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**Exploring the Decision-Making Process in Stoma
Surgery for Adolescents with Inflammatory Bowel
Disease: A Thematic Analysis**

And Clinical Research Portfolio

Volume 1

(Volume 2 bound separately)

Alison McCusker

BA (Honours) in Psychology

Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical
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Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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This is for Lesley.

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CHAPTER 1: SYSTEMATIC REVIEW

Experiences' of Stoma Surgery from the Patient's Perspective: A Systematic Review of Qualitative Literature

Alison McCusker*

Word count: 8, 619

*Address for Correspondence

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XY

E-mail: a.mccusker@nhs.net

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Abstract

Background and aims:

Research in stoma surgery has mainly focused on living with a stoma and quality of life. Research on an individual's preoperative experience of stoma formation is limited. To date, there has been no attempt to synthesise research in the process of stoma surgery from a qualitative perspective. Therefore, this review aimed to appraise the quality of the research and discuss themes that explore this experience.

Method:

Meta-ethnography was used to select and synthesise the studies from five electronic databases. Five studies were identified for inclusion and quality was assessed using a rating scale based on an existing quality rating framework.

Results:

Seven themes were identified: (1) Relationships; (2) Role of Information; (3) Public vs. Private; (4) Coping strategies; (5) Physical symptoms and Recovery; (6) Identity and Adjustment and (7) Control vs. Process. These themes appear to be significant factors in the experience and adjustment of stoma surgery.

Conclusions:

This review has highlighted that proactive coping strategies, such as information gathering and integrating the stoma into one's life, results in a better adjustment after surgery. Health professionals are in a good position to provide information and support in preparation for surgery. Higher quality reporting of qualitative studies is required to improve the overall evidence base.

Key words: Surgery, Stoma, Experience, Inflammatory Bowel Disease

Introduction

What is stoma surgery?

A stoma is a surgically formed opening into the bowel which is used to assist with bladder or bowel elimination (Sharpe, Patel & Clarke, 2011). Stoma surgery involves bringing a loop or end of the bowel to the surface of the skin through open surgery or a laparoscopic operation (Melville & Baker, 2010). There are two main types of stomas, which can be temporary or permanent; a colostomy which is an opening of the large bowel and an ileostomy which is an opening of the small bowel (Melville & Baker, 2010). The most common reasons for an individual requiring a stoma includes having Inflammatory Bowel Disease (IBD) or Bowel Cancer (Bray, Callery & Kirk, 2012). At least 261,000 people are affected by Ulcerative Colitis and Crohns Disease, the two most common forms of IBD, in the UK (Mowat et al, 2011). Usually, surgical intervention is not considered until medical management has failed (Hwang & Varma, 2008). With regards to bowel cancer, stoma surgery is commonly required as a consequence of operations to remove cancerous tissue. Incidence rates of bowel cancer have increased in Great Britain since the introduction of national bowel screening programs (Cancer Research UK, 2011). In 2011, there were 41,581 new cases of bowel cancer in the UK (Cancer Research UK, 2011). The increase in diagnosis of these conditions is positively correlated with an increase in stoma surgery and currently, there are approximately 100,000 people in the UK with a stoma (Windsor & Conn, 2008).

There are clear benefits in stoma surgery, including the removal of cancerous tissue and reducing symptoms related to IBD. As with other types of surgery however, it has its risks. A range of complications include parastomal hernias, stoma prolapse, skin irritation, stoma strictures and retractions (Bafford & Irani, 2013). Further complications such as high stoma output loss can lead to dehydration, electrolyte abnormalities, vitamin deficiencies and malnutrition (Bafford & Irani, 2013).

Living with a stoma

There is little doubt that having stoma surgery is a life changing experience. To date, research has mainly focused on living with a stoma and the resulting quality of life. Brown and Randle's (2005) systematic review (N=14) looked at the psychological and social impact of living with a stoma and found overwhelmingly negative feelings from patients

regarding stoma formation. Papers in this review included quantitative and qualitative studies using adult populations with varying participant sizes from 7 (Salter, 1997) to 215 (Wade, 1990). This review found a number of issues concerning individuals, who go through stoma formation, including body image, quality of life, sexuality and sexual concerns, psychosocial adjustment and coping, and also practical adjustment. It was identified that an individual may experience an array of emotions regarding their stoma, thus professionals involved need to be aware that an individual's reactions may change over time. Danielson, Soerensen, Burcharth and Rosenberg's (2013) systematic review (N=7) found that structured patient education, aimed at patients' psychosocial needs, did appear to positively affect quality of life. Both aforementioned reviews highlight important information regarding living with a stoma, and included individuals with IBD, colorectal cancer (Kimura, Kamada, Guilhem & Fortes, 2013; Sharpe et al, 2011; Tseng, Wang, Hsu & Weng, 2004), individuals with spina bifida (Bray et al, 2012), bladder dysfunction (Nordstrom & Nyman, 1991) and malignant pathological conditions (Jenks, Morin & Tomaselli, 1997; Piwonka & Merino, 1999).

Research focusing on an individual's preoperative experience of stoma formation is limited. A recent literature review completed by Spinelli and colleagues (2014) explored the psychological perspectives of individuals with IBD who were undergoing surgery. Using quantitative studies, results found that lack of control, risk of complications, body image issues, the need for a stoma and hospitalisation may be triggers for an individual's concerns and anxieties regarding surgery. Spinelli et al (2014) identified that surgery is often seen by patients as a last resort and that having knowledge before and after surgery is pivotal in adjustment. This paper encourages the involvement of peer support throughout the process of surgery. This is the only review to date that looks at the experience of stoma surgery, however there are a number of limitations. The lack of methodological detail, demographic information and systematic analysis of the included papers, prevents this review from providing an in-depth exploration of the literature.

Rationale for this Review

To date, there has been no attempt to synthesise research in the experience of stoma surgery from a qualitative perspective. As qualitative data provides in-depth, rich information, it is a valuable method to use when exploring under-researched areas. Therefore, it would be valuable to synthesise and rate the quality of qualitative data, in

order to understand the experience of stoma surgery in greater detail and to identify further avenues for exploration.

Objectives

This systematic review aims to:

- 1) Appraise the quality of qualitative research exploring the experiences of stoma surgery.
- 2) Synthesise and discuss emerging themes that explore individual's experiences of stoma surgery.

Method

Search Strategy

Medline (Ovid), Embase (Ovid), CINAHL (EBSCO), PsychINFO (EBSCO) and Google Scholar were searched. It is widely understood that locating qualitative research remains a challenge (Atkins, Lewin, Smith, Engel, Fretheim, & Volmink, 2008) therefore free text was also employed to increase identification of relevant papers. Additionally, reference lists of articles assessed, were searched for other eligible studies. There were no limitations placed on time to ensure comprehensiveness of the search. Boolean operators (OR and AND) were used to combine search strings. The same search terms were entered into Google Scholar to find additional papers; this search was stopped after 100 pages of results as there had not been any novel studies identified. Databases were searched between 01/12/2014 to 10/12/2014.

Index terms were discussed and agreed upon with a University Librarian. The following terms were included in the search strategy:

- 1) Inflammatory bowel disease.mp. or exp inflammatory bowel disease/ or exp ulcerative colitis/ or exp Crohn disease
- 2) exp experience/ or exp personal experience/ or experience.mp.
- 3) exp stoma/ or stoma.mp.
- 4) (ileostomy or colostomy).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

- 5) (surgery or surgica* or post operative or anastomosis or procedure).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]

Studies retrieved in the electronic search were assessed against the following criteria:

Inclusion Criteria:

- Focus of the research is on the participants experience of stoma surgery
- Participants have a diagnosis of IBD
- All age groups
- Peer reviewed studies using qualitative methodology and analysis.
- Studies published in English language.

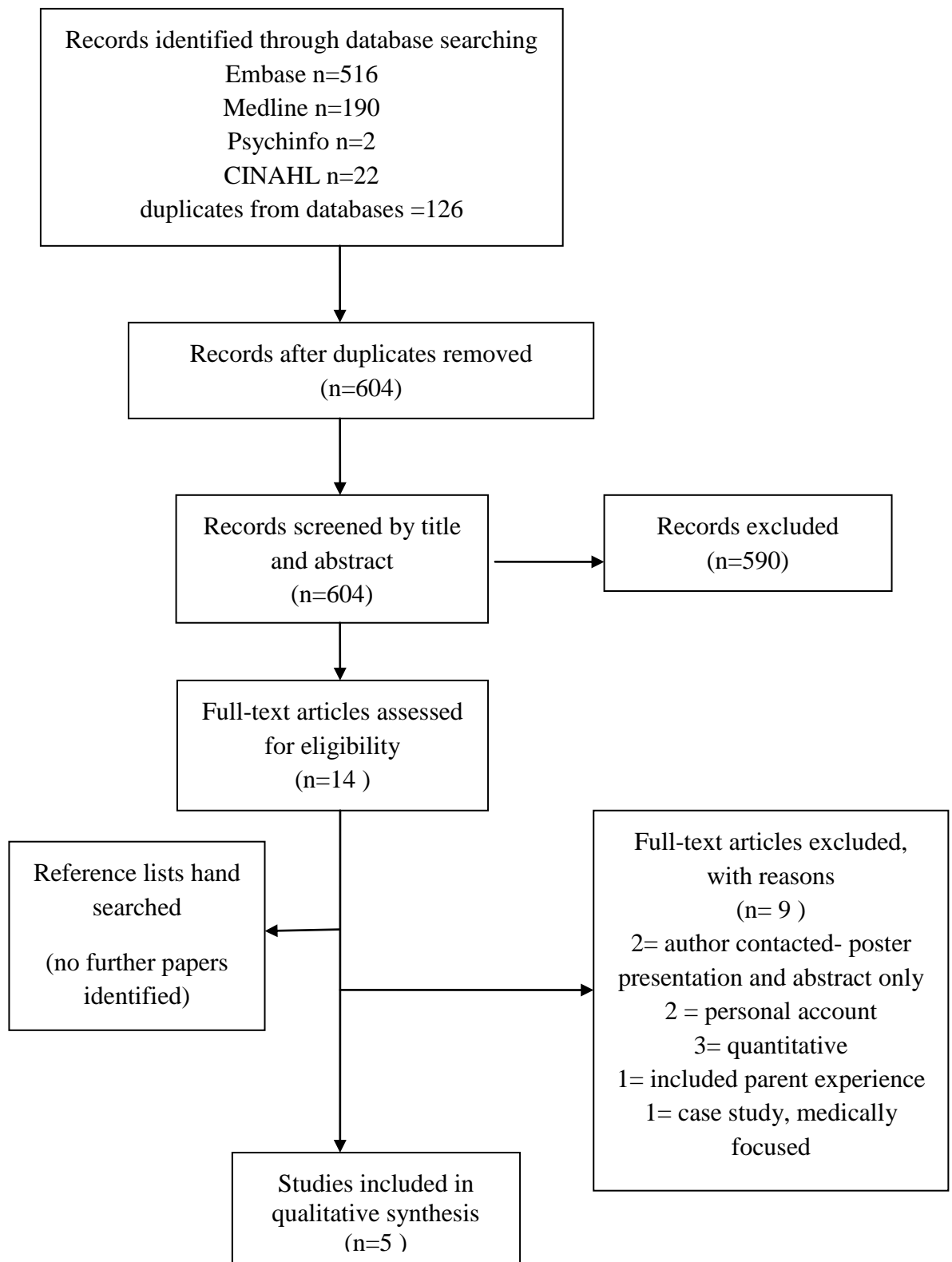
Exclusion Criteria:

- Employs quantitative methodology.
- Case studies
- Unpublished research

Procedure

A total of 604 papers were screened by title and abstract (Figure 1). Based on PRISMA guidance (Liberati et al, 2009), a two-step process was utilised accordingly: 1) title and abstract review, 2) full text review. Fourteen papers were identified from step one. From step two, nine were excluded and five studies were deemed suitable. Originally this review was only concerned with individuals with IBD and their experience with stoma surgery. It was identified however, that two of the included papers were not exclusive to IBD sufferers, which further highlighted how limited research is within this specific area. Therefore, an additional search was completed, between 05/01/2015 to 12/01/2015 that did not involve terms related to IBD in an attempt to assess the experience of stoma surgery generally. No additional papers were found and for that reason, the original search has been reported as the majority involve individuals with IBD.

Figure 1. Flowchart of search strategy (PRISMA statement, Liberati et al, 2009)



Quality Assessment

Several well established methods for appraising quantitative studies are available (Britten, Campbell, Pope, Donovan, Morgan & Pill, 2002). Methods for appraising qualitative studies, however is more variable (Walsh & Downe, 2006). Given the variety of theoretical positions, a consistent approach in appraising qualitative studies has been difficult to develop.

In an attempt to establish a unified approach, Walsh and Downe (2006) applied a 'redundancy approach' technique to categorise criteria from eight existing qualitative appraisal tools into those considered 'essential', 'desirable' and 'optional'. An adapted version of the Walsh and Downe (2006) tool was used for the purposes of this paper (Appendix 1.2) where only the essential criteria were applied. Each study was evaluated against a framework of eight main areas including scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions and relevance/transferability. The tool was adapted as the focus was not to exclude any papers instead to provide a framework for a general discussion of quality. The papers were scored against 29 criteria points; for each item, the paper was allocated a 0 if the item was not present or not possible to determine based on the information provided and a 1 if the criteria were met. Reliability was assessed by a second reviewer (Trainee Clinical Psychologist) who independently assessed all the papers. Agreement was 86% and discrepancies were settled through discussion and reflection.

Walsh and Downe (2006) oppose the production of a final quality score, as suggested by other authors (Cesario & Santa-Donato, 2002) and a more flexible approach is encouraged (Sandelowski & Barroso, 2008). Sandelowski and Barroso (2008) appreciate that some researchers may use inappropriate terminology but may still produce worthwhile results that can add to the evidence-base. For this review, a total quality rating score will be presented to provide a general guide on quality but emphasis will be focused on the findings produced.

Data Synthesis

Meta-ethnography was selected to synthesise the studies, as it has been argued that it is the most well developed method for synthesising qualitative data (Britten et al, 2002). Meta-ethnography involves selecting relevant studies to be synthesised, reading them repeatedly,

and recording key concepts from these original studies. These key concepts, interpretations, and explanations from the original studies then become the raw data for the synthesis. Britten and colleagues (2002) explain that in synthesis, studies can relate to each other in one of three ways. Firstly, they may be directly comparable as reciprocal translations. Secondly, they may stand in opposition to one another as conflicting translations. Finally, they may be taken together to represent a line of argument. Noblit and Hare (1988) described a seven step process for carrying out a meta-ethnography:

- 1) Getting started (the search)
- 2) Confirming initial interest (literature screening)
- 3) Reading studies and extracting data
- 4) Determining how the studies are related
- 5) Translating studies (checking first and/or second order concepts and themes against each other)
- 6) Synthesising translations (attempting to create new third order constructs)
- 7) Expressing the synthesis

This process, which allows for new interpretations through synthesising findings from individual interpretative accounts, will be followed in this review.

Results

Table. 1 shows the five studies that have been included in this review. The demographic detail for some of the papers is vague (Notter & Burnard, 2006; Kelly, 1994; Deeny & McRea, 1991) therefore full information is unable to be reported. From the data provided, analysis is based on a minimum of 135 participants from an adult population with the majority having a diagnosis of IBD.

