

Original Article

Participation in Primary Healthcare – using a Finnish version of the Patient Participation in Rehabilitation Questionnaire

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Abstract

Background: Patient participation is a highly valued goal within healthcare. Thus, there are needs for greater insight into optimal ways to implement participation in specific contexts, and more knowledge of patients' experiences and preferences regarding participation.

Aim: To unveil healthcare clients' perceptions of the importance, and their experience, of participation in care within the domains of respect and integrity; planning and decision-making; information and knowledge; motivation and encouragement; and involvement of family.

Methods: This study used the Finnish version of the Swedish Participation in Rehabilitation Questionnaire. A cross-sectional design was employed, which involved piloting above-mentioned questionnaire, with a sample of adult patients in eight primary health care units in Finland (n=88). The data were analyzed using descriptive statistical methods and Mann-Whitney U and Kruskal-Wallis tests, the importance and experience ratings separately.

Results: Respondents considered participation to be very important. For experience ratings the mean total was 3.46 on a scale where 3 indicated "sometimes" and 4 indicated "often." The best achieved domain was respect and integrity (mean 3.83), while involvement of family was assessed as the weakest (mean 2.81). At the item level, for each claim, some of the respondents felt that the case in question took place always or often while some found it rarely realized if ever. However, there was a rather large variation in those proportions between the various claims. Statistically significant differences were verified in the perceptions of participation related to clients' demographics. For importance ratings, they were found between the type of healthcare units where the client received care, gender, and age and for experience ratings between educational levels.

Conclusion: The findings indicate that clients find participation highly important, but their experience of implementing it varied. A further research challenge is examining the client experiences of participation in different healthcare contexts.

Keywords: instrument, patient participation, perceptions, primary healthcare, questionnaire, quantitative research

Introduction

Patient participation is a highly valued goal in healthcare. It is based on ethical principles, such as justice, dignity, integrity, and autonomy, and a key justification for participation is the right to influence matters that concern one's own life and receive services and care that correspond to one's needs and values (World Health Organization [WHO], 1994, 2008). Several Western countries have passed legislation to that effect. This is also the case in Finland.

Patient participation is a broad and multidimensional concept. While numerous close and parallel concepts and definitions are used, some common attributes have been reported—established collaborative relationships between the patient and professionals, and exchanges of information, knowledge, and power—which are requirements for mutual engagement in diverse activities within care (Sahlsten et al., 2008; Castro et al., 2016; Kvæl et al., 2018).

In healthcare encounters, personnel play a pivotal role in ensuring reciprocal participation. In previous studies, patients mentioned respect and equality as a necessary precondition for participation and emphasized the importance of accessing adequate information and knowledge and being listened to. Further, it is important to be recognized as a unique individual, based on one's opinions, life situation, and experience-based knowledge (Thórarinsdóttir & Kristjánsson, 2014). Patients have experienced personnel occasionally behaving in ways that limited their participation, such as demonstrating a lack of empathy or a paternalistic attitude (Tobiano et al., 2016), not taking the patient seriously or not considering their views, or not having enough time for them. Then, based on the attitudes and behaviors of personnel, the patient may perform a passive role or engage in active participation (Larsson et al., 2011a). Thus, the organizational practices and culture must enable patient participation (Castro et al., 2016).

Patients' willingness and ability to participate are different. Characteristics that may be related to patient participation are personality, health status, age (Höglund et al., 2010; Tambuyzer, Pieters, & Van Audenhove, 2014), education, and previous healthcare experiences (Kolovos et al., 2016). Preferences and capabilities may also vary over time and situations. For example, some patients may value discussion about care options, but not want to take an active role in medical

decision-making. The patient's choices must be respected, but it should be verified that these choices are not due to lack of skills. (Xie et al., 2012.) Patients' reported experiences indicate that perceived inability to participate in a specific situation may be due to feeling a lack of capacity, like absence of knowledge or self-confidence (Larsson et al., 2011b; Nordin, Gard, & Fjellman-Wiklund, 2013). Opportunities for participation need to be individualized and flexible.

