

Participation in nursing documentation: an interview study among home care patients

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Participation in nursing documentation: an interview study among home care patients

Abstract

Background: Patient participation contributes to the quality of care and patient satisfaction. Giving patients access to their health record strengthens patient empowerment which could enhance involvement. This study strives to expand the knowledge of participation of home care patients in nursing documentation to contribute to the quality of home care.

Research questions:

1. To what extent do home care patients want to participate in nursing documentation?
2. Which barriers and facilitators do home care patients experience regarding their participation in nursing documentation?
3. In which ways has a family caregiver to be involved in nursing documentation, according to home care patients?

Method: Qualitative study. The study is partially based on eight semi-structured interviews with home care patients and additional analysis of eleven previously conducted semi-structured interviews. The transcripts were analysed by the method of thematic analyses by Braun and Clarke.

Results: Four themes were identified: patient related factors, working methods of the nursing staff, the role of the family caregiver, and barriers and facilitators: the patients' condition and the digital system. Patients who want to participate in nursing documentation find it important to check the information and to be informed about their physical and mental condition. Some patients don't want to participate, they see it as a burden or simply don't feel the need to.

Conclusion: The needs of home care patients regarding to participating in nursing documentation differs. Most patients find talking about the written information most important, while other patients want to have access to the documentation and read it themselves.

Recommendations: Nurses should discuss with patients how they want to participate in nursing documentation. More research can be done on how to facilitate patients who cannot participate in nursing documentation due to their physical condition.

Keywords: Nursing documentation, patient participation, electronic health record, home care, experiences.

Samenvatting

Achtergrond: Patiënten participatie draagt bij aan de kwaliteit van zorg en patiënttevredenheid. Patiënten toegang tot hun zorgdossier geven versterkt hun empowerment, wat de betrokkenheid en kennis over de behandeling verbetert. Het doel van dit onderzoek is om de kennis over betrokkenheid van cliënten van wijkverpleging bij de verpleegkundige verslaglegging te vergroten.

Onderzoeksvragen:

1. In hoeverre willen cliënten van wijkverpleging deelnemen aan verpleegkundige verslaglegging?
2. Welke belemmerende en bevorderende factoren ervaren cliënten van wijkverpleging met betrekking tot hun betrokkenheid bij verpleegkundige verslaglegging?
3. Op welke manier moet een mantelzorger volgens de cliënten van wijkverpleging betrokken zijn bij de verpleegkundige verslaglegging?

Methode: Kwalitatief onderzoek. Het onderzoek is gedeeltelijk gebaseerd op analyse van acht semigestructureerde interviews en elf interviews die eerder zijn afgenomen. De transcripties werden geanalyseerd met de methode van thematische analyse van Braun en Clarke.

Resultaten: Er werden vier thema's geïdentificeerd: Patiënt gerelateerde factoren, werkwijze van het verplegend personeel, de rol van de mantelzorger en bevorderende en belemmerende factoren: de toestand van de patiënt en het digitale systeem. Patiënten die willen deelnemen aan verpleegkundige verslaglegging vinden het belangrijk om de informatie te controleren en op de hoogte te zijn van hun fysieke en mentale toestand. Sommige patiënten willen niet betrokken worden, ze zien het als een last of hebben er simpelweg geen behoefte aan.

Conclusie: De behoeften van cliënten van wijkverpleging met betrekking tot deelname aan verpleegkundige verslaglegging verschillen. De meeste patiënten vinden het belangrijk om over de geschreven informatie te praten, andere patiënten willen toegang hebben tot de verslaglegging en deze zelf lezen.

Aanbevelingen: Verpleegkundigen wordt geadviseerd met patiënten bespreken in hoeverre ze willen deelnemen aan verpleegkundige verslaglegging. Er kan meer onderzoek worden gedaan naar het helpen van patiënten die vanwege hun fysieke conditie niet kunnen deelnemen aan verpleegkundige verslaglegging

Keywords: Verpleegkundige verslaglegging, patiënt participatie, elektronisch zorgdossier wijkverpleging, ervaringen

Introduction

Patient participation is increasingly seen as a crucial part of healthcare and can relate to many aspects of care including goal setting, decision making and self-monitoring¹. It contributes to the quality of care, patient satisfaction and quality of life^{2,3}. Different studies have been done on the properties of- and influencing factors for patient participation⁴. Influencing factors for patients can be for example acceptance of the new patient role, health literacy and knowledge, and disease severity^{1,5}. Nowadays, most patients have an increased desire to participate in their health care and decision making⁶. The desire to participate can vary depending on for example the type of care or the patients age^{7,8}. A study about participation in care decision-making, mastery, self-esteem, empowerment and depressive feelings found that most patients want to be collaboratively or passively involved in nursing documentation⁹.

