Involving patients in nursing documentation

an interview study among home-care nurses

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Abstract

Background: There are signals that patients have limited involvement in nursing documentation (ND). However, patient involvement in the ND is known to increase both the quality of care and patient satisfaction. Moreover health care professionals, like nurses, are obligated by law to give patients access to their health record.
Aim: To gain insight in the experiences and the challenges home-care nurses face regarding the involvement of patients in ND and to explore which strategies home-care nurses use to deal with these challenges.
Design: A qualitative interview design.
Methods: Individual, face-to-face, semi-structured interviews were conducted with Dutch home-care nurses. The inclusion criteria were: being a registered nurse, currently working in home-care and using an Electronic Health Record. Interviews were conducted and analysed in an iterative process, using the principles of thematic analyses.
Results: Twelve nurses were interviewed, data was only saturated on the first research question.
The general themes mentioned are mutual trust and fitting the individual situation. This customized fit is based on the nurses' assessment of the patient and the phase of the nursing process. Nurses involve patients in various ways and experience challenges in formulating the progress report, involving patients in the handover and the access of elderly patients in the electronic patient portal.
Conclusion: Nurses involve patients in ND in different ways varying on the phase of the nursing process and the assessment the nurse makes of the patient. Different challenges are mentioned which make involvement difficult. It is recommended to undertake action to abate these challenges.
Recommendations: Future research should focus on the challenges nurses face and how they are dealing with those challenges. Furthermore, research should focus on the experiences of patients to gain a broad view on patient involvement in ND in home care.

Keywords: nursing documentation*, patient involvement[MeSH], challenges, home care*

Nederlandse Samenvatting

Achtergrond: Patiënten worden mogelijk beperkt betrokken bij de verpleegkundige verslaglegging. Het is bekend dat patiënt betrokkenheid in de verpleegkundige verslaglegging leidt tot het verbeteren van kwaliteit van zorg en patiënt tevredenheid. Bovendien zijn zorgverleners, zoals verpleegkundigen, bij wet verplicht om toegang te geven in het patiënten dossier.

Doel: Het verkrijgen van inzicht in de ervaringen en moeilijkheden waar verpleegkundigen, werkzaam in de wijkverpleging, tegen aan lopen in het betrekken van de patiënten bij de verpleegkundige verslaglegging en hoe zij hiermee om gaan.

Design: kwalitatief onderzoek.

Methode: Data zijn verzameld door middel van semi- gestructureerde interviews. De verpleegkundigen waren werkzaam in de wijkverpleging in Nederland. De transcripten werden geanalyseerd volgens de principes van thematische analyse in een iteratief proces.

Resultaten: Twaalf verpleegkundigen werden geïnterviewd, data was alleen gesatureerd op de eerst onderzoeksvraag. De belangrijkste thema's zijn wederzijds vertrouwen en maatwerk. Dit maatwerk is gebaseerd op de verpleegkundige beoordeling van de patiënt en de fase van het verpleegkundige proces. Moeilijkheden worden ervaren in het formuleren van een voortgangsrapportage, het betrekken tijdens de overdracht en de toegang tot een elektronisch patiënten portaal.

Conclusie: Verpleegkundigen betrekken patiënten in verpleegkundige verslaglegging op verschillende manier afhankelijk van de fase van het verpleegkundige proces en de verpleegkundige beoordeling van de patiënt. Verschillende moeilijkheden worden genoemd die het betrekken bemoeilijken, het wordt aangeraden om acties te ondernemen om deze moeilijkheden weg te nemen.

Aanbevelingen: vervolg onderzoek kan zich richten op de ervaren moeilijkheden in het betrekken van de patiënt en welke strategieën zij hanteren om hiermee om te gaan. Ook kan vervolg onderzoek zich richten op de ervaringen van de patiënt in de betrokkenheid bij de verpleegkundige verslaglegging. Door beide ervaringen te combineren wordt er een breed inzicht verkregen in patiënt betrokkenheid in de verpleegkundige verslaglegging in de wijkverpleging.

