Perceptions of Nurses Towards Participation of Cancer Patients and their Families in Nursing Care during Hospital Admissions - A Generic Qualitative Study

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Acknowledgements

Abstract

Title: Perceptions of nurses towards participation of cancer patients and their families in nursing care during hospital admissions – A Generic Qualitative Study.

Background: Patient and family participation (PFP) is proven to be beneficial and is associated with better health outcomes. There are still knowledge gaps about how nurses should integrate PFP in nursing cancer care. Patients who receive cancer treatments go through a physically and mentally demanding time in the hospital while admitted, and could benefit greatly from being involved in care by nurses. This is not standard care, and views on participation are therefore sought in order to improve nursing cancer care.

Aim: To explore perceptions of nurses towards participation of cancer patients and their families in nursing care during hospital admissions.

Method: A generic qualitative design was used guided through face-to-face and telephone interviews. A purposeful sample of 11 nurses who provided care in two oncology wards of one peripheral hospital in the east of the Netherlands were interviewed. Transcribed interviews were analysed using thematic analysis.

Results: The first theme *Defining Participation* showed that nurses did not know how to interpret PFP. *Preconditions for normalizing Participation* emerged as the second main theme, including the following subthemes: ensuring a privacy-based environment, preparing patients for participation, and nursing competencies, and were viewed as essential for PFP. *Power and Control within Participation* emerged as the third main theme and showed the complexity of participation with the following subthemes: struggling with structure, surrendering patients, and knowledge is power.

Conclusions: The emerging themes enriched the existing literature relating to PFP in oncology. Guaranteeing the preconditions, utilize the meaning and importance of PFP for nurses, and bridging the factors which makes participation complex appears to be the first step to stimulate nurses to grow in providing PCC for letting PFs actively participate.

Keywords

Cancer care, nurses perceptions, participation, qualitative thematic analysis

Nederlandse samenvatting

Titel: Percepties van verpleegkundigen ten aanzien van kankerpatiënten en hun families in de verpleegkundige zorg tijdens ziekenhuisopnames - een generieke kwalitatieve studie

Achtergrond: Patiënt- en familieparticipatie (PFP) is bewezen effectief en wordt geassocieerd met betere gezondheidsuitkomsten. Er is nog steeds een gebrek aan kennis over hoe verpleegkundigen PFP moeten integreren in oncologische zorg. Kankerpatiënten die behandelingen ondergaan, maken tijdens een opname fysiek en mentaal veel mee en kunnen veel baat hebben bij PFP. Dit is geen standaardzorg en daarom wordt naar opvattingen over participatie gezocht om de verpleegkundige zorg in de oncologie te verbeteren.

Doel: Het onderzoeken van verpleegkundige percepties ten aanzien van participatie van kankerpatiënten en hun families binnen de verpleegkundige zorg tijdens ziekenhuisopnames.

Methode: Een generiek kwalitatief design werd toegepast met semigestructureerde individuele en telefonische interviews. Elf verpleegkundigen van twee oncologische verpleegafdelingen in een perifeer ziekenhuis in het oosten van Nederland werden geïnterviewd. De getranscribeerde interviews werden geanalyseerd met behulp van thematische analyse van Braun&Clarke.

Resultaten: Het eerste thema *Definiëring van participatie* toonde aan dat verpleegkundigen PFP niet konden interpreteren. *Randvoorwaarden voor het normaliseren van participatie* kwamen naar voren als het tweede hoofdthema, inclusief de volgende subthema's: zorgen voor een op privacy gebaseerde omgeving, het voorbereiden van patiënten op participatie en verpleegkundige competenties, en werden beschouwd als essentieel voor PFP. *Macht en controle binnen participatie* kwam naar voren als het derde hoofdthema en toonde de complexiteit van participatie, inclusief de volgende subthema's: worstelen met structuur, patiënten overgeven en kennis is macht.

Conclusies: Resultaten hebben de bestaande literatuur gerelateerd aan PFP binnen de oncologie verrijkt. Het organiseren van PFP begint met het scheppen van basisvoorwaarden en het verduidelijken van de betekenis van PFP. Verder onderzoek naar de praktische betekenis van PFP en hoe een PFP-programma verpleegkundigen kan ondersteunen door middel van een grootschalige pre- en posttest wordt aanbevolen.

