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The experiences, needs and expectations of patients regarding participation at home : an explorative study in Belgium

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Title: “The experiences, needs and expectations of patients regarding participation at home: an explorative study in Belgium”

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Abstract:

Background: Patients have an important role in the improvement of their health. Patient participation is a key component to achieve this. Some form of patient participation is already present in home care and need to be optimised.

Aim: Gaining insight into the expectations, experiences and needs of patients regarding patient participation in home care.

Design: A qualitative design was used.

Setting: The study was conducted, in the Flemish part of Belgium, in a purposeful sample of patients who have already received nursing care at home for at least 6 weeks.

Methods: Semi-structured face to face in-depth interviews were conducted and analysed using QUAGOL.

Results: Patient participation in home care is a dynamic process. Six components, who interact with each other, were identified that explain this process.

Conclusion: Patient participation in home care is the interaction of different components of a whole mechanism. Within this mechanism, home nurses play a key role to facilitate participation for patients.

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ABSTRACT

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Keywords: Patient participation, home care, home nurses, qualitative study, perceptions, experiences

Keypoints

Patient participation in home care is the use of knowledge and experience of the patient to improve the quality of life for the patient and this in dialogue with the person, the informal carer, family and professionals (Wit-Gele Kruis, 2021). The current study gives insight into the mechanisms of patient participation at home.

The identified components based on the experiences of the patients are, being a patient, interaction, healthcare provider, meaning of patient participation, strategy and influencing characteristics of patients and healthcare providers.

The study also demonstrates that implementing patient participation in home care requires investment in the interaction of all components of the mechanism. Healthcare providers need to be the key players to initiate and to achieve proactive participation in home care.

Reflective questions

- What are the conditions and characteristics that healthcare providers must have in order to implement patient participation in home care?
- How can nurses play a key role in achieving patient participation in home care?
- Which are the first steps to be taken to implement patient participation (e.g. only focus on micro level, meso level, ...)?
- How can you convince healthcare providers, but also patient and their informal caregivers of the importance of patient participation?

Background

The aging population, the increasing number of individuals with chronic diseases, the multimorbidity, and the desire of older persons to stay at home as long as possible, results in a growing demand for (complex) home care and poses challenges for home care services (Paukkonen et al. 2018, Vik & Eide, 2012). The increasing importance on self-care, partly determined by budgetary constraints and pressure on healthcare in general, has resulted in a shift from the hierarchical and paternalistic models to partnership and a more patient-centred oriented care (Alvarez et al., 2016, Ortiz, 2018, Longtin et al., 2010). Patients have an important role in the improvement of their healthcare, and in the management of their healthcare process to achieve optimal health outcomes (Alvarez, 2016). Patient participation is a key component of achieving this. Since the 1960s patient participation is common in modern healthcare of many Western countries. This concept is interchangeably used with various overlapping terms such as ‘patient empowerment’, ‘patient-centeredness’, ‘patient involvement’, ‘collaboration’ or ‘partnership’. Also different descriptions occur in literature focusing on areas like shared decision making, patient safety, treatment or management of chronic illness (McCarron et al., 2019, Castro et al., 2016, Malfait, 2018, Debyser, 2020; Lyttle et al. 2010). A concept analysis based on a literature review revealed the following proposed definition for patient participation, making a distinction between individual and collective patient participation: *“Individual patient participation revolves around a patient’s rights and opportunities to influence and engage in the decision making about his care through a dialogue attuned to his preferences, potential and a combination of his experiential and the professional’s expert knowledge. Collective patient participation is the contribution of patients or their representing organizations in shaping health and social care services by means of active involvement in a range of*

activities at the individual, organizational and policy level that combine experiential and professional knowledge” (Castro et al., 2016, p. 1929).

Evidence indicates that patient participation has many advantages for patients. It is a mean to improve patient safety (e.g. sense of security, reduction in medical errors and adverse events), health outcomes (e.g. management of chronic illness, commitment to treatment, reducing the risk of dementia, preventing functional decline) and enhanced quality of life and care and the delivery of services (Paukkonen et al., 2018, Mc Carron et al., 2019, Vik & Eide, 2012). Patient participation varies over time and according to each situation. It depends on factors related to patients, healthcare providers and environment (Lyttle et al. 2010). Although participation is already present in home care, a thorough implementation of participation still needs to be prepared and integrated. Because of the advantages of patient participation (e.g. improved quality of care and welfare) and the principle that individuals have a say in matters that affect their own lives and receive care that corresponds to their needs, patient participation should also be well embedded in home care. Home nurses are one of the healthcare providers who play an important role in the integration and implementation of patient participation in home care because of their frequent contacts with patients. However, to integrate patient participation as a common way of practice in a professional organisation for home care nursing, more research is needed to understand patient’s expectations, experiences and their needs about this topic. These insights are important and need to be taken into account when setting out a implementation plan to improve patient participation within the context of home nursing.