Table. 1 Included study details and themes ordered by year of publication

Study	Sample (Gender, age range, diagnosis)	Time since surgery	Focus	Data collection, method and analytic approach	Themes
Allison et al (2013) UK	24 participants (11 males, 13 females) 18-25years old Crohns (17), UC (7)	Not specifically stated but paper acknowledges retrospective accounts on events “several years previously”	Experience of surgery	Narrative, semi-structured interviews. Story mapping & restorying	Perception of surgery Support Self Strategies
Notter & Burnard (2006) UK	50 participants (All females) 21-59 years old UC (39), Bowel obstruction (1), Crohns (2), cancer of bowel (4), familial polyposis (4)	Not specified	Preparation and experiences of surgery	Descriptive phenomenology	Pain and shock Body image and sexuality Loop ileostomy Professionals role
Beitz (1999) USA	10 participants (4 males, 6 females) 26-51 years old UC (9), UC+ rectal cancer (1)	2.6 years (Mean) 6 months – 5 years (Range)	Lived experience of construction of ileoanal reservoir	Interpretative Phenomenological Analysis	Restricted life world Living with uncertainty and fear Seeking control Vicious cycles Support Alienation from the body Living with body alterations Gift of time Role and relationship changes End of tunnel

Table 1 continued. Included study details and themes ordered by year of publication

Study	Sample (Gender, age range, diagnosis)	Time since surgery	Focus	Data collection, method and analytic approach	Themes
Kelly (1994) UK	45 participants UC with ileostomy	Not specified	Decision making for surgery	Checklist Thematic analysis	Surprise Ignorance Resistance Pressure to change Zone of transition Resisters and acceptors Seeking info Rationalising Counsellors
Deeny & McCrea (1991) UK	6 participants Ileostomy or colostomy	Not specified	Needs of patients and if they were met by staff	Grounded theory	Biophysical needs Psychological needs Sociocultural needs Other

*UC- Ulcerative Colitis

Critical Appraisal

Beitz (1999) achieved the maximum score of 29, suggesting a higher quality paper than Kelly (1994) who scored the lowest, with 17 (Appendix 1.2). In the process of analysing the findings however, all five papers contributed significantly. This reiterates the Sandelowski and Barroso (2008) view of taking a broader, more reflective stance than a prescriptive one. In general, the quality of the findings is high for each of the studies however poor detail in reporting these studies has reduced the total scores.

The scope and purpose of the research was well presented. Most of the studies provided a clear focus, rationale, and explicit statement of purpose, with the exception of Kelly (1994). Studies were situated within the context of existing theoretical and empirical literature, and linked their research to existing knowledge; three studies made explicit reference to having undertaken a literature review (Allison et al, 2013, Deeny & McCrea 1991; Notter & Burnard, 2006).

Study designs were consistent with research intent and all but one study (Kelly, 1994) contained a rationale for adopting their specific choice of qualitative method. Beitz (1999) provides an in depth explanation into why a Phenomenological approach was applied, which allows the reader to fully appreciate its application. Methods of data collection were apparent and appropriate. All five studies adopted a retrospective design when exploring stoma surgery. There is evidence to support this approach (Blane, 1996; Norris & Kaniasty, 1992), however the literature would benefit from more prospective designs.

With regards to sampling strategies, the quality and appropriateness was acceptable overall; only two studies provided specific inclusion criteria and justified their sampling strategy (Allison et al, 2013; Beitz, 1999). Qualitative studies generally have smaller sample sizes; nevertheless different methods recommend different participant numbers. No studies explicitly stated number of participants they hoped to achieve making it difficult for the reader to judge if appropriate numbers were recruited. For example, 20 to 30 participants are recommended for Grounded Theory (Marshall, Cardon, Poddar & Fontenot, 2013) which is a large disparity to the six participants recruited in Deeny and McRea's (1991) study.

Studies appeared to employ appropriate methods of analysis, with the exception of Kelly (1994). Allison et al (2013) explicitly stated when thematic saturation was achieved. Beitz (1999) involved the use of another researcher, and only two studies had participant involvement in analysis (Beitz 1999; Allison et al 2013). By including additional researchers or participant involvement, analysis is strengthened, and has been referred to as 'investigator or analyst triangulation' (Patton, 1999).

Clarity of interpretation varied. Insufficient detail was given by three studies with regards to an audit trail (Allison et al, 2013; Kelly, 1994; Notter & Burnard, 2006), however study contexts were explicitly acknowledged in all articles. All of the studies contained verbatim quotes to support interpretation. Reflexivity, the critical awareness of the factors that influence interpretation of the data (Reinhart & Reuland, 1993) which is an important aspect in qualitative research was described in only one article (Beitz 1999).

Only two studies explicitly stated that they received approval from an Ethical Committee and detailed how this consent was managed (Beitz, 1999; Allison et al 2013). Three studies did not discuss confidentiality (Allison et al 2013, Deeny & McRea 1991; Notter & Burnard, 2006). It is imperative that ethical considerations, consent and confidentiality are addressed, in order to respect and protect the right of participants (British Psychological Society, 2010).

Finally, the relevance and transferability of findings were sufficiently explored. Results were grounded in existing theory and conclusions were supported by both the results and existing evidence. Three studies (Deeny & McRea 1991; Allison et al 2013; Beitz, 1999) explicitly reflected on study limitations in addition to future potential research.

Meta-ethnography

The process of meta-ethnography, led to the creation of seven themes that appear to be relevant to individuals experiencing stoma surgery. They include

- 1) Relationships
- 2) Role of information
- 3) Public vs. Private
- 4) Coping strategies
- 5) Physical symptoms and Recovery

- 6) Identity and Adjustment
- 7) Control vs. Process

All seven themes were evident to some extent in each study and the following is a description of the themes, with verbatim data to illustrate:

1) Relationships

The main relationships that participants referred to, include those with health professionals, family, friends and fellow stoma patients. The role of the spiritual community was highlighted in two papers (Allison et al, 2013; Beitz, 1999).

I. Professionals

Relationships with professionals differ in quality and expectation. Reports appear to be divided between experiences with the surgical staff and specialist nurses. With regards to the surgical team, relationships focused on negotiation and information about the surgery. Participants appear to respond positively when involved in discussions about their surgery (Allison et al 2013) and negatively when there is limited information provided, or when surgery is not mentioned in a timely fashion (Notter & Burnard, 2006; Beitz 1999; Deeny & McRea, 1991). Kelly (1994) found that if the patient perceives that there is poor communication, this can seriously undermine the relationship with their doctor.

The relationship with nursing staff appears to be most valued. All papers highlighted the nursing role as a mode of fulfilment for most of their needs, with emotional support being crucial to the person's experience (Deeny & McRea, 1991). The role of the nurse appears to be broad and coupled with expectations that they will provide emotional, practical and medical support, with individuals feeling disappointed if these expectations are not met (Beitz, 1999).

"She's excellent...I'd be lost without her. She's amazing whenever there's a problem literally I ring her and she meets me straight away"(Allison et al 2013, p1572).

Although this suggests a positive experience from the patients' perspective, one has to acknowledge the burden that this may place on nurses. Evidence suggests that the nursing role is crucial to the patient's experience and they appear to be in the best position to provide support to the individual and their families.

II) Family and friends

Family and friends appear to play a supportive role throughout the process of stoma surgery, and it is evident that this support had a positive impact on the person's experience of surgery and having a stoma (Allison et al, 2013; Beitz, 1999). Not only did individuals value the support provided by friends and family, but it was acknowledged that family members, in particular may benefit from support themselves. Beitz (1999) contributes to this by highlighting that support from significant others or spouses, alleviates the fear of intimate relations.

“He [husband] looked aghast...he went white...I couldn't help I was so weak I cried and that made it worse for him...it's terrible they [families] should be counselled or warned” (Notter & Burnard, 2006, p152).

This displays how important an aspect of preparation is for the whole family when providing treatment to the individual. By not including significant others in the process, it can potentially have a negative effect on the relationships which are valued most by the individual. Deeny and McRea (1991) found this to be the case but, interestingly, it was identified that for some respondents, once they themselves demonstrated a positive attitude and showed acceptance of the stoma, their family members in turn adjusted better.

III) Peers

Although it has been identified that spouses and significant others are supportive, they are perceived to not fully understand the effects of surgery (Beitz, 1999). Individuals who have experienced stoma surgery appear to be most helpful to those who are going through the process for the first time.

“What puts a smile on their face or gets them really relating to you is when, when you're talking about bowel movements and...soiling your underwear...you can bond. It's very bonding when you have something like that in common and you can actually admit it”(Beitz, 1999, p193).

Deeny and McRea (1991) also make reference to this with participants suggesting that it would have been beneficial to talk to someone who had a stoma.

IV) Spiritual community

Spiritual access to a religious community was also identified (Allison et al, 2013; Beitz, 1999) as a relationship that may benefit individuals.

“It’s really important not to go into this alone. It changes everything, and in the end, it’s a very positive spiritual experience” (Beitz, 1999, p192).

It may be helpful to acknowledge a person’s religious beliefs when considering different avenues of support from them, in addition to how they are conceptualising the experience.

2) Role of Information

Health professionals were a major source of information, with nursing staff playing a significant role (Allison et al 2013; Notter & Burnard, 2006; Beitz, 1999; Kelly, 1994; Deeny & McRea, 1991). It was highlighted that staff have a responsibility to ensure that patients’ understand the information being provided and to check patient recall of the information throughout the entire process (Notter & Burnard, 2006) as, at times of high emotions, individuals can struggle to retain important information. There appears to be frustration experienced by individuals, if staff are unable to provide information that they want, with regards to surgery and postoperative factors.

“...and then I decided I wasn’t going to do anything, sign anything, until they showed me. I wanted to see a bag and I wanted to know how I would get them when I came home, how I would get a supply. I said ‘Right- I’m not doing anything until I get to know, what I want to know’ ...I just kept asking until he[medical practitioner] was able to give me just what I needed to know” (Kelly, 1994, p1173).

It is important, that staff are trained to an appropriate level to provide such information, or to signpost to appropriate services or resources. Support groups, self-education and electronic communication with peers were other avenues identified to obtain information (Allison et al, 2013; Beitz, 1999). Furthermore, information-gathering seems to be a form of coping in the process of surgery. Information appears to help the individual understand their experience, reduce anxiety, reassure and assist in decision-making (Allison et al, 2013).

Although it is imperative that individuals are fully informed about the process of surgery, it is unclear whether a person’s efforts to obtain information is fuelled by their motivation to

achieve certainty and control, or simply to make an informed decision. All studies acknowledged patient anxiety, but it is unclear how information mediated it.

3) Public vs. Private

This theme appears specific to IBD sufferers as they discuss symptoms before surgery and the management of the stoma after surgery. Notter and Burnard (2006) and Beitz (1999) demonstrate clearly a point that is merely hinted at in the other papers; the conflict between a very private problem and the management of it in the public domain.

What Beitz (1999) terms 'restricted life world', is a common experience for IBD sufferers. Prior to surgery, many find themselves having to restrict their social life and reduce their movements to close proximity of a bathroom. It is clear that a person's life is forcibly altered and there is an obvious drive for symptoms to be kept private from the public domain. This drive appears to be motivated by the need to protect self-identity, and the desire to be "normal" (Notter & Burnard, 2006). The theme of managing personal symptoms in public continues post-surgery. Some participants felt deprived of their privacy in the disposal of used bags (Notter & Burnard, 2006) and were unable to achieve 'normality'.

"It's demeaning...I mean you have to dispose of the bag... this is different you can't just bin them, so everyone knows you're different, that you have problems. How would you feel having to have special bags... you've got no privacy left" (Notter & Burnard, 2006, p154)

Not all participants had this experience, as the creation of a stoma lead to an opportunity for privacy again, with control of the disease being achieved. It seems that difficulties post-surgery may be more related to poor preparation in the form of lack of information and unhelpful coping. It is important that professionals acknowledge the sensitivity of a person's difficulties; there is a need to achieve a balance between staff normalising symptoms, in an attempt to reduce anxiety and stigma, and the need for the person to maintain their private self. This balance also related to a general conflict between private and public self, in the management of disclosing information.

4) Coping strategies

Individuals appear to use a variety of different coping strategies and generally, when participants took a positive approach and were proactive in their preparation, they adjusted better to the stoma. All papers highlighted a degree of mental resilience being utilised in preparation for surgery, with reference to “just do it” (Beitz, 1999, p192) and “getting on with it” (Allison et al, 2013, p1572). This acknowledges the inevitability of surgery and the attempt for the individual to establish control.

“Just keep thinking positively...If you think about things rationally you’ll get through a lot faster”(Allison et al, 2013, p1573).

Allison et al (2013) demonstrates that individuals who were more active in preparing for surgery, tended to describe less difficult postoperative experiences. Helpful coping in the preparation of surgery includes information gathering, making positive comparisons between health state before and after surgery, having a positive attitude and having mental resilience such as “getting on with it” (Allison et al 2013). Humour, was also acknowledged as an effective way of coping (Beitz, 1999). Kelly (1994) describes the preparation of surgery as a process rather than a decision to be made and the form of coping either assists or disrupts this process.

5) Physical symptoms and Recovery

All five papers discussed the worsening of symptoms as the main factor for requiring surgery. In addition, deterioration in symptoms appears to assist in an individual’s own decision making process, as some begin to realise that surgery is the only remaining option that will alleviate symptoms (Allison et al 2013) and without it, would put their life at risk (Kelly, 1994).

“I was so ill and thin...I went rapidly downhill...we discussed the history, the disease and [the doctors said] ‘we think it’s time now for the operation’. At that time I was not convinced I was ready for it...but they said I was. And I remember being very upset...And that was when they said ‘We think that if you leave it any longer its’ life threatening’. And from that point, I said ‘well, that’s it, that’s the decision made, if it’s going to be life threatening, I have to accept your advice’”(Kelly, 1994, p1172).

It has been identified that individuals may resist surgery due to having many postoperative fears and anxieties, such as fear of cancer, death, bodily changes and the uncertainty surrounding the outcome of surgery. The multiple physical changes appear to be linked to the threat to self-identity (Beitz, 1999). It is important that staff identify these fears in an attempt to assist the person through the process of surgery.

“They booked me in to have it done in the December. I went you’re joking. I ain’t having it done and I didn’t. Obviously I didn’t go” (Allison et al, 2013, p1570).

There is a need to prepare an individual for the postoperative stage. A lack of pre-operative preparation can lead to individuals experiencing extreme distress and can prolong the recovery period. Preparation is required with regard to the stoma itself, pain relief and bodily changes.

“I knew it was a big operation but afterwards I was just so weak and the pain was terrible...I had no idea, I thought I’d be tired but this was different...and it took me so long to get over it...I just felt like a wet rag, and I know I looked terrible...I didn’t want anyone else to see me, I knew they’d be shocked...all those drips and drains and things” (Notter & Burnard, 2006, p151).

The participants’ in Notter and Burnard’s (2006) study appear to have had a very negative and distressing experience post-surgery. Their expectations seem inconsistent with what they experienced which suggests they were inadequately prepared for the impending actualities of surgery.

Body image is a significant factor for almost all individuals. Beitz (1999) describes potential factors that staff can address in order to reduce body image issues, such as discussion of size and sensitivity of stoma, issues with odour and leakages in addition to general preparation of how the body may look post-surgery. It is important that individuals are fully prepared for surgery with regard to all possible outcomes as it appears that positive experiences of surgery help towards the individual’s attitude for future treatment (Allison et al, 2013).

The recovery process identified a number of different experiences. There appears to be recognition that stoma surgery significantly improves physical symptoms in comparison to symptoms before surgery (Allison et al, 2013; Beitz, 1999). Participants interviewed by Notter and Burnard (2006) however, had negative experiences, referring to their recovery

from surgery as “traumatic and debilitating”. This discrepancy seems to be in relation to lack of preparation and information provided to these participants in addition to the pain they were experiencing.

6) Identity and adjustment

Surgery appears to be a turning point with regards to identity. Throughout the process of stoma surgery, individuals will naturally oscillate between resistance and acceptance, with anxiety stemming from the impact on their identity. Kelly (1994) suggests the process for surgery involves the patient changing their view of themselves from someone who is merely ill and will recover, to someone whose life is at risk and who is in need of a major operation. He refers to this as the ‘Zone of Transition’.

It is not a straight forward process for an individual to accept a stoma and easily integrate it into their self-identity. People will try to distance themselves from the stoma and view their disease as separate from who they are. Extreme levels of disgust and distress can be experienced and individuals make reference to their stoma as “it” (Notter & Burnard, 2006) or discussed their bodies in the third person e.g. “the colon” (Beitz, 1999).

“I hated it, they wanted me to wait three months but I made such a fuss they took me back in after six weeks...they said I wasn’t really ready but I didn’t care I said I would cope with anything just to get rid of it [the ileostomy]” (Notter & Burnard, 2006, p154).

It seems there is a conflict within an individual with regards to identity and the role of their disease. Although there is resistance, it appears that a key factor in adjustment is acknowledging the positive changes that a stoma will bring to a person’s life (Allison et al, 2013). By individuals making a conscious effort to accept the stoma, their adjustment will be a more positive one (Deeny & McRea, 1991).

7) Control vs. Process

A major theme throughout all of the studies is the idea that individuals go through a process for stoma surgery. Every effort is made for an individual to remain in control of their treatment and the timing of their surgery, but the surgery itself eventually becomes a certainty. The themes already identified, appear to be the crucial factors in the extent to

which the individual feels in control. It appears that the more time to prepare and the more in control the person feels, the better adjustment and outcome.

