Patient experiences of shared decision-making in nursing care during hospital admission:

A qualitative, descriptive study

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**Abstract**

*Title*

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*Background*

Shared decision-making is a process in which care professionals help patients making choices in care. The nurse-patient relationship, exchange of knowledge about care options, and values and preferences of patients are starting point for shared decision. In historically grown care contexts, shared decision-making is not jet quite obvious.

*Aim*

Aim of this study is obtaining better insight in current experiences of patients with shared decision-making during hospital admission.

*Method*

A qualitative research design was applied. Research took place in the North of the Netherlands. Participants hospitalized in the period of February 2019 until February 2020 were included. They were eighteen years or older, Dutch speaking and capable of taking part in research. Sixteen interviews were base for thematic analysis. Interviews were transcribed and anonymized. (Peer-)reviews were part of the procedure.

*Results*

Seventeen participants were approached and interviewed, of which one interview was excluded. The importance of shared decision-making is obvious, but not self-evident. Nurse and patient working together in a care-relationship towards decision-making, patients’ need to be seen as unique person, experiencing healthcare as entering a system and the importance of nurses’ roles in shared decision-making, are the main themes arising from analysis.

*Conclusion*

Although Shared Decision-Making can affect patients deeply, it is not always applied. Recognizing a choice can be made, following steps of the shared-decision process and getting in-depth understanding of patients, sometimes seems difficult to coexist with daily work processes and nurse routine.

*Recommendations*

Findings could be used for further research into care-relationships related to shared decision-making, and into shared decision-making process during short hospital admissions. Also, creating opportunities within the constraints of healthcare systems need to get attention.

***Keywords*:** Shared Decision-Making, Patient Centered Care, Patient Experiences, Nursing, Hospitalization

**Introduction**

Shared Decision-Making (SDM) is an important pillar in Person Centered-Care (PCC), which is focused on the individual behind the patient with a personal and unique frame of reference and feelings.1-4

In the process of SDM, caregivers recognize patients' rights to become involved in care by including them in care decision-making.5,6 As a result, patients rate their quality of life higher, and also improvement of physical, mental and social functioning is described.5 The care relationship in which SDM takes shape is described as a partnership between care provider and patient working together in a process resulting in care choices.2,7,8 This relationship is considered to be an important base in which participatory, collaborative, open, respectful and trust are fundamental.9-13

Much has been written in literature about the process of SDM. Whitney et al. elaborated the SDM process in seven steps – 1.recognizing a care situation in which a decision has to be made, 2.making an inventory of possible actions, 3.selecting pros and cons of options, 4.weighing and discussing these options, 5.choosing an option or rejecting one, 6.decision-making, and 7.implementation of the choice.14 In their review, Truglio et al. designed a model of communication, relationship building, the particular context of HC environment and patient’s background. Also, patient-education by nurse and exchange of patient’s values, beliefs and preferences were elaborated and affect SDM.9 The extent to which patients wish to be involved can change over time depending on the nature of the health problem. For example, acute illness may foster a more provider-led approach compared to chronic illness.9,15-17

Both, nursing science and healthcare providers recognize patient participation including SDM as an important part of healthcare.18,19 However, until now, research in nursing care has focused mainly on the SDM process and nurses' perceptions, and less on patient experiences.18,20,21 In addition, in nursing changes cannot be taken for granted: care professionals work in historically grown contexts in which written and unwritten laws apply, care processes are routine and ritual, and offer just a few opportunities for a meaningful nurse-patient relationship.19 Understanding SDM-relevant topics for patients may lead to a more comprehensive understanding of nursing behaviors and factors patients value.18,22,23 Insights can be integrated into development of policy, programs and interventions to improve SDM.

This research aims to gain an in-depth insight in patient experiences of SDM in nursing care in hospital settings.