ND is the recording of the planned and given care to patients by nurses or other caregivers¹⁰. The nursing process is the systematic of planning, execution and evaluation of the patient care and is embedded in ND by the care plan, evaluation reports and progress reports. ND matches the nursing process which consists of data collection, determine nursing diagnoses, writing the care plan, execution of care, evaluation and handover¹¹⁻¹³. In order to take part in decision-making and enjoy increased participation, a patient needs to have knowledge of his/her treatment^{1,8}. This knowledge can be provided by ND. Nurses have experienced that providing patients access to their health record increases patient empowerment which could enhance involvement and knowledge of their treatment¹⁴.

Moreover, it is described in the legislation of many European countries, such as Norway¹⁴, Belgium, the United Kingdom¹⁵, and the Netherlands¹¹, (Dutch Medical Treatment Contracts Act and General Data Protection Regulation) that every patient has the right to access his/her health record at request and has the right to let information be removed or added. The Dutch guideline for ND states that the care plan has to be written in consultation with the patient or her/his representative and the patient or her/his representative has to give permission for the care plan¹¹. Dutch law enforces that from 2020 patients have to be digitally enabled to access their health record¹⁶.

Over the last years health records and ND shifted from paper-based to electronic. In 2019, 83% of the Dutch nurses in home care and nursing homes used electronic documentation^{17,18}. Electronic documentation facilitates structured documentation, and enables classification and analysis of collected data¹⁹. In most home care organizations patients can get access to their health record by an electronic patient portal, in which the Dutch home care takes a leading position¹⁸. The portal is a digital environment that is linked to the health record. Access to the patient portal enables the patient to read documentation and in some cases, digitally communicate with the nurse. With permission of the patient, the portal

can be shared with his/her family caregiver²⁰. For example children of home care patients can read along about the care on their own digital device. There is however a qualitative study among veterans from the United States who were receiving home care that found that computer and Internet access and low socioeconomic status can be obstacles to use patient portals²¹. A disadvantage for digital documentation mentioned by Dutch nurses in an online survey is that not every software developer enables patients to log in, which prohibits the patient to have insight in his own health record²². In the Netherlands a focus group study with patients and nurses found that patients and family caregivers often do not feel involved in documentation^{23,24}. The focus group consisted of four patients and four family caregivers from the northern part of the Netherlands. Due to the small sample the outcome of the study is merely a first indication which implicates the need for a thorough analysis on the experience of patients of home care about their participation in ND.

This study strives to expand the knowledge of the participation of patients of home care in ND to contribute to optimization of the quality of home care. In this study, the term 'nursing staff' will be used which covers registered nurses (RN) and certified nursing assistants. The following research questions will be answered in this study:

Research questions

1. a. To what extent do home care patients want to participate in nursing documentation? b. If they do not want to participate in nursing documentation, why not? c. If they want to participate, why do they consider this important, and in which ways do they want to participate in nursing documentation?
2. Which barriers and facilitators do home care patients experience regarding their participation in nursing documentation?
3. To what extent and in which ways has a family caregiver to be involved in nursing documentation, according to home care patients?

Methods

Design

The study was conducted following a qualitative interview design. This design fitted the aim to gain insight in the experiences, behaviour and feelings of patients from home care regarding their involvement in ND. The study was partially based on secondary analyses of eleven semi-structured interviews which were conducted prior to this study by bachelor nursing students, and on analyses of semi-structured interviews executed by the researcher (JD) (student Nursing science). For this report, the consolidated criteria for reporting qualitative research (COREQ) were used as guideline²⁵.

Setting and participants

The study population consisted of patients receiving home care. The participants had to meet the following criteria to be included in the study: receiving home care, speaks Dutch, no severe cognitive impairments, and use of electronic health record by the nursing staff. To obtain a sample of patients with variation relevant for the purpose of the study, purposeful sampling was applied. The characteristics cultural backgrounds, educational levels, and social-economic-status were taken into account.

