients were all taught stoma care on the ward until independent as judged by the stoma care checklist and given a booklet with information about stomal care. This study employed a quasi experimental design. Randomisation was carried out in assignment to groups but the researcher was not blinded to allocation. All patients were visited in hospital and asked if they would participate in the study. The researcher designed a questionnaire, a standard stoma care plan and a stoma performance check list for use in this study. These were utilised in the study for data collection. The Medical Outcomes Study (SF 36) was also used and had been validated for use with Turkish patients.

The control group was visited at three and six months after discharge and questioned about problems they were experiencing with their stoma but no assistance given. The experimental group received monthly visits from a nurse researcher who was also a stomal care specialist on discharge during which problems with stoma management were discussed and suggestions for improvements made. Participants in both groups were followed up and observed by the researcher while they changed their appliance so that the performance checklist could be filled out. The SF(36) was again completed at these visits.

Participants were at least 14 years of age, had newly formed stomas and were capable of providing information to the researcher when interviewed. All participants were recruited from acute care hospitals. Patients with ileostomies and colostomies were included. The most common cause of stoma formation was bowel cancer but other causes included ulcerative colitis, recto vaginal fistula, trauma, diverticulitis, small intestine perforation, small bowel tumour and mesenteric arterial / vein obstruction. In the study, 36% of patients in either group had undergone radiotherapy, chemotherapy of both. The overall sample size was 50 patients.

Data was collected by the researcher in the form of the Medical Outcomes Study 36 item short-form health survey (SF 36) Quality of Life Scale. The SF(36) was administered prior to discharge from hospital and at three and six months during home visits. The researcher also designed a questionnaire, a standard stoma care plan and a stoma performance check list which were all used to collect information. Demographic details were also collected.

Data collected by the SF(36) was divided into eight dimensions, namely physical functioning, role limitation due to physical problems, social functioning, role limitation due to emotional problems, general mental health, vitality, bodily pain and general health perceptions. Quality of life, as elicited by the SF(36), was explored at three and six months, matched with the sample characteristics data and

statistical analysis carried out. The questionnaire developed by the researcher recorded the health problems experienced by the patients after discharge.

Cohort Studies

Karadag et al looked at the effect of stomal therapy nursing care on quality of life in patients who had never previously received assistance of this type.⁴² The author achieved this by collecting quality of life scores before and after stomal therapy intervention using the digestive disease QOL questionnaire (DDQ-15) on forty three patients. This study also made use of another questionnaire which was developed at the Gazi University Stomatherapy Unit called the Gazi University Stomatherapy Questionnaire (GUSQ). It was comprised of eleven questions relating to stoma specific problems.

Karadag et al undertook pre test and post test after stomal therapy input to determine whether stomal therapy support contributed to quality of life. Forty three selected clients were allocated into three groups. The first group comprised clients with end ileostomies, the second group were colostomy patients who did not irrigate and the third group were colostomy clients who had elected to learn to irrigate. See Table 7 for quality of life scores before and after stomal therapy input.

Excluded from this study were patients with stage 4 or advanced rectal disease, distant metastases, recurrent or remnants of tumours. Other exclusions included patients with recurrent or ongoing problems with inflammatory bowel disease. Those with co-morbidities which might influence HRQOL such as diabetes or other metabolic or endocrine disorder, psychiatric history, history of recreational drug use and those with a temporary stoma were also excluded from the study.

Jimenez and colleagues undertook a cohort study in Spain to ascertain whether quality of life for patients with a stoma receiving standard follow up care was different to those receiving intensive telephone call follow up care.⁴³ Two groups of patients were followed, one group received standard care (S) and the other group (I) received standard care plus intensive telephone call follow up. This large cohort study included 336 patients recruited from 70 hospitals.⁴³ Study volunteers were recruited from outpatients departments. Eligibility criteria for the study included being 18 years or older, being ambulatory, able to communicate verbally and in writing and to have new bowel or urinary stoma that is permanent or to be present for three months.

Jimenez and colleagues measured quality of life via the SQLI instrument when conducting their study. This collected numerical data that was linearly transformed to provide ranges from zero to one hundred. The higher the score the better the quality of life. They also collected data on patient characteristics and history. Patients meeting study inclusion criteria completed three months of follow up. The S group had 187 participants and the I group was comprised of 149 participants. No statistically significant differences were found initially between the two groups in relation to type of illness requiring ostomy, type of ostomy, presence of postoperative complications and type of appliance used.

The researchers suggest that an outcome of their work is to illustrate that intensive follow-up using the Patient Feedback telephone service in addition to standard clinical follow up may improve patient

quality of life in several, but not all, aspects of patient care and concerns. The aspects that did not improve after three months were medical care received and medical experience.

Cross Sectional Study

Nichols conducted a study to characterize the prevalence of social isolation and determine the impact of factors that influenced isolation in a sample of adults with an ostomy.⁴⁴ Five hundred and sixty adults with a stoma participated in the study. The assessment of participants was performed within two years of the individual having a stoma formed. Two hundred and ninety nine respondents were from North America and two hundred and sixty one were from the United Kingdom. Fifty three percent were women and forty seven percent were men.

The study examined issues pertaining to social isolation after surgery for a stoma. Many new ostomates are afraid to go out for fear of appliance failure and leakage or because of embarrassment due to odour or noise from their faecal output. This fear of socializing is generally thought to be reflected in the poor quality of life that individuals have after stoma surgery and explains why social concerns are often measured in stoma quality of life tools.

The data for this study was extracted from a database called the Ostomy Comprehensive Health and Life Assessment (Hollister Incorporated, Libertyville, Illinois). Two groups were defined by the researcher and "characterized as polar opposites" (pg 63).⁴⁴ The first group had responses which indicate that they were very socially isolated and displayed dissatisfaction or low levels of life satisfaction while the second group whose responses indicated that they were socially connected and displaying moderate or high levels of life satisfaction. Nichols hypothesized that the life-influencing factors would be most obvious between these two groups.⁴⁴

The outcomes as outlined by Nichols are that social isolation affects a number of patients recovering from ostomy surgery and that this is associated with impaired life satisfaction. Results from the survey demonstrate that perceptions of body image differ between those demonstrating social connectivity and increased social connectivity with those showing social isolation. Lastly Nichols proposes that his study supports the findings that stomal therapy nurse intervention has a significant role in assisting the person with an ostomate to re-establish social connectivity, improve body image and attain acceptable level of life satisfaction.⁴⁴ These factors all play a role in quality of life.

Descriptive Studies

The study by Wade reported psychological adjustment of colostomy patients at 10 weeks and again at 1 year after surgery in districts which employed stomal therapy nurses and those that did not.²⁰ The stated objectives of this study included evaluating the possible benefits to people with a stoma of specialist nursing care and to provide information on problems encountered by people following stomal surgery.

The intervention involved was the presence of the stomal therapy nurse to assist with patient adaption to life with a stoma. This study was conducted in the United Kingdom. Participants were patients with

all types of newly created abdominal stoma. Patients under the age of 16 years and those with a poor prognosis were excluded. The participants had to agree to be interviewed in their own homes and to participate in the study.

The population of the sample was initially 215 patients taken from a stratified random sample of 12 health care districts which employed stoma patients and 8 health districts which did not. At one year, a further 85 patients who had survived and had not their stoma reversed were reinterviewed.

Psychological adjustment was measured by the Present State Examination which assesses the prevalence of anxiety and depression. A measure of the patients physical state and the level of their physical symptoms was devised for usage in this study.

The second descriptive study by Marquis et al included in this review observed the quality of life of stoma patients using a stoma specific tool SQLI.²¹ The SQLI was adapted from the Quality of Life Index which is used for cancer patients and adapted to the requirements of stoma patients.²¹ It contains thirty four items which are answered on a six point rating scale. Higher scores are elicited for a higher quality of life. The scores are tallied and linearly transformed for statistical analyses. Stomal therapy nurse interest in the patient was investigated and related to quality of life to provide some evidence for effectiveness of this specialist nursing care. This research was called the Montreux Study.