Trefwoorden

oncologische zorg, verpleegkundige percepties, participatie, kwalitatieve thematische analyse

INTRODUCTION

In nursing healthcare, patient and family participation (PFP) is proven to be beneficial for patients during hospital admissions[1,2]. Increasing the degree of participation is associated with improvements in health outcomes, such as better functional status of patients[3] and reduction of mortality[4]. PFP is also associated with shorter hospital stays[5] and reduced readmissions with lower costs[6]. PFP can be described as when views (i.e. individual desires and capabilities) of patients and families (PFs) are sought and taken into account in designing, delivering and improving new and existing healthcare services[7]. By performing PFP, a patient's essential needs (needs varying from personal cleansing, rest and sleep, privacy, dignity until emotional wellbeing etc.) are met to ensure their physical and psychosocial wellbeing[8], which is required for every patient regardless of their clinical condition or healthcare setting[9].

Nurses use PFP to build a positive and trusting relationship with patients being cared for, as well as their families. PFP also leads to a greater job satisfaction and work engagement of nurses, and performing helping behaviours (i.e. willing to go out of the scope of their duties to help patients when needed)[5] due to better communication between nurses and patients. Thereby, intentions to leave the hospital or the profession among nurses are diminished[10]. Similar concepts used in nursing healthcare are patient-centeredness[11], patient-empowerment[11], patient-involvement[12], and patient-activation[13]. Activities to perform PFP vary from having a dialogue (e.g. asking questions or asking approval prior to undertake tasks), sharing knowledge between patients and nurses and partaking in planning to manage self-care[14].

Despite the evidence for PFP, there are still gaps in knowledge about how PFP should be integrated during hospital admissions, especially for cancer patients[15]. The actual contribution of cancer patients in decision making is often limited[15]. These patients experience difficulties with asking questions or discussing emotions due to the impact of cancer, which makes it challenging to participate in their care. These patients retain distressing memories of how they are being cared for[16] and a majority of them feel less confident in communicating and participating in nursing care[17]. Furthermore, literature shows that nurses do encourage and support PFP[18], but in practice they do not know how to perform and document desires and capabilities of PFs[19]. This is confirmed by Kitson (2018), who developed the Fundamentals of Care framework, a pragmatic point-of-care theory that explains and guides practice around person-centred fundamental care. Kitson (2018) acknowledges that discussing PFP is an intellectual and emotional challenging skill to master for nurses[16]. This can be explained by the fact that PFP is related to a sort of shared power-and-control. Prior to PFP, nurses have to recognize the part of the patient as valuable and equal, and having power, control, and responsibility, and there must be a willingness on the part of the patient to assume that power, control and responsibility[20].

Although it is proven that PFs ability to participate could be supported by a communication tool[21], oncology units in hospitals have not yet been sufficiently investigated. Cancer patients are stimulated to participate when nurses create opportunities to ask questions, talk about possibilities and openly discuss difficult and intimate issues[17], but research indicates that the elaboration of PFP by nurses in oncology is still in its infancy. PFs experience the need to receive information about opportunities for participating (i.e. information about self-care) in nursing care[21], whereas nurses feel that they provide sufficient information to them[22]. Cancer patients who are admitted for cancer treatment go through a physically and mentally demanding time in the hospital, and could benefit greatly from being involved in care by nurses. This is however not standard care and indicated the need to seek for perceptions by nurses on PFP during hospital admissions in order to improve oncology care.

AIM

The aim was to explore perceptions of nurses towards participation of cancer patients and their families in nursing care during hospital admissions.

METHOD

Design

A generic qualitative design[23] was used by performing semi-structured face-to-face and telephone interviews with nurses to seek for a deeper and comprehensive understanding of the perceptions of nurses towards PFP.

Population and domain

The study was performed in one peripheral hospital, located in a rural environment in the east of the Netherlands. Interviews were performed at two oncology nursing wards where nurses already work with PFP.