Patient participation is valuable because it affects the patients and the results of care positively. Studies have established that the experience of participation has an empowering and therapeutic role (Tambuyzer et al., 2014), and it enhances the sense of security and control in care, commitment to treatment (Höglund et al., 2010), satisfaction and motivation (Sahlsten et al., 2008), patient-physician communication (Cegala, 2011), recall of treatment recommendations (Richard, Glaser, & Lussier, 2017), ability to engage in self-management activities (Luhr et al., 2017), and management of chronic illness (Longtin et al., 2010). In contrast, low participation in care has been found to strengthen feelings of powerlessness (Sheridan et al., 2013). From the perspective of the health system, participation is justified by the need to produce high-quality, effective services that correspond to customers' needs and preferences (Tambuyzer et al., 2014). Moreover, reportedly, higher levels of participation can improve patients' perceptions of the quality of care they receive and contribute to reductions in medical errors and adverse events (Weingart et al., 2011; Osborn & Squires, 2012), and thereby increase patient safety (Longtin et al., 2010).

In summary, patient participation plays a key role in healthcare, and there is a demand for more participation. Despite a few decades of research, there is still ambiguity regarding the process and circumstances of this multifaceted concept (Castro et al., 2016), and a lack of quantitative data (Tambuyzer et al., 2014). Thus, there is a need for insight into how it is implemented in different contexts and what patients' experiences of, and preferences for, it are. In this study, participation was described from the perspective of primary healthcare clients. Primary healthcare is the basis for the health system and worthy of development, particularly for promoting health, management of chronic disorders, and self-care. WHO (2008)

has emphasized patient participation in primary healthcare.

Study aim

The aim of this study was to unveil healthcare clients' perceptions of the importance, and their experience, of participation in care using the Finnish version of the Participation in Rehabilitation Questionnaire (FI-PPRQ). The study was also intended to explore possible differences in the perceptions related to clients' basic demographic characteristics (age, gender, marital status, education level, current healthcare unit, and number of healthcare appointment services visits in the preceding year).

Methods

Study design

A quantitative cross-sectional design was used with self-report questionnaires to collect data from primary healthcare clients.

Setting and participants

The study was carried out in a Finnish primary healthcare setting with frequent users of healthcare services, including inpatients undergoing rehabilitation and outpatients frequently attending appointment services. Participants were recruited from six appointment services units and two rehabilitation wards (one offering neurological testing and rehabilitation and the other orthopedic postoperative rehabilitation) in one municipality. All clients in rehabilitation wards, who had been cared for and discharged at the time of data collection, were eligible for participation. For appointment services clients, the selection criteria were multiple uses of the provided services (with no strict definition of the numbers or kinds of services used) and poor therapeutic equilibrium (which may be related to life-management or psycho-social difficulties). Clients under 18 years of age or unable to complete a questionnaire, due to language or cognitive barriers (according to professionals working with the clients and familiar with this study), were excluded.

Data collection procedure

Data were collected between June and October 2016. Prior to this, the researchers held briefings and provided written instructions. Personnel in the relevant units asked clients if they were willing to participate and, if so, they distributed

the questionnaire during appointments (appointment services) or at the end of their care period (rehabilitation wards). In total, 300 questionnaires were provided for distribution along with return envelopes and detailed written information. Participants were asked to return the completed questionnaires by putting them in closed envelopes and posting these in sealed boxes located in the units. Completion of this procedure was considered to imply informed consent to participate in the study.

Instrument

Permission to use the Finnish version of PPRQ was obtained from the developers of the original instrument: Lindberg, J., Kreuter, M., Person, L-O., & Taft, C. (2013). Patient participation in rehabilitation questionnaire (PPRQ) – development and psychometric evaluation. *Spinal Cord*, 51, 838–842.

The original PPRQ was developed in Sweden for patients with spinal cord injury to measure their perceptions of participation in care and rehabilitation (Lindberg et al., 2013a, 2013b). This self-report instrument comprises 23 items covering five scales: respect and integrity; planning and decision-making; information and knowledge; motivation and encouragement; and involvement of family. Both the importance and experience of participation are determined. Respondents rate each item in terms of perceived importance and how frequently they experienced it during their care. They assess their care as a whole, regardless of its duration, and refer to all personnel involved in their care during that period (inter alia, doctors, nurses, and physiotherapists). Each item is assessed on a 5-point Likert scale; the ratings for "importance" are extremely important (= 5), very important (= 4), important (= 3), slightly important (= 2), and not at all important (= 1), while the ratings for "experience" are always (= 5), often (= 4), sometimes (= 3), seldom (= 2), and never (= 1) (Lindberg et al., 2013b).

