

## The implications of autonomy: Viewed in the light of efforts to uphold patients dignity and integrity

CHARLOTTE DELMAR, PhD<sup>1</sup>, NANNY ALENIUS-KARLSSON, RN<sup>2</sup>, & ANETTE HØJER MIKKELSEN, MSC<sup>3</sup>

<sup>1</sup>Aalborg Hospital Science and Innovation Center, Aarhus University Hospital, Denmark, <sup>2</sup>Arcada Yrkeshögskola, Helsingfors, Finland, and <sup>3</sup>Department of Urology, Aalborg Hospital, Aarhus University Hospital, Denmark

### Abstract

This article focuses on Danish patients' experience of autonomy and its interplay with dignity and integrity in their meeting with health professionals. The aim is to chart the meanings and implications of autonomy for persons whose illness places them in a vulnerable life situation. The interplay between autonomy and personal dignity in the meeting with health care staff are central concepts in the framework. Data collection and findings are based on eight qualitative semi-structured interviews with patients. Patients with acute, chronic, and life threatening diseases were represented including surgical as well as medical patients. The values associated with autonomy are in many ways vitalising, but may become so dominant, autonomy seeking, and pervasive that the patient's dignity is affected. Three types of patient behaviour were identified. (1) The proactive patient: Patients feel that they assume responsibility for their own situation, but it may be a responsibility that they find hard to bear. (2) The rejected patient: proactive patients take responsibility on many occasions but very active patients are at risk of being rejected with consequences for their dignity. (3) The knowledgeable patient: when patients are health care professionals, the patient's right of self-determination was managed in a variety of ways, sometimes the patient's right of autonomy was treated in a dignified way but the opposite was also evident. In one way, patients are active and willing to take responsibility for themselves, and at the same time they are "forced" to do so by health care staff. Patients would like health professionals to be more attentive and proactive.

**Key words:** *Autonomy, self-management, independence, dignity, integrity*

(Accepted: 19 April 2011; Published: 27 May 2011)

The study reported here is based on a research project that started in 2005. The aim was to study patients', nurses', and nursing students' experience when meeting with the suffering—from a perspective that cultivates care ethics in which personal autonomy, dignity, and integrity are central concepts. This article focuses on Danish patients' experiences of autonomy and its interplay with human dignity and integrity when meeting with health professionals.

Nurses' professional care ethics are formed by the patient's suffering and vulnerability, which appeal to the health professional's ethics and morals, inducing him/her to help the patient (Delmar, 1999, 2006; Eriksson, 1993, 1994, 1995; Martinsen, 1993, 2005, 2006; Rundqvist, Sivonen, & Delmar, 2010; Välimäki et al., 2004).

However, the patient's appeal for help may fail for a number of reasons. The nurse's own ethical formation may be obstructed by her own vulnerability or by

a lack of opportunity to exercise care resulting from demands for efficiency, and so on. Furthermore, patients may suddenly find that their normal way of life is in jeopardy. They risk losing control of their own life and may, from one day to the next, have to depend on others for help.

But in the health care sector and our society in general, independence of others' help, self-dependence, self-determination, and the opportunity to choose and take responsibility for one's own life is a dominant value called autonomy. This is not only pointed out by empirical research; the ethical literature on the subject is also dominated by an interpretation of autonomy where the original meaning of autonomy relates to independence (Van Thiel & van Delden, 2001). When care aims at the patient's independence of others' help and self-dependence and the promotion of own choice and responsibility, there are questions to be raised to enlighten the limitations of autonomy.

## Background

Studies concerning meeting the suffering and vulnerable patient have increased during the last 10 years (e.g., Arman, 2003; Cronqvist, 2004; Delmar, 2002, 2004; Delmar et al., 2005; Delmar et al, submitted 2011; Eriksson, 1993, 1995; Hasselhorn, Tackenberg, & Muller, 2003; Heggen, 2003; Kelly, 1998; Lindqvist, 1991; Mitchell, 2003; Posig & Kickul, 2003; Rehnsfeldt, 1999; Rowe, 2003; Rundqvist, 2004; Söderberg, 1999; Sörlie, 2001; Thiedemann, 2005).

But literature searches (latest search from 31 January 2011) revealed a scarcity of empirical studies that specifically examine the meanings and implications of autonomy from a patient perspective and even fewer that concern their interplay with dignity when the patients are in need of health care. Some authors have attempted to define the concept of autonomy through literature studies and concept analyses (Keenan, 1999; Kravitz & Melnikow, 2001; Nessa & Malterud, 1998; Proot, Crebolder, Abu-Saad, & Ter Meulen, 1998). The authors conclude there is a need for further empirical research in relation to the patient perspective.