Sampling

Nurses were purposefully selected to create a diverse sample with regard to age, sex, work experience, and education level to obtain maximum variation[23]. Nurses were included when they provide direct patient care for at least 20 hours a week. Those who only worked nightshifts were excluded. To obtain rich data about the perceptions, the sample size was driven by data saturation, which was operationalized as when the final two interviews generated no new information relating to the aim of this study[17,24,25]. Nurses received a participant information letter (with all relevant information about the study) and consent form via email by the researcher (NL). One week thereafter, there was a team meeting where the researcher (NL) was invited to meet 54 nurses to provide additional information about the study and to answer questions. After this meeting, the researcher (NL) posted a list with scheduled

interview dates in the nurses workroom. If nurses want to participate, they could select their preferred interview date. Nurses who put their name on the list were contacted via email by the researcher (NL) one week after posting that list to confirm the interview date.

Data collection

Interviews were conducted by researcher NL in March and April 2020 through a semi-structured interview guide (Table 1) to help the researcher focus on data collection of perceptions of nurses. Relationship between researchers and nurses was not established prior to study commencement. Topics were based on literature relating to PFP[15,17,22,26]. Questions were composed by NL and peer-reviewed by EvB & MH ensuring all questions were open, broadly formulated, and in line with the literature and the study aim. The interview guide was piloted to train interview skills and to refine questions; no changes were made. All interviews were audio recorded. Due to the COVID-19 pandemic, the first three face-to-face interviews were conducted in the hospital. The remaining eight telephone interviews were conducted separately from the nurse and researchers own living environment. Consequently, more probes and prompts were used in keeping the nurse engaged, maintaining a natural flow during the conversation[27], and for building a rapport[23].

[Table 1: Interview guide with topics]

Data analysis

Data were analysed using thematic analysis of Braun&Clarke[30] to explore perceptions. Through thematic analysis various aspects of the perceptions could be described by identifying, analysing and reporting themes. Interviews were transcribed verbatim (NL) and uploaded in ATLAS.ti.8.4.2 (Scientific Software Development GmbH Berlin) to increase methodological quality. Transcripts were read several times to gain an overall understanding. The first six transcripts were inductively independently coded into 'meaningful segments' and checked for agreement (NL, MH&EvB) to increase inter-rater reliability. In vivo codes were used to obtain theoretical sensitivity. Discussions led to agreement in codes resulting in a code tree (see appendix). Constant comparison[24] was completed by identifying and evaluating differences and similarities through analysing transcripts iteratively. Equal codes were sorted according to their content into themes and were named (NL) for covering the overall story for each theme, resulting in a thematic map. Thereafter, the thematic map with themes were discussed and reviewed by all researchers (NL, MH&EvB). Baseline parameters (age, gender, number of years of work experience, education level of the nurse, and having an oncology education) were descriptively analysed using SPSS Statistics 25.

Rigorousness and trustworthiness

Rigorousness and trustworthiness were pursued in terms of confirmability, credibility, dependability and acceptability. Confirmability and dependability were carried out by an audit trail. The process of the data collection and data analysis are available for examination through a verbatim transcription with field notes, coding documents, and reflections of the researcher(NL). To strengthen the confirmability and credibility, researcher triangulation was complied with coding the first six transcripts independently. Moreover, this study was guided by experienced qualitative researchers(EvB & MH). Member check was completed to increase acceptability. Summaries of the transcripts were sent to all nurses in order to verify if the findings corresponded to their thoughts and to give the opportunity to provide feedback. Nine nurses confirmed that the summary was equal to their thoughts. Two nurses did not respond for unknown reasons. The consolidated criteria for reporting qualitative research (COREQ) was utilized to guide reporting and to increase reproducibility.

Ethical considerations

Ethical approval was granted by the Medical Ethical Committee of IQ Healthcare, the research institute (project number: 2020-6167). Written and audio recorded consent was obtained for face-to-face interviews. For telephone interviews only audio recorded consent was obtained. Identifiable information was deleted from the transcripts by allocating numbers (N1, N2 etc.) to the nurses to ensure anonymity.