“...and by that time, I was really coming round to an op. No one had mentioned it but I think I am one of these people that just take time to sort of decide...I mean I was fortunate. I was able to take my time and then decide for myself”(Kelly, 1994, p1172).

It may be that when the person is unable to go through the process at a pace that suits, difficulties can arise and their experiences are found to be more negative. Kelly (1994) highlights the importance of identifying the individual's fears and anxieties. For example, if a person views the 'threat' as the illness then surgery appears to be more positive, however if the surgery itself is viewed as the threat, then the person will attempt to resist it. Interestingly, one participant reflects on not having time to think about the whole process as a positive which possibly suggests being relieved of the burden of contemplating the fears and anxieties that others endure.

“It was a period of a few days that I took really ill, and then I landed in hospital...I had actually been in hospital for three days and they were saying ‘Well, you’re gonna have to have an operation’, and even then, it never occurred to me that I’d have to wear a bag or anything like that...Maybe it was a good thing in a way, because if I’d had time to think about it, it might have been a different reaction.”(Kelly, 1994, p1172)

This participant appears to have reframed her experience as positive however, what seems to be more appropriate is for individuals to have a balanced perspective in the process and for fears and anxieties to be addressed than avoided. What was unable to be extracted from the studies was any difference in the perceived 'threat' between those suffering from cancer compared to those with IBD.

Discussion

The studies identified for this review were heterogeneous in terms of diagnosis, method and analysis. Discrepancies have been acknowledged with regards to the reporting of these studies, in comparison to the overall quality of the findings. In order to improve the quality in reporting qualitative studies researchers should work within recommended frameworks

such as the COREQ (Tong, Sainsbury & Craig, 2007). Similar to previous reviews, this systematic review found that adjustment and coping (Brown & Randle, 2005), the role of information (Danielson et al, 2013) and sense of control (Spinelli et al 2014) in relation to stoma surgery, are very important factors.

There is a strong impression that the experience of stoma surgery is a process rather than a discrete event (Kelly, 1994). A threatening event such as stoma surgery can easily undermine one's sense of control (Taylor, 1983) and successful adjustment, or as Kelly (1994) refers the 'Zone of Transition', is the process of gaining a feeling of control over the surgery. The themes found all contribute to this process and links between the themes were evident. For example, positive coping and acceptance both lead to a better adjustment. Kelly (1994) illustrated this well by describing a normal oscillation between resistance and acceptance throughout the stoma process. To assist an individual through this process, it would be helpful to identify the 'threat' (Kelly, 1994) for the person to encourage a more positive adjustment and reduce resistance.

There are a number of theoretical frameworks that attempt to explain how individuals may adjust to threats to health and serious physical illness (Walker, Jackson & Littlejohn, 2004). Using Rheumatoid Arthritis as the health condition, Walker et al (2004) discussed the biopsychosocial model, to organise key components of health and adaptation to illness. This model suggests that the connections between psychological, social, and biological constructs enhance the explanatory power of models of adjustment to serious chronic conditions (Leventhal & Nerenz, 1983). The biopsychosocial model is highly applicable to individuals receiving stoma surgery and relevant to the findings from this review.

An important factor in adjustment and in the overall process is the role of information. Individuals who seemed more motivated to obtain information appeared to have a better experience. This again mirrors findings from Spinelli et al (2014) who found that informed patients demonstrated a better psychological status and were motivated to try different strategies to improve their outcome. It was unclear how information mediated patient anxiety and there is debate within the wider literature; evidence exists, which found better health-related quality of life and lower levels of anxiety and depression when doctors provided more person-centred information before surgery (Husson, Mols & van de Poll-Franse, 2011). Interestingly, Selinger et al (2013) investigated level of patient knowledge and found higher anxiety levels in those who had obtained more disease specific

knowledge in adults with IBD (Selinger et al, 2013). From this cross-sectional study, it was unclear if more anxious individuals sought out information rather than there being an increase in anxiety due to the information. From this evidence, it appears that information specific to the individual rather than the disease itself is more helpful in minimising anxiety.

Evidence within the oncology literature highlights that individuals dealing with potentially threatening information may use two cognitive coping styles: monitoring (tendency to seek threat-relevant information) and blunting (avoiding threatening information and actively seeking distraction under impending threat) (Rood et al, 2015). Therefore, information is more effective, and patients adapt better to the situation if the provided information is tailored to their monitoring or blunting coping style (Rood et al, 2015). This evidence may be highly applicable to those facing stoma surgery and more research is required to explore this theoretical construct.

Relationships appear crucial within the person's experience and the system around the individual has many different influences in meeting their needs in distinct ways. For example, the nursing role has been highlighted as crucial in providing information and preparing the person for surgery, in addition to providing emotional and practical support. Spinelli et al's (2014) literature review also reported that nurse involvement significantly accelerated recovery from stoma surgery in adults. In addition to the support provided by staff, the individual's social circle is crucial. Family support is important to the individual's experience, with research beginning to demonstrate that these supportive relationships help to contribute to positive adjustment and act as a buffer against stressors and adversities related to medical difficulties (Solomon, 2004). The benefit of mutual experience, which was found in this review, has also been found between adults suffering from cancer (Witkowski & Carlsson, 2004).

A psychosocial process which appears to underlie peer support is 'experiential knowledge' (Borkman, 1999). This experiential theory is linked with social learning theory in that peers, because of their experience of stoma surgery, are more credible role models. Therefore, interactions with peers who are successfully coping with their illness are more likely to result in positive behaviour change (Festinger, 1954). Social comparison theory offers further explanation into why peers are helpful. Individuals are attracted to others

with whom they share commonalities, such as having a stoma, in order to establish a sense of normalcy for themselves (Festinger, 1954).

Limitations of Review

A number of limitations have been identified within this review. Firstly, this review involved a number of diagnoses with the majority being IBD sufferers; this may have potentially overshadowed any themes related specifically to the participants with other conditions. Secondly, the studies were either completed in the UK or USA so there may be a lack of representation, however a recent epidemiology study (Cornes, Gower-Rousseau, Seksik & Cortot, 2011) highlighted some of the highest rates of IBD are found in the UK and North America. Thirdly, no restriction was placed on age of participants. Deeny and McRea (1991) and Kelly (1994) do not specify age but the other studies used an adult population, therefore findings may not generalise over the developmental stages. It is important that future research address the experiences of surgery from different developmental perspectives. Casati et al (2000) points out that IBD tends to be diagnosed in adolescence, when sexual and interpersonal identities are developing, making the necessity of surgery problematic and distressing. Therefore, exploring the experience of surgery from an adolescent perspective is important. Fourthly, not all the studies stated the length of time between surgery and time of interview. Although there is evidence to support retrospective accounts (Blane, 1996; Norris & Kaniasty, 1992) it would have been valuable to highlight any themes relevant to different stages in the process of surgery. Fifthly, it needs to be acknowledged that the five included studies had been produced over a period of 24 years. A number of technical improvements and advancements in stoma surgery have occurred in this time (Nunoo-Mensah, Chatterjee, Khanwalkar, & Nasmyth, 2004) therefore the experience of surgery may also have changed. As this review only focused on qualitative papers, evidence within the quantitative literature was not included and may have added to results. Finally, there remains controversy of the synthesis of different qualitative methods (Bondas & Hall, 2007).

Clinical Implications

Health professionals play a key role in an individual's support network. From the patient's perspective, health professionals should provide person-centred information regarding clinical care. It is important however, that health professionals find a balance in providing

appropriate and adequate support with signposting patients to relevant agencies in order to reduce a burden on professionals such as nursing staff.

Conclusions

In conclusion, stoma surgery is a process rather than a discrete event. This review found that patients benefit more from information relevant to their own needs rather than disease-related. It also highlights the importance of positive coping during the process of stoma surgery and in the overall adjustment process. At this point, there is a need for high quality papers to be produced. It is important that research does not become confined to the rigidity of quality checklists however the application of these frameworks may go towards developing higher quality research papers.

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CHAPTER TWO: MAJOR RESEARCH PROJECT

Exploring the Decision-Making Process in Stoma Surgery for Adolescents with Inflammatory Bowel Disease: A Thematic Analysis

Alison McCusker*

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*Address for Correspondence

Mental Health and Wellbeing

University of Glasgow

Gartnavel Royal Hospital

1055 Great Western Road

Glasgow

G12 0XY

E-mail: a.mccusker@nhs.net

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Plain English Summary

Inflammatory bowel disease (IBD) is a life-long condition related to the digestive system. Anyone can develop symptoms of IBD but generally a diagnosis of IBD is given in teenagers and young adults. Symptoms include diarrhoea, stomach cramps and lack of appetite. Medication is used to treat the symptoms of IBD but if that does not work then getting an operation can be an option. This operation would involve creating an opening on the abdomen, which is called a stoma. This allows stool or urine to exit the body. Although having surgery can really help the symptoms of IBD, the thought of surgery can be distressing especially for young people. It has been found that teenagers will delay stoma surgery due to the negative impact that it could have on their lives (Allison et al, 2013). Delaying surgery however, could put a teenager's life at risk.

Seven teenagers with IBD were asked about their experience of making a decision to have stoma surgery. What appears to be important when making a decision is knowing what the positives are of having a stoma, such as an improvement in their health, rather than just focusing on the negative factors. Support from other teenagers who have experienced stoma surgery, was highlighted as being the most important and helpful factor in making the decision to have surgery.

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Abstract

Background:

Inflammatory Bowel Disease is a life-long condition which involves inflammation of the gastrointestinal tract. Unfortunately, a large proportion of people who do not respond to medication have to undergo surgery. This involves the removal of an inflamed section of the digestive system which may require the creation of a stoma. Making the decision to have stoma surgery can be distressing and problematic, particularly within the adolescent population.

Objectives:

The aims of this study were to explore the decision-making process and pre-operative experiences involved in stoma surgery for adolescents with Inflammatory Bowel Disease.

Design and Method:

A retrospective qualitative design was used. Recruitment used purposeful sampling and semi-structured interviews were completed and transcribed. Data were subject to Thematic Analysis.

Participants:

Sixteen adolescents with Inflammatory Bowel Disease who had undergone stoma surgery were invited to participate in the study. Seven participants were involved in the final sample (at time of interview, age range 13-18years old).

Results:

Three super ordinate themes emerged from analysis and an analytic narrative was constructed under the headings 'Living with Inflammatory Bowel Disease', 'Journey to Surgery' and 'Support Network'.

Conclusions:

The decision-making process appears to be most successful when an adolescent has time to prepare and is provided with appropriate information to ensure understanding in order that they are able to take a balanced perspective and make an informed decision. The involvement of a peer appears crucial throughout this process by enhancing mutual understanding.

Key words: Adolescents, Stoma, Surgery, IBD, Experience

Introduction

What is Inflammatory Bowel Disease?

Inflammatory Bowel Disease (IBD) involves inflammation of the gastrointestinal tract and it is estimated to affect 200 per 100, 000 of the western population (Cornes, Gower-Rousseau, Seksik & Cortot, 2011). There are two main types of IBD; Ulcerative Colitis (UC) and Crohn's Disease (CD). An epidemiological review (Cornes et al, 2011) found that the highest rates of UC and CD are found in Northern Europe, United Kingdom and North America. The illness can occur at any age, but is often diagnosed in adolescence (Allison, Lindsay, Gould & Kelly, 2013). IBD at this age is more extensive and severe than in adults (Sawczenko & Sandhu, 2003). Symptoms can be unpredictable and uncontrollable, and can include severe or chronic stomach cramps, diarrhoea, sudden weight loss, lack of appetite and rectal bleeding. A recent Danish cohort study, (Moller, Andersen, Wohlfahrt & Jess, 2015) reported the risk of IBD is significantly increased in first, second and third-degree relatives of IBD, with up to 12% of all IBD cases being family cases. This illustrates the systemic issues related to IBD. Progress has been made in understanding these diseases, however aetiology remains unknown and IBD remains incurable.

As there is no current cure for IBD, treatment aims to relieve symptoms. Medications prescribed may include aminosalicylates, corticosteroids and immunosuppressants (British Society of Gastroenterology, 2009). These medications are generally aimed at reducing inflammation, and they differ in side effects (Mowat et al, 2011). The risk of experiencing side effects is dependent on factors such as dose, length of treatment and age, with young children more likely to experience side effects (Mowat et al, 2011). Unfortunately, a large proportion of people do not respond to the medication and surgery then has to be considered to remove an inflamed section of the digestive system.

Some individuals with IBD have the option of surgery, whereas for others it is a necessity due to complications of the disease. Surgery can be required for a number of reasons, including relieving a person of side effects of medications, improving their quality of life, or because the person is at risk of developing colorectal cancer. Delaying or refusing surgery can put the person's life at risk and may result in emergency surgery (Allison et al, 2013). Emergency surgery is generally required if there are serious acute symptoms or

complications, such as severe diarrhoea with bleeding, dehydration and a raised temperature or severe bleeding from the bowel, perforation (a hole or tear in the wall of the bowel), toxic megacolon (very severe disease of the colon), or a bowel obstruction (Crohns and Colitis, 2014). It is estimated that around 50% of people with CD will require stoma surgery¹ within 10 years of diagnosis and in UC the estimated lifetime rates for stoma surgery are between 20-30% (IBD standards, 2013).

Experience of stoma surgery

Living with IBD can have a significant impact on a person's psychological well-being and the prospect of surgery only adds to this (McCombie, Mulder & Gearry, 2012). A systematic review (N=14) investigating how individuals cope with IBD (Brown & Randle, 2005) found that individuals who have undergone stoma surgery are likely to experience problems relating to body image issues (McCombie et al 2012), anxiety and depression (Evertsz et al, 2011) and intimacy (Carlsson, Bosaeus & Nordgren, 2003). Most commonly, initial presentations occur in adolescence and young adults (IBD standards, 2013), which is a significant developmental stage with regards to self-identity, self-esteem, body image and relationships (Taylor, Gibson & Franck, 2008). Therefore, the possibility of surgery can be particularly problematic and distressing for this age group.

Stoma surgery is a major concern for individuals, especially for young people with IBD, some of whom will try to avoid or delay having an operation (Allison et al, 2013). A recent literature review (Spinelli et al, 2014) found that lack of control, risk of complications, body image issues and hospitalisation were among the concerns of IBD sufferers in the preoperative stages for stoma surgery. This review focused on quantitative studies but lacked methodological detail. Currently, only two qualitative studies have been identified that explore the preoperative preparation and decision making process in stoma surgery (Allison et al, 2013; Bray, Callery & Kirk, 2012).

Allison et al (2013) explored the experiences of 24 young adults (18-25 years old) with IBD who had had, or were about to have surgery. A qualitative narrative approach found that participants preferred to be involved in decision-making and responded negatively when medical professionals did not include them (Allison et al 2013). Interestingly,

¹ A stoma is an 'artificial opening of the abdomen' (Royal College of Nursing, 2009) which can be used to divert the flow of faeces or urine into an external pouch located outside of the body.

findings suggested that if appropriate dialogue did not take place, many refused necessary surgery (Allison et al, 2013). Bray et al (2012) completed a longitudinal study involving 49 interviews with 17 children and young people (9-19 years old) (and their parents). All participants were undergoing stoma surgery for various conditions (including bladder exstrophy, spina bifida and anorectal anomalies) and interviews were at key points throughout the surgical process. Findings suggested that most participants felt that the preoperative process could have been improved by providing more information specific for the individual e.g. family lifestyle, and that providing information to young people is not a one-off event, as children's understanding changes as they develop (Bray et al, 2012).

Decision-Making in surgical procedures

In relation to planned medical procedures, every patient needs to make an informed decision, which can be a particularly challenging process. Braddock and colleagues (2008) define informed decision-making as the process by which clinicians foster participation of patients and provide adequate information with which they can effectively participate in shared decision-making. A review paper exploring decision-making in adolescents using neuro-imaging studies found that decision-making may be modulated by emotional and social factors (Blackmore & Robbins, 2012).

Brown & Randle's (2005) systematic review on living with a stoma highlighted the impact of the emotional and social factors such as quality of life (Nugent, Daniels, Stewart, Patanker & Johnson, 1999), body image issues (Salter, 1997), sexual concerns (Nordstrom & Nyman, 1991), psychosocial adjustment and coping (Bekkers, van Knippenburg, van Dulmen, van den Borne & van Berge Henegouwen, 1997) and recommended the need for further examination into the decision-making process. This review did not provide demographic information so it is unclear whether findings are applicable to adolescents.

