

THE UNIVERSITY OF HULL

The impact of a temporary stoma on an individual's self-concept

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by

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Overview of the portfolio

The portfolio thesis is divided into three parts;

Part One

A systematic literature review – What is known about the lived experience of having a stoma? – A systematic review of qualitative literature

The systematic literature review aimed to consider what is known about the lived experience of having a stoma. A systematic search of electronic databases found 13 suitable articles for review. The qualitative articles were analysed using a narrative synthesis and the impact of the stoma on five main areas of lived experience were discussed. The implications of these areas of impact are discussed within the context of providing care for individuals.

Part Two

An empirical research paper – The impact of a temporary stoma on an individual's self-concept.

The empirical paper aimed to use qualitative methodology to understand the experiences of individuals with a temporary stoma, and in particular the impact of the temporary stoma on their self-concept. Eight individuals were interviewed, and following use of Thematic Analysis (Braun & Clarke, 2006), five superordinate and 13 subordinate (major and minor) themes were identified. The superordinate themes related to the impact of the stoma on the three areas of self-concept, the wider impact of the stoma, and how the temporary nature of the stoma is adjusted to. The superordinate themes were Balanced Perspectives and Future Thinking, with the subordinate themes encompassing these in further detail. The results were discussed in context of the

current literature with reference to future research and recommendations to services made.

Part Three

Part Three consists of the appendices associated with the systematic literature review and empirical paper.

Part One: Systematic Literature Review

What is known about the lived experience of having a stoma? – A systematic review of qualitative literature

What is known about the lived experience of having a stoma? – A systematic review of qualitative literature

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Abstract

Purpose: This literature review aimed to collate and analyse information from qualitative studies that considered the lived experience of having a stoma, in order to increase awareness of the issues faced by individuals with a stoma.

Method: Electronic journals were systematically searched using pre-determined search terms and inclusion and exclusion criteria, and relevant articles were included in the final analysis. Narrative synthesis was used to gather together the results.

Results: In total 13 articles were included, and five themes were identified; Day to Day Management of the Stoma, The 'Side-effects' of the Stoma, Emotions Associated with the Stoma, Social Life with a Stoma and Being in Relationships.

Conclusions: The stoma has an impact on many areas of an individual's life. There are many adjustments that take place in the process of individuals adapting to life with their stoma. It is imperative that healthcare professionals have a full awareness of the range of issues individuals may face once they have a stoma.

**What is known about the lived experience of having a stoma? – A systematic
review of qualitative literature**

Introduction

A 'stoma' is the visible opening on an individual's abdomen after having a surgical resection of the large intestine ([nhs.uk./conditions/colostomy](https://www.nhs.uk/conditions/colostomy)) during a colostomy or ileostomy procedure. The main reasons for an individual needing to undergo such a procedure are bowel cancer, Crohn's disease and diverticulitis ([nhs.uk./conditions/colostomy](https://www.nhs.uk/conditions/colostomy)), although other reasons for having a colostomy or ileostomy include genetic defects, accidental injury or to improve quality of life, such as for individuals who have a spinal injury (colostomyassociation.org.uk). The stoma may be temporary (and reversed in the future) or permanent (not ever reversed). In the UK alone, approximately 70,000 people are living with a stoma (colostomyassociation.org.uk) and each year approximately 6,400 people will be fitted with a permanent stoma ([nhs.uk./conditions/colostomy](https://www.nhs.uk/conditions/colostomy)). Therefore this is a relevant issue that is currently effecting a large proportion of the British population.

Research on the impact of having a stoma has tended to focus on a few discrete areas such as the impact of a stoma on an individual's body image. Body image is understood to be 'the picture of our body which we form in our minds' (Schilder, 1935, p.11). For individuals who have a stoma fitted, their body image and bodily confidence can be disrupted, as demonstrated in a literature review by Thorpe, McArthur and Richardson (2009).

The issues related to an altered body image can begin as soon as the individual sees the stoma for the first time (Coe & Klukla, 1998), and research has shown that for some individuals, this difficulty in acknowledging the appearance of the stoma does not improve over time (Manderson, 2005). Salter (1992) found that there was no perceived

difference in the body image of individuals who had a conventional stoma to that of individuals who had a conventional stoma and a continent pouch, therefore issues relating to the post-operative physical body image are not exclusive to one patient type.

The experience of loss with regard to having a stoma is also a common experience demonstrated in the research. McVey, Madhill and Fielding (2001) found that loss of personal control, particularly with regard to becoming dependant on others was one of the main impacts of the stoma a couple of weeks post-operatively. The narrative of loss can be expressed with regard to loss of professional identity, loss of pre-operative social life and loss of dignity (Rozmovits & Ziebland, 2004). Rozmovits and Ziebland (2004) found that some individuals were not able to continue in their professional role due to having a stoma. The loss of the pre-operative social life is also demonstrated in that individuals have found that they are unable to partake in some leisure activities such as swimming (Salter, 1992). Annells (2006) identified that the experience of loss of dignity can be a common experience, and in particular when there is an experience of flatus incontinence due to a stoma pouch. Therefore loss is a common theme that encapsulates many aspects of life that are effected from having a stoma.

A further area of life that has been documented in terms of the post-operative effects of a stoma is the issue surrounding sexuality and relationships. Gloeckner (1983) studied individuals' perceptions of their own sexual attractiveness following ostomy surgery. She found that post-operatively, individuals felt least sexually attractive; however this did improve after the first year after surgery. Burnham, Lennard-Jones and Brooke (1997) found that although the patients themselves felt less sexually attractive post-operatively, their partners did not share this view.

Body image, a sense of loss and reduced sexual attractiveness are three of the main areas considered within the body of literature in the area of stoma surgery. These issues are mainly researched in isolation, with studies considering one specific aspect of the impact of a stoma, and interviewing the participants regarding this area. Literature reviews have also focussed on one area of research. As previously discussed Thorpe et al (2009) considered the literature surrounding body image specifically, and Brown and Randle (2005) conducted a literature review that summarised relevant issues; body image, sexuality and sexual concerns, and psychosocial adjustment and coping. Whilst this is valuable information, and the literature in this area has informed clinical practice and increased professional knowledge, it is felt that no literature review has considered the general lived experience of having a stoma.

The existing body of literature is highly relevant to developing understanding of the lived experience of having a stoma, but given that previous literature reviews have focused on a particular area, such as body image, it may be possible that there are other areas of impact that are lesser known. It is important that all professionals involved with the care of individuals with a stoma be aware of relevant issues that individuals face, in order to provide the best possible care.

Therefore this systematic literature review aimed to answer the question ‘What is known about the lived experience of having a stoma?’ The results presented are compared and contrasted to the literature review by Brown and Randle (2005), as they had a similar aim of reviewing the literature about living with a stoma.

Method

Search Procedure

The procedure began with a search for articles in a systematic manner based upon predetermined inclusion and exclusion criteria. Secondly, suitable data were identified and extracted from the included articles, and finally a narrative synthesis was employed to present the results. The search was conducted in May 2015.

In total five databases were searched; Web of Science, Medline, Psycinfo, Cinahl Plus and Psycarticles. These databases were chosen as they included research articles that considered both psychological research and medical research, therefore this increased the chance that no relevant articles were excluded from the overall review. The following search terms were used to capture all potentially relevant articles;

Search terms

Stoma* OR ?ostom*

AND

Live* OR Life* OR Experience* OR Adjust* OR Cope* OR Coping*

The truncation symbol (*) represented the possibility of alternative endings to the search terms, and when used in an electronic database, all of the options were displayed within the search results. The wildcard (?) represented any other letter(s) that could have been used to start the word, and when used in an electronic database, all of the options were displayed within the search results. The search terms used in the final search were developed to include all possible articles that related to the aim of the literature review.

Inclusion/Exclusion Criteria

The following inclusion and exclusion criteria were applied to the articles;

Inclusion Criteria

- i. Written in English
- ii. Peer-reviewed
- iii. Used an adult sample population (over the age of 18)
- iv. Used qualitative methodology (exclusively or as part of a mixed-methods design)
- v. The study considered one or more element of lived experience of having a stoma

Exclusion Criteria

- i. Not written in English
- ii. Not peer-reviewed
- iii. One or more members of the sample were under the age of 18
- iv. Used exclusively quantitative methodology
- v. The study did not consider lived experience of having a stoma
- vi. The article was a review paper and contained no novel data
- vii. The article was a literature review and contained no novel data

It was decided only peer-reviewed articles would be included as this enables the literature review to have higher scientific rigour as the review will be more dependable and credible (Hamberg, Johansson, Lindgren & Westman, 1994). It was also decided to only include articles that used an adult population as it was considered that there may be differing issues that impact on adults and children with a stoma. Therefore by excluding

any sample that used a child population, the results were more homogenous and therefore had higher validity.

It was decided to exclude exclusively quantitative studies, as this literature review aimed to consider aspects of lived experience. Qualitative data is the most appropriate method of collecting data regarding lived experience (Ploeg, 1999), and therefore this provided the rationale for excluding exclusively quantitative data. It was decided that should any mixed methods studies be returned in the search, and they met the inclusion and exclusion criteria, the qualitative elements of those studies should be included in the synthesis of results as they could contribute valuable data.

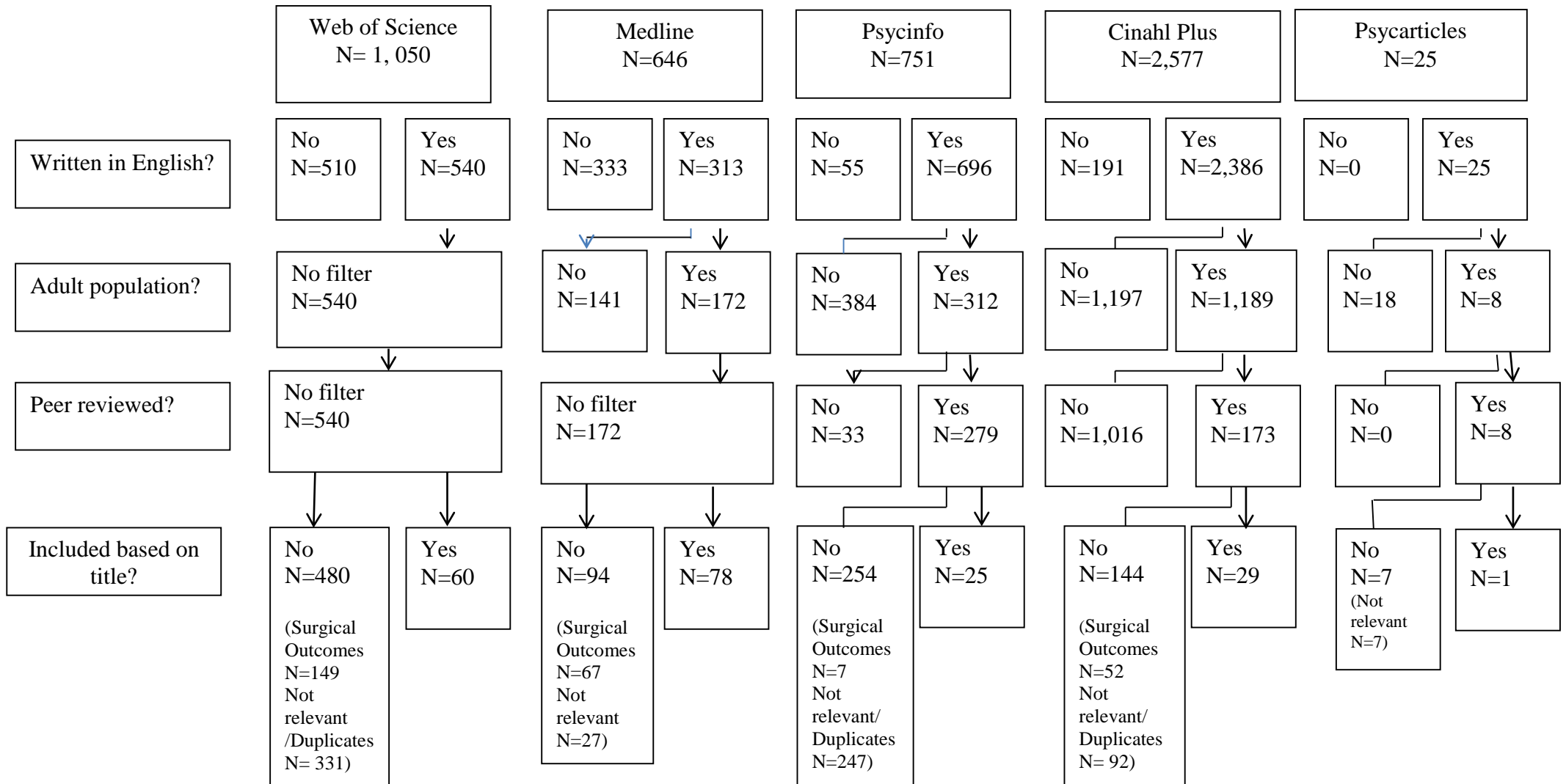
Details of Included and Excluded Studies

The initial search produced 5,049 articles in total, and the details of the databases these articles came from are represented in Figure 1. No limit was set on the dates of articles to potentially include, as this captured as much relevant information as possible, and there was no scientific justification for setting a limit. For each of the 5,049 articles, the initial inclusion criteria of being written in English, being peer-reviewed and using an adult population (aged 18+) were applied. The results of how many were excluded based on these criteria are shown in Figure 1.

The titles of the remaining potentially relevant articles were read and judged as to whether the research was relevant to the aim of the literature review. Where there was an uncertainty about the relevance, the article was processed to the next stage of analysis to avoid losing any potentially useful data. A total of 979 articles were excluded at this stage. The next stage of data sorting involved reading all of the abstracts of the potentially relevant articles. At this stage 148 articles were excluded based on the abstracts that were read. After this stage of data sorting, 45 articles met all inclusion criteria and full texts were obtained for these 45 articles. After reading the full

texts of these 45 articles, 13 were included in the final review, as they were deemed to meet all inclusion criteria, and are relevant to meet the aim of the literature review.

The reference lists of the final studies were hand searched, and key authors in this field were contacted, however no further studies were included.



