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ORIGINAL ARTICLE

A trajectory towards partnership in care – Patient experiences of autonomy in intensive care: A qualitative study

Catharina Lindberg^{a,b,*}, Bengt Sivberg^b, Ania Willman^{a,c},
Cecilia Fagerström^{a,d}

^a Department of Health, Blekinge Institute of Technology, SE-371 79 Karlskrona, Sweden

^b Department of Health Sciences, Lund University, SE-221 00 Lund, Sweden

^c Department of Care Science, Malmö University, SE-205 06 Malmö, Sweden

^d Blekinge Centre of Competence, SE-371 81 Karlskrona, Sweden

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Caring;
Content analysis;
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Patient Autonomy;
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Summary

Objective: The aim of this study was to describe and elucidate patient experiences of autonomy in an intensive care context from a caring perspective.

Background: Patients in intensive care units (ICUs) are critically ill and in a dependent and vulnerable position. There is thus a risk of staff taking command not only of the patients' vital functions but also of their decision-making.

Methods: A qualitative design was selected. Individual interviews were conducted with 11 adult patients with an intensive care episode of two days or more at six Swedish ICUs. The data were analysed using Inductive Content Analysis.

Findings: Patient autonomy in intensive care was shown to be 'A trajectory towards partnership in care depending on state of health and mutual understanding'. It was experienced through acknowledged dependence, being recognised as a person, invited participation and becoming a co-partner in care.

Conclusion: Patients in need of intensive care wanted to be involved in making decisions about their care as this creates a trusting and healthy care environment. Greater awareness is required about the ICU patient not only being a passive care recipient but also an active agent and where involvement in decision-making and participation in care are crucial.

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* Corresponding author at: Department of Health, Blekinge Institute of Technology, SE-371 79 Karlskrona, Sweden. Tel.: +46 455 38 54 29.
E-mail address: catharina.lindberg@bth.se (C. Lindberg).

Implications for Clinical Practice

- Patients in the ICU could be highly dependent and at the same time independent and it is therefore important to handle each nursing care activity in an adjusted way to ensure the patient feels included.
- Staff continuity is essential to ensure a tacit understanding that creates a good care relationship as the communicative skills of patients in the ICU are often impaired and they rely on a continuous stream of information in order to feel they are involved in their own care.
- Patients in need of intensive care want to be coached and pushed into activities in relation to their state of health as this reinforces their confidence in their own ability.
- Creating an ICU environment where the staff attitude is supportive and inclusive is of great importance to the patients' potential to influence their care and recovery as they want to play an active role relative to their capacity.

Introduction

Patients in intensive care units (ICUs) are critically ill, are often receiving life-sustaining treatment and in most cases their admission is unexpected, unplanned and traumatic. They become highly dependent on staff and technical equipment as their ability to perform self-care is reduced (Lykkesgaard and Delmar, 2013), thus putting them at risk of having their autonomy challenged. Increased vulnerability has been identified as the antecedent of patient autonomy in a caring context (Lindberg et al., 2014), i.e. a preceding phenomenon that through a changed interdependence and/or a need of care support challenges the potential for a person to manage autonomy. ICU staff must be sensitive to this vulnerability. They must be alert and develop a 'clinical eye', watching over the whole of the patient's body and not just focusing on parameters and technical equipment (Gjengedal et al., 2013). The forced dependence on equipment has been shown to make the patient feel passive and shut in, preventing them from performing simple actions, such as getting out of bed or going to the toilet (Almerud et al., 2007). This often creates a distance between the patient and the carer as a result of technical monitoring where the focus is on the biological body. There is therefore a risk that ICU staff not only take command of the patient's vital functions but also their decision-making, leaving the patients without control of their own body and mind.

The democratisation process in many western societies has included a change in discourse related to the power balance between staff and patient, with a shift in favour of the patient (Hewitt-Taylor, 2004). This is not always regarded as positive for the patient as decision-making can be stressful and confusing and could create a sense of unease (Pierce and Hicks, 2001). There is a risk that healthcare professionals develop irrelevant conceptions of a patient's ability to be active and self-managing if they regard autonomy to be an overarching goal of healthcare (Delmar et al., 2011). This may leave too much in the hands of the patients and have a possible disadvantageous effect on their dignity.

