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The Lived Experiences of Persons Hospitalized for Construction of an Urgent Fecal Ostomy

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ABSTRACT

PURPOSE: The purpose of this study was to describe the lived experiences of hospital stays for patients undergoing urgent ostomy surgery.

DESIGN: Qualitative, descriptive, phenomenological study.

SUBJECTS AND SETTING: Six persons undergoing acute hospital admission and urgent ileostomy or colostomy surgery (either permanent or temporary) participated in the study. Participants were of Danish ethnicity and between the ages of 48 and 75 years. The research setting was the surgical department at a university hospital in the Capital Region of Denmark.

METHODS: Data collection and analyses were guided by a Reflective Lifeworld Research approach; this approach is based on phenomenological philosophy. Data were collected during in-depth interviews using a semistructured interview guide. Their average length was 50 minutes (range, 30-65 minutes). Interviews were digitally recorded and transcribed. Transcriptions were analyzed in 4 phases according to the principles of Reflective Lifeworld Research.

RESULTS: The phenomenon we labeled "lived experiences of acute hospitalization with construction of an urgent unplanned fecal ostomy" comprised 4 constituents: (1) undergoing unexpected bodily changes, (2) partnership with professional caregivers, (3) experience of vulnerability, and (4) a lack of continuity. These constituents can be described as a number of challenges due to both hospitalization and ostomy creation.

CONCLUSION: We found that individuals experience a number of challenges due to acute hospitalization and urgent construction of a fecal ostomy. These challenges are due to the unexpected bodily changes and interpersonal and organizational conditions. Nurses should be aware of not only the physical implications of urgent creation of a fecal ostomy but also the individual and psychological implications of this event.

KEY WORDS: Nursing, Ostomy, Phenomenology, Qualitative research, Urgent fecal ostomy.

INTRODUCTION

There are approximately 10,000 to 12,000 people living with an ostomy in Denmark, and approximately 4000 patients undergo stoma surgery annually.[1] Approximately 1,000,000 persons in the United States have an ostomy, and 130,000 undergo stoma surgery annually.[2] A colostomy or ileostomy is constructed to divert the fecal flow in the treatment of intestinal disease.[3] They are created during a planned procedure or during an acute hospital admission where the decision to create an ostomy occurs within 24 hours of the decision to operate. Data from the Danish Stoma Database Capital Region indicate that 1123 ostomy operations were registered in 2013. Of these, 45% were instituted after acute surgery, which is initiated within 24 hours of the decision to operate.[1] Ostomy surgery, whether urgent or planned, affects a person's daily life in many areas including health-related quality of life, body image, sexuality, psychosocial adaptation, and practical issues.[4,5] Ostomy patients who have undergone acute surgery experience a greater negative impact on their daily lives than those whose operations were planned.[6,7] Patients undergoing a planned ostomy procedure can be briefed at a preoperative interview about surgery, hospitalization, outpatient follow-up, and living with a stoma. The information provided at the interview is important for the patient because it makes the process predictable and manageable.[8] Planning for admission, discharge, and subsequent rehabilitation starts with the identification of needs for support in rehabilitation.[9]

Research concerning the hospitalization period from patients' perspective is limited. Most studies of patients' participation in hospitalization have included persons with chronic diseases undergoing planned operations.[10,11] Only a few studies have examined patients' involvement in the surgical process from admission to discharge in an acute surgical care setting.[10,11] Greater knowledge may help nursing professionals gain a deeper understanding and provide a better foundation for nursing care. The purpose of this study was to provide a phenomenological description of the lived experiences of hospitalization for patients undergoing acute ostomy construction.