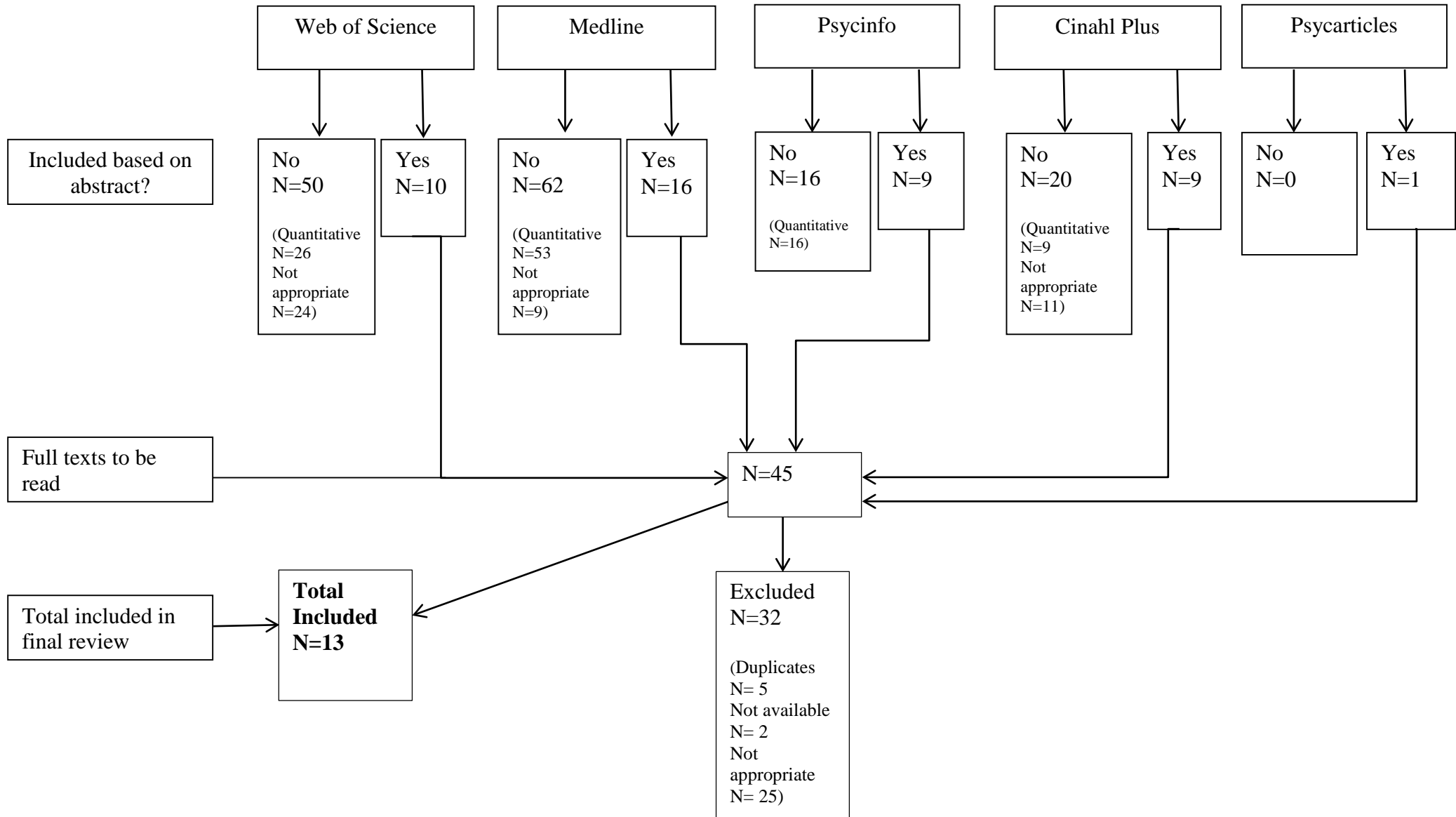


Figure 1. Depiction of search results

Quality Assessment

Each of the studies included in the final review were subject to quality assessment using the Critical Appraisal Skills Programme (CASP) tool (2013). This 10 point checklist was used to assess the quality of the studies across areas such as appropriate design and clear results, and the checklist can be found in Appendix A. Individual study scores can be found in Appendix B. This tool was used as it included a specifically designed checklist for use on qualitative studies, which was appropriate to the design of this literature review. The quality assessment of the studies are incorporated into the results and discussion.

Data Analysis

Narrative synthesis was the chosen method of data analysis, as it ‘adopts a textual approach to the process of synthesis to ‘tell a story’ of the findings from included studies’ (Popay et al, 2009, p1). Narrative synthesis is the most suitable method of analysis when there is methodological variation between the final included studies (Ryan, 2013). The methods used in the final included studies were; non-structured interviews, semi-structures interviews, and focus group interviews. The aim of narrative synthesis is to investigate the similarities and differences between the studies, and in particular present the patterns found within the data (Ryan, 2013).

Popay et al (2009) provide a framework for conducting narrative synthesis that was followed within this literature review. The first stage involved developing an understanding of which studies should be included in the synthesis. The search terms, and inclusion and exclusion criteria were designed to ensure that relevant articles would be returned. The second stage involved an initial descriptive synthesis of the studies that were included. This involved extracting relevant data from the studies, which included the participant groups, main results, overarching conclusions and further

recommendations. The third phase involved considering patterns and relationships between the data. This allowed for themes to develop, and a consideration for the similarities and differences between studies. The final stage focussed on a consideration of the robustness of the synthesis, to take into account the quality of articles included, and how the results compare and contrast with the current understanding in the field of research.

Results

Summary of Search Results

In total there were 13 articles that met the inclusion and exclusion criteria. Each of these studies were appraised using the CASP Tool (Appendix B) and all were found to have clear aims of the research, and clear justification for using qualitative analysis. All of the studies were considered to have a clear statement of results, which are presented throughout the review. Eleven of the thirteen studies were considered to have an appropriate method of recruitment; with 2 studies demonstrating an unclear recruitment procedure, so this could not be rated (Bonill-de-las-Nieves et al, 2014; Carlsson, Berglund & Nordgren, 2001).

The number of participants in the studies ranged from five (Owen, Paget & Papageorgiou, 2008) to 40 (Gloeckner, 1983). All of the participants had undergone surgery for colorectal issues, although the reasons for the surgery were not always specified. All of the participants in the studies had experienced having a temporary or permanent stoma, and the majority of data came from participants whilst they had their stoma. The exception to this was the participants from the study by Owen et al (2008) who had all had their stoma reversed before the commencement of the study. The participants varied in age within the studies, with the largest age ranges including; 20-83 (Danielsen, Soerensen, Burcharth & Rosenberg, 2013), 23-71 (Gloeckner, 1983) and 23-75 (Bonill-de-las-Nieves et al, 2014). The studies included both male and female participants, with the exception of Ramirez et al (2009) and Honkala and Bertero (2009) where only females were participants in the studies. Annels (2009) provided no specific information regarding age or gender of participants.

Of the 13 articles included, two were conducted in Britain (Owen et al, 2008; Gloeckner, 1983), three were conducted in Sweden (Persson and Hellstrom, 2002;

Carlsson et al, 2001 & Honkala & Bertero, 2009), two were conducted in Denmark (Danielsen, Soerensen, Burcharth & Rosenberg, 2012; Danielsen et al, 2013), one was conducted in Canada (Savard & Woodgate, 2008), one was conducted in Singapore (Lim, Chan & He, 2015), two were conducted in America (Neuman, Park, Fuzesi & Temple, 2012; Ramirez et al, 2009), one was conducted in Spain (Bonill-de-las-Nieves, 2014) and one was conducted in Australia (Annels, 2006). Whilst all of the studies were written in English, it was not clear whether they were translated from other languages.

All studies used qualitative interviews to collect the data to be analysed, which was considered appropriate for every study based upon their research aims (CASP Tool; Appendix A). An Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) was used in three of the studies (Owen et al, 2008; Persson & Hellstrom, 2002 & Honkala & Bertero, 2009), Grounded Theory was used in two studies (Neuman et al, 2012 & Ramirez et al, 2009), Qualitative Content Analysis was used in three studies (Danielsen et al, 2012; Danielsen et al, 2013 & Bonill-de-las-Nieves, 2014), Thematic Analysis was used in two studies (Lim et al, 2015 & Savard & Woodgate, 2008), Hermeneutic Phenomenology was used by Annels (2006) and the method of analysis used by Gloeckner (1983) and Carlsson et al (2001) was not specified although the results were expressed as themes in both studies.

It should be noted that seven of the studies did not demonstrate explicit consideration of the researcher's biases, which may have impacted on the results that are presented within this literature review (Bonill-de-las-Nieves et al, 2014; Honkala & Bertero, 2009; Savard & Woodgate, 2008; Gloeckner, 1984; Carlsson et al, 2001; Persson & Hellstrom, 2002; Neuman et al, 2012). With two of the studies (Ramirez et al, 2009 & Owen et al, 2008), it was not possible to determine whether they had considered their biases within the review and how this may have affected their overall

results. No studies were excluded on this basis and it was felt that as the studies provided similar results to others that are presented in the literature review, this was an indicator that the results demonstrated coherence with the overall body of literature. It was considered that 8 studies were deemed to have used a sufficiently rigorous analysis procedure, whilst for three studies it was not possible to determine this (Bonill-de-las-Nieves et al, 2014; Gloeckner et al, 1984; Carlsson et al, 2001). Although researcher biases were not explicitly noted to have been considered in all of the studies, a rigorous analysis procedure would allow for the emergent themes to be based in the data as much as possible, without researcher biases completely determining the overall results. Presentation of supporting quotes supported the robustness of the findings.

Whilst it was not possible to determine whether ethical considerations had been taken into account in three of the studies (Bonill-de-las-Nieves et al, 2014; Gloeckner et al, 1983; Carlsson et al, 2001) as they were not explicitly documented, the other studies clearly demonstrated ethical issues had been considered. This indicated that studies were conducted with full ethical approval, that participants gave informed consent to participate, and the conduct of the studies was regulated according to ethical guidelines.

Author(s) and Date	Initial aims identified	Method of data collection	Sample number and key participant information	Method of analysis	Main findings	Any outcomes/further recommendations?
Annells (2006)	To interpret meanings of flatus incontinence on life and being	Non-structured qualitative interviews	6 participants, 4 female, 2 male, aged 50-83, reasons for stoma not specified	Gadamerian Hermeneutic Phenomenology	9 themes identified; I am undignified, I am a secret, I am always with gas, I am not myself alone, I am without choice, I am a seeker of control, I am the smell, I am not normal, I am living a life, sort of.	Nurses should be made aware of the experiences of patients to assess wider needs, as patients' lives can be greatly impacted by flatus incontinence.
Bonill-de-las-Nieves, Celdran-Manas, Hueso-Montoro, Morales-Asencio, Rivas-Marin & Fernandez-Gallego (2014)	To describe the strategies used by patients to cope with their stoma	Qualitative Interviews (Semi-structured)	21 participants, male and female, varying reasons for having the stoma, aged 35-73.	Qualitative Content Analysis	3 main themes; Self-care, Adaption to the bodily change and Self-help	Discovering the strategies applied is fundamental for the nursing professionals to offer high-quality care, centred on people and their process.

Carlsson, Berglund & Nordgren (2001)	To explore the practical aspects and impact on daily life of having short bowel syndrome and a stoma	Qualitative Interview (semi-structured approach)	6 patients, aged 38-68	Method of Analysis not specified	Main findings; the limited ability to act spontaneously, difficulty accepting stoma, and experiences of fatigue.	A team approach to care is important as problems were experienced in many areas of life.
Danielsen, Soerensen, Burcharth and Rosenberg (2012)	To examine patients' experience of a temporary stoma on everyday life	Focus group interviews	7 participants; differing conditions, aged 40-75	Phenomenological Hermeneutic Approach	The creation of a temporary stoma created feelings of uncertainty, and resulted in feelings of stigma and concerns about disclosure.	Health professionals should facilitate disclosure of the stoma to reduce stigma, and education is central to help patients learnt to live with a stoma.
Danielsen, Soerensen, Burcharth & Rosenberg (2013)	To explore the impact of a permanent stoma on everyday life	Focus group interviews	15 patients, all with a permanent stoma; aged 22-83	Phenomenological Hermeneutic Approach	Two main themes; being different and training in living a life with a stoma.	For patient education to take into account settings and effective knowledge transfer between patients.
Gloeckner (1983)	To consider sexual adjustment following ostomy surgery, including partner reactions.	Qualitative interview (structure not specified)	40 participants, both male and female, aged 23-71, differing conditions	Method of analysis not specified.	Partner reactions were both positive and negative; there were variations in participants' experiences of support post-surgery, and some elements of the subject remaining taboo.	There is a need identified to provide support to sexual partners of individuals with a stoma, and they should be encouraged to participate in the care of their partner.

Honkala & Bertero (2009)	To gain knowledge and understanding of what living with a stoma means to a woman.	Qualitative Interviews (Semi-structured)	17 participants, female, aged 33-80, reasons for having the stoma not specified.	Interpretative Phenomenological Analysis	4 main themes; Bodily restraints, I as a woman, Reconciliation to a changed life, and Adaption to daily life.	Health care professionals should support participants to adjust to the long term aspects of life with a stoma. There is a need for future studies about long term aspects when living with an ostomy, looking both on women and men.
Lim, Chan & He (2015)	To investigate patients experience of performing self-care of stomas in the initial post-operative period	Qualitative interview (Semi-structured)	12 patients, aged 40-72, male and female,	Thematic Analysis	5 themes identified; process of acceptance and self-management of stoma, physical limitations, psychological reactions, social support, and need for timely and sufficient stoma preparation and education	Health professionals need to be aware of the physical, psychological, and social impact of stoma on patients in the initial 30-day postoperative period.
Neuman, Park, Fuzesi & Temple (2012)	To consider the experience of patients with rectal cancer to understand previous quantitative quality of life studies.	Semi-structured qualitative interview	26 participants, aged 36-85, all participants had rectal cancer	Grounded Theory	There were 6 areas of difficulty experienced with regard to the stoma; exercise, sleep, social activities, sexuality/body image, clothing and ostomy-specific difficulties. There was also a shift in response with regard to the stoma.	The authors suggest that the findings can inform pre-operative consultations with patients, and assist with aligning patient expectations of what life with a temporary stoma may be like.

Owen & Papageorgiou (2006)	To investigate how the experience of a stoma and reversal affect lives	Qualitative interview (structure not specified)	5 participants in total; both male and female, all aged 60+	Interpretative Phenomenological Analysis	3 Pre stoma reversal themes; Acceptance and Coping, Personal Impact and Anticipation of returning to normal. 3 Post stoma reversal themes; returning to normality, Interference with anticipated return to normal and Ongoing personal impact.	There is a need to provide accurate expectations to patients for post-reversal experiences and provide education about reversals.
Persson & Hellstrom (2002)	To examine experience after ostomy surgery	Qualitative Interview (structure not specified)	9 participants; differing conditions, aged 44-67	Interpretative Phenomenological Analysis	7 themes identified; alienation from the body, altered body image, influence on sexual life, uncertainty, influence on social life, influence on sports and leisure activities and physical influences related to the stoma.	Teaching patients before and after surgery needs to be an ongoing process.
Ramirez, McMullen, Grant, Altschuler, Hornbrook, & Krouse (2009)	To explore any sexual challenges for females with stomas following colorectal surgery.	Semi-structured qualitative interview.	30 participants, aged 44-93, all female, reasons for stoma not specified.	Grounded Theory	9 major codes; Comorbidities, Complications, Coping/Adjustment, Body Image, Ostomy Specific Issues, Sexuality, Sexual difficulties, Spousal Support, Sense of Self/Femininity.	An increased awareness of sexual issues could broaden the range of interventions available.

Savard and Woodgate (2008)	To understand the lived experience of young people with inflammatory bowel disease and an ostomy.	Qualitative Interviews (open-ended interview) on two separate occasions	6 patients, aged 19-24.	Thematic Analysis	Three main themes; Concealing and revealing the self, it's hard and renewed sense of self.	For nurses to develop empathic relationships with young people to vent feelings and concerns.
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Table 1. Data extraction of included studies.

Narrative Synthesis

The results of the systematic literature review are presented as a narrative synthesis of the findings, presenting similarities and differences between the studies included, demonstrating what is known about the lived experience of having a stoma. The information gathered is presented in themes of areas of lived experience that are related to having the stoma including; day to day management of the stoma, the side-effects of having the stoma, the emotions associated with the stoma, the impact on an individual's social life, and the experience of being in relationships whilst having the stoma.