Adolescence is a significant stage with regards to cognitive development. Therefore, it is important to acknowledge that decision-making at this point in development is more complex (Piaget, 1932). A systematic review (Martenson & Fagerskiold, 2008) (N=15) investigating children's competence in decision-making in health care settings found that age appropriate information and participation were prerequisites for allowing children to have possibilities of making competent decisions about their own care. Interestingly, they also found that decision-making competence is dependent on others, such as parents and healthcare professionals and not only on their own capacity.

From the literature available (Allison et al, 2013; Bray et al, 2012), it has been highlighted that the decision-making process and preoperative experience is an important aspect of an individual's journey which requires more research. In addition, the evidence suggests that adolescents will find the prospect of surgery particularly problematic and distressing due to their developmental stage (Sawczenko & Sandhu, 2003). There is yet to be a study however, to explore the preoperative process and factors that could impact on decision-making involving adolescents with IBD.

Current study

This study expands on the findings from Allison et al (2013) and Bray et al (2012) by interviewing adolescents with IBD specifically. This study aimed to explore the decision-making process and pre-operative experiences involved in stoma surgery for adolescents with IBD.

Objectives

- To explore the decision-making process experienced by the participants
- To explore the significant factors and experiences that impacted on the final decision regarding surgery.

Method

Design

The study used a retrospective qualitative design that involved conducting in-depth interviews with adolescents. In choosing such an approach, it is important to acknowledge that concerns regarding the reliability of retrospective reporting have previously been noted, specifically relating to recall bias (Moss & Goldstein, 1979). Evidence exists however, which suggests retrospective reporting and autobiographical memory are not necessarily and inevitably inaccurate and unstable, especially when discussing more salient events such as stoma surgery (Blane, 1996; Norris & Kaniasty 1992).

The interview questions (Appendix 2.1) were constructed based on the objectives and on questions used in previous studies (Allison et al, 2013; Bray et al, 2012) in an attempt to gain continuity in the evidence base. Consent was obtained from the first authors to refer to these interview questions. The interview guide was developed to be used flexibly with the intention to allow participants to lead the interview as much as possible. The interview

questions were piloted with a subset of the sample (n=3) in order to practice interview technique and assess the appropriateness of the topic areas. Participants were requested to provide feedback if any changes were required. No revisions of the interview questions were required and the three pilot participants were included in the main study sample.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria were developed to recruit as homogenous a sample as possible. Homogeneity is important when attempting to explore the experiences of a particular group in depth. Variables including gender, IBD diagnosis and type of surgery were acknowledged as possible factors that may influence individual experience, however as the literature is limited it is unclear if these factors would have an impact. Therefore, adolescents were invited to take part if they had a diagnosis of IBD, were open to IBD or Stoma Nurse Specialists and had participated in the decision-making process (Appendix 2.2) for stoma surgery during adolescence (12-18 years old). Exclusion criteria included non-English speaking and concern that participation in the study would be unhelpful to the mental health of the adolescent.

Participants

Sixteen adolescents, who met inclusion criteria, were sent an information pack which included; a covering letter from a member of the clinical gastroenterology team at the Royal Hospital for Sick Children (Glasgow) inviting them to participate (Appendix 2.3), an information sheet (Appendix 2.4) and stamped envelope addressed to the researcher's place of work. The information sheet instructed participants to express interest by returning the tear off slip, or by verbally instructing a gastroenterology team member over the phone or during a hospital appointment. One adolescent subsequently expressed interest by post and one contacted the researcher by phone. The remaining 14 were followed up by a telephone call by a member of the gastroenterology team; two declined to participate, five were unable to be contacted and seven agreed for the researcher to make contact. Of the nine individuals who initially showed interest, seven agreed to meet with the researcher. Recruitment occurred between December 2014 and April 2015. On completion of the seventh interview the decision was made to cease recruitment as no new themes had emerged (thematic saturation) and all adolescents who met inclusion criteria had been invited to participate in the study. Therefore, the resulting sample consisted of seven participants.

Data collection

Interviews were digitally recorded and conducted by the principal researcher. Six were conducted in interview rooms on hospital premises and one interview at the participant's accommodation. On attending the interview, participants (and when required, their guardians) were invited to read the information sheet again and to ask questions. They were then invited to sign the consent form (Appendix 2.5) agreeing to the interview being recorded and to quotations being used in published reports. Prior to commencing the interview, time was spent preparing participants and debriefing them due to the personal and potentially difficult content of the interview. If judged to be appropriate by the researcher, information on support services was provided (Appendix 2.6). Interviews lasted in length from 30 minutes to 60 minutes. All identifying information was removed and participants were assigned a pseudonym to preserve anonymity.

Process of analysis

Thematic analysis (TA) was the qualitative approach used to analyse the data. Thematic Analysis differs from other qualitative methods such as Grounded Theory (GT) or Interpretative Phenomenological Analysis (IPA). Both GT and IPA seek patterns in the data, but are theoretically bound. Interpretative Phenomenological Analysis is attached to a phenomenological epistemology (Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003), which prioritises a person's experience about understanding everyday experience of reality, in order to gain a conceptualisation of the phenomenon under investigation (McLeod, 2001). Grounded Theory, however, comes in a variety of versions. Regardless, the goal of a GT analysis is to generate a plausible and useful theory of the phenomenon that is grounded in the data (McLeod, 2001). In contrast to IPA and GT, Braun and Clarke (2006) argue that TA is a method which is not wedded to any pre-existing theoretical framework. Therefore, TA can be used within a variety of theoretical frameworks and used differently within them. Given TA does not require the detailed theoretical and technological knowledge of approaches such as GT and IPA it can offer a more accessible form of analysis, particularly for those with no previous experiences of qualitative research. This was an important factor in selecting TA as this was the first experience of qualitative work for the principal researcher.

Ethical Issues

Prior to the study commencing, ethical approval was gained from a Research Ethics Committee (Appendix 2.7) and local Research and Development Departments (Appendix 2.8). The Researcher was employed by NHS Lanarkshire and conducted her study in NHS Greater Glasgow and Clyde, therefore approval was required from both health boards. In addition, a minor amendment was authorised for an interview to be completed at a participant's place of residence during the study (Appendix 2.9). This research was conducted following the principles of the Declaration of Helsinki (World Medical Association, 1964).

In the absence of law dealing specifically with research, the principles of Scottish law relating to consent procedure and treatment (Age of legal capacity (Scotland) Act, 1991) was applied with both the participant and guardian completing consent forms when participants were under 16.

Reflexivity

An inductive, semantic and realist approach to TA was chosen by the principal researcher as she was concerned with understanding the patient's own subjective experience in the decision making process for stoma surgery. In taking such an epistemological stance, the personal experiences, meanings and the reality of participants could be explored, interpreted and reported. Due to the principal researcher's clinical training, she was within her level of competence with regards to understanding and interpreting the explicit, surface level meanings of participant data. Nonetheless, in recognition of the potential for bias in interpretation, both research supervisors analysed a sample of two transcripts blind to the principal researcher's analyses and identified the same themes.

During the interview process, a guardian was present at two of the interviews. The presence of a family member could have potentially influenced the participant's responses, however both participants reflected quite critically with regards to family support when discussing their experiences. This demonstrates that they were comfortable discussing issues that may have potentially offended their family member. Overall, it was felt that the presence of a family member did not significantly impact on their responses as information provided was in line with the general themes.

Results

Participant demographics

Of the seven participants involved in the final analysis, three were female and four were male. At the time of the interview, participants were aged between 13-18 years old (Mean=15.4 years old). Five had Crohns Disease and two had Ulcerative Colitis. Given the small participant pool and acknowledging results would be presented to the medical team, table 1 (Appendix 2.10), reports demographic information collectively.

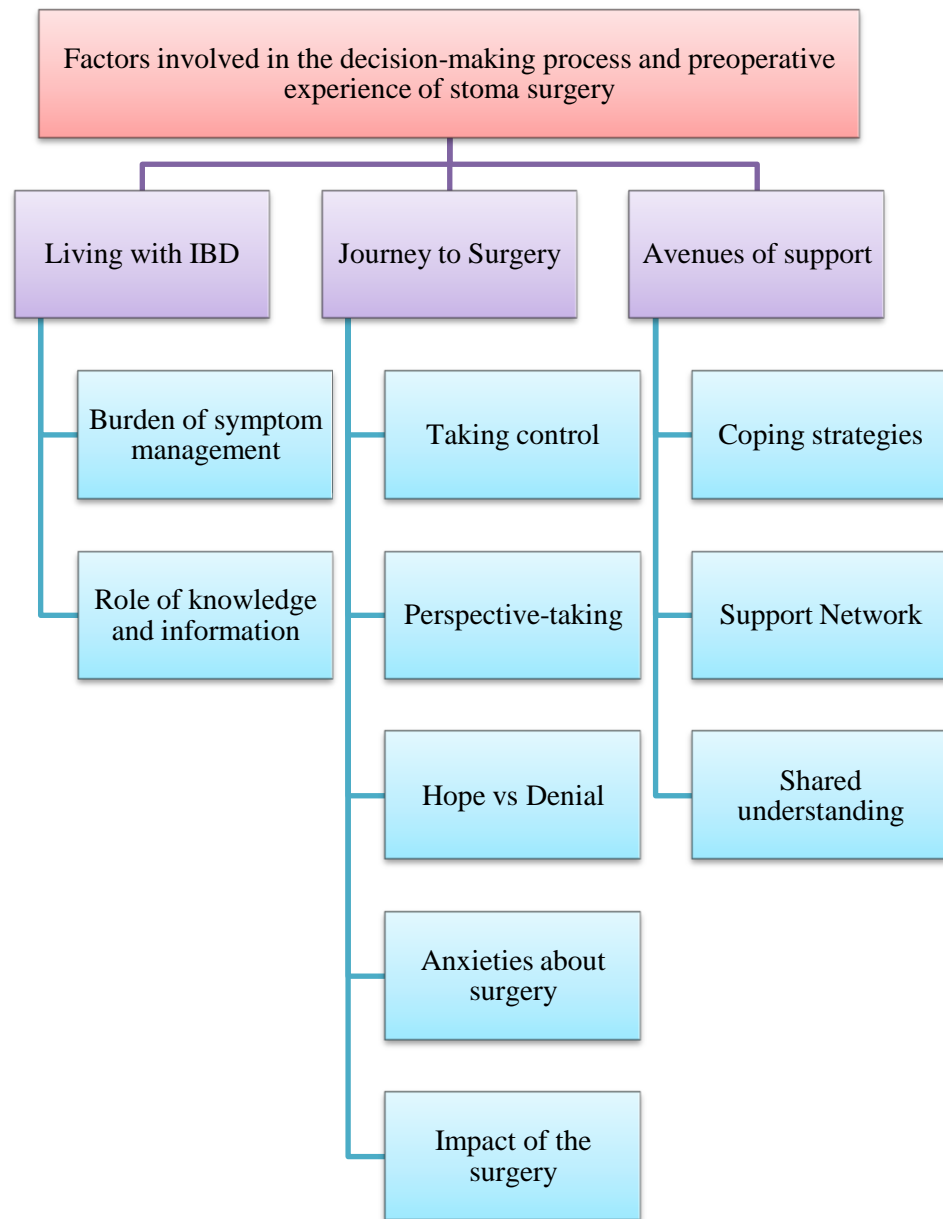
Participant experience of surgery

Surgery for six of the participants was planned and one had received emergency surgery within one month of being diagnosed. All seven participants had an Ileostomy; six were permanent and one was temporary. With regards to retrospective reporting, the longest period of time that was reflected on was eight years (Mean= 5.14 years).

Data analysis

Participants were able to reflect on their experiences prior to receiving surgery and discuss the factors that contributed to the decision making process. All of the participants reported that it was helpful to discuss their experience. The findings are discussed within an analytic narrative and presented under the three super-ordinate themes: 'Living with IBD', 'Journey to Surgery' and 'Avenues of Support' (Figure 1). Extracts from the transcripts are provided to illustrate the themes and a sample transcript excerpt has been included (Appendix 2.11).

Figure 1. Super-ordinate and sub-ordinate themes identified



Living with IBD

Living with IBD appears to be an uncertain and unpredictable experience. Gaining an understanding of the adolescents' experiences of IBD developed a context to which the decision-making process took place. Participants reflected on the uncontrollable nature of IBD and how the deterioration of symptoms contributed to their decision. Two subordinate themes were highlighted which explores the experiences of living with the symptoms of IBD in addition to the level of understanding and knowledge surrounding their diagnosis.

'Burden of symptom management'

The burden of living with IBD was evident from all seven accounts. Each participant describes the initial symptoms in a negative light and they reflect on a portfolio of failed medical and symptom management strategies. It is evident, that there is a genuine want to continue a normal healthy life but that they are limited in doing what they want due to the symptoms experienced.

"It was terrible at first, well like because you're constantly having to worry about is there a toilet near...and you don't want to eat and you're constantly tired and I don't wanna do anything and you get down because your friends are out...and then you want to be with them but you can't because you're not feeling well...it's just double...kind of social side to it and physical side to it." [Hamish]

Participants comment on the impact that the physical side of the disease has on their social life. It appears twofold, with the young people missing out on social events and activities due to the debilitating symptoms they experience, whilst choosing to restrict their life in order to manage their symptoms.

The treatment regime appears to be a great burden on the lives of the young people, with countless visits to the hospital, a variety of injections and medications in addition to the side effects that they have to endure.

"The medication I was injecting...it was every Friday night and every Saturday was just a write off. I just lay on the couch and done nothing which isn't the way you want to spend your weekends" [Stuart].

"My day to day tablets were about up to 15 times a day and then at night there would be a couple like 4 tablets at night so it was quite a lot" [Louise]

It is clear that the adolescents' lives are significantly affected by their IBD symptoms, yet six participants reflected on resisting the surgery and trying every other possible treatment available in the hope that one would be effective. This appears to be due to a number of factors relating to living with a stoma, with one participant referring to not wanting to live with regret.

“...look at the pros and cons of each different one and then through that I thought I would try the medication so that ten years down the line I’m not looking back and regretting” [Stuart].

A major turning point in the decision-making process is the worsening of physical symptoms. Each young person refers to a point when they could no longer tolerate the symptoms and surgery becomes a more appealing option for them. Many also acknowledge that surgery would take away the ‘burden of symptom management’.

“I was really sore and I was up all night...I just said to my mum ‘I need to go for this’. That was what tipped me over the edge” [Hamish].

“...that’s when I made the decision that I wanted to take the operation because I just couldn’t deal with having pain everyday and I was losing out on my education as well and so I decided to go for that” [Louise].

Resisting surgery to this debilitating position potentially leaves the young person with limited time to prepare for surgery itself and puts their health and education at significant risk. A number of participants reflected on receiving home tutoring, being held back in education and generally missing out on the school experience.

‘Role of knowledge and information’

This theme was discussed during initial diagnosis but appears to have significant weighting with regards to a young person’s decision-making.

“It has taken me awhile to figure out what it actually is. Like because I was so young I had no clue what it was. I knew the name but I didn’t know what was behind the name so for quite awhile I had no clue what it was” [Fiona]

“If I had known more information about it I would’ve went for it [stoma surgery] but because I didn’t really know a lot I was quite young at the time I just didn’t go for it because I didn’t know what it would be like” [Louise]

It is unclear whether there was a lack of appropriate information provided to the young person by the support network around them, or that they were unable to comprehend it. The stage in a person’s development appears to be significant in their capacity to

understand the information and process its' meaning, with a number of participants' referring to their young age and ability to understand their experience.

What was also apparent was that the two participants with limited knowledge of their own condition, reported poorer levels of adjustment in having the stoma compared to the other participants.

"I think it's a colostomy, it's one of them I'm not too sure" [Louise]

"I did go to a few parties...I kept thinking about my bag the full time. I just try and fit in" [Laura]

It seemed for one participant in particular, her difficulty in adjusting to her stoma was maintained by her resistance in accepting it as she tried to be more like her friends. This participant had received emergency surgery and had had little time to prepare herself for life with a stoma. This has resulted in poorer adjustment and lack of acceptance which appears to hinder her efforts in obtaining more information.

Journey to surgery

The journey to surgery is a complex and emotional one. It is apparent that for these young people, surgery became inevitable when there was deterioration in symptoms and the final decision was made by the health professionals. Therefore, the factors that were significant during the preoperative process were focused around the young person having control, attaining an informed and balanced outlook and identifying the general anxieties regarding the surgery itself. In addition to these points, the participants reflected on the impact that the surgery has had on their lives. Therefore the subordinate themes identified included 'Taking control', 'Perspective-taking', 'Hope vs. Denial', 'Anxieties about surgery' and 'Impact of the surgery'.