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METHODS

Data were collected using a semistructured interview guide. In-depth interviews were conducted using a descriptive, phenomenological approach, Reflective Lifeworld Research (RLR). The interviews were intended to capture the central elements of patients' experiences. It is possible for the researchers to describe the phenomenon's silent and implicit essence by distancing themselves and reflecting and using openness as the guiding principle in relation to the meeting with the other person's lifeworld.[12] Using RLR as a phenomenological approach contributed to an exploration of lived experiences associated with the construction of an urgent ostomy. Each participant had the opportunity to express his or her own lived experiences in the interview so that it was possible to obtain a varied and nuanced description of having an urgent ostomy. Based on the specific descriptions of having an urgent ostomy, the phenomenological analysis addresses the finding of patterns that define and reflect the diversity and context of undergoing urgent creation of a fecal ostomy.[12]

Informants and Study Setting

Informants were recruited from patients cared for at 3 university hospitals in the Capital Region of Denmark during their hospital stay; they were selected consecutively. The criteria for inclusion were patients who underwent acute hospitalization and urgent ostomy surgery and ability to communicate in Danish. Exclusion criteria were persons with ostomy prior to this hospitalization, and patients undergoing stoma closure (Figure). The study did not require approval from the Danish Ethical. Danish national policy and law provide exclusion of interview studies, since these do not involve biological material. Study procedures were reviewed and found to comply with ethical guidelines of the committees on biomedical research ethics of the Capital Region of Denmark and the Declaration of Helsinki.[13] Potential informants received verbal and written information about the study from the local stoma care nurse (SCN). The purpose of the study was repeated at the beginning of the interview, and participants were counseled that they could withdraw at any time without explanation.[13]

Study Procedures

Interviews occurred within 2 weeks of hospital discharge. Within this time frame, the interviews were scheduled based on the wishes of the participants. Five interviews took place in informants' homes, and one occurred in a meeting room at the hospital. All interviews were conducted by the first author (P.H.). The interview situation was characterized by openness and reflexivity.[12,14] In order to preserve openness, the investigator did not read the informants' journal notes but commenced the interview with a broadly formulated question, "Would you please tell me how you experienced the hospitalization where you had acute ostomy surgery?" This query was designed to focus on the fact that an urgent ostomy had taken place, rather than on the informant. A reflective and distancing procedure means a move in interest from "what" to "how." The way that the phenomenon, the lived experiences of acute hospitalization with construction of an urgent ostomy, has meaning for the participants. Reflexivity was expressed in the subsequent conversation with the informant that included follow-up and exploratory questions, designed to invite the informant to tell more. Examples of these follow-up questions were, "Would you please tell me more about that?" and "How did you feel in that situation?" The interviews lasted between 30 and 65 minutes; they were digitally recorded and transcribed erbatim. Data were collected in April 2014.

Data Analysis

Interview transcripts were analyzed in a 4-phase circular process according to guidelines described by Dahlberg and colleagues.[12,14] The first phase of analysis sought to establish a general sense of the whole; we read the transcripts separately, several times, and achieved an overall understanding when the researcher was able to briefly refer to the content of the individual text. In the second phase, the text was carefully read and highlighted each time the content was changed, enhancing our ability to effectively manage the text. Subsequent reading aimed to bring the meaning of the individual unit forward by adding key words to each single meaning unit. This process was carried out with maximum openness,