The population under consideration for this study were 4,739 stoma patients from sixteen European countries. They were recruited by stomal therapy nurses. To participate in the study, patients had to be able to read so that they could complete the questionnaire, and to have had their permanent stoma formed within the last month. Stomal therapy nurse were asked to enrol all eligible patients.

Patients completed their SQLI questionnaire prior to discharge and then at 3,6,9, and 12 months after surgery. During the following year participants were asked to voluntarily complete the SQLI questionnaire yet again at 18 and 24 months.

Description of Results

Of the six studies included in this systematic review, the types of data collected were variable in nature as most studies used different tools. Data has therefore been reported textually in a narrative style. Again the information will be organised by study design.

Quasi Experimental

Outcomes were comprehensively reported.⁴¹ Baseline data showed equal numbers of men and women in the sample with a mean age of 49.2 years. Most patients had completed basic education which consisted of both primary and secondary schooling. The main occupation for both groups was that of domestic duties.

Addis compared working status before and after surgery as previous studies have shown that stomal surgery results in patients leaving paid employment. There was no significant difference between the groups for this outcome.

Sample health characteristics were also recorded in this study. Both groups had the same number of people with ileostomies and colostomies. The most common reason for stoma creation in both groups was bowel cancer. At discharge, 40% of the experimental group practiced self-care while only 16% of the control group performed likewise. When assessed after six months, 80% of the experimental group were independent while only 36% of the control group were able to independently change their appliance and the difference was statistically significant ($P=0.004$). Degree of self care and quality of life were not compared.

Problems experienced by the ostomate after discharge were also examined by the researcher via the questionnaire, the standard stoma care plan and the stoma performance checklist. She also collected data on the physical, psychological, social and spiritual problems encountered by patients in both groups. This information was collected at the time of home visit in the third and sixth month.

The results of this data revealed that patients in both groups had problems with flatus, odour, sore skin and leakage. In the control group at three months, 56-64% of patients suffered from these problems compared to 24-36% of the experimental group. Data showed a gradual improvement in both groups until six months although the control group patients still had persistent problems with this area in 36-52% of patients. Statistical significance between groups for these items was not noted by the researcher.

Social isolation was an important issue for both groups at three months. At six months only 8 % of the experimental group had a problem with this but 72% of the control group still found this to be a major issue. Altered body image actually increased from 40% at three months to 48% after six months in the control group. In the experimental group, 28% had this problem at three months and this reduced to 8% at the six month mark. Sexual issues were another problem explored by the nurse researcher. Of the control group, 68% had issues with sex and sexuality at the three month time period and this increased to 72% at six months. For the experimental group, 64% had problems at three months and this number remained the same at six months.

Issues related to religious belief were also explored by the researcher. Many Turkish people are Muslims and there are strict rules relating to personal hygiene and prayer. The presence of a stoma creates issues in their religious practice which they must deal with. Of the control group, 52% at the three month mark had problems of a religious nature which reduced to 32% at six months. For the experimental group, religious problems dropped from 12% at three months to 0 at six months.

In the first interview, completed while the patient was in hospital after surgery there was no significant difference between the control and experimental groups in SF (36) scores. By the three month mark, there was significant differences in six out of eight of the SF (36) dimensions between the two groups. The dimensions of social functioning and general health perception were the only two that did not

show a statistical difference ($P < 0.05$) benefiting the intervention group. By the sixth month, data showed that there was a significant difference ($P < 0.05$) in quality of life scores between the control and the experimental group in all of the dimensions of the SF (36) (see Table 6 below). The control group had received no support service after discharge.

Table 6: SF 36 Domains at six months follow up.

SF (36) Dimensions	Experimental Group			Control Group			Statistical Analysis	
	Median	Min	Max	Median	Min	Max	U Value	P Value
6th Month Follow up								
Physical Function	90.0	70.0	100.0	60.0	10.0	90.0	24.0	0.0001
Role limitation due to physical problems	100.0	50.0	100.0	50.0	0.0	100.0	71.0	0.0001
Social Functioning	75.0	37.0	100.0	50.0	25.0	87.5	78.5	0.0001
Role Limitation due to emotional problems	100.0	66.0	100.0	66.6	0.0	100.0	107.0	0.0001
General Mental Health	80.0	60.0	100.0	52.0	20.0	92.0	23.0	0.0001
Vitality	65.0	40.0	90.0	35.0	15.0	70.0	42.0	0.0001
Bodily Pain	100.0	60.0	100.0	60.0	20.0	100.0	2.50	0.0001
General Health Perception	80.0	40.0	90.0	45.0	15.0	75.0	40.0	0.0001

U= Mann Whitney U value P= P value

The authors concluded that home visits after discharge improve quality of life for patients with a stoma at six months.

Cohort Studies

In the cohort study by Karadag et al,⁴² the participants were 43 selected patients with properly constructed and well functioning end ileostomies and end colostomies, aged between 24 and 77 years old.⁴³ All patients had undergone surgery, chemo or/and radiotherapy at least three months previously. The patients with ileostomies had their stoma due to Inflammatory bowel disease and the patients with colostomies had been diagnosed with stage 2 or 3 rectal cancer.

Outcomes of interest in Karadag's study were firstly the improvement in quality of life after stomal therapy input as measured by the DDQ-15. Secondly the frequency and comparisons of stoma related problems before and after stomal therapy as measured by the GUSQ.

Quality of life scores for the patients who were taught to irrigate their colostomy were initially in the range of twenty nine to sixty nine as measured by the DDQ-15. The higher the score, the better the quality of life is. After stomal therapy input the range rose to sixty to seventy five ($P < 0.001$). For the group of patients with a colostomy who did not irrigate, the initial quality of life score ranged from thirty three to sixty three. After stomal therapy input this rose to a range of forty to seventy ($p = 0.001$). For patients with ileostomy, initial quality of life score ranged from twenty four to sixty nine and again after stomal therapy input this rose to forty six to sixty eight ($P = 0.002$). The cumulative quality of life score for the combined patient group was initially twenty four to sixty nine and rose to forty to sixty eight ($P = 0.002$) after stomal therapy input.

Karadag et al documented the frequencies and comparisons of stoma related problems before and after stomal therapy input.⁴² The areas addressed were bathing, travelling, sports, dressing, bag evacuation, using stoma instruments, noise and ballooning, odour, meetings, sexual problems and skin problems. When the three groups were assessed as a cumulative score, all the areas improved significantly after stomal therapy input ($P < 0.001$).

When reviewed group by group, those irrigating colostomies showed improvements in all areas of stoma related problems reviewed. Statistical significance ranged from $P \leq 0.05$ for bathing, travelling, bag evacuation and skin problems to $P \leq 0.001$ for sports, using stoma instruments, noise and ballooning, odour and meetings. Sexual problems improved with a significant difference of $P \leq 0.01$, mean scores are not provided for this data.

For the patients with a colostomy who did not irrigate, dressing and skin problems improved with a statistical difference of $P \leq 0.05$. Meetings, odour, noise and ballooning and sports improved with statistical difference of $P \leq 0.01$. Bathing, travelling, bag evacuation and using stoma instruments improved with a statistical difference of $P \leq 0.001$. Values for sexual problems did not change after stomal therapy.

In the group of patients with an ileostomy, bathing and bag evacuation showed the greatest improvement related to quality of life $P \leq 0.001$. Travelling, dressing, using stoma instruments and noise and ballooning were next with a statistical significant difference of $P \leq 0.01$. Skin problems and meetings improved slightly $P \leq 0.05$. The areas that did not improve for this group were sexual problems, odour and sports.

The items that failed to improve significantly after stomal therapy input were the areas of sports and odour among the individuals with an ileostomy ($P > 0.05$). Sexual activity was an area that did not improve in the ileostomy or the non-irrigating colostomy group after stoma therapy input ($P > 0.005$).

