

CARING FOR YOUNG PEOPLE

A qualitative study of the pre-operative preparation of children, young people and their parents' for planned continence surgery: experiences and expectations

Lucy Bray, Peter Callery and Sue Kirk

Aim. The aim of this study is to explore children's, young people's and parents' pre-operative experiences of continent stoma formation.

Background. Current research investigating continent stoma surgery focuses on surgical outcomes including complication rates, adherence to management regimes, self-management practices and levels of continence achieved. Despite reports of pre-operative anxiety in families undergoing continent stoma surgery, there has been a lack of research exploring pre-operative experiences, information needs or decision-making processes in this group.

Design. A qualitative study.

Methods. Forty-nine semi-structured interviews were conducted with 17 children, young people and their parents. Data were collected at key points in the surgical process that aimed to represent a longitudinal perspective of continent stoma formation.

Results. The interviews suggested that children's, young people's and parents' information needs in relation to the long-term implications of surgery and for their day-to-day lives were not being adequately met. The preparation process was described as being positively influenced by contact with a nurse specialist, being given time to make the decision and having access to different sources of information.

Conclusion. Decisions regarding life-long planned surgery can be challenging. The individual involvement and information needs of children, young people and their parents need to be recognised during pre-operative preparation.

Relevance to clinical practice. Health professionals need to discuss the holistic implications of continent stoma surgery and provide families with the time and opportunity to consider surgery and access relevant sources of information pre-operatively.

Key words: children, continent stoma, decision-making, information, surgery, young people

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Introduction

Children and young people born with congenital conditions such as spina bifida, imperforate anus or bladder exstrophy

can often experience ongoing urinary and/or faecal incontinence throughout their childhood, which can affect their physical and psychosocial health (Ludman & Spitz 1996, Cavet 2000, Lundblad *et al.* 2007). Initial approaches to

Authors: *Lucy Bray*, RN, BA, MSc, PhD, Senior Clinical Research Fellow, Children's Nursing Research Unit, Alder Hey Children's NHS Foundation Trust and Evidence-based Practice Research Centre, Edge Hill University, Liverpool and Ormskirk; *Peter Callery*, RSCN, BA, MSc, PhD, Professor and Chair in Children's Nursing, School of Nursing, Midwifery and Social Work, The University of Manchester; *Sue Kirk*, BNurs, MSc, PhD, Senior

Lecturer, School of Nursing, Midwifery and Social Work, The University of Manchester, Manchester, UK

Correspondence: Lucy Bray, Senior Clinical Research Fellow, Children's Nursing Research Unit, Alder Hey Children's NHS Foundation Trust and Evidence-based Practice Research Centre, Edge Hill University, St Helens Road, Ormskirk, West Lancashire L39 4QP, UK. Telephone: +1695 580719. E-mail: brayl@edgehill.ac.uk

improving continence for these children and young people involve management with medication, urethral catheterisation, rectal washouts and incontinent stomas (colostomies or urostomies). However, surgical intervention may be considered whether acceptable control or management is not achieved.

Formation of a continent stoma is a surgical option where an abdominal channel is created through which a catheter can be passed to empty either the bladder or bowel. This is a relatively recent innovation, with the Mitrofanoff procedure for urinary conditions being first reported in 1980 (Mitrofanoff 1980) and the antegrade continence enema (ACE) for bowel conditions in 1990 (Malone *et al.* 1990). The aim of surgery is to improve the levels of continence achieved, reduce the visibility of continence devices (the stoma requires no bags or appliances to be worn) and also increase children's independence by reducing the need for parental involvement in management. The decision for surgery has life-long implications and although the stoma can be reversed, management is commonly ongoing throughout adult life.

Background

The majority of literature relating to continent stoma surgery is in the form of clinical papers, case series or short reports that examine the safety and efficacy of an increasingly refined surgical procedure. The focus is on levels of continence achieved, complications encountered, adherence to the regime and levels of independent self-management achieved; much of the data is drawn from continual audit processes in single surgical centres (Bray 2007b). Issues following surgery have been identified, which include surgical complications (Curry *et al.* 1998, Marshall *et al.* 2001, Barqawi *et al.* 2004), limited improvements in quality of life (Bau *et al.* 2001) and low levels of self-management (Perez *et al.* 1999, Yerkes *et al.* 2003). These issues can be encountered in the initial post-operative period or many years following surgery. There is very little reference in the literature to how children, young people and their parents are prepared for continent stoma surgery and their understanding of the long-term implications of the operation. Moreover, children and young people's involvement in the preparation for surgery has been overlooked. Despite reports of high levels of anxiety in families opting for stoma formation (Searles *et al.* 1995), it is not known what aspects of the pre-operative period cause anxiety or what support or information could reduce this anxiety and improve the experiences of children, young people or parents during this time.