<u>Narrative Synthesis Theme</u>	<u>Key Studies</u>
Day to day management of the stoma	Bonill-de-las-Nieves et al (2014); Carlsson et al (2001); Danielsen et al (2013); Honkala & Bertero (2009); Lim et al (2015); Neuman et al (2012) and Ramirez et al (2009).
The side-effects of the stoma	Annels (2006); Bonill-de-las-Nieves et al (2014); Danielsen et al (2013); Lim et al (2015); Neuman et al (2012); Owen et al (2008); Persson & Hellstrom (2002) and Ramirez et al (2009).
Emotions associated with the stoma	Annels (2006); Danielsen et al (2012); Honkala & Bertero (2009); Lim et al (2015); Owen et al (2008); Persson & Hellstrom (2002); Ramirez et al (2009) and Savard & Woodgate (2008);
Social life with a stoma	Bonill-de-las-Nieves et al (2014); Carlsson et al (2001);

	Danielsen et al (2012); Honkala & Bertero (2009); Lim et al (2015); Neuman et al (2012); Persson & Hellstrom (2002) and Savard & Woodgate (2008).
Being in relationships	Bonill-de-las-Nieves et al (2014); Carlsson et al (2001); Danielsen et al (2012); Danielsen et al (2013); Gloeckner (1983); Lim et al (2015); Neuman et al (2012); Persson & Hellstrom (2002); Ramirez et al (2009) and Savard & Woodgate (2008).

Table 2. Themes and key studies relating to the systematic literature review.

Day to day management of the stoma

The practical task of managing the stoma on a day to day basis incorporated many aspects including; the physical care of the stoma, adjusting to practically managing the stoma and education regarding stoma care. The physical elements included irrigation of the stoma (Bonill-de-las-Nieves et al, 2014; Ramirez et al, 2009), managing leakage of the stoma which can lead to sore skin (Neuman et al, 2012), and practically changing the stoma bag as required (Honkala & Bertero, 2009). These three particular studies did not demonstrate a consideration of the relationship between participants and the researcher, indicating there could potentially be issues regarding biases of the results. However the analysis procedures were considered to be rigorous in the studies by Ramirez et al (2009) and Honkala & Bertero (2009) which strengthens the robustness of the results as the data has been sufficiently analysed.

The process of having a stoma required adjustment to daily living, which can be difficult as individuals can feel unprepared (Lim et al, 2015). In learning how to adjust to the new daily required routines, participants in some of the studies expressed the

importance of education and information regarding the management of the stoma (Carlsson et al, 2001; Lim et al, 2015) and ‘training in living life with a stoma’ was a main theme in the study by Danielsen et al (2013). The training allowed the individuals to have support in adjusting to managing the stoma, whilst dispelling myths and misconceptions they held. This could be considered to be a very important intervention for individuals with a stoma. The studies by Lim et al (2015) and Danielsen et al (2013) demonstrated high quality across every point monitored by the CASP Tool (Appendix B). This indicated the results presented could be considered a true representation of patient experience, and should be taken into account when delivering care. For the study conducted by Carlsson et al (2001) it was not possible to discern whether the analysis procedure was sufficiently rigorous or whether researcher biases were taken into account. However, since other studies which did account for these factors demonstrated a similar result, the importance of helping individuals learn about their stoma, and be trained in how to care for it, still remains.

The ‘side-effects’ of the stoma

A further aspect of the lived experience of having a stoma, was the many unwanted ‘side-effects’ the stoma had on an individual. This incorporated odour of the stoma, unwanted noise due to flatus incontinence, difficulties sleeping, and physical bodily restraints. The concerns about the odour of the stoma were reported by many participants across the studies (Ramirez et al, 2009; Owen et al, 2008; Persson & Hellstrom, 2002) in situations such as changing in a public place, or first thing in the morning. It should be noted that the authors of these three studies did not demonstrate an awareness of their relationship with the participants. Whilst this may not directly impact the results presented, and all studies demonstrated a sufficiently rigorous analysis procedure, it may be possible that some biases are present. Flatus incontinence

was considered in great detail by Annels (2006). She aimed to interpret meanings given to flatus incontinence in participants' stories. The themes she identified included participants feeling undignified and without choice in the matter of whether they create a noise or not. The flatus incontinence was closely linked with the issues regarding odour previously described. The study by Annels (2006) demonstrated high quality across all areas considered, with the exception of whether ethical issues had been taken into account. Whilst it is not possible to determine what (if any) impact this may have had on the results, it is noted that since all other areas of quality were demonstrated, the results can be considered as an important contribution to the overall literature review.

Participants across the studies described difficulties with sleeping as being another 'side-effect' of the stoma. Participants described to Neuman et al (2012) and Lim et al (2015) that the stoma caused difficulty in sleeping as there were concerns about disrupting the stoma bag during the night, causing a leak, and having to wake up during the night to clean the bag. One participant described waking up between three and four times a night and having to clean the bag (Lim et al, 2015).

A further difficulty individuals faced as a result of the stoma was with regard to restrictions in the clothing they felt able to wear. Participants explained to Persson and Hellstrom (2002) that they chose specific clothing to counter issues faced. For example, some of the females described having to wear loose dresses to prevent exposing the stoma. Concealing the stoma with clothing was reported by Danielsen et al (2013), Neuman et al (2012), and Bonill-de-las-Nieves et al (2014). Some men reported to Persson and Hellstrom (2002) that they decided to wear braces instead of a belt, in order to avoid catching the stoma. The studies by Persson and Hellstrom (2002), Neuman et al (2012) and Bonill-de-las-Nieves et al (2014) did not demonstrate whether their relationship with participants had been considered. Furthermore it was not possible to

discern whether Bonill-de-las-Nieves et al (2014) had an appropriate recruitment method or a rigorous data analysis procedure. However, given the nature of the results presented with regard to restrictions on clothing, it can be assumed that participants did discuss these issues, as they are presented quite factually. Whilst researcher biases may have influenced the results in terms of any emotional aspect attributed to having to conceal the stoma for example, in terms of the results presented in this review, it is considered to be an important aspect of the lived experience individuals have.

Emotions associated with the stoma

The lived experience of having a stoma not only involved the physical wellbeing of the individuals but their emotional wellbeing too. Anxiety was a common emotion reported among the participants in the studies, particularly in relation to the previous issues mentioned regarding flatus incontinence (Persson & Hellstrom, 2002; Annels, 2006) and possible leakages (Honkala & Bertero, 2009). As previously mentioned, Persson and Hellstrom (2002) and Honkala & Bertero (2009) did not explicitly consider their own biases within the research. Any potential impact of this on the results is not clear; however both did demonstrate a sufficiently rigorous analysis procedure, suggesting the results presented were based within the original data. Further anxieties came from not wanting to be a burden on caregivers (Lim et al, 2015), and through not feeling prepared for discharge from hospital (Lim et al, 2015). Some participants were anxious about the illness associated with the stoma (Savard & Woodgate, 2008) and the impact on attendance at college (Savard & Woodgate, 2008). Whilst some anxieties were present, some participants reported not feeling anxious about the stoma as they were happy to be alive and realised having the stoma was lifesaving (Owen et al, 2008; Ramirez et al, 2009).

Embarrassment was a feature of lived experience for many of the participants. Participants described feeling embarrassed about disclosing the stoma to others (Savard & Woodgate, 2008), being embarrassed because of the side effects of the stoma including flatus incontinence (Annels, 2006), and being embarrassed due to the symptoms experienced prior to having the stoma (Savard & Woodgate, 2008). Participants also described being embarrassed because of the physical appearance of the stoma (Annels, 2006). Some participants experienced frustration at the ongoing care the stoma needed, and one participant said that their frustration led to having a tantrum (Lim et al, 2015).

Some participants described uncertainty about reversal and the forthcoming adaptations as being a difficult emotion to manage (Persson & Hellstrom, 2002). One participant reported to Danielsen et al (2012) that they could handle anything, but the uncertainty was the worst part. The uncertainty related to whether the stoma could be reversed (Owen et al, 2008), and uncertainty as to whether professionals were clear about the treatment pathway ahead (Danielsen et al, 2012). Uncertainty also related to the day to day management of the stoma, with uncertainty regarding whether accidents would happen should they go out for the day (Savard & Woodgate, 2008). It should be noted that Savard and Woodgate (2008) did not explicitly consider their relationship with the participants in relation to biases within the results. However, each of the studies presented, which demonstrated participants' emotions regarding the stoma, all had sufficient analysis procedures, therefore indicating the results were based within the data.

Social life with a stoma

There was a clear sense among the studies that the wider elements incorporated into an individual's life were also impacted by the stoma. The social lives of individuals

with a stoma were altered in varying ways. One participant described that the thought of having to change the bag in a public toilet was enough to stop them going outside of their home as much (Neuman et al, 2012), and even when they did have to go outside, it was of great importance to plan where the toilets would be (Savard & Woodgate, 2008). Some participants described avoiding functions such as parties due to flatus incontinence (Persson & Hellstrom, 2002). As previously mentioned, Savard and Woodgate (2008) did not explicitly consider their relationship with the participants. Furthermore, Neuman et al (2012) also did not demonstrate this. However, both studies achieved the quality standard in every other category indicating the results are sufficiently based in the data.

Less frequent social activities such as holidays were reported as difficult, as participants needed to be further prepared in case of accidents (Honkala & Bertero, 2009), and therefore trips such as these required further planning and preparation. Some individuals considered holidays abroad to be impossible with a stoma (Carlsson et al, 2001) due to the amount of equipment needed to care for the stoma. There was a sense that disclosure to friends and family could be helpful in terms of alerting them to the issues the stoma brought, enabling adaptations to be made to activities (Persson & Hellstrom, 2002; Honkala & Bertero, 2009), yet for many participants it was considered that their social life needed to be changed (Carlsson et al, 2001). It was not possible to discern whether Carlsson et al (2001) analysed their data with sufficient rigour, therefore the results should be read in context with this. However, there are other studies that report similar results which have demonstrated sufficient rigour.

One of the main changes to social life considered necessary by the participants was the type of activities they felt they could do if they were able to overcome the aforementioned difficulties. Participants felt unable to partake in sports activities due to

physical restraints (Carlsson et al, 2001; Lim et al, 2015; Neuman et al, 2012) and due to feeling tired more easily (Honkala & Bertero, 2009). Another participant described not wanting to go swimming often due to the issues surrounding tight-fitting clothes (Bonill-de-las-Nieves et al, 2014), and a participant explained they would not like to play golf as they could not be confident that the bag would not be defective (Owen et al, 2008). Therefore participants who wanted some activities in their day to day found alternative past-times that were not as affected by the stoma. These included activities such as writing, painting, and music, among others (Carlsson et al, 2001). With the exception of Lim et al (2015), each of the studies that considered adaptations being made to social lives did not explicitly demonstrate that the researchers had considered their relationships with the participants. However it is considered that as the results are deemed to have been analysed with sufficient rigour, the results should be considered as an important contribution.

The issues that impacted on individuals' social lives also had a similar impact on their employment. One individual stated that they felt 'grounded', both socially and professionally (Danielsen et al, 2012), in the context of feeling stuck that they could not go out socially, and were limited in their professional life. Two participants in the study by Carlsson et al (2001) had quit their jobs due to the stoma, and several others felt they were unable to work full time, or would not be able to manage when they returned to work. Participants reported to Persson and Hellstrom (2002) that they limited their physical activities at work, in order to prevent damage to the stoma or impede its usefulness in any way. Even for those without a physical job, the stoma restricted ability to work as, for example, one participant described not being able to travel for business purposes as she had previously, as she could not be sure how she could attend to the stoma should she need to (Honkala & Bertero, 2009).

Being in relationships

The lived experience of having a stoma also impacted on individuals' relationships, both relationships with friends and family, and sexual relationships. Some participants described being ashamed of their illness even from the early stages of developing symptoms (Savard & Woodgate, 2008) and hiding this from friends and family. Others were afraid to open up to their families through fear of being a burden on them (Lim et al, 2015). Concerns about how to inform friends and family and concerns about how they would react were also a common feature in individuals' lived experience (Persson & Hellstrom, 2002; Danielsen et al, 2012; Danielsen et al, 2013). Whilst there was some reluctance to be open and discuss issues with friends and family, it was clear that these relationships could also be a great source of support (Carlsson et al, 2001). Participants described it being very helpful that family helped to research information regarding stomas (Bonill-de-las-Nieves et al, 2014), and in some cases family were able to help practically by changing the stoma bag (Lim et al, 2015). Talking to others in the same situation was also reported as being very helpful (Bonill-de-las-Nieves et al, 2014; Danielsen et al, 2012).

Romantic relationships were also impacted by the stoma, with several studies reporting impact on individuals' sexual life. Gloeckner (1983) based her entire study around the reactions of partners following ostomy surgery. Participants described to her both the positive reactions of partners in a supportive, non-judgemental way, and also the negative reactions of partners, including expressions of disgust and relationships ending due to the stoma. The participants also expressed concern about finding a partner in the future, and when they should reveal to a new partner that they have a stoma (Gloeckner, 1983).

Gloeckner (1983) did not demonstrate that she had considered her relationship with the participants. It was not possible to discern whether ethical issues had been considered, or whether the data analysis procedure had been sufficiently rigorous. When considering the results of this study, these factors should be taken into account as it is possible there are researcher biases present, and it is not possible to be sure the results are sufficiently based in the data. However, as there are no clear indications to suggest this is definitely the case, the results have still been included alongside other research discussing the impact on sexual relationships. Another element to the impact on sexual relationships fitted with individuals' body image changing, with patients describing that they did not feel attractive to their partner any more (Neuman et al, 2012). There were also physical restraints as a result of the surgery that meant individuals were in pain during intercourse or remained concerned about leakages from the bag (Ramirez et al, 2009).

Discussion

The literature review considers what is currently known about the lived experience of having a stoma. In collecting together the findings of these papers, some of which had an open focus, and some of which had a more specific focus, it is possible to gain an overall impression of the lived experience of individuals who have a stoma. The findings demonstrate that the stoma impacts the lived experience of day to day events such as management of the stoma, and impacts on the lived experience of wider aspects of life such as socialising, and individual's professional lives. The results will be discussed in terms of adjustment, and will be compared and contrasted to Brown and Randle's 2005 literature review.

There are many interactions in the areas of lived experience that the stoma impacts. Participants describe a physical change that is both difficult to manage on a day to day basis practically; however the stoma is also lifesaving. The lifesaving stoma creates change within some relationships, particularly with regard to sexual concerns about intimate relationships. Whilst there is an impact on non-intimate relationships, particularly in the context of not being able to socialise exactly as before, much support is gleaned from friends and family which balances some of the negative impacts the stoma has. The impact the stoma has on individuals' futures is also interesting, as participants feel the temporary nature of the stoma is unpredictable and therefore it is difficult to plan ahead to the future. The stoma has both positive and negative consequences, whilst being uncontrollable and unpredictable.

Along with the practical adjustments and impact on others, participants describe the new emotions they felt as a consequence of having the stoma. These include anxiety, uncertainty and shame. Shame is particularly strong, due to previously private bodily functions potentially being exposed in public. Kinsey, Pretorius, Glover and Alexander

(2014) conducted a systematic review regarding the psychological experiences of an overactive bladder. It was found that shame and embarrassment were also key difficulties individuals faced by having private functions, such as toileting, being potentially exposed into the public forum.

Given the breadth of the impact of the stoma, it is considered that the process of adjusting to the stoma would be important for the participants. Taylor (1984) considered there to be three areas of adaption needed to make an adjustment to a chronic illness; making meaning of the experience, gaining control/mastery over the illness and a restoration of self-esteem.