Therefore, the aim of this study was to investigate patient’s perceptions, experiences and needs toward patient participation in home care in general and specifically within an organisation for home nursing.

Methods

Design

A qualitative study was performed to gain more insight into the experiences of patients toward patient participation in home nursing.

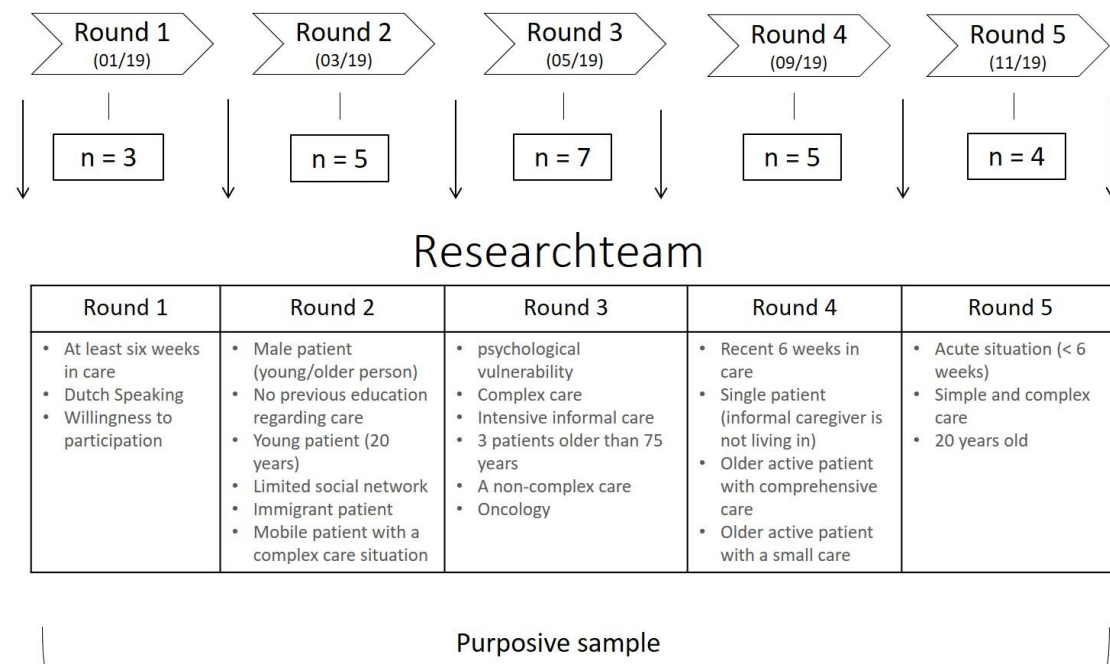
Setting and sample

The study was conducted in a large non-profit healthcare organisation. The goal of this organisation is to provide professional and person-centred home nursing in Flanders (Belgium). Parallel with the five provinces in Flanders, the organisation exists of five autonomous provincial organisations, each subdivided in district teams or divisions, and one Federation in Brussels. All home nurses and healthcare assistants working at the organisation are salaried employees who provide nursing care for patients at home. The mean age of the patient population within this organisation is 77.8 years, with 70.4% being older than 60 years and 33.6% older than 80 years (Annual report 2018). Professional home nursing is part of the social security system and is financed by the National Institute for Health and Disability Insurance (Scheepmans et al., 2014).

The current study focuses on patients with chronic care problems. We aimed, in the scope of transferability and saturation of the data, to include patients, spread over the five different provincial organisations for home nursing. We collected data using a purposive sample. For this, we searched and selected patients based on a variation in their specific characteristics (e.g. demographics) with the aim to include a broad scale of patients, representing a diversity of the patient population at home. Patients were included when they met the following inclusion criteria: (1) at least six weeks in care, (2) Dutch speaking and (3) willing to participate in an interview. After each round of

interviews, the criteria for the selection of participants were adapted and refined based on the analysis, the content of the interviews and the variables of the participants (e.g. personal history, health). The criteria for the selection of new participants are listed in figure 1. The total sampling process existed of 5 rounds.

