# ENCOURAGING PATIENT PARTICIPATION DURING FUNDAMENTAL CARE IN THE HOSPITAL

a qualitative study


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| Student number | 4080501 |
| Course | Thesis |
| Version | Final version 1.0 |
| Date | 29 June 2018 |
| Words: | 3793 |
| Words abstract | 295 |
| Words Dutch summary | 300 |
| Supervisor | Dr. M. Heinen |
| Lecturer | Dr. J. van Dijk |
| Reference style: | Vancouver style |
| Criteria transparent reportage | COREQ guidelines |
| Journal: | International of nursing studies |
| Education program: | Master Clinical Health Sciences, Nursing Science, University Utrecht |

**SUMMARY**

**Rationale:** In response to population ageing, healthcare policy emphasises the importance of encouraging older patients to participate in their care. The importance and positive effects of patient participation (PP) are clear but it is still not known how nurses can stimulate this participation. Such knowledge would be highly valuable for the nursing profession as it would help to optimize PP and improve quality of care.

**Aim**: To gain insight into how nurses can encourage patients to participate during fundamental care delivery.

**Method:** An ethnography study using participatory observations and content data analysis was conducted. Nurses who provide fundamental care to patients in the geriatric ward of a general hospital in the Netherlands were observed.

**Results:** The nurses' (n = 10) behaviour with regard to PP reflects four major themes: an established relationship; surrendering of some power/control; shared information and knowledge; and active mutual engagement in intellectual and physical activities.

**Conclusion:** The care seems to be task-oriented, whereby the nurses maintain control and rarely take into account the needs of the patient. Within this task-oriented care, all nurses show that they value building a nurse-patient relationship. The nurses stimulated self-care by giving patients orders. However, these orders do not arise from consultation with the patient and sometimes information is not shared. Identified hindering factors for participation were the patient characteristics' and time constraints.

**Recommendations:** The findings provide new and useful insights into facilitating PP in the geriatric patient population and are relevant to the problems facing "greying societies". Follow-up research, should focus specifically on this growing demographic group and try to identify and implement methodologies to enable PP. In this implementation, training for the nurses is an important precondition for increasing their knowledge and ability to enable PP.

**Keywords:** Ethnography, Observations, Patient participation, Fundamental care

**Samenvatting**

**Achtergrond:** Het gezondheidsbeleid anticipeert op vergrijzing van de bevolking en benadrukt het belang van patiëntparticipatie onder deze doelgroep. Het belang en de positieve effecten van patiëntparticipatie zijn aangetoond, maar het is nog niet bekend of en hoe verpleegkundigen deze participatie kunnen stimuleren. Dergelijke kennis zou zeer waardevol zijn voor het beroep van de verpleegkundigen, omdat dit zou helpen de patiëntparticipatie en de kwaliteit van de zorg te optimaliseren.
**Doel:** Inzicht krijgen in hoe verpleegkundigen patiënten stimuleren deel te nemen aan de verpleegkundige zorg.
**Methode**: Een etnografische studie met observaties en content data-analyse werd uitgevoerd. Verpleegkundigen die patiëntenzorg verlenen op de geriatrische afdeling van een regionaal ziekenhuis in Nederland werden geobserveerd.
**Resultaten**: De activiteiten en het gedrag van de verpleegkundigen (n = 10) met betrekking tot patiëntparticipatie onderscheiden vier hoofdthema's: verpleegkundige- patiënt relatie; overgave van wat macht en controle; informatie- en kennisvoorziening; en actieve wederzijdse betrokkenheid bij intellectuele en fysieke activiteiten.
**Conclusie:** De zorg lijkt taakgericht te zijn waarbij de verpleegkundigen de controle en macht houden en minder aansluiten bij de behoeften van de patiënt. Binnen deze taakgerichte zorg laten alle verpleegkundigen zien dat zij werken aan verpleegkundige-patiënt relatie. De verpleegkundigen lijken zelfzorg te stimuleren door orders te geven. Echter komen deze niet voort uit overleg met de patiënt en lijkt hierin het delen van informatie te ontbreken. De verpleegkundigen identificeren tijd en patiënt karakteristieken als belemmerende factoren voor patiënt participatie.
**Aanbevelingen:** De bevindingen bieden nuttige inzichten in het faciliteren van de patiënt participatie in de geriatrische patiëntenpopulatie en sluit aan bij de vergrijzing in de bevolking. Vervolgonderzoek moet zich richten op deze groeiende groep en proberen methodes te identificeren en te implementeren om patiënt participatie mogelijk te maken. In de implementatie is training van de verpleegkundigen een belangrijke voorwaarde patiënt participatie mogelijk te maken.
**Trefwoorden:** etnografie, patiëntparticipatie, fundamentele zorg