The process of making a decision to have surgery can be difficult and complex for children, young people and parents

(Deatrick 1994, Alderson & Montgomery 2001, Coyne 2006) and requires effective communication and information giving between health professionals and families (Deatrick 1994, Dickey & Deatrick 2000). Children and young people have described being poorly informed and prepared for procedures and excluded from decisions that can lead them to be anxious, upset, angry and frightened. (Noyes 2000, Runeson *et al.* 2002, Beresford & Sloper 2003, Young *et al.* 2003, Kilkelly & Donnelly 2006) When surgery is elective, there can be opportunities for the decision-making process to be planned to involve all those concerned in a meaningful way. However, research with children and young people undergoing planned orthopaedic, plastic and ENT surgery has suggested that children and young people may face difficulties in eliciting information and opinions from both the healthcare team and their parents (Alderson 1993, Deatrick 1994) and report limited knowledge of both procedural aspects of surgery and the sensory aspects (experiences and feelings) they may encounter (Buckley & Savage 2010). In some cases, this lack of accurate information has been shown to cause dissatisfaction in the outcome of surgery (Bricher & Darbyshire 2004). Parents have also expressed difficulties in negotiating information in the pre-operative period and making a decision for surgery on their child's behalf (Craig *et al.* 2003, Okubo *et al.* 2008). However, most research exploring decisions for planned surgery does not involve procedures that require ongoing daily management through a child's life into adulthood, and it is unknown what influence this may have on the decision-making process.

It is important that health professionals who care for children are able to listen to them, respect their need for information and to be prepared to give information in the right amount and in a way that is suitable for the child's age, so they can participate in decisions about their health (UNCRC 1989, Department of Health 2004). This respect applies to children and young people who seek comprehensive information as well as those who choose to receive minimal information (Callery 2011). Interviews with hospitalised young people (aged 13–16 years) demonstrated that the provision of accurate and appropriate information by health professionals influenced how the young people described their involvement, levels of autonomy and sense of empowerment in the decision-making processes during their stay (Kelsey *et al.* 2007). Little is known about how children, young people and their parents are prepared for continent stoma surgery and their expectations of the changes to management and lifestyle following the operation. This study aimed to explore the perspectives of children, young people and their parents to understand how the decision to

have continent stoma surgery is experienced and what could improve the process for the families involved.

Methods

Design

The aim of the study was to explore the interactions and experiences of children, young people and their parents undergoing continent stoma surgery and was informed by the principles of Grounded Theory (Glaser & Strauss 1967, Charmaz 2003). Data were collected at key points in the surgical process, allowing for exploration of pre-operative expectations and how these matched adaptation to a new regime and living day-to-day with a continent stoma; this aimed to represent a longitudinal perspective of continent stoma formation.

Sampling and recruitment

Children, young people and their parents were recruited through the paediatric surgical teams at two children's hospitals in the North of England. All those children and young people who planned to undergo surgery were approached to take part in the study. The initial sample of children and young people who had already undergone surgery was chosen purposively to explore a wide range of experiences and circumstances. Sampling then later developed by returning to some children, young people and their parents for further interviews and seeking further children, young people and parents whose experiences could inform the emerging analysis (Fig. 1). This process was informed by

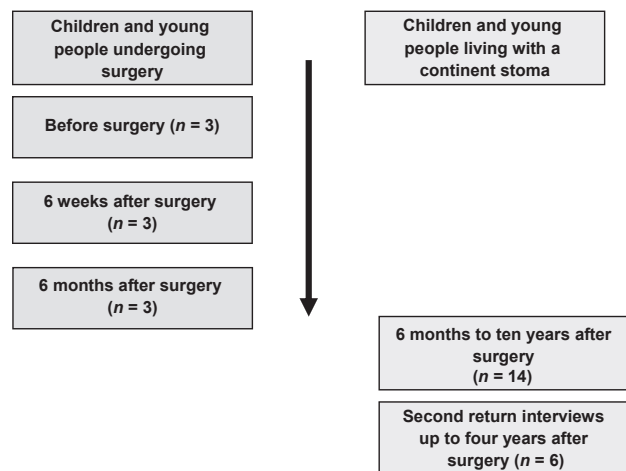


Figure 1 Interviews conducted.

the principles of theoretical sampling (Glaser & Strauss 1967).