**Method**

Current study is part of the project Quality of Care program: Accelerating, Broadening, Renewing; project LeerSaam Noord: learn and work together.19

A qualitative study of patient experiences of SDM in nursing care, during hospital admission was conducted. A thematic analysis was applied, suitable for investigating beliefs, experiences and opinions,24,25 in which inductive reasoning is used, proceeding from rich data, to general abstract themes.26,27

*Study population and domain*

The study was conducted in the North of the Netherlands and occurred from January 2020 until June 2020. The study domain concerned patients who were admitted to hospital in the past year. Eligible participants were at least eighteen, alert and orientated, able to participate in the research procedure, Dutch speaking, and hospitalized between February 2019 and February 2020. Patients with mental disabilities were excluded for ethical reasons.28,29

Purposeful sampling was applied, and three recruitment routes were used: an invitation to participate on the internet site of Zorgbelang to which patient associations are linked; own network of the research group and in addition snowball sampling.26,27 Thirdly an invitation on intranet of Meldkamer Noord Nederland (MKNN, Dispatch 112 center in the North of the Netherlands), which is a police, fire and ambulance organization. After the first registrations for participation, a targeted search was conducted for various ages and gender groups for the purpose of maximum variation.26,27,30

*Datacollection*

To explore patient’s thoughts, feelings and believes on specific topics semi-structured interviews were conducted and completed by one trained interviewer (JW), aimed at getting deeper insight.26,27,31 This took place between late March to mid-April 2020 till thematic saturation was reached.26,27,30 The interview guide was literature based on SDM and related subjects. An overview of the topics is displayed in table 1.

--Table 1 *Interview guide* –

approximately here

Feedback to the interview guide was requested during a qualitative interview training,32 peers of Clinical Health Sciences Nursing Science Utrecht University (UU), and members of the research team of LeerSaam Noord, NHL Stenden university for applied sciences. Also, two care-recipients as experience experts participating in the research-learning community of LeerSaam Noord, were asked for comment. Concerning data-collection, feedback was requested from UU fellow students. After the first three interviews an adjustment was made: participants were asked about a good and a worse experience of SDM and to compare both, in order to get more nuance in conversations.

*Data-analysis*

Demographics of participants were collected and presented in descriptive statistics. Interview transcripts were read and reread for the purpose of becoming familiar with the data.25,33 Data analysis of transcripts was performed with ATLAS.ti.34 Thematic analysis is used, in which the principle analytic induction confirms existing themes, or uncovers new ones.25 Coding and analyzing was executed by the same researcher who conducted the interviews. Member checks and organizing peer reviews during the coding process were included in the study procedures, intending to improve credibility and confirmability of the study.27 A native speaker was consulted for an accurate translation of participants’ quotes.

*Procedures*

In accordance with the general data protection regulation (Algemene Verordening Gegevensbescherming (AVG))35 contact data were collected. Participants received an information letter and a consent form by email. For the purpose of trust and building rapport, the procedure consisted of at least two contact moments prior to the interviews.31 At the time of the interviews, not all IC’s were returned. Therefore, IC’s were also taken by telephone, according to a special format(appendix A). Interviews were taped by iPhone app TapeACall, without personally identifiable information. All data are stored securely in accordance with approved data management plan.36 The consolidated criteria for reporting qualitative research (COREQ) checklist has been used for reporting study results.37

*Ethical issues*

This study is assessed and approved by the Medical Ethics Review Committee (METC) of University Medical Center Groningen (UMCG) with a template for research not subject to the law for medical scientific research with humans - in Dutch WMO.28,38

**Results**

The participant group consisted of seventeen people, hospitalized in the North of the Netherlands, one year prior to the interviews. One interview was excluded – generated research data did not fit in the aim of this study. An overview of participant characteristics is shown in table 2.

---Table 2 *Demographic data*---

Approximately here

In hindsight it turned out that the Tape-A-Call app sometimes was disconnected at the beginning of the conversation. This happened four times. Conversation reports were made of these interviews and presented to involved participants as member checks, who were asked for a reaction. One out of four made a comment. All four reports were included in the analysis.

Patients described their experiences: what they experienced and how. They also reported influencing conditions. Table 3 provides an overview of themes and subthemes obtained from data.33

--Table 3 *Thematic data* --

Approximately here

**Working together**

Patient and nurse collaborated for decision-making, what did patients experienced, and how did they experience it.

*Awareness*

In SDM, persons concerned need to recognize care situations that require a shared decision. It turned out participants, asked for a situation in which SDM occurred with a nurse, initially had difficulties finding an example in the nursing domain. SDM was regularly related to medical care and medical decision-making with a physician.