FINDINGS

Of 54 nurses approached, eleven female nurses responded and were interviewed, age ranging from 26 till 52 years. The main reason for not participating was that nurses had many other extra education lessons besides their own work and their work load was increased due to the COVID-19 pandemic. Maximum variation was achieved, except for gender. Face-to-face interviews (N=3) lasted between 24 and 49 minutes. Telephone interviews (N=8) lasted between 45 and 57 minutes. Table 2 presents all nurses baseline characteristics.

[Table 2: nurses baseline characteristics]

Three main themes emerged from the analysis: *Defining Participation*, *Preconditions for normalizing Participation* and *Power and Control within Participation* (Figure 1). These themes contained the following subthemes: *ensuring a privacy-based environment*, *preparing patients for participation*, *nursing competencies*, *surrendering patients*, *struggling with structure*, and *knowledge is power*.

[Figure 1: Thematic map of nurses' perceptions towards participation of cancer patients and their family during hospital admissions]

Defining Participation. Each interview started with the question how to interpret patient participation (PP) and the majority of nurses did not exactly know the meaning and importance of PP. The term 'shared decision-making' was often mentioned, in which nurses perceived that they consider a patient to participate if they gave voice to decisions in their own medical treatment instead of to decisions in their own nursing care process. A few nurses confused PP with family participation (FP).

"I think it is like the same as family participation, that we involve the patient in care instead of the family. And actually, it is like what we do now with shared decision making, so that we inform the patient together and decide together." (N5)

Most nurses perceived that PP contributes to the patient's autonomy. If patients feel responsible for their own well-being, they feel more like a person rather than a patient in the hospital. Furthermore, nurses perceived PP contributes to a better recovery with regard to nutrition, sleep and rest, and mobilization.

Nurses perceived FP as involving families in medical treatment and in care by undertaking activities with patients (e.g. playing a game, taking a walk to the visitor restaurant or reading the newspaper). Some nurses viewed only the presence of families as FP.

"I see two different things .. participate in the knowledge that the patient gets, that the family also gets. And also just want to be there or sleep together with the patient .. or go for a walk ." (N9)

FP was perceived as important for creating safety and rest, but also for patients adaptation to their home after discharge. When patients are being discharged, they will have to be able to take care of themselves with assistance of their partners and/or children. Therefore, transition of patients from the hospital to their home becomes easier, because partners and/or children know what happened when being involved in the care process. Withal, some nurses said that FP contributes to job satisfaction and a feeling of appreciation, because of nurses' role in listening and being there for families.

"Caring for patients becomes easier… and it makes my job more enjoyable. Yes, then I feel more like we are doing it together." (N4)

Preconditions for Normalizing Participation reflects nurses' preconditions to ensure that PFP is incorporated as a normal manner of nursing care.

Ensuring a privacy-based environment. Nurses emphasized the importance of ensuring an environment where privacy is guaranteed. PFs need privacy for conversations

with each other and with nurses about the disease process to cope with emotions while being treated in the hospital. Single-bed rooms and flexible visiting times were perceived as essential for privacy to stimulate nurses to engage in conversations with PFs for activating the participation-process.

"In my opinion.. the most important thing for the oncology patients are the individual rooms.. that you have much more privacy and can be alone." (N7)

Preparing patients for participation. Nurses perceived patients should be well informed about their care process by discussing mutual expectations (i.e. from nurses to patients and vice versa) to make it possible for patients to think about how they would like to participate. Nurses experienced that patients are enthusiastic when nurses suggest opportunities to participate. For this reason, nurses perceived that patients do not know what is going to happen during their care process and that patients are often unaware of the opportunities of participation at all. This made nurses believed they should yield an open attitude which invites patients for being active in their care process. Nurses perceived when patients feel they are invited to participate, they show initiatives by themselves (e.g. asking nurses whether they can be allowed on leave).

"If I let them know that I am open to their opinion, they say: hey oh .. I can also think and participate. Some patients are perplexed ... they don't know that at all, because they were used to everything being decided for them" (N8)

Furthermore, nurses experienced patients are much more active when they have prepared themselves for treatments by reading leaflets or searching the internet. According to nurses, these patients have had the opportunity to think for themselves about their wishes and needs whereby they better understand what is and what is not good for them.