Data collection

Data were collected by face-to-face semi-structured interviews with children, young people and their parents. Parents in all but one interview were mothers who fulfilled the main caring role for their child and in one instance the father. The majority of the interviews were conducted in the home environment, with two interviews being carried out in a non-clinical area in the hospital at the request of the parents and children involved. Most of the interviews ($n = 40$) were held separately with children, young people and their parents, but on some occasions ($n = 9$), a joint interview was conducted at the young person's request. There was no indication that joint interviews constrained the ability of the children or young people to discuss issues of importance to them or comment honestly on their experiences.

The interviews with the children and young people were made less formal and more interactive by using creative and flexible methods to support conversation. These included drawings and written activities, which attempted to engage children and young people in a more active manner, to reduce the level of eye contact necessary during discussion and to create a relaxed environment. The augmentation of interviews with drawings and activities has been shown to enhance the interviewing process (Backett & Alexander 1991, Pridmore & Bendelow 1995, Hill 1997, Punch 2002). The pictures and diagrams themselves were not analysed as data, but the conversation held during the activity formed part of the analysis, where children and young people were asked to interpret their own work themselves. All the interviews were audio-recorded with field notes being taken following the interaction to capture the context of the interview.

In total, 49 interviews were conducted with 17 children, young people and parents. Three children and young people who underwent continent stoma surgery and their parents were interviewed on three occasions. Fourteen children and young people who were already living with a continent stoma and their parents were interviewed, and six of these families were involved in a second interview after an extended period of time (Fig. 1). The children and young people involved were 9–19 years of age at the time of first interview; the majority of those involved ($n = 13$) were 9–13 years of age as this is the dominant age at which the surgery is conducted, four young people were over 13 years of age. Nine boys and eight girls took part in the study. The underlying conditions that led to bladder and bowel difficulty included bladder exstrophy, spina bifida, anorectal anomalies and bowel dysmotility.

Ethical considerations

The study was approved by a national research ethics committee (MREC) and the NHS trusts involved. Written informed consent was obtained from all parents involved in the study prior to interviews, and assent was obtained from all the children and young people who participated. A specially designed activity was used to support the process of gaining assent from the children and young people (Bray 2007a,b), which focused on the issues of confidentiality, anonymity and voluntary involvement. Consent and assent were reaffirmed prior to each interaction when participation in the study was longitudinal.

Data analysis

Data collection and analysis were conducted according to the principles of constant comparison (Glaser & Strauss 1967). Data were concurrently collected and analysed, and developing themes informed further theoretical sampling and data collection. All data were imported into NVIVO, a software package for qualitative analysis. The coding of the data followed the steps outlined by Glaser (1978) and Charmaz (2006) and involved initial coding that labelled small segments of data and aimed to maintain the voices of the participants through coding according to actions and processes. This led to focused coding, which involved the process becoming more directed, selective and conceptual (Glaser 1978) and resulted in the development of categories. These tentative categories were generated and then constantly compared (Glaser 1978). Memoing was used to record emerging ideas and meaning from the data (Glaser & Strauss 1967) and was seen to support theoretical sensitivity throughout the process (Glaser 1998). Diagramming was used in the later stages of analysis to help explore the interrelationships between categories and develop a core category. The core category of the study was the developing biography of children and young people, and this was influenced by how the children shared the information about their condition and how they interacted with others ('self-presentation') and their process of growing up into adolescence and adulthood and gaining independence (Fig. 2). The three categories that linked to the core category are highlighted in the following figure (Fig. 2). This study examines the pre-operative experiences of information giving and decision-making that was one of the categories ('information and decisions about the operation').

