Title: Important quality aspects in transfer processes

## Introduction

Critical illness and injuries often occur suddenly and without warning (Chaboyer, 2006). The admission to an intensive care unit (ICU) affects the patients and their relatives (Engström and Söderberg, 2004). Patients in the ICU can gain strength from the presence of their closest relations (Bergbom and Askwall, 2000), and these relatives can make the ICU patients feel safe and protected (Hupcey and Zimmerman, 2000). As soon as a patient begins the recovery process and his vital signs are stable, he/she will be transferred out of the intensive care unit. This transfer of care can be seen as a significant stage in the illness continuum and a positive step (Leith, 1999) but are also as a stressful time for patients' and their relatives (Coyle, 2001; Odell, 2000). The technical environment, uncertainty about the patients' prognosis and the wards' capability are important factors (Wesson, 1997). Feelings of helplessness among relatives can be reduced, for instance, by involving them in the care (Mitchell and Chaboyer, 2010). Additionally, providing relatives with information about the transfer (Choate and Stewart, 2002), for example by allowing the family to visit the ward before the patient is transferred (et al., 2012), providing informative brochures (Mitchell and Courtney, 2005a; Mitchell and Courtney, 2005b ; Linton et al., 2008) and conducting ICU follow-up visits (Engström et al., 2008) are all strategies that are performed to improve how the relatives and the patients experience the ICU transitional care.

Today's health care organizations and the professionals involved are expected to provide both high-quality care and be cost conscious and efficient (Roberti and Fitzpatrick, 2010). The quality of care from the patient's perspective and the relative's perspective has been measured in many studies. Wilde Larsson *et al.*, (Wilde *et al.*, 1993) showed in a grounded theory study that the quality of care can be observed in medical-technological competence, physical-technological conditions, identity-oriented approach and socio-cultural atmosphere. The quality of care is often measured by patient satisfaction, meaning the cognitive and emotional appraisal and the congruency between patient expectations of ideal nursing and patient perceptions of the received nursing care (Eriksen, 1995). Patients that have been cared for in the ICU are often too sick to determine a level of satisfaction regarding their care and often do not remember their ICU experience during their stay, which leaves family members to determine the level if they are satisfied with the provided care and with the overall critical care experience. Because relatives play an integral role in the patient care (Roberti and Fitzpatrick, 2010), it is important to learn how they perceived the intensive care and the subsequent care.

The relative's experience with the organization of transitional care is important, and the gap between the highly technological ICU and a general ward affects the personnel (Häggström *et al.*, 2009) and the patients and their relative(s) (Chaboyer *et al.*, 2005b). The patient's length of stay in the ICU may also be important and related to how the relatives' perceived the transfer process. In a previous study, it was shown that nurses believed that long-term patients and their relatives often needed more support than others and that adjustments were important to meet their needs (Häggström *et al.*, 2012). The relative's preparation and ability to cope with the transition is an important aspect of the nurse's role. This study focuses on the relative's perceptions regarding quality of care during the ICU transitional process.

#### **Purpose/Aim**

We aimed to investigate relatives' perceptions of quality of care during a patient's transfer process from an intensive care unit to a general ward. The research questions in the study were as follows:

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- How do relatives perceive the transfer process?
- What quality aspects are important for relatives, and what areas can be improved?

## Ethical considerations

The Regional Research and Ethical Committee at Umeå University Sweden, D-nr 2010/320-32M approved this study. In the informational letters that were sent to the participants, it was specified that the relatives' participation was voluntary. No identifying information was placed on the questionnaires, which were coded to ensure confidentiality. Relatives of patients who were in the ICU and had a disease were excluded to avoid any unnecessary burden, and no medical records were available for the researcher. The research team was aware that the questionnaire could stir up memories that potentially could cause a burden for the relatives. However, the positive aspects of the study were judged as stronger than the negative aspects.

## Method

The study had a descriptive and comparative design with a mixed method approach.

## Study context

The study included two hospitals in the northern-middle region of Sweden. The ICUs had patients of many specialisations. ICU-nurses and RNs in Sweden are required to be autonomous with a holistic view. They often work together with ENs (Enrolled nurses) that stays closest to the patient. In Sweden, patients often are transferred directly from ICU to a general ward but sometimes a step-down unit (intermediate care) are used prior the transfer. In this study, none of the ICUs had a liaison nurse, specific step-down procedures or an intermediate care unit. Information was occasionally given to the relatives and there were no specific standards regarding written information about the transfer as part of the care.

