Ventilated patients’ experiences of body awareness at an intensive care unit

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Abstract

Treatment with mechanical ventilation (MV) in an intensive care unit (ICU) can cause extensive problems for patients. There is, however, a dearth of research investigation into how ICU treatment affects a person’s body image. The aim of this study was to enhance the knowledge and understanding of body awareness and body image in persons treated with MV in an ICU. In order to capture the informants’ own perceptions and experiences, a qualitative method of Grounded Theory was chosen. Seven thematic in-depth interviews were carried out with former ICU patients. To increase credibility, triangulation of researchers and reference group checking was used. The analysis resulted in the core category Limited possibilities to act, which relates to the informants’ experiences of not being able to act as they normally would. The core category was derived from the experiences of feeling like another person, the perceptions of not being in contact with their body and reality and the feeling of being restrained. This study adds a perspective of body awareness to the interpretations of ICU patients’ experiences. It emphasizes the experience and movement aspects of the body and that physiotherapists have an important role in the rehabilitation of ICU patients.

Key words: Body image, intensive care, mechanical ventilation, physiotherapy, qualitative research

Introduction

Patients are treated in an intensive care unit (ICU) when requiring intensive monitoring, intensive therapy or both, due to threatening or manifest insufficiency of vital organ functions. Some of the patients are in need of mechanical ventilation (MV) (1,2). Treatment with MV and treatment in an ICU can cause extensive problems for patients both physically and psychologically (1,3). Various motor problems can appear, in many cases as a direct result of underlying medical or surgical illness or by immobilization due to bed rest (2,4,5). In others, it is the result of drugs (2) or complications of sepsis (4,5). Signs of lack of motor control, unco-ordinated movement and total immobility are described in literature (6).

ICU treatment and MV can affect a person’s body image. Body image distortion, altered body image, changed body image and extended body image are different terms used in the literature (1,7,8). The latter is used when a person incorporates equipment attached to her/him (8). In this article, we use the others as synonymous terms. In Gjengedal (1), it emerged that some patients described a sense of losing contact with their own bodies, and that the body became an object outside of themselves. They expressed a feeling of separation between body and mind. The indifference towards their bodies was thought to have been caused by medication as well as immobility (1). Descriptions exist of patients feeling their body boundaries being permeable and they incorporate the equipment attached to them into their body image (7,8). A person’s body image can also be affected by weight loss and oedema (7).

The terminologies used for describing how a person experiences the body and movement have no standard definitions. In this article, the definitions by Roxendal (9,10) and Mattson (11) are adopted. Body awareness is the superior concept for the experience and movement aspect of the body. It relates to the bodily aspect of a person’s total consciousness. Body image is built on a person’s own perception of the body and has to do with
attitudes to their own appearance, experiences of the body and perceptions of the size and proportions of the body. Body boundaries are the experience of the body’s delimitation towards other people and the world around. Body management is the ability to control the body’s position, movement and muscular tone (9–11).

There is a dearth of research investigating how ICU treatment affects a person’s body image (7) and the concept of changed body image is not well recognised (8). A literature search was performed on MEDLINE, Cinhal and PEDro in August 2003 using the keywords body image, body awareness, intensive care and critical care. In reviewing available literature using this search strategy, we have not found any study where the focus has been on a person’s personal perceptions of their body nor any study addressing the issue from a physiotherapy perspective.

The aim of this study was to enhance the knowledge and understanding of body awareness and body image in persons treated with MV in an ICU.

Methods

In order to capture the informants’ own perceptions and experiences a qualitative method, Grounded Theory, was chosen (12,13). An emergent design was applied, meaning that the design emerged during the study period, allowing the researchers to adapt the design as understanding deepened (12,14). The study was performed by the primary author (LJ), a physiotherapist in an ICU and the second author (AFW), a physiotherapist with experience of qualitative research and body awareness therapy.