Six empirical studies, four qualitative studies and two quantitative studies, also contribute to the demand for developing knowledge about the meanings and implications of autonomy. The two quantitative studies (Välimäki, 1998; Vernooij-Dassen, Osse, Schadé, & Grol, 2005) may contribute to a general operationalisation of the concept of patient autonomy, emphasising in particular factors such as dependency, loss of control, limitations of activities, and informational support offered by health care professionals on patients' informed decision making. The four qualitative studies (Dickert & Kass, 2009; Ellefsen, 2002; Lomborg, Bjørn, Dahl, & Kirkevold, 2005; Luoma & Hakamies-Blomqvist, 2004), however, point to specific experiences that report patients' attempts to preserve their dignity by various adaptive manoeuvres and compensatory acts. Lomborg et al. (2005) and Luoma and Hakamies-Blomqvist (2004) show that limitations in physical function create dependency on others, which provokes a sense of helplessness and, thus, constitutes a threat to patients' dignity and personal integrity. Ellefsen (2002) shows that obstacles to leading a normal life, such as those posed by home care administrations with erratic planning, may also compromise patients' self-esteem and integrity. The fourth qualitative study (Dickert & Kass, 2009) examines what it means to be respected as a person beyond autonomy. The researchers found that making patients feel respected is a multi-faceted task that incorporates empathy, care, provision of information, recognition of individuality, attention

to needs, autonomy, and dignity. But, in fact, the study did not describe the interplay between autonomy and dignity.

The values associated with autonomy that support independence, self-dependence, self-determination, and taking responsibility for one's own life are in many ways vitalising in that the health care provider is constantly obliged to take care not to patronise patients by usurping their responsibilities and not giving them the chance to cope on their own. The patients should be their own masters. The question is whether autonomy is always in the best interest of the patient or it may inspire an unfortunate conception of patients as being *always* active and self-managing, which may lead to neglect of the patient in regards to patient's dignity. The issue, however, is the dilemma between independence as a dominant value and the patients' dependency on others, constituting a threat to patients' dignity—as the literature searches show. Therefore, the aim of this empirical study is to chart the implications of the meaning of autonomy for patients whose illness places them in a vulnerable life situation.

## Theoretical and philosophical framework

The understanding of the original meaning of autonomy (independence) and the interplay with personal dignity in the meeting with health care staff are central concepts in the framework. The aim of fostering the growth of care ethics in the health care sector is to help the patient come to terms with himself/herself and his/her environment (Pahuus, 1994) with a mindful respect of the person's dignity. A person's dignity is linked to the ability to cope on one's own and being independent of others' help. Independence, self-determination, and the ability to choose and take responsibility for one's own life are summed up in a value system and view of life that may be called autonomy (Bauman, 2000; Delmar, 1999; Eriksson, 1993; Wyller, 2001).

Being mindful of a person's dignity also involves respecting integrity; originally meant "untouched" or "whole." It refers to the fact that every individual is bound up in a complex life situation that may disintegrate if tampered with. When a person falls ill, however, it is neither possible nor desirable that their integrity is left untouched, but it should be borne in mind that an intervention may be healing as well as invading (Andersson, 2008; Eriksson, 1993, 1994, 1995; Martinsen, 1993, 2005, 2006). In a concrete care ethical context the intervention may be healing in order to respect a persons more or less complex life situation.

In the Nordic countries, the patient's legal status and the general principles governing the patient's

autonomy and rights are regulated by national legislation. The aim is to ensure that the national health authorities respect the patient's dignity, integrity, and entitlement to self-management and that trust and confidence between patients and staff is promoted (Finlands författningssamling, 1992; Stortinget, 1999; Sundhedsministeriet i Danmark, 1998; Sveriges Hälso-och sjukvårdslag, 1982). The legal framework is thus intended to contribute to society's moral view of human nature as well as the health care professional's moral responsibility in relation to people who are in need of health care. But the framework can dictate only minimum requirements, which are always to be considered in the concrete meeting at hand.

### **Study design and methods**

This study is based on interviews with eight Danish patients. With a hermeneutical phenomenology approach, data were collected through qualitative interviews with semi-structured questions, as originally described by Kvale (1996). The data analysis was carried out on three interconnecting levels with the aim of creating a condensation of meaning.

#### *Selection of participants*

The participants were selected in a process using Polit and Hungler's (1999) strategic sampling technique while covering a broad field of specialties so that both acute, chronic, and life threatening diseases were represented including surgical as well as medical patients. This strategy was chosen because the experience of suffering and vulnerability depends on a number of specific factors relating to the disease and the degree to which it affects patient's total life situation.