Procedures

The study was performed from February to June 2020 by a nursing science student (JD), with supervision of two researchers (AF and KdG). The researcher (JD) is a home care nurse. This facilitated useful knowledge and experience about the setting of the participants. On the contrary, being a home care nurse, there is a risk of personal bias. To enhance credibility, JD followed a workshop about interviewing, and discussed her interview techniques with the supervisor (KdG).

The participants were recruited with the help of home care nurses within the network of the researcher. The nurses were informed about the study, including the purposive sampling aim by email. They selected patients who fitted the sampling aim and gave them an information letter to enable them to make an informed decision to participate. When the patient agreed to participate, the home care nurse shared the phone number of the participant with the researcher. Next, the researcher contacted the participant to make an appointment for the interview and to answer questions of the participant.

Data collection

The data exists of eleven transcripts of interviews by the bachelor nursing students executed in 2019 and eight transcripts of interviews by the researcher (JD) executed from March to April 2020. The eleven interviews by the nursing students were conducted face to

face. The initial purpose was to conduct all interviews face to face. However, during the study physical contact had to be minimized due to the COVID-19 pandemic. Therefore the first two interviews were face to face, followed by six telephonic interviews. The participants of the face to face interviews signed an informed consent form, the participants who were interviewed by phone agreed orally to the informed consent form. All interviews were audiotaped with a voice recorder. The duration of the interviews ranged from 17 to 35 minutes with an average of 22 minutes. The interview guide was based on a barrier analysis²² and the current laws and regulations^{11,16}. Before conducting the interviews, the first eleven transcripts were analysed by the researcher (JD) and discussed with supervisors AF and KdG, resulting in minor adjustments to the interview guide (see appendix A).

Data analysis

The transcripts were analysed by the method of thematic analyses²⁶. This method is particularly suitable for the identification of themes in qualitative data^{26,27}. First, the researcher (JD) became familiar with the data by (re)reading the existing eleven transcripts while making notes. Second, initial codes derived and were generated by the researchers. The supervisors each analysed two of the eleven transcripts and generated initial codes. In this phase, the researcher had a meeting with the supervisors to discuss their findings. Third, the codes were structured and categorised in themes. To create an overview and gain understanding in connections in the context, a thematic map was drawn by the researcher (JD). Fourth, the themes were reviewed. Fifth, the themes were defined and named. Although the process of analysing is described in a certain order, the process of analysing had an iterative nature. The researcher alternated between collecting data and different phases of the analysing process until data saturation was reached. During the process of analysing, supporting quotes from the interviews were collected in a document to be used when writing the results. The programme MAXQDA 2020 (VERBI Software, 2019) was used for analysis to structure the themes and codes²⁸.

Ethical issues

In this study, the principles of the Declaration of Helsinki (seventh revision) were taken into account²⁹. The study protocol is approved by the Medical Research Ethics Committee (METC) of the Amsterdam University Medical Centres (file number 2019-026).

Results

Eight interviews were conducted, which makes a total of nineteen transcripts. Patient characteristics can be found in table 1. The analysis of the transcripts resulted in four themes. The four themes are about patient related factors, the working methods of the nursing staff, the role of the family caregiver, and the barriers and facilitators for participation. The relation between these themes are presented in a thematic map (figure 1).

1. Patient related factors

The extent to which patients want to participate in ND is different for each patient, and sometimes even different per circumstance per patient. Some patients express to have no interest in ND at all, others don't want to read it but appreciate to talk about ND with the nursing staff, and a group of patients want to participate in ND by using a patient portal to read the documentation and correct if necessary. Different factors influence the need of patients to participate in ND.

Cooperation and communication – Patients who want to participate in ND see this as a way to cooperate with healthcare professionals as well in home care as in the hospital. Reading the documentation enables them to give helpful information to their doctors and nurses.

*“By reading the reports I can help by saying to the doctor in the hospital: ‘well, the home care nurses thought that this and that was happening’. So I can help by informing the doctor better.
Like, I know what to ask and what symptoms are involved.”*

Another argument is the ability to correct the reports if necessary. In some cases it occurred that the report didn't corresponded with the experience of the patient or the report was meant for another patient. In addition to checking the text for factual inaccuracies, the report also provides a general view of the quality of care.