The Swedish PPRQ was translated into Finnish by two professional translators using forward and backward translation. They produced a draft Finnish version of the questionnaire. Then a bilingual native of Finland, who had worked as a physiotherapist in Sweden for decades, produced a second translation of the original questionnaire. Final revisions of the Finnish version were then completed by the study group. One item from the

“respect and integrity” scale in the original PPRQ (*Personnel should leave the patient alone when he/she so desires*) was deleted because it was considered inappropriate for the appointment services clients. The modified FI-PPRQ, thus, comprised 22 items associated with the five Likert scales from the original version. Data on demographic characteristics were also collected.

The overall Cronbach’s alpha coefficients (considering all 22 items) were 0.94 for importance ratings and 0.95 for experience ratings. Cronbach’s alpha coefficients for all scales also exceeded the reliability threshold of 0.7 (DeVon et al., 2007), ranging between 0.76 and 0.89 for importance ratings and between 0.84 and 0.92 for experience ratings. These results are consistent with findings from previous studies (Lindberg et al., 2013b, 2014) being for importance ratings from 0.78 to 0.88 and 0.72 to 0.88 and for experience ratings from 0.89 to 0.91 and 0.89 to 0.95, respectively.

Data analysis

Statistical methods were used to evaluate the properties of the FI-PPRQ using the statistical software package SPSS 23 for Windows. The importance and experience ratings were evaluated separately. The mean sum variables were calculated for each respondent as averages of valid values. However, to maintain validity, no value was entered if the respondent answered fewer than half of the items on the scale.

The data obtained from the questionnaires were also reclassified for analysis. On the basis of the respondents’ highest educational level, the sample was divided into three classes: primary, secondary, and tertiary levels of education (the latest including university, university of applied sciences, and post-secondary qualifications). Data assessed on a 5-point Likert scale were also reclassified for some analyses into three categories (extremely or very important, important, slightly or not at all important; always or often, sometimes, seldom or never). Since the sample data were quite small and the distributions of some of data did not meet the normality criteria for parametric tests (according to the Kolmogorov–Smirnov test and visual inspection of the data), nonparametric tests were used (Grove, Burns, & Gray, 2013).

Descriptive statistics were used to characterize the sample as a whole, describing demographic characteristics and defining the measured or

calculated variables (distributions of item and scale scores, frequencies and percentage distributions, means, standard deviations, medians, ranges, missing values, and frequencies of ceiling and floor responses). Mann–Whitney U and Kruskal–Wallis tests were used to determine whether significant differences existed between the groups based on demographics and perceptions of participation within the domains. The level for statistical significance was set to $p < .05$ (Grove, Burns, & Gray, 2013).

Ethical considerations

This study followed the ethical standards outlined in the Declaration of Helsinki (World Medical Association, 2013) and responsible research practice (Finnish National Board on Research Integrity [TENK], 2012). Permission to use the Finnish version of the PPRQ was obtained from the developer of the original instrument. Prior to data collection, the study was approved by the hospital’s Institutional Review Board (2760/2016). All eligible participants were given detailed written information including the purpose and objectives of the study; assurance with regard to anonymity, confidentiality, and the voluntary nature of participation; and the principal researcher’s contact information. Completing and returning the anonymous questionnaire was considered to imply informed consent for participation in the study. Due to the anonymity of responses, no ethical approval was necessary.

Results

Baseline characteristics of study participants

The data included 88 responses. More than half of the respondents (59%) had been treated in the rehabilitation ward and 41% in appointment services. Their ages ranged from 24 to 90 years, with a mean of 69 years (SD 15.9). Almost equal numbers of respondents were women (52%) and men (48%). Table 1 summarizes the basic demographic characteristics of the sample.

Perceptions of the importance of participation

Respondents considered participation to be very important. The mean total was 4.07 (SD 0.63). Almost two thirds of respondents assessed participation as very important to extremely important ($4 \leq M \leq 5$) and one third assessed it as important ($3 \leq M < 4$), while the remaining approximately 7% assessed participation as slightly important ($2.43 \leq M < 3$).

Table 1. Basic demographic characteristics of participants (n, %)

Demographic variable (N = 88)	n	%
Healthcare unit		
Hospital services (Rehabilitation ward)	52	59.0
Appointment services	36	41.0
Age		
≤ 49 years	12	13.6
50–64 years	13	14.8
65–79 years	36	40.9
≥ 80 years	22	25.0
Missing data	5	5.7
Gender		
Women	46	52.3
Men	42	47.7
Education level		
Basic education	29	33.0
High school/Vocational level	27	30.7
Post-secondary education/University of applied sciences	24	27.3
University	4	4.5
Other	3	3.4
Missing data	1	1.1
Marital status		
Widowed	24	27.3
Single	22	25.0
Married	22	25.0
Divorced, separated	19	21.6
Other	1	1.1
Number of healthcare appointment services visits in the past year		
Five or more	44	50.0
1–4 visits	40	45.5
None	4	4.5

Information and knowledge was considered the most important domain ($M = 4.33$), while involvement of family was the least important domain ($M = 3.91$) (Table 2). At the item level, for each claim, most respondents considered them extremely or very important (Table 3).