## INTRODUCTION

Over the last few decades, healthcare has become more focused on a patient-centred approach, the nurse–patient relationship and meeting fundamental care needs in order to improve health outcomes, patient care experience and safety[1]. While fundamental care is not a new concept, in recent years the ways in which such care is delivered in practice, particularly by nurses, have received more attention[2]. One reason for this renewed focus is the increasing emphasis on patient-centred care (PCC)[2], which involves and recognizes the patient as a partner. Applying a bio-psychosocial perspective, rather than a purely biomedical perspective, is one of the mainstays of PCC[3].

According to Kitson et al.[4], fundamental care can be divided into 14 Fundamentals of Care (FoC).The Fundamentals of Care Framework (FoCF) was developed to provide guidance for the delivery of the FoC[1,5,6]. The framework has three core elements for the delivery of fundamental care, namely, establishing the nurse–patient relationship, integrating the patients' physical, psychosocial and relational fundamental care needs, and the context in which care is delivered[6,7]. The nurse–patient relationship, the context in which care is delivered and patient participation (PP) are core themes of PCC[8]. Among healthcare professionals, there is consensus that PP has been a key component in the redesign of healthcare processes in recent years[9,10]. In response to population ageing[11], healthcare policy emphasises the importance of encouraging older patients to participate in their care[12,13]. Among older patients, greater PP has been associated with higher patient ratings of quality of care as well as better adherence with prescribed medication and advice provided[13]**,** greater satisfaction with received care and improvement in health status[14]. Although nursing studies emphasise and have explored PP in different contexts and situations, there is still a lack of clarity regarding the elements and processes of PP in healthcare[15,16]. In this study, Sahlsten's[17] definition of PP is used and refers to *"an established nurse–patient relationship, a surrendering of some power or control by the nurse, shared information and knowledge, and active engagement together in intellectual and physical activities"[17]'.*

PP is an important basis for fundamental care and nurses play an indispensable role in this because they spend one third of their working hours with patients[18]. Over the last few decades, communication – the core principle in fundamental care to facilitate PP – has been getting more attention. For example, the Tell-us Card is a communication tool used to promote PP[19-21]. A quasi-experimental study has demonstrated that the use of the Tell-us Card results in significant improvements in patients' ability to participate in their care[19]. In another study[22], although nurses claimed to have a positive attitude towards PP and the Tell-us Card, they indicated that they have a heavy workload which they regard as a barrier to increasing PP.

Despite the various methods used to foster PP, and despite the consensus regarding its importance and positive effects[12-14], it is still not known how nurses can stimulate PP in the care of elderly patients in the hospital setting. As previous studies on the meaning of PP have tended to concentrate on the patient's perspective, the focus of this observational study was gain insight into the behaviour and activities of nurses in a hospital. Such insight is highly valuable for the nursing profession's aim to optimise PP[23,24].

## AIM

This study aims to explore how nurses encourage patients to participate during the fundamental care delivery in hospitals.

## METHODS

*Design*

An ethnographic approach was used, observations and informal interviews [25], to explore the nurses' normal, routine behaviours and activities regarding PP in the hospital setting. This approach is suitable to gain in-depth knowledge of a subject[25-27] with as much detail as possible in the context in which the action takes place, and what follows from it, when little information is known about the subject[28-30].

*Population and setting*

The study population consisted of nurses of the geriatric ward in a Dutch regional hospital and the patients who received care from the selected nurses. To gain a broad perspective on the subject, purposive sampling with maximum variation regarding age, gender, education level and work experience was used [26,27,31,32]. Nursing trainees were excluded from participation in the observations. All patients who received care from the nurses selected for observation and who gave oral permission to be observed were included.

