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**Patients' Conceptions of Integrity
within Health Care Illuminated
from a Gender and a Personal
Space Boundary Perspective**

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Abstract

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The aims of this licentiate thesis were to explore and describe female and male patients' conceptions of integrity within health care and to illuminate the conceptions from a gender as well as a personal space boundary perspective. A qualitative design with a phenomenographic approach was used. The participants, 17 male (Study I) and 15 female patients (Study II), all of whom had undergone medical or surgical care, were strategically selected and interviewed. The identified conceptions were also analysed from a gender as well as a personal space boundary perspective.

Three description categories emerged among the male patients (Study I); self-respect, dignity and confidence, while maintaining the self, dignity and confidence were the description categories found among the female patients (Study II). Male patients' description of self-respect and female patients' description of maintaining the self were for the most part similar although there were some differences. The conceptions revealed that integrity involves having the courage to set boundaries and having control over the private sphere, one's self and one's situation. While the male patients emphasised self-belief and being alone, their female counterparts stressed that preserving one's identity was essential in order to maintain the self. Dignity concerned being respected, and the male patients also described dignity as being seen as a trustworthy and whole person, while the women described it as not being exposed. Both male and female patients described confidence, which was related to handling patient information in a confidential way, trusting the professional caregivers, participating as well as balancing or changing the boundaries of integrity if necessary. The male patients also described confidence as being free.

The personal space boundary perspective was useful for explaining the process of respecting the self by opening or closing outgoing and incoming boundaries around the self. The patients had to consider who, when and to what degree others should have access to their personal spaces. The way in which the professional caregivers interacted with the patient influenced the openness of the boundaries.

Keywords: confidence, dignity, female patient, gender, health care, integrity, maintaining the self, male patient, personal space boundary, phenomenography, self-respect

Original papers

This licentiate thesis is based on the following studies, which are referred to in the text by their Roman numerals:

- I Widäng, I., & Fridlund, B. (2003). Self-respect, dignity and confidence: conceptions of integrity among male patients. *Journal of Advanced Nursing*, 42(1), 47-56.
- II Widäng, I., Fridlund, B., & Mårtensson, J. (2007). Female patients' conceptions of integrity within health care: A phenomenographic study. Submitted.

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Original Papers

Introduction

Integrity is a component of quality health care (Irurita, 1996) and implies that the patient is seen as a unique individual (Andersson, 1994, p. 179; Irurita, 1999; Nordam, Sørli and Förde, 2003) and given an opportunity to be autonomously (Granerud and Severinsson, 2003; Randers and Mattiasson, 2004) and also to control his/her life and to protect him/herself. During hospitalisation, many factors such as illness, interventions, loss of identity, lack of information, dependency on others and the imbalance of power between patient and professional caregivers can increase the patient's vulnerability (Irurita, 1996). Professional caregivers can also threaten the patient's integrity by acting in an undesired way and violating his/her different selves, for example, the personal, property or family self (Kihlgren and Thorsén, 1998) and common nursing activities such as assistance with bodily care can threaten a patient's integrity (Lomborg, Bjørn, Dahl and Kirkevold, 2005). Professional caregivers have an influence on patient satisfaction and the main predictor is the care provided by nurses (Larrabee, Ostrow, Withrow, Janney, Hobbs and Burant, 2004), while preserving the patient's integrity can decrease their vulnerability (Irurita, 1996). As illness and hospitalisation can threaten and infringe upon the patient's integrity, he/she has to compromise and employ coping strategies in order to manage the situation (Irurita and Williams, 2001; Jacelon, 2004).

Related to gender, female and male patients have both similar and different experiences of care and no clear pattern exists. Wilde Larsson, Larsson and Starrin (1999) found that, when asked about their expectations of care, female patients ranked most aspects higher compared to their male counterparts, although there was no significant difference in satisfaction with the care received. Moreover, Foss (2002) reported no significant differences between female and male patients' satisfaction related to medical treatment, emotional aspects of medical care, information, equipment, discharge planning and the physiotherapy service. However, satisfaction with most aspects of nursing care was significantly lower among female patients compared with their male counterparts. Both female and male patients have reported complaints about waiting times, but for different reasons (Foss and Hofoss, 2004). The relation between female and male patients and professional caregivers is complex. Patients of both sexes prefer female professional caregivers, probably due to

the fact that women are traditionally responsible for caring activities in the family (Edwards, 1998). According to Inoue, Chapman and Wynaden (2006), male nurses who provided women with intimate care felt uncomfortable, embarrassed or experienced difficulties when invading the women's personal space.

This demonstrates that caring is complex and that the outcomes are not obvious, which means that a caring situation is a challenge for the professional caregivers in terms of their awareness of the expectations and needs of both male and female patients as well as for the patients. Of the few studies which were found on the subject (Andersson, 1994; Irurita, 1996; Irurita and Williams, 2001; Jacelon, 2004; Kihlgren and Thorsén, 1998; Randers and Mattiasson, 2000, 2004), none had a gender perspective, which highlights the need to explore patients' perceptions of integrity.

Aims

The aims of this licentiate thesis were to explore and describe female and male patients' conceptions of integrity within health care and to illuminate the conceptions from a gender as well as a personal space boundary perspective.

This licentiate thesis comprises two studies each with a specific aim:

Paper I To describe how male patients conceive integrity.

Paper II To describe how female patients conceive integrity.

Theoretical standpoints

Integrity

Integrity is described as 'the self', which implies being a unique individual as well as an individual's identity (Andersson, 1994, p. 179; Fjellstrom, 2005; Kihlgren and Thorsén, 1998; Pellegrino, 1990). It also means wholeness in the sense of being an intact person, including physiological, psychosocial and intellectual dimensions in addition to individual values (Fjellstrom, 2005; Pellegrino, 1990). In this definition, wholeness refers to a state of health but also to moral integrity, which implies that a

person acts in accordance with his/her values. Integrity is also linked to dignity, which means that every human being has a worth, regardless of his/her status or ability (Fjellstrom, 2005; Jacelon, 2004; Pellegrino, 1990), and to autonomy and self-determination (Andersson, 1994, p.181-182; Jacelon, 2004; Pellegrino, 1990; Randers and Mattiasson, 2004).