Table 7 below shows the quality of life scores of the stoma patients before and after stomal therapy input. QOL scores were found to be significantly higher in all groups after stomal therapy assistance.

Table 7. Quality of life scores of the stoma patient before and after stomal therapy

	Before Mean \pm SD	Before Range	After Mean \pm SD	After Range	P^a
Irrigating colostomy (n=16)	55.25 \pm 9.0	29-69	69.12 \pm 4.3	60-75	<0.001
Non-irrigating colostomy (n=15)	42.06 \pm 9.4	33-63	55.0 \pm 8.5	40-70	0.001
Ileostomy (n=12)	34.5 \pm 9.5	24-55	57.9 \pm 6.4	46-68	0.002
Total (n=43)	44.8 \pm 12.5	24-69	61.0 \pm 9.0	40-75	<0.001

^a Wilcoxon's paired test and paired samples t test

The cohort study by Jimenez and colleagues sought to ascertain whether quality of life for patients with a stoma receiving standard follow up care was different to those receiving intensive telephone call follow up care in Spain. ⁴³ Patients were asked if they wished to receive follow up phone care and in this way, two groups of patients were formed. One group received standard care (S) and the other group (I) received standard care and volunteered for intensive telephone call follow up known as Patient Feedback. Patient Feedback consisted of trained company personnel contacting the participants at regular intervals and asking set questions. If the participant had any problems, the investigator ie. the stomal therapy nurse would be advised. They would then contact the participant to offer advice regarding the problem.

The average baseline SQLI score was 58.5 in the S group. When comparing between I and S group baseline scores, the only significant difference was in the social concerns domain. In the I group, the average scores in this area was 85.5 (SD 17.7) compared to the S group 79.5 (SD 21.6). This was a significantly higher score (P = 0.0123, Wilcoxon two-paired test).

As seen in Table 8 below, after three months, the S group improved more than the I group in the subscales of nutrition, social concerns, patient satisfaction with medical care received, improvements in medical care and medical experience. P value was measured at <0.05 and so the only areas to reach statistical significance were patient satisfaction and medical experience. The overall change in SQLI scores between the S and I groups was not significantly different.

Table 8 Change in Stoma Quality of Life Index scores after 3 months

	Standard Group^a (S)	Intensive Group (I)	P Value^a
N (%)	187 (55.7)	149 (44.3)	

Scales of SQLI^b			
Quality of life index	14.5± 18.1	13.5± 17.4	0.6222
Psychological well-being	12.9±23.3	12.4 ± 22.2	0.7017
Physical well-being	17.9± 21.2	16.5± 22.2	0.5747
Body Image	16.1± 26.8	17.3±25.3	0.7399
Pain	12.9± 27.3	12.7± 25.7	0.7268
Sexual activity	10.4± 37.5	10.4± 36	0.6318
Nutrition	13.8± 24.4	10.9 ± 22	0.2418
Social concerns	9.3 ± 21.4	4.7± 19.6	0.0677
Handling	13.5 ± 33.4	15.5± 27.5	0.6028
Satisfaction with medical care			
Patient satisfaction	8.6 ± 24.4	2.4 ± 15.3 ^c	0.0173
Improvement	6.4 ± 40.6	-1.4 ± 39.1	0.1026
Medical experience	1.9 ± 38	-3.3± 37.7 ^c	0.0330
Self efficacy			
Self-efficacy	17.9 ± 27.4	22.5 ± 29.8	0.3653
Help and advice	9.8 ± 32.9	9.9 ± 30.9	0.5598

^a Wilcoxon test, t-test, as appropriate

^b Average (+SD) score change

^c P<0.05 between S and I Group (Wilcoxon test)

The researchers also suggest that this study highlights the preoperative role of the stoma nurse as well as the postoperative role. Jimenez and co-workers proposed this was because the incidence of preoperative stomal therapy nurse visit was associated with a greater probability of improvement at three months in the subscales of physical well being, nutrition and social concerns (odds ratio =1.895, P = 0.02280, odds ratio = 2.571, P = 0.0003, odds ratio =2.143, P = 0.0012, respectively) . See Table 9 for probability of Stoma Quality of Life Index subscale by improvement by patient history/characteristic.

Less than half of the total number of patients (35%) received a preoperative visit from a stomal therapy nurse. A history of cancer was associated with a lower probability of improving quality of life in a number of areas namely psychological well being (odds ratio= 0.557, P = 0.0313), physical well being (odds ratio = 0.496, P= 0.0234), nutrition (odds ratio =0.463, P = 0.0060), social concerns (odds ratio = 0.623, P = 0.0532) and help and advice (odds ratio = 0.548, P= 0.0161). The use of an appliance with adhesive coupling was associated with a greater probability of improving in the

subscales of nutrition (odds ratio = 1.924, P = 0.0152) but with a lower probability of improving in the physical well being and medical care improvement scales. These researchers suggest that the "perception of dedicated care and follow up may be difficult to measure" and that this study illuminates some of the areas in which clinicians may be able to improve quality of life in stoma patients and perhaps areas in which they cannot (pg 52).⁴³ The authors however, do not elaborate on this statement but is probably a reference to low satisfaction with medical care.

Table 9 Probability of Stoma Quality of Life Index subscale Improvement by patient history/characteristic

Subscales of SQLI	Number (%) of patients improved	Pre-operative ostomy nurse visit	Carcinoma present	Use of appliance with adhesive coupling
Psychological well-being	226 (67.3)		0.557(0.327-.949) P=0.0313	
Physical well-being	250 (74.4)	1.895(1.071-.351) P=0.0280	0.496(0.270-.909) P=0.0234	0.284(0.111-.730) P=0.0090
Nutrition	211 (62.8)	2.571(1.533-.313) P=0.0003	0.463(0.267-.801) P=0.0060	1.924(1.134-.264) P=0.0152
Social concerns	154 (45.8)	2.413(1.350-.402) P=0.0012		
Patient satisfaction	119 (35.4)	1.384(0.866-.212) p=0.1747		
Improvement medical care	106 (31.6)			0.214(0.049-.934) P= 0.0403
Help and advice	105 (31.3)		0.548(0.335-.894) P=0.0161	

Data are expressed as odds ratio, OR (95% confidence interval IC).

The researchers concluded that intensive follow up using the Patient Feedback telephone service in addition to standard clinical follow up improved patient quality of life in several, but not all, aspects of patient care and concerns. The aspects that did not improve after three months were medical care received and medical experience.

Cross Sectional Study

In the cross sectional study by Nichols, outcome data was collected in numerical form and then statistically analysed and compared between certain factors.⁴⁴ These factors were emotional support, social support and life satisfaction. The instruments used to collect data were firstly a survey instrument called the Hollister Ostomy Comprehensive Health and Life Assessment. A life satisfaction index was compiled from this survey instrument and it used Likert style questions to elicit data.⁴⁵ Low

scores registered dissatisfaction and high scores equated with satisfaction. Emotional support was calculated by using the Medical Outcomes Study, Social Support Survey and Social isolation was assessed using Hawthorne's Index of Social Isolation.⁴⁴

Data analysis was employed. The information collected was stratified by type of stoma, gender, age and length of time since surgery. Odds ratios were used to calculate the likelihood of events between groups. The data was taken from 299 respondents from Northern America and 261 from the United Kingdom. Of this group 53% were women and 47% were men.

Data analysis from this study reports as statistically significant correlation between social isolation, emotional support and life satisfaction.⁴⁴ The correlation coefficient is a measure of the linear relationship between variables with zero being no relationship and minus one being the lower limit and plus one being the highest score. Between social isolation and life satisfaction the correlation coefficient (Pearson r) was 0.49. Between emotional support and social isolation the correlation coefficient was 0.65 and between life satisfaction and social isolation the correlation coefficient was 0.72. Nichols also found that social isolation diminished over the first twenty four months post operatively therefore individuals with stomas gradually appear to integrate the stoma into their lifestyle and take up their usual social connections, improving their quality of life from the immediate post operative phase.