*Data collection and procedure*

Data collection began in January 2018 and continued until data saturation was reached in March 2018[33,34]. Prior to the observations, all selected nurses by the researcher were informed about the study and asked to consider participation. At the start of the observation, the patients who received care from the selected nurse got information about the research and were asked to give oral consent to be observed. The researcher worked for one day in the ward to become

familiar with it. The observations took place between 7:30 and 10:30 AM on weekdays to minimize variation in data over time and many elements of the FoC are more apparent during the morning. During the observation, the researcher followed the nurse and took notes on the activities, behaviours and events that took place. The researcher wore a uniform to fit into the environment[35] and did not interact with the participants during the observations, with few exceptions. Directly after the observation, the notes were written out and the participants received the transcription the same day, which provided them an opportunity to comment on the interpretation of the findings[29,36.] During this informal interview, the nurse was asked about particular situations during the observation.

*Analysis*

The researcher analysed the data using a directed content analysis with a deductive and inductive approach[26]. The analysis was based on the FoCF[7] (table1).

<<<table 1>>

Additionally, the researcher remained open to new themes appearing in the data, adding these into the framework as the data was analysed or applying a theory or relevant findings to the themes generated through an inductive approach[37]. *The process of data collection and analysis is presented in figure 1.*

*<<figure 1>>*

The anonymized transcripts were imported into Atlas ti. Version 8 (GmbH, Berlin, Germany) to code and cluster the data. In the first part of the analysis, the researcher read the transcripts to establish an overview of the data. Second, the FoCF was used as the initial coding framework. Third, the data were read again and coded with the pre-set codes. The researcher identified specific pieces of data that corresponded with different pre-set codes. Text fragments that did not fit into the previously developed categories were coded with a new category. Categories were revised and systematized by developing subcategories and clustering categories. Fourth, charts were created using headings from the thematic framework. Fifth, the researcher searched for patterns, associations, concepts and explanations in the data and discussed these with the co-student (JG). The first three analyses were analysed independently in collaboration with a co-researcher to ensure accuracy of interpretation and the internal consistency of codes. The fourth and fifth analyses were cross-checked by the co-researcher, who objectively reflected on the coding. Moreover, memos were written during the coding process to capture impressions and to facilitate the identification of themes and patterns.

### Ethical considerations

The local ethics committee/Medical Ethics Committee (METC) confirmed that permission was not necessary according to the Medical Research Involving Human Subjects Acts. To ensure participation was voluntary, all nurses selected by the researcher gave both oral or written consent. The METC, deemed that written consent of the patients was not necessary because no patient identification information was gathered**.** Participants were guaranteed anonymity and confidentiality and were notified of their right to withdraw from participation. There were no (in)formal relationships with participants.

## RESULTS

In total 10 nurses participated in a total of 10 observations *(Table 2)* and covered a total of 30 hours of nurse activities and interactions *which were categorized into four themes.*

*<<table2>>*

### A surrendering of some power or control by the nurse

The nurses had control over the daily schedule of the care. There was no daily assessment of the wishes and needs of the patients in this regard. The observations show that the nurses took control of the daily coordination of personal care and made the decisions themselves. In the morning, the patient was awakened for morning care if the patient was still asleep. However, it is not clear whether this takes into account the wishes and needs of the patient. In the observations it is not clear whether the nurses hold the power and control if the patient has clear wishes and makes these known. In a few cases it became clear during the observation that the patient wanted to sleep late or return to bed after the morning care. In some cases it was seen that the nurse did not take the wishes of the patient into account in his/her own planning and work and in other cases it was seen that the nurses made choices in view of the well-being of the patient. This became clear during the informal interview with the various nurses. One nurse explained that she would have liked to have let the patient sleep but that it is not possible because she has to take into account the doctors' visit and other activities. Another nurse indicated that she did not let the patient go back to bed because it is important that the patient is mobile due to an increased risk of pressure ulcers. The following example illustrates an interaction in which the nurse had control and did not involve the patient in the decision to wash and when, nor did she explain why personal hygiene would be beneficial.