Gender perspective

A gender perspective is the subject of much attention within health care (Miers, 2000). A distinction must be made between the terms 'sex' and 'gender', as the former is related to biological differences, while the latter is broader and encompasses the psychological, social and cultural construction of being a man or a woman. Gender refers to attitudes and expectations in addition to the social behaviours associated with being a woman or a man, which are usually perceived as the norm and taken for granted. Gender involves various aspects of masculinity and femininity created by our behaviour and language, thus 'doing gender' is an on-going process (West and Zimmerman, 1987). The masculinities and femininities are not constant but change in relation to time and place and are influenced by the surrounding culture and society (Connell, 2003, p. 9). While femininity or masculinity is being constructed, it reinforces the gender norm (West and Zimmerman, 1987), as can be observed in, for example, language, where describing and talking about gender both reflects and creates it (Litosseliti, 2006, p. 9). Harding (1993, p.18) points out that gender is constructed at different levels and through different processes; *structural gender* which permeates society and which becomes visible in different institutions, *symbolic gender* which is more or less concealed, for example in advertisements and the way we dress, and *individual gender* which is each individual's expression of being a man or a woman.

Gender theories have undergone changes. The previous focus on the inequalities between females and males, where men were usually considered the norm and had more privileges and power than women, led to an awareness that gradually contributed to women's increased empowerment and equality with men, partly as a result of political reforms (Litosseliti, 2006, p. 27). Focus on gender differences, for example, men as independent, unemotional and self-confident and women as

interdependent, emotional and co-operative could reflect social roles but has been criticized for describing stereotypical characteristics and overemphasizing differences and ignoring similarities, as men and women within the same culture can have more in common than men and women from different cultures (Litosseliti, 2006, p. 39-44) and meta-analyses do not always confirm gender differences (Connell, 2003, p. 64-66).

However, gender must be understood as a complex and dynamic process, as gender identities vary and are dependent on the cultural context (Connell, 2003, p. 9; West and Zimmerman, 1987).

The theory of Personal Space Boundaries

Everyone sets boundaries in communication with others, and it also occurs in the interaction and communication between patient and professional caregivers. In the theory of Personal Space Boundaries (PSB), Scott (1993) and Scott and Dumas (1995) describe such boundaries as permeable boundaries around the human being that act as an essential filter in order to regulate the degree of access to others and the environment. Personal space is described in terms of four different areas of the internal physical, mental and spiritual environment (Scott, 1993; Scott and Dumas, 1995). The outermost space is the official self, *the superficial, public image* that a person wants to show others. The next space includes *thoughts and feelings perceived as acceptable to others*. A person shares this space with people they trust and who are interesting to take part of it. The third space is more private and consists of a person's deepest feelings, thoughts and secrets and is labelled *thoughts and feelings perceived as unacceptable to others*. The most private space is *the inner spirit core*, which constitutes a person's essential self. There are invisible and permeable boundaries around these spaces. There are outgoing boundaries, which regulate outgoing stimuli as well as incoming boundaries, which regulate incoming stimuli. A person may be receptive and allow stimuli from other people or the environment into the various spaces (incoming open) or block stimuli (incoming closed). A person can also give of herself/himself to others (outgoing open) or erect a wall and keep thoughts and feelings private (outgoing closed). The boundaries are flexible and fluid, and a person

who changes them after due consideration, may be either open and wish to invite others into his/her personal space or closed in order to support or protect his/her identity, both of which are a sign of health and adaptation (Scott, 1993; Scott and Dumas, 1995). In addition to flexibility, Scott (1988) points out that a person's ability to open or close and where necessary, negotiate boundaries, is dependent on mental and spiritual strength as well as awareness of and ability to communicate needs. An accurate perception of the environment and others also contributes to flexibility and the ability to adapt to a situation. Support from others influences capacity and the adaptation process (Scott, 1988). How a person perceives others, for example as trustworthy or interesting, increases willingness to open the boundaries. Cultural norms and circumstances also have impact on these boundaries (Scott, 1993; Scott and Dumas, 1995). The communication between nurse and patient is of importance, thus the nurse should invite the patient to engage in open communication (out- and ingoing open). Nurses can verbally demonstrate their openness by, for example, asking permission before performing a task, using language familiar to the patient or answering honestly. Concentrating on the patient, performing duties that are not strictly required, attempting to stay at eye level, varying the tone of voice, being flexible and taking time and touching the patient gently are non-verbal behaviours which promote openness and demonstrate a kind, generous and caring attitude (Scott, 1997).

Material and method

Design and method

This licentiate thesis has an explorative and descriptive design based on a qualitative approach. Qualitative research is well-established and often used in health care and nursing in order to capture patients' unique perspectives, experiences and thoughts (Holloway and Wheeler, 2002 p 10-13). As the aim of the two studies included in this licentiate thesis was to explore patients' conceptions of integrity, a phenomenographic approach was chosen (Marton, 1981). Phenomenography is frequently used in health care research (Barnard, McCosker, and Gerber, 1999; Fridlund and Hildingh, 2000, chap. 1; Sjöström and Dahlgren, 2002) and focuses on describing understanding or awareness of the meaning of a phenomenon, by showing qualitatively different ways

in which a phenomenon is experienced, conceptualised, understood, perceived and apprehended (Marton, 1986). Marton (1981) argues that a conception is influenced by an individual's previous experience, beliefs, values, faith and culture.

Phenomenography distinguishes between the first and second order perspective. The first order perspective deals with how the phenomenon is described, such as how things really are and 'what it is', while the second order perspective comprises how things are conceived with focus on the variations of the conceptions, e.g. 'how' people conceive a phenomenon. In phenomenographic research, the participants' conceptions are presented as conceptions, which are sorted into description categories and illustrated in the outcome space, which represents the collective conceptions (Marton, 1986).

The two studies in this licentiate thesis were carried out in a reciprocal way; one focused on male patients' and the other on female patients' conceptions of integrity within health care.

Participants

The participants comprised 17 male (Study I) and 15 female patients (Study II) who had been cared for in a medical or surgical ward at a county hospital in southern Sweden. Nurses on the wards recruited the patients by distributing a letter of invitation and obtaining informed consent. All patients were born in Sweden and Swedish was their first language. In line with phenomenography, they were strategically chosen (Fridlund and Hildingh, 2000, p. 21) with respect to age, education, marital status, place of residence, type of care and experience of hospital care (Table 1).

