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# Adolescents' Lived Experiences While Hospitalized After Surgery for Ulcerative Colitis

#### **ABSTRACT**

Adolescents are in a transitional phase of life characterized by major physical, emotional, and psychological challenges. Living with ulcerative colitis is experienced as a reduction of their life quality. Initial treatment of ulcerative colitis is medical, but surgery may be necessary when medical treatment ceases to have an effect. No research-based studies of adolescents' experience of the hospital period after surgery for ulcerative colitis exist. The objective of the study was to identify and describe adolescents' lived experiences while hospitalized after surgery for ulcerative colitis. This qualitative study was based on interviews with eight adolescents. Analysis and interpretation were based on a hermeneutic interpretation of meaning. Three themes were identified: *Body: Out of order, Seen and understood*; and *Where are all the others*? The adolescents experience a postoperative period characterized by physical and mental impairment. Being mentally unprepared for such challenges, they shun communication and interaction. The findings demonstrate the importance of individualized nursing care on the basis of the adolescent's age, maturity, and individual needs. Further study of adolescent patients' hospital stay, focusing on the implications of being young and ill at the same time, is needed.

his study focuses on adolescent hospital patients between 13 and 19 years of age who are admitted for ulcerative colitis surgery. From a nursing perspective, the course of the

Received January 10, 2014; accepted June 4, 2014.

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The authors declare no conflicts of interest.

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DOI: 10.1097/SGA.0000000000000154

adolescents' hospitalization was expected to present other and more challenging dimensions than those applying to adult patients (Sturrock, Masterson, & Steinbeck, 2007). With a view to developing new knowledge and improving clinical nursing practices, our aim was to identify and describe adolescents' lived experiences while they were hospitalized after surgery for ulcerative colitis. Emphasizing the importance of adapting our nursing praxis to the young person's age, maturity, and special needs, the findings contribute to the development of adolescent nursing (Olsen & Harder, 2009, 2010, 2011) and further meet the need for specific knowledge about adolescent patients and reflection on the future conditions for this patient group (Davies & Willsher, 2012; Sawyer et al., 2012).

# **Background**

Between 15% and 25% of all new cases of ulcerative colitis are diagnosed in adolescent persons under 20 years of age (Kim & Ferry, 2004; Rayhorn, 2001). The disease is characterized by recurrent episodes of abdominal pain, weight loss, and bloody diarrhea, and in some cases, the patient may suffer from malnutrition, growth failure, low energy, and delayed sexual

(Lindfred, Saalman, Nilsson, maturation Reichenberg, 2008). Studies of adolescents' experience of living with the disease indicate a pattern of reduced life quality characterized by feelings of embarrassment and alienation in relation both to themselves and to others (Fletcher, Schneider, Van Ravenswaay, & Leon, 2008; Mackner & Crandall, 2006; Reichenberg, Lindfred, & Saalman, 2007). A loss of control makes them dependent on constant access to toilet facilities, and they may fear being the target of "bathroom humor" that is popular among children and adolescents (Fletcher et al., 2008; Mackner & Crandall, 2006; Nicholas et al., 2007; Savard & Woodgate, 2009). While some findings emphasize negative psychosocial consequences such as alienation, feelings of helplessness, self-reproach, depression, and anxiety (Reigada et al., 2011; van der Zaag-Loonen, Grootenhuis, Last, & Derkx, 2004), other findings show these patients to cope well and be mentally healthy (Berntsson, Berg, Brydolf, & Hellström, 2007).

Adolescence has been defined by the World Health Organization as the period between 10 and 19 years of age (Michaud, Suris, & Viner, 2007). Apart from being ill, adolescents are undergoing a phase of life marked by dramatic changes from childhood to adulthood, with major physical, emotional, and psychological challenges (Bishop, Lemberg, & Day, 2014). While breaking free from parents and developing physically and sexually, adolescents are creating a new identity. As described by Sawyer, Drew, Yeo, and Britto (2007), being in this eventful phase of life has implications for adolescents' reactions to and handling of a chronic illness, something that must be taken into consideration.