‘I once had an operation in which I had a very bad drop in blood pressure, that was in 94, that did not go well, you know I did not get it done easily and I did not realize that at that time, but afterwards you think, ‘I could have ‘left’’. And if you have to be operated on again, that will sick a bit. So, I had already indicated that very well with the anesthesia and the intake.’ (Woman, 68 years)

Table 4 presents an overview of situations submitted by participants regarding SDM in the nursing domain. Half of the situations concerned nurses’ roles in medical protocol care applications. Others were about guidance, degree of physical care, mobility after surgery or event, or special nursing care.

--Table 3 *Situations of decision-making in nursing domain* —

Approximately here

In their account of SDM, all participants mentioned who started discussing the situation or choice. Nurses’ initiative was clearly preferred and highly appreciated by patients.

‘It was very nice that she came up with a proposal herself. She did this spontaneously and that was sweet’, (Woman 54 years)

*Working toward a decision.*

Patients experienced SDM and care in which they were not involved in decision-making. In case of SDM, in the preamble patients received information and advice by nurses, and talked about their needs, preferences and feelings. For example, information exchange concerning standard medical protocol of pain-medication, in which application was tailored to patient’s preferences who was not ‘a pill-swallower’. Such conversations differed in extensiveness. The quote below was the most comprehensive example.

‘Then I had a morphine pump and they told me, ‘Well, you have now a morphine pump, but tomorrow we will disconnect it, but think about the pain relief you would like, because you basically had paracetamol and diclofenac, and it ..’ Then they asked if I was allergic to anything. Then I said I was allergic to naproxen.’ (…) ‘And then they came back and said ‘we shouldn’t be giving you diclofenac, uh, we can offer you morphine tablets’. ‘Oh, well that’s good’ and then they asked: oh, but you wanted to breastfeed abs then you shouldn’t do that with morphine, so think about that’. (Woman 32 years)

Conversations related to formalizing nursing care, pertained to the ‘here and now’, were more practical and briefly reproduced by participants with altercations as – patient: ‘I actually want to take a shower’, nurse: ‘Um, it actually works out really bad at the moment, because I’m really busy’ – or – when the nurse asked if patient wanted to take a shower, but feeling insecure and afraid of getting dizzy they decided together that the nurse would stay until patient finished showering. Sometimes nurse’s assessment of patients was about what the patient could handle in terms of emotion, condition and knowledge. But in general, SDM conversations lasted a short time and took fewer steps than described in theory. The quote below was the most comprehensive example.

‘Your feelings were just really taken into account. Because it was a sad state of affairs, but that was really taken into account. There was always someone and if you were just afraid to look down (to the surgical wounds), it was just taken easy and you could indicate when you wanted to. That was also allowed the next day. That was very nice’.

(Woman 53 years)

When a desired shared decision was reached, patients experienced confidence and words as ‘very nice’ were mentioned a lot. However, when a shared decision was reached, participants’ word choice stood out: they used: ‘she was okay with it’, I was relieved I didn’t have to..’: as if the nurse made a proposal and patient agrees or vice versa. It suggests liking and agreeing to a proposal.

In case of worse decision-making experiences, patients usually experienced having a choice, whereas the nurse did not. As a result, the nurse-patient conversation was ineffective, or unsatisfactory arguments led to a final nurse-led decision.

[About medication] ‘I am very precise about that and I have an interest in taking that at the right time and things like that, I said that too ..’ ...’but now that it seems to me so confusing, I am not happy about it. I would like … or I would like to do it myself and I have done all that in the past. And if that’s not possible … well, according to her not …’.

(Man, 68 years)

In rare cases nurses adapted to patient’s desired care. If patients had to settle for a decision which was undesirable to them, nurse’s attitude became important. People felt treated unfairly and became emotional.

‘’Well you can do that [shower] by yourself’ [nurse said]. And I want to do everything myself. (..) If you can do it yourself then you do it yourself and then I notice at such moment: I did not cry, but I felt a bit, yes, a bit unstable, because yes you just had surgery. I did exactly what I was allowed to do and had to do and yes …’

(Woman 68 years)

Words as insecurity, disrespect, feeling neglected, not being welcome and powerlessness were used in this context. These situations caused fear, anxiety, anger and curse. Most patients resided in it or accessed other sources, like searching for scientific information or asking other healthcare professionals for example the attendant. They also sought for explanations: ‘maybe she was busy’, ‘did not reading well’, or ‘she was still young’.