'Taking control'

For all participants, available treatment had been unsuccessful in managing their IBD symptoms, so surgery was inevitable. Therefore, the control was not in making a decision to have surgery but instead it was having control, or lack of, in the process of getting surgery and its implications. The participants appear to acknowledge that they had no option or that they were told they were getting surgery, however many still referred to it as being their 'decision'.

“...surgery was the last option. I took surgery and I think it’s the best decision I’ve made.” [Craig].

“I knew it was a decision I had to make like it was either I had to say it could be done or they were gonna do it anyway” [Hamish]

It appears that taking this approach acts as a protective factor and as highlighted by one participant, it is better to be in control and have a “stress free” [Hamish] experience. A comparison can be made with one participant who experienced emergency surgery and found the process highly stressful. This suggests that participants acknowledge that the alternative (emergency surgery) would be stressful and therefore it is better to be in control of the decision.

‘Perspective-taking’

As expected, all participants report on specific concerns in relation to the surgery, but this potentially restricts their perspective when considering surgery. It appears that the most helpful approach in the decision-making process for participants is when they were able to take a more balanced view of the surgery. Many received input from Clinical Psychology to help them through this process, helping them to identify the pros and cons of having or not having surgery.

“I ended up having to see the psychologist about it...I was always looking at the negative side of it but they said ‘no look at the pros and cons of each different ones’” [Stuart]

By expanding the adolescents’ focus and considering different perspectives, this allows them to identify the positive impact the stoma may have on their life. For example, many of the young people made reference to comparing themselves to others and a want to be ‘normal’. This appears however, to be detrimental to the decision-making process and their well-being. Instead, what appears more helpful is being able to integrate their diagnosis into their own sense of self and compare their current situation with the life after surgery, rather than with the lives of others. One effective way of developing this perspective was introducing the participants to peers who have experience in the surgical process.

“He [Peer] was really helpful and it was good because like before when I was waiting to go into the meeting, we had seen him sitting outside and we looked over and we saw that he looked good and looked healthy so because we saw that he had a bag and looked healthy that made me feel better because at that point I was still quite down. After, like I get the surgery done obviously I felt that it would make me look a lot more healthy” [Stephen].

Participants were more accepting of the difficulties of having a stoma by holding the positive aspects in their mind. This technique of having a balanced perspective is helpful post-surgery also.

“I think it can take a long time to get there but you get there eventually and it’s not too bad. I think it was just the thought of having to deal with changing a bag every day. You know, it just doesn’t sound normal whereas now it’s my normal.” [Fiona]

“I’m still having bad days of still thinking that ‘you hate it’ but you need to remind yourself how much better life actually is. It puts it into perspective that for what it is and for what I got from it, it’s just night and day” [Stuart].

‘Hope vs. Denial’

Many of the participants describe surgery as always being discussed as a possibility, but still experience a sense of disbelief when surgery becomes a reality. This appears to result in a state of shock and disbelief in addition to an increase in anxiety. Participants appear to view surgery as the last resort which they hope they never have to experience.

“Well I didn’t want to get it done. I just wanted to find different ways to try and help me get better before we had to finally decide to do it because when we first heard about it we thought ‘well we’re not going to do that’ and that it would only be a last resort when there was nothing left to do” [Stephen].

“It had been mentioned for years and years. It would get mentioned then they [Health professionals] would do a couple of tests and be like ‘no it’s not the time yet. So I wasn’t actually expecting them to turn round and say ‘you know what, you are getting this operation’. So when they did I was a bit like ‘what say that again’?” [Fiona].

With the unpredictable nature of IBD, professionals have a difficult task in informing young people of all the potential outcomes whilst minimising unnecessary anxiety. For these participants however, the more time they had in acknowledging that surgery was a realistic outcome, the better the psychological preparation and adjustment.

'Anxieties about surgery'

As expected, participants experience apprehension in preparation for the surgery. There appears to be a number of worries for the adolescents including the operation itself, the aesthetics of the stoma and the impact it will have on their lives. The majority of participants appear to make a conscious effort to think more positively in an attempt to avoid what appears to be highly distressing emotions regarding the surgery.

"I had to keep myself going as well...if I thought negative thoughts...it would all just collapse and break down completely" [Craig].

The process to surgery appears to be more anxiety provoking than they disclose. This could be in relation to the time spent preparing for surgery. The impact on the person's social life appears to be the most prominent anxiety; concerns regarding relationships, socialising and physical appearance were the most dominant topics mentioned. In the final weeks before surgery however, the focus appears to shift to the procedure itself and the anxiety related to the operation becomes more intense if it has not been previously considered.

"I was actually excited...it was probably up until a week before my operation that I was like 'wait, what if something happens? What if this doesn't make me feel better? What if it's like all the other medications that I've been on for years and years?" [Fiona].

"It was really upsetting, I kept crying at night and I just couldn't get to sleep...the fact I had to go in and get the operation" [Louise].

With any type of surgical procedure, it is common to experience anxiety. Nonetheless, the participants report an increase in anxiety leading up to the surgery and it would be important for family members and professionals involved to be aware of this to minimise distress.

'Impact of the surgery'

All participants report a significant improvement in their physical health after surgery but there is a mix of experiences with regards to the impact on their social lives. The majority of participants welcome the improvement in their health as it allows them to participate in sports, activities and school. For a small number however, the stoma has caused a reduction in activity. For one participant, who had emergency surgery two years prior to the research interview, they have ceased in having sleepovers with friends, which was a regular occurrence before diagnosis. This appears to be in relation to the limited time to prepare from diagnosis to surgery and poor adjustment after surgery.

"Since it's happened I haven't stayed with anybody since then" [Laura]

The remaining participants report more positively, with the impact of surgery being described as an opportunity to travel, play sports and be like other teenagers their age. The only gender difference apparent in the data was in relation to the types of activity. The male participants focused more on physical activities such as sport whereas the females focused slightly more on the social aspect such as parties or sleepovers.

"I have got my life back. I don't need to worry about where the closest toilet is. I can go out, I can do anything I want apart from box but I've never had any interest in boxing anyway. Like, I went golfing this morning, play badminton, I can play football a lot. It's just literally everything that a teenage boy does." [Stuart].

Avenues of Support

This super-ordinate theme encompasses the full range of avenues that the young person utilises to help them through the decision-making process. The subordinate themes include 'Coping Strategies', 'Support Network' and 'Shared Understanding'.

'Coping Strategies'

The participants appear to utilise a range of coping strategies to manage the physical symptoms, whilst making the decision and managing the stoma post-surgery. The strategies they use appear to either be motivated in adjusting to the stoma and integrating it into their lives or denying its' existence and striving for normality.

“I used to for about a year or something I wore baggy stuff. Like stuff so you wouldn’t notice it but now I’ve learned that it is probably better to wear stuff that I would’ve worn before I was ill so that no-one would suspect anything and kind of don’t act as if I need the toilet all the time. I don’t really need the toilet as much but because of in my head I feel as if like ‘oh if I don’t go then I’ll kind of need to go”
[Laura]

The range of helpful coping strategies include positive thinking and statements, distraction, seeking support from others and information gathering, however some participants employed more unhelpful strategies such as avoidance of social situations, self-harm and denial of the stoma. These unhelpful strategies appear to be detrimental to the participants’ mental health and social functioning.

‘Support Network’

All participants discuss a large number of people that are involved in their care. Those mentioned include family and friends, Nurse Specialists, Surgeons, Doctors, Clinical Psychologists, school, and other stoma patients. Most of the participants acknowledge the positive support provided by those mentioned throughout the process of surgery, however participants hint to a sense of isolation in their experience.

“...mum and dad, they did support but they didn’t know what they were on about really” [Hamish].

Interestingly, a number of participants described that they used their support network in specific ways. For example, if the young people had questions specific to the surgery, they would direct this to the surgeon, or questions related to the management of the stoma bag would be directed to nursing. The participants valued their support network and appreciated the different roles people had in supporting them. The young people however, also highlighted that at times some questions went unanswered because they could not identify someone within their network suitable to answer the questions they had, and many questions would have been better answered by a peer. This suggests an unmet need during the decision-making process.

“I think every question I had would’ve been better answered by someone in the position because they know it. The surgeon knows all the complications about the operation which is fine for parents but I wasn’t interested in that. I was interested in the rest of my life as opposed to that short period.” [Stuart]

It is evident from the accounts that the nursing staff facilitated the initial introductions of young people who had experienced stoma surgery to the adolescents. The participants did reflect that peers were introduced when the decision for surgery had been made and it may have been more helpful to have met a peer earlier in their journey with IBD.

The role of parents and the extended family appears to be a supportive one however, three participants discussed tensions between family members since diagnosis. One family member experienced mental health problems due to feelings of helplessness and reference was made to family members experiencing “guilt” and feeling out of control. This suggests the experience of living with IBD and making a decision for stoma surgery is more of a systemic issue than specific to the individual.

As highlighted previously, it is common to have a family member with IBD. Two participants discussed having a family member (parent and aunt) who had experienced stoma surgery and the impact this can have on them.

“I couldn’t really talk to my auntie because I have a weird feeling that I don’t want anybody knowing...I can speak to my auntie now that I’ve went to psychology and I realise it’s good to talk to her but I don’t speak to her often enough to ask her about stuff and tell her how I’m feeling” [Laura]

Both participants acknowledge the benefit of talking to a family member who has experienced surgery. Accessing this resource appears to develop insight into the surgery whilst receiving more emotional support.

‘Shared Understanding’

Having a shared understanding is in relation to two aspects of the participant’s experience. Firstly, two participants discussed not feeling believed by professionals or family members about their symptoms. It appears for these participants, not being believed or understood significantly impacted on their mental health which resulted in them accessing psychological support.

“Well for awhile...some of my family weren’t 100% sure that I was being 100% honest. Sometimes they thought that I would maybe exaggerate how I felt so that I could get a day off school...you would expect him [parent] to understand...but when my colon was taken out they [Health professionals] said it really needed to come out and I think that was sort of my way of properly putting it to bed and proving that I never lie about my condition” [Fiona].

Secondly, participants openly state that although people provide support, there is a lack of understanding about what the participant is experiencing, which appears to dilute any advice or information provided.

“...somebody who is a doctor says to you ‘oh well its good’ but they don’t know what it’s like.” [Hamish]

It is evident that mutual understanding experienced between the young person and their peer is most helpful. The participants recognise that the professionals are constrained within the limits of their role, and that it is their peer that is able to truly provide an honest picture of the experience in the context of this shared understanding.

“I think there should be...groups there [at the hospital] for people who are young who have dealt with it...to meet other people. I would quite like to meet more people who have it” [Laura]

This appears to be the most significant factor in supporting the young person through this process and in making the decision for surgery.

Discussion

The main aim of this study was to explore the decision-making process and pre-operative experience of adolescents with IBD. Three super-ordinate themes emerged namely ‘Living with IBD’, ‘Journey to surgery’ and ‘Support Network’. Similar to Allison et al(2013) findings, participants wanted information that was appropriate to them. The majority of the adolescents reported that they would have considered surgery at an earlier point if certain information had been provided. Only one participant explicitly stated that he exhausted all avenues to avoid regret. From this study, making an informed decision appears to be dependent on a number of factors.

Firstly, participants reported difficulty, throughout their IBD journey, in understanding information due to their age (Range= 9–16 years old from diagnosis to surgery). Cognitive development is important to consider during a decision-making process. Piaget's (1932) theory of cognitive development highlighted that young people think differently to adults. Adolescents begin the Formal Operational stage which involves the development in the ability to think in an abstract manner, to combine and classify items in a more sophisticated way, and the capacity for higher-order reasoning. Therefore, some adolescents at the early stages may not be able to fully make an informed decision with regards to stoma surgery due to their immature cognitive development.

Secondly, competence in making an informed decision has been found to be dependent on others and not just their own cognitive capacity (Martenson & Fagerskiold, 2008). This study found that the young people have a large support network that was utilised in a variety of ways. Information was obtained from a variety of sources and was not a static occurrence. The General Medical Council (2013) provides guidance on the assessment on capacity in decision-making. It emphasises that capacity is not just dependent on age and that it can be affected by their physical and emotional development and by changes in their health and treatment (GMC, 2013). Providing information to young people should not be a one off event and it is important that health professionals repeat and reiterate information over a period of time (Bray et al, 2012).

This study found that, although surgery was always mentioned, there was a state of disbelief when it became a reality. Health professionals, have a difficult task of discussing all potential outcomes whilst minimising unnecessary distress. The IBD standards (2013) state that, between 30% to 50% of people with IBD, will require stoma surgery at some point. Therefore it may be worth discussing the possibility of surgery with all IBD sufferers rather than introducing it when the likelihood of surgery increases. The involvement of a peer may help with this issue as young people can explore issues with regards to treatment and experiences of surgery at an early point.

With regards to family, there was a mixture of findings, with a number of participants' reflecting on tensions in their relationships. The results from this study supported evidence that suggests family stress being positively correlated with disease severity (Gray et al, 2015). This could have serious implications on the decision-making process as stress within the family may disrupt communication. It is important that services acknowledge that the

process for stoma surgery is more of a systemic issue and providing support for family members is crucial to the overall experience.

Thirdly, for adolescents to make an informed decision it was found that having a balanced perspective and recognising the positives of stoma surgery was vital. A major factor in achieving this perspective was the involvement of a peer who had already experienced stoma surgery. This appears to be significant in changing the perspective of surgery from an anxiety provoking event to a positive alternative to the management of IBD. All participants advocated the involvement of a peer which appeared to be routine in the hospital setting where the study took place. It is unclear however, if this is routine in the wider setting of IBD services.

Social learning theory suggests that peers are more credible role models in the process of adjusting to stoma surgery (Festinger, 1975). Interactions with peers who are successfully coping with their illness and stoma are more likely to encourage more positive behaviour change in others who are facing surgery. This is a good example of ‘upward comparison’ (Festinger, 1975) whereby interacting with others who are perceived to be better than them, individuals are given a sense of hope and something to strive towards. In addition, social comparison theory suggests that individuals are attracted to others who share commonalities with themselves (Festinger, 1975). The involvement of peer support has been found to be beneficial for a variety of child and adult populations within diabetes (Dales, Williams & Bowyer, 2012), mental health (Repper & Carter, 2011) and cancer settings (Legg, Occhipinti, Ferguson, Dunn & Chambers, 2011).

Limitations

There were a number of limitations identified in this study. Firstly, due to the small sample size it would be premature to generalise these findings to the entire adolescent IBD population. Thematic saturation was achieved however which suggests that there are common themes that others could relate to. Secondly, the researcher has analysed the data using her own interpretation, however two transcripts were reviewed by both supervisors in order to minimise bias. Thirdly, participants volunteered for this study and may represent more extreme experiences. Finally as the interviews were one-to-one, participants may not have disclosed all information. They all reported finding it easier to speak to a peer and future studies should consider focus groups to obtain data as young people may be more open to discussing issues amongst themselves.

Implications for clinical practice

IBD continues to be an unpredictable disease and therefore, professionals are unable to provide definitive answers with regards to treatment options. It is difficult to judge when stoma surgery should be mentioned as it is important to minimise unnecessary anxiety and distress in a young person. Peer support however, has been shown to be helpful through a young person's journey with IBD and services should consider the involvement of a peer at diagnosis as an avenue for a young person to explore all options and outcomes.

It has been identified that there is an increase in anxiety in the final weeks prior to surgery, even for adolescents who had a reasonable time to prepare and adjust to their decision. It is important that professionals involved are aware of the anxieties experienced in order to provide appropriate support to the young person in the final stages leading up to surgery.

Implications for future research

It is imperative that future studies explore the decision-making process in more detail. Longitudinal studies would provide valuable information as positive outcomes could potential distort retrospective reporting. The wider family implications require further exploration and it would be helpful to investigate parental experience during the decision-making process. Peer support has been identified as important to adolescents and further research should explore the factors into what makes peer support so significant in the decision making process.

Conclusions

Surgery continues to be seen as a final option that young people try to avoid. The themes from this study have highlighted that young people tend to focus on their concerns when considering stoma surgery rather than taking a more balanced perspective. Through accessing support from health professionals and family members, young people can be assisted in considering all their options and any worries and concerns can be addressed. In addition, introducing a peer who has experienced stoma surgery can provide valuable support in the form of mutual understanding.