Initial treatment of ulcerative colitis is medical, but surgery may be necessary when this ceases to have an effect (Cima & Pemberton, 2005). Total proctocolectomy with ileal-pouch anal anastomoses is considered the procedure of choice for those patients (Barrena et al., 2011; Carmon, Keidar, Ravid, Goldman, & Rabau, 2003; Kirat & Remzi, 2009), and at this stage, adolescent patients are often cachectic, suffer from pain and bloody diarrhea, and are burdened by anxiety (Reigada et al., 2011).

There is a conspicuous absence of research-based knowledge about adolescents' lived experiences in relation to surgical treatment. Patients, whose involvement in treatment and care gives them a feeling of control over decisions, have been demonstrated to be more compliant and better satisfied (Jacobsen, Pedersen, & Albeck, 2008). The patient's resources and engagement are thus seen as the strongest assets in their treatment (Danish Patients, 2009; Jacobsen et al., 2008; Sawyer et al., 2007). The relevance of studying patients' experiences is obvious.

#### Aim

This study aimed to identify and describe adolescents' lived experiences while they were hospitalized after surgery for ulcerative colitis.

#### **Methods**

Five females and three males between 10 and 19 years of age were interviewed after their discharge from the hospital. The adolescent patients' experiences of the postoperative period in the hospital were captured in qualitative interviews based on a semistructured interview guide (Kvale & Brinkmann, 2009). The eight individual interviews took between 30 and 90 minutes and were conducted in 2010.

Interviewing adolescents requires consent from their parents and a decision about the parents' attendance (Docherty & Sandelowski, 1999; Ministry of Health, 2008). The participants' parents were encouraged to respect the integrity and codetermination of their offspring in relation to participation. The interviewers were guided by ethical principles (Kvale & Brinkmann, 2009; Northern Nurses' Federation, 2003) securing that the adolescent is guarded, protected, and respected as an independent and unique individual. The pertinence of this was clear as six of the informants chose to be interviewed in the hospital

For some participants, coming back to be interviewed proved strongly emotional, provoking heart palpitations, occasional crying, and recurrent images and recollections from their hospital stay. Their reactions forced interviewers to consider how to create a situation that allowed the adolescents to feel safe while securing a meaningful contribution to the interviews.

To stimulate an open and reflective dialogue, we encouraged the adolescents to elaborate on descriptions of concrete situations and their responses through questions such as the following: "What was your experience of ...?" and "Could you say a bit more about ...?" To establish a validation community between the interviewer and the interviewee (Kvale & Brinkmann, 2009), interpretations were verified through questions such as "Did you mean...?" and "Did I understand you correctly when ...?"

Interviews were audiorecorded and transcribed verbatim. Nonverbal elements such as crying and expressions of joy, reservation, anger, worry, and so forth were also noted and formed part of the basis for the analysis (Kvale & Brinkmann, 2009).

# **Analysis**

The analytic process started as the adolescents began describing their experiences. The interviews were analyzed in three steps using a hermeneutic interpretation of meaning (Kvale & Brinkmann, 2009): self-understanding, commonsense understanding, and theoretical understanding. The transcribed interviews were first read to gain an overview, through which units of meaning were identified and data condensed. From this condensation emerged a picture of the interviewees' self-understanding.

Second, a commonsense understanding was established from several readings of the transcriptions, thus providing a broader context of comprehension. The elements touched upon in the interviews were identified and transformed into meaningful units and subsequently coded into three themes: *Body: Out of order*; *Seen and understood*; and *Where are all the others?* The three themes and their interrelations are presented below as findings, which are illustrated by quotes from the informants to demonstrate their basis in the data.

The third, or theoretical, level of understanding implied uncovering a deeper meaning in which the relationship between the whole and the parts of the three themes became clearer. At this level, the three themes were discussed in the light of earlier research, as is shown in the "Discussion" section. The authors analyzed the data independently; findings were discussed by all the authors throughout the analysis process until agreement was reached.