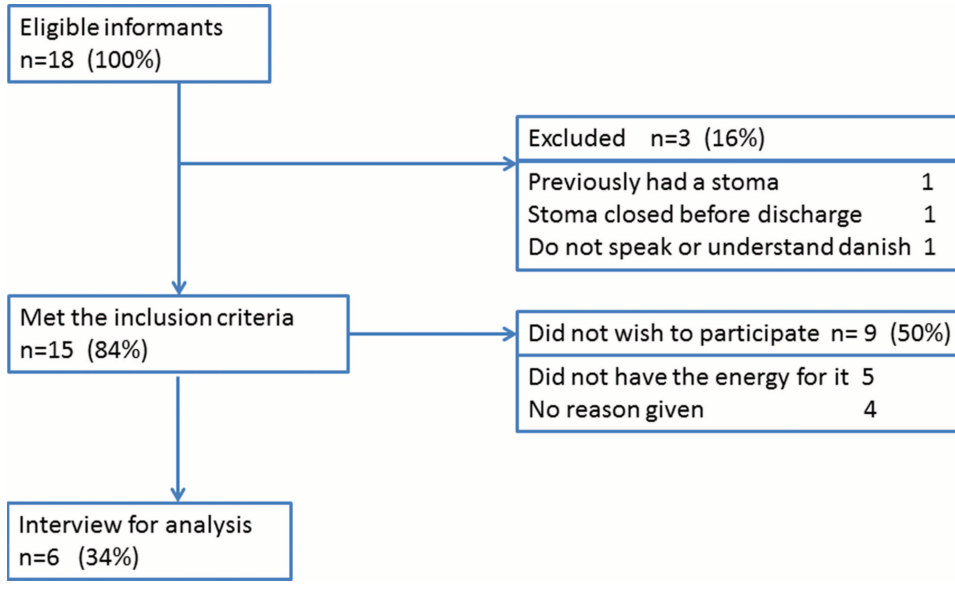

Figure. Flowchart of the approach of informants to interview. n indicates number.

TABLE.
Characteristics and Diagnosis of the Participants

Gender	Age, y	Type of Stoma	Diagnosis	Stoma Intention (Permanent/Temporary)
Female	70	Colostomy	Fibrosis	Permanent
Male	75	Colostomy	Cancer	Permanent
Male	54	Ileostomy	Colon necrosis	Temporary
Female	55	Ileostomy	Perforated appendix	Temporary
Male	67	Colostomy	Cancer	Temporary
Female	48	Ileostomy	Cancer	Permanent

and the specific purpose of the study was not taken into account.[14] In the third phase, various meaning units were clustered into patterns of understanding that mirrored their interrelationships. This was done by asking questions about the material and reflecting "What does this say about the hospitalization with acute ostomy surgery?" and "What does it say about the experiences, feelings, and thoughts expressed by the participants?" We moved back and forth between different phases in the data analysis, as new meanings and perspectives arose.[12] In the fourth phase, phenomenological analysis was used to define the essence of the phenomenon. The phenomenon of hospitalization with construction of an acute fecal ostomy was identified by synthesizing the clustered meaning units. What make this phenomenon what it is? The analysis is terminated by describing the various constituents and their mutual relationships.[12]

RESULTS

The study sample comprised 6 participants between the ages of 48 and 75 years; 3 were men and 3 were women (Table). Three persons had ileostomy and 3 had colostomy; in addition, 3 underwent creation of a temporary ostomy and 3 had a permanent ostomy created. Three underwent surgery for the treatment of colorectal cancer, one because of diverticulitis, one because of a perforated appendix, and one because of fibrosis/stenosis.

Essence of the Phenomenon

The phenomenon, lived experiences of acute hospitalization with construction of an urgent ostomy, comprised 4 constituents: (1) undergoing unexpected bodily changes, (2) partnership with professional caregivers, (3) experience of vulnerability, and (4) lack of continuity. These constituents can be described as a number of challenges due to hospitalization and urgent ostomy creation. Respondents indicated shock and experienced hospitalization as a turbulent experience. The informants described that their life suddenly changed; construction of an ostomy caused them to feel unprepared and to fear what it will be like to live with a stoma. Participants also experienced vulnerability and fragility, both before and after surgery. They also noted that this situation was focused exclusively on practical and physical care. Support and intimacy in their contact with professional caregivers exerted a significant impact on management of postoperative discomfort and training in ostomy self-management. Informants experienced professional caregivers as both teammates and opponents. They also experienced a lack of continuity during hospitalization. This lack of continuity negatively impacted respondents, especially in relation to participation and partnership with the nurses. The lack of continuity was apparent in learning situations, in practical stoma training, in wound care, and in situations where the nursing staff provided information to the participant.