Perceptions of the experience of participation

The mean for experience ratings was 3.46 (SD 0.78) on a scale where 3 indicated “sometimes” and 4 indicated “often.” For one fourth of respondents, the mean total was 4 or higher; correspondingly, one third of respondents felt that participation had been realized as a whole not more than sometimes ($M \leq 3$). The range of means was wide, from 1.45 to 5.

Respondents perceived respect and integrity as the best-realized domain ($M = 3.83$; SD 0.85). Furthermore, respectful treatment of the patient (77.7%) and respect for the patient’s private matters (73.8%) were always or often realized by their experience. However, 18.4% of respondents

experienced that personnel seldom or never treated the patient as a unique individual (Table 5).

Information and knowledge was deemed to be the second-best-realized domain ($M = 3.68$; SD 0.68). The best achieved issues were that personnel always or often provided the patient information in a way that he/she could understand (68.6%) and ensured that the patient received adequate information and knowledge to be able to participate in the planning of his/her care (63.5%). In turn, 16.3% of respondents experienced that personnel seldom or never took the time to answer the patient’s questions (Table 5).

For the domain of planning and decision-making ($M = 3.45$; SD 0.91), respondents stated that personnel always or often tried to learn the patient’s expectations of his/her care (65.1%). Half of the respondents also perceived that personnel always or often took into account the patient’s suggestions regarding care (51.5%) and

knew if the patient had any special problems that limited good care and rehabilitation (50.6%). Yet, regarding these same claims, one fifth felt that they only rarely happened if ever (Table 5).

Regarding the domain of motivation and encouragement (M 3.37; SD 0.87), the best-achieved issues were that personnel gave the patient hope (53.5%) and encouraged the patient to try new things, even when the patient was hesitant (52.4%). However, about a quarter of the respondents perceived that personnel rarely or never helped the patient set goals for different skills in his/her care (23.3%) or proposed that it was time for the patient to try something new (23.8%) (Table 5).

The family involvement was seen as the poorest domain (M 2.81; SD 1.31). The best-achieved issue was that the patient's relatives were given the opportunity to take part in care planning as the patient so wished, which was felt as having been realized always or often by 38% of respondents. Correspondingly, 46.8% of respondents felt the same thing was done only rarely or never (Table 5).

Perceptions of participation and related factors

For importance ratings, statistically significant connections were found with the type of healthcare unit where the client received care,

gender, and age. The type of healthcare unit had significant differences in respect and integrity (M-WU 1075.5, p .002) and planning and decision-making (M-WU 1157.0, p .023). Clients in appointment services assessed these domains as more important than did those in hospital services. Gender showed significant differences in the experience of respect and integrity (M-WU 690.5, p .045) and involvement of family (M-WU 562.5, p .006); females evaluated these domains as being more important than males did. Age showed significant differences in respect and integrity (K-W 9.731, p .021), planning and decision-making (K-W 14.506, p .002), and involvement of family (K-W 9.022, p .029). Younger clients were more likely than older clients to consider these areas as important (Table 6).

For experience ratings, there were also differences between means according to demographics. However, the only statistically significant difference was verified between educational levels in relation to respect and integrity (K-W 8.631, p .013). Clients with tertiary education perceived that respect and integrity had been realized more often in their care (M 4.1) as compared to primary graduates (M 3.8) and secondary graduates (M 3.5). All groups' means with standard deviations, medians, and p -values are shown in Table 7.

Table 2. Summary of results of FI-PPRQ scales for importance ratings (Mean, SD, Median, % at ceiling and floor)

Domain of participation (Scale of FI-PPRQ)	Number of items	n [†]	Mean (SD)	Observed range mean	Median	% at ceiling	% at floor
Information and knowledge	4	85	4.33 (0.58)	2.75–5	4.50	23.5	0
Respect and integrity	5	86	4.11 (0.77)	2–5	4.20	23.3	0
Planning and decision-making	4	86	4.05 (0.69)	1.5–5	4.25	10.5	0
Motivation and encouragement	5	87	4.05 (0.68)	2.25–5	4.00	13.8	0
Involvement of family	4	83	3.91 (0.89)	1.24–5	4.00	19.3	0

Likert scale: 5 = extremely important, 4 = very important, 3 = important, 2 = slightly important, 1 = not at all important. Theoretical range mean 1–5. † If the respondent answered fewer than half of the items on this scale, no value was entered; it was considered a missing value.