Figure 1: overview of sampling process



Each potential patient received from his home nurse a letter with information about the study and the informal consent. The provincial contact person passed on, with permission of the patient, the data from the patient who was interested in participating in the study, to the researcher (KS). The researcher who conducted the interview (KS / UD) made the appointment with the participant.

Data collection

Data were collected using face to face semi-structured interviews. The initial interview guide was developed based on the literature and adapted after discussions in the research team. The interview guide focused on patients views and experiences about

e.g. the meaning of participation and being involved in their care, the way of contact and interaction with the home nurses, their expectations about participation. The interview guide and the open-ended questions were refined throughout the iterative process of data collection and analysis in order to achieve relevant and in-depth data. The participants choose the place for the interview. All participants gave written consent. The two interviewers (KS: n= 16; UD: n= 8) trained in qualitative interviewing, had no professional and hierarchical relationship with the participants. All interviews were audiotaped and verbatim transcribed. One researcher (KS) controlled all the transcribed interviews on content and anonymity.

Data-analysis

Data collection and analysis were an iterative process. After each interview round (see figure 1), the transcribed interviews were analysed within the multidisciplinary research team according to the Qualitative Analyse Guide of Leuven (QUAGOL, Dierckx de Casterlé et al., 2012). The research team consisted of 6 researchers, 4 from the home care nursing organisation itself (KS, UD, LP, KDV) and 2 from the academic setting (SA, SV). The members had a mixture of expertise in the field of home care, nursing care, sociology and health policy. The analysis process involved several rounds of researcher triangulation. The Centre of Excellence Patient Participation, consisting of representatives of the home nursing organisation (n= 7), one patient and 3 academic experts in the field of patient participation, was involved in certain rounds to discuss the findings.

The interview transcripts were divided among the members of the research group and were coded separately and double. Each interviewer (KS / UD) wrote a short report

about the interviewee's and contextual characteristics of the interview, completed with a critical reflection on the questions asked (methodological report). One researcher (KS) analysed all interviews and prepared the documents according to the different phases of the analysis process according to QUAGOL (e.g. narrative interview report, coding, coding list, conceptual scheme). To further ensure rigour and reflexivity at each stage of the analysis process these preparations were discussed, adapted and completed within the research team and constantly compared with the transcripts. In addition, a first discussion text of interpretive analyse was written (KS) after the second round of interviews (1-8 interviews). This text and the developed conceptual scheme has been refined and adapted throughout the analysis process. The preliminary results and the evolving conceptual scheme of the results were presented and discussed several times with a group of experts in home nursing. NVivo 11 was used to facilitate data analysis.

Ethical approval

The Ethics Committee of the Antwerp University Hospital and the University of Antwerp approved the study (B300201938755).

Results

Sample

Data were collected from January 2019 to November 2019. All interviews were conducted at home, with exception of one interview that was conducted at the local home nursing division. The interview time ranged from approximately 30 minutes to 1 ½ hours. In total, 26 participants were contacted. Two participants refused to participate because they were no longer interested. For the last interview round, the research team decided to adjust the principal inclusion criteria (i.e. receiving home nursing during at least 6 weeks) to participants who are recently in care (i.e. less than 6 weeks) with the

aim to compare the analysis of these last interviews with the results of the analysis of the other interviews.