Table I. Socio-demographic and situational data of male (Study I) and female (Study II) patients

	Male patients = 17	Female patients = 15
Age		
20-29 years	1	1
30-39 years	2	2
40-49 years	4	1
50-59 years	4	6
≥ 60 years	6	5
Marital status		
Single	1	5
Married	16	10
Education		
Compulsory school	11	3
Upper secondary school	4	5
University level	2	7
Place of residence		
Urban	10	6
Rural	7	9
Experience of hospital care		
One occasion	7	3
More than one occasion during the past year	1	5
More than one occasion during the past 2-5 years	2	4
More than one occasion during the past 6-10 years	3	0
More than one occasion during the past 11 years or more	4	3
Type of care		
Surgical ward	10	7
Medical ward	7	8

Data collection

Data were collected by means of semi-structured interviews 1-5 weeks after discharge. An interview-guide was used and in order to ensure that the patient had an idea of the meaning of the word ‘integrity’, the interviews began with an open question, “Integrity is often mentioned as one aspect of health care. When you think

about integrity, what are your thoughts?” The opening question was followed by questions aimed at deepening the interview.

- How is integrity expressed in health care?
- How do you conceive that integrity is preserved, threatened or violated in health care?
- How do you conceive that the staff took your personal wishes and values into account?
- How do you conceive that privacy is preserved, threatened or violated in health care?
- Are there any differences between integrity in general and integrity in health care?
If so, what are these?

The interviews were audio-taped and transcribed verbatim in order to achieve maximal credibility in the data collection (Guba and Lincoln, 1989, chap. 8)

Data analysis

Phenomenographic analysis

The analyses were carried out by a female lecturer in nursing science and systematically and carefully scrutinised by male researchers who are very familiar with the methodology used. All researchers are nurses with medical and surgical experience. The data were analysed by following the steps described by Dahlgren and Fallsberg (1991). All transcribed interviews were read several times in order to become familiar with the empirical data and obtain a sense of the whole (familiarization). The analysis continued with identification of statements related to integrity (condensation) as well as their similarities and differences (comparison). Preliminary groups were created (grouping) based on statements that appeared to be similar. The statements were removed from their context and attention shifted to the meaning of the statements themselves in order to describe the essence of the similarity within each group (articulation). The analysis continued as an interaction between grouping and articulation, and preliminary conceptions were constructed. The various conceptions were carefully analysed and given a representative label (labelling). Labelling the conceptions was neither easy nor obvious, for example in the male study the conception ‘having control of oneself and the situation’ emerged while in the

female study a similar label 'having control of one's private spheres' was developed. The variation related to the interpretation of the different original data. Conceptions that contained qualitative similarities in a contextual sense were summarised into description categories (contrasting).

Analysis from a gender perspective

In order to illuminate a gender perspective, the patients' conceptions of integrity were analysed by searching for specific conceptions among male and female as well as similarities between how female and male patients conceive integrity.

Analysis from a personal space boundary perspective

In order to attain a deeper understanding of integrity and how patients change their boundaries, the theory of Personal Space Boundaries (Scott, 1993; Scott and Dumas, 1995) was applied to the conceptions identified. The theory was chosen due to its focus on preserving personal spaces and setting boundaries, which is in line with self-respect, maintaining the self, conceptions of changing their boundaries if necessary and having the courage to set boundaries. Furthermore, the theory focuses on the communication and interaction between individuals, which is in line with the description categories dignity and confidence between patients and professional caregivers. The conceptions were reflected upon and analysed by using the theory as a grid for the purpose of gaining an understanding of the process of preserving one's integrity.

Ethical considerations

The two studies in this thesis adhere to the ethical principles of autonomy, beneficence, non-maleficence and justice (Vetenskapsrådet, 2003). *Autonomy* was achieved due to the fact that participation was voluntary, the patients were guaranteed confidentiality as well as the right to withdraw at any time without the need to provide an explanation. Some of the patients who had consented to participate declined due to either being too ill or having changed their minds. Their refusal was respected and those who finally agreed to participate were interviewed in a place of their own choice. Most of the interviews were conducted in the patient's home, while a few took

place at the hospital in connection with a follow-up visit or at the first author's place of work. By demonstrating sensitivity, politeness and discretion as a guest in the patient's home, the researcher showed respect for the principle of *non-maleficance*. Furthermore, the interviews began with a general conversation in order to promote confidence and a pleasant atmosphere. Asking about integrity and especially about situations of threats to or violations of integrity can cause unease and distress and therefore a verbal agreement was reached with the head of the clinic about providing support to the informants, if necessary. During the interview, the researcher endeavoured to show the patients respect and not stress them. Although the patients did not exhibit distress as such, it must be borne in mind that their reactions are not always visible. There was no dependency between the patients and interviewer and the latter was unaware of their health status. Confidentiality was ensured, as no information related to the patients was revealed to the co-researchers or in the articles. The principle of *justice* was adhered to, as the patients were selected by a well-established method and the interviewer attempted to treat all patients in the same way. While this thesis will not provide the patients with any immediate *benefit*, the findings can contribute to increased knowledge about patients' conceptions of integrity and also to an increased awareness and deeper understanding of the importance of respecting patient integrity. The Ethics Committee at Linköping University, Sweden, approved the studies.

Findings

Male and female patients' conceptions of integrity within health care

Male patients' conception of integrity (Study I)

Based on the interviews with male patients, the following three description categories related to integrity emerged; *self-respect*, *dignity* and *confidence*, see Table 2. *Self-respect* was associated with the patient's relationship to himself. The male patients expressed the importance of 'believe in oneself', to trust that one's own feelings and experiences were right and not to rely too much on professional caregivers. *Self-respect* was also to have 'courage to set boundaries', which became evident when

their integrity was at a risk of being threatened or infringed. Furthermore, having ‘control over oneself and the situation’ as well as ‘being alone’ was associated with self-respect. Male patients perceived that they were treated with *dignity* when they were ‘respected’ and seen as ‘trustworthy’ and as ‘a whole person’ with physical, psychological, social and existential needs. *Confidence* as a mutual relationship between the patient and professional caregivers reflected conceptions such as patient ‘participation’, ‘being free’ and open and ‘trusting’ communication as well as the fact that information about the patient was treated ‘confidentially’. In order to obtain care or a diagnosis, the patients had to ‘balance between their own desires and those of others’.