#### **Informants**

All informants had been admitted to a surgical gastroenterology department at a university hospital in 2009. Inclusion in the study was based on age (10–19 years) and diagnostic code (ulcerative colitis). In a mailed letter with information about the study, 14 adolescents were invited to participate. A letter with information on the study was furthermore sent to the parents of underage (<18 years) informants, requesting permission to let their children participate in the study (Ministry of Health, 2008). After 2 weeks, the young people were contacted by telephone to invite them to ask questions about the study and consider their participation. Eight informants accepted participation in the study, while six declined as they felt unable to relive a painful and emotionally taxing period of their life.

All eight informants had prior to surgery been treated with various therapeutic options according to their individual disease pattern and disease complications. They were all offered a total proctocolectomy with ileal-pouch anal anastomoses, but because of their condition, single-stage surgical procedures had been the chosen option (Table 1). Some of the informants wanted to postpone further surgical intervention due to school. Others were advised to wait to improve their physical condition. At the time of interviewing, the informants' average age was 16.5 years (13–19 years);

the average time since diagnosis was 3.6 years (1–8 years). The interviews took place between 2 and 5 months after discharge; three of the informants had completed all procedures with restorative surgery, two were between operations, and the remaining three had chosen to postpone further surgical treatment to fit in with their education plans.

## **Ethical Considerations**

The study followed *Ethical Guidelines for Nursing Research in the Nordic Countries* as well as Central Research Ethics Committee requirements for informed consent. The adolescents and their parents were assured anonymity and freedom to withdraw from the study without consequences for future care and treatment (Danish National Committee on Biomedical research Ethics, 2008; Northern Nurses' Federation, 2003).

### Body: Out of Order

The adolescents described how the physical and mental challenges had brought them to the end of their tether: "If I really had to say what I thought at the time, it's that 'now it's over, I won't survive this, and that's probably for the best" (Informant 2). They indicated that they had been well informed before the first operation and had felt well prepared. But despite their previous experiences with a body that was "out of order" and had failed them through the many periods of illness before the operation, they had been surprised by the body's reactions in the postoperative course. Some put it this way, "You actually don't know what is going on inside your body" (Informants 6 and 8). The adolescents gave blunt descriptions of their physical condition; for example, "It was just bloody awful" (Informants 4 and 6). Their remarks reflected an image of a body beyond control: "How can you keep throwing up, in huge quantities, and for several days, when you're not eating anything?" (Informant 6). The nausea was experienced as paralyzing (Informant 4), hindering them from being mobilized, taking food, or even entering into conversation. One informant verbalized a sense of shock and anxiety, "I was nauseous and shaking ... I was shaking like mad. I just felt so sick" (Informant 7). There was a feeling that it would never stop. As if with one voice, they said, "I felt really awful," another frequent formulation being, "I felt absolutely rotten."

A temporary ostomy was performed as part of the series of operations. On the one hand, the ostomy was referred to as "gross" (Informants 1, 6, and 7), on the other hand, an informant said, "I thought it would be harder than it actually was—you know, it sounds so dramatic having the small intestine coming out of your stomach—you have these screwed up ideas (Informant 5).

**TABLE 1.** Informants' Age and Time of Interview According to Performed Surgical Procedures

		Age Age		Surgical Procedures	
Informant	Gender	At Diagnosis	When Interviewed	Performed at Various Intervals	Time of Interview
1	Male	11 years	13 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy	After second operation Waiting for closure of the loop ileostomy
2	Female	11 years	19 years	Colectomy and ileostomy with closure of the rectum	After first operation Optimizing condition before the next two operations toward an ileal-pouch anal anastomosis
3	Female	14 years	15 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy	Postponed further surgical
4	Female	14 years	18 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy Closure of the loop ileostomy	After last and third operation
5	Male	15 years	19 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy	Postponed further surgical
6	Female	11 years	14 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy Closure of the loop ileostomy	After last and third operation
7	Female	13 years	19 years	Colectomy and ileostomy with closure of the rectum Proctectomy ileo-anal pouch ileostomy Closure of the loop ileostomy	After last and third operation
8	Male	14 years	15 years	Colectomy and ileostomy (acute)	After first operation Postponed further surgical treatment due to condition and school

A distancing attitude to the ostomy was also evidenced by the use of metaphors such as "It was kind of like borrowing a dress from a friend" (Informant 6). When the ostomy began functioning properly, the adolescents were quick to learn how to cut from the template, clean the appliance, and change the bag. One informant put it like this, "After a little while, when I had learned to put it on myself, you know, I got the knack of cutting a hole in that sticky thing there that you have to put on" (Informant 1).