With regard to making meaning of the experience, this is not something that is explicitly described in the results of the individual studies included. It might be indicated that participants in the studies by Owen et al (2008) and Savard and Woodgate (2008) have made some meaning out of having the stoma, as it is recognised the stoma frees them from pain, although this is not clear. Danielsen et al (2013) demonstrated that individuals found training helpful to dispel myths about having a stoma. It could be that in the process of dispelling myths, accurate meanings are made regarding the stoma, including the reasons for having the stoma, and the true reality of the practical impact on day to day living.

Some of the difficulties in making meaning from the stoma could be as a result of the difficult emotions associated with the stoma such as anxiety, embarrassment and uncertainty. Baumeister (1991) considered making meaning to be ‘mental representation of possible relationships among things, events, and relationships. Thus, meaning *connects* things’. When individuals connect their stoma to the negative emotions of anxiety, embarrassment and uncertainty, along with the restrictions and frustrations this

places on their life, this may hinder the process of being able to create meaning from the situation.

There may be a difference as to whether adjustment occurs when meaning has been made of the original illness, as opposed to a meaning being made of the stoma. The model by Taylor (1984) was presented in a paper by Walker, Jackson & Littlejohn (2004) with regard to rheumatoid arthritis, so further research into how this may differ for patients with stomas would help to inform this further.

In terms of gaining control/mastery over the illness, in this case the stoma, the difficulties in doing this are documented frequently within the results. Examples of this are; the impact on social life and employment, the source of negative emotions, and the varying ways the stoma impacts day to day lived experience. There is a sense that individuals do not have control or mastery over either having the stoma, or indeed their own bodies anymore. Whilst individuals are given the training required to master the practical care for their stoma (Danielsen et al, 2012), it may be necessary for future research to consider how individuals may be able to develop psychological mastery over their stoma. Mishel (1988) described that uncertainty about an illness is the most distressing part in the initial diagnostic phase. The uncertainty decreases over time, yet can become acute uncertainty should there be any changes within the treatment process. The education regarding practical management is considered to be a very important intervention to alleviate some of the uncertainty (Mishel, 1988).

The final element in making a positive adjustment is with regard to restoration of self-esteem. Kilic, Taycan, Belli and Ozmen, 2007 argue that low self-esteem is one of the major issues facing individuals with a stoma and therefore restoration of self-esteem is extremely important. It is clear in the results from this study that self-esteem can be lowered due to concerns about flatus (Annels, 2009), restrictions in clothing

choices (Persson & Hellstrom, 2002; Danielsen et al, 2013, Neuman et al, 2012 & Bonill-de-las-Nieves, 2014), embarrassment at disclosing and talking about the stoma (Savard & Woodgate, 2009), not being able to go out and enjoy the same social activities (Neuman et al, 2012; Carlsson et al, 2001), feeling grounded professionally (Danielsen et al, 2012 & Carlsson et al, 2001) and sexual life being impacted (Gloeckner, 1983).

Owens (1993) considered self-esteem to be comprised of self-confidence and self-depreciation. It could be argued that the negative impact of a stoma would contribute to self-depreciation, therefore reducing overall self-esteem. It would therefore be imperative to understand how to increase the self-confidence of individuals with a stoma, in order to balance the negative effects of self-depreciation. With a paucity of studies demonstrating how to increase the self-confidence in individuals with a stoma, further research in this area would be highly important.

Further factors affecting adjustment to the stoma were considered by Simmons, Smith, Bobb and Liles (2007). These were identified as; acceptance of the stoma, interpersonal relationships and the location of the stoma. The acceptance of the stoma has already been discussed with regard to making meaning of the stoma. With regard to interpersonal relationships, it is clear from the results of this study that the stoma has a negative impact on the social lives of individuals; yet friends and family did also provide support. Since the support of others is a factor associated with positive adjustment to the stoma, it would be necessary for friends and family of those with a stoma to be given the correct advice about how to best support the individual with the stoma. It is not possible to determine the impact of the location of the stoma with regard to adjustment in this study, as this was not an obvious element within the results from the literature review.

The results from the current literature review described many similarities to the review conducted by Brown and Randle (2005). The first theme identified by Brown and Randle (2005) was with regard to Quality of Life. It was stated in their literature review that stoma formation usually had a negative impact on individual's quality of life. There were several facets to this negative impact, which were all identified within the current literature review too. Firstly, the physical care required to maintain the stoma was identified by Brown and Randle (2005) as a negative impact on quality of life. The current literature review identified that this was still an aspect individuals dealt with, along with other practicalities such as learning how to adjust to routines (Carlsson et al, 2001; Lim et al, 2015), and having to be prepared (Honkala & Bertero, 2009).

A further aspect of reduced quality of life was identified by Brown and Randle (2005) with regard to individuals having to consider clothing carefully. This was also a feature of the current literature review, when considering the 'unwanted side-effects' of the stoma (Persson & Hellstrom, 2001; Neuman et al, 2012; Danielsen et al, 2013 & Bonill-de-las-Nieves et al, 2014). Restrictions on the physical activities individuals could take part in due to the stoma, and overall reduction of quality of life was documented in both literature reviews. Furthermore, both literature reviews demonstrated that some individuals had to make changes to their employment due to the stoma, which also impacted their overall quality of life. Sexuality and sexual concerns were also demonstrated as themes in both literature reviews.

Brown and Randle (2005) linked sexual concerns closely with a change in body image, and body image was a clear theme in their literature review. In the current review, altered body image was also reported in the context of sexual concerns (Neuman et al, 2012), however body image was not a key theme identified. Further differences were also apparent between the reviews. Firstly there was more detail

provided in the current literature review regarding further unwanted 'side-effects' of the stoma including flatus incontinence (Annels, 2006) and issues sleeping (Neuman et al, 2012 & Lim et al, 2015). Secondly the current literature review represented the lived experience of emotions associated with having a stoma in more detail. Brown and Randle (2005) referred to anxiety expressed by some women with stomas; however the current review suggested a more complex picture in terms of emotions such as uncertainty and shame, and the factors that contributed towards this.

It was interesting to note that whilst only one study was included in both literature reviews (Persson & Hellstrom, 2002), similarities were present within the results of both reviews. One explanation for this was that a similar body of literature was searched by the researchers, with all data focussed around the impact of a stoma. Where the reviews differed was with regard to the more specific aims and purposes of the reviews. The current literature review looked at lived experience of having a stoma, whilst Brown and Randle (2005) aimed to research the psychological and social impact of stoma surgery. Given the different aims and therefore different search terms, it was inevitable that some themes were identified in the current study that were not represented in the review by Brown and Randle (2005). A second reason for the differences in the papers included, was due to the review by Brown and Randle (2005) being conducted 10 years prior to the current review. This allowed data to be included in a review that was produced post-2005. Finally, Brown and Randle (2005) included data from quantitative studies. As the current review focussed on lived experience, only qualitative data was included. This accounted for some of the differences between the literature reviews.

Limitations of studies

Each of the 13 studies included within the final literature review were quality assessed using the CASP tool (Appendix B). Three of the studies (Lim et al, 2015; Danielsen et al, 2012 & Danielsen et al, 2013) achieved every point of quality the tool assessed for. This demonstrated that there were no clear limitations of these studies and increased the overall quality of the literature review. The main area in which other studies were reduced in quality related to the researchers not explicitly considering the impact of their relationship with the participants and any potential biases that influenced the results. Whilst this did not necessarily indicate that researcher biases had influenced the results, without the explicit details of how biases were reduced, it could be argued that these potential influences needed to be considered within the wider literature review.

The three other areas that studies were reduced in quality related to; it not being possible to determine whether the recruitment strategy was appropriate to the aims of the research (Bonill-de-las-Nieves et al, 2014 & Carlsson et al, 2002), whether ethical issues had been considered (Ramirez et al, 2009; Gloeckner, 1984 & Annels, 2006), and whether the data analysis process was sufficiently rigorous (Bonill-de-las-Nieves et al, 2014, Gloeckner, 1984 & Carlsson et al, 2001). Each of these three areas could have had an impact on the results of their individual studies, particularly with regard to the lack of clarity over whether the analysis procedure was sufficiently rigorous. Although there was not enough explicit information to indicate the rigorous analysis procedure, it was not felt there was sufficient reason to exclude any results from the final literature review.

Limitations of the literature review

The main limitation of this literature review was the possibility that some studies that were relevant may have been missed or excluded in the procedure of searching for

papers, through either not complying with the search terms, or based on errors of the researcher whilst searching through the results. However, the search terms were carefully developed to capture all potentially relevant articles. Furthermore, peer consultation was used to ensure face validity of the search terms. There were processes in place to reduce the impact of human error including; conducting the search process twice to ensure there were no relevant papers excluded at any stage of the process, contacting authors regarding any relevant unpublished papers, and hand searching for relevant papers in reference lists.

Clinical Implications

The results of this review demonstrated the impact a stoma can have on an individual's lived experience. There are myriad adjustments that take place both in isolation, such as practically managing the stoma on a day to day basis, and the complex interactions, such as managing both emotions of shame and anxiety alongside relief to be alive. This review highlights the importance of healthcare professionals being aware of these many issues and adjustments, to ensure that some of the ways in which an individual may be impacted are not overlooked. For example it is clear that teaching an individual how to care for their stoma is very valuable, although it may be just as important to ensure they have support from friends and family (or a possible need for more professional support) in managing the shame that this can bring. It is important for healthcare professionals to be aware of the well-researched issues such as body image difficulties, however offering support in helping individuals choose clothes that might be more comfortable could be very valuable.

It may be necessary for support to be given to friends and family to prepare them for the new emotions the individual may feel, along with normalising this experience to

the patient. An example of this could be helping an individual manage their negative emotions by supporting them to develop a sense of meaning with regard to the stoma.

Furthermore, it would be useful for healthcare professionals to advise patients about adaptations that could be made to daily routines in order to assist with maintaining previous social lives as far as is possible. With patients being aware of the likely issues they may face, along with advice and support from both professionals and friends and family, this will enable preparation for such events, and therefore enable the patient to make as positive an adjustment to the temporary stoma as is possible.

Summary and conclusions

The review paper has demonstrated that having a stoma can impact many aspects of daily life, including individuals' social lives, their employment, and relationships with friends and family. Some of the main difficulties individuals faced as a result of this were both the practical difficulties of managing the stoma on a daily basis, and managing the negative emotions that individuals experienced throughout the adjustment to the stoma. One of the clinical implications for this study is that healthcare professionals should be aware of the wide ranging adjustments individuals make following having a stoma, aside from some of the most documented areas of adjustment. Furthermore it should be ensured that individuals have enough support in place from family, friends or indeed other professionals. It may also be important that individuals' friends and family are offered education and support about how to care for an individual with a stoma. Finally it is important that individuals with a stoma are informed of ways in which pre-operative social lives can be maintained where possible.

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Part Two: Empirical Paper

The impact of a temporary stoma on an individual's self-concept

The impact of a temporary stoma on an individual's self-concept

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Abstract

Purpose: This study aimed to consider the impact of a temporary stoma on an individual's self-concept.

Method: A semi-structured interview was conducted with eight participants to gain further insight into their experience. Thematic Analysis was used to analyse the results.

Results: Five superordinate themes were identified; The Impact of the Stoma on Self-image, The Impact of the Stoma on Self-esteem, The Impact of the Stoma on Ideal Self, What Else Makes Me Who I Am?, and The Temporary Nature of the Stoma. There were 13 subordinate themes identified.

Conclusions: The temporary stoma impacted the three elements of individuals' overall self-concept differently, with self-image and ideal self being more impacted than self-esteem. It is possible that the other factors that contribute to an individual's sense of self 'buffer' the self-esteem element to keep overall self-concept more stable. The results can inform healthcare professionals practise by increasing awareness of the myriad issues an individual may face when adapting to life with a temporary stoma.

The impact of a temporary stoma on an individual's self-concept

Introduction

This empirical research will consider the impact of a temporary stoma on an individual's self-concept. The issues of self-concept, temporary adjustment and physical change will be discussed within the context of the current literature.

A 'stoma' is the visible opening on an individual's abdomen after having a surgical resection of the large intestine ([nhs.uk./conditions/colostomy](https://www.nhs.uk/conditions/colostomy)) during a colostomy or ileostomy procedure. 'Self-concept' is understood to be a psychological construct that is a combination of an individual's self-image, self-esteem and an ideal self (Rogers, 1959). Each of these three areas of self-concept could be affected by a physical change or illness.

Self-image has been studied within the population of individuals with a stoma, and is most widely represented as literature regarding body image. Body image is understood to be an individuals' perception of the appearance and function of their body (Jenks, Morin & Tomaselli, 1997). Salter (1991) compared individuals with a conventional stoma to individuals who had a conventional stoma and then a continent pouch, regarding their body image. Both groups described an increase in negative feelings about their personal body image. In particular, some of the participants described being disgusted and repulsed by their stoma. In being disgusted with an acquired physical aspect of themselves, these individuals were now faced with a new body image, and an adjustment to a new self-concept may take place.

McVey, Madhill and Fielding (2001) found that for patients with a stoma, one of the main difficulties they faced was lowered personal control, in relation to lowered control over urinary and bowel function. This lowered control was as a result of the

stoma, and it is assumed this immediately presented the individual with a change in their 'self'. As these participants found this change difficult to adapt to, this could be interpreted as an incongruence between their 'current self', and 'ideal self' (as an individual with control over urinary and bowel function), and therefore their self-concept could have altered as a result of the stoma. Rozmovits and Ziebland (2004) also found that individuals with a stoma experienced a loss of adulthood with regard to loss of control over bowel function. This supported the notion that stoma surgery can create a disparity between 'current self' and 'ideal self', and therefore a change in overall self-concept.

Smith and Osborne (2007) studied the impact of chronic pain on an individual's sense of self. Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) was used to look at how back pain influenced an individual's life and overall the impact was negative. The pain studied had been experienced by the participants for at least six months and had no recognised cure, therefore could be considered a permanent condition as the individuals did not know when, or indeed if, this pain would cease. Interestingly, the results centred on the participants feeling as though their current situation was like experiencing a 'new-self'; a self with pain as opposed to the 'real' self they previously were without pain. This study reflected results found by Hellstrom (2001), where participants with chronic pain also described these differential selves and incongruence between current self, desired self, and the known past self, suggesting that overall self-concept is altered as a result of a permanent physical illness.

Polivy (1977) explored the impact of a mastectomy on a woman's feminine self-concept. It was found through quantitative measures that some mastectomy patients experienced a decline in body image and total self-image as a result of their physical

difference following surgery. The impact was also demonstrated by Pertschuk and Whitaker (1982), where individuals undergoing craniofacial surgery were found to have an increase in positive self-concept when appearance was deemed to have been improved. This literature demonstrates the influence physical surgery can have on an individual's overall self-concept by altering the element of self-image.

These studies show that with a chronic permanent condition, an individual's self-concept can also altered be permanently. It is interesting to consider how a change in overall self-concept may be experienced if the physical change is temporary as opposed to permanent.

Weiserbs and Gottlieb (2000) considered the difference in children's willingness to befriend a proposed new classmate who they were told had either a temporary or permanent physical disability. They found that children would rather befriend a temporarily disabled peer, indicating that difference in the state (whether temporary or permanent) of the disability has an impact not only on the individual, but how others around them may respond. This difference may also have an impact on the individuals' overall self-concept, in terms of changes to their self-esteem, and their ideal self; indicating that perhaps with a temporary physical change, there is a difference in how overall self-concept is affected.