Trefwoorden: verpleegkundige verslaglegging, patiënt betrokkenheid, wijkverpleging, moeilijkheden

Introduction

Nursing documentation (ND) is mainly used by nursing staff to share patient information with other care providers.[1] An accurate and complete ND is known to contribute to quality and continuity of care, to prevent errors, and to require justification of actions of the care provider.[2–4] The documentation should include all stages of the nursing process: assessment, nursing diagnosis, planning, implementation, evaluation and – if applicable - handover.[2,3,5] This accurate and complete ND is even more important in the home care setting, because this care is mainly provided individually.[5] Besides, it is a tool that makes the home care visible. [5]

ND is intended for all parties involved in the patient care. This does not only include care providers, but also the patient himself. Apart from giving the patient access to only read the documentation, it is advised to actively involve the patient in the ND because of the many known advantages of this involvement.[6] Involving patients in their ND results in a more complete and adequate documentation.[2,3,7] In addition it will increase the quality of care and factors like patient satisfaction, quality of life, and trust in the care provider.[7–9] Moreover, involving patients in their ND will give the patient more insight in their own health status.[7] In the Netherlands, like in many other European countries, nurses are even obligated to involve the patient in the ND.[9,10] The law reads that health care professionals, like nurses, should give patients access to their health record and the ability to have parts removed of added.[3,9,10] Furthermore care organisations are obligated to keep a health record for each individual patient.[3]

A new challenge in involving the patient in the ND is the introduction of the electronic health record (EHR). An increasing number of nurses use this EHRs for ND instead of paper-based health records. This might alter the way how patients are involved in the ND. For instance, the application of an electronic patient portal (EPP) is often used to give patients insight in their own EHR.[10,11] While this EPP can help to involve patients in the ND, a systematic review found that it introduces new challenges as well. For instance, patients had difficulties in gaining access to the portal, patients did not understand the functionalities, or had privacy and security concerns.[11]

Besides these new digital challenges, there are signals that nurses limited the involvement of patient in their ND.[12] Some nurses have suggested that this might have to do with factors like: the risk of confusion when a patient is unfamiliar with the nursing jargon, and a lack of insight by the patient in their disease.[12] Knowing the benefits from patient involvement this

signals of limited involvement are worrying.[6] Therefore, more knowledge about the current experiences of home-care nurses is needed. Until now, however, no empirical research exists that addressed home-care nurses experiences related to the involvement of patients in ND.

Therefore the ***aims*** of the study were to: (a) gain insight into the experience of home-care nurses regarding the involvement of patients in ND; (b) getting insight in which challenges home-care nurses face regarding the involvement of patients in ND; (C) explore which strategies home–care nurses use to deal with the challenges they face regarding the involvement of patients in ND.

Methods

Design

A qualitative interview design was used to gain insight into subjective experiences and views of home-care nurses regarding the involvement of patients in their ND.[13–15] For this report the COnsolidated criteria for REporting Qualitative studies (COREQ) guidelines have been used.[16]

Participants and recruitment

Nurses were eligible for inclusion if they met the following inclusion criteria:

(1) registered nurse with a bachelor degree in nursing (BN) or a senior secondary vocational education nursing diploma (SSVN);
(2) currently working in a Dutch home care organisation, and
(3) using an EHR which at least includes: anamnesis, care plan, and progress reports.

Eligible nurses were recruited by the researcher (ES) using the network of The Dutch home-care nurse society in combination with the individual network of the researchers (ES and KdG.)
Purposeful sampling was used in combination with snowball sampling. Variation on the following relevant characteristics were pursued: EHR systems used, whether or not a EPP was used, years of working experience, and standardized nursing terminology (SNT) used. This variation was pursued, because these characteristics may contribute to the ease of involving patients in the ND.[17] Dutch home-care nurses are obligated to use a SNT in ND.[18] They mostly use either Omaha System or the combination of NANDA International Nursing Intervention Classification Nursing Outcome Classification (NNN).[19,20]

Data collection

The interviews were conducted from January 2019 until April 2019. Individual, face-to-face, semi-structured interviews were used to gather rich in-depth knowledge concerning participants' experiences.[15] The interview guide wat constructed by the researcher (ES) and was based on previous research, which showed challenges with involving patients in the ND, and research on what ND includes.[2,3,5,12,21] The interview guide was tested for face-validity with two experienced researchers: KdG and AF. During the study the interview guide, as shown in table 1, was adjusted based on the data-analysis. The researcher (ES) conducted all the interviews in the office of the participant or at another quiet place that suited the participant. The interviews were audio taped and transcribed verbatim. (INSERT TABLE 1)

Data Analysis

Main principals of thematic analyses were used to analyse the data, which meant that in an iterative process of data collection-and-analyse, the following steps were passed: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report.[22,23] To improve the quality of the study, the first four interviews were analysed independently by pairs (ES and KdG, or ES and AF). The researchers compared and discussed codes and insights from their analyses to deepen insights. The themes, rising from the analyses, were refined and adapted in discussion with the research team.