Informants and data collection

Thematic, in-depth interviews (15) were performed with seven persons treated with MV in an ICU at a hospital situated in central Sweden. A maximum variation sample was chosen according to the following criteria (14): both women and men, variation in age, variation in length of time treated with MV, variation in reasons for admission to the ICU and variation in time after discharge from the ICU. Children under 18 years, persons with dementia and those who needed an interpreter or some other form of assistance to express themselves were excluded from the study. The first informant was a former patient at the clinic, chosen due to her willingness to share her experiences. The following informants were chosen one after another as interpretation of the data proceeded. All patients that met the inclusion criteria and contributed to the maximum variation sample were included in the study. Three informants were recruited during their stay at the hospital and four after discharge. Those interviewed were informed both orally and in writing of the aim of the study, and that their participation was voluntary and anonymous. All agreed to participate and signed a written consent before the interview. Three women and four men were interviewed; they varied in age between 48 and 68 years. Those interviewed received ventilation treatment for between 10 h and >30 days. They were admitted to the ICU because of planned surgery, acute surgery or because they required intensive therapy and/or support. They were interviewed from 10 days to 6 years after discharge from the ICU. In accordance with their own wishes, the informants were interviewed on the ward at the hospital, at the physiotherapy unit or in their own homes. Each interview lasted from 30 min to 1 h. All interviews were performed by the primary author, tape-recorded and transcribed verbatim. An interview guide was used covering two themes:

- The circumstances leading to treatment in the ICU;
- The informants’ attitudes and experiences of the body both during treatment with MV and during the time following the ventilator treatment.

The guide was used throughout the study, but the themes were changed slightly during the interpretations so that material from the former interviews could be taken into consideration in the later interviews.

Data analysis

The analyses were carried out using the Grounded Theory method of constant comparison (13,16). The analyses were initiated by an open coding procedure (16). To increase trustworthiness of the findings, triangulation of researchers (12) was used. It was established through an open coding procedure by both authors independently, followed by a mutual comparison and a final negotiated outcome (12). The open coding was performed using a computer program Open Code (17). In the following step of analyses, open codes with similar content were clustered into categories, categories were collated into intermediate categories and a core category emerged (16). To confirm the findings further, and to increase trustworthiness, a reference group check was performed. This was carried out by the findings being independently presented to two former ICU patients that had not previously been interviewed. The presentation was followed by a discussion to
explore how relevant the findings were to others treated with MV in an ICU.

Results

Consensus regarding several aspects about the experiences of MV and treatment in ICU was found. The experiences described were commonly shared among the informants although some of them may be more representative than others in each category and not all informants experienced everything described in every category. The persons involved in the reference group check recognized themselves very well in the description of the results. The analyses resulted in the following categories being identified: Affected body functions and difficulty to control the body; Changed appearance; Existential thoughts; Not at one with the body; Lack of trust in the body/themselves; Not in contact with reality and A feeling of being restrained. Two intermediate categories emerged: Another person and Insufficient access to the body. The intermediate category Another person was developed from categories of Affected body functions and difficulty to control the body, Changed appearance and Existential thoughts. The other intermediate category Insufficient access to the body was derived from categories of Not at one with the body, Lack of trust in the body/themselves and Affected body functions and difficulty to control the body. The core category, Limited possibilities to act, was derived from intermediate categories Another person and Insufficient access to the body and two categories Not in contact with reality and A feeling of being restrained. The relationship between the categories and the core category are shown in Figure 1.

The intermediate category Another person is derived from the informants’ experiences of not recognizing themselves as they were before the ICU stay. Their thoughts, appearance and bodily functions are changed and this has had a considerable impact on them. The intermediate category Insufficient access to the body is related to the informants’ perceptions of not being in contact with their body like they were used to being. They find it difficult to control their body, they do not feel as one with the body and they lack trust in the body/themselves while being treated in the ICU and for a period thereafter. The core category Limited possibilities to act relates to the informants experiences of changed conditions during their stay at the ICU and for a period thereafter. They do not perceive their bodies as before, they are not able to move as they normally would. This leads to the informants’ experiences of being unable to act and interact as normal. There is also a lack of freedom to move perceived by informants. The feeling of being another person, having a body they do not have full access to in combination with not being in full contact with reality and feelings of being restrained leads to the overall experience of limited possibilities to act. Examples of open codes, the categories and the core category are shown in Figure 2.

Figure 1. The informants’ perceptions of body awareness and body image. The relations between the categories and the core category.
Three categories were combined in this intermediate category: **Affected body functions and difficulty to control the body**, **Changed appearance** and **Existential thoughts**. The existential thoughts category is partly derived from the affected body functions and difficulty to control the body and changed experience categories. All three categories relate to the intermediate category independently. A striking consensus was noted regarding the informants’ perceptions of body management. They experienced **Affected body functions and difficulty to control the body** during and after their time in MV in the ICU. They had difficulty in moving their arms and legs, moving in bed, sitting up on the bedside and problems when they started trying to stand up and walk.