Due to medication, or for disease- or treatment-related reasons, patients do not always have the metacognitive capacity to make decisions about their own care (Levinsson, 2008). This dependence requires the care staff to be 'standing by', attentive to the patient at all times and to have the courage, willpower and knowledge to support the patients in their attempts to achieve independence and a sense of control (Karlsson et al., 2012). Consequently, the

caring and technological aspects of ICU care should not be seen as separate entities, or viewed in relation to a specific health profession, but as parts of 'the crafting process', balancing the many skills that are intrinsic to patient care in a high-tech environment and working in the patients' best interests (Price, 2013, p. 284).

There is a lack of research in the field of patient autonomy related to ICU care that involves the patient's own experiences. Patients in need of intensive care are critically ill, the mortality rate is high and their recollection of the time spent in the ICU is often affected (Bergbom-Engberg et al., 1988; Capuzzo et al., 2001), all of which impede involvement in research or the ability to reflect on care provision (Lykkesgaard and Delmar, 2013). Other concepts, such as empowerment, have been investigated and the results reveal that 'nursing maternalism' could be an obstacle to restoring patient control (Christensen and Hewitt-Taylor, 2007, p. 160) and that 'strengthening and stimulating the patient's inherent joy of life and will to fight' could be a prerequisite for restoring patient control (Wahlén et al., 2006, p. 375). Nevertheless, it has been shown that it is not self-evident for intensive care RNs to regard the patient as an active subject, since patient self-determination is not a specific goal for nursing care in this high-tech environment (Meijers and Gustafsson, 2008) even though Western health-care is oriented more and more towards person-centred care (Ekman et al., 2011; McCormack and McCance, 2010). If patient autonomy is to be considered an issue in future intensive care, where the patient is thought of as an active agent, there is a need to address the patient's perspective.

Aim

The aim of this study was to describe and elucidate patient experiences of autonomy in an intensive care context from a caring perspective.

Ethical considerations

This study was conducted in line with the ethical principles for research outlined in the Declaration of Helsinki (World Medical Association, 2013), and was approved by the Regional Ethical Review Board in Lund (No. 2012:343), Sweden. The patients were given oral and written information about the study and their right to discontinue

participation at any time. Prior to the interviews, informed consent to participate in the study was signed and the patients were offered the opportunity to contact the members of the research group if necessary.

Methods

A qualitative design was chosen and the point of departure was the phenomenological tradition with a holistic understanding of human experiences (Patton, 2002). Qualitative methods facilitate the in-depth study of issues and with openness to data, often involving the researcher as the instrument. The sample is generally smaller, allowing the researcher to understand the world as viewed by the respondents (ibid.). Individual interviews were conducted in order to reveal the very personal level of patient experiences and feelings when being cared for in an intensive care unit.

Data collection

Settings

The study was carried out between March 2013 and April 2014 at five county hospitals in south-east Sweden (A–E). One thoracic and five general ICUs were included. Each ward could accommodate five or six patients, had a nurse-to-patient ratio of 1:1–2 and was staffed by RNs (intensive care specialisation is mandatory for RNs in Swedish ICUs) and auxiliary nurses. The exception was the thoracic ICU, which was staffed exclusively by RNs. The rooms were either single rooms with isolation facilities or multi-bed rooms (two to four patients) with folding screens to help preserve patient integrity. The patients were not physically restrained, were never left alone and visitors were allowed at any time, day or night.

Data collection process

The study was performed with assistance from intensive care RNs, the majority of whom were linked to the intensive care after-care service. The RNs identified the informants, provided verbal information about the study and handed over an information letter on behalf of the researcher to avoid the patient feeling obliged to participate. For the purposes of short-term memory transition, the interviews took place on the general hospital wards to which the informants had been transferred following discharge from the ICU. The interviews took place within the following post-ICU time ranges – 1 week ($n=7$), 2 weeks ($n=1$), 3 weeks ($n=1$), 4 weeks ($n=1$) and 7 weeks ($n=1$) – and in relation to the process of identifying informants and their health condition. The interviews followed a guide based on the following two main open-ended questions:

“Could you tell me about your stay at the intensive care unit?”