A change in self-concept has been shown to be more difficult to adapt to with a temporary physical change or illness, than with a permanent physical change or illness. Bogart (2014) found that individuals with a congenital disability were more likely to adapt this into their overall self-concept and therefore report higher quality of life, than individuals who acquired a physical disability, who struggled to adapt their overall self-concept to incorporate their new physical disability. Munstedt, Manthey, Sachsse and Vahrson (1997) investigated self-concept and body image of individuals with alopecia

due to chemotherapy treatment for cancer. It was found that whilst the individual experienced the alopecia, their body image and self-esteem was negative, and overall self-concept was impacted as a result. Whilst the alopecia was temporary, self-esteem was lower than before the commencement of treatment, even when hair had grown back completely. It must be considered that a diagnosis of cancer may impact overall self-concept and it is not possible to determine completely which element of their experience impacted their self-concept totally. However this study demonstrated how some of the elements that contribute to overall self-concept, in this case self-esteem, can be impacted, even when the reason for this may only be for a temporary period of time.

Smith, Loewenstein, Jankovic and Ubel (2009) considered how individuals managed with either reversible (temporary) or irreversible (permanent) stoma. They also reported that individuals with a temporary stoma found it harder to adapt, and results on quality of life measures show that they felt less satisfied and happy with life than their peers with a permanent stoma.

Danielsen, Soerensen, Burcharth and Rosenberg (2012) researched the lived experience of individuals whilst they waited for the closure of a temporary stoma. It was discovered that one of the biggest challenges individuals faced was managing feelings of uncertainty, and in particular uncertainty regarding the closure of the temporary stoma. This is significant as other research has demonstrated a temporary change or difficulty can be viewed as a positive result, in that the situation will not last forever. However, particularly with temporary stomas, the current literature demonstrates the paradoxical difficulties in managing these.

For individuals who have a stoma, their self-image has been physically altered, their self-esteem may have changed because of this, and there may be a disparity

between their 'current self' and 'ideal self'. Therefore, there is an assumption that their overall self-concept may be altered.

This study aims to investigate further the impact of a stoma on an individual's self-concept as a whole. The research presented previously, considered singular areas of impact of a permanent stoma such as body image, and some of the difficulties of managing feelings of uncertainty if the stoma is temporary. However, no study at present has considered the impact of a temporary stoma on an individual's overall self-concept, and the implications this could have in terms of adjustment, adaption and the wider implications for services.

Whilst Danielsen et al (2012) demonstrated the presented paradoxical difficulty in adjusting to a temporary stoma; they did not specifically investigate self-concept in depth. Therefore, further understanding regarding the impact of a temporary stoma on self-concept would usefully add to the literature. Whilst self-concept can be measured quantitatively (Fitts, 1991), it is considered that a deeper level of understanding can be found through the use of qualitative methods, for example, interviewing individuals regarding their experiences, as used in this study.

This further understanding could increase knowledge about how to best support individuals with a temporary stoma, and could inform the care individuals receive with a view to improving patients' experience of adjustment.

Therefore the aim of this research was to use qualitative methodology to investigate the impact of a temporary stoma on an individual's self-concept.

Method

Design

This study used a qualitative method based on a semi-structured interview design to allow for exploration of further issues not considered by the researcher. The qualitative interviews were transcribed and Thematic Analysis (Braun & Clark, 2006) was used to identify themes within the data. Thematic Analysis was considered the most appropriate method of data analysis as it allows for emergent themes within the data to inform further knowledge regarding the research question. The epistemological stance of the researcher is presented in Appendix C.

Participants

There were 8 participants in total (6 males and 2 females) aged 46-84 (average age 63.8 years). Participant data can be found in Table 2 below. All participants were recruited through specialist stoma nurses at a large hospital in England. The inclusion criteria for potential participants was that they could speak English, were over the age of 18, had a temporary stoma fitted surgically, and were physically well enough to take part in the interview. The length of time since having the operation ranged from 5 days to 8 months and the reasons for individuals having a stoma included colitis, bowel cancer and inflammatory bowel disease.

<u>Participant</u>	<u>Gender</u>	<u>Age (Range)</u>	<u>Length of time since operation</u>	<u>Emergency or Non-Emergency</u>
A	M	50-55	1 week to 1 month	Non-emergency
B	M	60-65	1 week to 1 month	Emergency
C	M	80-85	1 month to 2 months	Emergency
D	F	65-70	Less than 2 weeks	Non-emergency
E	M	55-60	Less than 2 weeks	Non-emergency
F	M	70-75	Less than 2	Emergency

			weeks	
G	M	65-70	1 week to 1 month	Emergency
H	F	45-50	Less than 2 weeks	Non-emergency

Table 3. Participant information

Measures

Demographic data was gathered from all participants. This included age, gender, the length of time since their operation, and the reason for their need to have a stoma fitted. This was presented as either *Emergency* or *Non-emergency* to indicate the nature of their stoma.

A semi-structured interview schedule (Appendix D) was used to gather the qualitative data to explore the impact of a temporary stoma on the individuals' self-concept. The design of the interview schedule was based on the literature available about the impact of a stoma, and on research into self-concept. The interview schedule was piloted on the specialist stoma nurses, who were familiar with the issues for patients with a temporary stoma, and three members of the public, who gave feedback on whether the wording of the questions was clear.

All questions were open ended, to allow for the participants to respond with their own personal experience, and so their answer did not have to comply with a pre-determined outcome. The interview schedule was followed with probing questions such as 'Can you tell me a bit more about that?' to gain clarification, or if it was felt more information was available for the question.

Procedure

Data Collection

The specialist stoma nurses working at the research site hospital identified potential participants by consulting the planned surgical list for the department. Any

patient who met the previously identified inclusion criteria was given an invitation letter for the research study (Appendix E) during a pre-operative consultation. Any participant who wanted to know more about the study was given an information sheet (Appendix F) to take away and read. The researcher's contact details were on this information sheet should the potential participants wish to ask any questions about the study. There was also a consent to be contacted slip on the invitation sheet that potential participants could complete should they consent to their details being passed to the researcher as confirmation they were interested in taking part.

The consent to be contacted forms were collected by the specialist stoma nurses pre-operatively. After the potential participant had had their operation, had been fitted with a temporary stoma and was well enough to take part, their consent to be contacted form was passed to the researcher to make contact.

For the participants recruited as emergency cases, the same process was followed as for non-emergency participants; however they were given the invitation and information sheets post-operatively. They were still given time to consider taking part, and their details were only passed to the researcher if they still consented to be contacted, and were well enough to take part.

All potential participants who had completed the form were contacted by the researcher after their operation. In total 11 individuals were invited to take part in the study, all consented to be contacted, however 3 interviews could not take place due to illness of the participants.

The researcher then visited each of the potential participants. This took place either in hospital post-operatively, or in their home after they had been discharged. Formal consent to participate was gained (consent form Appendix G) after the limits of confidentiality were explained once again. Participants who gave consent were then

interviewed using the semi-structured interview schedule (Appendix D) and were prompted when necessary as per the previously described qualitative interview process. In total three interviews were conducted in hospital and five interviews were conducted in homes. The interviews were audio recorded on an encrypted Dictaphone. Following the interview participants were reminded that they could contact the researcher after the interview should they have any questions they would like to ask.

Each recording of the interview was then transcribed verbatim to allow analysis to take place.

Data Analysis

Thematic Analysis was considered the most appropriate method of data analysis, due to the aim of the research to consider any patterns or relationships between the temporary stoma and individuals' self-concept. Braun and Clark's 2006 paper regarding use of Thematic Analysis in psychology was used to inform data analysis. They described the process of Thematic Analysis in six phases, and these phases were followed with the analysis of the data in this study. Phase one involved the researcher reading the transcripts to familiarise themselves with the data. Initial notes were made regarding any thoughts the researcher had, or initial concepts that may be relevant for the coding process. The researcher read each transcript and made initial notes before moving to the next one. Phase two involved generating initial codes for the data. The researcher began to code segments of the data that could represent the data in a meaningful way. In this stage the researcher was careful to retain any differing accounts, and continued to consider that data can be represented within different codes at this stage. The initial coding related to general areas of interest, and in specific relation to the areas of self-concept. The third phase involved the researcher grouping codes into initial themes. At this stage consideration was given to the areas of coding,

and how they may relate to areas of self-concept; self-esteem, self-image and ideal self, and how the codes may relate to the temporary nature of the stoma. In this manner the data coding related to the specific question of the research. There were further codes that emerged from the data that were also grouped into initial themes. The fourth phase of Thematic Analysis was concerned with refining these initial themes. For the refining process, the codes within initial themes were considered, and subthemes began to emerge as codes were deemed to relate to each other. During phase four, the refining process also ensured that there were identifiable distinctions between themes and subthemes, and the refining continued until this process was complete. Phase five included naming and defining themes. The themes identified through the previous phases were organised and represented a narrative account of the information contained within them. The final phase was the narrative written account of the themes, which is presented within the results section.

The transcripts were also independently read and annotated by a peer. This ensured a level of quality in the analysis and development of qualitative results as the researcher's biases in the analysis stage were balanced with a secondary perspective. However it was noted that with any qualitative research, the researcher's biases, previous experience and perhaps unconscious expectations of the research will influence the results to an extent and this was difficult to completely exclude from the analysis. The researcher reflected on their own biases and how this may influence the results, both throughout the analysis process and within supervisory sessions. In particular the researcher reflected on previously held views regarding the anticipated impact a stoma would have, should they have had one. Generally this was perceived as a negative experience, with a view that the researcher would feel self-conscious of the physical appearance of the stoma. Furthermore, as a fortunate individual without any previous health conditions, the perspective of having an ongoing severe health condition was also

perceived as being a negative experience that would be difficult to cope with. The researcher was aware that these previously held views could bias the interpretation of the results. In particular it was considered that the researcher may be liable to focus on the results that concur with the previously held views, and perhaps pay less attention to results that do not. By being aware of these particular biases and openly considering them, the researcher was able to actively consider all elements of the results that were both congruent and incongruent with previously held views, reducing the biases within the final results presented.

Results

From the analysis, five superordinate themes were identified, with subordinate themes within each. A summary of the themes is presented in the table below;

<u>Superordinate themes</u>	<u>Subordinate themes</u>
The impact of the stoma on self-image	Looks versus Life Specific change in self-image
The impact of the stoma on self-esteem	Valuable as a person Stability of self-esteem
The impact of the stoma on ideal self	Pain is not ideal Impact on ability Importance of milestones and goals
What else makes me who I am?	I exist within a supportive network I am mortal I am both in and out of control
The temporary nature of the stoma	Uncertain future of the stoma Pros and cons of the temporary nature of the stoma Taking a realistic perspective

Table 4. Superordinate and Subordinate themes

The first three superordinate themes emerged in direct relation to the research question. These related to the impact of the stoma on the elements of self-concept; self-image, self-esteem and ideal self. A further superordinate theme emerged from the data that incorporated information about other elements that contributed to an individual's sense of self. The final superordinate theme also emerged in relation to the research question, regarding the impact of the stoma being temporary.

It is interesting to note that there was a sense of overall self-concept remaining stable among participants.

“I’m still the same as I was before...” – Participant C, 54

“I’m still the same person...” – Participant F, 31

The different elements that contribute to self-concept will be presented within the results, and the stability of overall self-concept and possible reasons for this will be considered within the discussion.

Superordinate theme one; *The impact of the stoma on self-image*

The first superordinate theme that related to the impact of the stoma on self-image was further categorised into two subordinate themes; Looks versus life, and Isolated change in self-image.

Subordinate theme one; Looks versus Life

For all of the participants, there was a clear notion that physical appearance was obviously altered due to their stoma. The impact of having an altered physical state was experienced differently by the participants, with some feeling self-conscious about the change, and others not thinking about this too much.

“...it isn’t a very pleasant thing, we all know this...if anybody says ‘eurgh I don’t quite like the look of that’, you think oh crikey...”

-Participant B, 193-196

“...particularly a lot of self-image...it’s actually more imagination than real, and actually people generally aren’t too bothered about things that perhaps you’re aware of yourself...”

-Participant A, 72-75

There were differing perspectives presented that may have influenced the way the physical change was experienced by individuals. One perspective that influenced how an individual may manage the change in self-image was previous views about self-image and the importance of looks.

“...to be perfectly honest I never think about it, I never have. I’ve always been at ease with who I am, I don’t have any wish to be like anybody, look like girl, be any other girl...so self-image really doesn’t come into my being I don’t think...”

-Participant D, 136-139

Whilst there were differences regarding the extent of the impact of a literal difference in self-image, there was consistency in that an altered physical appearance was a small price to pay to be alive, as the stoma was fitted as part of a lifesaving operation.

“...it’s not very nice to look at, once you’re well and you can see it, you think ‘oh I don’t like the look of that’, but as I say you’ve got to put your priorities haven’t you so I’d rather be here and have that than not...”

-Participant D, 96-99

“...it’s either you have it (the stoma) or you suffer the consequences, in which case self-image wouldn’t matter...”

-Participant E, 40-41

This subordinate theme demonstrated the clear impact the stoma had on individuals’ self-image, the differing ways this was experienced by the individuals, and how physical looks being altered was considered as a small consequence of being given the chance to stay alive.

Subordinate theme two; Specific change in self-image

The second subordinate theme with regard to the impact of a stoma on self-image was that the change in self-image was viewed as a change in a very specific way by the participants.

“...it’s strange, like in the shower it’s almost not your body, especially the scar is even worse at the moment, I think it will take some time to view it as my body, but apart from that it’s only a small part of my body so the rest will stay the same...”

-Participant H, 78-80

The specific change in self-image was literal, in that only one part of the individual's body had changed and therefore the physical impact was limited to this one particular area of the body. Some participants described this specific change in self-image in terms of only specific people knowing about the stoma. Therefore, as the knowledge of the stoma was restricted to certain individuals, and remained undetectable to the eye of a stranger, this reinforced the notion that self-image, and the image presented to others, remained changed only in a specific area.

"...so I've got a stoma, who knows about it? Nobody else but me and of course you and the hospital people..." *-Participant C, 63-64*

"...I don't think they take any notice...they wouldn't see anything of it, so they wouldn't know unless I told them, they don't know..." *-Participant C, 95-96*

As the stoma was a specific and isolated change, one individual also further externalised his stoma by choosing to give the stoma a name.

"...so we decided that because it's got a bag, we'll call it Bernard, so if I'm with a group of friends and it makes a noise, we can sort of say, oh Bernard, Bernard's being silly or something..." *-Participant A, 49-51*

Superordinate theme two; The impact of the stoma on self-esteem

The second superordinate theme focussed on the impact the stoma had on individuals' self-esteem. There were two subordinate themes identified with regard to self-esteem; the value of individuals as people, and the experienced stability of self-esteem before and after having the stoma.

Subordinate theme one; Valuable as a person

The subordinate theme around values emerged as individuals began to discuss both their personally held values, how they value themselves and other people, and to an extent their post-operative value within the workplace in particular. The value the individuals placed on themselves, whether high or low, was closely linked with their self-esteem. This participant described that he considered the value of a person to be the person themselves.

“...I’ve been aware over the past few years that people themselves are more important, and actually the things that I feel put value on things is within relationships, the people themselves, and if other people don’t feel that way then that’s their problem...”

-Participant A, 78-82

This view was contrasted for some participants, where a different element of value was considered; the value of an individual in the workplace.