## Participants and procedures

A broad definition of the term relative is taken in this paper and includes family members, close friends or other people that may be close to the patient. The sample was consecutively chosen and consisted of the relatives to patients who were admitted to an intensive care unit between May 2011 and January 2012. The criteria for inclusion in the study were:

- the relatives were adults (18 years of age or older)
- the patient was in intensive care for longer than 3 days
- the patient left ICU alive.

Each hospital had 50 participants and responses were obtained from 65 relatives (65% of all the relatives that were included). The relatives that matched the inclusion criteria were identified by a person working in the ICU (nurse or secretary). The relatives' actual names and phone numbers were noted from the patients' medical record and were used to search for the address. Two reminder letters were sent to the non-respondents – the first after one month and the second after two months. There was no significant difference (tested with chi-square test) between non-respondents and respondents regarding relationship or sex.

## Questionnaires

The relative's perceptions of transitional aspects were collected from the relatives who responded to the questionnaire, "Quality from the Patient's Perspective" (QPP). The QPP questionnaire is a validated instrument based on a Grounded Theory study (Wilde *et al.*, 1993; Wilde *et al.*, 1994) and has been used in several studies that aim to evaluate the quality of care (c.f. Persson *et al.*, 2005; Wilde-Larsson and Larsson, 2009). Eight of 14 questions were derived from the QPP questionnaire. The other six questions were focused on perceptions of

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the transitional care and discharge planning. The design of the questionnaire was based on the QPP and on previous research about ICU transitional care. The questions addressed the relative's experience, the information and support that were given before and after transfer from the ICU to a general ward. To test the validity of the questions, two professionals (RNs) and three relatives that were not part of the actual survey completed the questionnaire to determine how they perceived the questions. As a result, only minor word changes were made. Furthermore, it was assumed that the questions were well-suited for the intended purpose (Dawson and Trapp, 2004) and were easy to understand based on the sample results. Correspondence was sent to the holder of the original QPP questionnaire and we got an approval to add the new questions (ImproveIT). An example from the questionnaire is the statement; "I experienced the transfer as well planned and performed". Each question or statement was evaluated in the following two ways:

- the relative's personal experience (perceived reality)
- how important the care aspect was (subjective importance).

This design was based on the assumption that if one is dissatisfied with something that are important to him or her, it can have a strong influence on the perception of the quality of care. In the questions that were taken from the QPP questionnaire, the word patient was changed to (Wilde Larsson, 2001). The response categories for perceived reality (PR) ranged from 1, do not agree at all, and to 4 totally agree. The response categories for the subjective importance (SI) ranged from 1, of little importance, to 4 of high importance. Both response categories included a five-point rating scale with the alternative "not applicable," which was excluded in the analysis. Potentially confounding variables, such as age, sex, educational level, work experience in health care and the patients' actual health-status, were also assessed. The reliability of the questionnaire was assessed using Cronbach's alpha coefficient of 0.79 for the perceived reality (PR) and 0.8 for the subjective importance (SI).

## Data analysis - Statistical analysis

Statistical analysis was conducted using the Statistical Package for Social Sciences (SPSS) version 20. The answer "not applicable" was regarded as a missing value. The chi-squared test was used to determine whether there were differences in the proportions between the subgroups ("long and short time in ICU"). Statistical significance was assumed at the p<0.05 level. The items in the questionnaire were divided into the following three dimensions: information, attitudes and treatment and specific transfer issues. The analysis began with the calculation of the means of all items. If the mean of PR was over 3.5, it was excluded in the index analysis because it was judged as too high to allow for quality improvement (ImproveIT, 2005). By combining answers to questions about PR and SI (Table I) a quality improvement index was created. This seven-grade index was divided into three categories: inadequate quality (IQ), balanced care (BC) and excessive quality (EQ) (Wilde Larsson, 2001).

## Table I here

Inadequate care describes areas where the quality of care was less than good but was considered as important for the respondent. Balanced care indicates that the quality of care was in line with how important it was to the relatives. Excessive care describes aspects of care that exceeded expectations but were considered as not important. According to the QPP developers, actions to improve quality should be taken if >20 % of the respondents report inadequate quality for a specific issue (Wilde Larsson, 2001). A comparison between the scores regarding how the respondents perceived the reality and the care (PR) and how they rated the subjective importance (SI) was performed using the nonparametric Mann-Whitney

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U-test. The same test was used to determine if the scores differed in association with the potential confounders. The mean value was calculated in the two groups to add a visual effect, but it was not used in the comparative analysis. Statistical significance was assumed at the p<0.05 level.

