

Experiencing Participation in Health Care: “Through the Eyes of Older Adults”

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Abstract

Background: Patient participation is well understood by health care professionals but not many studies have focused on the older adults and their perceptions of patient participation. **Aim and Objectives:** To report an analysis of the concept of participation from the perspective of the older adult. **Design:** Concept analysis. **Methods:** An integrative review approach was undertaken and the searches were limited from January 2003 to December 2014, guiding question was; “what constitutes patient participation according to the older adult?” **Results:** Through the eyes of the older adults, a two-way communication should be initiated by the staff. Equality and sharing power between older adults and staffs was perceived as a precondition. Been given time was an essential issue, implying that older adults wished to have enough time from staffs and be in the right context surrounded by the appropriate environment in order to experience participation. **Conclusion:** In order to experience participation for older adults, it is important that the health care professionals are aware of how and in what ways they can contribute to participation among older adults. The need or wish to create participation is not enough; the health care professional needs to see and understand participation through the older adult’s eyes. Thus, a person-centered nursing approach is relevant for the health care professional in order to both give and maintain the experience of participation to the older adult.

Keywords

Concept Analysis, Patient Participation, Older Adults’ Perspective, Nursing

1. Introduction

Although patient participation is a complex and broad concept, it is common and used on a daily basis in health care by health care professionals. Patient participation is defined as “patient involvement in the decision-making

process in matters pertaining to health,” in the National Library of Medicine’s Medical Subject Headings, [MeSH] [1].

While the concept of patient participation is well understood by health care professionals, it is equally important for patients to be aware of and conscious about it. Since, to be aware makes it possible to take part. To actively take part in one’s own care results in making better decisions related to self-care and to being which are more likely to be content with the care received and its outcomes. Brennan [2] described the normative decision theory and its applicability to using patient preferences in order to plan care and to construct measures of patient satisfaction meaningful to the patient. A study indicated that experts working with safety issues in health care reported that if their patients play a more active part, it would help to prevent medical errors [3]. According to the International Council of Nurses (ICN), nurses should listen to the needs of the patient as expressed by the patients <http://www.patientstalk.info/psinfo/patients03.htm>. Furthermore, WHO emphasizes patient participation partly to meet patients’ needs and partly to provide more effective care, for example, in management of chronic diseases and prevention of medical problems http://www.euro.who.int/_data/assets/pdf_file/0010/185779/e96814.pdf?ua=1.

The Swedish National Board of Health and Welfare [4] emphasizes the importance of the interaction between the caregiver and the patient. Moreover, it has declared that during the interaction, specific health-care needs are identified and this provides better outcomes for the patient [4] [5].

A study done in Sweden showed that, according to the patients, patient participation was about having knowledge and interacting with health care professionals [6]. This study confirms that patient participation is important for the patient and for the quality and outcome of care. The findings are also consistent with new Swedish legislation the “Patient Act,” which emphasizes patient involvement and the patient’s right to participate in all decisions [7]. The background to and the intention of the law are a shift of power to the patient [8].

Patient participation is a well-researched concept. Several studies focus on adults as a general group and/or focus on patient participation in different contexts [9]-[11].

However, the views of adults on patient participation, a complex and multifactorial concept [12], cannot be seen or described as though adults are a homogenous group. Rather, they need to be explored from the perspectives of different age groups in order to capture the essence of the concept. In a survey from 2008, the authors concluded that patient participation differed substantially because of the patients’ preferences and would be best elicited by assessing the need of the individual patient [13]. Not many studies have focused on the older adult and their perceptions of what constitutes patient participation. A review from 2010 concluded that there was a lack of research showing patient participation from the perspective of the older adult. The authors of the review found seven key themes in the literature: the concept of participation, the need for older people to be involved, autonomy and empowerment, patients’ expectations, benefits of participation, factors influencing participation, and precursors to participation [14]. Although this review covered several important areas, it did not deal with what constitutes patient participation from the perspective of the older adult. A review from the United Kingdom in 2012 was conducted using the term “shared decision-making” with a focus on older adults and it showed that older adults valued involvement in decisions concerning their treatment and care. However, this review described what constituted participation from the perspective of the older adult. This gap in knowledge suggests that more research is needed to map out what constitutes participation in health care according to the older adult [15].

This crucial need to describe participation in health care from the older adult’s perspective comes to be aware of the aging population globally. In the Western world, the number of people reaching an old age is rising and it is estimated that soon the older population will outnumber the younger population [16]. By 2050, 22% of the world population will be older adults [17]. Sweden has one of the highest proportions of older adults in the world, especially in the group of 80 and over. Due to better living conditions, life expectancy will increase [18].

Because health care professionals will meet this group of patients in all contexts where health care is provided, it is important to explore and describe patient participation according to the older adult. Understanding the older adults’ can enhance and promote the caring conversation that nurses and other health care professionals conduct. A first step in filling the gap is to review the literature and discover the scope out of what constitutes patient participation from the view of the older adult.