*Care-relationship as workspace*

As important it is found in literature, so a few participants spoke about care-relationships. Proactivity in care provision by nurses inspired confidence, and good feelings in patients. One participant added ‘So you then rely on someone you have a proper contact with’. Some participants noticed differences in nurses. Instead of describing or hinting at a nurse-patient relationship, participants mentioned nurse characteristics in terms of ‘sweet’, or ‘young’, or experienced, or less experienced. Some also mentioned differences in characters and skills. However, there was no pattern in linking good or bad experiences to a specific typing.

‘You just have a differences: you also have very young nurses, I also have experiences with it, but I also had twice, what I call you and then at the first admission, and there are really people or, just like you are a piece of stuff what comes in and has to come out again. You know? A little bit impersonal’. (Woman 68 years)

**Individual behind the patient**

Background, feelings emotions and needs as component in SDM.

*Patient as unique person*

Strongly emerging from research data was patients’ desire to be seen and approached as a unique person: ‘everyone is different’, ‘people know their own bodies and reactions best’.

I am not afraid of pain, I am not afraid of surgery, I am terrified of anesthesia, because ‘you’ will hand over control. And that is not my strongest feature’.

(P008, woman 68 years)

Participants’ narratives showed they respond from a certain frame of reference. They wanted to include personal beliefs and experiences in decisions. For example, one said she was no ‘pill-swallower’ or another one had difficulties relinquishing control. In a number of cases, patients were diseased and hospitalized before. They knew how care works and prefer procedures they are familiar with and like.

’The first time before surgery in June, when I had a schedule for myself with paracetamol. (…) And when I had to have surgery for the second time in November, they gave me a slightly different schedule. But then I said I was used to doing so and so (in a certain way), to do like this. She thought that was fine’. (Woman 43 years)

Due to the disease, treatment and condition during hospital admission patient’s reactions differed. They experienced anesthesia, fatigue and emotions, which made them feel vulnerable, and less open to conversation. They lost part of their assertiveness, conformed to nurses’ choices, which did not always work out well.

*The share of information*

As important as sharing their own specific story, their fears, weaknesses and preferences, patients also remarkably often indicated their need to receive information. Within the SDM-process the information-need mainly concerned practical matters as future drug use, insulin protocol, phasing out medicines, and also support in physical care. Although participants stated they assumed medical and nursing professionals know where they talk about, they still needed information about their disease, procedure, treatment and recovery process. Being informed influenced patient’s situation in a practical way as improving self-management, being better able to ask questions and anticipate on their care-process. In addition, information removed uncertainty: people entered the operation with peace of mind, had feelings of being taken seriously and that gave confidence.

‘… a kind of preliminary conversation before, in this case the cardiologist visits, because you are better informed and better able to ask questions.’ (Woman, 50 years)

**The Healthcare system**

Healthcare, hospital, nurse ward and nurse work-processes facilitate and limit.

*Healthcare as a system*

When talking about their hospitalization patients sometimes suggested entering a system: people made a choice with their physician and entering a procedure with medical and care protocols, work processes, and nurse ward policy. During their hospitalization, patients were aware of that and experienced their care within that context.

‘It’s really, um, tightly organized. You hardly know what to do with that. Well, yes if your admission is during the transition from summertime to wintertime or vice versa. Because then certain tasks remain for the day shift’ and ‘then you notice that certain things are left, but otherwise it is tighly organized (…) All I was allowed to, was choose my meal. In which choices were reduced to a choice menu.’, (Man 57 years)

Healthcare organizations facilitate care within the margins of the hospital such as the supply of medical aids, while other patients indicated that medication used at home, was not available in the hospital or received different insulin during admission. One patient became unsure and was afraid that his care would become a mess. Another surrendered with an attitude of ‘they will know what they are doing’.

‘Sometimes I say:" You are at the mercy of the Gods (laugh)! I mean, uh, you're assuming people know what they're doing '. (Man, 55 years)

*Nurse ward as a workplace*

In this context, understaffing and lack of time are considered as being inevitable. Patients observed the great effort staff members made and understand the stressful working conditions. When it comes to nursing work and departmental routine, participants indicated they were willing to adapt, they arranged and joined in. Standardized procedures were experienced in varying ways, as limiting and facilitating. Patients understood that some processes are fixed, or whether there is a limited choice. However, the system can also make you feel safe. A number of participants commented that tightly directed care and routine can also be experienced as impersonal or unidentifiable.