## Content analysis

The questionnaire also included open-ended questions concerning the intensive care and the aftercare, and the answers were separately analysed through content analysis. There were several open-ended questions included in the questionnaire under the heading own comments. In the last part of the questionnaire, the following questions/statements were placed: This was excellent when my relative was transferred to a general ward, This could have been performed better when my relative was transferred from ICU to a general ward, This could be improved regarding the preparation for transfer from the ICU to a general ward, This made me especially satisfied with the care in the ICU, and Other suggestions to improve the care in the ICU or after.

All statements and answers to the open questions were juxtaposed by the first author, and the unit of the analysis consisted 12 pages that were filled out by 57 % (n=37) of the relatives. At first, all three authors read the text individually to become familiar with the content. Coding and naming of the categories were performed together with no disagreements. The content analysis began with sorting the data in the content areas (information, attitudes and treatment and specific transfer questions). Then, meaning units were identified and condensed by a description close to the text, abstracted and labelled with a code. The different codes were compared and divided into categories and subcategories based on their differences and similarities (Graneheim and Lundman, 2004).

## Findings

In total, 65 relatives answered the questionnaire, representing 32 relatives in one hospital and 33 relatives in the other hospital. Most relatives were the spouses of a former ICU patient, and the most common age among the relatives was 61-70 years old. Of the 65 relatives, 62 (95%) had visited the ICU and the remaining three had contact with the staff via telephone during the patients' stay. Furthermore, 57 relatives (88%) had no doubt about being cared for in the same ICU if needed, while seven (10%) felt some doubt. Subgroup differences related to length of patient stay (LOS) in ICU were calculated (Table 2).

## Table 2 here

No significant differences were found regarding how the relatives scored the patients' present health status in the subgroups (Table 3). Finally, seven of the 65 relatives revealed that their family member passed away after they left ICU.

## Table 3 here

We detected areas for quality improvement in 13 of the 14 items. The result of the open-ended questions (aimed to describe the relatives' perceptions regarding aspects that are important for quality) produced the following seven categories: participation, own insight and control, respectful encounters, proximity, reassurance, continuous quality and reconnection and feedback. These results are illustrated in a table (Table 4).

## Table 4 here

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## Information

The results showed that the relatives perceived information provision as important. This was an area for improvement because the quality index showed that over 20 % felt that the care was inadequate concerning information (Table 5).

## Table 5 here

A significant difference was observed between those who spent less than seven days in the ICU and relatives of patients who spent seven days or more in the ICU, concerning the importance (SI) of information (Table 6).

## Table 6 here

## Open -ended questions; information

The result showed that information regarding patient transfer was important for the relatives because they wanted to be a part of the care of the patient (participation), and felt important to have some insight and control over the care (own insight and control). They also commented on their disappointments when lack of information made them unable to participate. Information was also important to own insight and control. The relatives expressed that an on-going provision of information during the process of care was important. They wanted knowledge about of what was happening without having to ask questions about every detail.

## Attitudes and treatment

Many relatives perceived the attitudes and treatment both pre and post transfer as inadequate and therefore an area for improvement. The quality index analysis showed that >20 % of the respondents felt that care was inadequate for four out of five items. The statement; registered nurses and enrolled nurses seemed to understand how I experienced my situation, had a mean value > 3.5 and was therefore not in need of quality improvement (Table 7).

## Table 7 here

There were significant differences between the two groups concerning the subjective importance of attitudes and treatment (Table 6). Relatives who spent seven days or more in the ICU indicated that these items were of greater importance (mean 3.6) than relatives who spent less than seven days in the ICU (mean 3.22).

## Open-ended questions; attitudes and treatment

The results showed that respectful encounters and proximity were important quality aspects for relatives in the transfer process. The comments concerning attitudes and treatment were both positive and negative. The results from the category respectful encounters emphasised the importance of empathy and positive meetings. This category also illustrates the disappointments associated with being met with bad attitudes and poor treatment.

Proximity and closeness, was an important aspect and was defined as allowing the relative be remaining next to his or her ill family member and to be able to call the staff at any time.

## Specific transfer aspects

All items concerning the specific transfer process need improving. The items related to personal participation in the transfer process had the highest scores for inadequate quality. Sixty-one percent of the relatives judged their own participation in the transfer process as inadequate (Table 8). The support and follow-up of the patient after the ICU stay was perceived as inadequate by 53 %.

#### Table 8 here

The majority of the relatives perceived a well-planned and performed transfer to be important (Table 9); however, 40% who spent seven days or more in the ICU, rated the transfer planning and the execution of the transfer as not satisfactory.