Insight from analysis were member checked among participants, to improve trustworthiness of the research and assesses the researchers' understanding and interpretation of the data.[15] Each nurse was presented a thematic map and a recapitulation of all the results. The nurses were then invited to give feedback on the findings. The member check was performed at the end of the data collection, when data saturation was reached on the first research question.[24] The last measure that was taken to improve quality of the study was peer debriefing. Two peer nursing scientist were presented the findings from analysis. They were then invited to give feedback. Both the results of the member check and the peer debriefing were discussed within the research team (ES and KdG), ultimately leading to deepening of the results. For the data-analysis no software program was used.

Ethical considerations

This study was approved by the Medical Research Ethics Committee of the Amsterdam University Medical Centres. The study was conducted in compliance with the declaration of Helsinki, the European law General Data Protection Regulation and the standards of good clinical practice.[25–27]

Participants received written and verbal information about the study, they were informed that participation was voluntary and that they could leave the study without any consequences. They were told that their information will be handled confidentially and encrypted. All participating nurses provided written informed consent. Data will be stored within the Netherlands Institute for Health Services Research[28] for fifteen years, in accordance with the Dutch code for conducting science.[29]

Results

Twelve interviews were conducted of which eleven participants were female, the characteristics are shown in Table 2. Two main themes which all participants refer to regarding the involvement of the patient in ND is fitting the individual situation and mutual trust (Figure 1). The interviews lasted between 30 and 67 minutes. (INSERT Table 2)

Fitting the individual situation

Most nurse experience that involvement of patient in ND varies per situation. Therefore nurses indicate that involvement has to be tailored to the patient. Nurses express that this customized fit depends on the phase of the nursing process which needs to be documented and on how the nurses assess the characteristics and situation of an individual patient. Both themes are important, according to nurses, to fit the needs of an individual patient. The deliberation between these two themes makes involvement of the patient in ND a customised fit for each individual situation. Nurses express different ways of involving patient in the ND, for instance: orally summarizing main agreements and documenting those, reading out loud the literal documentation, letting the patient read the documentation (in real life or later through an EPP), or formulating the documentation together. If and how nurses involve patients varies with the situation at hand. For instance, a nurse expressed that when she evaluated the care given she involved the patient in ND by orally summarizing main points and documenting these points.

> *"Interviewer: How do you involve patients in the documentation of the evaluation of care? Participant: The patients knows that I am reporting the evaluation and they can read the documentation through the electronic patient portal and they can respond to that. But I am not going to mention that again. No I only orally summarize key points, the rest of the documentation patients can read in writing. (Participant 7)"*

Some nurses stated that they try to involve all patients in the same way. Despite this the patient situation varies which causes the involvement in ND to be a customized fit.

> *"Interviewer: How do you involve patients that are new for you, whom you only see once?*
> *Participant: It goes as it goes. I never make assumptions on how that is going to be. (…) The situation is determinative in how far you go in explaining of the documentation.(Participant 10)"*

(INSERT Figure 1)

Phase of the nursing process

Nurses experience that it is not always possible to involve the patient in ND in all phases of the nursing process. This differs per phase of the nursing process.

Nurses expressed they usually involve patients when taking an *anamnesis* by having an conversation with the patient and summarizing agreement that are made orally. Nurses will document these agreements. Thereafter most nurses leave the patients' home and work out the anamnesis, and prepare a *care plan* with the *nursing diagnosis* at their office. Nurses deliberately choose to not amplify the anamnesis, care plan, and nursing diagnosis at the patients home. They find this challenging because of busyness at the patients home or being there a long time. Beneficial at the office the nurse can consult a colleague. Thereafter nurses return to the patient and discuss the care plan. Then patients signs the care plan either on paper or in the EHR.

Nurses indicate that they not always report the *progress report* directly after care given, because they find it challenging and sometimes easier to write the report afterwards due to work pressure, the patient situation, laziness or problems with ICT. On the other hand, some participants discuss the progress report directly after care given: they either discuss these reports globally or sometimes literally read the progress report aloud. Nurses express finding it challenging to document on a device because it makes them feel uncomfortable when the patient is not aware what they are doing. Therefore nurses globally orally express to the patient what they are documenting. Since the participants work with an EHR some state that it is easier not involving the patient in ND because the documentation can be written afterwards. However, other nurses express that, just because of the EHR, they involve patients more then with the paper based health record.