Thus, the aim of this study was to review the literature on what constitutes participation from the perspective of the older adult in the encounter in a health care setting.

2. Material and Methods

An integrative review approach was undertaken with the guiding question, “what constitutes patient participation according to the older adult?” The choice of method was in order to define the concept further and to have the possibility of combining different data from quantitative studies as well as qualitative studies.

Integrative reviews are the broadest type of research review methods that allow for combining data from the theoretical and empirical literature. Moreover, integrated reviews incorporate defining concepts [19]. This study used the methodology of Whittemore and Knafl during the whole process, including *problem identification stage*, *literature search stage*, *data evaluation stage*, and *data analysis stage*. Problem identification has been thoroughly described in the above section, which explained the lack of knowledge and importance of conducting this review.

2.1. Literature Search Stage

Concepts closely related to participatory care were used in the search process to see whether they had corresponding terms or explanations on the MeSH-tree. Related concepts were chosen in consultation with two experienced researchers in the field of concept development/concept analysis. Among the concepts were “participatory medicine”, “participatory care”, “interdependence”, “collaborative care”, “cooperative care” and “patient participation” (in PsychINFO “client participation”). Only patient participation had an explanation as a MeSH-term: “patient involvement in the decision-making process in matters pertaining to health.” Although the other concepts did not have any explanation, they were used in rest of the search to capture the core of the concept. Three electronic databases were used to conduct the review: PubMed[®], CINAHL and PsycINFO. All the searches were limited to January 2003 to December 2014 to capture the most recent research, to the English language to receive articles written only in English, and to +65 years of age to obtain articles involving older adults. In PubMed and CINAHL, the search word “patient participation” resulted in too many search results so the search range was reduced to six years, thus January 2008 to December 2014. Inclusion criteria were: according to the older adult, cognitively intact older adults, and studies conducted in Western countries. Exclusion criteria were studies about co-operation/participation between professions. When duplicates were removed, a total of 15 articles were included in the review because they met the aim of the study (see **Figures 1(a)-(c)**). Lastly, a control search was conducted and one more article was found, for a total of 16 articles.

2.2. Data Evaluation Stage

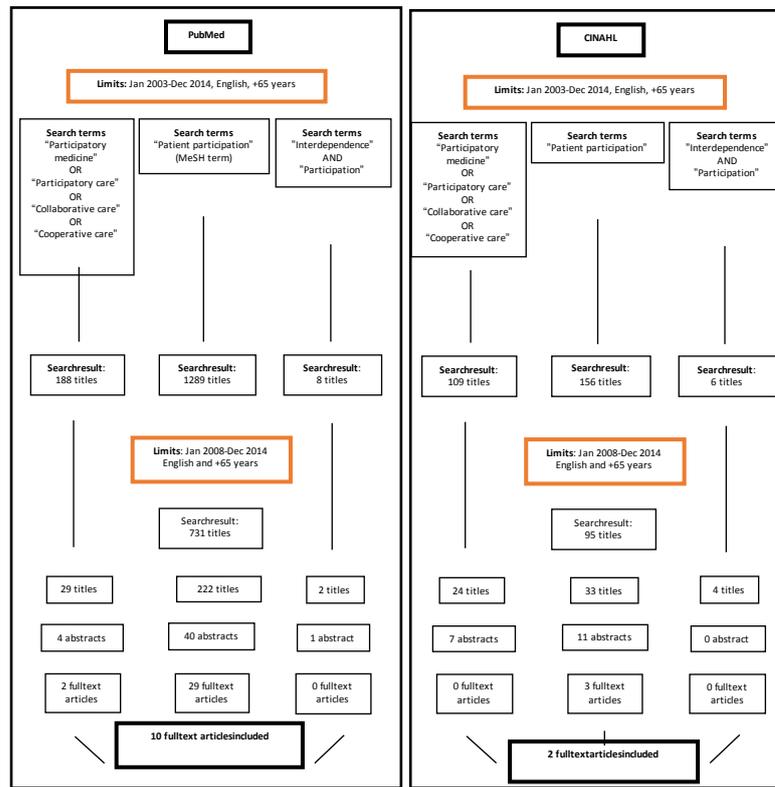
The study included all the articles that were peer-reviewed and focused on experiences/perceptions on patient participation from the perspective of the older adult. The final sample was a total of 16 articles; both empirical and theoretical articles were included to gain a broader description on what constitutes patient participation according to the older adult. At this stage, a matrix was created in order to sort out data that corresponded to the aim (see **Table 1**).

2.3. Data Analysis Stage

Inductive content analysis with open coding was used to analyze the data retrieved [20]. The primary research methods of analysis, which were developed for qualitative design, are applicable to the integrative review method [19]. Inductive content analysis with open coding took five steps: first the data was obtained, (e.g. the literature that corresponded to the aim was read through and notes were written in the text while reading). Then the data was read through again and as many headings as possible were written in the margins to describe all aspects of the content. The headings were then moved onto coding sheets and categories were freely generated, which created subcategories. Further, the categories were grouped under higher order headings, which in turn provided the categories. The categories then resulted in four main themes (see **Tables 2(a)-(c)**).