## Table 9 here

#### Open-ended questions: Specific transfer aspects

The categories; reassurance, continuous care and reconnection and feedback describe care aspects that were important to relatives in the transfer process. The relatives sought reassurance and wanted to feel safe about the care throughout the transfer process. It was important to ensure that their relative (the patient) was well enough to be transferred from the ICU to a general ward. The category continuous care describes the importance of the competence and quality throughout the healthcare chain. Some wrote that they were disappointed with the differences between the ICU and the ward, and even questioned the competence of the staff in the ward. Others wrote about the difference in care in the general ward when compared to the ICU care. They believed a ward should provide more intense care from the start. The relatives also felt that it was necessary for the ward's staff to take time to care for both the patient and the patient's relatives from the start. Examples of minor and major unwanted events were provided, one relative wrote about how his father's respiratory problems and the need for suction were ignored at the ward. He described how he had to take his father to the ICU himself to have the suction performed. Routines and a proper handover between ICU and the ward were also important for the relatives, and they wanted to be sure that all information was given between the units. The importance of proper planning of the transfer and a wish that it not it did not just happen - were also commented on. The category reconnection and feedback described the relatives' wish to help the patients getting a sense for what has happened. After the recovery their relative (the patient) had questions about what has happened and they were glad to be helped in fulfilling this request. The comments illustrated that they felt supported when the ICU-staff showed interest and visited them at the ward after the transfer. A diary written by ICU staff, that illustrated the patients ICU stay, was appreciated by many relatives. The comments illustrated how the relative tried to explain what happened but also that they needed professional feedback with this mission.

## Potentially confounding variables

To identify possible confounding variables, a comparison between male and female relatives, age and different relationships yielded more or less the same pattern as shown for the whole group - there were no significant difference in how they perceived the different dimensions of transitional care and how important it was for them (PR/SI). None of the other variables observed in table 1 was statistically significant; except for relatives with own healthcare education, which scored lower concerning SI of information than others. The impact of how the relative's perceived the patient's present health status was also measured. The result showed that relatives where the patient had a bad actual physiological or physiological health status did not score significantly different than the others. There was no significant difference in the three domains concerning PI or SI between the two hospitals.

#### Discussion

We aimed to investigate relatives' perceptions of quality of care during a patient's transfer process from an intensive care unit to a general ward. The result showed that relatives judged that a well-planned transfer is very important and a majority also perceived that its quality needs to be improved. Forty percent of relatives to patients with seven days or more in ICU

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judged the transfer planning and the transfer as not satisfactory. The relatives want to be part of the transfer process and to be prepared in advance for the change. An unplanned transfer can confuse the relatives; which is consistent with the result in a previous study (Chaboyer *et al.*, 2005a). For many relatives, ICU became a place of safety and security and therefore it's understandable that the transfer process can be negative experience for relatives (Streater *et al.*, 2001). Many also perceived the information about the environmental differences between ICU and the ward to be inadequate. Some relatives described how they felt disappointment concerning a less focused attention and care when arriving to the ward. This can be consistent with a previous study where relatives' described that they felt unimportant after the transfer to the ward (Chaboyer *et al.*, 2005a).

The findings in this study indicates that a caring atmosphere with continuous, straightforward information and own participation can be strengthening for relatives. This was consistent with a study by Wåhlin et al., (2009). In a study by Stricker et al., (2007) higher satisfaction was reported with written admissions and discharge instructions. Several other studies confirm that different sources of information prior to discharges are important and a structured individual transfer significantly can reduce uncertainty scores (Mitchell and Courtney, 2004). Hence, not being aware of the transfer plans is a factor that can contribute to anxiety for the relatives (Bailey, 2010). Participation can include family conferences prior to discharge or a possibility to follow the patient from ICU to general ward. It also seems important for the ward personnel to have a positive attitude, to notice and see the relatives to secure a good encounter after the transfer to a ward. Support after ICU was also important and needed to be improved. To return to ICU and meeting the staff can be a valuable tool for coping with the ICU experience (Engström et al., 2008). The relatives wanted help to fill in the memory gap, and written diaries were an appreciated part to fulfil this desire, which is confirmed by other studies (Engström et al., 2009). However, the result showed both satisfied and dissatisfied relatives. What this variation depends on is not all clear. There were no differences in the scores related to age, sex and relationship or from the relatives to patients with a poor health status compared to others. Some differences can be explained by the fact that relatives with prior healthcare education judged the importance of information as less important than other relatives because they already know what to expect based on their knowledge; however, they were only a select few. More likely the differences depend on the individual self and their coping strategies. Hence, RNs and physicians must meet individual needs and try to adjust their actions to every patient (cf Häggström *et al*, 2012), and not treat everyone as a group. The differences may also reflect the randomness in how the staff worked with this transfer and the fact that there was no specific transfer organization created. The length of stay in ICU explained some differences. This may reflect how the relatives' needs depend on the patient's severity of illness but also it may reflect how a longer relation to the ICU staff and the technological environment influences the relatives' experiences of the transfer. The result showed no significant differences in how relatives in the shorter group perceived the care compared to the longer stay group. However, there were differences in how they judged the importance of information and attitudes and treatment. The result of the content analysis showed that own insight and control, participation, respectful encounters, proximity, reassurance, continues care quality and reconnection and feedback was important quality aspects for the relatives in the transfer process. The need for relatives to be close to their loved ones and being allowed to call at any time has been observed in other studies. A recent phenomenological study (McKiernan and McCarthy, 2010) showed that family members' in the intensive care unit experienced a need to know, wanted being there with them and felt that the staff was caring and supporting the patient.