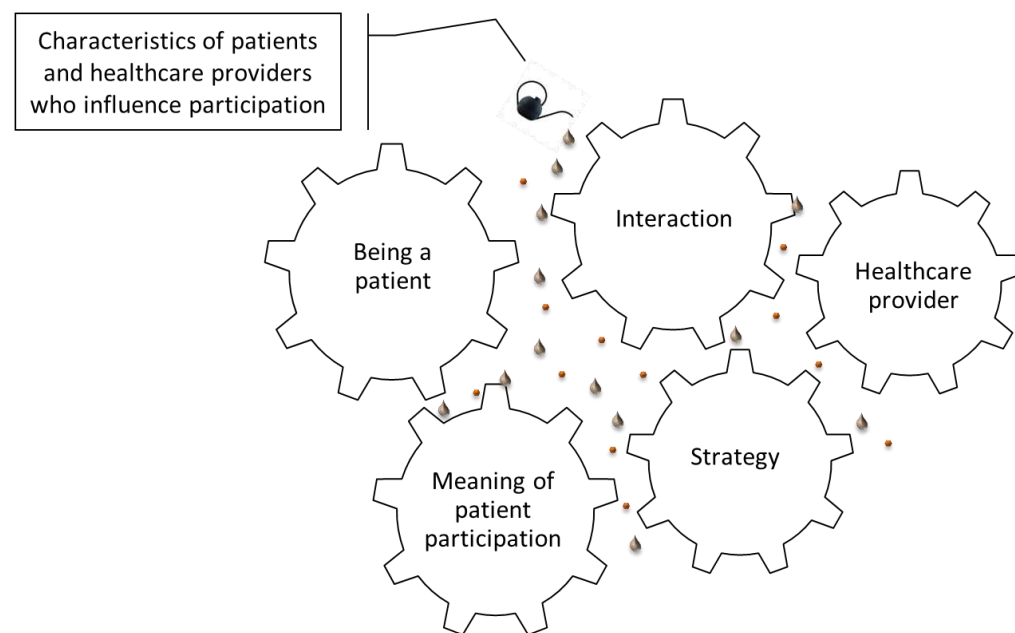
Reasons for home nursing included wound care, diabetes, psychiatric disease, increased dependence, surgery, multiple sclerosis (MS), infusion therapy, ostomy care, hygienic care, total parenteral nutrition, generalised deterioration, stoma care, preparation of medication

Table 1. Characteristics of the sample (n = 24)	
Age, mean	67
Age, range	19 - 90 years
Female, n	16
Men, n	8
Living together	15
Living alone	9
Number of years in care	4 weeks – 20 years
Reasons for home nursing	e.g. wound care, diabetes, psychiatric disease, increased dependence, surgery, MS, infusion therapy, ostomy care, hygienic care, total parenteral nutrition, generalized deterioration, stoma care, preparation of medication.

From our findings we identified 6 themes that are interrelated as patient participation in home nursing. This is a dynamic process, consisting of several interacting and accordingly changeable components. The process starts with the experience of ‘being a patient’. This is the moment when a person becomes a patient and often receive nursing care at home. Patients give meaning to the concept ‘patient participation’ based

on their experiences of ‘being a patient’. Starting from their experiences and in the scope of the situation and the circumstances, patients use strategies to secure their participation. The interaction between the patient and the healthcare professionals influences the perception of ‘being a patient’, provides an additional interpretation of the meaning of the concept of patient participation and, consequently, the strategy to participate or not. Finally, characteristics of the patient and the healthcare professional influence the degree of participation (Figure 2).

Figure 2: overview of the results



1. The experience of ‘being a patient’

Patient participation starts with the experience of ‘being a patient’. Patients give meaning to this experience based on their history (e.g. illness and care). Also being dependent on healthcare providers characterizes these experiences as building an equal relationship with them is difficult and affects the degree of patient participation. The social network of the patient (i.e. the availability and involvement of the informal caregiver) influences the experience of being a patient in an important way.

Patients express limited expectations of patient participation. The patients in this study have implicit expectations, which they find difficult to describe. Previous (negative) experiences related to 'being a patient' and receiving care, sharpens patients views and it influences their degree of participation. Negative experiences lead to low expectations and a lower degree of participation. Patient's perception of lack of time of the healthcare professionals and that care is rather a routine execution, influences the participation in a negative way. During the interviews, patients indicate that e.g. having time for them, being listened to, being considered as a human or being interested in them as a person by asking questions, are important factors that positively affect their participation.

Patients take on different roles in the way they participate in their care. This depends on their continuously evolving experience of being a patient. They adjust their expectations about patient participation and the role that they take. This role must have an added value and depends of the interaction and relationship with the healthcare provider. The roles vary from a rather submissive non participatory role because of their position of dependency, towards, if necessary, a reactive role. Some patients explain that certain healthcare providers acknowledge them in their role as expert in their illness and actively ask the patient what can be helpful.