The patient group included:

- Two patients diagnosed with life-threatening cancer contacted within a few days after the diagnosis.
- Two patients whose everyday lives were formed by a chronic illness. The patients were identified through patient associations.
- Two patients admitted to an emergency ward to undergo an operation.
- Two patients called in for a diagnostic evaluation.
- Seven patients were contacted via the hospitals' managing nurses, who acted as gatekeepers. Contact to one of the chronically ill persons was mediated by the patient association.

#### *Material and analysis*

The semi-structured interview guide concerned the implications for an ill person to take responsibility for himself/herself and of making significant choices. The questions were intended to uncover how the patient, in his/her role as someone who depends on others help, can preserve his/her self-determination and responsibility. The interviews lasted from 1 to 2 h, which corresponds with other qualitative research interviews of this kind. The interviews were taped and transcribed verbatim. The analysis and interpretation was carried out in three cycles: the interviewees' self-understanding, a critical common-sense analysis that gradually introduced the third level, and the identification of unifying themes (Kvale, 1996; Kvale & Brinkmann, 2009).

The first cycle resulted in a preliminary and open systematization of the interview data. Each of the statements was taken at face value to get a first understanding of "What is being said here?" The next cycle led to a more focused interpretation in which the researcher asked questions such as "What does this mean?"; "What is being discussed here?", and so on. In this phase recurring themes can be identified, leading to an incipient generation of theory in the sense that Kvale uses it. Theory was finally applied in moving from a pre-interpretation to a discussion of the themes. The choice of theory was based partly on the themes that emerged as a result of the analyses and partly on the researcher's estimation of what would help connect the data in new fruitful ways. The texts underwent a total of analysis 10 times, trying to interpret the meaning deeper and deeper each time.

### **Findings**

With the aim to chart the implications of the meaning of autonomy, three types of behaviour were found: (1) the proactive patient, (2) the rejected patient, and (3) the knowledgeable patient. Each of the types contributes to a deeper understanding of the patient's feelings and expectations by being a person in a vulnerable life situation.

1. The proactive patient—feelings of responsibility and guilt

The study shows that patients assume a strong sense of responsibility by insisting on active participation through the course of their treatment. It also appears that when patients are unable to maintain their involvement, they may start blaming themselves and they may develop a sense of guilt. The following statement was made by a 48-year-old blind woman,

who had lived with chronic diabetes for many years. She had been receiving dialysis treatment since 1987 and had had a kidney transplant.

...nobody ever seems to follow up on things ... they'd got the results of one of the tests. I didn't ask ... but then after the [summer] holidays I began to ask, but they'd certainly keep a look out for them, and then, when I was there the next time, no, there was nobody who'd looked and I'm sure I asked three times // It turned out they'd been lying there for a month, the results. That's when I start to think: who's supposed to deal with them. // [I have to] remember it all myself, but sometimes when there's a bit too much going on [I can] forget ... I'm not the one who's supposed to remember all the time, I certainly don't think so.

In the first line the patient indicates that there was no proper co-ordination of examinations. She repeatedly asked staff for information and did not give up taking the initiative, although she feels that this was not her responsibility—in any case not all the time. When there is no one to follow-up on things, the patient takes over responsibility for the process. She also feels it is difficult to take responsibility if there are lots of things going on around her. No proper answer was given when she came forward to ask and she experiences this as a rejection.

We also found that patients are not always adequately involved when decisions are made about treatment options. A 63-year-old woman, whose metastases had necessitated back surgery to relieve some of the symptoms, said:

I just think they [the doctors] had certain considerations [about the treatment], but I might well have wanted them to hear my thoughts on the matter, too, don't you think //And I blame myself as well that I didn't do anything about it while there was still the time...

The patient indicates that she was not involved in the deliberations about her treatment to the extent that she would have liked. She places great demands on herself in following up on her questions and taking part in the discussion of treatments options. Afterwards, she blames herself and seems to harbour a sense of guilt because she was not more actively involved in the situation.

In order to make an informed choice, patients have to have some basis on which to make their choice and they, therefore, have to rely on health care professionals to involve them in discussions about the various options concerning treatment. However, the question is how much responsibility

patients should be expected to take in the decision-making process. The patients who, by the very nature of things, find themselves in a vulnerable situation.

## 2. The rejected patient—proactivity and dignity

The study shows that the proactive patient ventures out with the expectation that his appeal will be taken seriously and that he will be met with understanding and help. If this expectation is not fulfilled, the patient is left in a helpless position and this may affect his personal integrity and dignity.

The following experience was related by a 24-year-old woman who had developed an acute appendicitis. The patient was rejected when she got the emergency doctor on the phone, but having been in pain all day, she summoned the strength to get to the hospital emergency service.