Family members or relatives in this setting are in general satisfied with care (Roberti and Fitzpatrick, 2010), which makes it even more important to react to this result. The transfer

means a transition for all involved, because they are moving from a place where they most likely have felt safe to a place with less staff and a minor observation.

Relatives of critically ill patients form a crucial link with staff in the healthcare continuum (Engstrom *et al.*, 2011), and they can provide both physical and emotional support to the patient. This study focuses on relatives, but the result is similar to the result of another study regarding patients' experiences of transfer – the patients also wished that the transfer had been better planned, appreciated helpful staff and to have information and control during the transfer (Forsberg *et al.*, 2011). Health care services have limited resources, which also results in a strained work situation for the staff. In order to create a humanized and efficient health care, leaders should elaborate guidelines and routines regarding transitions from ICUs that ensure quality, and they should consider restructuring their transfer process. In the best interest of the relatives (and the patients), now is the time to take a total grip on improving the transfer process.

#### Study limitations and methodological discussion

The result is limited because of the small sample size, the limited time period and the small hospital settings. Sixty-five percent answered the questionnaire. This percentage of respondents has been observed in this fragile group in other studies; 61% in a study of Roberti and Fitzpatrick (2010). There were no differences between male and female respondents and non-respondents; however, no further analysis was possible because the ethics, professional secrecy and confidentiality restricted the information about the relatives. A majority of the respondents reported that their family members' present health status was good. Although, it seems reasonable to assume that relatives to a patient with severe sickness who still are in need of much care will rate care conditions as more important than relatives to a patient with less problems (Larsson and Larsson, 1999).

The QPP questionnaire is a well validated instrument, but the new additional questions have not been used before this study. Cronbach Alpha was used to measure the items' reliability with high values and the questions were pretested before use to see how they were perceived. The additional questions had less missing values than others in the questionnaire, which also can be observed as that they were understandable and important for the relatives. The result showed significant differences between relatives with a patient 3-6 days in ICU and relatives with a patient more than 7 days. However, the differences and the samples are small. It is also important to discuss that more than a quarter of the participants had a prior health care knowledge/education with a possible implication for their expectations. They also rated their perception of how important the given information was for them, lower than others but did not score different in how they perceived the reality in the care and the transfer process.

The mixed method design has been useful in the study. The relative's comments to the open questions have added depth to the quantitative part of the study. All authors were involved in the content analysis to achieve credibility and validity. The open questions also can be observed as a somewhat limited, in terms of the depth of qualitative data. Not all participants wrote and answered the open questions and it can be reasonable to assume that mostly negative incidents were reported. However, the responses illustrated both positive and negative perceptions of the care.

#### **Implications for nursing**

The findings have important implications for nursing and above all, for nursing management. We conclude that relatives need a well-planned ICU transitional process organization with continuous quality before and after transfer. Informational strategies that encourage the relatives to be involved and an organization with competence throughout the healthcare chain are vital for quality.

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Table I. QPP index.

| SI |   |   |   |   |    |
|----|---|---|---|---|----|
| 4  | 1 | 1 | 2 | 5 |    |
| 3  | 1 | 2 | 4 | 6 |    |
| 2  | 2 | 3 | 6 | 7 |    |
| 1  | 3 | 6 | 7 | 7 |    |
|    | 1 | 2 | 3 | 4 | PR |

1.2: Inadequate quality (IQ)

3.4.5: Balance high/Balance low= balanced care (BC)

6.7; Excessive quality (EQ)

Example: if PR was scored as 4 and SI as 2, the result was 7 (excessive quality) in the index.