“Could you tell me about the opportunity to participate in and influence decisions about your care?”

Additional questions and probe questions were asked when appropriate. The length of the interviews varied from

12 to 97 minutes (median 54) and they were recorded and transcribed verbatim, including remarks on pauses, laughter and so on.

Participants

Thirteen patients who met the inclusion criteria were asked to participate in the study. They were all adults (18 years or over) and they had an ICU care episode of two days or more, including a need for various forms of medical technology (indicating their dependence and the severity of their health condition, see Table 1). They could also recall the ICU care episode and they were oriented in terms of time and space. Seven men and four women ($n=11$) were included (drop-outs $n=2$, [death prior to interview $n=1$; late withdrawal $n=1$]). They were aged 34–75 years (median 54.5), had an ICU care episode of 2–28 days ($n=7$), 29–56 days ($n=2$), 57–84 days ($n=1$), 85–112 days ($n=1$), (median 10) and a variety of admission diagnoses, mainly related to major surgery, severe infections and/or respiratory failure. None of the participants suffered from a chronic condition prior to the ICU care episode and they had all been admitted to an ICU for the first time.

Data analysis

The analysis was carried out in accordance with the inductive approach of the content analysis model produced by Elo and Kyngäs (2008), thus corresponding to conventional content analysis (Hsieh and Shannon, 2005), which is often used when existing theory or research literature is limited, as was the case in this study. Each step in the model involving overview reading, open coding, grouping, the use of coding sheets, categorising and abstracting the revealed data (Fig. 1) was performed in relation to the aim of the study. The first two steps were performed by the first author. The first and second authors then worked together on the remaining parts of the analysis. Finally, to avoid bias, the last author validated the analysis by reading all the interviews and checking the categorisation and interpretation of the texts.

Findings

Patient experiences of autonomy in intensive care were shown as “*A trajectory towards partnership in care depending on state of health and mutual understanding*”. The findings showed that this partnership begins with acknowledgement of the patient’s dependence, and ends with the patient becoming a co-partner in care. The partnership was experienced as varying between different states of dependence and independence and was guided by the patient’s return to health. This return could change rapidly, and quite often unexpectedly, thus causing a setback or a step forward in the recovery process. The different states of autonomy could also overlap and in a way that the patient could be in more than one of the states at the same time and that the recovery process could lead to increased capacity related to certain nursing care procedures but not to others. In the presentation of the findings,

Table 1 Technical equipment used (A–H) for each of the informants (1–11).^{*}

Patient No.	Ventilator ^A	NIV ^B	Iv infusion pumps ^C	Monitoring ^D	Enteral feeding pump ^E	Epidural analgesia pump ^F	VAC pump ^G	Dialysis ^H
1	A ^a	B ^a	C ^{lab}	D ^{abcf}	E ^a			
2	A ^a		C ^{lab}	D ^{abcf}	E ^a			
3			C ^{lab}	D ^{abcf}		F		
4		B ^b	C ^{lab}	D ^{abcef}	E ^a	F		
5			C ^{lab}	D ^{abcf}				
6	A ^{ab}		C ^{lab}	D ^{abcf}	E ^{ab}	F		
7	A ^{ab}		C ^{lab}	D ^{abcf}	E ^a		G	
8	A ^{ab}		C ^{lab}	D ^{acf}	E ^a			
9		B ^{ac}		D ^{acf}				H ^a
10	A ^a	B ^b	C ^{lab}	D ^{abcf}		F	G	
11			C ^{lab}	D ^{abcf}				

^{*} Information obtained from RNs.

Clarification of purpose and/or equipment used:

^AEndotracheal tube^a, tracheostomy tube^b.

^BCPAP (continuous positive airway pressure)^a, NIPPV (non-invasive positive pressure ventilation)^b, Oxyflow^c.

^CCVC (central venous catheter)^l, Port-à-Cath^l, medication^a, nutrition^b, blood transfusion^c.

^DECG^a, CVP^b, Artery cannula^c, PA catheter^d, Intra-abdominal pressure^e, Pulse oximetry^f.

^EFeeding tube^a, PEG (percutaneous endoscopic gastrostomy)^b.