When I got in to see him [the doctor on duty] he said, SOOO [distorts her voice], I suppose you've come in to see whether it's your appendix or not. Then I said, no, I wouldn't say that's the reason exactly; I've come because my tummy really hurts, that's why. I've no way of telling whether it's one thing or another, have I? // and then he said that he doubted whether it hurt enough for them to do anything about it.

...it's not that I go running to the doctor every day of the week. Honest, I can't even remember the last time I was in a hospital// I phone cos I need help, cos it really hurt, and then they refuse to take you ... I thought he just couldn't be bothered to take me seriously [pause] ... but I just think when you don't call that often, it's not a joke, you're not phoning just to have someone to talk to, are you now?

The patient felt that she had created a disturbance and that she had not been taken seriously. The doctor seems to have expected to meet a patient who had a diagnosis ready, which she just needed to have confirmed, while she had come because of the pain. He immediately adopted a defensive attitude. In spite of her pain, the doctor was unsure if her pain was strong enough for her to be admitted. The doctor's conduct and actions may lead the patient to see herself as a hypochondriac—she said twice that she did not call just for the sake of it.

In being active, the patient takes responsibility for her own health but is rejected. By questioning the sincerity of her appeal for help, the doctor's scepticism causes the patient to feel ignored. The patient has ventured forward, only to be met by a lack of

understanding that she takes as misgivings about her credibility.

The following example, which was related by the blind woman with chronic diabetes, also shows that her expectation of being taken seriously is transformed into a feeling of having been rejected:

...of course I can be bothered. I just have to, otherwise something'll happen, something strange that can have really disastrous consequences. But sometimes I do think, oh no, how wearing it all is. It is really, that's how I feel // you always have to be one step ahead ... that's for sure and then there's no sense of understanding when you eventually lose your tether and start to howl, or whatever you do. Then they back off, don't they. Heavens, why on earth is she making such a scene.

The patient indicates that she must take on the role of being the driving force, and that she finds this to be extremely exhausting. Her fear is that otherwise the consequences may be fatal. She feels that staff express a lack of understanding for her position, and that being categorised as hysterical or histrionic is a threat to her dignity.

The examples above concern two proactive patients who have assumed responsibility for their own life situation but are met by rejection from the health care professionals.

Another aspect of rejection concerns patients' experiences when they are deprived of the opportunity to make their own choices, show initiative, and take responsibility. The 63-year-old woman that had metastases to the bones said:

I'd have liked to have heard some of the arguments for why [it would be sufficient to insert rods to straighten and support the back] and how long it can be expected to last // Maybe I'd have chosen to live with the drawbacks that would have caused. But I wasn't given the choice, now was I?

The patient indicates her wish to have been involved in the deliberations that led her doctors to offer a specific treatment and that they had elucidated the advantages and drawbacks of alternative treatments. She feels that she was not offered the chance to be sufficiently involved in the choice of treatments. This may be interpreted as a lack of respect for the patient's autonomy. The information presented does not allow us to offer a simple answer as to why health care professionals deprive patients of the opportunity to take responsibility. It may be questioned whether they do this in an attempt to protect the patient or themselves "... there is some sort of deep rooted desire to protect me from unpleasant

information, I think ... Maybe it isn't always easy to have insight. They can be right on that" (63-year-old woman).

It seems that patients have difficulty in being told the results of their examination when this involves "bad news." They have to insist on being told, as health care professionals apparently tend to protect patients from information of this kind. Acknowledging that there are limits to how much a human being can bear to hear, we would point out the risk of withholding from patients the information they need to make the best choices and decisions for their life. This kind of rejection may pose a threat to the patient's integrity and dignity.

### 3. The knowledgeable patient—resources and self-management

This finding occurs because three of the participants were (unexpected) health care professionals. The study shows that patients with professional insight into their illness and treatment express their wishes and suggestions for treatment. We saw that the patient's right of self-determination was managed in a variety of ways, for example, when patients took an initiative concerning treatment opportunities. Sometimes this was treated with respect and accommodated in a dignified way, but the opposite was also evident when patients had to insist on receiving sufficient information.

The 63-year-old woman quoted above was a very experienced medical laboratory technician. She continued:

The first time I brought it up and said what if [the vertebrae collapsed]? ... was it not better to stiffen it beforehand, and then I was told that that was far too big and complicated an operation for it to be one that they did like that beforehand.

Then they observed that the [tumour] had broken through the front surface [of the bone]. So I brought it up once more, and that's when she [the doctor] said, all right so she'd refer me to the orthopaedics then, and I had the feeling that then I had absolutely no reason to complain that nothing had been done.

The patient is left with the impression that her concern has not been taken seriously. She experiences that the oncologist's first reaction was not particularly helpful in clearing up whether her suggestion with regard to treatment was relevant as this would have required an orthopaedic assessment. But because of her insistence, she was ultimately referred to the other ward, but she was left with the impression that she had not been taken seriously.