Female patients’ conceptions of integrity (Study II)

The female patients’ conceptions of integrity formed three description categories; *maintaining the self*, *dignity* and *confidence*, see Table 2. *Maintaining the self* was related to the patient’s relationship to herself. The female patients expressed the importance of having ‘control over their private spheres’, which varied from patient to patient and was related to circumstances as well as the consequences of revealing personal information. Control was gained when they made autonomous decisions and knew how others perceived them. It was important to ‘preserve the identity’ and be seen as the person they really were. They experienced a risk of losing their identity when they became ill or were in need of care. Having the ‘courage to set boundaries’ was also conceived as important for maintaining the self. *Dignity* was associated with ‘being respected’, the patients were confirmed and understood. It also implied that all patients have the same value and rights. The professional caregivers who treated the patient with dignity maintained a balance between closeness and distance. Another conception was ‘not being exposed’. They had an experience of being exposed and left out and could not influence their situation. A mutual relationship between the patient and professional caregivers characterised by *confidence* presupposed that ‘keeping information confidential’ was important, although weak points were medical rounds and the provision of care in the presence of other patients. Sometimes the patients had to ‘change their boundaries’ of integrity, for example when being cared for in a room with more than one patient, when asked to disclose sensitive personal information or when they had to endure different examinations in order to obtain care.

Patient ‘participation’ and ‘trust’ in professional caregivers were other conceptions related to confidence.

Table 2. Description categories and conceptions of integrity among male (Study I, n = 17) and female (Study II, n=15) patients

Self-respect (♂) / Maintaining the self (♀)	
Having the courage to set boundaries	♂ ♀
Having control over oneself and the situation/ Having control over one's private sphere	♂ ♀
Being alone	♂
Having self-belief	♂
Preserving one's identity	♀
Dignity (♂ ♀)	
Being respected	♂ ♀
Being seen as a whole person	♂
Being seen as trustworthy	♂
Not being exposed	♀
Confidence (♂ ♀)	
Keeping information confidential	♂ ♀
Trusting the professionals	♂ ♀
Participation	♂ ♀
Having a balance between one's own desires and those of others/ Changing the boundaries of integrity if necessary	♂ ♀
Being free	♂

Integrity from a gender perspective

The patients’ conceptions of integrity were presented in description categories, one of which differed between male and female patients; ‘self-respect’ emerged from the male and ‘maintaining the self’ from the female patients’ conceptions and both were connected to the patient’s interaction with the self. The other two description categories, ‘dignity’ and ‘confidence’, were similar, but included some different conceptions, see Table 2.

Unlike female patients, the male patients conceived integrity as ‘having self-belief’ and expressed that they trusted themselves; their thoughts were right and they knew

best, they were responsible for themselves and did not allow professional caregivers take over. Male patients expressed the conception 'being seen as a whole person'. They emphasized the importance of being treated as a whole person and not as a person with different or separate physical, psychological, social and existential needs. On the other hand, the female patients described integrity as 'preserving their identity', 'who they are', which can also be considered as being a whole person. Their identity was related to themselves as their public self, a healthy person and their profession. These conceptions differed due to the fact that the female patients' conception represented the patient's interaction with herself and was thereby linked to the description category 'maintaining the self', while the male patients' conception was more an expression of how the professional caregivers should treat the patient, thus it was linked to the description category dignity.

'Being respected' was an obvious conception perceived by both the male and the female patients. They felt respected when professional caregivers paid attention to and listened to their wishes and needs. In order to fulfil the patients' needs and provide care in a comfortable and dignified manner, the professional caregivers have to be sensitive to and tactful when dealing with the individual patient as well as maintaining a balance between closeness and distance. Another conception 'not being exposed' emerged among the female patients. This conception implies a state of being exposed, left out and abandoned as well as decreased ability to influence one's situation. The female patients experienced being abandoned when they had to undergo an investigation in order to receive a diagnosis or endure different forms of treatment which they did not want. The outcome and prognosis were uncertain, irrespective of whether or not they underwent such examinations.

Within the description category confidence, the conceptions of male and female patients were quite similar. The conception 'being free' was only found among male patients, who emphasized that being free and independent is associated with confidence. The other conceptions were consistent among both female and male patients (Table 2).

Integrity illuminated by means of the Personal Space Boundaries theory

Analysis of the patients' conceptions of integrity by applying the theory of Personal Space Boundaries (PSB) (Scott, 1993; Scott and Dumas, 1995) resulted in two themes; 'respecting the self' and 'maintaining a balance between open and closed boundaries'. In the theme 'respecting the self' there were parallels between the personal spaces and preserving identity, being seen as a whole person, having courage to set boundaries and having control over one's private sphere or oneself and one's situation. The theme 'maintaining a balance between open and closed boundaries' was related to having a balance between one's own desires and those of others and to changing the boundaries if necessary and the interaction between patients and professional caregivers.

Respecting the self

The patients expressed that the patient him/herself has an impact on the preservation of his/her own integrity by respecting or maintaining the self. According to the PSB (Scott, 1993; Scott and Dumas, 1995), this means that the patient interacts with the self as well as with others by means of opening or closing the personal boundaries. The patient has to decide who to permit or prevent from entering into his/her personal spaces and when, as well as which outgoing and incoming boundaries should be opened and closed. The conception 'having the courage to set boundaries' revealed the need for courage on the part of the patient to communicate his/her wishes and needs and also to set boundaries around his/her private spheres. Sometimes the patients only permitted the professional caregivers access to the public self, as illustrated by the following quotation 'I've had a very high barrier, I don't let anyone behind the fence (♀ pt.)'. This quotation clearly shows that patients erect fences in order to block both incoming and outgoing boundaries as a means of preventing others from entering their personal spaces and not to disclose information about themselves. The patients also expressed that they believe in themselves, which implies that they rely on themselves, thus enabling them to open the outgoing boundaries and express their problems and wishes. Both self-belief and courage related to what Scott (1988) describes as mental and spiritual strength. The patients used different strategies to close boundaries such as avoiding giving an answer, arguing, questioning and

withholding information. For example, one female patient expressed that she withheld some information as it could influence her future employment opportunities. The patients also wanted to be alone and keep others outside, which can be seen as an expression of both closed incoming and outgoing boundaries. Patients who had the courage to set boundaries around their personal spaces managed to achieve control of their situation and private spheres. According to the theory of PSB, they experienced that they had managed to open or close the permeable incoming and outgoing boundaries and thus respected themselves.