Findings

The category 'information and decisions about the surgery' related to how the children, young people and their parents

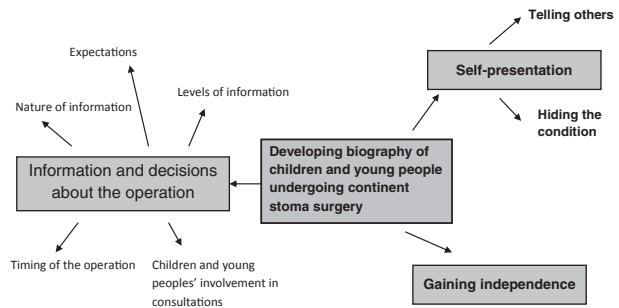


Figure 2 Categories and core category.

discussed their preparation and expectations of surgery and how this influenced their post-operative experiences.

Information about the surgery

Context and content of preparation for surgery

The children, young people and their parents described preparation for surgery as being delivered in an outpatient setting, either in routine medical clinics or during planned clinical meetings with a nurse specialist. Not all the families interviewed had contact with a nurse specialist prior to surgery. The decision to undergo the operation for the majority of children, young people and parents involves deciding whether to continue with current management regimes (enemas, urethral catheterisation, manual evacuations, nappies and incontinent devices) or having a continent stoma formed. Some parents spent many months or years deciding whether their child should have the operation and when would be the most appropriate time for this, whereas other children, young people and parents described a relatively short length of time between being told about the possibility of surgery and undergoing the operation. The parents who took time to decide to proceed describe this process positively, and this appeared to enable them to prepare for what the operation would involve. The following mother had purposefully delayed the decision for her child to undergo a Mitrofanoff to enable time to think it through and make sure it was the right decision:

Yes and I would say to that 'don't make a decision instantly, sit back and think about it and take as much time as you need' because if they are offering you an operation, unless it is a life and death operation where they say 'you are having it done or it's over', sit back and take all the time you need. I took over a year, from the moment they asked me the first time. (Katie's mother, 18 months after the operation)

In contrast to this, another mother described how she had been told about the surgical procedure in the outpatient clinic and was encouraged to go home and discuss it within the

family. On the next visit to clinic, they were told that the young person was already 'pencilled' in with a date to have the operation:

It was mentioned on one of the visits to clinic and we came home and talked about it and she [Emily] said she would have it done because she thought it would be much easier and when we went to tell him, it was already pencilled in because I think he thought that she would want it doing and she were in within two or three weeks. They were really quick. (Emily's mother, 18 months after the operation)

This had left the young person and their parents little time to discuss the implications of surgery and reflect on whether the decision was right for them. Those children, young people and their parents who described being well informed pre-operatively discussed ongoing contact with a clinical nurse specialist over a period of time, and this was seen to support the dialogue and pre-operative preparation. The following mothers describe the clinical nurse specialist as facilitating pre-operative and ongoing information giving and sharing because of established relationships and spending time with the families:

'He (the surgeon) told us what would be happening but then **** (clinical nurse specialist) was the one who always listened and has always explained'. (Peter's mother, six months after the operation)

**** was very, very good with him. Without her we would have got nowhere because she is so calm and spent so much time with us'. (Julian's mother, two and a half years after the operation)

These mothers describe sustained contact with the clinical nurse specialist; the nurses contributed to the process by spending time with the parents and children over a period of time, and this was described as supporting information sharing and making decisions about the condition.

Nature of pre-operative information provision

Pre-operative preparation for the operation was described as focusing on biological and physiological information with minimal exploration of the psychosocial or practical implications of surgery. Additionally, many of the parents' descriptions suggest presentation of judgments that surgery could improve function. The following family had received detailed information on the conduct of the actual surgical procedure, but limited information regarding the implications to daily life:

We said 'we don't want to know actually how they were going to do the operation, we don't want to know all the gory bits..... just is it

right for her and is it going to work for her?' (Sarah's mother, 12 months after surgery)

In some cases, parents described feeling that their child and family's lifestyle had not been adequately considered during the process of decision-making and information giving pre-operatively. This was reinforced by some parents suggesting that several health professionals had limited knowledge of the context of how families actually lived their day-to-day lives, which could cause difficulties in pre-operative discussions:

I would say the doctors and the healthcare professional, yes, they know what they are talking about medically but they only see you when you are at hospital. They don't see you at home, they don't know how you live your life at all and it is alright them saying 'but this is the best thing for you', Sometimes, with all the good will in the world, doctors and nurses aren't always right. You have got to do what you feel is right. (Katie's mother, 18 months after surgery)