Constituent 1: Undergoing Unexpected Bodily Changes

Participants were confronted with the unexpected as they were informed about the possibility of receiving an ostomy during their acute surgery. Marking the location of the stoma on the body was distressing. Even though patients understood why stoma site marking was done, they felt shocked and unprepared, and described contemplation of a stoma as among their worst fears. It also represented a challenge in body image. Respondents described viewing their bodily changes related to the stoma and pouching system for the first time after their surgery. One participant stated, "When I look at myself…, I can't relate to a bag hanging there." The way the nurses chose to handle these situations, providing psychological support, was significant to participants. As one informant noted, "I think it has been very difficult. Mentally. The practical aspects I'll learn. It's not that. But it's mentally difficult."

Constituent 2: Partnership With Professional Caregivers

Respondents had both positive and negative experiences in partnership with the nurses during hospitalization. Confidence, presence, and security were fundamentally important to participants in their cooperation with the nurses: "I can't really remember … because I think … I tried to go, you see … and I thought now there is someone who has taken control, you see." Hospitalization, acute surgery, a new ostomy, and associated diagnoses created distress. Participants expressed the need to share thoughts and experiences of a more existential character with the nurses, rather than merely receiving advice about practical approaches. "Well it looks great"; "The swelling will disappear"—I just stand there and think: "I will not have that … I'm not a machine lying in bed." "There I could have used someone to talk to." Situations where nurses showed a genuine interest in the patient seemed favorable to the participants, whereas situations where nurses only paid attention to the physical impact were perceived as impersonal.

Constituent 3: Experience of Vulnerability

Participants indicated that they were vulnerable throughout their hospital stay. The sudden and unexpected hospitalization and surgery challenged their comfort zone and resulted in feelings of being out of control. "That I was called in alone … for conversation … and was told … that it [cancer] had spread to

the liver and maybe also the lungs … and there I sat alone … and it's unprofessional." They also experienced vulnerability as the coherence of their lives was changed by the unplanned ostomy. The pain and unexpected aspects of hospitalization and surgery challenged their comfort zone and gave rise to feelings of being out of control. Having a dependency relationship with an ostomy care nurse also made patients feel vulnerable, although they also saw it as an opportunity to reconcile with the new ostomy. "I can't see myself out here—and all of a sudden I have to come running in with her [the SCN] too—it's so confusing." During and after discharge respondents indicated that they felt vulnerable; as one shared, "And so I had also agreed with them that there was a home care nurse here for the first couple of days…. just to make sure I'm coming through unscathed…."

Constituent 4: Lack of Continuity

Informants experienced a lack of continuity or consistency during their hospital course that they found distressing. However, the significance of this lack of continuity or consistency differed based on context. For example, establishing a relationship of trust when receiving stoma care training was perceived as essential, "It wasn't the same person who taught me every time … it ought to have been, because then you learn a little faster." The lack of continuity among the frontline staff and ostomy care nurses when providing specific aspects of stoma-related care also distressed participants. As one informant stated, "Then you get told by one the bag can last for two days, and another member of staff tells you that it can last for three days." From the patient's perspective, continuity can provide confidence and security, for example, if an SCN is allocated to the patient during hospitalization and continues to see the patient in follow-up visits after discharge.

DISCUSSION

Patients undergoing urgent ostomy surgery as part of acute hospital admission experienced a number of different challenges. For example, they described bodily changes during hospitalization as significant. This finding is consistent with Thorpe and colleagues,[15] who described the impact of the experience of living with a stoma on the embodied self. They reported that a more actionable insight allows nurses to provide a better opportunity for supporting ostomy patients' adjustment after stoma formation. The nurse's choice of action should be both practically and psychologically appropriate in order to promote the patient's acceptance of the bodily changes.

Informants in our study also indicated that bodily changes associated with stoma surgery gave cause for concern. Pieper and Mikols[16] also indicated that such concerns are common among persons with a new ostomy. Their study underpins our analysis that indicates that bodily changes are experienced as a particularly dominant concern for patients with a new acute ostomy.