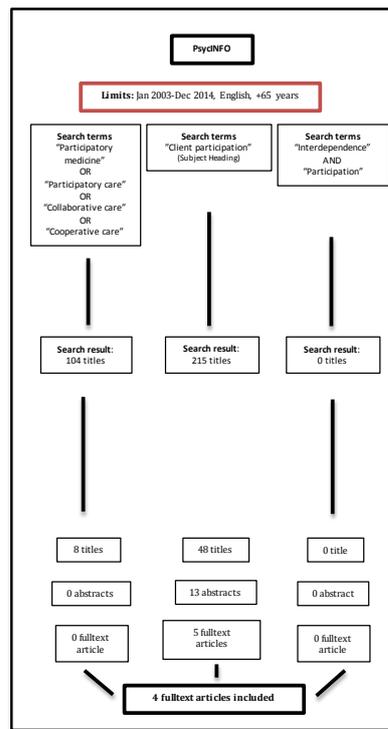
3. Results

The studies in this review include reports, reviews and empirical papers. A summary of 16 articles addressed the main aim of the review and formed the base findings. Four main themes emerged from the literature: *a two-way communication*, *being on equal terms*, *being given time* and *being in the right place* (see **Tables 2(a)-(c)**).



(a)

(b)



(c)

Figure 1. (a) Overview of the research strategy and process in PubMed; (b) Overview of the research strategy and process in Cinahl; (c) Overview of the research strategy and process in PsycINFO.

Table 1. A matrix of the included articles.

Database	Citation	Year	Context/ participant	Label	Definition	Critical attribute/ characteristics	Result
	Susan Mary Benbow						
PubMed	“Patient and carer participation in old age psychiatry in England. Part II: models of participation” <i>International Psychogeriatrics</i> . 2012, 24, 185-196.	2012	Old age psychiatry Review Models of participation is reviewed.	Partnership/ collaboration	Participation is a spectrum	Older adults Staff/Patient/ carers	Participation is similar status, shared power, equality of influence over the agenda.
PubMed	Erika Leemann Price, Sylvia Bereknyei, Alma Kubly, Wendy Levinson, Clarence Henry Braddock “New elements for informed decision making: A qualitative study of older adults’ views” <i>Patient Education and Counseling</i> , 2012, 86, 335-341.	2012	Senior centers and nursing homes 5 focus group interviews with 59 older adults 65 – 85 and older years	Patient participation	Informed decision making	Older patients-physician	Inviting the involvement of trusted others and exploring the impact of the decision in the context of the patient’s life.
PubMed	Christina Foss “Elders and patient participation revisited—a discourse analytic approach to older persons’ reflections on patient participation” <i>Journal of Clinical Nursing</i> , 2011, 20, 2014-2022.	2011	At home 1 - 2 weeks after discharge from hospital In depth interviews 18 older adults (10 men, 8 women) 80 - 92 years.	Patient participation	Participation means balancing your own needs against the need of others	Patients-health care staff	Being heard requires self-confidence to be able to participate. Participation depended on the hospital’s pace. Participation is not practiced in a direct and outspoken manner but in subtle ways, not as a right but as an opportunity and it need strategies and self-confidence from the older adults to gaining influence.
PubMed	Christina Foss, Dag Hofoss “Elderly persons’ experiences of participation in hospital discharge process” <i>Patient Education and Counseling</i> , 2011, 85, 68-73.	2011	Hospital discharge process interviews via questionnaires with 254 older adults 80+ mean age 86,9 years	Participation	Participation is co-deciding	Patients-health care staff	The majority of the older adults did not experience real participation. They want to influence different examinations and treatments. Being able to co-decide in the discharge process.
PubMed	Rebecca Johnson, Lori L. Popejoy and M. Elise Radina “Older Adults’ participation in nursing home placement decisions” <i>Clinical Nursing Research</i> , 2010, 19, 358-375.	2010	Nursing home relocation Semi structured interviews with 16 older adults 60 - 97 years (9 women, 7 men)	Participation	Decision-making participations	Patients-family, friends others Older adults’ participation in the nursing home relocation decision.	Being involved in your decision making when relocating to a nursing home. Some of the older adults reported that they have a total or some participations in the decision-making about moving to a nursing home others reported from minimal to no participation.