The psychosocial consequences of surgery were not described by any of the parents, children or young people as being discussed pre-operatively, despite the long-term emotional and psychosocial implications of continence surgery being documented in adults (Notter & Burnard 2006). Interactions that were seen as useful pre-operatively included the opportunity to meet with other children and young people who had undergone continent stoma formation. The following young person described how meeting people living with a continent stoma before surgery was helpful and enabled her to discuss life after surgery:

It was helpful, I think it is nice to see that other people are still normal maybe that have it, that it has not changed them. It did help, it was nice. (Evie, aged 18, 10 years after surgery)

The dialogue that occurred between the children, young people and parents with other families related to all aspects of living with a continent stoma and enabled realistic expectations to be developed. Some children and young people described seeing other, often older, young people living with a continent stoma as providing positive role models.

Information about the surgery and managing expectations of success

Some children, young people and parents described not receiving enough information before the operation and linked this to difficult experiences post-operatively including adapting to an unexpected regime or encountering complications such as stomal, urethral or rectal leakage or wound infections. Parents and children could be shocked when the

regime had more impact than they had expected on their everyday lives and suggested that they 'went in blind' (Sarah's mother) to the operation. Some children and young people appeared to have a poor understanding of what the surgery and life after surgery would entail. Several children and young people's accounts suggested lack of awareness of potential problems that could be encountered following surgery with comments including: 'the troubles will just be gone away' (Ben aged 11 years) or 'it will change my life and make things better' (Sarah aged 13 years). When expectations were not matched by post-surgery reality, there could be loss of trust in the healthcare team:

I thought I was going to have a little hole, again the doctors didn't tell me the truth, they said I was going to have a little hole on that side and I went and I turned out on that side and when I noticed the tube I went 'I thought I was having a little hole'. (Louise, aged 15, three years after surgery)

It was not just children and young people who described lack of information, but parents described feeling ill informed. The following mother described not receiving enough information near the time of the admission and felt responsible for not asking more questions about the surgery. This family had considerable previous healthcare experience, and the young person had undergone many surgical procedures in the past:

No, I don't even know what I expected. I did go sick when I seen it because I don't think it was explained properly to be honest, it was explained such a long time ago and then I phoned the hospital and asked them to send more information for me and they never did and I think it was my own fault because I never sat down and asked questions. (Chloe's mother, two months after surgery)

Parents, children and young people described lack of awareness of how much the procedure would impinge on their routine and life, and they reported feelings of shock and disappointment about dealing with the new continent stoma. Regular bowel washouts were sometimes described as taking up to two hours each night rather than the half hour that they were told to expect. In the aforesaid family, this limited the activities the young person and wider family could engage in and effectively 'tied them to the house' between six and eight o'clock each night. This family had also incorrectly thought that the ACE stoma was only temporary, and the young person described that she was having 'it out in the summer' (Chloe, aged 12). This had caused a re-examination of whether the extended regime and implications for the young person's social interaction was something they could commit to long term. The provision of information and the preparation of children, young people and parents for surgery were

strongly intertwined with the descriptions of the pre-operative decision-making process.

Decisions about surgery

Involvement of children and young people in decisions about surgery

Many factors influenced the degree to which children and young people were involved in making decisions about having a continent stoma formed, including their parents, the healthcare team and their own choice of how involved they wanted to be. The following young person aged 16, described his positive experience of the process before surgery of information sharing and decision-making as one that occurred over a period of time and involved discussion between himself, his parents and the healthcare team:

When I went to see the Consultant about the bowel and bladder operation, he weighed up the pro's and cons of it and we obviously didn't make a decision there and then, we had about two or three consultations about it and then finally made the decision. We went away and we sat down and discussed it between us and they discussed with me about how I felt about it and we basically had a long discussion about it and in the end I decided that I wanted it doing and my mother and dad have supported me all the way through it. (Paul, aged 16, two years after surgery)

It seems this young person was able to make an informed decision based on a thorough and considered approach to information sharing supported by both parents and healthcare professionals.