We found that trust, intimacy, and emotional support were important in both practical and existential situations surrounding patients' partnership with professional nurses during hospitalization. Empathy and presence were considered good qualities among the nursing staff in clinical practice, and this perspective was also found to be the case in a study by Jonsson and colleagues[17] that included patients with and without an ostomy. Jonsson's group[17] also reported that patients often perceived that their nurses only managed to see their physical side. In both studies, patients experienced themselves as being reduced to a physical body rather than a whole person when nurses failed to interpret their signals of psychosocial distress. This might indicate that nurses prioritize physical and practical aspects of patient care over psychosocial components. Alternatively, Mockford and associates[18] hypothesized that a focus on physical aspects of care might occur when a nurse is not taught the communication tools/skills required to engage with the patient with empathy. Planned surgery gives caregivers a greater opportunity to establish a trusting, caring relationship prior to admission; in contrast, the acute ostomy forces nurses to establish a trusting, caring relationship within a rapid time frame and during a period when the patient has multiple acute physical care needs. However, Persson and Hellstrom[19] reported that informants undergoing both planned and unplanned ostomy surgery found that the stoma affected them in unexpected ways, even though 8 out of the 9 informants had received preoperative information about the pending ostomy and its management.

In our study, acute surgical ostomy patients perceived nurses as extremely important to their adaptation to life with a stoma. The participants did not think that the nurses themselves knew how important they were for the individual participant, especially in terms of more existential conversations. For example, some of the patients mentioned that they would have liked to have a nurse to talk to about their new situation. Some patients said that they had not only had an ostomy but also had a cancer diagnosis. Thorpe and colleagues[20] also evaluated individuals undergoing planned and acute ostomy creation and emphasized the importance of nurses understanding the emotional impact of an ostomy and asserted that a lack of understanding of the emotional components of a new ostomy can compromise care and the quality of the nurse-patient partnership.

Our participants indicated that the change in their lives caused by sudden hospital admission and construction of an ostomy caused them to feel out of control, vulnerable, and insecure. The patients' experiences can be related to Antonovsky's[21] sense of coherence. According to Antonovsky,[21] one's sense of coherence has 3 components: comprehensibility, manageability, and meaningfulness, with the third element being most important. Patients undergoing unplanned ostomy surgery feel vulnerable during hospitalization, and the manner in which the nurses handle psychosocial adaptation to life with an ostomy is particularly relevant, particularly immediately following stoma surgery.[20] Ostomy nurse specialists have knowledge and skills to manage these challenges, but they are not available 24 hours a day, which is a dilemma. Participants in our study indicated that consistency was important, and they indicated they were distressed by inconsistency among the staff or the messages conveyed by the staff such as when teaching about the length of ostomy pouch wear time varied between nurses. The frontline nursing staff are frequently challenged when seeking to provide continuity for the patients where admissions are short and staff turnover is high.[22] Williams[23] identified a lack of continuity in delivery of ostomy care received by patients with new ostomies. Designing and implementing a standardized approach to ostomy management may benefit patients undergoing emergent ostomy care, in particular patients who have not had planned preoperative education prior to hospital admission. An increased awareness among the nurses should be based on what the individual person with an acute ostomy perceives

as important. This awareness may have important implications for the experiences related to the new life situation.

STRENGTHS AND LIMITATIONS

Detailed data from in-depth interviews and regular validation of concepts by participants during the interview represent strengths of the study.[24] The inclusion of only 6 informants is a limitation, but such a small number of participants is not uncommon in qualitative studies.[25] The study was conducted within a Western European culture, and the meaning of hospitalization with construction of an acute ostomy may be different in other cultural settings.

CONCLUSIONS

We found that participants faced a number of challenges due to acute hospitalization and urgent construction of an ostomy. The unexpected bodily changes associated with creation of a stoma had a dramatic effect on the patients. Their sense of vulnerability arose in partnership with the nursing staff where patients experienced a lack of perceived support and attentiveness. Participants also perceived an absence of continuity when collaborating with the staff in situations of education in practical stoma care and information processes. The focus of care for these patients must incorporate practical issues and an awareness and sensitivity to the meaning of these experiences for each individual. Based on these findings, we advocate psychological support for these patients as crucial and further exploration of this phenomenon.

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