"I think sometimes you really need to have something to say. Because, I've already been gone through so much, I think you can add something because you learn so much in all those years from all that help that come here. Sometimes I think: 'perhaps you can do it differently'. But at that moment, you don't dare to say something, because you think you're embarrassing them. So I actually think it's good that this (patient participation) is possible. But you cannot determine everything, I think nurses still offer better care

than patients themselves. But sometimes, it is easy when you can say: 'How stop, this can be different.' (Interview 1, woman, 51 years old)''

2. Meaning of patient participation

2.1. Concept of participation

Patients express that they are not familiar with the concept of patient participation which makes it difficult to describe. Patients become increasingly aware of what patient participation (could) mean to them during the interview. Common elements that emerge in the interviews to describe patient participation stems from their dependent position in their relation to the healthcare professional. From that position they describe important elements like *being taken into account, care adapted to their needs, being listened to, being involved, having the possibility to express feelings and concerns, being informed, reciprocal alignment / reconciliation and support*. Central is that patients want to be considered and respected as a unique individual.

Patient participation seems to focus mainly on the present (care) situation as well as on matters that are important in that particular moment for the patient. According to the participants, proactive thinking about decisions on daily care and therapy that would make home care easier for the patient, are not addressed in the current care provision. Patient's existential questions about their health seem to be more difficult for healthcare providers to address. Some patients are concerned about future problems and how their care will be done when they are no longer able to speak for themselves or make their needs and wishes clear. As some patients indicate, patient participation is necessary because it offers them the opportunity to clarify what is important to them in the care at home, now and for the future. They hope that continuity will be guaranteed and that

healthcare providers inform their colleagues about what they, as a patient, find important.

Although the interviews show that patient participation is insufficiently embedded in daily practice, patients experience the concept as valuable. Patient participation contributes to the feeling of ‘still being human’. Despite of their illness and dependency position, patients are not reduced to a *number, an animal or to someone who is less and has nothing more to say*.

“That they also listen to me, because as an MS patient (multiple sclerosis), sometimes I have pains that cannot be seen, but I feel them... and that they still watch me familiarly like ‘aha’ and not like ‘yes but no, there is nothing and hop they go further’. But they know me, so they take that into account, together with my illness. ” (Interview 2, woman, 49 years old)

2.2. Focus of participation

2.2.1. Micro level

Patient participation in home care mainly takes place at micro level between the patient and the healthcare provider (i.e. nurse) and focuses on care-related, organisational and interactional components. Depending on the patient and his network, the informal caregiver can also be involved in patient participation.

The care-related aspect of patient participation focuses on daily care. Patients initially participate less in technical related procedures such as wound care because they expect and rely on the expertise and competence of the home nurses. However, the interviews indicate that patients have clear expectations about how hygienic care (e.g. bathing, toileting) should be carried out because they are familiar with this. They feel competent

and know what should be taken into account, and see themselves as experts. Patients also express their involvement in organisational aspects by questioning certain issues related to the organisation of care (e.g. timing of care, number of different home nurses).

[Context: participants indicate that they see several home nurses driving by every day to care for patients in the same building] *“If you have three patients here in this building who need care, let them be cared by the same person, but not that a care (with a nurse) should come here three times a day.” (Interview 9, woman, 84 years old)*

2.2.2. Meso level

Patient participation on meso level (focused on the organisation and not the individual) is not spontaneously discussed by the participants. However, patients indicate that they are convinced of the added value when specifically asked about this topic during the interview. Some patients perceive participation on meso level as a way to increase the quality of the organisation and a means to avoid unnecessary suffering for other patients. They indicate that the credibility of the organisation to actually listen to their voice and to integrate patient participation into its structure, is an essential criterium for wanting to participate at meso level. The level of interest in participating depends on the personal interest and feelings of having enough competence to take on this role.

2.3. Changing initiative to participate

Participants stipulate that patient participating is influenced by the patient and the healthcare provider, depending on the ‘type’ of patient and healthcare provider. According to our participants, home nurses may act differently in patients with a serious chronic illness or who suffer from a serious visible condition or disorder. In these

situations, they discuss more actively issues such as pain and patients receive their care more timely. Patients believe that home nurses find it easier to empathize with these patients, or to find a more justified need for person centered care (e.g. to spend more time with the patient, more listening).