In contrast, some children and young people described being involved only at the final stages of the decision-making process, with young people discussing making the decision for surgery 'in the end':

LB: When it came to having the operation, who decided?
Me in the end

LB: So how did you decide then, what made you decide?
I just thought 'oh I'll have to get it done'. (Sarah, aged 13, one year after surgery)

The terminology used by this young person of 'me in the end' and 'have to get it done' imply a sense of expectation for them to agree at the last part of the process to what appeared to be in many cases an inevitable choice of surgery. Other children and young people also confirmed that they had based their decision on minimal information:

LB: Did you feel that you knew enough about it, because it is quite a big decision to make, isn't it really?

No, I didn't know enough, I just thought I'd get it done. I didn't know what would happen, I just said I was getting it done (Alice, aged 11, two and a half years after surgery)

In these cases, not knowing much about the operation was acceptable to the children and young people, and they trusted the decisions made by their parents and the healthcare team. In many instances, parents decided to what extent their child would be involved in the decision-making process and actively or unintentionally acted as gatekeepers of information. The following mother, who led the decision-making process, discussed not agreeing with the increasing culture in health care of involving children in decisions regarding their treatment:

This new law, that they have got to be honest and the child has got to consent and all this, I think a child of six or seven is far too young to discuss an operation with, because she is terrified. As soon as they mention what they are going to do, that is when she starts panicking. If she didn't know what they were going to do, she would have the pre med, go under anaesthetic and she would have everything done. (Lizzy's mother, one week before surgery)

It seemed this mother felt the need to protect her daughter (aged 12 years) from information that could upset her, even though this limited her capability to understand the procedure or be involved in any decisions. This young person was aware that she was being excluded from decisions and information and she separately described how conversations between her mother and the healthcare team had been conducted in a secretive manner:

They always whisper to my mum and I don't know what they are on about.

LB: What do you think they might be saying?

That I might be having an operation (Lizzy, aged 12, one week before surgery)

Several other parents also described the conflict they experienced between protecting their children from upsetting information and allowing them to be involved in the decision-making process. The desire to protect children resulted in many parents withholding information about certain aspects of the expected surgical journey. The withheld information included possible complications, the time it can take in some cases to establish a successful continent regime, the procedure being life-long or the chance the operation would not work or lead to subsequent operations being needed (revision, incontinent stomas, leakage). Parents described excluding their children from this information to prevent them from being upset by too much knowledge, concluding that it was better for them to know less.

Discussion

Although there were instances of positive experiences of being prepared for surgery, the findings suggest that many of the children, young people and their parents felt that their pre-operative preparation could have been improved and many highlighted a lack of information or information delivered, which was not appropriate to their individual needs. These findings build on evidence that providing appropriate information is a vital part of preparing children and young people for procedures and surgery (Deatrick 1984, Dickey & Deatrick 2000, Smith & Callery 2005, Forbier *et al.* 2009). Children and young people have previously identified that one of the most important characteristics of a health professional is their ability to explain and share information in an understandable way (Kilkelly & Donnelly 2006). Not all children will want to know everything (Boylan 2004), and because children can find information overwhelming (Gibson *et al.* 2005), it can be as harmful to provide too much as well as too little information (Kelsey & Abelson-Mitchell 2007). The majority of 143 children (aged 7–17 years) in a study undergoing surgery wanted comprehensive information, and only a minority of children and young people expressed a desire for limited information (Forbier *et al.* 2009). The children and young people in this study described a range of experiences of receiving information before surgery for a continent stoma and in many cases described how more information or information delivered in a different way would have helped. This highlights the importance of ensuring that information is tailored to meet the needs of individual children and young people and information giving should be an ongoing process over time to support the communication and information giving process.

The decision to have a continent stoma formed was usually made during a planned outpatient clinic; the interviews highlighted that more time is needed to discuss surgery than is afforded in an outpatient setting or on one interaction with a health professional. The process of information giving and decision-making was supported by children, young people and parents being given time to think through and discuss the procedure. Simons (2000, p. 10) suggested that the provision of information to children is not a one-off event, but that as children's understanding changes with their development, 'information needs to be repeated, reiterated and discussed over a period of time'. The relationship that can develop between families and clinical nurse specialists could place them in the ideal position to assess children's, young people's and parents' information needs.