*Standards and routine*

‘I can imagine that if, uh, things are tightly directed, uh, then you would very quickly and easily radiate the feeling of uh, uh ... Then you could come across as a bit uninvited, so to speak’. (Man, 57 years)

Standard protocols about duration of or admission to nursing care are not subject of choice. Patients realized that, they recognized it as arrangements and routine. They tended to fit in and described it as ‘such a scenario ',' cycle ', or ‘that’s the way it is at the ward'. In a number of cases this is felt restrictive. For example, when self-management concerning medication

was not allowed. Sometimes patients did not notice a choice, because of the routine. They wondered about issues like ‘what is normal’ or ‘how does it work?’. And at times nurses showed differences in their insights and routine.

And then I thought huh? Is this something, what … is it really busy or something? Or hasn’t she read it correctly? Or does she think I can do it by myself because I hadn’t really needed anyone all the time? So, I thought that was a bit of uhm ‘come on’. And I realized: you can make arrangements [with the nurse the day before], but ….’. (Woman, 68 years)

Finally, patients saw nurses were busy. They saw the bustle in the ward and that nurses were forced to make choices in care. Patients adapted and asked fewer questions about their care. In contrast, in some nurse wards taking time for patients seemed intertwined in the nurse routine: as standard, patients were asked about the perception of pain, if they were ready to be confronted with wounds and come to SDM together.

"From the surgery, the nurse asked me daily whether I was experiencing pain’ … ‘In consultation with the nurse, I was allowed to try to stop the Oxicodon’.

(Woman 52 years)

**Nurse roles**

This theme is about specific roles of nurses in SDM experienced by patients.

*Nurse as facilitator*

Data show a strong part of SDM approach is nurse dependent. Patients were aware of nurse’s role in recognizing a choice being made and patient involvement were crucial. Otherwise SDM did not start or had no progress. Standard nursing care and nursing routine were mentioned in relation to the way in which nurses organized their work. When a nurse did not initiate, patients sometimes started talking about having a choice. In both cases opportunities within the organization and how the nurse approached this, determined the progress of the SDM process.

[Patient would like to have his own baxter \* user] "When I was admitted to the department for the first time, of course I already had the necessary medication. Enneh, that medication, that, uh, that was stiff, that was not always in, in the right dose, and so she couldn't offer that if it was at other times. (…)… I had that (baxter) at home by now. And that was eh, since a few years and I liked it, liked it very well and I had ... I am very interested in that, to take that at the right times and I said that there too. Well, then the nurse was there, that, uh, that, she didn't agree. He was against that. "Or" So I did say that, but she stayed with it, because it was best for me and for other patients in the department that they would take care of it themselves, who dispensing medication, well I didn't agree with that’.

(Man 68 years)

\*Baxter: individualized drug distribution system

*Nurse as professional*

During the process of SDM, patients experienced the role of nurse related competences, knowledge and skills, preferring neutral and "not telling her what to do". One respondent said that it is often clear what they think is best. When asked, patients indicate what their views are on the role of the nurse: consultation, good explanation and the reason behind a guideline are particularly important when making decisions. Being proactive, attentive, involved, correct mannered and mutually interested was important.

‘ … then I notice that nurses are very important to you uh, yes how do I say it, occasionally to give you occasional attention and also uh well, and then you notice your vulnerability. Then the role of a nurse is extremely important’. (Woman, 68 years)

**Discussion**

 This study shows SDM in hospital settings cannot be taken for granted. First of all, SDM was often associated with medical care. Half of the examples submitted by participants were still related to nurse’s roles in medical care implementation. Choice awareness and the follow-up determined the outcome: whether or not SDM. Often SDM conversations were short, in-depth questions were hardly reported, and SDM seemed to be more about agreeing and approving. Both, achieving SDM or not, affected patients very much. Besides, patients wanted recognition of their uniqueness. They experienced their care within the healthcare framework, hospital and nurse ward. Finally, the important role of nurses in the SDM-process, have to be highlighted.