This study also looked at the difference between respondents (Group A) who were socially isolated and those who were socially connected (Group B). Participants in Group B were more likely to have high levels of emotional support available than those in group A (odds ratio =21, P<0.001).⁴⁵ If the respondent was in the socially connected group (B), they were more likely to state that their stoma had a positive effect on their lives than respondents from Group A (odds ratio = 3.5, P<0.0002). Group B respondents were also more likely to agree that they had adapted to living with an ostomy (odds ratio =28.2, P<0.0001) and less likely to perceive themselves as disabled due to their stoma (odds ratio =9.4, P<0.0001).⁴⁴ The respondents in Group B were also more likely to have had pre and postoperative care from a stomal therapy nurse (odds ratio =1.84, P < 0.0002). See Table 10 for notable differences between groups.⁴⁴

Of the respondents in Group A, 88.9% stated that they did not like their appearance and that the stoma had disfigured or changed them, compared to 30.8%in Group B. There was an eighteen times greater likelihood of a Group A respondent appearing in the "I do not like the way I look/changed my appearance/disfigured me" categories than a respondent from Group B (odds ratio = 18, P < 0.0001).⁴⁴

Table 10: Notable Differences between Groups

	Group A	Group A	Group B	Group B
	n	%	n	%
High levels of emotional support indicated	27	36.5	326	92.4

Stating the stoma has had a positive effect on their lives	11	14.9	134	37.7
Have not at all adapted to living with a stoma	18	24.3	4	1.24.
Disabled, related to stoma	35	47.3	31	8.8
Pre-/post surgery Stomal Therapy (WOC) nurse care	35	47.3	220	62.3

*Pre and post surgery Stomal Therapy (WOC) nurse care data was reported as a single figure and cannot be separated into two components for the purpose of this review.

The finding of most relevance to this review is that stomal therapy nurse intervention played a statistically significant and clinically relevant part in the recovery period for individuals recovering from ostomy surgery with 47.3% of patients in the socially isolated group involved with a stomal therapy nurse compared to 62.3% on the high level of social support (odds ratio = 1.84, P=.0022).⁴⁴ The rationale for this result being that the stomal therapy nurse specialized care improved management of the stoma or their psychological care assisting the ostomate to integrate back into society.⁴⁴

Descriptive Studies

Wade's study was published in the United Kingdom in 1990.²⁰ It differs from the other included papers in that the author observed and described the difference in stoma care nurse intervention in terms of psychological adjustment using the PSE. The other five studies have all attempted to use tools which involved the stoma and/or stomal management.

For this research study, 142 patients from 14 health care districts who employed stoma care nurses and 73 patients from 8 health districts who did not employ stoma care nurses comprised the sample. Wade states that although there were minor differences in the groups, covariance analysis controlled for this.²⁰

Results of covariance analysis at ten weeks after surgery showed that the patient's physical state was strongly related to psychological adjustment ($P < 0.001$).²⁰ Age was found to be unrelated to psychological adjustment when controlled for extent and severity of symptoms. The extent and severity of symptoms may affect quality of life in individuals who are unwell. The researchers adjusted for this so that measuring quality of life as related to psychological adjustment to the stoma was clearer.²⁰

After controlling for dependent variables, access to stoma care nurse was found to be associated with patients being significantly less prone to affective disorder than patients who did not access to a stoma care nurse ($P < 0.05$).²⁰ Single, widowed or divorced men were also less prone to affective disorder than other groups $P < 0.01$.²⁰

Eighty-five patients from the study were reinterviewed one year later. PSE scores underwent covariance analysis and the results largely reconfirmed earlier findings from the study. A large amount of the variance, 42%, was due to extent and severity of physical symptoms ($P < 0.001$).²⁰ At this stage, access to a stoma care nurse was not significantly related to psychological adjustment.²⁰ The finding that unmarried men seemed to have better emotional health than women was replicated ($P < 0.05$).

Emotional health was found to be associated with adaption to a stoma. if emotional health improves then adaption to a stoma is better. See Table 11 for the detailed results of analysis of covariance of psychological adjustment at one year after surgery.²⁰

At the ten week post-surgical interview, one quarter of the colostomates (n = 215) interviewed were assessed as anxious or depressed, 6% being severely depressed and 5 % had contemplated suicide. In health districts with a stoma care nurse, 23% of all patients and 20% of patients with a temporary colostomy were anxious or depressed.²⁰ In districts without stoma care nurses, 30% of all patients and 34% of patients with temporary colostomies were anxious or depressed, however, it was not possible calculate a mean or SD from the published data.

Leakage from the appliance at this ten week stage was more frequently experienced by those patients who were anxious or depressed (17% vs 7%).²⁰ This was also more common among those with temporary stomas, 13% vs 6% for those patients with permanent stomas. It was more common for patients who did not access to a stoma care nurse to have frequent leakage, 16% vs 6 %.²⁰

At the second interview, of the total number of patients, 7% were anxious, 9% depressed and a further 9% were severely depressed. Of those patients in stoma care nurse districts 27% were anxious or depressed compared to 23% in other districts.²⁰ Patients who were anxious or depressed at ten weeks were more likely to be anxious or depressed at one year. Having access to a stoma care nurse at this stage was not significantly related to psychological adjustment. Of the group that did not have access to a stoma care nurse, 41% had seen a representative or nurse from an appliance company in the hospital prior to discharge and by the ten week stage this had increased to 61% and rose to 75% at 12 months. See Table 11 for result at one year following surgery.²⁰

There was no difference found by this study in prevalence of affective disorder between colostomates in health districts with stoma care nurses and districts without at 1 year.²⁰ Wade proposes that the presence of company nurses may have affected data outcomes at 12 months or that perhaps successful psychological adaption to an ostomy in the longer term may be independent of nursing intervention.²⁰

Table 11 Analysis of covariance psychological adjustment at 1 year after surgery (A square root transformation (SQRT) was carried out on the PSE scores which were also standardized).

Source of variance	Sum of squares	df	Mean square	F
Covariates				
Age	0.27	1	0.27	0.47
Physical State (SQRT)	35.43	1	35.43	62.64***
Main Effects				
Access to a stoma nurse	0.18	1	0.18	0.31

Sex	0.14	1	0.14	0.25
Support of a spouse	0.84	1	0.84	1.48
Temporary/permanent stoma	1.19	1	1.19	2.11
Two way interactions	4.99	6	0.83	1.47
Sex x support of a spouse	3.47	1	3.47	6.14*
Error	40.73	72	0.57	

***P<0.001 *P<0.05 df = degrees of freedom F = F ratio

The second included descriptive study by Marquis et al used a stoma specific tool, the Stoma Quality of Life Index (SQLI). Information collected is used to measure quality of life for people with a stoma.²¹ One of the main aims of this study by Marquis and co-workers, was to test whether their instrument the SQLI could be used to measure QOL in stoma patients.²¹ The mean age of participants was 61.6 years (± 13.4 years) and 53.7% were males and 37.3% were females. Most patients had a colostomy (66.5%), 16.4% had a ileostomy and there were 16.5% of respondents with a urostomy.²¹ There was 0.6% of data missing. Carcinoma was the most common condition requiring stoma surgery with 70% of respondents having this. A concurrent illness was present in 36.3% of the sample, the most common problem being cardiovascular disease, followed by respiratory and then rheumatic disease.²¹

Results from the SQLI showed that QOL was fairly consistent in all patients in Europe in the immediate postoperative period following surgery.²¹ The mean score ranged from 54(± 16) in Israel up to 70(± 13) in Belgium. The average SQLI score rose sharply in the first three months post surgery with modest improvement in the ensuing period.²¹ This initial rise in quality of life score was statistically significant (P<0.001 - Wilcoxon signed rank test). The other data was not published and therefore was unavailable for this systematic review.