The patients also reported that they wanted to preserve their identity and be seen as a whole person. Closing the outgoing boundaries and not letting others know how they felt or how ill they were indicated that they wanted to be recognized as the person they really are in order to maintain their public identity. However, it can also imply that they had to close the incoming boundaries and not allow themselves to be influenced by comments, such as ‘the cancer patient’ and ‘childless’, or open the outgoing boundaries in order to make their identity clear and visible.

Maintaining a balance between open and closed boundaries

The patients expressed that they had to change their boundaries of integrity when it was necessary and also to find a balance between one’s own desires and the professional caregivers, for example when they became ill and had to undergo different investigations or were in need of care. According to the theory of PSB, the boundaries are flexible and can be opened or closed depending on the situation and culture (Scott and Dumas, 1995). The patients have to consider how and to what degree they should open or close the incoming and outgoing boundaries. They have to estimate the cost and benefit as well as the consequences. Patients have to consider, for instance, which information should be given to the professional caregivers (outgoing from the personal spaces) and which exhaustive questions and intrusive assessments they should accept (incoming to the personal spaces) in order to obtain help and care, for example regarding catheterizing, one patients said ‘...when it is between the waist and the knee it is worst... (♂ pt.)’.

In the light of the theory of PSB, the patients' conceptions of integrity such as being respected, keeping information confidential, trusting the professional caregivers' and participation can be seen as a dignified and confidential relationship with a balance between open and closed boundaries. Professional caregivers who are aware of and respect the patient's outgoing and incoming boundaries do not enter into the patient's unacceptable spaces. The patients gave several examples of aspects of interaction with professional caregivers that can increase their ability to open and close boundaries, such as waiting for the patient's permission before commencing caring activities, listening to and respecting the patient's answer and being attentive. There is mutuality in the relationship when the professional caregivers had demonstrated that they are competent and handle patient information in a safe way. The patients felt that they could trust and rely on the caregivers. Patient participation was also built on mutual sharing of knowledge and experiences. This enables patients to open both the outgoing and incoming boundaries, for example to provide the professionals with sensitive and private information about themselves and to accept sensitive examinations. The degree to which the boundaries are open or closed is linked to the relationship between the patient and the professional caregivers. Patients who experienced being left out or exposed had probably opened their outgoing or incoming boundaries too much, whereby others had gained unacceptably deep access into their space, for example when obliged to expose their body and provide sensitive information. It could also be that the incoming stimulus may have been too strong and penetrated their boundaries, for instance when professional caregivers did not respect patients or limited their participation.

According to the theory of PSB, the patients have to decide the degree to which the hospital environment should be allowed to 'enter' their personal spaces. Patients sharing a room have to consider when, in relation to whom and how they should change their boundaries e.g. the degree to which they want to change them, such as disclosing personal information when there is a risk of being overheard (closed or open boundaries) and allowing nursing or medical activities to be performed in front of others (outgoing and incoming boundaries).

Discussion

Gender perspective on integrity

This licentiate thesis reveals some differences between female and male patients' conceptions of integrity. The female patients conceived integrity as preserving one's identity, and described their identity as the person they really are as well as being related to themselves as a healthy person. Illness, being a patient or loss of a part of the body could influence identity. Identity seems to be essential for female patients. This is in accordance with Wilde Larsson et al. (1999), who found that female patients subjectively placed a significantly higher value on care that confirms and supports the patient's identity compared to their male counterparts. Confirming and thus strengthening female patients' identity can improve their ability to maintain their self and integrity. To provide more identity-oriented caring, professional caregivers need to be encouraging, show sympathy as well as an interest in psychological circumstances and the patient's perspective on life (Wilde Larsson et al. 1999). The male patients emphasized the importance of being treated as a trustworthy and 'whole person'. This could probably be interpreted as male patients know "who they are" and therefore they are expecting to be respected and treated with dignity.

The female patients also mentioned that integrity means 'not being exposed'. Being unable to influence their situation decreased their level of empowerment and led to an experience of being in the hands of others. This is quite similar to the femininities 'being alienated' and 'living in the shadow of others', which Aléx, Hammarström, Gustafson, Norberg, and Lundman, (2006) found among women. These women had an experience of being set aside in a social context and being dominated by others. The male patients expressed that 'belief in oneself' was an important contribution to self-respect. In spite of the risk of vulnerability as a patient (Irurita, 1996), men bring their self-confidence into the patient role, which could enhance their ability to manage the situation.

These different conceptions of integrity are probably influenced by the fact that the female and male patients were partly referring to different situations, had different experiences of care and did not conceive the care in the same way. Another aspect could be that professional caregivers, most of whom are female, interact with male

and female patients differently. The above is supported by Foss and Sundby (2002), who found that professional caregivers perceived female and male patients differently, to the disadvantage of the former. Female patients are perceived as more troublesome compared to their male counterparts and, according to Pukk, Lundberg, Penaloza-Pesantes, Brommels and Gaffney (2003), they are maltreated to a greater extent. The possibility cannot be excluded that the female respondents in this licentiate thesis had received lower quality care compared to the male patients. Furthermore, Foss and Hofoss (2004) found that female patients' dissatisfaction with care was related to the attitude of professional caregivers, who failed to take them seriously, treat them with respect or see them as a whole person. These explanations may contribute to the understanding of the conception 'not being exposed' as expressed by the female patients. Such conceptions among male and female patients may also be an expression of the fact that gender is a social and cultural construction (Connell, 2003; West and Zimmerman, 1987). The male patients were probably socialised to trust in themselves, be self-reliant and expected to be listened to, while 'doing gender' was different for their female counterparts, who were accustomed to being ignored or had had less opportunity to influence and change their situation. Another aspect may be that female and male patients use different words to describe more or less the same phenomenon. Litosseliti (2006, p. 39) points out that women and men have different ways of speaking, which may explain the differences and variations in conceptions of integrity that emerged between men and women in the present study. However, these tend to support the assumption that male and female conceptions probably could be affected by gender, although other aspects such as age, education and occupation may also have exerted an influence.