 Not all results in our study are supported by literature. For instance, SDM was hardly associated with nursing care. In literature no explanation was found. Due to hospitalization medical care may be more dominant in participant’s memory. It also struck that SDM steps in this study, seemed insufficient taken and fewer in-depth questions were asked. Motivation has not been found for this in literature either. The retrospective nature of this research may have played a role, given that people summarized what they remembered or wanted to tell about it.39 The question whether this is related to the type of nursing care, could also be raised. Finally, the times SDM did not occurred. Although stories of our patients show similarities with barriers and facilitators described in literature.9

 Despite the importance of the nurse-patient relationship described in other studies as fundamental,1,40,41 participants in our study described nurses in terms of characteristics. This may be due to the length of hospitalization. Literature discusses time required to build a relationship.9,42,43 In this sample, the average hospital stay was four days, with a range of seven days. Describing nurses in characteristics is partly in line with a study by Truglio ‘.. patients responded to a nurse who was familiar and approachable, which created a sense of comfort’.1,p414

 Patients’ need to integrate their uniqueness in care and decision-making is in-line with PCC in which SDM is fundamental. PCC is rooted in the holistic paradigm19 and fits in the description of the fundamental aspects of nursing care: integrating holistic and scientific principles form the base for compassionate, quality-based care.44-48

 Participants in our study described their hospitalization as ‘entering a system’. In literature barriers and facilitators were mentioned in that respect.9 Truglio mentioned ‘‘know the best’ because the patient had a lack of knowledge’,1-p504,49 in this respect paternalistic.1 In our study however ‘the system’ was considered as limiting but also referred being safe for the same reason: ‘they know what’s best’.

Speaking from experience, participants in our study indicated it was nurse-dependent whether he/she was aware of care that needed a decision and gave a follow-up to SDM. This is in-line with literature.50,51 Gualano et al. concluded in their study that in a perceived SDM approach the strongest determinants are healthcare professional-depending.51 Knowledge, skills and attitude mentioned in SDM extracted from data, affects all seven competences of the nursing profession based on the system Canadian Medical Education Direction for Specialists.1,52,53

 In this study, participants’ words were noticed suggesting SDM is about agreeing. This is in line with Begley’s and Berger's studies, in which Begley states that 'a decision by one, and the mere agreement of the other' is not SDM.50 Berger calls SDM a more aspirational process, in which the patient is supported to make an informed decision.54

*Strengths and Limitations*

For the purpose of this study, data-saturation was reached. Maximum variation was sought in age and gender. However, there are limitations to this study. Due to the effects of the Covid-19 measures on human research and social distance, data collection has been delayed and choices had to been made in method and analysis processes. Initially it was intended to discuss coding and extracting sub-themes and themes from data in its entirely in the research group. In the end, only a part was discussed by e-mail and video call.

Participant group mainly consisted of higher educated people, a relatively large number of healthcare workers, living in the North Netherlands and were all Caucasian. Patient’s age, gender, race, spiritual and cultural beliefs, education and life experiences, influence patient’s beliefs and values about SDM.1,9,48 This research is not complete in this.

The retrospective nature of the study, whereby the time between the experience and interview, can be seen as a limitation.39 This concerns descriptions or summaries of situations in which participant choose what they want to tell.1,39 The outcomes also apply to this diversity of patients, regarding types of disorders, different hospitals, with a hospital stay of 2 to 7 days. By asking for both good and worse experiences of SDM, an indication that both happened is given, nor the extent of what people think about first. This may give a distorted picture. However, there is no intention to generalize to a larger population

*Implications and clinical relevance*

This study contributes insight into patient experiences of SDM during hospitalization. Future research could 1.strengthen insights by exploring nurse-patient relationships in SDM during short-term admissions, 2.gain insight in SDM-processes in the predominantly task-oriented nursing practice in which the patient-nurse interaction mainly occurs during functional activities, and 3.gain insight into limiting aspects of the health system: should a hospital setting always as be limiting as it is?

For clinical practice results of this study contribute to awareness of nursing staff and administration. Results can be included in further development respecting SDM. In the overarching project LeerSaam Noord, results can be compared with SDM in long-term care, similarities and differences, which eventually leads to input for improving SDM.

*Conclusion*

Patients experienced decision-making in their care during hospitalization within the context of health care, hospital and nursing department, in which medical protocol care, work processes and routine are felt, patients need monitoring as an individual rather than a patient. The nurse plays an important, facilitating role in SDM!