“...I am going to be a passenger, there’s no question about it really, I’m not going to be able to earn the living that I used to, I’m not going to be as useful to people

as I was, you know I'm looking at myself and thinking because of my limitations, I'm not worth as much... ”
-Participant B, 108-111

In this case the stoma was viewed as something that devalued the individual, in terms of their literal ability to earn money, and in terms of their value as a colleague being able to work independently.

Subordinate theme two; Stability of self-esteem

The second subordinate theme that emerged related to the participants' experience of stability of their self-esteem. Whilst there was a difference between some participants expressing a higher self-esteem, and some participants expressing a lower self-esteem, a consistent theme was that participants reported their self-esteem as being similar to before they had their stoma.

“...I've always been at ease with who I am...once you get to a certain age you're happy in your skin...”
-Participant D, 136-137: 144-145

“...as I said, it (self-esteem) hasn't been affected, I mean it might be better (after the reversal) because I'd be back to normal, but it only depends on how much it has been affected now, and it hasn't really been affected...” *-Participant E, 51-53*

Other participants also stated that their self-esteem had not changed because of their stoma and remained stable post-operatively. These themes indicated that an

individual's sense of self-esteem may remain more stable as there were other factors that contributed towards self-esteem.

Superordinate theme three; The impact of the stoma on ideal self

The third superordinate theme that emerged was the impact the stoma had on the congruence between the individual's current self, and their ideal self. There were three subordinate themes that demonstrated incongruence as a result of the stoma in relation to; pain experienced, physical abilities and future milestones and goals.

Subordinate theme one; Pain is not ideal

The first theme that emerged, which demonstrated a way in which current self and ideal self were not congruent, was the pain that individuals experienced, even post-operatively. Whilst there was a clear demonstration of pain with the illnesses the individuals experienced that led to their stoma, the pain they continued to experience with their stoma led to a less than ideal current self.

"...well the first thing that's in my mind is that it is very very painful, a little bit scary..."

-Participant B, 5-6

"...so far, it's been painful..."

-Participant F, 3

"...very uncomfortable...in some ways very painful, it's quite unpleasant..."

-Participant E, 3

Whilst the pain experienced post-operatively was reduced compared to pre-operative pain in some cases, the participants described the desire to feel well again, and by not being in pain anymore, their current self and ideal self would be realigned. Therefore the impact of physical pain on self-concept was clear, and as the pain increased, the ideal self became less tangible.

Subordinate theme two; Impact on ability

The second subordinate theme to emerge was the impact of the temporary stoma on the participant's physical ability. The stoma clearly affected this, whilst also being mindful of the impact of any major surgery. The stoma impacted on ability to complete day to day tasks such as doing gardening, housework, maintenance of a regular social life and basic functions such as toileting.

“...I can't do my garden to start with, I can't lift anything, I can't do much of anything, I can't drive at the moment...” *-Participant C, 166-167*

“...it's just a lot of frustration because you can't do what you want to, I've always been busy always done something and now I can't, I feel useless and that gets you miserable, it has knocked me down ...” *-Participant G, 123-125*

The participants expressed frustration at the power the stoma had to restrict day to day life in that manner. The impact was greater than just limited practical and physical ability. The stoma held some power to impact how they felt about themselves,

which caused a newfound sense of uselessness and dependence in some participants.

“ ...I won’t be able to do as much around the house as I’d like, I probably will need to be dependent on other people to help me for a bit which isn’t great, I’d ideally like my functions to be normal, it’s hard getting used to going to the toilet in a different way through the bag...”

-Participant E, 55-58

The physical implications for the participants on their day to day abilities clearly demonstrated the impact of the stoma, and in particular demonstrated the incongruence between their current and ideal self. Their current self was not always able to complete tasks they would have been able to within their ideal self.

Subordinate theme three: The importance of milestones and goals

The final subordinate theme that emerged was with regard to the participants’ thoughts of the future, and where they would ideally like to be. This was a multifaceted concept, with the ideal future comprising of meeting milestones, and achieving things that did not seem possible in their current situation. This contributed to the notion that their current and ideal self could begin to realign, yet also demonstrated the impact the stoma had on their ideal self.

Whether the goals seemed small or large, they provided some hope that the participants would not be in that state forever. The milestones and goals ranged from going home from hospital, to being able to exercise or return to work, to ultimately having the reversal and becoming ‘normal’ again. They all served a purpose to maintain motivation to comply with treatment, and to persist with the process in the knowledge that the milestones and goals were ultimately achievable.

“...there’s the thought in the back of my mind of well regardless of whether or not this stoma is going to be permanent, the stoma as it is, will only therefore be there for perhaps another three months or so. I’ve kind of got that as a milestone, so regardless of that, I can work through that, I can deal with that...”

-Participant A, 134-137

“...my thought was well yeah currently I’ve got 3 to 4 months then hopefully that will be removed so that does make it easier, the thought that I’m not with it permanently...”

-Participant A, 31-33

“...I’m hoping that maybe if I think long term, I get to think next summer I’ll be normal again...”

-Participant H, 105-106

Superordinate theme four; What else makes me who I am?

The fourth superordinate theme that emerged from the data was the notion that there were many other aspects to an individual’s existence that did not directly correspond to one of the three areas of self-concept (body image, self-esteem and ideal self), but may still contribute to an individual’s sense of self in the context of adjustment to living with a stoma. These areas related to existing within a network of family and friends, and not in isolation, facing the mortality of being human and being both in and out of control with regard to the stoma.

Subordinate theme one; I exist within a supportive network

The first subordinate theme was in relation to the fact an individual exists within a network of close family and friends. The stoma impacted the individual as previously described, but this also impacted others in their life. Considering that other people in the participants' lives contributed to a sense of who they were as individuals, the stoma also impacted their sense of self in a way that was less obvious than within the main facets of self-concept.

There was a sense that the stoma could have a negative impact on others in the participant's life, yet these other people could have a positive impact on the participant with the stoma. The other people were also impacted in the sense that the participant was in need of support, yet generally did not want to become dependent on others. The individuals in the participants' lives that the stoma immediately impacted included spouses, family members and even colleagues who took on more work to compensate for an individual who was unable to work exactly as before their stoma operation.

“...I need to accept it so others will accept it...for my children to accept it, for them it's made hard to accept it, it's scarier for them...” *-Participant H, 57-59*

“...and obviously it's going to have an impact on my family...”

-Participant E, 20-21

“I am going to be a passenger, there's no two ways about it...”

-Participant B, 108-109

It was also clear that others in the participants' lives could have an impact on the management of the stoma, whether this was the people in the hospital including other patients and staff, their families, or just knowing that other individuals had also struggled with varying physical illnesses too.

"...with the friends we've got, people are very sympathetic... they're aware that I've been through quite a lot and people are very caring about it..."

-Participant A, 185-187

"My main friends have been on holiday this week, but they are back tomorrow so can come and see me, and my daughter will be home tonight, so visits are just a daily thing that really help..."

-Participant F, 77-79

"...actually our daughter in law had something very similar, she was 26 when it happened to her, so we compare notes, count staples and I beat her, things like that, so I'll say something and she'll say oh I remember that, so she has been quite helpful..."

-Participant G, 168-171

There was also a sense of individuals developing a shared experience to help manage the stoma with those closest to them. One individual and his wife named his stoma Bernard. This provided a shared term of reference for the stoma that both the couple, and his friends, could use. Furthermore this provided an element of humour

which the whole social group were included within, further developing the sense of the participant being part of a wider network, not an isolated individual.

“... I think with me as a person, it’s not really been a problem because I’ve been quite open with other people about it so, I think we’ve adopted a strategy to deal with it, because I’ve got quite a sense of humour so we decided that because it’s got a bag, we’ll call it Bernard, so if I’m with groups of friends and it makes a noise, we can sort of say, oh Bernard, Bernard’s being silly or something, and it becomes just a way of dealing with it...”

-Participant A, 47-52

Subordinate theme two; I am mortal

The second subordinate theme that arose from the data was the sense that given the severity of the stoma operation, the participants were faced with their own mortality. Further to the immediate impact on physical looks and self-image as previously described, many of the participants described how they faced a literal life or death situation, and although the stoma was inconvenient and not at all ideal, it was literally lifesaving. The knowledge that they potentially faced death was a life altering event to deal with both at the time, and during the recovery process. For the participants who experienced an emergency operation, the life and death situation was a very quick experience, and even for those participants who had time to prepare, there was still a life and death experience as their medical conditions were severe enough to be treated with an operation.

“...you’ve got to have an operation or you’ll probably be dead in the morning...obviously it’s a no brainer isn’t it...” -Participant B, 24-25

“I wouldn’t be pleased at the prospect of having to do this until, until the day I die, but it that’s the price of living then that’s the price of living, you’ve got to do it haven’t you...” -Participant B, 82-84

“...if it’s saved your life, no contest is it...” -Participant D, 81

Subordinate theme three; I am both in and out of control

The third theme that arose within the data related to the participants taking control over their stoma, in a situation that they had relatively no control over. The participants did not have control over whether they had the stoma, or indeed their illness.

“...I think I need to accept it, there’s nothing I can do...” -Participant H, 57

“...I don’t like it, let’s put it that way, but it’s a case of having to have it, I’ve got no option really...I have to have it” -Participant C, 109-

However there was also a sense that participants wanted to take charge over their experience, and this motivation to continue with their life was a further element that contributed to who an individual was, outside of the other elements of self-concept.

“...I think you’ve got to kind of get it into context with the rest of your life and think about, I think at the outset it was like a choice of either I’m going to let this thing dictate my life, or I’m going to be in charge of my life as much as I can, and the stoma will fall into my life, rather than it dictating my life...” -Participant A, 227-230

“... I mean everything that comes up I just accept it, it has to be done so that it can be finished with...I just get on with it, it’s all in the mind really, if it has to be done it has to be done, there’s nothing you can do about it, and if it’s going to make it better and more comfortable fair enough, get on with it, get it done...”

-Participant C, 170-177

Superordinate theme five: The temporary nature of the stoma

The final superordinate theme related to the impact of the temporary nature of the stoma. Three subordinate themes emerged from the data; the uncertainty around having a temporary stoma, the positives and negatives of the stoma being temporary, and the need to take a realistic perspective regarding the temporary nature of the stoma.

Subordinate theme one: Uncertain future of the stoma

This subordinate theme related to the notion that whilst all of the participants had a temporary stoma, whether this would actually be reversed was not certain. There were many other factors that could have impacted the future of the stoma, and therefore

there was a sense that individuals were hopeful for a reversal, without wanting to rely completely on this happening.

“...I think up to the operation it was always mentioned it should be temporary and I think until they remove it, I don’t want to think of it too much as a temporary thing, so I know it’s temporary but I don’t want to, if anything happens that it isn’t temporary I’d rather just accept that and live with it, on the other hand I’m scared to have another operation, but I suppose it helps knowing it’s temporary, when I think about it I should go back to normal with a few scars...” -Participant H, 38-43

Superordinate theme two; Pros and Cons of the temporary nature of the stoma

The final subordinate theme related to the potential benefits and costs of knowing the stoma was temporary. For some participants this provided hope that they would not remain in the unwanted state forever and that there was hope for an end to that state. However for others, the uncertainty of what a reversal may be like, and whether this would be detrimental somehow remained a concern, and the positive outlook from medical staff regarding the stoma being temporary, perhaps did not match individuals’ perception of a temporary stoma.

“...I think I’ll be glad to see the back of the stoma, but what I’m aware of is... that it can actually take up to two years to settle down to as good as it gets, and even as good as it gets, for some people might be even more extreme than having the stoma...”

-Participant A, 149-157

“...basically you go from where I am now, to essentially having to go to the toilet normally, but having to go potentially 20 times a day to start with...so at the end of up to two years some people then decide that actually I’m better off with a permanent stoma, yeah it’s not clear cut but at the end of the day as I say it’s going into it not being optimistic but being aware that things might not be as good...”

-Participant A, 153-160

“...I think up to the operation it was always mentioned it should be temporary and I think until they remove it, I don’t want to think of it too much as a temporary thing...but I suppose it helps knowing it’s temporary...”

-Participant H, 38-43

Subordinate theme three: Taking a realistic perspective

The third subordinate theme that emerged related to the perspective participants held regarding their stoma and their future, both optimistically and realistically. Whilst participants wanted to remain realistic about their prospects, given the uncertainty regarding the future of the stoma, there was a sense that being optimistic could also be helpful. The choice to take a certain perspective was another part to their self-identity that contributes to ‘what else makes me who I am?’

“...basically you go from where I am now to, essentially having to go to the toilet normally, but having to go potentially 20 times a day to start with...so at the end of up to two years some people then decide that actually I’m better off with a permanent

stoma, yeah it's not clear cut but at the end of the day as I say it's going into it not being optimistic but being aware that things might not be as good... ”

-Participant A, 153-160

“...so I think that once I get over this next operation I think probably I should be alright, I'll probably be okay, if I'm not I'm not...”

-Participant C, 125-126

“...I think up to the operation it was always mentioned it should be temporary and I think until they remove it, I don't want to think of it too much as a temporary thing, so I know it's temporary but I don't want to, if anything happens that it isn't temporary I'd rather just accept that and live with it, on the other hand I'm scared to have another operation, but with a few scars...”

-Participant H, 38-43.

Summary of results

The results from this study demonstrated that the stoma impacts the three facets of self-concept to varying degrees. There was an impact on how the individual manages this due to the temporary nature of the stoma and the unreliability this brings. The results are discussed within the context of the wider literature available.

Discussion

This study aimed to consider the impact of a temporary stoma on an individual's self-concept. The results presented were based on responses to questions designed to explore the individual's experience of having a temporary stoma, with a specific interest in exploring the impact on the three elements that are incorporated into self-concept; self-image, self-esteem and ideal self. These themes were presented with an additional two themes regarding what else makes an individual who they are, and regarding the temporary nature of the stoma. The discussion considers the results of the study in the context of models of self-concept and other research regarding temporary and permanent stomas. The impact on self-concept from other body changing surgery is also considered. The limitations of this research are discussed, and finally the opportunities for further research are presented.

One model of understanding self-concept was presented by Stein (1995). She describes self-concept as encompassing schemas; a mental process of grouping information as points of reference (Piaget, 1928). This model recognises that there is a temporal nature of the information available to incorporate into self-concept which allows for reflection on the past self, recognition of the current self, and allows imagination and hope for the future self. For the participants with a stoma, the information available at that time regarding current self, incorporated the elements of discomfort and pain of the stoma, and the negative impact the stoma had on abilities to complete some tasks. The change in current state and therefore the information available at the time, could have led to development of flexible coping strategies (Cheng, Lau & Chang, 2014), which allows adaption to life changes. One of the largest areas where the ideal self and current self did not compare was in relation to physical ability, and ability to maintain their pre-operative social life (Gooszen, Geelkerken,

Hermans, & Gooszen, 2000). It was clear from the results that the participants would like to be able to do more, and this is demonstrated through dependence on others during recovery from the operation (Majola, Ntombela & Zungu, 1995). Furthermore, their ideal self would not be in pain or discomfort and would be able to toilet in the standard way. This reflected the findings from McVey et al (2001), where lowered personal control was a key outcome for stoma patients. Within this research the newfound dependence on others and altered toileting functions can contribute to lowered personal control.

Therefore the participants' current self was in one way incongruent to their ideal self. For the participants to imagine their ideal self, the information available at that moment in time, influenced how they viewed their future prospects. This was demonstrated by participants describing future goals and milestones they were hoping to achieve, whether this was with regard to pain management, becoming used to, and therefore adapting to, completing tasks with the stoma, or ultimately the reversal. The information largely came from medical professionals, indicating whether the procedure was reversible and discussions with stoma nurses about the progression that can be made.