... everything was just awful, it felt tough, terribly tough, one became tired, and exhausted easily, breathlessness even when sitting and then standing up, it was like the worst experience of your life...

Some of them found it impossible to move at all or could move only some small part of the body such as their toes. Others could move, but experienced difficulty and were in need of help either from ambulatory aids and/or personnel. The informants experienced difficulty in controlling the body to different extents. Before they became ill they were used to being in control of their bodies but now they did not have full control of all body parts, or had to make a great effort to keep control of their body.

For example I was going to brush my teeth after I got here.

- Can you do it yourself?
- Yes I can, and then the toothbrush was up here (pointing at his cheek close to his ear).

The informants experienced weakness and stiffness when trying to move. The weakness affected their abilities to walk, to hold the knife and fork when eating and other similar activities in their everyday life. For some it was difficult or impossible to sit on the bedside because they lacked the strength to sit up straight and tended to collapse. Things that had been natural and automatic before the illness were now impossible. The informants considered their muscles as being withered, malfunctioning, weakened or absent. Some of the informants related...
that they were stiff and that muscles were too short. They also noticed that their senses had been affected during their illness. Some of them lacked sensibility in certain parts of the body while others had poor sensibility and feelings of numbness occurred. The experiences of affected body functions and difficulty to control the body evoked considerable emotions in the informants.

No, it didn’t feel like my body because I lacked the strength.

Thoughts about what had happened, why it had happened and if this was a permanent state came to some, while one informant continually had faith that everything was just temporary. The informants experienced feelings of hopelessness, powerlessness, dependence and resignation. They lost faith in ever recovering. For some it was difficult to be dependent on others and they felt that they were a nuisance, whereas others had no problem in depending on carers. The informants expressed relief and happiness when they noticed that their ability to move was improved, and the greatest satisfaction when they regained their independence. During their period of illness, the informants perceived a Changed appearance: they did not look the same as before their illness. They had all lost weight; to some it was a welcome weight loss, whereas others who had been satisfied with their weight before their infirmity wanted to regain all or at least some of the weight that they had lost. It was not only the weight loss that had changed their looks. Some of the interventions and surgical procedures undertaken had affected their appearances. Changed appearance could be difficult to accept.

... the face in the mirror was no longer mine. It was so hollow, a tooth missing, it was like, there was nothing left of me as I was used to seeing myself, which I experienced awfully.

Not recognizing themselves as they were before the ICU stay, both regarding looks and abilities, evoked feelings and thoughts for the informants that made an immense impact on them. Feelings such as shock, fear, sorrow and alienation were expressed, and the informants experienced Existential thoughts. Also the experience of having been very sick, some of them close to death, and the subsequent experiences of helplessness and dependency had affected them deeply. Some of them had reassessed life or gained a greater understanding for others after the period of illness. These thoughts came to the informants after they had had time to reflect on what they had experienced and what had happened or could have happened.

... I have revalued my time and intend spending more time with my family and grandchildren and children ...

Insufficient access to the body

The categories Not one with the body, Lack of trust in the body/themselves and Affected body functions and difficulty to control the body constitute this intermediate category. The categories relate to the intermediate category independently and to each other mutually. The informants expressed in different ways that they were Not at one with the body all the time, which made it more difficult for them to move and act. Difficulties in knowing the position and location of different parts of the body were expressed. At times, some of the informants could not tell if they were breathing themselves or were assisted by the ventilator. They expressed dissociation from their body and talked about parts of their body as “things”.

It was only my head that I could move. The other body parts were just there somewhere. I didn’t know where my arms and legs were, they were gone.

They experienced body boundaries diffusely, which made it difficult to tell exactly the difference between the body and the surroundings. One experienced the ventilator as a backpack attached to his back and that the ventilator was connected both to his mouth and his throat.

The worse part I think is the legs and the feet when you’re lying like this, you experience bad contact with any surface so it’s a bit weird but it will come, won’t it, once I get up a bit more ... It’s like; it feels almost like the ground is round under my feet ... A bit thick. I have my senses and all that, but they don’t feel like my real feet, they don’t.