The adolescents described how the exhaustion left them drained of energy and initiative, "I couldn't even swallow a paracetamol" (Informant 5), and, "I said

'but I can't, I can't'—I simply could not do it" (Informant 8). Besides experiencing physical exhaustion they felt mentally weakened, "I was vomiting and feeling really ill—I could hardly face having my family visiting ... all they could do was to just sit there and watch me throw up all over the place" (Informant 5). Their exhaustion was accompanied by a feeling that they would not survive, or thoughts of suicide:

If I had been able to, I'd have jumped out of that window there. I really would. I was totally incapable of seeing how I could face the future. Since then, I haven't had suicidal thoughts, but that night I'd just had it. (Informant 6)

Suicidal thoughts were seen as inescapable:

There was several times when I said, "Let me just have the final jab and then it's over, because I can't take any more." I did not want to be here any longer because I felt so bad and it just hurt. (Informant 7)

The adolescents did not share their thoughts about death with parents or nurses: "Those things you cannot talk about" (Informants 4) and "I could sense that it was hard on my parents ... so maybe [dying] would just be the easiest thing" (Informant 4).

The emotional chaos gave rise to a need for deep rest, and their single rooms allowed them to close out the world and leave communication and other matters to the parents: "So I'd close my ears thinking, 'Mum will be hearing that'" (Informant 5).

#### Seen and Understood

The adolescents gave accounts of the several lengthy illness episodes they had undergone before the operation. Their experiences had had a profound effect on school and their social and family life: "I have done my best to delete all the images from that time" (Informant 4). They spoke about ups and downs according to whether the medical treatment had been successful or not. They had experienced constantly recurring stomach pain, bloody diarrheas, side effects causing massive weight gain, changes in facial form, and acne: "Some of my cousins came over to me [at a social function] and introduced themselves, because they were unable to recognize me—they had no idea who they were talking to. They thought I was somebody's girlfriend" (Informant 7). Some had felt rejected by their doctor's remarks that their stomach problems were "just a mental thing" (Informant 7). Outside of the hospital world, the adolescents had also felt deserted, misunderstood, and ignored: "By the end of year 9 [aged 15] I had no friends left. I was placed at a single desk, because, as the others said, I was never there anyway, so why should they bother sitting next to me" (Informant 7). This made it even more important that their parents were admitted with them. The parents' ability to see through the illness and suffering enabled them to offer protection and to act as their guardians when the situation became too difficult for them. This was indirectly expressed in the remark, "I know what a bloody nuisance one's parents can be, but after all, they do know how their child is doing, and how they prefer things to be done, so I was extremely happy that they were with me" (Informant 4).

The adolescents did not directly question the nurses' technical instrumental skills, for example, whether they were heavy-handed, or did too much or too little in relation to ostomy, catheter, or wound care, and so forth. They did distinguish, however, between those

nurses they said were "nice" or "fantastic" and those they called "surly" or "cold." Being nice or fantastic related to the nurse's ability to meet and understand the individual person: "She was so nice and understood everything-about friends, interests and that sort of thing. She was cheerful and positive, and able to put herself in my place" (Informant 4). The ability to appear calm and take the necessary time was emphasized: "It was absolutely as if for her, it didn't matter how long it took" (Informant 1). It was clear that the meeting with the nurses also had other dimensions: "What I liked was that they would take the initiative. ... [It was] as good as speaking to a psychologist. ... They actually cared and didn't just do it because they had to" (Informant 1). The presence of nurses with these qualities was seen as particularly important: "When they were there, I did not have the same need for my parents to be there" (Informant 4). The adolescents stressed the significance of being seen and taken seriously, and when this happened, the nurse was seen as someone who respected them and tried to understand the extent and importance of what they were going through:

That was the impression they gave me, anyway—that it mattered to them who took care of me, and that I shouldn't be seeing too many different nurses, and we had sort of bonded with each other, and that they would also like to build on that. (Informant 4)

Nurses' surliness or coldness was associated with various dismissive kinds of behavior, as indicated by remarks such as the following: "Some of them were very stiff. There was no way you could swing with them at all" (Informant 8), or "But those cross and cold nurses ... it was mostly the older ones ... they'd say 'There, it's like this and like that" (Informant 7). Interaction with these nurses became strained when the adolescents felt that nothing was negotiable and that they were neither being heard nor understood: "She was just so cold ... she had no feelings whatsoever" (Informant 4). This would happen when they felt that the nurses pressed them beyond their limits and in ways that had no appeal for them. The result was a distance between the adolescent, the nurse, and what should have been their common goal of healing: "I think she was very domineering ... 'Now we do this' and 'Now we do that', you know" (Informant 1). It seems that the adolescent patients were occasionally pressed beyond control: "I simply gave her such a mouthful" (Informant 8).

Interaction with the nurses took many different forms. A humorous approach was often emphasized as a redeeming feature of a chaotic time, "Maybe they poked fun at me if I was a bit cross, but that would just cheer me up" (Informant 8). The importance of the

tone was stressed, however, "'In a soft way, please'not the rough way, you know" (Informant 6). Even when a more serious tone was used, it was acknowledged to have the effect of stimulating cooperation, "...like a well-meant verbal kick in the backside" (Informant 5). In heart-to-heart conversations, the adolescents were given opportunity to discuss their worries and other problems that they avoided sharing with their parents.

#### Where Are All the Others?

Surgery was conducted in a specialized unit that admitted both adults and adolescents, and the adolescents expressed a feeling of being out of place, "Oh no, no, no-those old people, I just can't face that" (Informant 5). To them, the age difference obstructed the possibility of social interaction: "You don't have a lot in common with them [the adult copatients]" (Informant 2). Having to be with and look at the elderly copatients was distasteful to the adolescents: "They were all ill people, old ladies, who I didn't fancy looking at" (Informant 3).

The adolescents missed the company of peers. Their longing for a glimpse of other young people in the corridors was frequently voiced. This would have created recognition and camaraderie, they felt:

Then you would get out of your single room, because that's a hell of a bore after a while. There's no socializing there, you know. Let's say there was a [young patient] further along the corridor. So the two of us could sit down together in the visiting room and watch TV and have a snack—we might have had a bit of fun then. (Informant 5)

Before the operation, the adolescents were offered contact with or a visit from a young person who had undergone the procedure. They had all declined the offer, however, worrying that they might hear about bad experiences. So, despite their sense of being well informed before the operation, they were in fact totally unprepared for how their body would be affected. They realized that learning from a peer's experiences might have helped them start eating again, getting mobilized, and understand that their situation was nothing out of the ordinary: "Yeah, [talking to] someone who had been a patient like me—I missed that" (Informant 7).

#### **Discussion**

The study aimed to identify and describe the adolescents' lived experiences in relation to their hospital stay after surgery for ulcerative colitis. The physical, psychological, and emotional challenges of the time after operation were very difficult for them. Feelings of anxiety, impotence, and a lack of preparation for

coping in the period following the operation were characteristic. This finding is put into perspective by the fact that they had previously been challenged and would be expected to have experienced unpredictable physical reactions. But in the postoperative phase, the adolescents were no longer able to assess their body's signals, pace, or rhythm, or in any way adapt to the state of chaos in which it had left them. The estrangement from their body led to a feeling that life was coming to an end.