Nurses express they involve patients in the *evaluation* by having a conversation and orally summarizing this conversation. The agreements that emerged from this conversation are documented. Nurses involve patients by orally discussing the summary or letting the patient read the summary.

Almost all nurses express finding it challenging to involve patients during the *handover* of care between different organisations. Partly because patients are rapidly transferred in an emergency situation, this speed makes involvement difficult, and partly because the scheduled transfers are mostly patients who are transferred to a nursing home. Due to the

underlying medical condition, as most of these patients are suffering from dementia, involvement is experienced challenging. Nurses try to involve patients in a way suited to them.

> *''Well, most people who are admitted to a nursing home are already, that is because of dementia and then there is not much involved. Then you involve the patient it in a different way, you will say "well, but we give a note or we make a note that the nurses there also know that you love this or that or that you don't want to wet your hair under the shower". So we involve in that way. But we don't sit down with them to make a handover. (Participant 9)''*

Nurses assessment of the patient

Nurses indicate that it is challenging to involve patients when they are dealing with a complex or vulnerable patient situation. Nurses try to stay in contact with these patients, but express finding it difficult to formulate a documentation, especially when the patient can view the EPP. Some nurses express that they adjust their report accordingly, some will report less and others engage in conversation with the patient. Nurses express that in those situations it helps to take more time to formulate the documentation.

> *''This only happens when you are in a situation where there is, for example, abuse or other forms of violence, physical or mental. (…) We are, of course, obliged to simply report what happens, what you see, and what you need to do with it. However, I think that you have to nuance what you formulate. Because sometimes things happen that are unacceptable, you have to report that. If you don't write that down you have no prove of the actions you have undertaken, but you have to be careful at how you write that down because a patient can sometimes read along. On the other hand you also have to remain transparent at the same time. (Participant 10)''*

Nurses express that they sometimes deliberately do not involve the patient in the documentation. Nurses make this choose because they do not want to (unnecessarily) worry the patient, or if they estimated that involvement has no added value, or if they estimated that the patient does not want to be involved. This estimation is made on the basis of the patient situation, the underlying medical history and how the ***nurse assess the patient.***

> *''Yes, if someone is very ill, I don't always want to burden them with what I write down or what you hand over to your colleagues. Then yes, I do not always involve them in the reports when documenting. (Participant 5)''*

Nurses state that there are few patients who ask questions about the documentation and are involved in ND. Mostly these patients are a bit younger and have a higher education, or are patients that have a psychiatric background. However, even younger patients sometimes may not feel the need to be involved and might even experience involvement as a burden.

> *''At the moment we have a young terminal woman as a patient, she has something like "do I need to keep up with that?" A young woman in her 20s has technically no difficulty with the digital system, but she has something like ''I also have to keep track of all that, I have to keep track of enough things at the moment". (…)'' And I also don't want my parents to be burdened with it". So this shows involving the patient can also be a burden to the patient. (Participant 2)"*

Nurses express that whether they involve patients in ND depends on the ***individual needs and* interest** of the patients, patients have varying wishes when it comes to being involved. For instance, nurses indicate they involve patients when patients are interested in being involved, but do not involve patients when patients expressed not wanting to be involved. Nurses find it challenging to involve these patient with ND. Nurses determine patient wishes based on their knowledge and experience with this patient. If the nurse is not acquainted of patient wishes, she will do what she deems appropriate in the situation.

Nurses state that the EPP is mainly used by patients to be able to view the planning agreements. However, the EPP has also formed a challenge for most patients because they need to have some ***digital skills*** and have access to a device with internet and must know how to use it. It varies per district, patients skills and needs of the patient if they have an EPP.

Not all nurses are informed when patients write a message in the EPP, this challenge obstructs them in their provision of care because they are lacking information. As a solution for this, nurses thought of a pop-up message in the EHR which state which patient wrote a documentation. So nurses are informed of a new message.

Not all patients understand the care plan or progress report, according to the nurses. Nurses then will explain this in a way suited to the patient. Nurses also expressed that some patients already are signing a care plan before the content of this plan is discussed with them.