It is also interesting to note that most of the female and male patients' conceptions of integrity were in agreement, see Table 2. This can probably be explained by the fact that integrity is a fundamental and genuine dimension of the human being (Pellegrino, 1990) and therefore relatively stable regarding gender differences. Other studies show similarities among male and female patients (Foss, 2002; Wilde Larsson, 1999). In addition, gender is created in a cultural and social context (West and Zimmerman, 1987), and the patients included in this licentiate thesis represent similar contexts in that they all had experience of being more or less vulnerable as a result of illness and being recipients of care. Furthermore, the fact that they were all Swedish and had

experience of medical and surgical care may support the assumption that the conceptions are more likely to be similar than different.

However, while this licentiate thesis shows that male and female conceptions of integrity are mainly in agreement, there are also gender differences and that ought to be taken into consideration within health care.

Respecting the self and maintaining a balance between open and closed boundaries

Integrity as illuminated by the Personal Space Boundaries theory (PSB) of Scott (1988, 1993) and Scott and Dumas (1995) supports the finding that integrity concerns the patient's interaction with him/herself by means of self-respect and maintaining the self. This interaction cannot be seen as separate, as the patient constantly interacts with others or the environment and has to choose open or closed boundaries (Scott and Dumas, 1995). Professional caregivers as well the hospital environment can be seen as a stimulus that can support the patient in setting boundaries or threaten and infringe them, related to his/her personal spaces. In addition, the transition from person to patient, or from healthy to ill, increases vulnerability (Irurita, 1999). According to the theory of PSB, integrity can be understood as being a whole person with intact personal space to which nobody should have access without permission. Thus the conceptions of the female and male patients within the description categories 'maintaining the self' and 'self-respect' can be interpreted as factors that influence patients' ability to preserve their integrity.

Courage required power and boldness in order to act in accordance with one's needs and convictions. The patients expressed that they believed in themselves and trusted that their assessments were correct. They showed courage when they set boundaries by arguing, avoiding answering questions or withdrawing without permission as well as by showing that they wanted to be alone, e.g. by putting up a fence around the self. According to Scott, (1988), courage relates to mental and spiritual strength, while Finfgeld (1999) points out that self-confidence, hope and support from others are factors that enhance the patient's ability to show courage and can even transform threats into challenges. This means that, during the hospital stay, fellow patients, professional caregivers and next of kin can exert an important influence by giving

good advice, encouraging and acting as a good role model although the opposite can also be the case.

The patients stressed that they had to change their boundaries of integrity if necessary and compromise in order to obtain care or undergo examinations. As the boundaries are permeable and flexible (Scott and Dumas, 1995), the patient has to choose which of the professional caregivers or others who should have access to which area of personal space and when. However, it can be a difficult decision, as the patient has to open both outgoing boundaries, for example, by disclosing information about themselves, and ingoing boundaries, such as allowing professional caregivers to come closer than they would like, for example, when providing assistance with toileting. If the patient fails to protect his/her personal spaces by balancing open and closed personal space boundaries, his/her personal spaces will be entered and violated. According to Scott and Dumas (1995), the threat of violation can penetrate more or less deeply, from the public to the private personal space e.g. from the acceptable to the unacceptable person space or even as far as the inner spirit core. These personal spaces can be interpreted as different selves. Kihlgren and Thorsén (1998) stressed that professional caregivers can violate several spheres of self. These spheres consist of personal properties, private territory, the body self, the psychological self, the information self, the culture self, the family self, the professional self and the personality, to which Randers, Mattiasson and Olsson (2003) added the social self. These selves can explain personal spaces, and lead to deeper knowledge about personal spaces, which can increase the ability of professional caregivers to respect patients' personal spaces.

Professional caregivers have to be aware of their vital role in enhancing patients' ability to preserve their integrity. Professional caregivers can show the patient respect by regarding him/her as a person, being empathetic and treating him/her in the same way as his/her fellow patients irrespective of disease, occupation or social status. Showing respect also means that professional caregivers have to be invited by the patient to 'visit' his/her personal spaces. In order to show respect, there are several situations and activities in daily practice that have to be carefully considered, for instance not exposing the patient's body, not talking over the patient's head or treating an adult patient like a child, in addition to keeping information about the patient confidential, which is also confirmed by Kihlgren and Thorsén (1998). Lomborg et al.

(2005) point out that patients are very sensitive to reactions and attitudes and that personal body care is an exceptionally delicate situation. The patients also expressed the importance of being invited to participate and play an active part in the care and that decisions should be taken in a climate of mutual understanding. A prerequisite for patient participation is that professional caregivers assist the patient to make his/her own decisions and try to minimise their own power (Henderson, 2003). However, Eldh, Ekman and Ehnfors (2006) emphasize that this is not an imbalance of power, but rather that the patient lacks adequate knowledge to be able to participate. Participation has shown to be of major importance in order to achieve integrity especially when preparing for discharge (Jacelon, 2004), while Hedberg, Cederborg and Johansson (2007) also highlight the importance of patients' participation regarding the question of discharge. Another important factor that facilitated integrity was that patient information was handled confidentially. Sharing a room with other patients does not provide privacy. Medical and nursing rounds, asking the patient for care planning data, providing information or carrying out medical or nursing interventions more or less in front of others were conceived as critical situations. According to Malcolm (2005), patients who share a room only partly accept the circumstances. Performing care procedures, medical and nursing rounds in an examination room, having curtains around the bed, holding conversations and providing counselling in a comfortable reception room as well as a room for visitors increase confidentiality.

The ability to set boundaries is dependent on the patient's awareness of her/his personal spaces as well as on his/her ability to communicate open or closed boundaries. According to Scott (1988), it is also dependent on the patient's ability to perceive the reality of the situation. It is not always possible to obtain care or undergo investigations without allowing the professional caregivers access to one's private spaces. Such situations must be taken into consideration and dealt with seriously. Jacelon (2004) found that patients make various decisions regarding the situation and their priorities varied during the hospital stay. Patients will endure some violation of their personal spaces and integrity in order to obtain care or relief from suffering, but, when no longer seriously ill, being treated with dignity is of greater importance.