The informants expressed that they, in some situations, had experienced Lack of trust in the body/themselves. Often it had to do with when they were going to do things such as sit on the bedside or stand up. They did not think that their bodies were capable of the task or that it was an impossible thing for them to do.

The legs wanted to, you had to make sure you had straight legs because otherwise
They felt that the lack of trust limited them from trying to do things; they were too afraid, too cautious. Instead of having confidence in themselves and their bodies, they put their trust in ambulatory aids and devices or in the ward staff. It was difficult for the informants to know what they could or could not do. Some overestimated their abilities and tried to do things they could not cope with while others underestimated themselves and had to be pushed into trying. As their faith in themselves and their bodies grew stronger, they dared to do more and expressed happiness regarding their achievements. The *Affected body functions and difficulty to control the body* category are described under the intermediate category Another person.

The informants perceived that they were *Not in contact with reality* while being in the ICU under ventilator treatment. The most striking feature in this category was the loss of memory. They all had clear memories from the ICU; some of them remembered a lot, others less. Some remembered ventilator treatment while others had no memory of that at all. They had appreciated learning about what had happened during the period they suffered from amnesia or they wanted to know after some time had passed. They had strange dreams, nightmares and hallucinations, which they experienced as frightening and horrible. As a consequence of the dreams and hallucinations, some of them had problems knowing what was real and what was a temporary dream.

...there were some nights after concluded ventilator treatment when I didn’t dare fall asleep. And then I guess I didn’t want to admit my concerns fearing that I would be send away to Poland, to the witches so I didn’t dare close my eyes.

The MV and the time in ICU confirmed that they temporarily lost all sense of time. To them it could just as easily have been night as day and they had little understanding or appreciation as to the duration of their illness. Possibilities of communicating during ventilator treatment or with a tracheotomy tube varied. Because they had problems moving and controlling their arms, writing or communicating with gestures was a problem for some. One of them felt trapped because he was unable to communicate with the ICU staff.

The informants expressed *A feeling of being restrained* physically and psychologically by all the equipment that was attached to their body in form of lines and tubes to machines, drips and medicines. Some experienced that the lines and tubes prevented them from moving in bed.

One felt fixed to all the equipment . . .

For others it was more like a feeling of being restrained rather than feeling that they were actually immobile because they were attached to the equipment. Some expressed a feeling of being liberated when the lines and tubes were removed. Others did not feel restrained by the equipment or accepted it and made the best of the situation.

**Discussion**

This study focuses on perceptions of body awareness and body image in persons treated with MV in an ICU and the impact that had on them. The findings show that limited possibilities to act was the core experience among the informants.

The findings do not deviate significantly from the results of other studies that focus on patient experiences of MV in ICU (1,18–21). The informants in this study experienced that their body management had been affected. That patients can experience it as being difficult or even impossible to move when treated with MV in ICU is quite well documented (1,18,22). Severe weakness and fatigue resulting in severe physical disability is the most common physical problem reported by patients treated with MV in ICU (22). Limited mobility, difficulties feeling the body and the consequences of that in combination with the environment in ICU can affect the patients’ awareness of her/his body boundaries, subsequently leading to body image distortion or an extended body image (7,8). In our study, the informants experienced a diffusion of the body boundaries in a similar way. Smith (8) suggests that passive limb exercise could help the patient redefine the body boundaries and Zubeck (cited in reference 7) has shown that limb movements can reduce the effect of sensory deprivation causing body image distortion. The suggested impact of limb movements on body image emphasizes the importance of limb movements for the ICU patients.

The informants’ experiences of diffuse body boundaries are one part of their perception that they were no longer at one with their body. Similar examples from the literature are the patients’ feelings of being disconnected from the body (8) and that the body does not exist. The informants’ perceived difficulties to control the body and to trust their body and themselves, is also reported in the literature. The lack of control of the body and the efforts of regaining control of the body are reported to lead
to difficulties in the patients’ understanding that they were unable to do certain things because of weakness (18).