""I think patients can only participate in their care process if they know exactly what they are talking about… and it provides clarity for everyone if you have good conversations with patients about it." (N9)

Nursing competencies reflects' the way participation is enabled by using adequate communication skills and individual nursing leadership, and by optimizing nursing working styles. Nurses perceived adequate communication skills as essential for engaging PFs in their care process. This allows nurses to identify what PFs consider as important in their care process, whereby nurses can provide person-centered care (PCC). Nurses operationalized adequate communications skills as knowing how to start a conversation and listen to PFs (i.e. learning what PFs want).

"Well, I think empathy is very important, and yes, listen well, have patience for patients, commitment… If I pass the patient like a whirlwind, they will never come up with things themselves..." (N11)

However, nurses admitted that they use those communication skills far too little, because they prioritize other tasks to be done. Some nurses acknowledged it is difficult to let PFs take initiative in their care process, because it is nurses' nature to care constantly. Nurses emphasized they should be able to receive non-verbal signals and see when patients are uncomfortable but do not talk about that. Linked to this, nurses indicated the need for individual nursing leadership to tackle the cases where patients are unable to control and to participate in care. Nurses perceived that patients do not always mention all of their physical or mental problems to doctors. Therefore, nurses found it important to encourage patients to express themselves and not let them get overruled by doctors.

"At least I think conversation skills.. so that you know how to start the conversation. And I also think of a signaling role to take initiative to the patient and to dare to do things, and also towards the doctor, to stand up for the patient." (N10)

Furthermore, nurses perceived their working style has to be optimized, which refers to the continuity in reporting. Nurses experienced it as a huge barrier when discussions with PFs about wishes and needs or agreements that were made in the care process are difficult to find in nursing records. This leads to nurses who have to discover PFs individual wishes and needs in every single shift, which was perceived as not desirable for both PFs and nurses because that is a time consuming task.

"…I notice it when I go to a patient for the first time… he says; but I discussed that with your colleague yesterday. And I think, I did not find it anywhere... it is especially annoying that a patient has to tell something again and again, which he may have told that three or four times earlier, but simply has not been reported." (N6)

Nurses suggested to optimize reporting by making arrangements with their own nursing team about how and what needs to be reported, which contributes to the continuity of care. Some nurses perceived that nurses' working style regarding PFP is being influenced by the way nurses were educated. Nurses perceived junior nurses were taught to see patients as equal in the care process. This made nurses believed that senior nurses experience difficulties to put patients in the central of their own care process, because they were used to take over tasks from patients.

"I feel that senior nurses, who have worked in the nursing field longer, tend to automatically take more activities and decisions out of the patient's hands than the more junior nurses.... My teacher taught me to let patients take control during my nursing education... I think in the older, more classical (inservice) educations, it was never taught that I have to give a patient control over their own care ..." (N5)

Power and Control within participation reflects the way power and control exists between PFs, nurses and doctors regarding participation. The subthemes were struggling with structure, surrendering patients and knowledge is power.

Struggling with structure. Nurses perceived they need flexibility from the hospital and they admitted they struggle with strict daily routines when trying to let PFs participate. Therefore, nurses emphasized it is necessary to examine current processes how they can be rearranged to use their time as efficiently as possible for integrating PFP. Additionally, nurses perceived they need structure (i.e. a format or tool) to let PFs participate, because of various working styles of each nurse. A format or tool could help nurses to organize participation during their shifts.

"…Actually, I would like the organization to be more open to deviating from the beaten track… less rules and less structure, so that I can indeed adapt to the patient. I would really like that." (N3)

Surrendering patients. Nurses perceived that most patients have a feeling of surrender and that they are put in a completely dependent position by themselves and by doctors, causing patients feel they lose control. Older patients were viewed as cautious and watchful and they are more inclined to listen to nurses and doctors, because they grew up with this perception. Younger patients were viewed as assertive, which makes these patients more capable to participate. Moreover, nurses perceived that younger patients have access to digital tools (laptops, smartphones) through which they are better informed resulting in participating more effectively.