Continued

PubMed	<p>George Demiris</p> <p>Independence and shared decision making: the role of smart home technology in empowering older adults</p> <p>31st Annual International Conference of the IEEE EMBS Minneapolis, Minnesota, USA, September 3-6, 2009, 6432-6436.</p>	2009	<p>Community dwelling older adults</p> <p>Smart home technologies</p> <p>Dephi study</p> <p>Review</p> <p>Smart home designers</p> <p>Researchers</p> <p>48 dwelling older adults</p>	Shared decision making	It is an active and empowered role	<p>Older adults and clinical encounter</p> <p>Literature review</p> <p>Older adults and smart home designers/researchers</p>	<p>Shared decisions was perceived as being able to make decisions about treatment options during clinical encounter and having control over what technology to use, when and how. Because smart home technology can interfere the private life.</p>
PubMed	<p>Anne W. Ekdahl, Lars Andersson, Maria Friedrichsen</p> <p>“They do what they think is the best for me.” “Frail elderly patients’ preferences for participation in their care during hospitalization”</p> <p><i>Patient Education and Counseling</i>, 2010, 80, 233-240.</p>	2010	<p>Recently hospitalized frail older adults</p> <p>Interviews with 15 “fragile” elderly patients</p>	Patient participation	Participation means information and good communication.	<p>Patients (and health care staff)</p>	<p>Participation (in medical decisions) means receiving information and good communication the older adults do not want to take an active part in medical decisions about their treatment. But they wanted to be given the chance to be heard and to express their thoughts and feeling about symptoms and illnesses.</p>
Pubmed	<p>Helena Harder, Rachel Ballinger, Carolyn Langridge, Alistair Ring, Lesley J. Fallowfield</p> <p>“Adjuvant chemotherapy in elderly women with breast cancer: patients’ perspectives on information giving and decision making”</p> <p><i>Psycho-Oncology</i>, 2013, 22, 2729-2735.</p>	2013	<p>Women aged ≥ 70 years with newly diagnosed</p> <p>EBC (Early Stage Breast Cancer)</p> <p>Structured interviews with 58 women 70 - 83 years</p>	Breast-cancer-treatment decision	Level of participation in treatment decision making	<p>Patient and clinician ie. doctor and family</p>	<p>The majority (58.5%) of the women wanted to make a shared decision about adjuvant chemotherapy with a clinician. 22.6% delegated the decision to a clinician 18. 9% made their own decision.</p>
PsycInfo	<p>Elisabeth Lindberg, Ulrica Hörberg , Eva Persson, Margaretha Ekebergh</p> <p>“It made me feel human”: A phenomenological study of older patients’ experiences of participating in a team meeting.</p> <p><i>International Journal of Qualitative Studies on Health & Well-Being</i>, 2013, May 28, 20014.</p>	2013	<p>Team meetings (TM) in hospitals</p> <p>Interviews with 15 patient 74 - 94 years (12 women 3 men)</p>	Participation	The encounter between the career and the patient needs to be developed (in order to get away) from the view of the patient as an object to view the patient as a unique person	<p>Patient and career</p>	<p>There is a desire in caring and TM to be recognized and confirmed as a unique but vulnerable human gives feelings of participation.</p>

Continued

PsycInfo	<p>Veronica Vicente, Maaret Castren, Fredrik Sjöstrand, Birgitta W Sundström</p> <p>“Elderly patients’ participation in emergency medical services when offered an alternative care pathway”</p> <p><i>Int J Qual Stud Health Well-being</i>, 2013, Feb 26, 8, 20014.</p>	2013	<p>The choice of health care when being offered an alternative care pathway by the emergency medical services. Ambulance service and a geriatric ward</p> <p>Semi structured Interviews with 11 older adults (9 women, 2 men)</p>	Patient participation	Interpersonal relationship	Patient and career in the ambulance service	<p>“There was a ray of hope about a caring encounter and about being treated like a unique human being.”</p> <p>Participation is about being seen and cared about.</p> <p>To be treated with an open and friendly attitude, respect integrity by creating an atmosphere where older adults gain courage to express their needs.</p>
PsycInfo	<p>Vernee N. Belcher, Terri R. Fried, Joseph V. Agostini, Mary E. Tinetti</p> <p>“Views of older adults on patient participation in medication-related decision making”</p> <p><i>Journal of General Internal Medicine</i>, 2006, 21, 298-303.</p>	2006	<p>Older adults were recruited from senior centers and from primary care practice.</p> <p>Interviews 51 older adults 65 - 89 years</p>	Participation in medication-related decision making	<p>Physicians’ attitudes and behaviors as well as system factors were obstacles or could facilitate participation.</p> <p>Physician and system factors that were felt to facilitate or impede patient participation included communication skills, the expanding number of medications available, multiple physicians prescribing for the same patient, and a focus on treating numbers</p>	Patients and physicians	<p>Participation can be on different levels. Physician can facilitate participation, asking questions, being active in decision making, let the patients’ know about their medications and conditions, trust the physician. The role of the physician was important to participation.</p> <p>Not all patients WANT to participate in decision making(that is also participation).</p>
PsycInfo	<p>Hilde Bastiaens, Paul Van Royen, Danica RotarPavlic, Victor Raposo, Richard Baker</p> <p>“Older people’s preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries”</p> <p><i>Patient Education and Counseling</i>, 2007, 68, 33-42.</p>	2007	<p>Older adults within primary care</p> <p>Semi structured interviews with 406 older adults (222 women, 184 men) in 11 countries 70 - 96 years.</p>	Patient participation	Patient involvement in care	Patients and general practitioners	<p>Good communication, building a trusting relationship, being respected, having enough time and receiving information.</p> <p>A “caring environment” is more important than the outcome of involvement.</p> <p>An important base for patient involvement is the doctor, practice, and health care organization.</p>