The degree of participation is influenced by the attitude of the healthcare provider and the past experiences of patients with healthcare. When a nurse explicitly expresses the overload of work to the patient (e.g. there is little time as there are many other patients to be seen), a patient will not express his/her wishes or needs and just undergoes the care. Patients label themselves as 'I am just a wound care' or 'there are other patients who are worse off' and choose not to participate actively in order not to take time from other patients.

2.4. Safety and information

Spontaneously being informed about items that concern the welfare of the patient like care options, care devices, adapted possibilities for travelling or holidays, contributes to a sense of security and trust and consequently facilitates the degree of participation. This information, tailored to the needs of the patient, is important for them to make clear agreements about their care.

2.5. Trigger to participate

As already mentioned the roles of patients vary from a submissive non participatory role towards a reactive role to participate. The interviews indicate that currently patient participation is rather 'reactive'. Patients participate when they are triggered to do so, in order to e.g. avoid unnecessary suffering or when they perceive their care as insufficient. The participants emphasize that it is important that home nurses listen to

them at these moments and take into account their advice, because the nursing actions have a direct impact on their quality of life. Patients expect competent and professional home nurses, having medical knowledge and correctly performing technical, preventive or hygienic procedures in collaboration with the patient. The patients in the interviews participate actively when they have no other choice; when a boundary has been reached or when their expectations are not met, causing them unnecessarily suffering or disadvantages for themselves and for their own safety. Therefore patients look for strategies to communicate their preferences and wishes in order to avoid additional discomfort or to make their lives easier.

“I approached the head nurse because my regular nurse had to take care of other patients so she came later to me. But if you want to go outside, I'm hanging on to my IV. It was almost half past eleven when the nurse arrived. That was almost two hours later! Imagine that your day only starts in the afternoon. And then I said, I'm sorry, but this won't work. You guys just need to be on time so I can get off the IV in time, so I can do my job on time. Period. And then they realized. I also told them not to take my regular nurse away of this or I would leave.” (Interview 15, woman, 60 years old)

3. Strategies

Patients seek and apply strategies that enable them to participate and to create conditions for themselves when participation is necessary.

A common strategy is that patients, from their dependent position and their previous experience, do not want to portray themselves as *a burden* or *a person who complains* as they want to get on the ‘good side’ of the healthcare provider. It is important that home nurses are happy to care for them and feel comfortable with them. In order to be

able to have input when it is necessary (e.g. prevention of pain,...), they need to maintain a good relationship with the nurse.

Another frequently used strategy is 'rationalising'. With the help of cognitive reframing, patients compare themselves with other patients who would be in a worse situation (e.g. illness). By using this strategy and focusing on *I'm only a wound care*, patients minimize their own care and minimize the things they cannot obtain from the nurse. As a result, patients do not ask or expect much from the healthcare providers and focus on the essential care.

Some patients use humour as another strategy to put their situation into perspective. It makes it easier to communicate and discuss issues with the healthcare providers.

When all the above strategies do not work in their one to one contact with the healthcare provider they will contact the head nurse or somebody higher in the hierarchy of the organisation.

4. Healthcare providers

Patients distinguish different types of healthcare providers based on their age, experience, ways to approach the patient (e.g. holistic versus task-oriented) and their personality (e.g. open, warm and listening attitude, being a social person), and accordingly adapt their strategy and degree of participation.

"That is in a very friendly atmosphere, just based on trust. I have a head nurse, she is already an older lady who actually, who has never really has enough time, but also spends a lot of time on her patients. So if you have to divide them into two categories, then you have the nurses who do their job perfectly, but who leave very quickly, and

then you have nurses who do their job very well, who are interested in you and act accordingly. ” (Interview 5, male, 59 years)

Patients have clear expectations of home nurses. They feel more reassured by kind and cheerful healthcare providers who indicate that caring for them is not a burden. Home nurses need to be polite, involved and empathic, and giving the perception of having time, despite the amount of work by listening and paying attention to small matters. They must be interested in the patient as a person and motivate them to express their thoughts. At the same time, home nurses need to be neutral and discrete. Respecting the patient's privacy is an important attitude.

5. Interaction

The interaction with the healthcare providers and how they deal with patients as individuals and humans influences the role that patients take and the strategy they use to enable participation. Patients indicate that this is a daily exercise, which evolves depending on the nurse caring for them at that particular time.