**“**

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|---|
| *The nurse indicates that she has come to help with washing. The patient says that he has already been washed yesterday. The nurse says: We are going to wash today and wear a new pair of pants.* |

## Shared information and knowledge

*Individually adapted information*

In the previously described theme, it was made clear that the nurses sometimes do not take into account the wishes of the patient, even in the interest of the patients. In informal interviews, nurses explained that they sometimes do not take the patients' wishes into account because they must ensure the well-being of the patient. However, in observations it was not seen that the nurses provide the patients with information about, for example, a fluid restriction. In this example, the nurse indicated that the patient is not allowed to drink that much. The nurse did not provide any further information about the fluid restriction or why the patient has a fluid restriction. In another example, a patient asked after the morning care to lie back in bed. The nurse indicated that the patient should stay in the chair because it is better. However, it was not explained why it is important.

Furthermore, in other observations the nurses did not always adequately share information with the patient about medication. The information is not individually adapted because the nurses do not ask the patients if they are familiar with the medication, whether the patient actually takes the medication or why the patient takes the medicine. The information is incomplete because the information regarding the medications' effects and possible side effects is missing. In a specific case, a patient received antibiotics from the nurse. The patient said he did not want to take this, and then the nurse ordered the patient to take the antibiotics. The nurse spent at least 10 minutes with the patient trying to convince him. However, the information was lacking and the nurse did not ask why the patient did not want to take it. In another situation with another nurse, a patient had pain in her tongue. The nurse observed the tongue and saw that it was possibly a fungal infection. The nurse indicated this would be discussed this with the doctor. In consultation with the doctor, the nurse indicated that the patient probably has a fungal infection as a result of taking the antibiotics. It was striking that the nurse did not share this relevant information with the patient.

In two situations, patients seemed to be in need of information and verified with the nurse how many tablets they received. This seems to indicate that the patients have a good overview of their medication and would like to keep this. In the context of PP and safety, these patients seem to need information. In the observations it was seen that the nurse confirmed how many tablets the patient has but did not ask why the patient asked the question or about the patient's experiences with medication use.

*Obtaining the patient's need*

The nurses mainly paid attention to the patients' physical problems and practical issues by paying attention to any verbal and non-verbal expressions during morning care that may indicate discomfort or pain. For example;

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*Nurse: Shall I wash you?*
*Patient: I do not feel well today. I am short of breath.*
*Nurse: Then I will first measure your blood pressure and saturation.*
*Nurse: Your blood pressure is good. And the saturation is 98%, just as good as my own oxygen level.*
*The patient does not respond.*
*Nurse: Since you are short of breath I will wash you in bed because that is less strenuous.*
*The patient sighs.*
*Nurse collects the supplies and starts washing the patient.*

"

The nurse notices that the patient is short of breath. The nurse records the vital signs. Then the nurse shares these with the patient. The nurse lays the patient down to wash in bed because the patient is short of breath. This shows the empathy and clinical reasoning of the nurse, who probably feels that the morning care is too strenuous for the patient. However, it is unclear what the wishes and needs of the patient are. The sigh of the patient is a non-verbal expression that seems to indicate that the patient does not want to be washed.
In other observations the nurses also do not ask much regarding the wishes and needs of the patient. The nurses seem to identify problems during morning care by asking patients about them, but most of the time they do not ask follow-up questions. The nurse, for example, switched to a different subject instead of continuing to explore or acknowledge the problem. During morning care when the patient is getting dressed, the nurse noticed that the patient's skirt is very large and asked her about this, as shown in the transcript below. She gives the patient the recommendation to eat well, and informs the patient about dietary choices. However, she does not ask any follow-up questions about the reasons for the weight loss or how the patient is dealing with it.

**An established relationship**

The nurses all had a friendly, warm and involved demeanour. Based on the tone of the interactions during patient care, it was clear that the nurses were patient oriented. In addition, the nurses confirmed that during patient contact they take into account the fact that the patient is elderly. For example, the nurses spoke clearly and in short sentences with hearing-impaired patients. Their orientation toward the geriatric patient was also apparent in their attitude. Nurses created involvement with the patient by, for example, sitting next to the patient at eye level. The nurse's communication and attitude were responsive to the patient's mood, showing that the nurses respect the patients and took into account their limitations and possibilities. In addition, the nurses and patients exchanged information about everyday matters. Furthermore, the observations show that nurses used verbal expressions (e.g., humour and reassuring remarks), which contributed to a pleasant atmosphere. The nurses have built a relationship with the patients by showing interest in them during the care. It was noticeable that when the nurse delivers the care he/she is interested in the patient and does not merely have functional contact. However, it was also observed that there were few contact moments with the patient outside the care moments. It seems that the care is mainly task oriented, where the nurses only visit the patients when they want to take care. However, during these functional visits patient-oriented communication and attitude were seen.