Mutual trust

Nurses experience that there is mutual trust of patients regarding the ND and this trust is considered very important by nurses. This mutual trust is based on the professional relationship they have established and runs throughout the entire care process, both for

short-term and long-term care. Nurses express that a lot of patients trust them, this has an effect on the needs of patients to be involved. Nurses experience that patients find it more important that nurses will provide good care, instead of being involved in ND. Nurses experience that patients often easily trust them, just because of their profession or the organisation they work for, and therefore tend to assume the ND states the truth.

'' I made care agreements with a blind patient. I asked 'how can I leave the documentations behind, because I tell everything, but I cannot leave these agreements for you to read." (…) The patient said "no, but since you work for the organization X, I assume you speak the truth, so that you documented what we discussed." (Participant 6)"

However, nurses experience that some patients have less trust in them especially when these patients have a psychiatric background. Nurses find involvement of these patients challenging, because these patients tend to be more suspicious about the ND. They deal with this differently, but always tailor fitting it to the patient situation. Some nurses engage in a conversation, some adjust their ND accordingly, and others will report less.

''A patient of mine, with a psychiatric background, found it very upsetting that other disciplines could access the same system as we did and so could read everything we reported in his electronic health record. Since he confronted us with his concern we started to report much less then we normally would. He would indicate that some things should not be documented. That makes it very difficult. (Participant 6)"

Discussion

This study aimed to establish insight into the experience of nurses regarding the involvement of patients in ND. Furthermore, this study aimed to get insight in the challenges nurses face and how they are dealing with those challenges when involving the patients in ND.
The study revealed that involving the patient in ND is a customized fit, tailored to the individual characteristics and situation of the patient. This is in line with previous research that suggested that patient involvement in the bedside shift handover should be tailored to the patient according to their preferences and expectations, as well as to the self-confidence of the patients.[30,31] Despite that this is mentioned in a different care setting, it shows that involvement in ND is recommended to be tailored to the individual characteristics of the patient.

Furthermore, nurses express that involving the patient in ND depends on how they assess the patient situation. This assessment is based on their own assessment of the patient situation, the needs and interest of the patients, and the patients' skills. The need to be involved can differ per patient, depending on the demographic characteristics and medical conditions of this patient. This corresponds to earlier research, conducted in a different care setting, that found patient involvement to differ depending on the stage and severity of the illness and the demographic characteristics.[32,33]
Research in hospital care also showed that the involvement in ND is sometimes not preferred or even experienced as burdensome by the patients, e.g. when patients are very ill.[30,32] Since this is in line with the assessment home-care nurses made in this study, the nurses, based on this hospital research, made a correct assessment that corresponds with patient wishes.

A challenge nurses experienced was difficulty to involve patients in ND using an EPP because many elderly patients were lacking digital skills to use the EPP. This is in line with previous research that also found the elderly patients were lacking skills to work with the digital systems.[34] Therefore it is recommended to tailor the EPP to elderly patients and facilitate them when they want to have insight in the EPP.

Nurses indicated that mutual trust is an important factor when involving patients in ND. Previous
research showed that patients also find trust an important factor.[6] Patients in a study expressed that they limit information sharing with their healthcare provider if they distrusted them.[6] Interestingly, mutual trust was both mentioned by BN and SSVN as an important

theme. Despite of that both nurses might built a trusting relationship in a different way because of specific job tasks. The BN will build trust at the moment she is taking an anamnesis or evaluating care, and the SSVN will build trust when providing care. Literature found that evaluating care, getting to know a patient as a person first (for instance when taking an anamnesis), and providing care were all factors that influenced trust.[35] This shows that it is important for nurses to invest in a trusting relationship between them and the patient and that mutual trust will help in providing care and involving patient in ND because the patient is them more willing to share information.

Strengths & Limitations of the study

A strength of this study was that four interviews were analysed independently by two researchers, the other interviews were analysed by one researcher (ES), all data was discussed within the research team. An iterative process and member checks were used to enhance the quality of the study.

Furthermore, data saturation was reached of the experience of nurse regarding the involvement of patients in the ND. Another strength of this study is the maximum variation of participants. In 2017 in the average age of home-care nurses was about 44 years of which 7.8 % were male.[36] Of the nurses that uses a SNT a majority of 65.3% uses the Omaha System were as 9.8% used the NNN.[19] If this numbers are compared with the participants of this study (Table 2), we find that while the population of this study is a little younger the population is representative for the nursing population in home care. Note that in this study nurses that do not use a SNT were not included, which causes the percentage of Omaha System and NNN users in this study to be a bit higher than in found in literature.