The patients expressed that they had to change their boundaries of integrity if necessary, which also is described as balancing and compromising by Irurita and

Williams (2001) and Woogara (2005) and as redefining boundaries and finding a balance by Jacelon (2004) and Matiti and Trorey (2004). Such changes are a sign of healthy boundaries; the patient is once again in control over who and at what time others should have access to which personal space, thereby ‘retaining’ the self. However, boundaries that are either too open or too closed are unhealthy and lead to problems in interactions with others (Scott, 1993). According to preserving integrity, it is the patient who should ‘own’ the power to open and close his/her boundaries and the professional caregivers should not use their power to infringe upon them.

Methodological considerations

A qualitative method with a phenomenographic approach was considered to best correspond to the aim, which was to describe male and female patients’ conceptions of integrity. Qualitative methods shed light on the participant’s perspectives, the emic perspective (Holloway and Wheeler, 2002, p. 12-13) while the phenomenographic approach makes it possible to grasp people’s different conceptions of a phenomenon (Marton, 1981). In order to achieve a gender perspective, study I and study II were performed separately. The gender perspective was only generally elucidated in terms of similarities and differences. The theory of PSB showed high applicability (Fridlund, 1998), as it relates to self-respect and maintaining the self, balancing and changing the boundaries of integrity as well as the interaction between patients and professional caregivers.

The phenomenographic studies (Study I and Study II)

Trustworthiness is evaluated by means of the following criteria; credibility, dependability, confirmability and transferability developed by Guba and Lincoln (1989, chap. 8) and described by Polit and Beck (2004, pp. 430-437). (Please see the articles for a more detailed evaluation.)

Credibility concerns the research design and the plausibility of the data collection and analysis and is ensured by the adequate description of the participants and the use of a

strategic sample as recommended in phenomenographic studies (Fridlund and Hildingh, 2000, chap.1) for the purpose of identifying as many different conceptions as possible. The patients' socio-demographic data varied according to education level and marital status, and it is difficult to know whether the findings were influenced by the fact. The data collection was carried out by means of semi-structured interviews as recommended in phenomenographic research (Marton, 1986; Fridlund och Hildingh, 2000, chap. 1) and all patients were able to communicate verbally. As integrity is a rather abstract concept, the opening question was essential in order to ensure that the patients had a basic grasp of the meaning of the word 'integrity'.

To guarantee *dependability*, and stability of data over time, all interviews were conducted by the same researcher (IW), the identical interview guide was used and there was no dependent relationship between the interviewer and interviewees. The fact that a rather long period elapsed between studies I and II minimized bias in the analysis of study II and allowed the data in the second study to be seen as new and unique. The conceptions 'being respected' (♀♂) and 'not being exposed' (♀) emerged based on the differences in the original data. The female patients made statements such as "... you arrive at a point you don't want to come to, and then you are really on your own ..." [*the patients had to undergo treatment and they did not know the outcomes, author's comment*]. The patients experienced being abandoned and exposed. The conception 'not being exposed' was based on such statements and also included exposing the body and losing face in front of others. However, in the male study the latter two aspects were included as an example of not being respected in the conception 'being respected'. Scrutinizing the conceptions 'having a balance between one's own desires and those of others' (♂) and 'changing the boundaries if necessary' (♀) as well as the conceptions 'having control over oneself and the situation' (♂) and 'having control over one's private sphere' (♀) showed that they are similar in content but different in labelling and therefore these differences are not given an attention in this licentiate thesis.

Confirmability concerns accuracy and objectivity. The research process was accurately described and the analysis carried out by a female lecturer in nursing science as well as systematically and followed in detail by male researchers thus increasing security and minimising the influence of gender bias. In order to achieve confirmability, the interviews were audio-taped and transcribed, and the analysis was accurately described, as were the conceptions represented by the statements. Some

conceptions of integrity are also found as aspects of dignity, for example respect, confidentiality, participation and privacy (Matiti & Trorey, 2004), which could be explained by the fact that the concepts, especially integrity, are not well-defined (Fjellstrom, 2005) and to some extent overlapping.

The *transferability* of the findings to other groups of patients was considered. The extent of agreement between the female and male patients' conceptions of integrity could probably indicate transferability to similar patient groups with experience of somatic hospital care and the findings are also partly in line with Jacelon's (2004) and Irutita's (1996) findings. On the other hand, the sample was rather small and age, culture as well as experience of hospital care may also influence the conceptions of integrity.

Conclusion

This licentiate thesis has deepened our understanding and knowledge of the fact that:

- Integrity comprises self-respect and maintaining the self.
- An interaction between the patient and the professional caregivers characterised by dignity and confidence is important for preserving the patient's integrity.
- The environment of the ward as well as the design influences the patient's ability to maintain integrity.
- Despite some differences, female and male patients' conceptions of integrity are mainly in agreement. Female patients emphasize the need to preserve their identity, while their male counterparts emphasize self-belief.
- Integrity means being a whole person; respecting, maintaining and preserving the self. It is an active process, which permits or prevents others entering the different personal spaces via open or closed personal boundaries.
- The professional caregivers can assist patients to preserve their integrity by respecting the invitation to enter or their defence of their personal spaces.

Implications

- In order to preserve patients' integrity, it is important that professional caregivers have knowledge of patients' different conceptions of integrity and are sensitive to personal boundaries.
- There is no reason for treating male and female patients differently although attention to how male and female patients respond is of importance
- Reflections and ethical reasoning by small groups of professional caregivers with focus on strengths and weaknesses in their daily work could contribute to an awareness of and sensitivity towards patient integrity. Participation in such groups can also contribute knowledge of how to respect the patient's boundaries. As professional caregivers mainly work in a team, it could be beneficial to have groups with a mix of professional categories and groups confined to a particular professional category. Such groups could be of importance both in clinical settings and educational programmes.
- The Personal Space Boundary theory can serve as a pedagogical tool to clarify and make visible the process of preserving integrity by means of open or closed personal space boundaries. The theory of PSB can be used in further education for professional caregivers and basic health care education as well as in patient education programmes in order to enhance the patients' ability to preserve his/her integrity.