**Active mutual commitment to intellectual and physical activities**

In the informal interviews, the nurses indicated that they consider self-care to be very important. Nurses said that stimulating self-care was important for the promotion of self-esteem, control and independence of a patient and that patients are stimulated to keep caring for themselves for as long as possible. Various nurses indicated that it is their explicit intention to review every time (day) what the patient can do and what not. The cognitive and physical limitations of the geriatric patient population may be an impeding factor in this**.** This review was not seen during the observations.

The observations show that the nurses seemed to try to encourage self-care by asking the patient, for example, to wash his face. These questions did not seem to come from established goals but rather seemed like direct orders to a patient about what to wash, instead of the patient deciding for him or herself. Some nurses make a distinction in stimulating self-care by giving clear instructions and compliments. On the other hand, the researcher also observed situations in which it seemed that the patient was capable of doing something himself, but the nurse took it over from the patient without discussing it. During the informal interviews, this was specifically asked about and some nurses explained that stimulating self-care is too inefficient, especially because taking control of the patient was often faster. The

nurses indicate that they have other obligations such as the medical round. In the observations it was also seen that some nurses did not seem to take the time to discuss self-care activities with the patient, while other nurses were seen to take the time to prioritize the time and care for the patient and chose to let other patients or healthcare professionals wait a bit in order to involve the patient in their care.

In a specific observation, a nurse took her time and made caring for the patient a priority. Several times she was asked to do the medical round but she clearly indicated her limit and that the doctor had to wait. In the interaction with the patient, the nurse did not seem hurried and she allowed the patient to carry out his care as much as possible.

## DISCUSSION

This study explored how nurses promote PP. The findings show that there were few contact moments with the patient outside the care moments. It seems that the care is mainly task oriented, as the nurses only visit the patients to take care of them or administer medication. However, during these functional visits patient-oriented communication and attitude were seen, which indicates the establishment of a nurse–patient relationship. Regarding task-oriented care, this study also showed that control and power lie mainly with the nurse. According to the nurses, they often make decisions without consulting the patient but with the well-being of the patient in mind. However, often the nurses did not consider the wishes of the patients and did not share information with them. The nurses in this study attempted to stimulate the patient's self-care. However, the nurses' power was demonstrated by the fact that they mainly give orders instead of consulting with the patient to discuss what is possible and how the nurse can encourage this. Nurses gave instructions and compliments to facilitate PP at a low level.

The picture that emerged indicated a considerable variability of practice, not only between nurses but also within the practice of individual nurses. This variation in practice suggests that, with some exceptions, the nurses do not practice in a uniform manner but rather vary their practice from patient to patient. This variation suggests that the extent to which patients participate in the care is dependent on a number of factors. It seems there are three factors that limit PP. The nurses indicated that a lack of time and the need to carry out other activities were impeding factors which made them reluctant to give up their power or control. This reluctance was also observed by Tobiano et al.[38], who suggest that it may be caused by, among other things, time and work pressure, which is a current problem within care. The nurse's inability to relinquish control and give patients responsibility for their own care is an

impeding factor. The nurses state that they maintain control in the interest of the patients' well-being. Previous studies have also found that relinquishing power appears to be difficult for nurses, and that paternalistic attitudes are still evident in practice[39,40]. Another important impeding factor in achieving PP is the geriatric patients' lack of willingness to participate in the care. A patient's willingness is associated with a number of factors, including age and condition[41]. Various studies have shown that older patients have less desire to participate in care, independent of their condition. Moreover, as condition can limit PP, geriatric patients are also limited by comorbidity[42-45]. The nurses in this study noted that it is difficult to stimulate geriatric patients to participate in their care due to their cognitive and physical limitations and lack of interest in participation. This is not in line with previous studies[46,47], which have shown that patients are often participating in physical activities less than they would prefer[48,49]. This difference is an important finding and indicates that it is necessary to look critically at where participation is important and in what way. PP should not become an ideological dogma as it is not always desirable.