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CHAPTER 3: ADVANCED PRACTICE 1

CRITICAL REFLECTIVE ACCOUNT

(Abstract only)

Abstract

Reflective practice has always been an area that has stimulated enthusiasm and passion within me. The realities of effective reflective practice however, can be challenging and can uncover some difficult thoughts and feelings. In this reflective account I will introduce two models, Borton's (1970) Developmental model and Karpman's (1968) 'Drama Triangle'. These models will be applied to demonstrate my personal and professional development throughout my time in training. I have provided examples from each year in my training as a way to illustrate my development in addition to how the 'Drama Triangle' can be activated in different context. In addition to this I have considered my future developments with regard to the 'Drama Triangle' along with the implication that this model can have in the changing role of a Clinical Psychologist.

CHAPTER 4: ADVANCED PRACTICE 2

CRITICAL REFLECTIVE ACCOUNT

(Abstract only)

Abstract

The focus of this account will be on my experience of research throughout training. To successfully reflect on my experiences, Boud, Keogh and Walker's (1985) model was used which involves describing the experience, identifying the emotions triggered and re-evaluating the experience using new information and identifying future learning. I have reflected on my Service Based Evaluation Project, applying to Ethics and interviewing my first research participant. By reflecting on these experiences, I have gained perspective which will help me in similar situations in the future. I acknowledge that research and audit does not fill me with great enthusiasm, however I am now more aware of the many aspects involved in research which I am able to successfully and competently complete. This has increased my confidence and appreciation for the role of research and audit within Clinical Psychology.

Appendix 1.1: Author guidelines

International Journal of Nursing Studies: Author guidelines

ALLSUBMISSIONS

The following documents are needed for all submissions (please refer to the Author Checklist for further guidance on preparing your manuscript).

Title page (with author details) – This should include the title, authors' names and affiliations, and a complete address for the corresponding author including telephone and e-mail address.

Blinded manuscript (no author details) – The main body of the paper (including the references, figures, tables and any Acknowledgements) should not include any identifying information, such as the authors' names or affiliations. Please ensure that the manuscript includes page numbers for ease of reference during the review process.

Author Checklist – completed reporting guidelines for the relevant research design.

Covering letter – to the editor in which you detail authorship contributions and other matters you wish the editors to consider.

Contribution of the Paper

All submissions (with the exception of Letters and Editorials) should include a "Contribution of the Paper": statements of what is known already about the topic and what the paper adds; and this should be uploaded as a separate file at submission.

This is a clear summary of the 'Contribution of the Paper'. This should take the form of a clear summary of 'What is already known about the topic?' and 'What this paper adds', identifying existing research knowledge relating to the specific research question / topic and a summary of the new knowledge added by this study. Under each of these headings, please provide clear OUTCOME statements in the form of two or three bullet points for each. Do NOT give process statements of what the paper does. eg. This review demonstrates that nurse-led intermediate care reduces hospital stay but increases total inpatient stay (outcome) NOT This review considers the impact of nurse-led intermediate care on acute stay and total inpatient stay (process).

GENERAL GUIDANCE

Essential title page information

Title. Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

Author names and affiliations. Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

Corresponding author. Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.

Present/permanent address. If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Title

The title should be in the format 'Topic / question: design/type of paper' and identify the population / care setting studied.(e.g. The effectiveness of telephone support for adolescents with insulin dependent diabetes: controlled before and after study).

Abstract

Abstracts should be less than 400 words, and should not include references or abbreviations. Abstracts of research papers must be structured and should adopt the headings suggested by the relevant reporting guidelines (see below). In general they should include the following: Background; Objectives; Design; Settings (do not specify actual centres, but give the number and types of centre and geographical location if important); Participants (details of how selected, inclusion and exclusion criteria, numbers entering and leaving the study, relevant clinical and demographic characteristics); Methods; Results, report main outcome(s)/findings including (where relevant) levels of statistical significance and confidence intervals; and Conclusions, which should relate to study aims and hypotheses. Abstracts for reviews should provide a summary under the following headings, where possible: Objectives, Design, Data sources, Review methods, Results,

Conclusions. Abstracts for Discussion Papers should provide a concise summary of the line of argument pursued and conclusions.

Keywords

Provide between four and ten key words in alphabetical order, which accurately identify the paper's subject, purpose, method and focus. Use the Medical Subject Headings (MeSH®) thesaurus or Cumulative Index to Nursing and Allied Health (CINAHL) headings where possible (see <http://www.nlm.nih.gov/mesh/meshhome.html>).

Abbreviations

Avoid the use of abbreviations unless they are likely to be widely recognised. In particular you should avoid abbreviating key concepts in your paper where readers might not already be familiar with the abbreviation. Any abbreviations which the authors intend to use should be written out in full and followed by the letters in brackets the first time they appear, thereafter only the letters without brackets should be used.

Statistics

Standard methods of presenting statistical material should be used. Where methods used are not widely recognised explanation and full reference to widely accessible sources must be given. Exact p values should be given to no more than three decimal places. Wherever possible give both point estimates and 95% confidence intervals for all population parameters estimated by the study (e.g. group differences, frequency of characteristics). Identify the statistical package used (please note that SPSS has not been "Statistical Package for the Social Sciences" for many years).

Tables and figures

There should be no more than five tables and figures in total and included in a separate file. All tables and figures should be clearly labelled. If your manuscript includes more than 5 tables in total, or for very large tables, these can be submitted as Supplementary Data and will be included as such in the online version of your article.

Appendices

Ordinarily there should be no appendices although in the case of papers reporting tool development or the use of novel questionnaires authors must include a copy of the tool as an appendix unless all items appear in a table in the text.

Informed consent

Where applicable authors should confirm that informed consent was obtained from human subjects and that ethical clearance was obtained from the appropriate authority.

Permissions

Permission to reproduce previously published material must be obtained in writing from the copyright holder (usually the publisher) and acknowledged in the manuscript.

Word limits

Our experience suggests that all things being equal, readers find shorter papers more useful than longer ones. Given this, and competition for space in the Journal, shorter papers of between 2,000 and 3,500 words are preferred. However, full papers may be up to 7,000 words in length, plus tables, figures, and references. Ordinarily there should be no appendices although in the case of papers reporting tool development or the use of novel questionnaires it is usual to include a copy of the tool as an appendix.

Appendix 1.2: Quality Rating Scale for included papers (based on Walsh & Downe, 2006)

Stage	Essential criteria	Study				
		Beitz (1999)	Allison et al (2013)	Deeny & McRea (1991)	Notter & Burnard (2006)	Kelly (1994)
Scope and purpose	Clear statement of focus for research purpose	✓	✓	✓	✓	✓
	Rationale for research: explicit purpose given	✓	✓	✓	✓	✓
	Questions/aims/purpose	✓	✓	✓	✓	-
	Study thoroughly contextualised by existing literature	✓	✓	✓	✓	✓
Design	Method/design apparent	✓	✓	✓	✓	✓
	Above consistent with research intent	✓	✓	✓	✓	✓
	Rationale given for use of qualitative design	✓	✓	✓	✓	-
	Data collection strategy apparent	✓	✓	✓	✓	✓
	Data collection strategy appropriate	✓	✓	✓	✓	✓
Sampling strategy	Sample and sampling method explained	✓	✓	✓	✓	✓
	Above justified	✓	✓	✓	✓	✓
	Above appropriate	✓	✓	-	✓	✓
Analysis	Analytic approach explained	✓	✓	-	✓	✓
	Above appropriate	✓	✓	✓	✓	-
	More than one researcher involved if appropriate	✓	-	-	-	-
	Participant involvement in analysis	✓	✓	-	-	-
	Evidence of data saturation/discussion or rationale if did not	✓	✓	-	-	-
Interpretation	Context described	✓	✓	✓	✓	✓
	Context taken account of in interpretation	✓	-	✓	✓	✓
	Clear audit trail (sufficient so others can follow decision trail)	✓	-	✓	-	-
	Data used to support interpretation	✓	✓	✓	✓	✓
Reflexivity	Researcher reflexivity demonstrated	✓	-	-	-	-
Ethical dimensions	Ethical approval granted	✓	✓	-	-	-
	Documentation of how consent was managed	✓	✓	-	-	-
	Documentation of how confidentiality and anonymity were managed	✓	-	-	-	✓
Relevance and transferability	Relevance and transferability evidence	✓	✓	✓	✓	✓
	Links to theories and literature	✓	✓	✓	✓	✓
	Limitations/weaknesses outlines	✓	✓	✓	-	-
	Outlines further directions for research	✓	✓	✓	-	-
	TOTAL	29	24	20	19	17

Appendix 2:1: Interview guide

Introduction

- My name is Alison McCusker, I work as a psychologist and I am interested in finding out about people with IBD and their experiences.
- Ensure all paperwork has been completed (consent/ assent forms) and go over confidentiality and right to withdraw again.
- Today we are going to talk about your experience when you had to make a decision whether to have stoma surgery or not.
- You might wonder why I am asking certain questions but I am trying to get as much information as possible about your experience during the decision making process regarding the stoma surgery. You are the expert here so I need you to tell me. There is no right or wrong answer.
- In order for me to remember everything you say I am going to record the interview so I don't miss anything is that ok?
- Sometimes I might ask you to tell me a bit more about something, is that ok?
- Any questions before we begin?

Demographic questions

- Age?
- IBD diagnosis?
- Outcome of decision for surgery?

<u>Agreed to surgery/ has had surgery</u>	<u>Declined surgery?</u>
Age at time of decision?	Age at time of decision
Planned or unplanned?	Type of surgery offered?
Type of surgery?	Temporary or permanent?
Temporary or permanent?	

Before surgery

Agreed to surgery	Declined surgery
<ul style="list-style-type: none">• When you first heard that you might have to have surgery how did you feel about that?• What main concerns did you have?• How did you come to the decision that you would go ahead with surgery?• How were you prepared for surgery?<ul style="list-style-type: none">○ Did you feel prepared?	<ul style="list-style-type: none">• When you first heard that you might have to have surgery how did you feel about that?• What main concerns did you have?• How did you come to the decision to refuse surgery?• Is there anything else you want to tell me about your experience or anything that you think would be helpful for staff to know?

After surgery

- What do you think has been the impact of this surgery on your everyday life?
- What would you say to somebody else facing surgery for their IBD?
- Is there anything else you think I should know?

Appendix 2.2: Decision-making process

It is highlighted in the IBD Standards (2013) section C ‘Maintaining a Patient-Centred Service’ under Standard C3 ‘Supporting Patients to Exercise Choice between Treatments’ that:

“Patients should be offered choice between their treatments, after receiving the necessary support and information”

The approach in meeting Standard C3 will vary between NHS services, however the ‘decision-making process’ set out by RHSC involves the following stages:

1. If a patient is identified as requiring surgery, this decision is made at a weekly Multi-Disciplinary Team (MDT) meeting
2. An IBD nurse co-ordinates a meeting involving the identified patient, Gastroenterology Consultant, IBD Nurse and Consultant Surgeon
3. This meeting takes place in the Ambulatory Day Care area which is conducive to lengthy and complex conversations without the likelihood of interruptions.
4. IBD nurse contacts the patient a few days later to facilitate their decision making (if necessary).

For the purposes of this research, an individual will only be considered for the study once they have gone through these 4 stages.

Appendix 2.3: Covering letter for participants (Ver 1 June 2014)



Dear Young Person and Parent/ Guardian

RE: Participation in research study

As you know, I am part of a team of people who are involved in you/ your child's ongoing care. As your healthcare professional I would like to inform you of some new research that is being carried out, as I thought that you may be interested in taking part.

The research is investigating what it is like to be a young person with IBD, who has had to think about whether or not to undergo stoma surgery. It is hoped that the results of the study will provide us with further insight into the experience of deciding on stoma surgery and what issues are important when making the decision.

Taking part would essentially involve you/ your child meeting with the researcher for approximately one hour at the Royal Hospital for Sick Children (Yorkhill), during which time the researcher will talk to your child about their experience of deciding on stoma surgery, what was good and bad about it and their opinion of any changes that could be made in this process.

If you think that you would like to take part then please read the enclosed information forms for further details. If you wish to take part, then you can contact Alison McCusker (Trainee Clinical Psychologist) directly on [mobile number] or complete the opt-in slip and I will inform Alison to contact you. I will not pass your details on to the researcher without your consent.

Kind regards,

Local Clinician

Appendix 2.4: Participant Information sheet (Ver 2 11/09/2014)



Participant Information sheet

Study title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD

We are inviting you to join a research study to get information about your experience in deciding whether or not to have stoma surgery.

Before you decide if you want to join in, it is important to understand why the research is being done and what you will have to do. Please take your time in reading the information and talk about it to your family or nurse specialist if you want to.

Why are we doing the research?

Research tells us that deciding whether to have surgery or not is a difficult time for a young person which can result in a delay in treatment and distress for the person. However, there is little research that tells us how staff can help a young person through this difficult time.

This research hopes to find this information out.

Why am I invited to take part?

You have been invited to take part because you have IBD and at one point have had to think about possibly having to have stoma surgery.

Do I have to take part?

No. It is up to you and your parent/ guardian to decide if you want to take part. If you decide you do want to take part you will get a copy of this information to keep and you will be asked to sign a form to show you have agreed to take part. Your parent/ guardian will also sign a form to agree to it. You can change your mind at any point and you do not have to give us a reason for this. It will not affect your treatment at all.

What will happen to me if I decide to take part?

Taking part will involve meeting with the researcher, Ms Alison McCusker, for about an hour.

If you agree, the interview will be recorded so the researcher does not forget what was talked about. Anything you say will be kept private and no one else will know about what

you have said, apart from the researcher and her supervisors, who are also involved in doing the research. Anything you say can be used in the research but no-one will be able to tell that it was you that said it because everything will be anonymised, which means that your name or personal details will all be removed.

The only thing that would mean the researcher having to speak to someone else is if you tell her something that makes her think that you or someone else is in danger. If this happened then she would have to tell the appropriate people, but she would tell you about that first, this would be done to make sure that you are safe.

If you want to stop for a break during the meeting then you can tell the researcher. Also, if you decide at any time that you don't want to carry on with the interview, then that is ok and we will stop. You can decide not to take part at any point and this is ok too.

Will anyone else know I am doing this?

No. We will keep your information private. We will only use information that has been anonymised, which means that no one can recognise you from your information as your name, address or date of birth have been removed.

What will happen to the information you collect in the interview?

The things you talk about will be recorded and typed into a secure computer. This information will be analysed by the researcher and her supervisors who are also involved in the research. The results of the study will be printed as part of a project, while we may print something you have said, no one will know that you said it because it will be anonymised and unidentifiable.

What are the possible risks and benefits of taking part?

During the interview, you will be asked questions about how you felt during your experience in deciding whether or not to have surgery. This may bring up difficult feelings which can be upsetting for some people. You will not be forced to discuss anything you do not want to and if you are finding the interview too distressing, you can have a break or the interview can be stopped.

The benefit of taking part is that by telling us about your experience, this will help staff provide better support and information to young people. This will hopefully make the decision making process to have surgery or not, an easier process for a young person to experience.

If you are interested in taking part?

If you and your parent/ guardian are happy for you to take part, please complete the tear off slip on the information sheet and return it in the envelope provide (no stamp required), or pass this on to a member of the RHSC Gastroenterology Team. Or please

contact Alison McCusker at a.mccusker.1@research.gla.ac.uk / [mobile number] or you can tell the person who gave you this information form.

If you would like further information about this study, please feel free to contact us. Or if you would like to talk to an independent person who is not in the research team, please contact Dr Hamish McLeod at the University of Glasgow, on 0141 211 3920.

Your help is much appreciated. Any information you can give us about your experience would be very helpful for us, so that we can make sure we are providing the best service we can to child and young people with IBD.

Thank you for taking the time to read this Information Sheet and for thinking about taking part in this study.