Continued

CINAHL	Elin M. Aasen, Marit Kvangarsnes, Kåre Heggen "Perceptions of patient participation among elderly patients with end-stage renal disease in a dialysis unit" <i>Scandinavian Journal of Caring Sciences</i> , 2012, 26, 61-69.	2012	Elderly patients in a dialysis unit Interviews with 11 older adults/patients (4 women, 7 men) 72 - 90 years.	Patient participation	The health-care teams have the power and dominance. The patients have a passive role.	Patients and health care staff	Conditions for participation are influenced by the context (environmental conditions). In this study: feelings of being controlled, sensing a loss of freedom and powerlessness. Combination of trust and fear can create passiveness and be a possible obstacle to communicate and shared decision making.
CINAHL	Elizabeth M.M. Tutton "Patient participation on a ward for frail older people" <i>Journal of Advanced Nursing</i> , 2005, 50, 143-152.	2005	Hospitalized older adults 19 interviews with older adults/patients aged 60 were the majority were over 75 years. 3 FGD and 2 interviews with staff	Patient participation	Participation is a dynamic process that is integral to the work of nurses and carers. The process is enacted through the themes of facilitation, partnership, understanding the person, and emotional work	Patients and health care staff	Participation is not seen as a hierarchy but as a process that depended on the context of care giving. Partnership was an essential process in participation by identifying values and beliefs of the older adult and was also based on negotiation.
Pubmed	Julie P. W. Bynum, Laura Barre, Catherine Reed, Honor Passow, "Participation of very old adults in health care decisions" <i>Medical Decision Making</i> , 2014, 34, 216-230.	2014	Subjects from regions with high and low health care utilization. Subsidized housing, senior centers, and subsidize dellder day care. Semi structured interviews 29 older adults 80 - 93 years	Patient participation in health care decisions making in the clinical setting decision making	A decision episode was defined as Including a judgment about taking or not taking an action.	Patients and clinicians ie. doctors	Participation varied among the patients, they participate to some degree and have the potential to be active participants in decision making. There is a need of open communication about options which could facilitate patients participations in health care decisions
PubMed	Hanneke W. M. Van Laarhoven, Inge Henselmans, J. (Hanneke) C. De Haes "To treat or not to treat: who should decide?" <i>The Oncologist</i> , 2014, 19, 433-436.	2014	Outpatient clinic Case study One older adults MR C 79 years old	Shared decision making	The focus should be put on the steps taken for decision, not the amount of "sharedness"	A patient and a physicians doctor at an outpatient clinic for oncological treatment	Some older adults can find it difficult to cope with the burden of decision making. Health care personnel can have to take on the responsibility for decision. However, it is critical to explore older adults' values and adopt their perspective.

Table 2. (a) Subcategories and categories for the main theme: A two-way communication; (b) Subcategories and categories for the main theme: being on equal terms; (c) Subcategories and categories for the main theme: being in the right place and Being given time.

(a)

Subcategories	Categories	Main Theme
Receiving information		
To receive information		
Important to be informed		
Good communication		
Good communication between older adults and staff		
Wanting information about	To be informed about health status	
- illness		
- planned investigation		
Health care staff explains what is going on		
To make efforts to get information		
Participation is not a right		A two-way communication
Participation is an opportunity	Participation is indirect	
Participation is a process		
The hospital could make the decisions on behalf of the older adult		
To be given the chance to be heard		
Being Heard	To be heard	
The possibility to express thoughts and feeling about symptoms and illnesses		
To be able to influence examinations and treatment	To be able to influence	
To participate in medical decisions		
It is about negotiation	Negotiation	

(b)

Subcategories	Categories	Main theme
To be recognized as a unique and vulnerable human		
To be confirmed as a unique and vulnerable human		
Treated like a unique human being		
Being seen	To be treated as an individual	
Being cared about		
Treated with an open attitude		
Treated with a friendly attitude		
For staff to identify values and beliefs of the older adult		
Similar status		
Shared power		
Given space to the voice of the older adult		
Equal influence over agenda	Equality/shared power	
Co-decide on how practical problems are solved after discharge		
Not seen as a hierarchy		Being on equal terms
Patient activation		
Having control over:		
- what technology to use		
- who should have access		
- the conditions of care		
Being able to make decisions about treatment options (during clinical encounter)		
Shared decision with physician		
Not wishing to take an active part in medical decisions	To have a choice	
Being involved when relocating to a nursing home		
Not wanting to participate in decision making		
Having the choice of (other) health care alternatives		
Accepting or rejecting what was offered		
To take an active decision		
Non adherent or to do what you self-want		
Trusting the physician		
Build a trusting relationship		
Inviting the involvement of trusting others	Trusting relationship	
The relationship between the nurse and the older persons affect the older person's participation		
Respect the integrity of the older adult (by staff)		
Being respected (by personnel)	Being treated with respect	