The current study has some limitations. The results primarily provide a view of a specific department of a hospital; therefore general conclusions cannot be drawn. To increase the transferability and reliability of the findings, the selection and characteristics of participants, data collection and the process of analysis are described, which is also known as thick description. All observations were conducted midweek during the morning shift, but nurses indicated that this part of their shift is comparable. Finally, the researcher's inexperience with the research method may have some influence on the validity of the results. That is why the first observation was done with an experienced co-observer (EB). Other strengths of the study are its use of member check and analysis triangulation, which helped to increase trustworthiness. On the one hand, the researcher's nursing background gave her more insight but on the other hand there was the danger of "going native". This was prevented by using methodological memos with reflection on the research role.

The care seems to be task oriented, whereby the nurses maintain control and rarely take into account the needs of the patient. Within this task-oriented care, all nurses show that they value building a nurse-patient relationship and show a positive attitude. The nurses stimulated self-care by giving patients orders. However, these orders do not arise from consultation with the patient and sometimes information is not shared. The nurses use instructions and compliments to stimulate self-care. Time restraints and the work routine, as well as the geriatric patients themselves, are identified by nurses as factors that impede them from enabling PP.

The findings provide useful insights into facilitating PP in the geriatric patient population and are relevant to the problems facing “greying societies”. Follow-up research, should focus specifically on this growing demographic group and try to identify and implement methodologies to enable elderly patients to participate in their care. In this implementation, training for the nurses is an important precondition for increasing their knowledge and ability to enable PP.