"…the elderly do not, because I think it also has to do with the generation. Today's patients are much more independent and want to do more themselves .. and know how to do it." (N5)

Introvert patients were viewed as difficult for nurses to let them participate, because these patients do not often express themselves (i.e. about physical or mental problems) to nurses, which makes it challenging to communicate at all. Nurses also believed that it is difficult to let patients with a lower education-level participate, because these patients also seem to surrender. Higher educated patients seem to want to know more about their disease or care process, whereby nurses easily start to communicate with them.

"I do think higher educated patients devote themselves to think along in their treatment and that lower educated patients feel more like; what is being said, that is what I do. I think that lower educated patients do not think about the consequences any further." (N10)

Furthermore, nurses find it is challenging to let very ill patients participate, because these patients do not have the energy to consider how they would like to participate whereby they lose control. Nurses think it is important for families of very ill patients to be involved, so they can support patients emotionally.

"…It is also very important for processing emotions of the patient .. patients and families experience the same. Both know how it was during their time in the hospital, how dependent the patient was with all the tubes, how intense it was the first time out of bed..." (N3)

Knowledge is power. Nurses perceived that patients respect doctors (and sometimes nurses), but that it should actually be the opposite. Nurses believed when patients do participate more prominent by taking the lead in their care process, perhaps they could overrule the authority of the doctor resulting in making choices on their own (as far as possible). Nevertheless, nurses acknowledged that patients are (partly) dependent on doctors and nurses, and that patients have less (medical) knowledge than them. Based on nurses' clinical expertise and knowledge, nurses sometimes want to influence patients on making choices in care. Nurses perceived they have to share their clinical expertise and knowledge with patients to strengthen them in participating.

"Knowledge is power... if you have knowledge then you can make good basic decisions... if you have half of the knowledge, you have little power... the patient has less knowledge but must get that knowledge to deal with his illness..." (N9)

During ward rounds, nurses viewed that patients are powerless and doctors have control. Patients are not invited to ask questions and often there is not even family present. Nurses try to discuss with patients afterwards whether everything is understood, but expressed that as not desirable. Consequently, many family conversations are planned. This is extremely time consuming for nurses, because nurses have to solve questions from families.

"I think that very often the doctor comes in and says: okay, this has been agreed… Today, the patient very often says: oh yes I agree, while they have not really been able to express their own opinion or dare to suggest ..." (N10)

DISCUSSION

This study explored the perceptions of nurses towards participation of cancer patients and their families during hospital admissions. Nurses interpret PFP differently and nurses

perceived it essential to normalize PFP in oncology by ensuring a privacy-based environment, preparing patients for participation, and when nursing competences are met. Furthermore, nurses viewed PFP as influenced by nurses who struggle with structure, patients who surrender and by differences in knowledge between PFs, doctors, and nurses.

Our subthemes *Preparing patients for Participation* and *Patients surrender* are in agreement with two subcategories reported by Pongthavornkamol et al. (2018) who conducted two focus group interviews with nurses[28]. Thai oncology nurses in that study also showed that it is important to provide patients with all the relevant information that patients may want to enable them to participate, and that participation tends to depend on differences among patients (shy, reluctant or very ill patients). However, our findings emerged from nurses who were mainly focused on factors of PFs and the organization influencing PFP, instead of considering their own nursing behavior and functioning. This indicated need to equip nurses with leadership skills including self-reflecting skills to give nurses insight into what they could improve themselves to enhance PFP, which is consistent with literature[28,29]. Developing nursing leadership requires nurses having a navigator role[29], but our findings showed that nurses are not (fully) aware of that navigator role. Furthermore, our findings showed that PFP is influenced by power-control imbalances between PFs, doctors and nurses. This is congruent with recent evidence in which patients were interviewed[30] about their preferences for participation. Two themes (power imbalances and passive roles) were similar to our findings. Interestingly, Ringdal et al. (2017) refers to imbalances due to nurses lacking of knowledge about pátients as experts, whereas nurses we interviewed were more focused on PFs lacking medical knowledge and clinical expertise. Relating this contrast to our predefined definition of PFP, indicates the need for operationalizing the meaning and importance of PFP.