Future research

There is a need for knowledge of patients' conceptions of integrity associated with experiences of care in other contexts such as primary health care and home care. It would be interesting to focus on patient integrity in specific nursing contexts or activities, which could be useful for clinical practice but also for educational settings. While the gender perspective was only generally illuminated in this licentiate thesis, there is need for further research. Professional caregivers' conceptions of integrity are also of interest and the evaluation of interventions using the Personal Space Boundary theory as an education tool could be an additional project.

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Sammanfattning på svenska (Summary in Swedish)

Integritet innebär att bli respekterad som en unik person med specifika egenskaper men också att vara självständig och att ha kontroll över sig själv och sitt liv. Ett kännetecken på god vård är att patienters personliga integritet respekteras. Att bli patient kan innebära en ökad sårbarhet. Vårdpersonalen kan genom sitt agerande och sina attityder påverka patienters sårbarhet och därmed både bevara och kränka en patients olika 'privata rum'. De privata rummen kan beskrivas utifrån Scott och Dumans teori som olika personliga rum, allt från det officiella jaget till de mer privata rummen med tankar och känslor som en person inte vill dela med andra.

Syftet med licentiatavhandlingen var att beskriva manliga och kvinnliga patienters uppfattningar av integritet samt att belysa uppfattningarna ur ett genusperspektiv. Vidare var syftet att belysa integritet utifrån gränser för de personliga rummen eller sfärerna. En deskriptiv kvalitativ design med fenomenografisk ansats användes i både studie I och studie II. Patienter med erfarenhet av kirurgisk eller medicinsk vård på sjukhus intervjuades (17 manliga och 15 kvinnliga patienter). I resultatet framkom olika uppfattningar av integritet som sammanfattades i tre beskrivningskategorier; **respektera sig själv** (manliga patienter) eller **att upprätthålla 'jaget'** (kvinnliga patienter) vilket innebar hur patienten förhåller sig till sig själv samt **värdighet och förtroende**. Värdighet avsåg hur vårdpersonalen förhåller sig till och bemöter patienten medan förtroende återspeglade det ömsesidiga förhållandet mellan patient och vårdpersonal. Beskrivningskategorin **att respektera sig själv eller att upprätthålla 'jaget'** inkluderade uppfattningarna *ha kurage att sätta gränser* och *att ha kontroll över sig själv och sin situation* både bland de manliga och de kvinnliga patienterna. Patienter som upplevde att deras integritet var hotad eller kränkt kunde visa det genom att t.ex. undvika att svara, argumentera eller undanhålla information. På detta sätt markerade de sina gränser och kunde på så sätt få kontroll över sig själv, sin situation och det privata. Relationer, livsstil, sjukdom och hjälp med personlig hygien nämndes som privata områden. De manliga patienterna uppfattade också att integritet är att *ha tilltro till sig själv*, att lita på att de själva känner sin kropp och sin sjukdom bäst och *att vara för sig själv*, t.ex. genom att dra för draperiet runt sängen eller att stänga dörren var ett uttryck för att stänga ute andra och få vara för sig själv. De kvinnliga patienterna uttryckte att integritet är att *bevara sin identitet*, de önskade att

behålla sin identitet som den friska person de var och inte som 'den cancersjuka' eller 'barnlösa'. Att förlora en kroppsdel, att visa sig som sjuk och svag eller att inte kunna utföra sitt arbete kunde bidra till att identiteten påverkades.

Beskrivningskategorin **värdighet**, innebar att *bli respekterad* enligt både de manliga och kvinnliga patienterna. Att visa respekt innebar att vårdpersonalen lyssnar till patienten, respekterar deras svar och behov och också att ha förmågan att växla mellan närhet och distans i förhållandet till patienter. Att *bli sedd som en hel människa* med t.ex. fysiologiska, psykologiska, sociala och existentiella behov och att *bli sedd som en trovärdig* person betonades av de manliga medan hos de kvinnliga patienterna framkom uppfattningen att *inte vara utlämnad*. Beskrivningskategorin **förtroende** relaterades till relationen mellan patienten och vårdpersonalen. Enligt både de manliga och kvinnliga patienterna innebar det att *information om patienten ska behandlas konfidentiellt* och ska inte spridas vidare till andra samt att patienterna har reella möjligheter att vara *delaktiga* i vården. En annan uppfattning var att *lita på de professionella* samt ett ömsesidigt erkännande av varandras kunskaper. Förtroende innebar också att *balansera och kompromissa* t.ex. när patienterna för att få vård eller få en diagnos måste genomgå undersökningar och behandlingar som kunde upplevas som kränkande. Bland de manliga patienterna förekom även en uppfattning av *att var fri*, vilket innebar att vara oberoende och att kunna gå utanför traditionella gränser.

Denna avhandling visar att manliga och kvinnliga patienter har samstämmiga uppfattningar av integritet men också att manliga respektive kvinnliga patienter har specifika uppfattningar. De kvinnliga patienterna uttryckte värdet av att bevara sin identitet och att inte bli utlämnad medan de manliga patienterna uttryckte värdet av att lita på sig själv och att bli sedd som en hel människa och som trovärdig. Detta kan möjligen vara ett uttryck för att män och kvinnor tänker olika om integritet men även att de kan ha olika erfarenheter av vård.

Teorin om gränser för personliga rum eller sfärer visade sig vara användbar för att förklara hur integriteten kan respekteras och bevaras. Främst handlat integritet om att respektera sig själv, och att ha mod att sätta gränser och också att våga visa andra var gränserna går. Patienten måste överväga vem/vilka, när och till vilket personligt rum som vårdpersonalen och andra t ex patienter på samma sal ska ha tillträde till. Patienterna måste ibland kompromissa och ändra sina gränser för de personliga

rummen för att få vård och behandling. Att få hjälp med personlig hygien eller att genomgå medicinska undersökningar kan innebära att patienten får ändra sina gränser och låta andra t.ex. vårdpersonalen beträda sina 'personliga rum'. Vårdpersonalen kan genom sitt agerande underlätta för patienten att både öppna och stänga sina gränser.

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