Communication is an important instrument in the interaction between the patient and the healthcare provider. The way in which communication takes place (verbally and non-verbally) influences the patient's experience. Communication varies from jovial, professional, to superficial or efficient, as well as to the "small talk" and the sincere interest in how the person is doing. Interaction and dialogue based on recognition and mutual respect and the nurse's attitude facilitate the communication.

Social talk about daily matters is an important subject of the communication. Home nurses who frequently visit patients have a relationship based on trust with these

patients. However, some patients indicate that ‘trust’ may also be present with healthcare providers who visit less frequently but who achieve this through their attitude towards the patient and their way of interaction. This trust is an evolving process that is built up over time. Knowing that healthcare providers communicate and inform each other about the patient promotes this confidence, their feeling of safety and reassurance, which all contribute to a climate of participation.

“Yes, I think that you should be mutually atuned to each other. I can understand what the nurses are saying, but the nurses must also be able to understand what I am saying. ” (Interview 11, woman, 84 years old)”

Discussion

The current study provides insight into how patients experience participation in home care and into the mechanisms they use to achieve participation. The study shows that from the patients’ view, patient participation is insufficiently embedded in daily practice and it takes place in a ‘reactive’ way to avoid unnecessary suffering, and mainly at microlevel between the patient and the nurse. The attitude and interaction of the nurse with the patient is key to create opportunities for participation. Being heard, approached as a person, informed and involved, are important elements for the participants in the care they receive. These elements facilitate their way and the degree of participation and are imbedded in person-centred care or patient-centered(ness) (Castro et al., 2016).

The essential role of the healthcare provider (e.g. nurses) to facilitate patient interaction by encouraging patients to ask questions and motivate them to take an active part in their care, is confirmed in literature (Erikson et al., 2019; Alvarez et al., 2016). It is important that home nurses capture these questions and actively deal with them. It

should be taken into account that they may not be able to answer them all, but that they discuss them in a reciprocal dialogue with the patient. For example, explaining how the organization works, can help the participants to better understand a number of organizational issues which may affect their care. In addition, the results of the study show that home nurses also can take the initiative to invite patients to participate and to evolve towards a proactive way of participation.

However, as our results suggest, and also indicated by Longtin et al. (2010), there are not only barriers inherent to the role of nurses that hinder patient participation (e.g. lack of acceptance of the new role and to abandon traditional roles) but there are also obstacles related to the patient (e.g. disease, comorbidity, less or a loss in interest in being involved in decision-making). As indicated in literature and despite a recent review article (Castro et al., 2016), there is still a lot of uncertainty about the content of patient participation. This lack of clarity is also reflected in the results of the current study. Most patients do not know or understand the concept of patient participation as such. In the current study, as in the literature, patient participation is often linked to safety issues, which is only one outcome of patient participation. Participants participate in a rather reactive way, to avoid disrupting their care relationship and the balance in this relationship but also because they are not used to their care being built in a participatory way. It is important that home nurses already discuss participation during the intake and how they can organize care for and together with the patient in this regard.

Another explanation is that when patients are invited by the home nurses to shape the care together, participants see this as an essential part of good care. In these situations patients do not have the need to voice their concerns actively. On the other hand where

there are particular unwanted caring situation, they will raise their concerns and wishes as it is seen as the 'necessary evil'

Although the participants indicate that they have little to no explicit expectations regarding patient participation, most patients consider being involved and informed, two components of patient participation, as important and desirable. Informing patients, by preference on their own initiative, whereby the information is adapted to their unique context and person, and deals about topics that concern them, is an important role of home nurses in facilitating participation.

Longtin et al. (2010) points out that the patient plays a leading role in the new definition of health. As a consequence, it is important that patients take an active and participative role. This could mean that patients, and the healthcare providers, should evolve towards a 'patient participation culture' and that they also need to take on a new role. However, not every patient is willing or is able to do this because of their capabilities or interests (Longtin, et al., 2010). Based on the results of the current study, it seems that when home nurses are sufficiently open to participation and their attitude is according to the principles of patient participation, patients will evolve towards patient participation and it will be a logic outcome.

The question is whether it is a challenge for nurses, but also for all healthcare providers, to prepare patients to take on this new role, regardless of their dependency position or their health skills, while respecting the wishes, preferences, points of view and the 'participation process' of the patients, or whether the challenge focuses on healthcare providers (e.g. nurses) to fully integrate and implement patient participation. According to the researchers it is an 'and-and' story in which the healthcare provider (e.g. nurse) is the key player in both challenges. All healthcare providers have a role and they need

to get training and tools in order to enhance patient participation. Patient participation means a shift in culture, whereby it is not that easy to implement this immediately, it will be in different stages.