(c)

Subcategories	Categories	Main theme
Caring environment more important than outcome Influenced by context Dependent on practice Dependent on health care organization Exploring the impact of the decision in the context of the patient's life	Environment- and context-dependent	Being in the right place
Staff take time and sit down Dependent on hospital pace Having enough time	To be given time	Being given time

3.1. A Two-Way Communication

According to the older adults, communication between the older adults and health care professionals was a central element in experiencing participation in care [21]-[25]. In discussing communication, they did not focus only on speaking with each other, although that was seen as important, but also on connection on several levels. The older adults talked about the ability and possibility to influence their care, meaning that they wanted to take an active part in the planning of different examinations and treatments and have a say in medical decisions concerning their care [22] [24]. Others wanted information but did not want to take an active part in medical decision making. They mean that the hospital could make the decisions on behalf of them because the hospital made the right decisions [22].

Being heard by health care professionals was a significant and self-evident factor of participation and differed from being listened to. According to the older adults, being heard was not seen as a requirement but they wished to be given the chance to be heard [22] [23], which represented good communication [22].

Participating in their own care was mentioned in terms of negotiating their way to participation [25]. Participation was experienced as something that lies under the surface of what is said and done. It was seen as something indirect and subtle, not as a right but as an opportunity that has to be taken to achieve participation [23] [25], where participation could change over time and become a dynamic process [25].

Opportunity for participating in their care was seen as something that was given by health care professionals and taken by the older adults. A direct and verbal communication between the older adults and health care professionals was perceived as a central factor in experiencing participation. For the older adult it was crucial to receive information about an illness and planned investigations and to have the possibility of expressing feelings about symptoms and illnesses [22] [26]. Some patients found it so crucial that they made their own efforts to get information [26] and others do even more struggling for shared decision-making [27]. According to the older adults, it was also important that the health care professionals explain what is going on [21] [22] regarding treatment [28], were they want to have a well-informed decision making [28].

3.2. Being on Equal Terms

Being on equal terms in decisions regarding health was something that emerged and thus seen as a salient dimension for experiencing participation in health care [21] [24] [25] [29]-[35]. To be treated with an open and friendly attitude, to be seen and cared about, as a unique and individual human being was perceived as valuable for participation [34] [35]. It was seen as important to be asked questions by health care professionals and that the health care staff identify values and beliefs of the older adult [25] [29] [36] where the voice of the older person needs to be given space [35].

Older woman wanted to participate in clinical decision making about their chemotherapy treatment. However, a majority wanted to share the decision with their clinician where his or her recommendation was important for their decision were they could accept or reject chemotherapy. Only 18.9 % made their own decision [26].

Being able to participate was described in terms of shared power between the older adult and the health care professionals. Sharing power meant similar status and equality in influencing the health care plan, both during hospitalization and when being discharged [24] [25] [30]. It meant being partners with shared responsibility in the decision-making process. Shared decision making was not described as about the amount of "sharedness" but as a stepwise process taken together [36], without hierarchy [25].

The older adults took an active role in own health; they asked questions about anything they wanted to know

and were also able to assert their own beliefs and values [26]. Others involved their family members when they made decisions regarding receiving chemotherapy [28]. Respecting the role that an older adult adopts to respond to her or him as an individual [36].

To have the possibility of choices and to be able to make them was a pressing issue for the older adults in experiencing participation [26] [29] [31] [32]. In situations such as if and when to relocate to a nursing home, having treatments during clinical encounter and if technology was to be used, the older adults wished to be involved in the decision making [29] [31] [32].

To be able to make the choice of not wanting to participate in decisions regarding health care was also a way of feeling involved [29] [36]. Experiences of participation could also be obtained by being respected by the health care professionals [21] and the professionals respecting the older adults' integrity [34].

Trust was a basic concept that concerned many people around the older adults, including physician, nurses and relatives. To trust your physician, to involve the ones you trust in the care agenda and to have a trusting relationship with nurses and/or nurses' aides were all key points in the pursuit of experiencing participation [21] [29] [33].

3.3. Being in the Right Place

According to the older adults, being in the right place, for example, on the right hospital ward when receiving care, generated experiences of being involved and resulted in feelings of participation. Participation is consequently dependent on context, environmental conditions and organization. Contributing factors for experiencing participation were dependent on practice and also health care organization [21].

External factors such as environment and context were of importance and also seen as a condition to experiencing participation [27]. Contextual factors concerned both external and internal factors that were derived from the older adult's own context. The older adults found it significant to explore how a decision could affect the context of the life of the older adult [33].