However there are some limitations of this study. This study only reached saturation on the first aim of the study, on other two aims saturation was not reached. Furthermore, this study only focussed on the nurses in how they experience the involvement of the patient in the ND. It is not known how the patients that receive home care are experiencing involvement in the ND.

Therefore, future research should focus on the challenges nurses face when involving patients in the ND and how home-care nurses are dealing with those challenges. Additionally future research should also focus on the experiences of the patients in involvement in ND. Combining both results with the results of this study will give a broad view on patient involvement in the ND in home care and will help guide nurses and policy makers to take action in involving patients in ND.

Conclusions

Nurses experience that involvement of patient in ND is a customized fit to the individual situation in which mutual trust is considered very important. The way nurses involve patients in ND is varying on the phase of the nursing process and the assessment the nurse makes of the patient.
Nurses experience different challenges like: formulating the progress report in complex patient situations, involving patients in the handover and the access elderly patients have in the EPP. Nurses take more time when writing a progress report in a complex situation. Furthermore, involvement in the handover remains challenging, nurse try to involve the patients when possible. Additionally, it is recommended to undertake action to abate these challenges by for instance tailor fitting the EPP more to the elderly patients and facilitating these patients when then want to have insight in their EHR.

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About the author

Both researchers ES and KdG were working part-time as home-care nurse during the study.

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Conflict of interest

No conflict of interest has been declared by the authors.

References

1. Urquhart C, Currell R, Grant MJ, Hardiker NR. Nursing record systems: effects on nursing practice and healthcare outcomes. Cochrane Database Syst Rev. 2009 Jan 20;(1):1–67.

2. Wang N, Hailey D, Yu P. Quality of nursing documentation and approaches to its evaluation: a mixed-method systematic review. J Adv Nurs. 2011 Sep;67(9):1858–75.

3. Verpleegkundigen&VerzorgendenNederland(V&VN). Richtlijn Verpleegkundige en verzorgende verslaglegging [Internet]. Utrecht; 2011 [cited 2018 Sep 6]. Available from: http://www.venvn.nl/Portals/1/Nieuws/2015 documenten/Richtlijn Verpleegkundige en verzorgende verslaglegging.pdf

4. Broderick MC, Coffey A. Person-centred care in nursing documentation. Int J Older People Nurs. 2013 Dec;8(4):309–18.

5. Gjevjon ER, Hellesø R. The quality of home care nurses' documentation in new electronic patient records. J Clin Nurs. 2010 Jan;19(1–2):100–8.

6. Flink M, Öhlén G, Hansagi H, Barach P, Olsson M. Beliefs and experiences can influence patient participation in handover between primary and secondary care—a qualitative study of patient perspectives. BMJ Qual Saf. 2012 Dec;21(Suppl 1):i76–83.

7. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: a review. Iran Red Crescent Med J. 2014 Jan;16(1):e12454.

8. Longtin Y, Sax H, Leape LL, Sheridan SE, Donaldson L, Pittet D. Patient participation: current knowledge and applicability to patient safety. Mayo Clin Proc. 2010 Jan;85(1):53–62.

9. Vermeir P, Degroote S, Vandijck D, Tiggelen H Van, Peleman R, Verhaeghe R, et al. The patient perspective on the effects of medical record accessibility: a systematic review. Acta Clin Belg. 2017 Jun 4;72(3):186–94.

10. Ministerie van Volksgezondheid Welzijn en Sport. Elektronische gegevensuitwisseling in de zorg De wet cliëntenrechten bij electronische verwerking van gegevens in de zorg [Internet]. 2017 [cited 2018 Dec 16]. Available from: https://www.rijksoverheid.nl/documenten/brochures/2017/06/01/elektronische-gegevensuitwisseling-in-de-zorg

11. Powell KR. Patient-Perceived Facilitators of and Barriers to Electronic Portal Use. CIN Comput Informatics, Nurs [Internet]. 2017 Nov [cited 2019 Apr 18];35(11):565–73. Available from: http://www.ncbi.nlm.nih.gov/pubmed/28723832

12. Groot K De, Paans W, Veer AJE De, Francke AL. Knelpunten bij verslaglegging door verpleegkundigen en verzorgenden. Tijdschr voor verpleegkundigen. 2017;(6):34–6.