SQLI scores in most countries were similar however, Portugal and Israel were significantly lower than the rest. A possible reason for this is simple climatic conditions. The longer the time between discharge from hospital and first assessment of SQLI, the higher the score attained.²¹ There were slight differences between dimension scores over the time period but the overall pattern was of improved quality of life in patients. Again this data cannot be presented as it was only shown as a bar graph in the paper.

Of particular interest to this review, 2,852 patients out of a total of 3,042 patients indicated that their stoma care nurse had a genuine interest in them.²¹ These patients scored higher on the SQLI than patients who felt that their stoma nurse was not interested in them. This difference was significant (Kruskal-Wallis test P<0.001). Other significant findings were for patients responding to the question "how confident are you in changing your appliance?" Patients with higher confidence rated higher SQLI scores and following from that higher quality of life scores (Kruskal-Wallis test P<0.001).²¹

Another area of significant finding was generated in response to the statement "I am very satisfied with the medical care that I received". Those patients more satisfied with medical care received

scored higher SQLI marks and therefore had a higher quality of life score than those dissatisfied with their care (Kruskal-Wallis test $P < 0.001$).²¹ This study's major purpose was to evaluate whether the SQLI was a suitable tool to assess the quality of life for people with a stoma.

Chapter 4: Discussion and Conclusions

General Discussion

This review aimed to identify, appraise, extract and synthesize the best available evidence of the effectiveness of follow up care for quality of life as provided by stomal therapy nurses to adults and adolescents. Of the seventeen studies considered relevant based on detailed reading, ten were subsequently screened out, the seven that met the inclusion criteria were subject to critical appraisal and six studies were subsequently included in the analysis.

Quasi Experimental

A single quasi experimental study examined the effects of home visits after discharge on patients with an ileostomy or colostomy.⁴¹ The SF-36 was used to assess health related quality of life and consists of eight dimension which were measured. Both groups were evaluated at the time of hospital discharge and again at three and six months follow up.

At the initial interview in hospital, no statistically significant difference was found between the two groups ($P>0.05$) in QOL using the SF-36. Then, at the third month after discharge from hospital, data indicated that there was a statistically significant difference ($P<0.05$) between the control and the experimental group in six out of eight of the SF-36 dimensions. The two dimensions that failed to show statistical improvement were social functioning and general health perceptions.

The researcher proposed that the reason that general health perceptions did not improve was because all the patients "may have had a similar general health perception because of the healing which occurs in the first three months" (pg 30).⁴¹ Addis attributes similarities in social functioning at this stage to "patient embarrassment about odour and the noise of flatus" (pg 30.)⁴¹

When measured at the sixth month, a statistically significant difference ($P<0.05$) was found in all eight dimensions of the SF-36. This difference may be due to continued visits to encourage self care and continued education that the patients in the experimental group received. Patients in the control group did not receive any assistance, as at this time, there was no formal support given to stoma patients in Turkey after discharge from hospital.

Therefore, the improvement in the physical, psychological, social and spiritual areas of the experimental group may be attributable to stoma nurse visits and education. However, despite visiting the experimental group, there was no improvement in the area of sexual problems in this group or the control group. Addis concludes that the lack of improvement may be due to patients requesting specific sexual advice which she was unable to provide.

The researcher concluded that home visits after discharge improves QOL for patients and decreased stoma related problems for patients. Results from the collected data appear to provide some evidence for this assertion. This study was however lacking an adequate sample size to detect a true effect, additionally, stoma specific tools were not utilized and issues with researcher bias may be inherent in

the study implementation. The author was aware of which groups the patients were allocated to and this may have inadvertently affected the way the researcher interacted with participants. The study also compared individuals who received assistance with follow up care for their stoma to those who received virtually no assistance at all. It would seem apparent that any assistance would be more beneficial than no assistance.

Quasi experimental designs are similar to experimental designs (the researcher still manipulates a variable to explore the outcome) but there are some differences; " the researcher omits some aspects of control that are observed in a true experiment" (pg 159).⁴⁵ Because of this, quasi experimental designs do not provide the same level of certainty in regard to cause and effect that an experimental design does. ⁴⁵

One of the areas that limits Addis's research is the fact that although the patients were randomly assigned to groups, the researcher did the home visits herself. This means that the researcher was not blinded to which participants were in the control group and which were in the experimental group. Researcher bias may have influenced the study outcomes because of this.

The sample sizes were small with both groups having 25 randomly selected participants. Addis's study found no significant differences between groups in terms of sample characteristics ($P > 0.05$). This lack of difference can occur when there are too few subjects (the study is underpowered) to elicit a difference.⁴⁶ Confidence intervals, which produce clearer evidence of the effect measure have not been reported in this study, a characteristic which also limits interpretation, but is common among research studies in this field.⁴⁶

The other area of concern in this study is the measurement outcome tools. Here the researcher has used the SF-36 to measure HRQOL. Again this measures HRQOL but does not gauge specific concerns related to the presence of a stoma. The other data collected related to sample characteristics of the participants, including problems experienced after discharge which incorporated physical, psychological, social and spiritual issues. Collection of this data was carried out by the researcher and this process is not clearly explained.

The issue with data collection is that the SF-36 is not stoma specific and therefore not entirely relevant to measuring quality of life for a patient with a stoma. The QOL results that Addis has elicited may in fact reflect the relationship between poorer QOL and severity of physical health issues. The poorer health characteristics can be gauged by the data that Addis has collected which summarises problems experienced after discharge. This relationship is also seen in Wade's study where the patient's physical symptoms are strongly related to affective disorder.²⁰

The evidence in this study is then promising but due to small sample size of participants and use of tools not specific to stoma outcomes the outcomes need to be considered in light of these potential limitations.

Cohort Studies

Two cohort studies evaluated the effect of stomal therapy nursing input on QOL for patients with a stoma. It was not possible for the reviewer to combine the findings of any of the studies in this section due to heterogeneity of intervention and outcome measures.

The first cohort study by Karadag et al concludes that bowel stomas have a profoundly negative impact on QOL and that specialized counselling can improve outcomes for this patient group.⁴² This study compared three groups of patients before and then three months after stomal therapy input.⁴² These groups were comprised of individuals with irrigating colostomies in one group, another group of people with non-irrigating colostomies and lastly another group of people with ileostomies. The measures used to evaluate quality of life were the Digestive Disease QOL questionnaire (DDQ-15) and a second questionnaire formulated by the researchers from the Gazi University used to assess common stoma problems.

Karadag's study show that quality of life scores improved significantly for all three groups when compared to pre stomal therapy intervention scores.⁴² The patients who were taught the techniques and processes for colostomy irrigation by a stomal therapist had the highest QOL scores but this was the case at pretest as well. The authors suggest that this reflects the higher cognitive function needed to master irrigation. As reported in the results chapter, the improvement was statistically significant for irrigating colostomates ($P < 0.001$), non-irrigating colostomates improved also ($P = 0.001$) and for individuals with an ileostomy ($P = 0.002$). On overall scores ($n = 43$) the improvement was statistically significant ($P < 0.001$).

In terms of stoma related problems all the items under investigation improved significantly after stomal therapy input when measured at three months. In regard to sexual problems, the reason for improvement among the irrigating colostomates probably stems from successful irrigation making evacuation more predictable and this then enables the colostomate to have more confidence when engaging in sexual activities. Irrigation empties the bowel and therefore a more discreet covering can be applied to the stoma improving body image and an empty bowel is less prone to the passage of flatus and stool during intimate moments therefore being less embarrassing.²

The issues of sports and odour failed to improve significantly in the ileostomate group. The output from an ileostomy is fluid, and usually higher in volume than the output from a colostomy. More leakage and management issues are found in this group of patients due to the composition of the effluent produced.