The informants’ experiences of not being in unison with their body are also expressed as a feeling of dissociation and an alienation from the body. They talk about parts of their bodies as “things”, as having trust in the body, which is separated from having trust in themselves, and they talk as if the body is not a part of them. This is consistent with the findings in another study where patients expressed a sense of losing contact with their own bodies (1). The concept that body and mind are separated has its roots far back in time and has influenced philosophy, religion, psychology and medicine. The mind is seen as being superior to the body and the body as a tool for the mind (23). It is suggested that MV and ICU treatment enhance this feeling of a separation between body and mind. The study data indicates that the feeling is stronger at the time or soon after the ICU treatment and as patients recover and rehabilitate they become more in tune with their entire body.

The changed appearance perceived by the informants is supported by previous studies where the patients have noticed that their looks are changed after a period of illness (7,22). That changed appearance affects the body image is also observed and is considered as a part of the body image distortion seen in ICU patients (7).

The informants experienced that they were not in contact with reality all the time. Loss of memory is very common and quite well documented (1,18–22). Nightmares, disturbing and unpleasant dreams, hallucinations and fantasies are also seen to be very common (6,18–22). Difficulties in separating dream from reality (1,20,22) and distinguishing night from day (18–20,24) are also reportedly expressed by ICU patients treated with MV. Communication problems are well documented, often because of intubation (1,19,21,25) but also because of immobility, weakened body control, reduced muscular strength or impaired memory (1).

The informants experienced a feeling of being restrained, in common with previous studies (1,7,18,21,24). In our study, in order for the informants to feel restrained by the equipment attached to them, they had to retain an ability to move. This suggests that healthcare professionals can add to the patients feeling of being restrained by how they act and communicate with them. Often the patient may not be encouraged to spontaneous movement by caring acts which attempt to avoid risking patients accidentally pulling out some line or tube.

The informants experienced affected physique, lack of control of the body and lack of trust in the body/themselves. They had difficulty knowing what they could/could not do and sometimes lacked the initiative to move in bed, or to sit up. These experiences point to a specific role in the rehabilitation of ICU patients for physiotherapists in assessment, planning and conducting treatment together with ward staff to ensure that the rehabilitation process continues throughout the hospital day.

Adopting approaches drawn from body oriented therapies such as body awareness therapy (BAT) (9), Feldenkrais pedagogy (26) or T’ai-chi Ch’uan (27) may help these patients to redefine their body boundaries, to be at one with their bodies, to feel confident in themselves and to be in contact with reality. The core elements in body-oriented therapies include use of a holistic perspective, which focus on the body-as-a-whole and body and movement awareness (28,29).

There is a need for more knowledge both about these patients, their problems and the contribution body oriented therapies can make to their rehabilitation. It is important to stress that experience indicates that the problems of altered body awareness in ICU patients do not disappear when they are discharged from the ICU. Physiotherapists and other healthcare professionals who meet these patients later on hospital wards and at rehabilitations clinics need to know more about how to approach and treat them.

**Trustworthiness**

A greater variation in both age and causes of ICU treatment represented in this study could broaden the picture of how body awareness and body image are experienced during/after MV in an ICU. A larger number of informants’ reports of their memories of their time with MV could also give further information. These informants were interviewed from 10 days to 6 years after discharge from ICU. The length of time between ICU stay and interview may have affected how much they remembered; however, it was noted that the informants interviewed early after their ICU stay had not reflected as much upon their experiences as those interviewed at a later stage. These results are based on a small sample. The experiences of change in ICU patients’ body awareness and body image has not been well studied and further research is needed in order to learn how to approach these patients in the best possible way. To increase credibility we used triangulation of researchers with different background (12) and reference group checking. Prolonged engagement (12,30) and the insider perspective were represented.
by one interviewer's (LJ) in-depth knowledge about ICU treatment. The fact that the informants knew the interviewer possibly made it easier to talk about these topics, which are not easy to express, although the former patient–physiotherapist relationship may also have provided the informants with feelings of dependency, which curbed them from expressing their true feelings and opinions. However the interviews did not aim at exploring the physiotherapists’ role. The other investigator (AFW) did not know the informants and represented the outsider perspective.

Conclusions
This study adds a further perspective of body awareness to the interpretations of ICU patients’ experiences carried out in previous studies by other professions. It broadens an understanding for physiotherapists of this group of patients. It emphasizes the experience and movement aspects of the body in the ICU environment, and the consequences these experiences have on the patients’ abilities to act and interact within their surroundings. The findings suggest that physiotherapists, with knowledge and experience of body and movement, have an important role in the rehabilitation of these patients.

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References