^FEpidural catheter.

^GVacuum-assisted closure.

^HIntermittent haemodialysis.

the sub-categories (see Fig. 2) are interwoven in the overall presentation of the generic categories. To safeguard the anonymity of the quoted informants, the patients are named 1–11 (in accordance with Table 1) and the hospitals are designated A–E.

Acknowledged dependence

“In the beginning I was so sick. I felt grateful that there was someone to make the decisions for me! Waking up in the morning and being shaved, we bathed ... I mean, it was incredibly nice. And, I felt that it was part of ... my recovery.” (A2)

Due to a lack of experience and knowledge about being critically ill, as well as a lack of strength, the ICU patients often had limited interest in exercising autonomy. They did not feel vulnerable despite their condition as they felt a sense of safety and gratitude for being able to put their power into someone else's hands. They wanted to be able to ask for help and thus enjoyed *acknowledged dependence*. The patients experienced the technical aspect of care as normal, a necessity and a source of security, which were non-negotiable in this life-saving environment. They could not and did not want to interfere with the technology-related procedures and, as the staff were always close by, the patients handed over responsibility to those who had the knowledge and experience, i.e. the specialists. The difference in the level of attainment created docility and the

Figure 1 The analysis process – overview.

Figure 2 Overview of the findings; main category, generic categories and subcategories.

patients felt confident that the staff members were doing their very best:

“... in the ICU ... it was never an issue for me to have views on (care decisions) ... I realised that they (the staff) were doing things that were necessary.” (C11)

The patients’ poor state of health caused them to surrender things that they usually controlled, such as their insulin doses and injections. At the beginning of the intensive care period in particular, most of the patients suffered from impaired cognition and for that reason they put themselves in the hands of the staff:

“... I didn’t think of anything. No. I put up with it. ... I just let them decide ... I wasn’t really aware of what they did at first ... No.” (C5)

The patients’ physical limitations, such as swollen hands, being connected to a ventilator or suffering from paralysis, sometimes led to a feeling of resignation as their strength was poor and the effort was too great. Despite explanations by the staff and their comforting conduct, the patients felt a loss of control in this unfamiliar environment. They were being monitored constantly and they sometimes became nervous because of the wires and tubes surrounding them. Their dependence was partial or total and they found themselves in the hands of others, dependent on both the technology and the staff, and at times this scared them.

“No, but I was very dependent, especially on the ventilator. It was my lifeline ... I was grateful for it after having ... traumatically experienced, little by little, the loss of breathing ... Finally ... you sort of die, before

you are connected .../... scared to death that something would happen to it (the ventilator) ... and I was also scared that they ... would leave me ... At the beginning I was very scared when I couldn’t see or hear the nurses.” (D8)

Being critically ill created passivity and very often the patients accepted being persuaded as they relied on the staff’s professional knowledge. Patients with long periods of ICU care freely accepted being dependent. They said that they learned to put aside their control as a way of handling their vulnerable health condition, which had become their everyday life situation.

Being recognised as a person

The attitude of the staff caused the ICU patients to feel confirmed and sometimes unique. They wanted to be cared for as individuals, including the need to be noticed.

“Well, they did have more time... they have more staff .../... in my room there were two beds, but at times I was there on my own, and then all the attention was on me, so that was just perfect.” (E9)

They also wanted to be asked for their opinion, as being consulted helped them to participate in nursing care decisions:

“And then the staff ask you questions all the time. How you feel. If it is good in this way or that, or if you want it another way, and all the time you can say what you think.” (A3)

The patients had also experienced situations where there was no discussion and where they were treated as objects. Their interpretation of these situations was that the staff were acting rationally and were used to caring for heavily sedated patients. This reduced the patients' comfort and confidence. At the same time, they assumed that in certain situations, i.e. caring for the critically ill, the staff needed to override the patients: "... a lot of things are done routinely, it's second nature. That's what I think. ... they know best. After all it is their profession." (D8). The patients felt a sense of participation when they were listened to. The more their communicative skills increased, from simple mimic to direct speech, the more the patients felt that their will was being taken into account: "... they listened to me... It was important." (A1). The sensitivity of the staff, found more frequently among the younger RNs, helped them to work up the courage to express their wishes, which could take the form of having the pace adjusted to their strength when getting out of bed or a non-verbal expression of pain being heeded. There were also experiences of *not* being listened to, e.g. in relation to a reduction in pain management when they had not consented to a reduction. At the time there was a sense of being bypassed but after they had recovered they had a feeling of acceptance and gratitude for not becoming addicted to opium. Sometimes new dependences arose as a result of the recovery process, requiring the staff to be attentive in a different way than before:

"When they removed my urinary catheter, it was a little chaotic./And I didn't really make it all the way ... but I was not offended or anything but I did say that they had to hurry up because I couldn't make it much further." (A2)

In some situations, as in the case of personal hygiene, patients felt exposed and wanted respectful treatment and not, as some patients had experienced, insulting, impersonal treatment with the RNs standing in the room talking not with the person concerned but about him. At times they needed some privacy with their partner or family and it was appreciated when this need was respected and arranged well by the staff. The patients were in most cases unfamiliar with the ICU setting. When they were not able to talk or did not have enough knowledge or strength to ask questions, it was extremely important for the patients to be given information continuously. Sometimes it became a monologue, with explanations, which the patient had to adjust to as they were not able to give their consent although they often found this to be sufficient to acquire a feeling of participation. Among the narratives, a traumatic situation, related to *not* being given information, arose and caused a sense of violation on the part of the patient in question.

"It was actually a doctor who did something bad ... with the best of intentions. They wanted to see if I could breathe unaided, so they reset the ventilator ... without telling me ... or the staff and they then left the room. After a minute or two I began to panic and the staff didn't understand a thing until they realised that the ventilator had been reset. First I was afraid and then I became angry, realising what had happened. It was a tremendous violation." (D8)

Invited participation

The ICU patients felt that they were trusted by the staff and that they were expected to be a party in their own care. There was always room for questions, which created a trusting atmosphere and this encouraged the patient's participation in the decision-making process. They were coached and pushed into trying different activities, which gave them confidence in their own ability.

"They were so good at it, trying all the time to push me ... To see if I could move myself a little bit in bed ... small things that made ... It was a step forward every time you managed ... Then you grew – this went really well." (B4)

As their health improved and they became less dependent, the patients felt greater strength and motivation to take the lead regarding activities such as getting out of bed. They felt that they wanted to be of help, initially by telling the staff how they wanted to be positioned in bed, and later on they tried to assist by moving themselves, even if they could not do so fully. At times they had an immediate feeling of both dependence and independence:

"Well, I could turn myself in bed as I wanted to, but I couldn't go to the toilet because I still had the urinary catheter as they were measuring how much ... because I had infusions, you know." (C5)

When they were being weaned off the ventilator, the patients' fear diminished as they became more and more independent and from time to time they were able to cope without the technology, thus increasing their ability to initiate nursing care activities. Although they were still unable to act entirely on their own, they sensed that they were being encouraged to be a part of the care relationship, which they felt was important for their self-esteem and to activate the brain. The patients found the atmosphere inviting, as if they existed in a 'philosophy of care', characterised by mutual understanding, interplay and consensus among staff, which helped facilitate their move towards autonomy. Staff continuity was essential to a tacit understanding that created a good care relationship, marked by mutual respect and working towards a common goal. To be invited to be a part of the relationship was a prerequisite for cooperation with the staff, with whom they wanted to get on well.

"It is the staff's attitude towards me and the environment that you experience as a patient that determine whether you want to 'plant yourself in the grove of flowers' or not (The patient described the ward as a 'grove of flowers')./... if the staff's attitude had been the opposite... surely it would have turned out the same, but I wouldn't have felt as good and I guess neither would they." (A2)

Becoming a co-partner in care

The patients stated that the participatory aspect of making decisions about their care was essential for their recovery, acquiring a greater degree of control and by doing so avoiding being left to the goodwill of the staff. A common way of being involved in the decision-making process was through

informed consent to different nursing care activities: “... it was consent, as they asked if I wanted to get rid of it (the feeding tube) and I said yes.” (D8). At times, when the patients had difficulty communicating their needs or wishes, this was done by a next of kin becoming a proxy, thus creating a sense of safety.