Patient participation varies over time and situation (Longtin, et al., 2010). Participants indicate that the interaction with and the person of the nurse are important aspects that influence the degree of participation. For example, the patient's perception of the nurse's lack of time due to the non-verbal attitude, influences participation in a negative way. Despite their low expectations regarding patient participation and the lack of clarity about the concept, there are patients who in certain situations do not wish to participate and rely on the professional expertise of the home nurses. Longtin et al., (2010) also mentions that patient participation depends on the type of the decision to be made. In the current study the interaction between the patient and the nurse determines the way in which participation takes place. In addition, informal caregivers (e.g. family) play an important role in the continuity of home care for their loved ones. These persons are not included in any description or concept of patient participation. Given their prominent role in home care, it is unclear where and whether the informal caregiver should be given a place within the definition. A clear concept is essential to increase awareness about patient participation so that everyone can evolve into their new role. In addition, further research is necessary to know the perceptions of the informal caregivers regarding patient participation and to consider whether they should be included in the definition and whether the focus of participation in home care differs from the other settings.

The beliefs, attitudes and behaviour of healthcare workers can affect the implementation of patient participation. Items to improve patient self-management, a greater patient activation, supporting patient behaviour change or how they understand or perceive their role as a healthcare provider, has not been part of their education (Alvarez et al., 2010). In the current education of healthcare providers and more particularly of nurses, more attention is needed about e.g. patient-centered care, patient participation and communication skills of healthcare providers to support the implementation of patient participation in care. Therefore, home nurses need to be supported (e.g. education and the necessary tools) to integrate this new role and beliefs, and to create the opportunities for patient participation.

Implications for practice

Guiding patients towards an active way of participation instead of a reactive way of participation is necessary to avoid unnecessary suffering and to achieve better quality of life for patients at home. Therefore, good communication skills, an open attitude and awareness about the scope, meaning and added value of participation, are important characteristics and conditions that should be present in nurses and other healthcare providers. These elements should be given more attention during the training and education of future healthcare providers but also to nurses who are already working in the field and use certain interventions (e.g. adding the aspect of patient participation during the intake).

Healthcare organizations that want to integrate patient participation in their organisation must prepare this thoroughly. Therefore, a clear policy, available guidelines, investing in time and resources (like education), and supporting the healthcare providers with tools, are important elements to be taken into account. The

credibility and image of the organization that they attach great importance to patient participation, lead by example, making the input of patients visible in actions at micro and meso level, are an important triggers for patients to participate. Important aspects are the sensibilisation and awareness of nurses about participation (e.g. concept, added value, challenges and limits of participation) by supporting them in thinking and acting from a person centred care, as well as learning to deal with conflicting interests (organisation versus those of the patients).

Strengths and limitations

The strengths of this study are the careful data collection, the data analysis methods and the various techniques to establish trustworthiness (i.e. research triangulation, intensive peer debriefings, supervision of the interview techniques, the adapted interview guide to get an answer to the research question). This study has also limitations. First, the interviews were conducted by two researchers working in the Federation of the same organization, however they had no professional relationship with the patients and are not part of any of the five provincial organizations for home care nursing in Flanders. Second, the study focuses on patients with chronic care problems (i.e. receiving nursing home care during at least 6 weeks). Patient participation should include all patients, regardless of age or length of time that they are in care or illness. Although the research team decided to adapt the inclusion criteria to ‘patients who are recently in care (i.e. less than 6 weeks)’ for the last interview round, the question remains whether it would have been better to adjust the whole sample in this way from the start. The results indicate that participation is important in all patients. Another limitation is the lack of clarity of the concept of patient participation.

Conclusions

This study provides insights into the perceptions, experiences and needs toward participation of patients receiving home nursing. The results highlight the important role of home nurses as key for creating options for participation and facilitating it for patients. The results of this study suggest that achieving patient participation in an organisation for home nursing is a long process. It implies that a culture change is required for the healthcare workers and the organisation as well as for patients. Despite the many challenges, it is important to start and complete/persevere this process because of the benefits of participation for the quality of life for the patient.

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