“It's just important to know what the current status is, how she (patient) responds and whether we are doing well. And then I can also check whether they (nursing staff) are doing well, at least that is the interaction.” (spouse)

Most participants express their preference for face to face communication. Some patients didn't felt the need to read the ND because they gain enough information by talking with the nurse. It was mentioned that the participant could see by the attitude of the nurses if everything is going well.

"I: Yes. How important is it for you to participate in ND? P: Well not so important in my case. No. It's actually all quite simple, the care I needed. No, no. Look, you talk to the nurses while they are here. So then you hear something, too."

Participants stated that oral communication is quicker than written communication and they feel they can better express themselves orally. Some patients combine oral and written communication by telling new information to the nursing staff and asking him/her to write it down. By doing this, the patient doesn't have to repeat new information every time another nurse is visiting.

Trust - Some patients don't want to interfere in the documentation and feel like that would be pedantic to the nurses. Almost all participants who didn't had the need to read the documentation said that when the quality of care is good, the documentation will be good as well. They explicitly speak out their trust in the nursing staff and their educational background.

*"I: You don't feel the need to ask 'Would you like to read the documentation aloud?'" P: No 'you tell me', then I'm such a teacher. I always say: 'write down that it is a mess in here and that everything is good.' Done. No not that educational, no I don't like that.
I: no, it feels like checking?
P: yes! yes, well, that's not necessary. They are doing their job and they are doing it right. So. so be it."*

Tailored approach – The experienced complexity of care seems to influence the need for participation. Some patients don't feel the need to read or ask for the documentation because they see their health situation and delivered care as non-complex. This finding is enforced by multiple patients who explain that they've had more interest in reading the documentation of the hospital of rehabilitation clinic than the documentation of home care. One patient enjoyed reading the documentation of the rehabilitation clinic because she could reflect on the progress she has made. However in a steady home situation the interest in reading the documentation faded away since no more progress was made. Some patients only read the documentation when there are peculiarities. On the contrary, other patients don't want to participate because they already have to spent much of their time to their illness. They see participating in ND as a burden. Furthermore, the participants who expressed the need to participate in ND had a lower average age than the participants who didn't want to participate.

All of these different circumstances ask for a tailored approach to meet the changing needs of the patient.

2. Working methods of the nursing staff

Many participants say that it differs per nurse whether they get the opportunity to participate. Some nurses read the report they're writing aloud and sometimes ask for consent, while others write in silence.

Writing the documentation in the house of the patient – Most participants say the nurse writes the documentation in the house of the patient. However, six participants said some nurses write the report in the car or at the end of the day. Participants say this is due to a lack of time or the need of the nurse to write without disturbances. When asked, patients don't have a problem with the nurse writing the report outside their house, mainly because these patients can read the reports themselves on an electronic device. One participant thought it would be better to write the documentation at the patients' home. She said that sometimes the nurses forget to report information because they wait too long to write it down.

Care plan - Regarding the care plan, most patients said that the nurse has written the plan in advance and that the patient got the opportunity to read, correct and sign it. Some say that the care plan was written by the hospital, mainly when the care existed solely of technical nursing care. Most patients were aware of a frequent evaluation of the care plan.

3. Participation of the family caregiver

Not all participants felt the need to share their health record with their family caregiver. They explain that they tell relevant information to their family themselves. In many cases, the family caregiver is one of the children of the patient. Participants say that they don't want to burden their children with their care, including the documentation. On the other hand they do think it is good to have the option to let their family caregiver participate if it becomes necessary in the future. However, some participants said that they have given their children or spouse access to the patient portal. It gives them the reassuring feeling that someone thinks along with them. That they don't have to deal with their health situation on their own.

"I think it's great my daughter can read the documentation. Well, she can have her judgement if something has to be done. I don't have to make decisions on my own."

4. Barriers and facilitators: the patients' condition and the digital system

Patients mental and physical condition - While the degree of illness can be a motivational factor for participation, it can also be a barrier. As stated by many participants,

they cannot remember much from the home care intake and signing the care plan because they were recovering and in some cases using heavy medicine. One participant explained that he lets his spouse participate in ND because he is sometimes too ill. Some patients have problems with their vision or concentration which makes it difficult to read the ND. One participant with low vision explained that her mentor can read the documentation to her, but she prefers to read them on her own because it contains sensitive and private information. She agreed that it would be a good solution if the nursing staff reads the reports to her, or a electronic feature to let the computer read the reports.