Whilst setting goals for the future was seen as helpful, there was the risk that these would not be achieved, and this could hinder progress if the participant becomes disheartened (Rasmussen, Wrosch, Scheier & Carver, 2006). Optimism versus realism was a concept that was clear within participants' experiences. Optimism helped the participants greatly in terms of motivation and positive adjustment (Carver & Scheier, 1999), whereas realism also helped to prevent the aforementioned disappointment if goals were unrealistic.

One of the issues individuals faced was the uncertainty attached to the elements of information that contributed to their future and ideal self. For example, whilst

participants were fitted with reversible stomas, until this had happened, participants did not want to place too much hope in this. If this element of the impact of a temporary stoma on self-concept was considered in isolation, it would have indicated that individuals' self-concept would have been less positive since having the stoma as they could not place full hope in reaching their ideal self. This aligned with the paradoxical notion that a temporary stoma is more difficult to adapt to than a permanent one reported by Danielsen et al (2012).

The impact of the stoma being temporary is an important issue to consider. A temporary stoma is usually considered a more positive outcome than being fitted with a permanent stoma as there is the hope that the issues the stoma presents will not be forever. However the results from this study show that the stoma being temporary can be difficult to adjust to. One notion about why this may be so is that individuals may not be able to fully engage in problem focussed coping (Lazarus & Folkman, 1984). The individuals may be able to make some changes to adapt to their new stoma, however the knowledge this will only be temporary may mean they do not fully engage in the problem focussed solutions, as these solutions will be redundant post-reversal.

Furthermore, the stoma being temporary at the time of the operation was not a guarantee that the individual would not be fitted with a permanent stoma in the future, should there be further complications. One participant identified that a permanent stoma would be more beneficial as he could adjust quicker and it would be easier to manage. Therefore it is important for patients to be fully aware of the potential downsides to having a temporary stoma and whilst the immediate life-threatening illness has been dealt with, there may still be issues to face and a temporary stoma is not necessarily going to be entirely positive for them. The difficulties found in adapting to a temporary stoma in this study are consistent with the quantitative findings from Smith et al (2009).

The participants could not be certain of what the future holds in terms of recovery, yet they were aware that the state they were in was not permanent so they could not adjust fully as they would be in a different situation post-reversal. This meant they could neither fully look to the future, nor fully accept the present, which left them in an unstable position of uncertainty with no clear guarantee of how the next days, weeks, and indeed months would develop. There was a sense that the reversal could be beneficial, however again there was no guarantee this would be the case. This uncertainty about the future demonstrated the importance of support from both professionals and individuals surrounding the patient, particularly as uncertainty regarding a situation has been shown to have an impact on affect (Bar-Anan, Wilson & Gilbert, 2009).

The results from the current study actually indicated that whilst one element of overall self-concept (ideal self) was unreliable for the reasons already discussed, another element of self-concept, self-esteem, was stable. This demonstrates the flexibility in the elements that comprise overall self-concept being impacted differently. Research has explored the stability of self-esteem across the lifespan (Orth, Maes & Schmitt, 2015; Wagner, Hoppmann, Ram & Gerstorf, 2015) and good health is a contributor to positive self-esteem. The participants in this study have all suffered ill-health, yet self-esteem appeared to remain generally stable. This therefore indicated there were other factors that contributed to overall self-concept in order to keep the element of self-esteem relatively stable when some of the other elements of overall self-concept (self-image and ideal self) are weakened. Argyle (2008) suggested there are four elements that contribute to the development of self-concept; the way others react to us, how we think we compare to others, our social roles, and the extent to which we identify with other people. These elements were all present within the results of this study, and it is

possible that these factors acted as a 'buffer' to maintain the element of self-esteem within overall self-concept.

Firstly, the reactions of others were demonstrated in the results as individuals described themselves as existing within a supportive network. Whilst there were some negative comments, positive reactions of others towards the stoma clearly allowed for self-esteem to remain fairly stable. Markus and Kunda (1986) describe overall self-concept as being a fluid, context dependent process. It appeared that as the support from others was so positive and beneficial, this contributed to the stabilisation of self-esteem, and therefore then stabilising overall self-concept. If the individuals had been faced with negative reactions from others, this may have been different.

Secondly, comparison to others was also a feature that appeared within the results. Individuals in this study described feeling fortunate to be alive, that many others had worse outcomes for similar conditions and indeed many people unfortunately pass away. The comparison to those less fortunate was described as a positive coping strategy (Wills, 1981), and whilst acknowledging that their situation was not ideal, it was felt that it could have been worse. This was also particularly relevant as it was noted that others would not likely realise the individual had a stoma unless they were told and therefore the process of comparison would not have been instigated from others in the individuals' world.

Thirdly, social roles were identified as both remaining stable and being unstable as a consequence of the temporary stoma. For example the social roles of being humorous, still being a husband, wife or a parent, remained stable. This allowed the individuals to have stability in self-concept as they gained positive support from these relationships, whilst also maintaining their individual role. The autonomy gained from maintaining some roles was considered a key factor in adjustment to, and coping with, a

stoma (Bonill-de-las-Nieves et al, 2014). However, some roles were less stable, and this was indicated by individuals describing their role within the work place. In some cases individuals felt that they were a passenger, and less valuable as a colleague overall. This indicated that there was a difference between social roles and how stable they may remain, therefore the stability of self-esteem with regard to social roles contributing towards this, may also differ. It would be important to consider which roles individuals consider as most valuable and therefore understanding which roles contributed most to the construction of the 'buffer' of self-esteem, and therefore their overall self-concept. As some roles were more widely impacted by the stoma than others, this may indicate for others that there could be some variation in the stability of their overall self-concept.

The final area that Argyle (2008) stated contributes to self-concept is the extent to which we identify with other people. Again this was relevant to the results of this study in several ways. Individuals stated that it was helpful to compare themselves to others with a stoma to gain support and perspective of their situation. Furthermore, this provided support as individuals felt part of a supportive network with other individuals going through a similar experience. There was also a wider sense of identifying with others with other illnesses, as individuals experiencing a part of life that is unpredictable, scary, unexpected, yet with hope that the future will be different. The widest notion of identifying with others was reported with the fundamental understanding that at some point every human will face mortality and this was one experience that identified individuals with every other person they meet. To have potentially nearly faced death and survive, can provide a positive adjustment (Brumm, 2006), however this can also be traumatic, and individuals may experience a grief process (Kubler-Ross, 1969) as they come to terms with the loss of their 'healthy' body.

Self-concept has been studied within the context of other body changing surgery where loss of a health and subsequent physical loss of a breast was experienced. Reaby and Hort (1994) considered the self-concept of women who underwent mastectomy surgery. They found that individuals who had reconstructive surgery or who wore external prostheses had an overall more positive self-image and self-esteem than individuals who did not, however there was no difference between the two groups in terms of overall self-concept. This demonstrated similar results to the current study, in that whilst elements of self-concept, particularly self-image, were changed as a result of body change surgery, there are other factors that contribute towards overall self-concept. Similar findings were also reported by Mock (1993). These results supported the findings from the current study by showing that physical change does not necessarily have an overall negative impact on self-concept as a whole even if body image has been altered.

The results from this study showed some impact of the temporary stoma on an individual's self-image. In particular some individuals described the stoma as not being nice to look at, and that they felt self-conscious about the way they looked. This was quickly balanced with the idea that actually although their physical looks had changed, this was a means to have their life saved. The impact on self-image is consistent to an extent with the results from Salter (1991). Whilst some participants did identify their self-image as being less positive as a result of the stoma, there were no strong self-descriptors such as 'disgusting' as there were within the Salter (1991) study. It was considered possible that in the 15 years since the Salter publication, the public perception of an individual with a stoma has altered, and therefore individual perception was less critical whilst still being honest about the difficulties of an altered self-image.

Limitations

One of the limitations of this study is that five participants were interviewed after they had been discharged from hospital, and the other three participants were interviewed in the hospital. This meant that some participants had different experiences, particularly in terms of being able to adjust to their life and routines at home. Given that being at home enabled the participants to see how their current self compares to their ideal self, particularly with a view to the medium term time frame, it may be that if all participants had been interviewed at home, then a clearer view of how the stoma affected their ideal self may have been developed. However, even the participants that were interviewed in the hospital appeared to have a realistic perspective of what their abilities would be at home, and were considering how their ideal self would be different to their current state.

There were differences in how the participants became aware of their operation. Four operations were emergency, and four were non-emergency. Whilst all of the participants had no choice in whether they had the operation, the non-emergency procedure participants were told of the operation beforehand, and had time to prepare themselves mentally for receiving the stoma. It has been noted that pre-operative patient preparation is very important in terms of post-operative adjustment (Nugent, Daniels, Stewart, Patankar & Johnson, 1999). It was interesting to note that there was no apparent difference between the participants who had an emergency operation and those who had pre-planned operations in terms of adjustment or coping, suggesting that the process of preparation before a planned operation might not be as useful as it could be.

A further identified limitation to consider is the age of the participants. The average age for a patient to have a stoma is 68.3 years old (Husain & Cataldo, 2008). The average age for the participants in this study is 63.8 years old. It would be

important for further research to consider whether age is a factor that influences the impact a temporary stoma has on an individual's self-concept. One participant identified that if she had the same operation when she was younger, then she would have felt worse about it, in terms of being more self-conscious about her body image. Whilst this was not a question asked, it is possible that the participants' age and stage of life has influenced the way they view their current state and the impact of the stoma on their self-concept. Other research has shown that younger participants have reported a negative impact on their self-esteem (Savard & Woodgate, 2008). It is not possible to say for definite whether this is related to age, however the pattern is interesting to note, and further research would be beneficial into this specific area. Furthermore, the impact on services is important, as it is clear that patients of different ages have differing concerns. As there is not a 'one size fits all' concern about having a temporary stoma, it cannot be assumed that there is a 'one size fits all' approach to helping individuals adjust either.

Conclusions and Clinical Implications

This study provided further knowledge to the existing body of literature regarding the impact of a temporary stoma. Many of the studies currently in the field have furthered understanding regarding the impact on body image, or another particular aspect of life, such as the ability to socialise. The findings from this study have demonstrated some of the subtleties involved in the process of adapting to a temporary stoma, such as confirming that indeed body image has changed, but this was within the context of remaining alive, and actually the participants in this particular study were not so impacted by body image changes. Furthermore there is a developed understanding of the influences that can 'buffer' the overall impact on self-concept, such as self-esteem remaining stable due to other factors contributing to this. This study sits within the

wider body of literature, but also adds to the knowledge base regarding adapting to a temporary stoma. The results from this study compliment, and further the results from the Danielsen et al (2013) study by increasing the knowledge about how the wider element of self-concept can be impacted by a temporary event.

One of the clinical implications from this study is that stoma nurses should be aware, and facilitate patients' awareness of some of the less reported impacts of having a temporary stoma. For example it would be important to facilitate discussions with patients normalising the experience of perhaps feeling less able as a colleague, whilst ensuring that the positive support from friends and family is in place to help sustain self-esteem to ensure overall self-concept remains as positive as can be during the process or recovery. As a temporary stoma is often seen as a positive result, it would be important to normalise the difficulties in coping with a temporary stoma, which are reported as placing hope in something that has not happened yet. The normalisation of the difficulties could alleviate any potential feelings of guilt or ungratefulness experienced by patients who find a temporary stoma difficult to adjust to.

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Appendix A - Critical Appraisal Skills Programme Qualitative Research Checklist

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Appendix B - Study Specific Critical Appraisal Skills Programme Tool Ratings

	1	2	3	4	5	6	7	8	9	10
Annels (2006)	Y	Y	Y	Y	Y	Y	CT	Y	Y	Very
Bonill-de-las-Nieves et al (2014)	Y	Y	Y	CT	Y	N	Y	CT	Y	Very
Carlsson et al (2001)	Y	Y	Y	CT	Y	N	Y	CT	Y	Very
Danielsen et al (2012)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Very
Danielsen (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Very
Gloeckner (1983)	Y	Y	Y	Y	Y	N	CT	CT	Y	Very
Honkala et al (2009)	Y	Y	Y	Y	Y	N	Y	Y	Y	Very
Lim et al (2015)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Very
Neuman et al (2012)	Y	Y	Y	Y	Y	N	Y	Y	Y	Very
Owen et al (2006)	Y	Y	Y	Y	Y	N	Y	Y	Y	Very
Persson et al (2002)	Y	Y	Y	Y	Y	N	Y	Y	Y	Very
Ramirez et al (2009)	Y	Y	Y	Y	Y	N	CT	Y	Y	Very
Savard et al (2008)	Y	Y	Y	Y	Y	N	Y	Y	Y	Very

Y – Yes

CT – Can't tell

N – No

Appendix C – Epistemological Statement

“To know, is to know that you know nothing. That is the meaning of true knowledge”

- Socrates

On the quest for further knowledge, how is it possible to know what we know, or to be sure that we know what we do not know? Is to have true knowledge really knowing we know nothing? What does this mean with regard for furthering personal knowledge, and the knowledge of others? These initial musings of the researcher have informed the epistemological stance, and this will be considered within this statement.

Crotty (1998) describes epistemology as being “concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate”.

When initially designing the study, there appeared to be many quantitative studies already in existence, particularly focussed on the impact on measures of quality of life (Krouse et al, 2007). When the researcher began to wonder about individual experience of having a temporary stoma, there were few pre-existing studies exploring this. The questions ‘how do we know what we do not know?’ and therefore ‘how do we go about finding out what we do not know?’ were immediately raised at this point, with the researcher taking a curious stance (Chenail, 1994) at the existing body of literature.

As the curiosity of the researcher developed, this indicated that a qualitative approach was most appropriate as qualitative research is concerned with ‘people’s grasp

of their world' (Smith, 2008, p4). Given the researcher was interested in starting to understand individuals' perspectives and experiences, as opposed to interpreting measures or scales, this decision was reinforced. Furthermore, it appeared there was scope for further qualitative research in this field as quantitative research is highly represented within the current body of literature.

Qualitative psychology rejects the stance of a traditional scientific perspective of positivism (Smith, 2008). Positivism suggests that the only truths are those that can be observed. Similarly to this, a realism perspective suggests theories may develop as variables are manipulated and the outcomes are observed (Smith, 2008). Whilst the researcher can appreciate the value of these stances in many circumstances, for the purposes of this study, the researcher rejects these stances. A constructionist perspective would suggest that instead of having a reality that is true, each person's reality is constructed through their own experience, so therefore there is no real, observable truth (Berger & Luckmann, 1991).

There are several methods of collecting and interpreting data that are encompassed within qualitative research and some of these will be briefly discussed before an explanation of why Thematic Analysis (Braun & Clarke, 2006) was chosen as the method of analysis for this particular study.

Grounded Theory encompasses analysing data to construct a theory (Smith, 2008) and uses a method of 'identification and integration of categories of meaning' to achieve this (Willig, 2001). This method of qualitative analysis was not considered to be appropriate by the researcher as the study was developed out of curiosity regarding

individual experience, not with the aim to develop a new theory or categorical understanding of having a temporary stoma.

Discourse Analysis is ‘concerned with language and its role in the constitution of social and psychological life’ (Willig, 2001). The notions that inform this method of qualitative analysis are that individuals express themselves through language, and therefore analysing the textual representation allows for constructs within the data to be determined (Smith, 2008). As this method is based primarily around analysis of the language and textual data, this does not allow for the researcher to answer their question about what is known about the individuals’ perspectives and experiences of how the temporary stoma has impacted self-concept. It is not felt that Discourse Analysis would facilitate the researcher in their exploration of discovering what is currently unknown.