When patients are resourceful and are both insistent and knowledgeable, health care professionals are not always capable of treating their suggestions in a respectful way. The patient's right to self-determination is not always managed appropriately.

The proactive patient is aware that successful treatment depends on his own efforts. He therefore needs to mobilise all his experience and professional knowledge and invest his personality. A 34-year-old doctor who had broken his ankle in a bicycle accident indicated that his professional knowledge was crucial in gaining influence on his treatment.

We argued a bit about the anticoagulant [Fragmin], about whether it was really necessary and so on, but, mmm, somewhere along the line they can see that I'm right.

Although this patient took an active role in his treatment, claimed his right to self-determination, and his wishes were accommodated by staff, it is interesting to note that at first he chose to remain passive when his need of care was neglected:

Because they're so bloody busy in this ward, here ... I've chosen to be a patient who doesn't create a fuss, unless they don't come // on Saturday, there they forgot to give me my food, time passed, two hours passed // so I called and asked if maybe there was a bit more food or what?

It seems that the patient was able to use his professionalism in directing attention towards certain treatments, although this was not accepted without resistance. A patient with a relevant profession background could stand a better chance of being heard.

Health care professionals are obliged to safeguard the patient's right to self-determination and should be mindful of patients who for various reasons are unable to play the role of a resourceful person. There may be a danger that resourceful patients will influence health care professionals' conception in an inappropriate way by leading them to understand self-management as the undisputed goal of health care.

Another interviewee's testimony showed that a combination of initiative and professional insight may be necessary to gain sufficient information. The patient was a trained nurse who had left the profession.

I broke my thigh on Christmas Eve last year // then the nurse comes in and [asks] have you fasted? No, uh, I haven't. All right, so you'll start from now, then. Uh okay, are you going to operate, I

then ask. Yes we are ... sometimes they must think we're mind readers.

The mention of fasting made the patient aware that an operation had been planned, but no one had apparently informed her about this. A proactive patient who asks questions in time could stand a better chance of receiving information. Once again we see that the staff's oversight of the basic obligation to give information leads patients to conclude that they have to be proactive.

The study also gave examples that show that it is left up to patients themselves to make sure that they are not left helpless. The above quoted patient said:

... just lying down there in the emergency ward and they leave without checking if I have a pull cord, imagine ... again because of my background, I've managed to say—hello, couldn't I just have a pull cord, it's rather good to have. Mmm, I do think that you're often treated as though you're a bag of potatoes.

According to the patient, it was her training as a nurse or her long experience as a chronic patient that made her take the initiative and react.

The way it is interpreted by the patient as being overlooked by the staff, affects the patient's sense of self-esteem and human value. It amounts to the reification of the patient—a bag of potatoes—and a gross transgression of care traditions that should uphold the innate value of the individual, whatever their formation or position.

### Summary of findings

An interpretative summary of the connection between the three themes is presented. In the meeting between patients and health professionals the dignity of patients may actually be imperilled. When autonomy becomes the overarching goal of health care, there is a risk that health care professionals develop inappropriate conceptions of patients' ability to be active and self-managing. There is a risk that the health professional may leave too much in the hands of the patient; the situation may get out of control with possible detrimental effects for the dignity of the patient.

The patients themselves feel that they assume responsibility for their own situation, but it may be a responsibility that they find hard to bear because the purportedly self-managing patients may not be able to master their lives when the insecurity fostered by the volatility and the vulnerability of their situation becomes too great a burden.

Proactive patients take responsibility on many occasions; that is, in their co-operation with health care professionals, in steering the course of their hospitalisation, and in connection with care interventions and decisions concerning treatment. The patients consider their proactive stance as necessary for forming their life situation as a whole and, indeed, their very survival. Their accumulated experience seems to strengthen their conviction that it is their personal effort that determines whether or not the result will be successful. Likewise, the patients' past experiences, knowledge, and personality play a role in whether they take the initiative in their meeting with the health care professional.

By taking the initiative, the patient ventures forward with an implicit appeal for help, hoping that he will be taken seriously, and being met with understanding. The situation contains an inherent conflict, as the patient's expectations may collide with the health care professional's preconception of the "good" or "co-operative" patient. Very active patients are at risk of being rejected, with consequences for their dignity. Asking for help may be difficult for a patient because of the exposure involved. It could affect personal integrity in such a way that resignation and feelings of loneliness sets in. The patient's dignity is imperilled and the implicit appeal for help is in danger of being overlooked and ignored.