3.4. Being Given Enough Time

The older adults saw time as an important aspect and a contributing factor for experiencing participation [22] [24] [25].

Time was a pressing issue and the older adults emphasized it when they were addressing the concept of time. The presence of time was so important that the absence of it could enable feelings of alienations with the health care staff. The feeling of being involved or alienated could depend on the pace in the ward, according to the older adults [23]. The older adults also approached this issue by saying that the health care professionals needed to take the time and sit down with the older adults and talk [22]. The time allocated was also seen as important for participation, not meaning how much time the older adults should be given, but having enough time [21].

4. Discussion

4.1. Discussion of the Methodology

The aim of this review was to describe what constitutes participation in a health care setting from the perspective of the older adult, by looking at current research. We have achieved this even though one article was a review of models of participation.

The integrative approach proved the possibility of retrieving a comprehensive understanding of the concept of interest [19]. The review has contributed to a broader and more comprehensive understanding of the concept of participation in a health care setting. The authors sought to be systematic and rigorous, and the integrative review approach emphasized the importance of these two qualities [19].

With the methodology chosen, this review obtained findings that could be applicable for nurses working in health care settings when caring for older adults. To deepen the understanding of the concept and really frame it, a mixed method approach could have been applied. According to Whittemore and Knafl [19], using a mixed method technique provides the possibility of reducing errors and thus helping to deepen and capture the concept of interest [19]. One way to further deepen the concept and receive confirmation of the findings would be to conduct qualitative interviews with older adults in different health care settings. Whittemore and Knafl confirm that qualitative research also gives less room for errors and more room for confirmation of the findings [19].

The findings of this review were obtained because certain and only a few key search terms were used when conducting the search in the databases. There is a possibility that using more key search terms would have resulted in more suitable and relevant articles to frame the concept of interest. Several articles had to be excluded because the studies contained more age groups than those +65 years of age and it was impossible to distinguish statements from those +65 years of age.

This review reveals the importance of really focusing on the older adult and what is important for them in experiencing participation, putting aside age, sex and health status. Other articles and papers have clearly shown what is important for the older adult when it comes to participation and focused on the older adult and what they value [4] [15] but they have not really asked the older adults what it takes to experience participation.

4.2. Discussion of the Findings

According to the older adult in the current study, participation comprises a two-way communication, being on equal terms, finding the time and being in the right place. Health care professional should initiate communication, equality, giving enough time and to make sure that the older adult is in the right place for participation to take place, in order for the older adult to experience participation.

Through the eyes of the older adults communication should be initiated by the health care professional, as it was needed in order to perceive participation. The communication was about the information being given and about indirect communication, meaning the ability to influence one's care and to be given the possibility of being heard. This indicates that if the two-way communication does not work, feelings of participation will be lost and this may lead to a person being displeased with the health care. This was clearly confirmed in a study conducted in 1999, showing that information given in simple ways can provide satisfaction with care [37]. However it can also be perceived as power aspect and questions can arise of why the information should be provided in a simple way to grown up adults with long life experience. There may be a power structure at play, so-called ageism, where the staff sees the elderly as a group who are weak, not having knowledge and/or are frail [38] [39]. For example, it has been stated that older adults are not informed of health-care staff because the information can be seen as meaningless to frail older adults [38]. Further, this tells us how crucial it is that health care professionals give information to the older adults.

The importance of giving information because, as seen in this review, older adults do not see it just as being given information but as something that makes them feel involved in their care and thus satisfied with it. According to the older adults, it was also important that the health care professionals explain what was going on [21] [22].

Although the findings of this review suggest that communication is important in all contexts, it is of value to have the individual in mind, meaning that different levels of communication can be of different importance for older adults. This review presents the results from a group perspective, but it is still valuable to consider the older adult's subjective view in order to increase experiences of participation and thus satisfaction with care. Participants in a study conducted in Canada had various opinions about being part of decision making: some were comfortable with just being heard out and others wished to have a real influence [40]. However, it is not always enough to hear out (listen to) the older adults. Older adults can try to avoid conflicts by complying, which can be interpreted as the older adults not wanting to make decisions [26].

Equality and sharing power between older adults and health care staff in the health-care setting was perceived as a precondition for experiencing participation. "Respect," "integrity" and "similar status" were the terms used by the older adults when talking about feelings of participation [21] [34].

These terms revealed that the older adult wished to take part, be involved in the care, but it was the staff providing for the care that needed to involve the older adults and invite them to participate. This exposes the fact that just wanting to participate did not result in participation but there was a need for interaction to co-create participation. This is confirmed in research indicating that participation is about social interaction [41] and something that is determined by patients and health care professionals together through communication and shared decision making [42]. However, there is a question of whether it is enough to have shared decision making in all situations and contexts. The Swedish law state that the patient should have participation and that the power of the care should be shifted to the patient [7]. In addition, regardless if the patient is living in an ordinary housing or a nursing home, it is the older adults' home, and in your own home you want to decide for yourselves.