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) is an ‘examination of how people make sense of their major life experiences’ (Smith, Flowers & Larkin, 2009). This method of analysis was considered, particularly as the researcher had a curious stance of aiming to make sense of how an individual experiences a temporary stoma.

Having considered other methods of qualitative research, Thematic Analysis (Braun & Clarke, 2006) was considered to be the most appropriate method of analysis given the aims of the research. Thematic Analysis ensures that the results are grounded within the data through generation of codes, and subsequent themes, whilst also accounting for the experiences of the individuals.

With regard to the initial musings of the researcher, particularly ‘how do we know what we do not know?’, the researcher has considered that by using Thematic Analysis to gain an insight into understanding further the concepts explored within the research, this may lead to further questions of exploration within this field of research. By beginning to explore areas that are currently less understood, this may reveal further areas to explore, or indeed may allow for a curious stance to continue, with the understanding that one can never know everything.

Perhaps by realising we can never know everything, we have only then gained true knowledge.

References for Epistemological Statement

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Appendix D – Interview Schedule

Questions based on Roger's (1959) theory of self-concept and developed in liaison with the stoma nurses.

Please can you tell me a little bit about your experience of having a stoma?

How does knowing it is temporary impact on your feelings?

How would you feel different if it was permanent?

Can you explain about how having a temporary stoma has affected the way you view yourself?

What do you understand self-image to be?

How would you have described your self-image before your operation?

Has your self-image changed at all because of the stoma?

Does knowing the stoma could be reversed impact on your self-image?

What do you understand self-esteem to be?

How would you have described your self-esteem before your operation?

Has your self-esteem changed at all because of the stoma?

Does knowing the stoma could be reversed impact on your self-esteem?

How does the stoma affect the way you would ideally like to be?

Does knowing the stoma could be reversed impact on your ideal self at all?

How do you think you might feel after having the reversal?

Have you told anybody else about your stoma?

If so, who?

What has led you to do/not do this?

If you have told someone, how do they view your stoma?

If you have told someone, how do their views affect your views of the temporary stoma?

If you haven't told someone, what do you think they might think about your stoma?

Is there anything else you would like me to know about how the stoma has impacted on your life?

Do you have a temporary stoma?

You could be invaluable to this research project

Kristen Youngman, a Trainee Clinical Psychologist from the University of Hull is looking for people who have experienced a temporary stoma, to share their story.

Understanding your experiences could help to improve services for others who may need a temporary stoma in the future.

Kristen is looking at the impact a temporary stoma can have, especially in terms of the way it can affect self-esteem and self-image.

If you are willing to take part in this study, you will be interviewed by Kristen after your operation, and asked about how the stoma has impacted you, particularly with regard to self-esteem and self-image. All information will be kept completely confidential.

By sharing your experiences, you really could help to make a difference for someone else in the future.

If you are interested in taking part, or have any questions and would like more information, please do not hesitate to contact Kristen Youngman on the contact details below;

Email – k.youngman@2008.hull.ac.uk

Telephone – 07743 311010

Or please fill in the *consent to be contacted* form below and Kristen Youngman will be in touch to discuss any queries and potentially arrange an appointment for the interview;

Name;

Telephone contact;

Secondary Contact;

Email;

Appendix F – Information letter for potential participants



Information about this research study

Title of Project: The impact of a temporary stoma on an individual's self-concept.

Name of Researcher: Kristen Youngman

I would like to invite you to take part in this research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. Please feel free to talk to others about the study if you wish.

Part 1 will tell you the purpose of this study and what will happen to you if you take part. Part 2 will give you more detailed information about the conduct of the study.

Part 1

This study is investigating the impact of having a temporary stoma on an individual's self-concept. The purpose of this study is to understand from a patient's perspective, the impact the temporary stoma has, with the aim that this information could help in the future to shape the service and care patients receive. This particular study aims to understand the early post-operative experience of having a temporary stoma.

You have been approached by the stoma nurses as a potential participant, as you meet the criteria for this study. You are due to have an operation in which it is anticipated you will have a temporary stoma fitted. It is up to you to decide whether or not to join the study. If you are interested in taking part, please read the rest of this information sheet. You are free to withdraw at any time, without giving a reason. This will not affect the standard of care you receive.

If you think you might be interested in taking part, you can fill in the consent to be contacted form that is given along with this information sheet. After your operation, if you have been fitted with a temporary stoma, and the nurses think you are well enough to take part, they can pass your consent to be contacted form to me. After your operation, I will visit you in hospital to answer any questions you may have. If you still want to take part we can arrange a time to conduct the interview, and this will likely be within the 10 days following your operation.

What will happen if I take part?

The interview will most likely take part in the hospital, however if you would prefer it to take place somewhere else, for example your home, then we can discuss this.

Before the interview commences, I will first ask you to sign a consent form. I will then interview you about your experience of having a temporary stoma, and if this impacts on your self-concept. The interview will be recorded on an encrypted Dictaphone and the recording will be deleted once transcribed. The transcription will be anonymised and kept securely. The interview should last between 1-1.5 hours, but can be done over more than one occasion. If you want to know more about the outcome of the study, this can be arranged at a later date.

Are there any risks or benefits in taking part in the study?

A possible risk in taking part in this study is that you may find it upsetting to answer questions about how the temporary stoma has affected you.

A possible benefit of taking part in this study is that the information gathered could help to improve care and services for other individuals with a temporary stoma. Also some people can find that talking about their experiences can be helpful on a personal level.

If you are interested in this study, please continue to read part 2.

Part 2

If you begin to take part, and then decide you do not wish to continue, any information you have given will be destroyed and no longer accessible to anybody. The interview will be recorded on an encrypted Dictaphone and stored in a secured case. The recording will only be listened to by the researcher, as the interview will be transcribed. The transcription will be anonymised and will only be read in full by the researcher, and the research supervisor. Anonymised extracts may be read by a peer research group to aid the analysis process.

The transcriptions will be kept securely at the University of Hull, and will not be accessed by anyone other than the above mentioned people. All identifiable information will be anonymised.

The intention is to publish the results of this study, including anonymous quotations if appropriate. The consent form will have a specific section for you to consent for anonymous quotations being published. After completion of the study, you will be welcome to have access to a summary of the research findings or the final written study.

The research is being sponsored by the University of Hull Clinical Psychology and Psychological Therapies Department.

If you have a concern about any aspect of this study, you should ask to speak to the researcher who can answer your questions. If you remain unhappy and wish to complain formally, you can do this via the NHS complaints procedure. To make a

complaint, the first point of contact should be to the Patient Advice and Liaison Service (PALS), and they can be contacted on 01904 726262 or pals.york@york.nhs.uk.

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Research Ethics Committee.

If after reading this information sheet, you would like to take part in the study, please indicate that you would like to complete the form to consent to be contacted for this study if appropriate after your operation.

Researcher Contact Information;

Kristen Youngman, based at the University of Hull.

Telephone – 07743 311010 Email – k.youngman@2008.hull.ac.uk

Appendix G – Consent form**Consent form**

Participant identification number:

Title of Project: The impact of a temporary stoma on an individual's self-concept.

Name of Researcher: Kristen Youngman

1. I confirm that I have read and understood the information sheet for the above study.
I have had opportunity to consider the information and to ask questions, and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and I am free to leave the study at any time, without having to give a reason, and without my medical care, or legal rights being affected.

☐

3. I understand that if I choose to leave the study before the end, any recordings or data will be deleted permanently.

☐

4. I consent to have anonymised direct quotations printed in the publication of this study.

☐

5. I consent to take part in this study.

☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix H - Guidelines for Authors for submission to the Journal of Health Psychology.



Manuscript Submission Guidelines

Journal of Health Psychology



1. [Peer review policy](#)
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Journal of Health Psychology is an international peer reviewed journal that aims to support and help shape research in health psychology from around the world. It provides a platform for traditional empirical analyses as well as more qualitative and/or critically oriented approaches. It also addresses the social contexts in which psychological and health processes are embedded.

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Journal of Health Psychology operates a strictly blinded peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed.

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2. Article types

The Editorial Board of the **Journal of Health Psychology** considers for publication:

- (a) Reports of empirical studies likely to further our understanding of health psychology
- (b) Critical reviews of the literature
- (c) Theoretical contributions and commentaries
- (d) Intervention studies
- (e) Brief reports
- (e) Signed editorials (about 1000 words) on significant issues.

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Publication guidelines for intervention studies are published in volume 15, number 1, pages 5-7. The journal normally publishes papers reporting intervention studies of up to 8,000 words allowing 500 words per table and figure.

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Please consult the Editorial concerning "Publication Guidelines for Intervention Studies in the Journal of Health Psychology" by David F. Marks J Health Psychol January 2010 vol. 15 no. 1 5-7: <http://hpg.sagepub.com/content/15/1/5.full.pdf+html> The criteria for publication include the application of the CONSORT, TREND and PRISMA statements.

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Article length and house style

Articles should be as short as is consistent with clear presentation of subject matter. There is no absolute limit on length but 6,000 words, including footnotes and reference list, is a useful maximum. Longer articles will be considered at the discretion of the Editor. Tables and figures count as 500 words each which should be attached as separate pages at the end. "INSERT HERE" signs should be noted within the text. The title should indicate exactly, but as briefly as possible, the subject of the article. It is essential that your literature review is completely up to date. Please check recent issues of the **Journal of Health Psychology** and other key journals to ensure that any relevant papers are cited. Papers that fail to do this will be rejected. An Abstract should be at the start of the manuscript and not exceed **100 words** (in spite of what is stated on the ScholarOne website) accompanied by **five** keywords should be selected from the list provided on the JHP ScholarOne website. References are not numbered but appear in alphabetical order by first author surname.

To enable blind, impartial review, all documentation must be anonymized. A common error is to include the author's name in the Word document title, as in:

Smith (blind copy).doc

Such manuscripts will be rejected for re-submission in fully blinded fashion.

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The Journal requires authors to have obtained ethical approval from the appropriate local, regional or national review boards or committees. Of particular importance are the treatment of participants with dignity and respect, and the obtaining of fully informed consent. The methods section of the paper must contain reference to the forum used to obtain ethical approval.

Authors must follow the Guidelines to Reduce Bias in Language of the Publication Manual of the American Psychological Association (6th ed). These guidelines relate to level of specificity, labels, participation, gender, sexual orientation, racial and ethnic identity, disabilities and age. Authors should also be sensitive to issues of social class, religion and culture.

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7. Acknowledgements

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an 'Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

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9. Manuscript style

9.1 File types

Only electronic files conforming to the journal's guidelines will be accepted. Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. Please also refer to additional guideline on submitting artwork and supplemental files below.

9.2 Journal Style

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9.4. Manuscript Preparation

The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

9.4.1 Your Title, Keywords and Abstracts: Helping readers find your article online

The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title

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Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

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11. Further information

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office as follows:

David Marks PhD: editorjhp@gmail.com

Appendix I - Reflective Statement

This statement comprises my reflections through the entire research process, and is divided into the different stages of the process.

Previous experience of research

My previous experience of research is very limited, although entirely positive. Conducting a dissertation for my undergraduate qualification was a very enjoyable process. Knowing that I had generated and consequently contributed a new piece of research into the field of psychology was quite an incredible feeling.

My dissertation considered individuals' perceptions of fame, and the influence this had on their desire to become famous. Whilst this is not a traditional topic of research, particularly within clinical psychology, it was a privilege to interview individuals, and to learn first-hand about their perceptions and desires, or not as the case may be, regarding fame. I knew that when embarking on further research in the future, I would love to expand my experience of using qualitative methods, and again share in a part of an individual's life, an experience that is not always possible outside of the research remit.

Development of the research proposal

When beginning to consider an area for research, I was drawn to the idea of a temporary state of physical change that could impact on psychological well-being.

Whilst working on health psychology placements, I have always admired the individuals who are suddenly faced with a physical illness or disease, and their ability to cope, or indeed their bravery in asking for support. Whilst I have been fortunate myself to not have directly faced illness or disease, I have been in the privileged position to be

a confidant for several people who have. It is this experience that led me to want to contribute some research into an area of health psychology, in the hope that this fraction of new knowledge could play a part in the bigger picture of helping individuals faced with what can often be their biggest challenge in life.

Originally I was considering looking at how individuals faced with a temporary period of time in a wheelchair view themselves. However after a time of trying to access services, it became apparent that this was not a possible route to pursue. It was following a suggestion by a tutor at university, that I considered looking at temporary stomas. It was not an area I was too familiar with, but after looking at some of the research, I felt that this would be an invaluable area to research further. I was struck by how relatively common having a stoma is, and began to wonder how many people I had come into contact with who may have been dealing with issues related to a stoma, or the underlying causes that can lead to a stoma. I am a great believer that things always work out for good in the end, and could only think that my original idea was not the best route for me to research.

Whilst thinking about individuals with a stoma, it seemed that some of the main areas that were affected were related to body image. I was familiar with body image within the construct of self-concept, and was struck by how seemingly few studies considered overall self-concept as a whole. I also was curious to wonder how self-concept could, or would be different with a temporary stoma compared to a permanent stoma, and it seemed at this point that my idea had been formed.

Collecting the data

I had been assured that data collection was the ‘fun’ part of research, and I did manage to experience this after many months of frustration with slow and at times non-existent recruitment! Once I began to meet with patients to interview them, I was struck

by how open and honest they were with me, after meeting me for only a few minutes. It was incredible hearing each of their stories, and the similarities and differences in their experiences so far. As soon as the first interview was conducted, I couldn't wait for the next ones, as I was eager to learn more and ask more questions. The entire process of collecting data was extremely drawn out for reasons I may never understand fully, however looking back this gave me time to really reflect properly between interviews, and have time to develop my ideas which may not have been the case for others who were more fortunate in the timings of their recruitment process.

The time constraints of finishing the research placed an added pressure on the recruitment process. However once this deadline had passed, I partly felt more panicked as my peers had completed their work, however I mostly felt more free, in that I could spend the time reflecting on the work so far, which I had really enjoyed.

Data Analysis

As I began to look at the transcripts with the view to make sense of the data, I was struck by so many aspects of humanity, particularly just how resilient people can be in the face of adversity, and how incredible the power of support from others can be. It gave me further hope that the work I was doing could be really worthwhile, both from a research perspective, but also my choice to have a career in clinical psychology where I was in a position to provide this support to others who may not have the supportive individuals around them to do so.

Writing up the data into a 'results' section was challenging as I wanted to make sure I had included every bit of detail I could, whilst also making sense of the wealth of data somehow. I felt responsibility to represent the participants correctly, acting as the collective voice for individuals who may not have had their views expressed on paper

before. However as I began, this process was really enjoyable, and I hope I have represented the participants in a way they would have wished.

Conclusions

This piece of research has been both stressful and extremely rewarding, and I am thankful that the positives have outweighed the negatives. It has been a pleasure meeting individuals with a stoma, and hearing their stories, and I am grateful to everyone who has helped along the way. I have not changed my perspective that qualitative research is more rewarding than analysing statistics, as there is no better experience in my mind than meeting a stranger and hearing a story that is so important to them, and being able to think about this and present it to perhaps help others too. I set out with the simple aim to find something out that might help someone else, and I hope I will achieve this, if not immediately, but in the future.

Appendix J - Ethical Approval and Research and Development Approval**Removed for hard binding**