(Tear off slip)-----

Please return to: Ms Alison McCusker/ Dr Alison Jackson, University of Glasgow, Mental Health and Wellbeing, Gartnavel Royal Hospital, Administration Building, 1055 Great Western Road, Glasgow, G12 0XH

Study title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD

Chief Investigator: Ms Alison McCusker, Trainee Clinical Psychologist (University of Glasgow, NHS Lanarkshire)

Name of young person:

Name of Parent/ Guardian:

Signature

Telephone:

For office use: *Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD: A Thematic Analysis*

Participant number: _____

Appendix 2.5: Participant Consent/ Assent form (Ver 2 11/09/14)



University
of Glasgow



***CONSENT/ ASSENT FORM FOR CHILDREN** (*delete as appropriate)

Participant Number: _____

Study Title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD

Researcher: Alison McCusker (Trainee Clinical Psychologist)

(To be completed by the child)

Please initial box

1. I read information sheet dated 11/09/14 (Version 2) and an explanation has been provided.
2. I have asked the researcher any questions I had about the study
3. The researcher helped me to understand what will happen
4. I know that the interview will be recorded and the researcher will listen to it again. I know that our talk is private and no-one else, apart from those involved in the research, will get to listen to it.
5. I know that if something I say is put into the study, no-one will know it was me that said it.
6. I know that I don't have to take part in this study and that I can stop at any time.
7. I would like to take part in this study

If you do want to take part, you can sign your name below

_____	_____	_____
Your Name	Date	Signature
_____	_____	_____
Name of Person taking assent/ consent	Date	Signature

Thank you for your help

When complete: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Alison McCusker
University of Glasgow
Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Appendix 2.6: Information on support services

Support services available		
 The logo for Crohn's and Colitis UK (NACC) features a red stylized knot-like symbol. To the right, the text 'crohn's and colitis UK' is written in green and blue, with 'Inform Support Research' in smaller green text below it.	Crohn's and Colitis UK has a number of confidential helpline services for anyone affected by Inflammatory Bowel Disease (IBD).	0845 130 3344 www.crohnsandcolitis.org.uk
 The ChildLine logo consists of the word 'ChildLine' in a bold, black, sans-serif font inside a green speech bubble. Below it, the number '0800 1111' is written in green, followed by a small icon of a telephone handset.	ChildLine is a private and confidential service for children and young people up to the age of nineteen. You can contact a ChildLine counsellor about anything - no problem is too big or too small	0800 1111 www.childline.org.uk

Appendix 2.7: Ethics approval (REC)

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone : 01267 225045
E-mail : sue.byng@wales.nhs.uk
Website : www.hra.nhs.uk

Miss Alison McCusker
University of Glasgow
1st floor, Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

22 October 2014

Dear Miss McCusker

Study title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with Inflammatory Bowel Disease: A Thematic Analysis
REC reference: 14/WA/1196
Protocol number: L14069
IRAS project ID: 151548

The Research Ethics Committee reviewed the above application at the meeting held on 21 October 2014. Thank you for participating by telephone to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Sue Byng.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

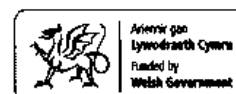
Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rctforum.nhs.uk>



Cynllun Cymdeithasol Gyhoeddus Iechyd a Chymedig y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board





**Gwasanaeth
Moeseg
Ymchwil**
Miss Alison McCusker
University of Glasgow
1st floor, Administration Building
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

RES

**Research
Ethics
Service**

WALES REC 7
PO Box 108
Building 1
Jobswell Road
St David's Park
Carmarthen SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone : 01267 225045
E-mail : sue.byng@wales.nhs.uk
Website : www.hra.nhs.uk

23 February 2015

Dear Miss McCusker

Study title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with Inflammatory Bowel Disease: A Thematic Analysis

REC reference: 14/WA/1196

Protocol number: L14069

Amendment number: Minor amendment 1 (extending recruitment to non-NHS site)

Amendment date: February 2015

IRAS project ID: 151548

Thank you for your email of 19 February 2015, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Email notification of minor amendment		19 February 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/WA/1196: Please quote this number on all correspondence

Ms Sue Byng
REC Manager

Copy to: **Mr Raymond Hamill, Research and Development, NHS Lanarkshire**



GIG
NHS
Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board



Ariennir gan
Llywodraeth Cymru
Funded by
Welsh Government

Appendix 2.8: R & D approval (NHS GG&C and NHS Lanarkshire)



Administrator: Lorn Mackenzie
Telephone Number: 0141 211 1743
E-Mail: Lorn.Mackenzie@ggc.scot.nhs.uk
Website: www.nhsggc.org.uk/r&d

R&D Management Office
Western Infirmary
Tennent Institute
1st Floor 38 Church Street
Glasgow, G11 6NT,

07/11/2014

Dr Janie Donnan
NHS GG&C
Royal Hospital for Sick Children
Dalnair Street
Glasgow, G3 8SJ

NHS GG&C Board Approval

Dear Dr Donnan,

Study Title:	Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD: A Thematic Analysis
Principal Investigator:	Dr Janie Donnan
GG&C HB site	Royal Hospital for Sick Children
Sponsor	NHS Lanarkshire
R&D reference:	GN14SU564
REC reference:	14/WA/1196
Protocol no: (including version and date)	V5.0; Date: 02.07.14

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
 - a. During the life span of the study GGHB requires the following information relating to this site
 - i. Notification of any potential serious breaches.
 - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
 - a. Recruitment Numbers on a quarterly basis
 - b. Any change of staff named on the original SSI form
 - c. Any amendments – Substantial or Non Substantial
 - d. Notification of Trial/study end including final recruitment figures
 - e. Final Report & Copies of Publications/Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Lorn Mackenzie
Senior Research Assistant

Cc: Alison McCusker, Trainee Clinical Psychologist, NHS Lanarkshire

R&D Ref GN14SU564 Minor Amendment 01 (31.03.14)

Mackenzie, Lorn [Lorn.Mackenzie@ggc.scot.nhs.uk]

Sent: 01 April 2015 13:26

To: Donnan, Janie [Janie.Donnan@ggc.scot.nhs.uk]

Cc: Alison Mccusker; lorraine.quinn@lanarkshire.scot.nhs.uk

Dear Dr Donnan,

R&D Ref: GN14SU564 **Ethics Ref:** 14/WA/1196

Investigator: Dr Donnan

Project Title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD:
A Thematic Analysis

Amendment: Minor Amendment 01 (31.03.14)

Sponsor: NHS Lanarkshire

I am pleased to inform you that R&D have reviewed the above study's Amendment and can confirm that Management Approval is still valid for this study.

I wish you every success with this research project.

Reviewed Documents:	Version	Dated
Sponsor Confirmation Email	---	31/03/15
Head of Department Confirmation Email	---	31/03/15

Kind Regards,

Lorn Mackenzie

Senior Research Administrator

R&D Proportionate Review Team

NHS Greater Glasgow and Clyde

Research and Development Central Office

Tennent Institute 1st Floor

Western Infirmary

38 Church Street

Glasgow, G11 6NT

Scotland, UK

Memorandum of Understanding

between

NHS LANARKSHIRE and UNIVERSITY OF GLASGOW



This Memorandum of Understanding sets out the division of Sponsor responsibilities between NHS Lanarkshire, (lead research Sponsor), and the University of Glasgow.

Project Title: Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD: A Thematic Analysis

NHS Lanarkshire R&D ID Number: L14069

Chief Investigator: Alison McCusker, Trainee Clinical Psychologist at the University of Glasgow

NHS LANARKSHIRE RESPONSIBILITIES AS LEAD SPONSOR	DELEGATED RESPONSIBILITIES TO UNIVERSITY OF GLASGOW
<p>As lead Sponsor, NHS Lanarkshire will:</p> <ol style="list-style-type: none"> 1. Provide Indemnity cover for potential legal liability for harm to participants arising from the conduct of the study by NHS members of the research team. 2. Discuss the research proposal with the Chief Investigator, agree in principle to Sponsor the research, and provide the Chief Investigator with a formal written summary of their responsibilities as Chief Investigator. 3. Provide a formal written agreement of Co-Sponsorship conditions, and notification of confirmation of the Sponsorship role – i.e. this MoU. 4. Be satisfied that the Chief Investigator has the necessary expertise and experience to conduct the research successfully. 5. Ensure that, where necessary, an appropriate NHS Research Ethics Committee has given favourable opinion for the study. 6. Ensure that adequate archiving arrangements are in place for essential study documents. 7. Ensure that its duties and as set out in the Research Governance Framework for Health and Social Care are undertaken in relation to this research. 8. Ensure that the Chief Investigator has arrangements in place to alert the Sponsor and other stakeholder organisations if significant developments occur as the study progresses, whether in relation to the safety of individuals or to scientific direction. 	<p>As Co-Sponsor, University of Glasgow will:</p> <ol style="list-style-type: none"> 1. Provide Indemnity cover for potential legal liability for harm to participants arising from the management or design of the study by University of Glasgow staff or students. 2. Ensure that an appropriate process of scientific critique has demonstrated that the research proposal is worthwhile of high scientific quality. 3. Ensure that their duties as detailed in this MoU are undertaken in relation to this research. 4. Ensure that responsibilities for management monitoring and reporting of the research are in place. 5. Ensure that the Chief Investigator has arrangements in place for the conclusion of the study including disseminating findings and, where applicable, exploiting any potential Intellectual Property. 6. Provide ongoing advice and guidance to promote quality study management and conduct. 7. Must ensure that the Chief Investigator has made arrangements to access all necessary resources and support to deliver the research as proposed.

Lead Sponsor representative, NHS Lanarkshire

Name: Raym [REDACTED] Title: Corporate R&D Manager

Signature: [REDACTED] Date: 21/10/2014

Co-Sponsor representative, University of Glasgow

Name: DEBRA STUART Title: RGM

Signature: [REDACTED] Date: 9/10/14

[L14096_EXT] - Exploring the Decision Making Process in Stoma Surgery for Adolescents

Quinn, Lorraine (MK) - R&D Facilitator Research and Development
[Lorraine.Quinn@lanarkshire.scot.nhs.uk]

Sent: 31 March 2015 15:02

To: Alison Mccusker

Dear Alison,

following on from our earlier conversation regarding the following study

R&D ID: L14096_EXT

Title: Exploring the Decision Making Process in Stoma Surgery for Adolescents

I can confirm there is no objection from NHS Lanarkshire R&D Department re. the location of patient interview.

If you require anything further, please don't hesitate to get in touch.

Kind regards

Lorraine

Lorraine Quinn

R&D Facilitator

R&D Department

Corporate Services Building

Monklands Hospital

Monkscourt Avenue

Airdrie

ML6 0JS

E-mail: lorraine.quinn@lanarkshire.scot.nhs.uk

Telephone: 01236 712445

Appendix 2.9: Health and Safety form (Ver 2 March 2015)

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

DOCTORATE IN CLINICAL PSYCHOLOGY

HEALTH AND SAFETY FOR RESEARCHERS

1. Title of Project	Investigating the Decision-Making Process in Stoma Surgery for Adolescents with IBD: A Thematic Analysis
2. Trainee	Alison McCusker
3. University Supervisor	Dr Alison Jackson
4. Other Supervisor(s)	Dr Janie Donnan
5. Local Lead Clinician	
6. Participants: (age, group or sub-group, pre- or post-treatment, etc)	Patients with IBD attending the Royal Hospital for Sick Children (Yorkhill) identified as having experienced the decision-making process for stoma surgery during their adolescent years (12-18 years)
7. Procedures to be applied (eg, questionnaire, interview, etc)	Semi structured qualitative interview
8. Setting (where will procedures be carried out?) i) General	Interview rooms within the Royal Hospital for Sick Children and a residential care unit for Young People.
ii) Are home visits involved	No

WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

DOCTORATE IN CLINICAL PSYCHOLOGY

HEALTH AND SAFETY FOR RESEARCHERS

9. Potential Risk Factors Identified	<p>It is acknowledged that the interview content may be personal and sensitive, and could potentially cause distress for the participant.</p> <p>The researcher may also encounter some vicarious distress as participants discuss their experiences of having IBD and deciding on surgery.</p> <p>It is not anticipated that there will be any risk factors within the setting. At Yorkhill, participants will be patients known to the medical team. Within the residential care unit, the patient will be well known to staff. However, safety protocol will be put in place for the duration of the study, described below.</p>
10. Actions to minimise risk (refer to 9)	<p>Measures will be in place should a participant become distressed during the interview (such as taking a break, stopping the interview) and all participants will be provided with a leaflet with details of support sources and contact details (appendix). If psychological difficulties are reported, or are otherwise apparent, this will be discussed with the Psychologist embedded within the Gastroenterology team at the RHSC to ensure participant receives appropriate psychological assessment and intervention and / or is signposted to other relevant support agencies.</p> <p>The researcher will use supervision with both university and clinical supervisor to reflect on challenging interviews and to receive guidance and advice on how to manage this in future interviews.</p> <p>Interviews will be conducted within the hospital setting and a residential unit. The researcher will adhere to general NHS safety protocol and the safety protocol within the residential unit. The researcher will also ensure that the Field supervisor is aware of the dates and times of interviews that are taking place within the hospital and will contact them at the end of each interview for the purposes of researcher safety.</p>

Trainee signature: Date:

University supervisor signature: Date:

Appendix 2.10: Participant demographics

Table. 1. Demographic information for adolescents who have received stoma surgery

Gender	Diagnosis	Age Mean (Range)			Time between diagnosis and surgery (mean, range)	Time between surgery and interview (mean, range)	Time between diagnosis and interview (mean, range)	Surgery	Type of stoma	Permanent/ temporary
		Diagnosis	Surgery	Interview						
3 female 4 male	2 Ulcerative Colitis 5 Crohns	10.5 years old (9-13)	14.5 years old (13-16)	15.4 years old (13- 18)	4 years (1 month – 6 years)	10 months (11 weeks -24 months)	5.14 years (2 years – 8 years)	6 planned 1 unplanned	7 ileostomy	6 permanent 1 temporary

Appendix 2.11: Example of Interview Transcript

Int = Interviewer

Craig = Participant

	Interview	Notes/ codes
.....		
Craig	Well I think maybe a week before, I needed to get ready you know, you know a week to go, you know it's going to just completely change everything that one day will just change everything. It will make me feel better so I had to really prepare for all that and mmm you know like, it was quite difficult. I was really really nervous going there.	4. perspective- change 9. worry- re: surgery 3. taking control- prepare 6. coping- prepare self
Int	Were you nervous actually getting the surgery?	
Craig	Yeah going from the, you know it was early in the morning, maybe 9 o'clock so it was early there and then going like from the bed to the surgery place you know I was nervous, shaking but I just kept thinking positive and hopefully everything would go well.	9. worry- surgery 6. coping 5. hope
Int	So when you are saying you were thinking positive, what was coming to your mind that was helping you?	
Craig	Well as soon as I went, they put me to sleep with the milky stuff, I dunno what it's called. You know so as soon as you fall asleep your gonna wake up so happy I mean, you'll wake up good you might have a bag for a good 6 months during that 6 months you'll get so much better you'll feel well in the morning you're gonna get up and go places and not feel awful.	4. perspective- change 6. coping 10. Impact of surgery
Int	Those thoughts, where had you got that information from. Was that people telling you or was that you just telling yourself?	
Craig	Well a bit of both, obviously the people I have met have been really helpful and put good thoughts in my mind and you know I had to keep myself going as well I couldn't if I thought negative thoughts and it would all just collapse and break down completely.	7. Roles 6. coping 9. worry- surgery
Int	And how did you come to the decision to go ahead with surgery? What made you decide?	
Craig	I didn't want to feel not well. I didn't want to be on all these drugs, all these medicines. Going to the hospital all the time coz I'm not well. Obviously my poo had blood and it was all runny and going to the toilet 4, 5 times a day, that was annoying and mmm wanting to be good be happy not always feeling down every day it was really	1. Burden of treatment 4. perspective- change

	really poor, really bad. It's a horrible feeling.	
Int	So how was the decision made? Was it something that the hospital offered to you and said 'go away and make a decision' or did you make a decision there and then?	
Craig	Well there was a choice where you could go on a medicine for maybe a couple of months and see how that goes if it works then good stay on that. If it doesn't work then surgery would be next. So obviously I wanted to try the drug first it was going well until it got to the long periods where mmm take one, 8 weeks later take another one. In about 4 weeks in I would feel good but the next 4 weeks I would feel bad and then they had to up the dose, do like a double dose and that still didn't work and then I think we just thought 'well surgery is next, I think we're just gonna have to go with that because that's the only thing left'	3. Control 1. Burden of treatment 4. perspective- change
Int	Did you feel that was a decision you made or did you feel actually surgery was going to happen eventually?	
Craig	I think surgery was going to happen eventually. It was sort of like a family decision. I was obviously, it was really up to me and you know when that medicine wasn't working I thought 'I've had enough of this, I want to be back to normal' so I think I wanted to go for the surgery, obviously my family were a bit upset as well but that's just what happens, I just had to go for it, make things better.	3. Control 7. Roles 4. Perspective-change
Int	Did you still feel in control of the decision? So you said right I'll go for the surgery. So when you were on the medicine, at what point was the decision made right this isn't working it's time for surgery?	
Craig	It was more during the long periods, I mean during the short periods of having the medication like 4 weeks that was fine. 6 weeks, that was fine. But when it hit the 8 weeks it couldn't last, it wasn't working, it couldn't last the 8 weeks and it just mmm it didn't work. I thought this isn't good, I don't like this I'm not having this anymore, I want to get things back to normal. Surgery was next so I thought it's the last thing I'm gonna have to go for it. It's probably the best thing as well.	3. Control 1. Burden of treatment 4. Perspective-change
Int	Ok so did you feel that it was the best thing to do?	
Craig	Yeah and obviously my mum and dad, they were a bit fed up of me not being well and missing a lot of school and they were for surgery as well.	7. Roles