In this review, time was considered an essential issue, implying that older adults wished to have enough time from health care professionals in order to experience participation. Taking it a step further, time was also something that had to be given by health care professionals so the older adult could experience participation. It is important to mention that in-patients may have difficulties experiencing participation because of the hospital pace and of not having enough time with health care staff.

In one study, nurses working in hospitals needed strategies such as routinization and prioritizing to manage time [43]. Time is of the essence in a hospital ward, therefore it is preferable if the older adults are informed by health care personnel regarding the time aspect if it affects the care of the older adults. Giving information to the older adults may increase feelings of participation if the older adults know about the time aspect. According to the same study there is a reliance on patients in supporting nurses' effort to manage their time [43]. However, we mean this perspective can be harmful. Older adults can adapt to the staffs lack of time and give up their own participation and needs and by that the staff regain control over time which can result in an institutions-centered care instead of person-centered care [44].

In order to experience participation, older adults have to be in the right context and surrounded by the appropriate environment. As a result the emphasize is on the health care staff making older adults feel that they are in the correct place and thus contributing to the older adult's experience of participation. This means that if and how much a patient wishes to participate depends on the context and the patient's relationships with the health care professionals [40]. This is also confirmed by another study that emphasizes the importance of the relationship with the health care staff [45]. This can be tied together with the fact that being able to experience participation due to context is something that has to be provided by the health care staff.

Altogether, the main findings revealed that for older adults to be able to experience participation, factors like communication, equality, being given enough time and being in the right place were in order. But more important, the older adult revealed that for them to experience participation the health care professionals are the key and thus can make it happen by initiating the factors above. One way to initiating it is trough person-centered care. An approach means that it is the older adults' perspective that is prevailing in the performance of care and the decision making process not the organization's procedures or the professional's routines [46]. It's a part of the profession to create a relationship so that the older adults' perspective can be adopted [47]. Further there is a need of engagement and commitment in the relationship, it is namely in the interpersonal relationship that health care professionals become aware of the older adults beliefs and values [47]. These beliefs and values will become controlling for participation. The right to participate is also stated by the law and the guidelines for health care in Sweden. Experiencing participation when receiving care will lead to increased quality of care and in turn help the older adult attain optimal functionality [48]. In this integrative review it came out that it was important for the older adult to feel important enough to be given time, to be asked questions, to be seen as an equal, to be informed and to be in the right environment. The perception of being important can lead to experiences of subjective health and in turn experiences of optimal functionality. The older adults emphasized the importance of being seen as a human being, building trusting relationships with health care professionals, indicating that the older adults wished for quality in the encounter with health care. One way to receive quality may be through the experience of participation since it includes factors for experiences of quality in care.

5. Conclusions

According to the older adults in this study, to feel participation the need or wish to participate is not enough; the health care professionals need to initiate and invite the older adult into a relationship, on equal terms where participation is created. It should create a two-way communication, give the older adult enough time and take the responsibility to make the older adults feel that they are in the right place. Thus, a person-centered nursing approach is relevant for the health care professional in order to both give and maintain the experience of participation for the older adult. By that, the health care professional can understand participation through the older adults' eyes (see [Figure 2](#)),

The elements which are shown in [Figure 2](#) show a future and clinical implication and a tangible and concrete concept that might be used as a framework in nursing care.

Contributions

Study design: SA, IJ, AK; data collection: SA; data analysis: SA, IJ, AK and manuscript preparation: SA, IJ, AK.

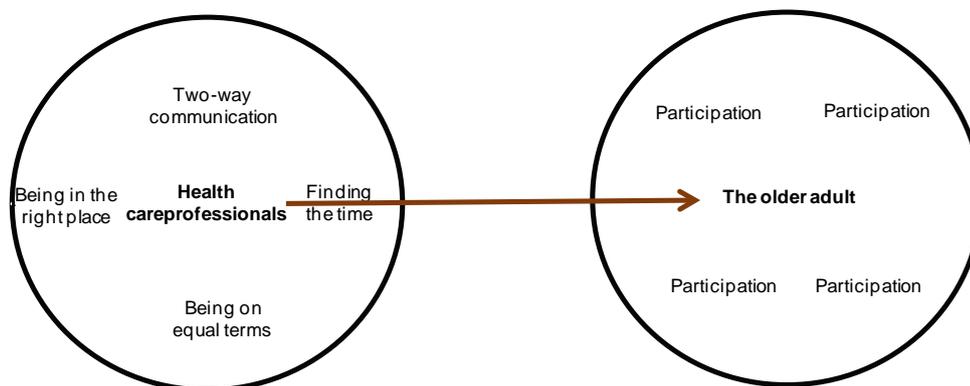


Figure 2. The important elements that the health care professional need to see and understand participation through the older adult's eyes.

Conflict of Interest

No conflict of interest has been declared by the authors.

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