A cohort study involves the formation of two groups of participants, one that receives the exposure of interest and one that does not.⁴⁸ Although it is ranked lower than a Randomised Control Trial or a Quasi experimental study, JBI rank cohort studies at level 3.⁴⁹

The disadvantages attached to cohort studies are that randomisation and blinding procedures are not used. Also unknown confounding factors may affect outcomes and therefore be responsible for

measured differences. This means that causation of outcomes cannot be established in these studies. Thadhani and Tonelli (2006) report that there is an increased likelihood of bias in cohort studies which can result in incorrect inferences being made.⁴⁷

Confounding factors are also a problem in cohort studies. This occurs when a factor interferes with the association between an intervention and outcome.⁴⁷ There are many confounding factors involved in quality of life studies for patients with a stoma as outlined in the introduction and background to this thesis and these may have affected results.

In the study by Karadag et al, the researcher has tried to rid the research of confounding factors through rigorous inclusion criteria which excludes potentially confounding factors.⁴² This is the only cohort study found which attempted to do so. The study also address the problem that most research is carried out when the ostomate has just had his/her stoma formed. The participants in this study had to have had their stoma for at least three months. As reported in the background this early post-operative period is one of rapid change and therefore many variables influence perceived quality of life. By implementing the research on patients who had their stoma for some time, the adaption process taking place would have been well underway and therefore have less of an impact on QOL measurement. However, participants were subject to selection bias in that the 3 groups are formed based on what type of stoma the participant has and/or if they desire to irrigate their colostomy. In addition to this, further bias is evident in that the group that elected to learn irrigation would have needed to have a higher level of cognition and dexterity to perform this procedure as it does require both of these skills plus a commitment to learn.

Another issue with this study is that the group that learnt to irrigate really showed that irrigation can improve quality of life rather than that stomal therapy nursing care improved quality of life. Although the stoma care nurse may have taught the patient to irrigate, it is really the irrigation technique and not having to wear an appliance which improved quality of life.

This study also makes use of a P value of 0.05 which is thought to be inaccurate at times especially with a small sample size with no confidence levels mentioned in the data.

The measurement tool DDQ-15, although found to have a reasonable convergent and divergent validity, was not stoma specific.⁴² The researcher had noted the absence of stoma specific instruments when explaining the decision to use this particular tool. The implication arising from this is that quality of life for people with a stoma may not have been measured with a degree of sensitivity and specificity that would be expected of a stoma validated instrument.

The strength of this study lies in the comparison of the before and after testing. As stated in the study, each patient acts as their own control and eliminates confounding factors.⁴⁶ In this way it does offer evidence that stomal therapy care is of benefit to patients with a stoma.

The second study evaluated the effect of follow up by intensive phone calls on 356 ostomy patients in Spain.⁴³ Two groups were compared, one being the control or standard (S) group and the other

group, the experimental or (I) group received intensive phone follow up. The Stoma Quality of Life Index (SQLI) was measured at the beginning and the end of the research and used to compare groups.

In this study undertaken by Jimenez et al ⁴³, the S group improved their QOL score more from initial visit to follow up interview than the I group in five sub groups. These subgroups were nutrition, social concerns, patient satisfaction with medical care received, improvement in medical care and medical experience ($P < 0.05$). This outcome may have resulted from the I group containing more patients with cancer and permanent stomas. This group was also found to include fewer patients with a preoperative ostomy nurse visit. Jimenez et al also suggest that the differences between the I and the S group in the area of medical care could " be reflected to a correlation between the absence of a preoperative stoma care nurse visit and the overall quality of stoma/medical care in a particular facility" (pg 50).⁴³

The proportion of patients in the I group seeking emergency assistance or hospitalization was lower than in the S group. Although possibly the numbers were too small to detect a statistically significant difference, this result may be clinically significant according to the researchers. However, random sampling should be used for further exploration of this area to examine this outcome, ensuring that sampling bias is adequately controlled for.

A key point from the study was that intensive telephone follow up using Patient Feedback service in addition to follow up care may improve some aspects of patient care. The authors also report that dedicated care and follow up may be difficult to measure. They further highlight that results from their study underscores the role that stomal therapy nurse in the area of patient quality of life but do not clarify what this may include.

Jimenez et al again uses the SQLI which is stoma specific and reliable as a measuring tool. The sample size for this study is larger, although again selection bias is present as patients have to agree to participate and also agree to intensive phone follow up to be included in the experimental group and randomisation was not performed. The period that the study was conducted over was three months, which is a short duration for a stoma that may have lifelong impact. Usually adaption to the stoma takes up to six months post operatively at least and measurement of quality of life is usually taken then as well.

A P value of < 0.05 was given as reaching statistical difference. Thadhani and Tonelli write that an incorrect conclusion may be made by chance alone when setting the P value at this level.⁴⁷ As previously mentioned, one outcome in every twenty may be incorrectly associated with the exposure giving false conclusions.

The evidence presented by this study in supporting the benefit of stomal therapy nursing is inconclusive. After 3 months follow up care the proportion of patients in the I group requiring emergency assistance or hospitalisation or assistance with stoma related complications was lower than in the S group, however, this difference did not reach statistical difference.

Cross Sectional Study

One cross sectional study examined the prevalence of social isolation and tried to determine the impact of other factors on a sample of adults with stomas.⁴⁴ The researcher concluded that social isolation affects a proportion of people after stoma surgery and that this is associated with impaired life satisfaction. He reported that there is a difference in perception of body image between patients with social connectivity and increased life satisfaction and those showing social isolation and life dissatisfaction. Nichols also proposed that his study showed that stomal therapy nurses play a statistically significant and relevant role in the care of patients with ostomies as they work to regain social connectivity, maintain a positive body image and achieve an acceptable level of life satisfaction.

Social isolation appeared to be the greatest in the early postoperative period and then decreased over the following twenty-four months. The researcher reports that this may result from "appraisal and reappraisal as situational resources develop" (pg 66).⁴⁴ It may also be that as their health improves, patients are more able to enter into social activities again hence lessening their social isolation. The role of the stoma therapy nurse in this recovery is subtle but illustrated by the higher proportion of patients in Group B 62.3% compared to Group A with 47.3% (See Table 10).

Nichols study found a "statistically significant and clinically relevant role" of the stomal therapy nurse in the rehabilitation of individuals with an ostomy (pg 67).⁴⁴ This is demonstrated in the relationship between stomal therapy nurse contact and improved social connectivity. This supports the findings by Marquis and colleagues in that a positive relationship with the stomal therapy nurse resulted in increased quality of life scores.²⁰

Cross sectional studies have several advantages such as being low cost, with a reduced risk of bias due to loss of follow up, however they also have several disadvantages (Thadhani Tonelli).⁴⁸ Responder bias is one, another is that because exposure and causality occur at the same time, causality cannot exactly be determined. Finally because cross sectional studies include prevalent rather than incident cases, incidence-prevalence bias may be a problem.⁴⁷

The survey collated by Nichols retrieved information pooled by an electronic data base.⁴⁵ The participants are post stoma surgery up to twenty four months. As a cross sectional survey, this seems to be a broad spectrum of time from which to identify patients as being in a similar group, especially since, as previously noted, quality of life rises most rapidly in the first twelve months post operatively.³¹

The sample number of participants include in the survey was large but the data was selectively chosen to highlight differences introducing bias into the results. Nichols does report the use stratification of some sample characteristics to reduce the risk of confounding factors. This included stratifying by type of ostomy, age, gender and length of time from surgery. Odds ratios were employed to calculate the likelihood of events. Confidence intervals of ninety five percent were also utilised.

Nichols reports that this survey reveals a significant relationship between social connectivity, life satisfaction and body image. However this type of study does not establish causality and therefore the question regarding what aspects of stomal therapy nursing improves care in is left unanswered. Nichols also acknowledges that "the study addressed inter-individual differences but not longitudinal changes between respondents" (pg 68).⁴⁴

This study therefore lends some support to the role of the stomal therapy nurse in relation to these patients but the strength of the association is unclear from the data.

Descriptive Studies

Two descriptive studies were included that reported follow up care from stomal therapy nurses.^{20,21} The first examined the psychological adjustment of patients with stomas, comparing districts with stomal therapy nurses with those that did not have stomal therapy nurses. The researcher used the Present State Examination (PSE) to test psychological state.