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Table 1

Table 1 *Interview guide1,5,55-63*

|  |
| --- |
| Topics interview guide |
| Can you tell about a situation/ situations in which you and your nurse made a joint decision about your care? A good experience and a less good experience1,63Which decision was made?What proceeded it?Where did you talk about?How did you experience the process?Comparing these situations, what determines the differences? |

Table 2

Table 2 *Demographic data*

|  |  |
| --- | --- |
| Participant characteristics (n=16) |  |
| GenderMaleFemale | 511 |
| Age  | Mean: 52,75; Range: 32-79; SD: 13,6;  |
| Education level\*WOHBOMBOVWO | 4651 |
| ProfessionHealthcare and wellbeingOther | 88 |
| Hospital admission characteristicsType of admission:* Planned
* Emergency

Duration hospitalization (days)Previous hospital admission experiences (times) \*\*Type of hospital:* Academic
* General
* Both

Type of disorder* Chronic
* Temporary

Type of treatment* Curative
* Palliative
 | 70%30%Mean: 4.6; Range: 2-10; SD: 2.7,Range: 0 - >53103412100%0% |

\*Dutch education model: WO: scientific education; HBO: higher professional education; MBO: secundary vocational education; VWO: pre-university education, \*\*not all answers are exact memories

Table 3

Table 3 *Thematic data*33

|  |  |
| --- | --- |
| Themes and subthemes | Interpretation |
| Working together* Awareness
* Working toward a decision
* Care-relationship
 | Nurse and patient collaborated for decision-making: what did they experience and how they experienced it |
| Individual behind the patient* Patient as unique person
* The share of information
 | Background, feelings, emotions and needs as component in shared decision-making |
| The healthcare system* Healthcare as a system
* Nurse ward as a workplace
* Standards and routine
 | Healthcare, hospital, nurse ward and nurse work processes facilitate and limit |
| Nurses’ roles* Nurse as facilitator
* Nurse as professional
 | The specific role of the nurse experienced by the patient |

Table 4

Table 4 *Situations of decision-making in nursing domain*

|  |
| --- |
| Situations for (S)DM (several times mentioned) |
| Fitting a temporary prothesis, breast careApplication of pain medication protocol, in hosptal and after discharge (6)Coordination discharge at hospital admissionNurse guidance and care in case of physical care (8)Medication during admission, bij patient or by department?Used materials by ostomy care Nursing care during an acute admissionChoice about coaching after hospitalizationNurse attention when preparing for medical interventionApplication insuline protocol in pregnancy diabetes mellitisNursing care in childbirth careNursing guidance during an acute admissionApplication insuline protocol after gastric bypassMobilize after cardiac eventGet rid of glue residues from ECG\* stickersNursing care after discomfort during self-care |

\*ECG: electrocardiogram

**Appendix A**

**Introductie**- Introductie van de interviewer
*Voorbeeld: Mijn naam is …….. ik doe onderzoek naar …. U heeft aangegeven mee te willen doen aan een interview over … Wij hebben deze telefonische afspraak daarvoor ingepland.*- Bespreken van het doel van het interview- Praktische informatie

* *Het interview zal ongeveer … minuten duren*
* *Het gesprek zal opgenomen worden*
* *Uitleg over vertrouwelijke omgang met de gegevens*

- Uitleg start audio-opname
*Voorbeeld: Ik zal zo meteen de opname starten. Als ik de opname start noem ik eerst wat zakelijke gegevens (zoals de datum van het gesprek en uw deelnemer nummer) en dan geef ik 6 stellingen die u met ja of nee kunt beantwoorden (stellingen + antwoorden bespreken).*- Inventariseren of participant begrepen heeft wat de bedoeling is en of er vragen zijn.

**START AUDIO-OPNAME**

Het is vandaag…..(datum), …(tijdstip)
Ik spreek met participant *(eventueel: met deelnemer nummer….(deelnemer nummer))*
Er volgen nu 6 stellingen voor informed consent, die de participant zal beantwoorden:
1. Ik heb de informatiebrief over het vraaggesprek gelezen en de informatie begrepen.
2. Ik heb geen aanvullende vragen meer.
3. Ik verklaar vrijwillig mee te doen aan dit interview.
4. Ik geef toestemming voor het opnemen van dit interview en weet dat ik deze toestemming op elk moment weer in kan trekken.
5. Ik weet dat de inhoud van dit gesprek wordt gebruikt voor wetenschappelijk onderzoek, zonder dat deze herleidbaar is naar de persoon.
6. Ik weet dat mijn gegevens altijd vertrouwelijk zullen behandeld.

Indien alle vragen met “ja” zijn beantwoord, dan vervolgen met het interview.