The accounts of the informants' feelings of impotence showed how difficult they found any kind of interaction. Only their parents' natural care was tolerable, whereas the meeting with professionals, with its demands for other interrelations, seemed to be a major challenge. It was difficult for the adolescents to participate in wound care, hygiene, taking food, mobilization, and so forth, and such matters were largely left to the nurses. Studies of chronically ill adolescents have uncovered that the everyday challenges posed by the illness are met with task-oriented coping strategies, emotion-oriented coping strategies, and avoidance coping strategies to the same extent (Calsbeek, Rijken, Bekkers, ven Berge Henegouwen, & Dekker, 2006).

Adolescents with ulcerative colitis use more avoidant coping styles than their healthy peers, which may be a result of the unique disease features: frequent stools and associated smells, rumbling stomach noises, or perianal manifestation of the disease are embarrassing (van der Zaag-Loonen et al., 2004). This is corroborated by the predominantly emotional reactions reported here, such as the shunning of participation in practical tasks, which support findings that these young people who are exposed to massive stress meet this with avoidance reactions and strategies. Furthermore, it is well known that the ability to plan and make long-term and proactive choices is not fully developed in the young. As they react intuitively to body language, relying solely on a rational discourse would be unproductive. Instead, the guidance offered should be far more individual, depending on the adolescent's age, development phase, and maturity (Britto et al., 2007; Christie & Viner, 2005). Our study supports established knowledge about the importance of "the present moment" (Stern, 2004); that is, of basing nursing on the situation, balancing between consideration of age, maturity, and coping strategies, while also considering ethical and professional issues.

Possibly as a reflection of emotional and avoidanceorientated strategies, the informants did not directly question the nurses' technical initiatives in relation to ostomy and catheter and wound care (Calsbeek et al., 2006; van der Zaag-Loonen et al., 2004). However, reactions to the nurses' care approach were verbalized in a distinction between those who were called "nice"

or "fantastic" and those who were found to be "surly" or "cold." Martinsen (2001) describes a matter-of-fact observational mode in which the nurse's attention to the other is reduced to merely instrumental patient characteristics and qualities. The described "surly" or "cold" nurses may be seen as such dispassionate spectators who enter the ward with a predetermined and functional purpose expressed in what their adolescent patients described as a now-we-do-this-now-we-do-that attitude, with no involvement of their charges.

While nurses traditionally consider technical tasks and procedures as their primary professional obligation (Milton, 2002), the adolescents indicated a need for stronger individual focus. This is in keeping with the conclusion of Hale et al. that both children and parents found that the "strongest and most effective nursing" was exercised by nurses who "introduced themselves not only as professionals, but also as real people" (Hale, Long, Sanderson, & Carr, 2008). Their study indicates that the adolescents' foremost expectation of the nurse concerns their personal or attitudinal characteristics, such as honesty, empathy, patience, friendliness, and humor, combined with supporting, attentive, and communicating behavior. The findings of Hale et al (2008) are thus corroborated by our informants' remarks about the "nice" or "fantastic" nurses who exhibited understanding, empathy, and presence without apparently being restricted by time.

Previous work has already established the importance of interaction between patients, their families, and the nurse. There are indications, however, that this aspect is particularly important in adolescent nursing, in which the patient is in a transitional phase of life marked by the dramatic changes from childhood to adulthood (Davies & Willsher, 2012; Osterkamp, Costanzo, Ehrhardt, & Gormley, 2013).

As previously demonstrated, a humorous approach appeared to be an essential element of the successful interaction between the adolescents and nurses (Fallon, Smith, Morgan, Stoner, & Austin, 2008). The use of humor in nursing is documented to have a stress-reducing effect (Borod, 2006; Christie & Moore, 2005), and it may create a space for conversations that allow hidden and suppressed feelings and needs to be processed (Craig, 2009; McCreaddie & Wiggins, 2008). The present study has highlighted the importance of considering how and when humor may be introduced into clinical practice and in professional communication with adolescents. The challenge lies in finding the appropriate time and place (Astedt-Kurki & Isola, 2001).