13. Kahlke RM. Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. Int J Qual Methods. 2014 Feb 1;13(1):37–52.

14. Creswell JW, Preceded by: Creswell JW. Qualitative inquiry & research design : choosing among five approaches. 3rd editio. Sage Publications; 2013.

15. Holloway I, Wheeler S. Qualitative Research in Nursing and Healthcare. 3rd editio. Oxford: Wiley-Blackwell; 2010.

16. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Heal care J Int Soc Qual Heal Care. 2007 Dec 16;19(6):349–57.

17. Paans W, Nieweg RM, Schans CP Van Der, Sermeus W. What factors influence the prevalence and accuracy of nursing diagnoses documentation in clinical practice? A systematic literature review. J Clin Nurs. 2011 Sep;20(17–18):2386–403.

18. Nursing. Gebruik classificaties verplicht voor wijkverpleging - Nursing [Internet]. [cited 2019 May 23]. Available from: https://www.nursing.nl/gebruik-classificaties-verplicht-voor-wijkverpleging-1764887w/

19. Groot K De, Veer AJE De, Paans W, Francke AL. Use of electronic health records in relation to standardized terminologies : a nationwide survey of nursing staff experiences Abstract. submitted. :1–21.

20. Nictiz expertisescentrum e-health. NIC Nursing Interventions Classification [Internet]. [cited 2019 May 23]. Available from: https://www.nictiz.nl/standaarden/nic/

21. Kamphuis H, Nanninga M. Ontwikkeling kwaliteitsstandaard : herziening richtlijn verpleegkundige en verzorgende verslaglegging en overdracht Focusgroep met zorggebruikers en naasten. 2017;1–8.

22. Braun V, Clarke V. What can "thematic analysis" offer health and wellbeing researchers? Int J Qual Stud Health Well-being. 2014;9:26152.

23. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 Jan;3(2):77–101.

24. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? Field methods. 2006 Feb 21;18(1):59–82.

25. Official Journal of the European Union. I (Legislative acts) REGULATIONS REGULATION (EU) 2016/679 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repeali [Internet]. [cited 2019 Jun 24]. Available from: https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679

26. Declaration of Helsinki – WMA – The World Medical Association [Internet]. [cited 2018 Nov 27]. Available from: https://www.wma.net/what-we-do/medical-ethics/declaration-of-helsinki/

27. Administration USD of H and HSF and D, (CBER) C for DE and R (CDER) C for BE and R. E6(R2) Good Clinical Practice: Integrated Addendum to ICH E6(R1) Guidance for Industry [Internet]. 2018 [cited 2018 Dec 10]. Available from: http://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/default.htmand/orhttp://www.fda.gov/BiologicsBloodVaccines/GuidanceComplianceRegulatoryInformation/Guidances/default.htm

28. NIVEL. Het Nivel in 2 minuten | Nivel [Internet]. [cited 2019 Jun 24]. Available from: https://www.nivel.nl/nl/het-nivel-2-minuten

29. Vereniging van Universiteiten. De Nederlandse Gedragscode Wetenschapsbeoefening [Internet]. [cited 2018 Nov 27]. Available from: http://www.vsnu.nl/files/documenten/Domeinen/Onderzoek/Code_wetenschapsbeoefening_2004_%282014%29.pdf

30. Tobiano G, Bucknall T, Sladdin I, Whitty JA, Chaboyer W. Patient participation in nursing bedside handover: A systematic mixed-methods review. Int J Nurs Stud. 2018 Jan;77:243–58.

31. Bressan V, Cadorin L, Stevanin S, Palese A. Patients experiences of bedside handover: findings from a meta-synthesis. Scand J Caring Sci. 2019 Mar 13;

32. Davis RE, Jacklin R, Sevdalis N, Vincent CA. Patient involvement in patient safety: what factors influence patient participation and engagement? Heal Expect. 2007 Sep;10(3):259–67.

33. Flink M, Hesselink G, Pijnenborg L, Wollersheim H, Vernooij-Dassen M, Dudzik-Urbaniak E, et al. The key actor: a qualitative study of patient participation in the handover process in Europe. BMJ Qual Saf. 2012 Dec;21(Suppl 1):i89–96.

34. Wildenbos GA, Peute L, Jaspers M. Facilitators and Barriers of Electronic Health Record Patient Portal Adoption by Older Adults: A Literature Study. Stud Health Technol Inform. 2017;235:308–12.