The ICU patients found it difficult to think of participating in decision-making in terms of *self*-determination as they were in a more or less constant state of dependence, and they preferred to talk about *co*-determination. The better the patient's communication skills became the more they felt that they could influence care, and getting to know the staff made this easier. This influence was expressed as *wishing* (e.g. not using the same trolley for feeding and lower body hygiene procedures), *directing* (e.g. instructing the staff in how to decrease the pain when taking a shower), *pre/post-planning* (i.e. changing the relative timing of nursing care activities and hence the planning of daily routines), or firmly *questioning/rejecting* different nursing care activities (e.g. when they did not make sense or when their lack of strength was too tangible). When it came to influencing the technology it had to do with what, when and for how long they were used, especially different respiratory devices:

“... I'm tired and it is kind of hard to breathe... I could say. I want the mask (CPAP) for a while... then, I got it.” (B4)

They did not assign the same level of influence to the medical care because of the many medical considerations, but they did let the staff know if they felt bad due to their medication. Their gradual recovery was a precondition for resuming command.

“... I could also exert more influence as time passed, as I became more and more healthy. Then it was not ... such an acute phase ... as it was at the beginning. Besides ... I was affected less and less by strong medication and that caused me to have ... reason to actually ... make decisions and have opinions about things.” (D8)

As the patient was gradually weaned off the ventilator, independence and freedom increased as the general atmosphere became more relaxed and the staff adopted a less watchful approach. The patients regarded independence as gaining control, for example, of their personal hygiene and the ability to eat unaided when the feeding tube was removed – even sweets. Other examples of gaining control that were cited were related to the medication for patients who were used to taking a lot of different medicines, and the simplicity of the self-controlled pain management device that led to a sense of freedom as they did not need to disturb the staff as often. Although the patients could be in a very vulnerable situation they stated that their responsibility for assuming an active role in their recovery, in relation to their capacity, was important and that they should not simply accept things passively but should also make informed decisions. They also stated that their attitude to their personal care was an inner force behind wanting to get well and it was an extremely important part of the recovery process.

“I think that my attitude ... is very important for my care and I believe that ... to recover you also need the desire

to recover ... you need to show them that you have ... You have to decide!” (B4)

Discussion

The patients' state of health and level of knowledge prevented autonomy from becoming fully extended participation. Nevertheless, the patients wanted to become a co-partner in care but preferred to think about *co*-determination rather than *self*-determination, which has also been shown in an earlier study of autonomy related to patients in need of palliative care (Sahlberg-Blom et al., 2000). The findings revealed patients' experiences of autonomy to be a *trajectory towards partnership in care*, which starts when the patients' dependence is acknowledged by the staff and accepted by the patients. Historically, partnership in care has not been considered evident as 'informed consent' has been the primary expression of autonomy related to medical ethics (Rendtorff and Kemp, 2000). Creating a partnership calls for mutual understanding, leaving both parties in a state of interdependence (Lögstrup, 1992). The interests of patients are intertwined with those of the healthcare professionals and are discussed in terms of patients being experts in their field, acknowledging at least two bodies of knowledge – that of the staff and that of the patient (Kennedy, 2003). The former is related to professional clinical knowledge and experience, the latter to the experiences, fears, feelings, hopes and desires of the patients. Lögstrup (1992) refers to humans as having a will to be respected and to share power and if a person, due to illness, is impeded in the development of abilities and strength, other people need to intervene without taking away the person's independence. Will seemed to have an important role to play in the recovery process of the patients in this study and in becoming a co-partner in care. The patients talked about their will to fight as an inner force for wanting to get well. This concurs with the findings of Wåhlin et al. (2006) regarding patient empowerment in an ICU and a study by Alpers et al. (2012) dealing with experiences of inner strength in critically ill patients on ventilator treatment, where factors such as 'the wish to go on living' and 'to be seen', were shown to promote this inner strength. Nevertheless, this study showed that recognising the patient as a person and to be noticed, asked, listened to, shown respect and given information, are ways of assisting the vulnerable patient on the trajectory towards partnership in care.