***Tables and figures***

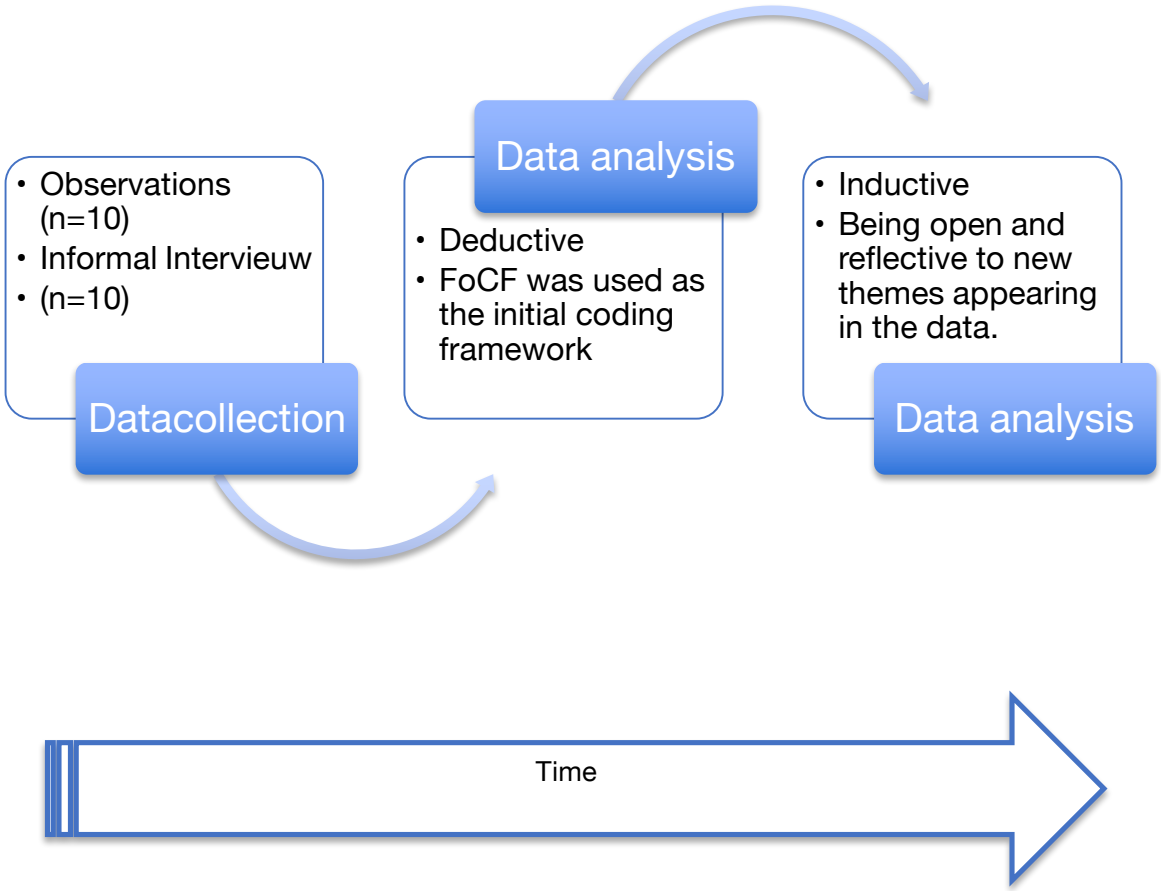


*Figure 1: Process of data collection and analysis*

| Physical | | Psychosocial | | Relational | |
|---|---|---|---|---|---|
| Fundamental of care | Description | Fundamental of care | Description | Fundamental of care | Description |
| Safety | Patients are safe from physical, psychosocial and environmental harm | Calm | Patients' concerns and frustrations are addressed. Noise and distractions are minimised. | Being empathic | Professionals seek to understand patients' perspectives, are sincere, and genuinely care about what happens to patients |
| Comfort (including warmth and rest) | Patients are comfortable, receive adequate relief from nausea and/or pain and receive adequate rest and sleep | Able to cope | Patients are encouraged to talk about their needs, and these are genuinely listened to. Patients' emotional reactions are validated. Professionals use plain language. | Being respectful | The health professional-patient relationship is positive and does no harm. Professionals are courteous and considerate when interacting with patients. |
| Nutrition and hydration | Patients have adequate food and drink. Patients are assisted to eat/drink when mobility or cognitive impairment is an issue. Patients' dietary requirements are respected. | Hopeful | Goals for care are set to help patients feel hopeful about their situation and their care regardless of their clinical condition or chance of recovery | Being compassionate | Professionals are conscious of others' distress, suffering, and misfortune, and demonstrate sensitivity, kindness and warmth |
| Mobility | Patients' mobility is assessed and they are assisted in activities that require them to be mobile | Respected | Patients' choices relating to their care, including religious or cultural practices that might be affected by (or affect) care, are respected | Being consistent | Professionals ensure coordinated and uninterrupted healthcare |
| Hygiene and personal dressing | Patients' preferences with regard to hygiene and physical appearance are respected. Patients' right to privacy when cleaning and dressing is respected. | Involved and Informed | Patients are consulted and given opportunities to contribute to decisions about their care. Patients are kept up-to-date about their proposed and ongoing care. | Ensuring goals are set | Mutually agreed, realistic targets for care are set. Patients are free to re-negotiate these goals at any point during their care. |
| Elimination and continence | Patients' toileting needs are met (e.g., assisting them to the toilet, helping them to toilet and providing alternative means for toileting) | Dignified | Patients are treated with dignity regardless of age, gender, sexual orientation, religion, linguistic or cultural background or the presence of a mental health issue, disability, illness or injury | Ensuring continuity | There is continuity across the delivery, facilitation and coordination of care |

***Table 1: Work definitions of the Fundamentals of Care***

| Item | Response | Frequency |
|---|---|---|
| Age (years) | 21-30 | 6 |
| | 31-40 | 3 |
| | 41-40 | 1 |
| Gender | Female | 9 |
| | Male | 1 |
| Nationality | Dutch | 10 |
| | Others | 0 |
| Education level | MBO | 6 |
| | HBO | 4 |
| Year graduated | 2000-2009 | 3 |
| | 2010-2018 | 7 |
| Experience as nurse (years) | 0-5 | 6 |
| | 6-10 | 2 |
| | 11-20 | 2 |
| Experience as nurse in geriatric ward (years) | 0-5 | 7 |
| | 6-10 | 2 |
| | 11-20 | 1 |

***Table 2: Demographic characteristics***

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