35. Dinç L, Gastmans C. Trust in nurse–patient relationships. Nurs Ethics. 2013 Aug 20;20(5):501–16.

36. AZW Info - Factsheet personeelskenmerken [Internet]. [cited 2019 May 24]. Available from: https://www.azwinfo.nl/jive/jive/report/?id=fs_personeel

Appendix 1: Table 1, Table 2 and Figure 1

Table 1 Interview guide

1. In general, do you involve patients in nursing documentation? If not, why not? If so, how?
2. What do you gain, as a nurse, to involve a patient in the nursing documentation?
3. Does the patient understand the nursing documentation, both care plan, reporting etcetera?
4. Are there differences in patients in how you involve patients in the nursing documentation? If so, which differences do you see? Under which circumstances do you involve patients and in which circumstances do you not involve patients?

   The nursing documentation consist of:
   - Anamnesis
   - Nursing diagnosis
   - Care plan
   - Progress reports
   - Evaluation
   - Handover

A. Do you recognize the above-mentioned parts, of the nursing documentation?
B. To what extent is it generally possible to involve patients in all aspects of nursing documentation? In which aspects is it possible, and in which parts is it not possible?
C. Why do you choose whether or not to involve patients in the aforementioned components of the nursing documentation?
D. Does the electronic health record that you work with makes involving a patient in reporting easy or difficult?
E. Do you use an electronic patient portal to involve patients in nursing documentation?
   If so, what do you gain from using an electronic patient portal when involving a patients in nursing documentation? What does the patient gains from using an electronic patient portal?

5. Do you experience challenges in involving patients in the nursing documentation? If so, which challenges do you experience when involving patients in the nursing documentation? Why do you experience those challenges to be difficult?
6. How do you deal with the challenges you experience when involving patients in the nursing documentation?
7. How do you think that involving patients in the nursing documentation can be made easier for you?
   In which way do you think involving the patient can be made easier for you?
8. Do you see any differences in involving patients in the nursing documentation between the paper file and the electronic health record?
   Do you experience differences between the paper and digital file regarding the involvement of patients in the nursing documentation?

Table 2 Participant characteristics

Characteristics	n	%
Gender		
Male	1	8.3 %
Female	11	91.7 %
Level of education		
Bachelor's degree	8	
Secondary vocational education	4	
Information system for electronic health record		
Nedap	7	
Ecare	3	
Unit 4	2	
Use of Electronic Patient Portal		
Yes	11	
No	1	
Standardized nursing terminology		
Omaha System	10	83.4 %
NANDA-I NIC NOC	2	16.6 %
Age (in years)		
21-34	6	50.0 %
35-50	4	33.3 %
51>	2	16.6 %
Working experiences as registered nurse (in years)		
0-5	4	33.3 %
6-10	3	25.0 %
11-20	2	16.6 %
21- 30	1	8.3 %
31-40	2	16.6 %

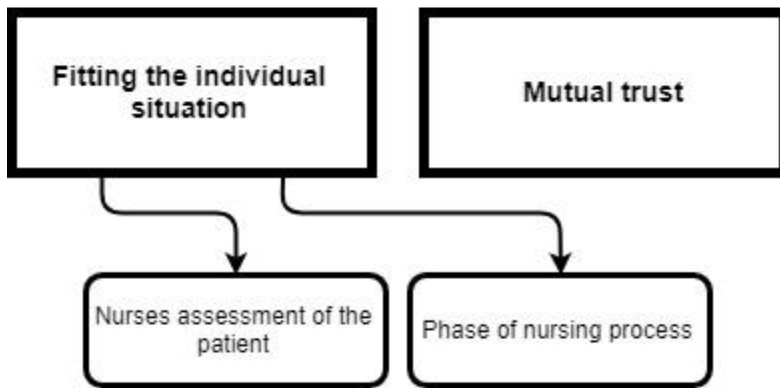

Figure 1 Thematic Map

Appendix 2: List of abbreviations

Abbreviations	Meaning
BN	Registered nurse with a bachelor degree in nursing
EHR	Electronic Health Record
EPP	Electronic Patient Portal
ND	Nursing documentation
NNN	NANDA International, Nursing Intervention Classification, Nursing Outcome Classification
SNT	Standardized Nursing Terminology
SSVN	Registered nurse with a senior secondary vocational education nursing diploma