Our study also has several limitations and strengths. The first limitation is that this was a single-center study. Second, maximum variation on gender was not achieved, because all interviewees were women. For these reasons, the transferability may be limited. The question is how heavily these limits should weigh, because it is known that PFP requires a certain degree of tailored care. Data saturation was achieved and strengthen our findings. No new data was obtained since the ninth interview[25]. Telephone interviews decreased the feeling of pressure to give formally approved answers by the fact that nurses spoke freely during their interviews, as can be seen from the interviewtime[31]. This has ensured that our results are valid and provide a realistic description of the perceptions of nurses regarding PFP. Additionally, in vivo codes strengthen our findings, because this has ensured that the nurses' voices are embedded in the themes we found. Furthermore, six of the eleven transcripts were analyzed fully independently which also strengthen the quality of this study.

Based on our findings, recommendations for clinical practice and further research have to be described. PFs in oncology belong to a special group that require complex care due to

disease progression and treatment-related complications[32] and therefore, it is recommended to investigate how a PFP-programme could support nurses to let PFs participate. This should be designed as implementation research[33] with a pre- and posttest for oncology wards for both university hospitals and peripheral hospitals. This could guidance nurses to implement the preconditions and the elaboration of the meaning and importance of PFP in oncology and also helps nurses to solve the difficulties they perceived when trying to let PFs participate. Additionally, it is recommended to further investigate needs of different patient groups in oncology (older and younger patients, higher and lower educated) to develop strategies for enhancing participation.

Perceptions of Dutch nurses of PFP in the context of oncology were explored. Privacy-based environments, preparing patients for participation, and nursing competencies were all perceived as preconditions essential for normalizing PFP. However, a number of findings illustrated how PFP is being influenced according to nurses. Although understanding the definition of PFP is challenging for nurses, they did perceived PFP as important for PFs to cope, adapt after discharge, and ultimately for nurses' job satisfaction. Nevertheless, further research is needed. Guaranteeing the preconditions, utilize the meaning and importance of PFP for nurses, and bridging the factors which makes participation complex appears to be the first step to stimulate nurses to grow in providing PCC for letting PFs actively participate.

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TABLES AND FIGURES

Table 1

Interview guide with topics	
Importance of patient participation	How do you interpret patient participation?
	What are the benefits if a patient is actively involved in nursing care?
The role of the nurse	What do you do to involve patients in nursing care?
	What skills do you need to achieve this?
The role of the patient	How do patients ensure that they are involved in their own care process?
Sharing power	What do these words evoke in you when you think of participation? *power, control, prestige, professionalism, responsibility*
Influencing factors	What do you need from the organization to enable patients to participate in their care process?
Importance of family participation	How important do you consider involving family in the care process?
	What are the benefits of family participating in nursing care?
The role of the family	What are the experiences you have with having family members participate in care?
	How does family ensure that they are involved in the care process?

Table 2

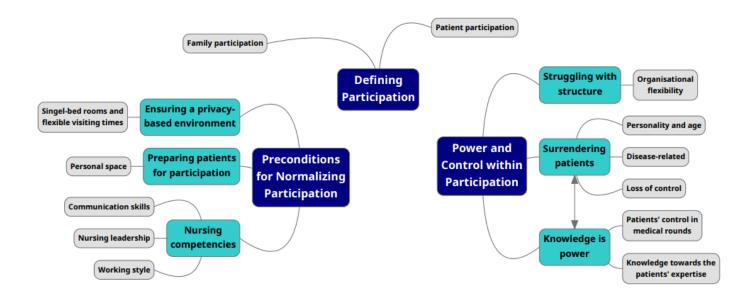| Nurses baseline characteristics	
Age, median (IQR), *in years*	42 (26-52)
Gender, *N*	
Female	11
Nurses educational level, *N*	
Vocational educated	6
Bachelor educated	5
Nurses trained with an additional oncology education, *N*	
Yes	9
No	2
Work experience, median (IQR), *in years*	21 (3-34)

Figure 1: Thematic map of nurses perceptions towards participation of cancer patients and their families during hospital admissions.