The interviewers were surprised by the adolescents' musings about death. They expressed such an over-whelming feeling of impotence that their hopes for life seemed to be temporarily crushed. Several studies have

found higher frequencies and stronger manifestations of anxiety and depression in children and young people with ulcerative colitis (Reigada et al., 2011; Szigethy, McLafferty & Goyal, 2011). As is true of previous work (Lindfred et al., 2008), our study gives no basis for contending that this group of adolescents, with their many experiences, have become more mentally vulnerable. However, the presence of death is an essential theme in these adolescent patients' hospital stay. This raises a number of questions, in particular concerning the kinds of intervention that may be implemented to prevent similar experiences for other adolescents.

Reflecting previous reports, the adolescents indicated that they had missed social interaction with peers during their stay in a specialized hospital unit for both adults and adolescents. An English study found that adolescent patients admitted to special youth departments are more trustful of staff and in general better satisfied in comparison with peers who had been admitted to child or adult departments (Viner, 2007). By recording these adolescent patients' stories, our study has allowed a more subtle understanding of their needs, and we contend that those needs should be met far more individually, as in some respects they resemble those of adults while in other respects they are like those of children.

The need to balance demands for autonomy with concern for the adolescents' developmental stage is only one of the challenges of acting in this variable and occasionally contradictive field. The ability to navigate between the excesses of care, that is, between overprotection and neglect (Martinsen, 2001), requires nuanced and robust knowledge of adolescent nursing. This could be supported, for example, in hospitals, departments, or wards specifically designed for young people. In their study, Teilmann, Hertz, Blix, and Boisen (2012) found that 71% of a group of 15- to 17-year-old patients preferred hospitalization in a youth ward. Changes in this respect, however, would challenge the present organization of Scandinavian hospital services as treatment is typically organized in relation to medical specialties.

Our study has demonstrated the advantages of more adolescent and child-friendly hospitalizations in a Danish setting, and we recommend that our work be taken into consideration, along with similar work from other countries. At a time when massive investments in new super-hospitals are being made in Denmark, it seems particularly appropriate for politicians, managers, nurses, and doctors to argue for the establishment of children's hospitals, departments, or wards such as are found in the United States, United Kingdom, and Australia (Kelley-Quon, Tseng, Jen, Ziring, & Shew, 2012; Russell et al., 2013; Sawyer et al., 2012).

#### Limitations

This study is limited by its retrospective design. The data are based on the informants' recollections of their admissions, and as human recall is inaccurate, our findings may have been affected. In qualitative research, however, lived experience gains significance as individuals reflect on the past. In Van Manen's description, such reflection is seen as retrospective reflection rather than as introspective reflection (Van Manen, 1990). Other factors may also have played a role for the interviewees' interpretation and understanding of experiences, such as the age at which they were interviewed and the fact that the interviews took place at different stages in the course of treatment. Despite this, we believe that our findings are unique and thoughtprovoking, and should be considered in rethinking clinical nursing practice.

## **Clinical Implications**

Adopting the perspective of the adolescent patient may help optimize the course of future postoperative hospitalizations. Further study of adolescent patients' hospital stay, focusing on the implications of being young and ill at the same time, is needed. It is likewise relevant to reflect on clinical practices in relation to the adolescents' vulnerable situation, taking into account variation conditioned by age, developmental stage, and earlier experiences with illness. It is recommended that findings from this and similar studies be considered in the discussion of future hospital construction in Scandinavia.

#### Conclusion

Our study focused on adolescents who were admitted for ulcerative colitis surgery. Our aim was to identify and describe their lived experiences in the postoperative hospital period. Adolescents experience the postoperative period as difficult and characterized by physical and mental impairment. Confrontation with various kinds of bodily disorder drives them to think about whether life is coming to an end. Typically unable to contribute actively to the nursing required for restitution, they tend to shun communication and interaction. Their accounts of failed treatments, disappointment, and loss of friends emphasize the importance of admitting parents with their child. As they recover during the postoperative period, adolescents with ulcerative colitis seek a more humorous interaction with the nurses. We furthermore detect a need for more individualized nursing care based on the age, maturity, and individual needs of the adolescent patient. 3

# **Epilogue**

Six months after the research was completed, the studied department opened two so-called youth wards designed in bright color schemes and with large-screen television sets.

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