Patient digital skills and limitations of the digital system – The transition to a digital health record entails advantages and disadvantages for participation. Participants who have muscle diseases had trouble with carrying the binder with the health record. The electronic health record makes it possible to read it without physical effort. On the other hand, not everyone is equipped with digital devices or has digital skills. However, many of the participants who did not have a digital device or the required skills also did not want access to their health record. Errors in the mechanism of the electronic system can be a barrier to participate, multiple participants named problems with the system when it comes to login, the possibility to correct or delete reports, and sending messages.

Discussion

This study provides an insight in the needs and experiences of patients of home care regarding participation in ND. In brief it consists of patient related factors, working methods of the nursing staff, the role of the family caregiver, and barriers and facilitators: the patients' condition and the digital system. The introduction of electronic health records opens up new possibilities but also constraints for participation in ND. The need for participation can be influenced by the complexity of care, trust, communication, and physical or mental limitations due to the patients' condition.

Correspondingly to these findings, a qualitative study on frail elderly's preferences for participation found that patients were sometimes too sick or fatigued to participate⁸. Furthermore, a conceptual model on patient participation states that an influencing factor can be the acceptance of the new patient role. Historically the relationship between patient and nurse followed a paternalist model, nowadays the patient is seen as key player¹. This can be related to the participants in this study who didn't felt the need to participate and speak out their trust in the nursing staff and their educational level. Similarly, the patients who want to participate in ND, see it as a tool to cooperate (key player) with their healthcare professionals.. Although this study did not strive to find correlations, it confirms the findings of multiple studies that the desire to participate decreases with age^{8,30,31}. The mean age of participants who read ND was 51, the mean age of participants who didn't was 80 years. This study found that illness

or certain symptoms as reduced concentration or sight can be a barrier for participation in ND. Some studies about patient participation found that patient sometimes feel they do not have enough knowledge to participate⁹. This conflicts with the findings in this study where the participants didn't express that they feel they lack knowledge.

To judge the methodological quality of this study, a few aspects should be taken into account. The study was based on interviews by multiple interviewers, 11 of the 19 interviews were conducted by bachelor nursing students with no prior experience with qualitative research. The last 8 interviews and the analysing process however, was performed by a master student (JD) with little experience in interviewing. A strength of the study is that the first transcripts were analysed and discussed with the two supervisors and interim analyses was discussed in the same setting. Saturation was reached within the last interview. Although the researcher strived for variation in the sample, this was not fully achieved since all of the participants were Caucasian and from the eight interviews by the researcher (JD) only one participant was male. Due to the corona crisis, face to face interviews had to be changed into telephonic interviews. This might have had influence on the depth of the gained information.

The lessons that can be learned from this study is to be conscious of your role as a nurse when it comes to patient participation and ND. Nurses have to be aware that when they write reports in their car, they exclude patient participation in advance. Nurses should explain to the patient what ND means and ask how he/she wants to participate. In the same way they should explain the possibilities to include a family caregiver in ND since it can give the patients a reassuring feeling when a family caregiver participates in ND. For researchers this study confirms findings about the motives of patients to participate and implicates future research questions. To contribute to daily practise, more research can be done on facilitators for participation in ND. For example on how to help patients participate who are ill, tired or have low vision. In this study participants shared their experience and opinion about the working methods of the nursing staff regarding the documentation. Future research can be done on the experience of nurses about patient participation in ND to merge the experience from patients and nursing staff.

This study reveals to what extent patients of home care want to participate in ND. Not every patient shows interest in reading the documentation, but most patients find talking about the documented information most important. Other patients do want to participate by reading the documentation, correct and propose changes if necessary. Influencing factors for the need to participate in ND can be: the complexity of care, trust in nursing staff, desire to cooperate, and physical and mental condition.