At ten weeks after stoma surgery, patients in districts which employed stoma care nurses were less prone to affective disorder as measured by PSE scores than those districts that did not. One year after stoma surgery there was no difference in this problem in patients from either type of district. The author proposed that the presence of company nurses may have affected data outcomes at twelve months or that perhaps successful psychological adaptation to an ostomy in the longer term may be independent of nursing intervention.

Wade's research investigated the "relationship between gender, marital status and affective disorder" (pg 1303).²⁰ Having controlled for age, physical symptoms and other important effects, there appears to be minimal differences between married and unmarried women for affective disorder.

Findings from Wade's study do not appear to provide evidence that spousal support is crucial to stomal acceptance. The author proposes that stoma care nurse intervention "offset any disadvantages" for elderly, widowed or single women as this group were visited more often by this specialist group (pg 1303).²⁰ Married men were found to have higher PSE scores than unmarried men. The author proposes that loss of libido in the married man plus that it may be easier for this group to "express their feelings" account for this finding (pg1303).²⁰

Age was found to be unrelated to affective disorder at any stage in the study but physical symptom severity is strongly related to affective disorder at ten weeks and continued to be even more strongly related at one year.²⁰

Wade's study was well planned, however, a limitation was the lack of a stoma specific tool. The presence of company nurses in areas where there were no stoma care nurses also caused the outcomes to be a little less certain. Due to study design, the relationship between cause and effect were again unclear.

Other problems with data collection at one year were that only eight five of the original two hundred and fifteen patients with a colostomy completed the PSE. There were many reasons for this change in number and the researcher has accounted for them all. Twenty-two patients who had had colostomy surgery and 12 patients with temporary colostomies had died. Sixty-eight patients had had their colostomy reversed and 9 other participants were too ill to be interviewed. Because of this, the sample size was decreased by a large margin when compared to initial sample size.

Again the problem of causation and outcome is an issue. Although at ten weeks the study presents some evidence to support the proposal that stoma care nurses benefit the patient with a stoma, the reason for this continues to be unclear. The results at 1 year also do not help clarify longer term benefits due to losses to follow-up.

In the second study the researchers found that the weeks following hospital discharge were important in improving quality of life for patients in all countries.²¹ Other factors which were also important appeared to be satisfaction with care received, confidence in changing the appliance and the relationship with their stoma care nurse. This study reveals that patients who believe that their stoma care nurse took a genuine interest in their well-being had the highest quality of life scores after surgery. Other areas where quality of life scores post surgery were better are "patients who had a good relationship with the nurse, satisfied with care received and confident with changing their appliance" (pg 55).²¹ These findings provide evidence for the benefits of stoma therapy nurse support. They also suggest that improving patient confidence with appliance changes through education enhances quality of life in these patients.

Quality of life is improved with stoma care nurse contact and specialist care in the first three months post operatively. The evidence also suggests that quality of life following ostomy surgery can be objectively assessed and that the SQLI provides a valid and reliable instrument for this purpose.

The evidence that stomal therapy nurses benefit patients with a stoma is able to be inferred from the association between improvements in quality of life score and the patient having a good relationship with their stomal therapy nurse. This inference does not give any indication of the strength of the association and therefore it is not known what specific aspects of stomal therapy nursing care which caused the improvements.

Implications for Practice

The evidence considered in this review is consistent with a Grade B recommendation based upon the Joanna Briggs Institute Grades of Recommendation.⁵⁰ This infers that follow up care provided by stomal therapy nurses results in desirable effects outweighed by any undesirable effects although the magnitude of this effect is not clear. There is evidence supporting the association between postoperative follow up and patient quality of life, therefore:

- Patients whose quality of life is at risk for physical, psychological, social and spiritual functioning should be offered postoperative follow up. (Grade B)

- Postoperative follow up in person or via telephone is equally effective for subjective measures of quality of life and either can be used to support stoma patients through the postoperative period (Grade B)
- Technical skill training should be incorporated in postoperative follow up to improve quality of life and ability to self manage problems. (Grade B)
- Satisfaction with sexual functioning remains low, therefore, referral for counselling is appropriate for patients with a stoma in a relationship. (Grade B)
- The social engagement resulting from stomal therapist follow up has been shown through subjective measures to increase quality of life and decrease social isolation, this outcome should be considered a function of all post operative follow up of stoma patients. (Grade B)

In view of these recommendations, stomal therapy nursing practice needs to explicitly include postoperative planning that addresses quality of life measures. Practice that builds upon the findings of this systematic review will enable the development of a stronger evidence base that better supports the needs of patients in the postoperative phase with their stoma.

Implications for Research

A number of research priorities for stomal therapy were identified through this systematic review. Future studies should be based upon adequately powered samples with randomization to groups, or consist of large prospective cohort designs for measurement of long term outcomes related to quality of life. Further research responding to the following questions would represent a significant contribution to this field of knowledge:

- What is the duration and intensity of follow up required to sustain improved quality of life?
- What is the long term (greater than 12 month) effect of postoperative stomal nurse interventions on quality of life?
- Is telephone support as effective as personal follow up for technical management of the stoma appliance?
- Why is sexual satisfaction low among stoma patients in established relationships, and how might this be addressed to improve quality of life?
- Is there a dose/response association between stomal therapy nursing interventions and quality of life?

The review has also highlighted the need for the use of a stoma specific tool in conjunction with a HRQOL tool to assess patients with a stoma. HRQOL does not directly assess some of the problems encountered by the individual with an ostomy.

It may be that the benefit of stomal therapy nursing would be better illustrated by investigating and documenting specific interventions rather than 'follow up' care and from this, compiling a dossier of evidence to inform their worth and benefit to patients. This evidence needs to be compiled and evaluated to accurately illustrate the benefit of stomal therapy nurse input.

Cohort studies, while producing some evidence to support specialised nursing care, fail in pinpointing causation and outcome effects. A systematic review by Pittman et al³¹ identified only two randomized control trials which identified nursing interventions which improved HRQOL in persons with ostomy. Although difficult to implement in the clinical setting, this form of research may produce more definitive results.

Conclusion

This review has found evidence that follow up care by stomal therapy nurses benefits the patient with a stoma. However, most of this evidence does not clarify what it is about the care that is beneficial. This is mainly due to the effect of study design. The lack of stoma specific tool for use in some studies also hampers results.

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Appendices

Appendix 1: Critical Appraisal Instruments

MAsTARI appraisal instruments

JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Was the assignment to treatment groups truly random?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were participants blinded to treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was allocation to treatment groups concealed from the allocator?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were those assessing outcomes blind to the treatment allocation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were the control and treatment groups comparable at entry?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were groups treated identically other than for the named interventions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in the same way for all groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info.

Comments (Including reason for exclusion)

JBI Critical Appraisal Checklist for Descriptive / Case Series

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Was study based on a random or pseudo-random sample?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Were confounding factors identified and strategies to deal with them stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were outcomes assessed using objective criteria?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. If comparisons are being made, was there sufficient descriptions of the groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was follow up carried out over a sufficient time period?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (Including reason for exclusion)

JBI Critical Appraisal Checklist for Comparable Cohort/ Case Control

Reviewer Date

Author Year Record Number

	Yes	No	Unclear	Not Applicable
1. Is sample representative of patients in the population as a whole?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Are the patients at a similar point in the course of their condition/illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Has bias been minimised in relation to selection of cases and of controls?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Are confounding factors identified and strategies to deal with them stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Are outcomes assessed using objective criteria?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Was follow up carried out over a sufficient time period?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes of people who withdrew described and included in the analysis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Were outcomes measured in a reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info.