In contrast to the study by Almerud et al. (2007), where clinical vigilance was experienced as marginalising and the patient became invisible at the personal level, the part of care involving technical equipment was found to be normal for the patients in this study and was thus not regarded as being a threat to their autonomy. They felt safe with regard to the technical equipment, over which they did not envisage exerting any personal influence, and they trusted the staff. In another study, which examined the meaning of being cared for in an ICU patient room, the room and space were described, among other things, as a place of trust and security through the interaction with staff (Olausson et al., 2013). The life-saving technology was of paramount importance for feeling safe and trust was fundamental. These different ways of experiencing technology in the ICU do not

need to be exclusive, as the aims of the studies differ in focus but still reveal the difficulty of balancing the numerous patient care skills in a high-tech environment (Price, 2013).

To become a co-partner in care, the patient must be thought of as *homo capax* (Ricoeur, 2011), i.e. capable of health and well-being irrespective of disease and illness even in an environment such as an ICU. This presumption is firmly in line with the strategies underlying Health Promoting Nursing (HPN) (WHO, 1984). In the Health Promotion Model, nursing practice involves assumptions, such as persons having the capacity for reflective self-awareness, including assessment of their own competencies, and for interacting with both the external and interpersonal environment (Pender, 1996). In a philosophical discussion on health and adaptedness, Pörn (1993) argues that humans experience good health when there is a balance between abilities, capacities and the wish to adapt, and that a person's health is less good/the person is ill if and only if the repertoire of adaptedness is inadequate. This definition omits the concept of disease as well as disease-oriented views on health and opens up alternative views. HPN could be a way of focusing on a non-traditional way of understanding patient autonomy in intensive care, regarding the patients as being capable and having a will of their own. Further research focusing on this perspective in an ICU context would be an interesting way of linking the values of today's society into a highly technological healthcare environment.

Study strength and limitations

In order to ensure variation and avoid ward- or setting-dependent findings, six different ICUs at five different hospitals were included. The patients had all experienced first-time admission to the ICU but formed a heterogenic sample in terms of age, sex, admission history and length of stay as well as medical diagnosis, which strengthens the trustworthiness (Lincoln and Guba, 1985) of the findings with regard to variety. The planning and gathering of data took place alongside the selection of articles included in a study (Lindberg et al., 2014), the aim being to identify and construct the meaning of the concept of patient autonomy in a caring context. The extensive reading of articles related to patient autonomy may have influenced the authors, hence their preunderstanding. This influence could be seen as a prerequisite for face validity and credibility (Patton, 2002), asking probe questions during the interviews and gaining a better understanding of how the concept might appear in the data. However, discussions did take place among the authors to reveal preunderstanding and thus enhance objectivity towards the analysis.

Conclusions

Patients in need of intensive care wanted to be involved in decisions about their care as this creates a trusting and healthy care environment. When their state of health did not allow them to participate in the decision-making process they wanted to be able to surrender control. When recovering, their experiences of patient autonomy were related to different ways of co-determination, i.e. being invited to

participate, thus leading to a partnership in care. To enhance the autonomy of patients in intensive care there is a need for greater awareness about the patient not only being a passive care recipient but also being an active agent and where involvement in decision-making and participation in care are crucial.