Table II. An overview of the participants.

| Socio-demographic background                | ICU 3-6 days     | ICU 7 days and more $n=25/9/2$ | p-    |
|---|------------------|--------------------------------|-------|
|   | n - 30 (70)      | n - 33(70)                     | value |
|   |                  |                                |       |
| Age groups                                  |                  |                                |       |
| 20-40 years                                 | 3 (10)           | 3 (8)                          |       |
| 41-60 years                                 | 14 (47)          | 12 (34)                        |       |
| 61-80 years                                 | 13 (43)          | 18 (52)                        |       |
| > 80 years                                  | 0                | 2 (6)                          |       |
| Sex   |                  |                                |       |
| Male  | 8 (26,7)         | 13 (37,1)                      |       |
| Woman                                       | 22(73,3)         | 22 (62,9)                      |       |
| Origin                                      |                  |                                |       |
|   |                  |                                |       |
| Sweden                                      | 28(93,3)         | 34 (97,1)                      |       |
| Other northern country                      | 2 (6,7)          | 1 (2,9)                        |       |
| Relationship                                |                  |                                |       |
| Spouse / partner                            | 13 (43,3)        | 22 (62,9)                      |       |
|   |                  |                                |       |
| Sister/ brother                             | 3 (10,0)         | 2(5,7)                         |       |
| Children                                    | 11 (36,7)        | 8 (22,9)                       |       |
| Grand children                              | 1 (3,3)          | 0                              |       |
| Parent                                      | 2(6,7)           | 3 (8,6)                        |       |
| Educational level                           |                  |                                |       |
| Comprehensive school                        | 11 (36,7)        | 12 (34,3)                      |       |
| High-school                                 | 11 (36,7)        | 11(31,4)                       |       |
| University                                  | 8 (26,7)         | 12 (34,3)                      |       |
| Time since their relative (the patient) was | transferred from | ICU                            |       |
| < 1 month                                   | 4 (13,3)         | 4 (11,4)                       |       |
| 1 month                                     | 7 (23,3)         | 8 (22,9)                       |       |
| 2-3 months                                  | 13 (43,3)        | 19 (54,3)                      |       |
| >4 months                                   | 6 (20,0)         | 4 (11,4)                       |       |
| Their relative (the patient) was treated    |                  |                                |       |
| using a mechanical ventilator in ICU        |                  |                                |       |
| yes   | 15 (50)          | 30 (85,7)                      | *     |
| no  | 12 (40)          | 3 (8,6)                        | *     |
| Do not know                                 | 3 (10)           | 2(5,7)                         |       |
| Their relative (the patient) has being care | d for in an ICU  |                                |       |
| some other time?                            |                  |                                |       |
| yes   | 13 (43,3)        | 9 (25,7)                       |       |
| no  | 15 (50)          | 22 (62,9)                      |       |
| Do not know                                 | 2 (6,7)          | 4 (11,4)                       |       |
| Respondents' education in health care?      |                  |                                |       |
| yes   | 8 (27)           | 10 (28)                        |       |
| no  | 22 (73)          | 24 (70)                        |       |
| Do not know                                 | _                | 1(2)                           |       |

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| Any doubt being cared for in the given ICU if needed? |    |    |
|---|----|----|
| yes   | 4  | 3  |
| no  | 26 | 31 |

A description and comparison of the proportions of the subgroups.\* p = <0.05

**Table III.** The relative's perception of the patient's condition and present health status on the day that the questionnaire was filled.

|   | Short tim<br>ICU | ie in        | Longer ti<br>ICU | me in        | P-value          |
|---|------------------|--------------|------------------|--------------|------------------|
|   | Good<br>n (%)    | Bad<br>n (%) | Good<br>n (%)    | Bad<br>n (%) | (between groups) |
| Your relative's<br>(the patients)<br>actual<br>psychological<br>status? | 17<br>(68%)      | 8(32%)       | 23(72%)          | 9(28%)       | 0.47             |
| Your relative's<br>(the patients)<br>actual<br>physiological<br>status? | 22(88%)          | 3(12%)       | 23(71%)          | 9(28%)       | 0.13             |

Significant differences between subgroups were calculated with the Chi-squared test with a significance level of 95 % (0.05).