The children and young people undergoing continent stoma surgery, despite having long-term conditions and high

levels of contact with health professionals and services, still reported low levels of involvement or information relating to the surgical procedure and outcomes. This contrasts with the dominant belief that children and young people with impairments and those with chronic illnesses can be very knowledgeable about their condition. Competence to be involved in decision-making has been shown to develop in response to experience rather than just with ages or developmental stages (Alderson 1993), and it has been suggested that children and young people with long-term conditions, who are frequently involved in treatment are likely to be more highly informed in relation to providing consent for procedures than those with acute illnesses (Alderson 2007). Work by Coyne (2006, p. 67) included reports from parents 'where their children knew the 'best way' to do certain procedures because of knowledge gained over time with receiving such care'. However, the accounts of children, young people and their parents in the current study indicate that long-term, experience with continence problems does not necessarily confer the knowledge to make informed decisions about surgery, and they may require just as much explanation of proposed surgery as less experienced families. This supports work that has suggested that children with a history of surgery do not need less information about surgery than those who are undergoing surgery for the first time (Forbier *et al.* 2009). The interviews indicated different experiences of involvement in the decision-making process and different levels and forms of information received pre-operatively. As demonstrated in the quotes, some children and young people received minimal information and felt that they had not known enough, while others received more in-depth information and involvement over a period of time. More children and young people described feeling unprepared than those who discussed a positive preparation process. This is consistent with previous work that identified that there is not an 'ideal level' at which children and young people should be involved in decisions or communication, but that the level of involvement children and young people want should be negotiated and respected (Lambert *et al.* 2008). This requires that health professionals discuss and agree the level of involvement and information exchange favoured by a particular parent and child (Taylor *et al.* 2010).

Many of the children, young people and their parents in this study described how they wanted more information pre-operatively which addressed how the continent stoma would affect all aspects of their life following surgery. Current preparation was described as focussing on the medical and technical aspects of surgery within the initial post-operative period. It was felt that preparation should also focus on the holistic and longer-term implications of

stoma surgery and should take account of the potential impact on their everyday life. This supports previous evidence that it is not necessarily physiological details that worry children pre-operatively (Smith & Callery 2005), but it can be the wider implications of surgery or the influence of surgery on all aspects of family life, which can cause the greatest concern. Parents of children having insertion of a gastrostomy have also reported that pre-operative information can focus too heavily on physiological information and results of test and investigations and not explore the emotional consequences of surgery or the impact of procedures on families everyday lives (Craig *et al.* 2003). This information is especially important, given the long-term management required following the formation of a continent stoma and the subsequent changes to the young person's self-identity. There has been a lack of research investigating the longer-term psychosocial implications of continent stoma surgery for children and young people, in particular their information needs over time as their condition changes and they experience different life transitions.

Conclusion

To date, research examining continent stoma surgery has focused on measuring surgical outcomes and the impact of surgery on quality of life, self-management and independence. Comparatively little research has been conducted to understand the preparation and expectations of children, young people and parents pre-operatively, and how they experience making the decision to have a continent stoma formed. The interviews with children, young people and their parents suggested that their information needs are not being met in relation to the day-to-day and longer-term implications of surgery. The preparation process was described as being positively influenced by contact with a nurse specialist and being given time to make the decision and access different sources of information.

The effective involvement of children and young people in surgical decision-making is particularly important in relation to continent stoma surgery, because of the life-long nature of the procedure. Children and young people will be expected, where possible, to manage their own continence regime into adulthood and develop relationships and identities living with a continent stoma.

Relevance to clinical practice

This study has demonstrated the importance of health professionals discussing the holistic implications of continent

stoma surgery. Support and appropriate information in the pre-operative period were described as positively influencing the experiences of children, young people and parents following the operation and allowed realistic expectations to be established. The provision of pre-operative information can be supported by providing families the time and opportunity to consider surgery and access relevant sources of information pre-operatively.

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Contributions

Study design: LB, PC, SK; data collection and analysis: LB and manuscript preparation: LB, PC, SK.

Conflict of interest

There are no conflicts of interest in the conduct or presentation of this research project.

- Healthcare Setting: Perspectives of Children, Parents and Health Professionals*. Office of the Minister for Children, Dublin. Available at: http://www.omc.gov.ie/documents/research/The_Childs_Right_to_be_Heard_in_the_Healthcare_Setting.pdf (accessed 5 July 2010).
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