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References

- Almerud S, Alapack RJ, Fridlund B, Ekebergh M. Of vigilance and invisibility – being a patient in technologically intense environments. *Nurs Crit Care* 2007;12:151–8.
- Alpers L-M, Helseth S, Bergbom I. Experiences of inner strength in critically ill patients – a hermeneutical approach. *Intensive Crit Care Nurs* 2012;28:150–8.
- Bergbom-Engberg I, Hallenberg B, Wickstrom I, Haljamae H. A retrospective study of patients' recall of respirator treatment (1): study design and basic findings. *Intensive Care Nurs* 1988;4:56–61.
- Capuzzo M, Pinamonti A, Cingolani E, Grassi L, Bianconi M, Contu P, et al. Analgesia, sedation, and memory of intensive care. *J Crit Care* 2001;16:83–9.
- Christensen M, Hewitt-Taylor J. Patient empowerment: does it still occur in the ICU? *Intensive Crit Care Nurs* 2007;23:156–61.
- Delmar C, Alenius-Karlsson N, Mikkelsen AH. The implications of autonomy: viewed in the light of efforts to uphold patients dignity and integrity. *Int J Qual Stud Health Well-Being* 2011;6.
- Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care – ready for prime time. *Eur J Cardiovasc Nurs* 2011;10:248–51.
- Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62:107–15.
- Gjengedal E, Ekra EM, Hol H, Kjelsvik M, Lykkeslet E, Michaelsen R, et al. Vulnerability in health care – reflections on encounters in every day practice. *Nurs Philos* 2013;14:127–38.
- Hewitt-Taylor J. Challenging the balance of power: patient empowerment. *Nurs Stand* 2004;18:33–7.
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
- Karlsson V, Bergbom I, Forsberg A. The lived experiences of adult intensive care patients who were conscious during mechanical ventilation: a phenomenological hermeneutic study. *Intensive Crit Care Nurs* 2012;6–15.
- Kennedy I. Patients are experts in their own field. *BMJ* 2003;326:1276–7.
- Levinsson H. Autonomy and metacognition. A healthcare perspective. Lund: Lund University; 2008 [Phd thesis].
- Lincoln YS, Guba E. *Naturalistic inquiry*. Newbury Park: SAGE Publications, Inc; 1985.
- Lindberg C, Fagerstrom C, Sivberg B, Willman A. Concept analysis: patient autonomy in a caring context. *J Adv Nurs* 2014;70(10):2208–21.
- Lögstrup KE. *Det etiska kravet [The Ethical Demand]*. Gothenburg: Bokförlaget Daidalos AB; 1992.

- Lykkegaard K, Delmar C. A threat to the understanding of one-self: intensive care patients' experiences of dependency. *Int J Qual Stud Health Well-Being* 2013;8, <http://dx.doi.org/10.3402/qhw.v8i0.20934>.
- McCormack B, McCance T. *Person-centered nursing. Theory and practice*. Chichester: Wiley-Blackwell; 2010.
- Meijers KE, Gustafsson B. Patient's self-determination in intensive care – from an action- and confirmation theoretical perspective: the intensive care nurse view. *Intensive Crit Care Nurs* 2008;24:222–32.
- Olausson S, Lindahl B, Ekebergh M. A phenomenological study of experiences of being cared for in a critical care setting: the meanings of the patient room as a place of care. *Intensive Crit Care Nurs* 2013;29:234–43.
- Patton MQ. *Qualitative research and evaluation methods*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2002.
- Pender NJ. *Health promotion in nursing practice*. 3rd ed. Stamford, CT: Appleton & Lange; 1996.
- Pierce PF, Hicks F. Patient decision-making behavior. An emerging paradigm for nursing science. *Nurs Res* 2001;50:267–74.
- Pörn I. Health and adaptedness. *Theor Med* 1993;14:295–303.
- Price AM. *Caring and technology in an intensive care unit: an ethnographic study*. *Nurs Crit Care* 2013;18:278–88.
- Rendtorff JD, Kemp P. *Basic ethical principles in European bioethics and biolaw: report to the European Commission of the Biomed-II project*. Basic ethical principles in bioethics and biolaw 1995–1998, vol. 1. Autonomy, dignity, integrity and vulnerability. Copenhagen: Centre for Ethics and Law; 2000.
- Ricoeur P. *Homo Capax*. Texter av Paul Ricoeur om etik och filosofisk antropologi i urval av Bengt Kristensson Uggla [Eng: Homo Capax. Texts of Paul Ricoeur on ethics and philosophical anthropology selected by Bengt Kristensson Uggla]. Gothenburg: Bokförlaget Daidalos AB; 2011.
- Sahlberg-Blom E, Ternstedt B-M, Johansson J-E. Patient participation in decision making at the end of life as seen by a close relative. *Nurs Ethics* 2000;7:296–313.
- WHO. *Health promotion: a discussion document on the concept of and principles*. Geneva: WHO; 1984.
- World Medical Association. *Declaration of Helsinki: ethical principles for medical research involving humans*. World Medical Association; 2013.
- Wählin I, Ek A-C, Idvall E. Patient empowerment in intensive care – an interview study. *Intensive Crit Care Nurs* 2006;22:370–7.