Comments (Including reason for exclusion)

Appendix 2: Data Extraction Instruments

MAStARI data extraction instrument

JBI Data Extraction Form for Experimental / Observational Studies

Reviewer Date

Author Year

Journal_ Record Number

Study Method

RCT Quasi-RCT Longitudinal

Retrospective Observational Other

Participants

Setting _____

Population _____

Sample size

Group A _____ Group B _____

Interventions

Intervention A _____

Intervention B _____

Authors Conclusions: _____

Reviewers Conclusions: _____

Study results

Dichotomous data

Outcome	Intervention () number / total number	Intervention () number / total number

Continuous data

Outcome	Intervention () number / total number	Intervention () number / total number

Appendix 3: Detailed Search Strategies

CINAHL Search

Thursday, November 08, 2012 1:10:21 AM

#	Query	Limiters/Expanders	Last Run Via	Results
S3	S1 and S2	Search modes- Boolean/Phrases	Interface- EBSCOhost Search Screen Database - CINAHL Plus with Full Text	84
S2	(MH "Quality of Life")	Search modes- Boolean/Phrase	Interface EBSCOhost Search Screen Database - CINAHL Plus with Full Text	46371
S1	(MH Ostomy/EV/NU/PF/RH")	Search modes- Boolean/Phrase	Interface EBSCOhost Search Screen Database - CINAHL Plus with Full Text	507

The CINAHL search strategy was performed by firstly searching for the term ostomy as a main heading using the limiters of evaluation, nursing, rehabilitation and psychosocial factors. A second search was done using quality of life as a main heading. The two search terms were then combined to retrieve eighty-four results. Of the eighty-four results, twenty-six citations were examined in detail. One article came up twice as it had been published in two different journals, leaving twenty-five citations to be reviewed. From these, ten abstracts were retrieved for detailed examination and four articles were included in the review.

The Pubmed search strategy was performed as follows: ("surgical stomas"[MeSH Terms] AND ("quality of life"[MeSH Terms] OR ("quality"(All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields])) AND ("follow-up studies"[MeSH Terms]OR ("follow-up"[All Fields] AND "studies"[All Fields]) OR "follow-up studies"[All Fields]OR ("follow"[All Fields] ANC "up"[All Fields] AND "studies"[All Fields]) OR "follow up studies"[All Fields]). This strategy retrieved 30 citations. Three abstracts were examined but one was in Polish and so it was excluded, another was located in a previous search and the other was unsuitable for inclusion on the basis of text.

For the Embase search, an initial search was made using the term 'enterostomy'/exp OR enterostomy. This was followed by another search using the term 'quality of life':de,ab,ti and a final search strand using the term 'follow up':de,ab,ti. These three searches were joined with AND, resulting in four hundred and eighteen citations. Seven abstracts were retrieved and examined in detail. One of the articles was repeated elsewhere and the other articles were excluded as they were not pertinent to the study.

The Mednar database was searched using the terms quality of life AND stom* AND nurs* AND follow*. Six hundred and sixty three citations were found and nine abstracts retrieved for examination. Two articles had been found by previous searches in other databases and the rest of the search was discarded as not useful.

Proquest Dissertation and theses was searched using the terms stoma and quality of life. Two hundred and forty seven results were obtained and of these two abstracts were examined. Neither of these articles was included in the review.

Clinicaltrials.org was searched using the terms quality of life and ostomy. Eight article were found , two abstracts reviewed but none selected. Of the two articles found, neither of these had been released for publication at date of search so they could not be retrieved. The authors were contacted by email but did not respond.

Appendix 4: Included Studies

1. Addis G. The effect of home visits after discharge on patients who have had an ileostomy or a colostomy WCET Journal, 2003, Jan-Mar; 23 (1): 26-33.
2. de la Quintana Jimenez P, Pastor Juan C, I Prados Herrero, Perez Lopez C, Gonzalez Fuentes M, de Mena Casaseca C, Real Romaguera A, Tejido Valenti M, GArcia-Alamino JM, Espirac B. A Prospective, longitudinal, multicenter, cohort quality-of-life evaluation of an intensive follow-up program for patients with a stoma. Ostomy Wound Manage, 2010, May; 56 (5) 44-6, 48-52.
3. Karadag A, Bulent Menten B, Uner A, Irkorucu O, Ayaz S, Ozkan S. Impact of stomatherapy on quality of life in patients with permanent colostomies or ileostomies. Int J Colorectal Dis, 2003, 18: 234-238.
4. Marquis P; Marrel A; Jambon B; Quality of life in patients with stomas: the Montreux Study. Ostomy Wound Manage, 2003, Feb; 49 (2): 48-50, 52, 54-5.
5. Nichols T. Social connectivity in those 24 months or less post surgery J WOCN 2011; 38:1 63-68.
6. Wade B. Colostomy patients: psychological adjustment at 10 weeks and 1 year after surgery in districts which employed stoma-care nurses and districts which did not. J Adv Nurs, 1990;15,1297-1304.

Appendix 5: Characteristics of Included Studies (in order of Publication Date)

Author(s) Year , Country	Purpose	Samples	Method	Study Design	Statistical Analysis	Measure/ instrument	Reliability/ Validity of tool
Wade, 1990, United Kingdom	To evaluate possible benefits of specialist nursing care to ostomates. To provide information on problems faced by ostomates post surgery	Stratified random sample in twelve districts with stoma care nurses. Eight districts assigned as a convenience sample for comparison.	Quantitative, comparing the two types of districts at 10 weeks and 1 year	Cohort design	Analysis of covariance	Present State Examination	? appropriateness but valid and reliable to assess mental health state.
Addis, 2003, Turkey.	To determine the effects of home visits on people with a faecal stoma	50 patients randomly divided between two groups	Quantitative. Comparing between experimental and control groups at intervals	Quasi experimental design	Percentages, Chi-square, Fisher's exact test, t test, Man Whitney U.	SF36 Questionnaire	Reliable and valid for HQOL.
Karadag et al 2003, Turkey	Examines the problems faced by patients with faecal stomas. Possible impact of stomal therapy on ostomates	Forty three selected patients with faecal stomas.	Quantitative. Comparing QOL before and after stomal therapy	Prospective, before and after test	Means+/- standard deviation. Kruskal-Wallis, X ² , Mann-Whitney U, Wilcoxon's.	Digestive disease questionnaire DDQ-15 Gazi University Stomatherapy Unit questionnaire	Not specifically designed for stoma patients.
Marquis et	To determine whether an adapted	600 stomal therapy nurses enrolled all	Quantitative. SQOL administered	Prospective cohort study.	Kruskal-Wallis test, P value	Stoma Quality of Life Index	Valid and reliable for faecal and urinary

2003. Europe.	Quality of Life Index was suitable for patients with a stoma. To obtain data on QOL on ostomates in Europe .	eligible clients - 4,739 recruited.	at 3,6 and 12 months.				stomas
Jimenez et al 2010, Spain	To evaluate a system of patient phone feedback To describe QOL with a stoma Determine which factors greatly influence patient QOL.	336 patients volunteered to participate. 187 in standard group and 149 in intensive care group	Quantitative SQOL performed at initial and final visits.	Prospective, longitudinal cohort study.	Quantitative variables analysed by chi-square or Fisher test. Qualitative variables by student's <i>t</i> test, nonparametric tests in absence of a normal distribution.	Stoma Quality of Life Index	Valid and reliable for faecal and urinary stomas
Nicholls, 2011, United States of America	To characterize the prevalence of social isolation and determine the impact of influencing factors in a sample of adults with ostomies.	Data from the Ostomy Comprehensive Health and Life Assessment (Hollister Inc.) database. Collected from 560 clients living in UK and North America.	Quantitative. Ostomy Comprehensive Health and Life Assessment performed within 24 months of stoma surgery	Cross sectional survey	Pearson <i>r</i> , odds ratio, confidence interval.	Ostomy Comprehensive Health and Life Assessment	Valid and reliable

Appendix 6: Excluded Studies

1. Aronovitch SA, Sharp R, Harduar-Morano L. Quality of Life for Patients living with Ostomies: Influence of Contact with an Ostomy Nurse. J WOCN, 2009; Nov/Dec: 649-653. Excluded as results unable to be verified due to poor reporting and lack of audit trail for data collection.