## **Discussion**

Our examination of the connection between the three themes—the proactive patient, the rejected patient, and the knowledgeable patient—has demonstrated that patients are active and willing to take responsibility for making their own choices, and at the same time they are "forced" to do so by health care staff. Health professionals bear a certain amount of responsibility for the patient's treatment and care, but as our study shows, there seems to be an imbalanced distribution of responsibility with the result that too much is imposed on the patient. This involves everything related to being a patient, such as care interventions and decisions about treatment decisions, as well as their relationship and cooperation with staff. Their proactive stance seems to be a result of their own inclinations, the circumstances, and the expectations of the health staff. Nevertheless, this role may be a difficult one, especially when the situation deteriorates or other circumstances divert their attention. Proactive patients are convinced that a good outcome depends on their own efforts, a position that makes them vulnerable to self-recrimination and feelings of guilt, particularly if their situation later

makes them incapable of maintaining an active participation.

Although health care professionals seem to encourage patients to take an active role, there is an imminent risk of rejection if they are experienced as being too active. Patients may be seen as over-reacting, a situation that puts the patient's dignity at stake.

Asking for help may affect a person's feelings of dignity and personal integrity, with the result that the feeling of helplessness gets the upper hand (Andersson, 2008; Delmar, 1999). Our findings have shown that patients would like health staff to be more attentive and proactive and that they expect to be taken seriously and to be consulted in accordance with their competences, resources, and knowledge.

The ethical formation of carers aims at supporting the patient in coming to terms with himself/herself and his/her situation (Pahuus, 1994), and one way of achieving this is for the patient to be able to take care of himself/herself, to take the initiative, and to assume responsibility for his/her own choices. Although encouraging this in the patient is life-giving in many ways, an overly strong emphasis on the value of autonomy may inspire the unfortunate conception that patients will, and can, always be active, self-managing, and capable of making the right decisions for themselves.

In such cases, the philosophy of life and human nature that informs our liberalistic and individualistic society may have contributed to a suppression of the basis for care that helps patient's retain their dignity and integrity (Delmar, 1999; Martinsen, 1993). When this occurs, self-management has become such a dominant value that there is a risk of abandoning the patients. Rather than becoming a life-giving value in support of the patient's dignity, the ideal picture of the autonomous patient tends to become disconnected from the specific situation. The oversight of patients and their concrete situation is a threat to their integrity and is detrimental to the nurturing of care ethics that would help patients in coming to terms with themselves.

We have also seen that the relationship between patients and health professionals is two-faced. On the one hand, it is based on a realistic assessment of the patient's situation, his wishes, expectations, and level of ability, but on the other hand, we detect efforts that are informed by the professionals' picture of an ideal, autonomous patient—leading to care that ignores the patient's appeal for help and attention. This represents the health care professionals' failure to fulfil their professional responsibilities, with the result that the patient must endure

unnecessary suffering when submitted to care (Eriksson, 1994).

It is a well-documented fact that the fear of becoming dependent on others' help is firmly rooted in our individualistic values (Van Thiel & van Delden, 2001). The saying that every man is the architect of his/her own fortune still seems to carry much credit. Dignity is closely connected with retaining the ability to manage on one's own and remain independent of others' help. In situations where help is needed, there is a risk that the individual will feel inadequate and guilty. A sense of guilt and self-inflicted problems thus go hand-in-hand with the responsibilities associated with self-management.

We may legitimately ask whether the ideal of self-management is always in the patient's best interest or whether it can pose a threat to the patient's dignity and integrity. Our position is that upholding the ideals of self-management and independence as the foundation of nursing may place the patient in an extremely vulnerable position when he/she is in dire need of authoritative professional care.

## Conclusion

The values associated with autonomy are in many ways vitalising in that the nurse is constantly obliged to take care not to patronise patients by usurping their responsibilities and self-government. The problem, however, is that this perspective on dignity may become so dominant and autonomy seeking and pervasive that the patient's dignity is affected and, therefore, be at the risk of obstructing the patient's call for help. In one way patients are active and willing to take responsibility for making their own choices, and at the same time they are "forced" to do so by health care staff.

Three types of behaviour were found: the proactive patient, the rejected patient, and the knowledgeable patient. Each of these types contributes to a deeper understanding of the patient's feelings and expectations by being a person in a vulnerable life situation. Patients would like health professionals to be more attentive and proactive.

## Ethical approval

All participants were informed about the purpose of the research. They signed a declaration of informed content and were ensured anonymity in the published work as well as confidentiality as far their identity was concerned. As this type of study does not require registration with the Danish Science Ethics Committee, the ethical guidelines for nursing research in the Nordic countries were applied during

the whole research process, especially respecting the patient's dignity and integrity in the interview situation (SSN, 2003).

## Acknowledgements

We wish to thank the patients of the study for sharing their life experience with the researchers.