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Tables and figures

Table 1

Demographic data

| | n | Missing |
|--------------------------------------|------------|---------|
| N | 19 | |
| Female | 13 | |
| Age, mean (range) | 77 (24-88) | 3 |
| Education | | 2 |
| Low | 6 | |
| Medium | 6 | |
| High | 5 | |
| Type of care | | 2 |
| Activities of daily living (ADL) | 11 | |
| Preserved nursing procedures | 5 | |
| ADL and preserved nursing procedures | 1 | |

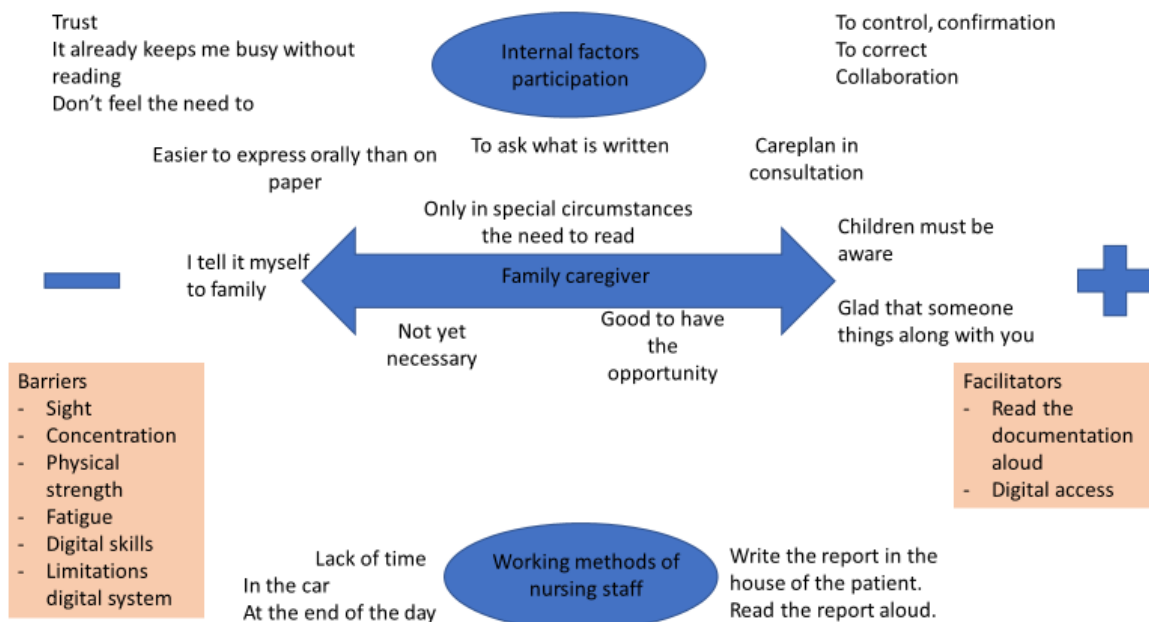


Figure 1: mindmap

APPENDIX A

interview guide

Leeftijd:

Geslacht: Man/ Vrouw/ Anders

Opleiding:

1. Kunt u vertellen welke zorg u krijgt van de wijkverpleging en om waarom u die zorg krijgt ?

2. Hoe lang krijgt u al zorg van de wijkverpleging?

3. Wordt u betrokken bij wat zij opschrijven over de zorg die u krijgt? Bijvoorbeeld in het elektronisch dossier of het zorgplan.

Doorvragen: Zo nee, waarom niet?

Wat vindt u ervan dat u als patiënt *niet* bij de verslaglegging wordt betrokken?

Zo ja, op welke wijze? Bij welke onderdelen van de verslaglegging (het dossier) wordt u betrokken? Wat vindt u ervan dat u als patiënt bij de verslaglegging wordt betrokken? Had u het anders gewild

4. Hoe belangrijk vindt u het om betrokken te worden door de wijkverpleging bij de verslaglegging?

Doorvragen: Zo nee, waarom niet?

Zo ja, waarom vindt u het belangrijk?

Hoe zou de wijkverpleging dat het best kunnen doen?

5. Maakt u gebruik van een patiëntportaal? (uitleggen wat een patiëntportaal is).

Doorvragen: Zo nee, waarom niet?

Zo ja, wat vindt u daarvan? Heeft u daarover contact met de wijkverpleging?

Leest familie ook mee? Wat vindt u daar van?

Bij patiënten die wel willen maar aangeven dat het niet makkelijk gaat:

6. Hoe denkt dat het u gemakkelijker gemaakt kan worden om als patiënt betrokken te worden bij de verslaglegging door de wijkverpleging?

Doorvraag rechten en plichten als ze de gelegenheid wel of niet krijgen.