APPENDIX

Code tree

Aanzien(reactie)_kennis
Aanzien(reactie)_patiënt
Aanzien(reactie)_zorgprofessionals
Afdelingscultuur_medische visite
Afdelingscultuur_opleiding
Afdelingscultuur_verpleegkundig_andere manier van werken
Afdelingscultuur_verpleegkundig_werkplanning
Afdelingscultuur_verpleegkundig_willen zorgen voor
Autonomie patiënt_belangrijk
Controle(reactie)_hoort bij patiënt
Controle(reactie)_jonge patiënt meer voorbereid
Controle(reactie)_kennis versus wens
Controle(reactie)_ligt bij vpk
Controle(reactie)_verlies controle bij opname
Fampart_belang
Fampart_bevorderend
Fampart_behoefte
Fampart_beinvloedend_rol patiënt binnen gezin
Fampart_belang_adaptatie na ontslag
Fampart_belang_coping patiënt en fam
Fampart_belemmerend_geen familie aanwezig
Fampart_belemmerend_overbelaste mantelzorg
Fampart_belemmerend_verschillende meningen
Fampart_definitie_activiteiten
Fampart_definitie_betrekken behandeling
Fampart_hoe vormgeven
Fampart_jongeren_meer digitaal contact
Fampart_visite
Fampart_visite_belemmerend
Fampart_visite_hoe anders
Fampart_visite_verschillende disciplines
Fampart_voordeel_ontlasten vpk
Fampart_voordelen_vpk
Fampart_voorwaarde_attitude vpk
Fampart_voorwaarde_bezoektijden
Fampart_voorwaarden_1persoonskamer
Fampart_vormgeven_betrekken verzorging
Fampart-Patpart_voorwaarde_volledige informatievoorziening (mesoniveau)
Leidinggevende_invloed op artsen
Leidinggevende_organisatorisch nodig
Leidinggevende_steun
Macht(reactie)_afhankelijkheid(deels) van vpk
Macht(reactie)_kennis versus wens
Macht(reactie)_ligt bij de zorgprofessional
Macht(reactie)_regie hoort bij patiënt
Patpart_afweging kennis versus wens

Patpart_arts_bewoording
Patpart_arts_familiegesprek
Patpart_arts_medische visite
Patpart_beïnvloedend_persoonlijkheid_patiënt
Patpart_belang_adaptatie na ontslag
Patpart_belang_coping patiënt
Patpart_belang_doelen patiënt
Patpart_belang_gemotiveerde patiënt
Patpart_belang_gezondheidsuitkomsten
Patpart_belang_kwaliteit van zorg
Patpart_belemmerend_attitude_patiënt_overgave
Patpart_belemmerend_proces ziekenhuis
Patpart_belemmerend_ziekte
Patpart_bevorderend_digitaal dossier(interactief)
Patpart_bevorderend_gesprekken voeren
Patpart_bevorderend_patiënt_voorbereid
Patpart_bevorderend_ruimte geven
Patpart_definitie
Patpart_goed voorbeeld
Patpart_goed voorbeeld_visite
Patpart_hoe vormgeven
Patpart_kenmerken pat_leeftijd
Patpart_leuker werk vpk
Patpart_patiënt_aandacht uitslagen
Patpart_voorwaarde_continuïteit
Patpart_voorwaarde_durven zeggen
Patpart_voorwaarde_flexibiliteit organisatie
Patpart_voorwaarde_geïnformeerde patiënt
Patpart_voorwaarde_prioriteiten stellen
Patpart_voorwaarde_tijd voor gesprek
Patpart_voorwaarde_vaardigheden vpk_communicatie
Patpart_voorwaarde_verslaglegging
Patpart_voorwaarde_vpk kennis
Patpart_voorwaarde_vpk leiderschap
Patpart_voorwaarde_vpk relatie patiënt
Patpart_vpk_medische visite
Patpart_weet niet
Persoonsgericht_tijd en ruimte arts
Professionaliteit(reactie)
Teamfactoren_belemmerend_structuur
Teamfactoren_bevorderend
Verantwoordelijkheid(reactie)