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| Content              | Categories /subcategories  | Examples of quotations   |
|----------------------|--|--|
| area                 |  |  |
| ation                | Participation - To be a part of the care   | I am glad that we were told when the transfer was going to be so<br>we could be there for him. (Relative; LOS 7-15 days)<br>When I called the ICU, I was told that he had already been<br>transferred! Please call the relatives before transfer!" (Relative;<br>LOS >15days)  |
| Inform               | Own insight and control<br>-Detailed information<br>- Knowledge about the plans  | The relatives should be informed about the plans for the care of<br>our loved ones. More specific information should be given and<br>not just brief answers to my questions (Relative; LOS > 15<br>days)<br>Having knowledge makes it all easier – because this means more<br>control (Relative; LOS < 7 days)   |
| Attitudes /Treatment | <ul> <li>Respectful encounters <ul> <li>Empathy</li> <li>Staff with a professional and positive attitude</li> </ul> </li> <li>Proximity <ul> <li>Closeness</li> <li>To be allowed to call</li> </ul> </li> </ul> | I am touched by the empathy from the ICU staff; it's amazing,<br>and it made everything easier (Relative; LOS > 7 days)<br>The best thing about the transfer was the positive encounter at<br>the ward! (Relative; LOS < 7 days)<br>I am disappointed in the care at the ward//The staff was lazy and<br>uninterested, the care was very bad (Relative; LOS > 7 days)<br>I felt so calm while he lay there They (the ICU staff) were<br>wonderful, and I was allowed to be there as long as I wanted.<br>(Relative; LOS >7 days)<br>I am glad I could call whenever I wanted – 24 hours a day!<br>(Relative; LOS > 7 days) |
|                      | Reassurance<br>- A safe, secure transfer   | It was important that I felt that my relative wasn't transferred<br>until all vital signs were stable – and I am really glad that his<br>rehabilitation was started before he was moved – he could stand<br>on his feet, move and speak (Relative; LOS > 7 days)   |
| ansfer aspects       | Continuous care<br>-Observations before and after<br>transfer<br>-A proper handover<br>-Competent staff  | The most difficult thing about being transferred is that the patient doesn't receive the same observation and monitoring in a general ward This makes it unsecure for us relatives (Relative; LOS > 7 days)<br>The communication between the units and the handover has worked very well, and that makes me glad! / Relative, LOS >7 days.<br>Good care and competent staff is most important, both before   |
| Specific tr          | <b>Reconnection and feedback</b><br>-Pictures and written diary's<br>-Help to fill in the missing<br>parts   | and after the transfer! / Relative, $LOS < 7$ days<br>The best thing was that he got a written diary and photos from<br>ICU! They described how the patient has been every day- and<br>what the staff has performed // every hospital should have this<br>routine (Relative; LOS > 7 days)<br>It would have been fine to receive help to fill in the missing<br>parts for my relative (the patient). There are things that we<br>cannot explain, and it would ease the rehabilitation process for<br>her if she knew! (Relative; LOS > 7 days)   |

# Table IV. Relatives' perceptions of quality of care during a patient's transfer

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# Table V: Quality of care; information

(+) Additional questions, not derived from QPP

|       |   | Inadequate<br>quality<br>n (%) | Balanced<br>quality<br>n (%) | Excessive<br>quality<br>n (%) |
|-------|---|--------------------------------|------------------------------|-------------------------------|
|       | Statement   |                                |                              |                               |
|       | I have received useful information<br>about which doctor that is responsible<br>for his/her<br>medical care       | 29 (44)                        | 23 (35)                      | 13 (20)                       |
| ıtion | I have received useful information<br>about which nurses are responsible for<br>his/her nursing                   | 19 ( <b>29</b> )               | 33 (51)                      | 13(20)                        |
| form  | I have received useful information about the progress of care   | 15 ( <b>23</b> )               | 33 (50)                      | 17 (26)                       |
| In    | I have received useful information<br>about the planning prior t transfer to<br>the general ward (+)              | 28 ( <b>43</b> )               | 33 (50)                      | 5 (7)                         |
|       | I have received useful information<br>about how the environment differed in<br>a general ward compared to ICU (+) | 36 ( <b>59)</b>                | 22 (36)                      | 3 (4)                         |

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|                    | Dimensions                   | 3-6 days in<br>ICU<br>mean (std dev) | >7 days in<br>ICU<br>mean (std dev) | p-<br>value |
|--------------------|------------------------------|--------------------------------------|-------------------------------------|-------------|
| Perceived reality  | Information (5)              | 2.61 (1.0)                           | 3.0 (0.68)                          | 0.89        |
| (PR)               | Attitudes and treatment (5)  | 2.88 (0.74)                          | 3.18 (0.68)                         | 0.07        |
|                    | Specific transfer issues (4) | 2.69 (0.79)                          | 2.55 (0.91)                         | 0.45        |
|                    | All items PR                 |                                      |                                     | 0.19        |
| Subjective         | Information (5)              | 3.15 (0.61)                          | 3.5 (0.51)                          | 0.03        |
| importance<br>(SI) | Attitudes and treatment (5)  | 3.22 (0.51)                          | 3.6 (0.55)                          | 0.00        |
|                    | Specific transfer issues (4) | 3.17 (0.61)                          | 3.45 (0.51)                         | 0.06        |
|                    | All items SI                 |                                      |                                     | 0.00        |
| <u> </u>           | 4 • 4 •                      | 11 1 /1                              | 1 1 64 101                          | Τ.          |