## Conflict of interest and funding

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

## References

- Andersson, M. (2008). *Integritet som begrepp och princip. En studie av ett vårdetisk ideal i utveckling* [Integrity as a concept and a principle. A study focusing on the development of a caring ethical ideal]. Akademisk avhandling, Åbo: Åbo Akademis Förlag.
- Arman, M. (2003). *Lidande och existens i patientens värld: kvinnors upplevelser av att leva med bröstcancer* [Suffering and being in the world of the patient: Women's experiences of living with breast cancer]. Akademisk avhandling, Åbo: Åbo Akademis Förlag.
- Bauman, Z. (2000). *Savnet fellesskap* [Missing a sense of community]. Oslo: Cappelen Akademisk Forlag.
- Cronqvist, A. (2004). *The moral enterprise in intensive care nursing*. Stockholm: Karolinska Institute.
- Delmar, C. (1999). *Tillid og Magt*. En moralsk udfordring [Trust and power. A moral challenge]. Copenhagen: Munksgaard.
- Delmar, C. (2002). Omsorgsetik—også et spørgsmål om videnudvikling [Care ethics: Also a question of knowledge development]. *Klinisk Sygepleje*, 16(2), 35–40.
- Delmar, C. (2004). Development of ethical expertise: A question of courage. *International Journal for Human Caring*, 8(3), 8–12.
- Delmar, C. (2006). The phenomenology of life phenomena—In a nursing context. *Nursing Philosophy*, 7(4), 235–246.
- Delmar, C., Bøje, T., Dylmer, D., Forup, L., Jakobsen, C., Møller, M., et al. (2005). Achieving harmony with oneself: Life with a chronic illness. *Scandinavian Journal of Caring Sciences*, 19(3), 204–212.
- Delmar, C., Rundqvist, E., & Sivonen, K. (submitted March 2011). The interplay between autonomy and dignity—A resumé review within a patient perspective. *Nordic Nursing Research*.
- Dickert, N. W., & Kass, N. E. (2009). Understanding respect: Learning from patients. *Journal of Medical Ethics*, 35(7), 419–423.
- Ellefsen, B. (2002). Dependency as disadvantage—Patients' experiences. *Scandinavian Journal of Caring Sciences*, 16, 157–164.
- Eriksson, K. (Ed.). (1993). *Möten med lidanden* [On meetings with suffering]. vårdforskning, rapport 4/1993. Åbo: Institutionen för vårdvetenskap, Åbo Akademi.
- Eriksson, K. (1994). *Den Lidande Människan* [The suffering human being]. Häftad: Liber AB.
- Eriksson, K. (1995). *Mot en caritativ vårdetik* [Towards a caritative health ethics]. Åbo: Institutionen för vårdvetenskap, Åbo Akademi.