Int	So tell me a wee bit more about the family decision?	
Craig	Well obviously, we spoke about it, even my sister was involved as well. We all just didn't want me to feel bad. They wanted me to feel good, happy, normal so they mmm we all really decided that surgery was the best thing. It's probably only really thing that's gonna work for me and if it goes good then look at all the things you can do. If it goes bad, it just goes bad but I was really...mmm the surgeon he was really positive about everything and that made me feel really good and you know if the surgeons positive then he is going to do well.	3. Control 4. perspective- change 7. Roles 9. worry- surgery 10. Impact of surgery
Int	So was it helpful talking to the surgeon about it?	
Craig	Yeah	
Int	And how were you prepared for surgery? Did you feel prepared for it?	
Craig	Well before I met the boy George, I was really upset I didn't want to go for it. The feeling of, you know, the feeling of having surgery was horrible, I wasn't sleeping good. During the day, I was like, I kept thinking and all that and everything started going downhill. But then my mum organised for me to meet this boy and I actually didn't want to see him at first, I mean obviously, going for surgery is a really hard thing to do and I just thought that's why I'm not feeling good about it. It's not something that people do every day so mmm he really did help. He really brought me back up and really positive about surgery so the build up got much easier.	8. Understanding 4. perspective- change 9. worry- surgery

Appendix 2.12: Major Research Project Proposal

Exploring the Decision-Making Process in Stoma Surgery for Adolescents with IBD: A Thematic Analysis

Date of Submission: 02/07/14

Version: 5

Word Count: 3, 294

Abstract

The aim of this study is to explore the pre-operative experience and decision-making process involved in stoma surgery for adolescents with Inflammatory Bowel Disease (IBD).

Background:

IBD is a life-long condition which involves inflammation of the gastrointestinal tract (British Society of Gastroenterology, 2009). Unfortunately, a large proportion of people who do not respond to medication have to consider surgery. This involves the removal of an inflamed section of the digestive system which may include the creation of a stoma. The possibility of stoma surgery can be distressing and problematic, particularly within the adolescent population.

Method:

Eight to twelve adolescents with IBD will be interviewed to discuss their experience of stoma surgery. Participants will be purposively recruited from the IBD team at the Royal Hospital for Sick Children (RHSC) in Glasgow on a first come basis. Each participant will be asked to complete an in-depth interview, lasting approximately 1 hour.

Analysis:

Qualitative data will be subject to Thematic Analysis.

Practical Applications:

There is limited research in the decision-making process for young people requiring stoma surgery. This exploratory study will allow themes to be identified that could help IBD staff assist young people through the decision-making process.

1. Introduction

Inflammatory Bowel Disease (IBD) involves inflammation of the gastrointestinal tract and affects about 240, 000 people in the UK (British Society of Gastroenterology, 2009). There are two main types of IBD; Ulcerative Colitis (UC) and Crohn's disease. The illness can occur at any age, but is often diagnosed in younger people (Allison, Lindsay, Gould & Kelly, 2013). IBD at this age is more extensive and severe than in adults (Sawczenko & Sandhu, 2003).

As there is no cure for IBD, treatment aims to relieve symptoms. Medications prescribed may include aminosalicylates, corticosteroids and immunosuppressants (British Society of Gastroenterology, 2009). Unfortunately, a large proportion of people do not respond to the medication and surgery has to be considered to remove an inflamed section of the digestive system. It is estimated that around 50% of people with Crohns disease require stoma surgery² within 10 years of diagnosis and in UC the estimated lifetime rates for stoma surgery are between 20-30% (IBD standards, 2013).

Living with IBD can have a significant impact on a person's psychological well-being and the prospect of surgery only adds to this (McCombie, Mulder & Gearry, 2012). Studies are continuing to identify that individuals who have undergone stoma surgery are likely to experience problems relating to body image issues (McCombie et al 2012), anxiety and depression (Evertsz et al, 2011). Most commonly, initial presentations occur in adolescence and young adults (IBD standards, 2013) which is a significant developmental stage in regards to self-identity, self-esteem and body image (Taylor, Gibson & Franck, 2008). Therefore, the possibility of surgery can be particularly problematic and distressing for this age group.

1.1 Literature review

The literature regarding stoma formation focuses mainly on the impact of living with a stoma (Brown & Randle, 2005) with two systematic reviews having been completed to date. Brown & Randle's (2005) systematic review (N=14 studies) identified that living with a stoma can affect a person's quality of life and psychological well-being. In addition, Danielson, Soetensen, Burcharth & Rosenberg(2012) completed a systematic review (N=7)

² A stoma is an 'artificial opening of the abdomen' (Royal College of Nursing, 2009) which can be used to divert the flow of faeces or urine into an external pouch located outside of the body.

to assess whether patient education improves quality of life and found that structured patient education aimed at patients' psychosocial needs did appear to positively affect quality of life. Both reviews highlight important information regarding an individual's experience of living with a stoma however these reviews were not exclusive to the IBD population and some studies included colorectal cancer patients (Kimura, Kamada, Guilhem & Fortes, 2013; Sharpe, Patel & Clarke, 2011; Tseng, Wang, Hsu & Weng, 2004) and individuals with Spina bifida (Bray, Callery & Kirk, 2012).

Within the limited literature available the majority of studies look at the impact of living with a stoma compared with studies exploring the process of deciding on stoma formation. Brown & Randle (2005) highlighted the need for further examination into the process involved in stoma formation.

1.2 Further research required

Surgery is a major concern for individuals, especially for young people with IBD, some of whom will try to avoid or delay having an operation (Allison et al, 2013). Currently, only 2 studies have been identified that explore the preoperative preparation and decision making process in stoma surgery (Allison et al, 2013; Bray et al, 2012).

Allison et al (2013) explored the experiences of 24 young adults with IBD who had had, or were about to have surgery. A qualitative narrative approach found that participants preferred to be involved in decision-making and responded negatively when medical professionals did not include them (Allison et al 2013). Bray et al (2012) interviewed 49 young people and their parents at key points throughout the surgical process. This study did not specifically look at IBD, with the young people involved having a number of conditions including bladder exstrophy, spina bifida and anorectal anomalies. Using Grounded Theory, findings suggested that the majority of the participants felt that the preoperative process could have been improved with more information that was specific for the individual.

From the two studies available, it has been highlighted that the preoperative stage and decision making process regarding stoma surgery is an important aspect of an individuals' journey which requires more research. In addition, the evidence suggests that adolescents will find the prospect of surgery particularly problematic and distressing due to their developmental stage (Sawczenko & Sandhu, 2003). However there is yet to be a study to

explore the preoperative process and factors that could impact on decision-making using adolescents with IBD.

1.3 Current study

This study hopes to expand on the findings from Bray et al (2012) and Allison et al (2013) by interviewing adolescents only who have IBD specifically. This study aims to explore the pre-operative experiences and decision-making process involved in stoma surgery for adolescents with IBD.

1.4 Objectives

- To explore the decision-making process experienced by the participants
- To explore the significant factors and experiences that impacted on the final decision regarding surgery.

2. Plan of investigation

2.1 Participants

Purposive sampling will be employed. Participants will be recruited via IBD and Stoma Nurse Specialists within the IBD team at the Royal Hospital for Sick Children (RHSC) in Glasgow. Participants will have been required to decide on stoma surgery during their adolescent years (12-18 years old). This will include individuals who have agreed to and are awaiting surgery, have or have had a stoma or have declined surgery at the time of interviewing.

2.2 Inclusion/ Exclusion criteria

Inclusion criteria	Exclusion criteria
Diagnosis of IBD	Need a translator to communicate to an English speaker (funds are not available to employ a translator)
Have sufficient command of the English language to communicate their views effectively	Experiencing mental ill-health to the extent that the interview may be unhelpful for them (e.g. severe depression)
Open to IBD and Stoma Nurse Specialists at RHSC Glasgow.	Identified by staff as inappropriate to be approached
Participated in the decision-making process (Appendix 2.2) for stoma surgery during adolescence (12-18 years old).	Experienced stoma surgery pre-adolescence

Homogeneity is important when conducting a qualitative study. Variables including gender, IBD diagnosis and type of surgery were acknowledged as possible factors that may influence individual experience, however as the literature is limited it is unclear if these factors would have an impact. The age range and time of surgery has remained specific to adolescence to protect the homogeneity of the group

3. Recruitment procedure

3.1 Recruitment

Three recruitment strategies are being proposed and have been initially agreed to by the Stoma Nurse Specialist at the RHSC.

1. The Stoma Nurse Specialist will review her caseload to identify patients who meet the inclusion criteria. A 'potential participants' list will be created and reviewed by the IBD Nurse Specialists. The IBD Nurse Specialists will review their caseload to identify further potential participants.
2. Information packs will then be posted to potential participants and their guardian. Packs will include a covering letter, information sheets, opt-in/out slip and a freepost envelope addressed to the researcher at Mental Health and Wellbeing

(MHW), University of Glasgow, Gartnavel Royal Hospital (GRH). Participants will be required to complete an opt-in/out slip and return to researcher, contact the researcher by telephone or provide verbal consent to their Nurse Specialist for the researcher to contact them.

3. Information packs may be provided to the Nurse Specialists, to be handed out during clinic appointments if deemed appropriate. This strategy will only be utilised if there is a low response rate from strategy one.

Once permission has been received, either verbally or by opt-in slip, the participant will be contacted via telephone by the researcher. An appointment will subsequently be arranged with interested participants and a guardian, either at the time of their next appointment with the Nurse Specialist, or a time that is most convenient. Participants will be recruited on a first come basis; this will continue until the required number of participants has been met, or thematic saturation has been achieved (Lyons & Coyle, 2007).

3.2 Interview

An individual semi-structured interview will be conducted and will be recorded verbatim using a digital voice recorder. All interviews will take place within RHSC Glasgow and will last approximately 1 hour.

Participants will already have provided verbal consent to participate on attendance to the interview. On the day of the interview, both the participant and their guardian will complete a consent form. The participant and guardian will both be present at the beginning of the interview to discuss consent and confidentiality. The guardian will then be asked to depart for the duration of the interview. However, if the participant wishes for their guardian to be present then this will not be disputed.

3.3 Design

The study will use a qualitative design that involves conducting in-depth interviews with adolescents. The interview questions (Appendix 2.1) have been constructed based on the objectives and on questions used in previous studies (Allison et al, 2013; Bray et al, 2012) in an attempt to gain continuity in the evidence base. Consent has been obtained from the authors to refer to these interview questions.

The interview questions will be piloted with a subset of the sample (n=3) in order to practice interview technique and assess the appropriateness of the topic areas. Feedback may result in some changes to the interview transcript however these interviews will still be used as part of the qualitative analysis.

Certain time restrictions will be applied in this study. Firstly, if any participants undergo surgery there will be a gap of 6 weeks, minimum, before an interview takes place. This time frame is similar to Bray et al's (2012) study although the exact time will be discussed with the Nurse Specialist involved, the participant and their guardian as the recovery from surgery and the well-being of the individual is paramount. Secondly, as purposive sampling is being used and participants are being recruited from RHSC Glasgow the maximum age will be 18 years at interview as this is the age when the young person moves to adult services. Thirdly, as the focus is on stoma surgery during adolescence (12-18years old) the time period from surgery to interview could be up to 7 years. The time between surgery and interview is variable in the existing literature but previous research interviewing adolescents and young people using qualitative methods since surgery ranges from 6 weeks (Bray et al, 2012) to 8 years (Savard & Woodgate, 2009; Brydolf & Segeston, 1996). In addition, the maximum time between surgery and interview has been deemed appropriate as evidence exists which suggests retrospective reporting and autobiographical memory are not necessarily and inevitably inaccurate and unstable, especially when discussing more salient events for an individual (Blane, 1996; Norris & Kaniatsy, 1992).

3.4 Data analysis

Thematic analysis (TA) will be used to analyse the interview transcripts. TA has been identified as a suitable qualitative approach for a number of reasons. Firstly, TA is a suitable approach when researching areas that have limited evidence (Joffe, 2011) or with participants whose views on the topic are not known (Braun & Clarke, 2006). Secondly, it is highly flexible in that it can be used across a range of research questions and thirdly, it helps to summarise key features of a large body of data (Braun & Clarke, 2006).

Braun and Clarke (2006) conceptualise TA as a method of identifying, analyzing and reporting patterns (themes) within a data set. The transcripts will be analysed using Braun and Clarke's Stages of Thematic Analysis (2006). An inductive, semantic and realist approach to TA will be carried out. Firstly, an inductive approach means that the themes

identified are strongly linked to the data themselves (Frith & Gleeson, 2004). Secondly, with a semantic approach, the themes are identified within the explicit or surface meanings of the data and the analyst is not looking for anything beyond what a participant has said (Braun & Clarke, 2006). Finally, utilizing a realist approach will allow the researcher to theorise motivations, experience and meaning in a straightforward way, since a simple, unidirectional relationship is assumed between meaning, experience and language (i.e. language reflects and enables us to articulate meaning and experience) (Braun & Clarke, 2006).

3.5. Justification of sample size

The estimated number of young people to receive stoma surgery at the RHSC Glasgow is between, 5-8 per year. Given this estimation, the approximate number of individuals to meet the inclusion criteria is around 40.

It is common within qualitative methods on the use of small sample sizes (Lyons & Coyle, 2007) with a recommendation of 10 and 20 for a UK Professional Doctorate project when using TA (Smith, Flowers & Larkin, 2009).

When considering previous sample sizes in the literature, the recommended number for TA, the approximate individuals available and the limited time frame the researcher has, a sample of 8 to 12 participants was deemed appropriate to provide an informative analysis. Once theoretical saturation is apparent (i.e. gathering further examples of meaningful themes as one proceeds through the transcripts until no new instances of a particular category emerge), this will serve as an indication for data collection to cease (Lyons & Coyle, 2007).

3.6. Settings and Equipment

Individual interviews will be conducted by the researcher within an available private room in RHSC. Interviews will be audio recorded using a digital voice recorder and will be transcribed verbatim by the researcher. All identifiable information will be removed to preserve anonymity and the recordings will be stored on an encrypted laptop and destroyed on completion of transcription.

4. Health and safety issues

4.1 Researcher safety issues

The interviews will be conducted within normal working hours and will comply with NHS GG&C standard safety procedures. Domiciliary visits will not be conducted.

4.2 Participant safety issues

It is acknowledged that the interview content may be personal and sensitive, and could potentially cause distress. Measures will be in place should a participant become distressed.

5. Ethical issues

Ethical approval will be obtained from West of Scotland NHS Trust Ethics Committee as well as the local Research and Development department.

Data will be handled in accordance with The Data Protection Act (1998), the Freedom of Information Act (2000) and the NHS Confidentiality Code of Practice Guidelines (2003). All identifiable information will be removed to preserve anonymity. In the absence of law dealing specifically with research, the principles of Scottish law relating to consent procedure (Age of legal capacity (Scotland) Act 1991) and treatment will reasonably be applied to this study with both the participant and guardian completing consent forms.

6. Financial issues

Equipment costs will amount to one digital voice recorder (to be borrowed from The University of Glasgow) and photocopying costs.

7. Timetable

April 2014: Submit proposal to University

May - Oct 2014: Apply for ethical approval

October 2014: Begin recruitment

Jan - March 2015: Analysis

April-June 2015: Write up research

July 2015: Submit research to University

September 2015: Viva

8. Practical applications

There is limited research in the decision-making process for young people requiring stoma surgery. This study may identify themes that could help staff support young people through the decision-making process to avoid delay in the most appropriate treatment and enhance their quality of life.

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