**Table VI.** A comparative analysis of relatives' perceptions: short or long length-of-stay (LOS) in the ICU.

Comparisons between the scores in the groups assigned based on the length of the ICU stay was calculated with the Mann-Whitney U-test. PR: Scale scores could range between 1 (least favourable evaluation) and 4 (most favourable evaluation). p = <0.05

Table VII. Quality of care; attitudes and treatment.

|             |   | Inadequate<br>quality<br>n (%) | Balanced<br>quality<br>n (%) | Excessive<br>quality<br>n (%) |
|-------------|---|--------------------------------|------------------------------|-------------------------------|
|             | Statement   |                                |                              |                               |
|             | The doctors seemed to<br>understand how I<br>experienced my<br>situation                  | 22 (36)                        | 33 (54)                      | 6 (9)                         |
| eatment     | The nurses and ENs<br>seemed to understand<br>how I experienced my<br>situation           | -                              | -                            | -                             |
| ides and tr | I had good opportunity<br>to discuss my own<br>anxiety and fear with<br>ICU staff         | 20 (37)                        | 30 (55)                      | 4 (7)                         |
| Attitu      | I had good opportunity<br>to discuss my relatives<br>anxiety with ICU staff               | 19 (45)                        | 21 (50)                      | 2 (4)                         |
|             | I had a good encounter<br>after my relative was<br>transferred to the<br>general ward (+) | 27( <b>43</b> )                | 32 (52)                      | 3 (5)                         |

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|             |   | Inadequate<br>quality<br>n (%) | Balanced<br>quality<br>n (%) | Excessive<br>quality<br>n (%) |
|-------------|---|--------------------------------|------------------------------|-------------------------------|
|             | Statement   |                                |                              |                               |
|             | I felt safe and secure<br>when my relative was<br>going to be transferred<br>to a ward(+)       | 25 (40)                        | 34 (54)                      | 4 (6)                         |
| transfer    | I experienced the<br>transfer as well planned<br>and performed (+)                              | 26 (40)                        | 33 (51)                      | 6 (9)                         |
| sues about  | I felt that my relative<br>had good support after<br>the ICU and was<br>followed-up (+)         | 29 (53)                        | 22 (40)                      | 4 (7)                         |
| Specific is | I felt that I could<br>participate and be a part<br>of the transfer process<br>from the ICU (+) | 35 (61)                        | 20 (35)                      | 2 (4)                         |

Table VIII. Quality of care: specific issues about transfer

**Table IX.** Perceived reality and subjective importance of a well-planned and performed transfer from the ICU.

| Perceived reality: A well-planned and |                                      |                                     |  |  |
|---------------------------------------|--------------------------------------|-------------------------------------|--|--|
| performed transfe                     | er from ICU                          | n /(%)                              |  |  |
| 3-6 days                              | not satisfactory                     | 5 (17)                              |  |  |
|                                       | satisfactory                         | 25 (83)                             |  |  |
|                                       | Total                                | 30 (100)                            |  |  |
| 7 days or more                        | not satisfactory                     | 14 (40)                             |  |  |
|                                       | satisfactory                         | 21 (60)                             |  |  |
|                                       | Total                                | 35 (100)                            |  |  |
| Subjective import                     | n/(%)                                |                                     |  |  |
| and performed tra                     | ansfer from ICU                      |                                     |  |  |
| 3-6 days                              | less important                       | 4 (13)                              |  |  |
|                                       | important                            | 26 (87)                             |  |  |
|                                       | P                                    |                                     |  |  |
|                                       | Total                                | 30 (100)                            |  |  |
| 7 days or more                        | Total<br>less important              | <u>30 (100)</u><br>2 (6)            |  |  |
| 7 days or more                        | Total<br>less important<br>important | <u>30 (100)</u><br>2 (6)<br>33 (94) |  |  |

Response categories of great importance and of very great importance were dichotomised to important. Response categories do not agree and do not agree at all, were dichotomised to not satisfactory.

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