- Finlands författningssamling. (1992). [The collection of the statutes of Finland]. *Lag om patientens ställning och rättigheter 17.8.1992/785*. [The law on the patient's legal status and rights 17.8.1992/785].
- Hasselhorn, H.-M., Tackenberg, P., & Muller, B. H. (2003). *Working conditions and intent to leave the profession among nursing staff in Europe*. No. 7. Wuppertal: University of Wuppertal, Hem. MH.
- Heggen, K. (2003). Being professional and being human: One nurse's relationship with a psychiatric patient. *Journal of Advanced Nursing*, 43(1), 101–108.
- Keenan, J. (1999). A concept analysis of autonomy. *Journal of Advanced Nursing*, 29(3), 556–562.
- Kelly, B. (1998). Preserving moral integrity: A follow-up study with new graduate nurses. *Journal of Advanced Nursing*, 28(5), 1134–1145.
- Kravitz, R. I., & Melnikow, J. (2001). Engaging patients in medical decision making. *BMJ*, 323, 584–585.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, CA: Sage.
- Kvale, S., & Brinkmann, S. (2009). *Interview—Introduktion til et håndværk* [Interview—Introduction to a craft]. 2nd ed. Copenhagen: Hans Reitzels Forlag.
- Lindqvist, M. (1991). *Med människan som yrke. Om etik och värderingar inom vården* [With human beings as one's calling. On ethics and values in healthcare]. Helsinki: VAPK-Förlaget.
- Lomborg, K., Bjørn, A., Dahl, R., & Kirkevold, M. (2005). Body care experienced by people hospitalized with severe respiratory disease. *Journal of Advanced Nursing*, 50(3), 262–271.
- Luoma, M.-L., & Hakamies-Blomqvist, L. (2004). The meaning of quality of life in patients being treated for advanced breast cancer: A qualitative study. *Psycho-oncology*, 13, 729–739.
- Martinsen, K. (1993). *Fra Marx til Løgstrup. Om moral, samfunnskritikk og sanselighet i sykepleien* [From Marx to Løgstrup. On morals, social criticism and sensuousness in nursing]. Oslo: A/S Tano.
- Martinsen, K. (2005). *Samtalen, skjønnem og evidensen* [Dialogue, judgment and evidence]. Oslo: Akribe.
- Martinsen, K. (2006). *Care and vulnerability*. Oslo: Akribe.
- Mitchell, V. (2003). A loss of compassion. *Nursing Standard*, 17(18), 23.
- Nessa, J., & Malterud, K. (1998). Tell me what's wrong with me: A discourse analysis approach to the concept of patient autonomy. *Journal of Medical Ethics*, 24, 394–400.
- Pahuus, M. (1994). *Sandhed og storhed. Om nogle eksistentielle dyder og laster* [Truth and greatness. On some existential virtues and vices]. Copenhagen: Gyldendal.
- Polit, D., & Hungler, B. (1999). *Nursing research principles and methods*. Philadelphia, PA: Appelton-Crofts.
- Posig, M., & Kickul, J. (2003). Extending our understanding of burnout. *Journal of Health Physics Society*, 8(1), 3–19.
- Proot, I. M., Crebolder, F. J. M. H., Abu-Saad, H. H., & Ter Meulen, H. J. R. (1998). Autonomy in the rehabilitation of stroke patients in nursing homes. A concept analysis. *Scandinavian Journal of Caring Sciences*, 12, 139–145.
- Rehnsfeldt, A. (1999). *Möte med patienten i ett livsavgörande skeende* [Meeting the patient at a crucial point in time]. Åbo: Åbo Akademi's Förlag.
- Rowe, J. (2003). The suffering of the healer. *Nursing Forum*, 38(4), 16–20.
- Rundqvist, E. (2004). *Makt som fullmakt. Et vårdvetenskapligt perspektiv* [Power by proxy. A healthcare science perspective]. Åbo: Åbo Akademi's Förlag.
- Rundqvist, E., Sivonen, K., & Delmar, C. (2010). Sources of caring in professional nursing—A review of current nursing literature. *International Journal for Human Caring*, 14(1), 36–43.
- Söderberg, A. (1999). *The practical wisdom of enrolled nurses, registered nurses and physicians in situations of ethical difficulty in intensive care*. Umeå University Medical Dissertations, no. 603.
- Sörlic, V. (2001). *Being in ethically difficult care situations. Narrative interviews with registered nurses and physicians within internal medicine, oncology and paediatrics*. Umeå University Medical Dissertations, no. 727.
- SSN, Sykepleiernes Samarbeid i Norden. (2003). *Etiske retningslinier for sygeplejeforskning i Norden*. [Cooperation amongst nursing staff in the Nordic countries. Ethical guidelines for nursing research in the Nordic countries]. Copenhagen: DSR.
- Stortinget. (1999). [The Norwegian Parliament]. *Pasientrettigheter af 2. juli 1999, no. 63 om pasienters rettsstilling*. [Patients' Rights of 2 July 1999, no. 63 on the legal status of patients].
- Sundhedsministeriet i Danmark. (1998). [The Danish Ministry of Health]. *Lov nr. 482 af 1. juli 1998 om patienters rettsstilling*. [The Danish Ministry of Health. Law no 482 of 1 July 1998].
- Sveriges Hälso-och sjukvårdslag 1982:763 (1982). [The Swedish law on patients' legal status].
- Thiedemann, I. J. (2005). Den sårbara læringsarenen—om praxisfelleskapets implikasjoner for sykepleiers læring og kompetensutvikling. [The vulnerable learning arena—The implications of having a common praxis for nurses' learning and the development of their competences. *Vård i Norden*, 75(1), 10–15.
- Välämäki, M. (1998). *Self-determination in psychiatric patients*. Doctoral dissertation, Turku, Turun yliopisto, Annales Universitatis Turkuensis D 288.
- Välämäki, M., Leino-Kilpi, H., Gronroos, M., Dassen, T., Gasull, M., Lemonidou, C., et al. (2004). Self-determination in surgical patients in five European countries. *Journal of Nursing Scholarship*, 36(4), 305–311.
- Van Thiel, G. J. M. W., & van Delden, J. J. M. (2001). The principle of respect for autonomy in the care of nursing home residents. *Nursing Ethics*, 8(5), 419–431.
- Vernooij-Dassen, M. J. F. J., Osse, B. H. P., Schadé, E., & Grol, R. P. T. M. (2005). Patient autonomy problems in palliative care: Systematic development and evaluation of a questionnaire. *Journal of Pain and Symptom Management*, 30(3), 264–270.
- Wyller, T. (Ed.). (2001). *Skam—Perspektiver på skam, ære og skamløshet i det moderne* [Shame: Perspectives on shame, honour and shamelessness in modern society]. Bergen: Fagbokforlaget.