Table 3. Perceptions of importance of participation at the item level (n, %)

Domain of participation Item	n	extremely or very important %	important %	slightly or not at all important %
Respect and integrity				
Personnel should respect the patient's private/personal matters	86	82.5	14.0	3.5
Personnel should treat the patient with respect	86	80.2	14.0	5.8
Personnel should respect patient's wishes/desires in all contexts	85	80	12.9	7.1
Personnel should treat each patient as a unique individual	86	72.1	17.4	10.5
Personnel should respect the patient's personality and way of being	86	67.3	25.6	7.1
Planning and decision-making				
Personnel should know if the patient has any special obstacles/problems that limit good care and rehabilitation	86	80.2	15.1	4.7
Personnel should take into account the patient's suggestions regarding care	84	76.1	16.7	7.2
Personnel should try to learn what capabilities the patient believes he/she has for care	84	73.8	23.8	2.4
Personnel should try to learn what expectations the patient has about his/her care	86	69.8	26.7	3.5
Information and knowledge				
Personnel should take time to give the patient answers to the questions he/she had	84	92.8	6.0	1.2
Personnel should provide the patient information in a way that he/she can understand	86	89.5	10.5	0
Personnel should ensure that the patient receives adequate information and knowledge to be able to participate in the planning of his/her care	85	81.2	17.6	1.2
The patient should be informed at the "right" time for him/her by the personnel	85	80	14.1	5.9
Motivation and encouragement				
Personnel should give the patient hope	85	85.9	12.9	1.2
Personnel should encourage the patient to try/learn new things even when the patient is hesitant or reluctant	84	76.2	16.7	7.1
Personnel should motivate the patient	85	75.3	21.2	3.5
Personnel should be able to propose to the patient when it is time to try something new in care, based on their clinical experience	85	74.1	21.2	4.7
Personnel should help the patient to set realistic goals for different skills	86	64	30.2	5.8
Involvement of family				
Relatives should be given the opportunity to take part in care planning, if the patient so wishes	85	69.9	21.7	8.4
Relatives should be given the opportunity to take part in planning meetings if the patient so wishes	81	69.1	17.3	13.6
Relatives should be given the opportunity to take part in special meetings for relatives if the patient so wishes	82	67.0	23.2	9.8
The patient should be asked if he/she wishes to have a relative participate in care planning	85	64.7	22.4	12.9

Table 4. Summary of results of FI-PPRQ scales for experience ratings (Mean, SD, Median, % at ceiling and floor)

Domain of participation (Scale of FI-PPRQ)	Number of items	n [†]	Mean (SD)	Observed range mean	Median	% at ceiling	% at floor
Respect and integrity	5	86	3.83 (0.85)	1–5	4.00	8.1	1.2
Information and knowledge	4	86	3.68 (0.86)	1–5	3.75	8.1	1.2
Planning and decision- making	4	85	3.45 (0.91)	1–5	3.50	7.1	1.2
Motivation and encouragement	5	88	3.37 (0.87)	1.4–5	3.40	4.5	0
Involvement of family	4	80	2.81 (1.31)	1–5	2.50	8.8	16.3

Likert scale: 5 = always, 4 = often, 3 = sometimes, 2 = seldom, 1 = never Theoretical range mean 1–5

† If the respondent answered fewer than half of the items on this scale, no value was entered; it was considered a missing value

Table 5. Experience of participation at the item level (n, %)

Domain of participation Item	n	Always or often %	Some- times %	Seldom or never %
Respect and integrity				
Personnel should treat the patient with respect	85	77.7	12.9	9.4
Personnel should respect the patient's private/personal matters	84	73.8	15.5	10.7
Personnel should respect the patient's personality and way of being	86	70.9	16.3	12.8
Personnel should respect patient's wishes/desires in all contexts	86	65.1	25.6	9.3
Personnel should treat each patient as a unique individual	87	63.2	18.4	18.4
Information and knowledge				
Personnel should provide the patient information in a way that he/she can understand	86	68.6	20.9	10.5
Personnel should ensure that the patient receives adequate information and knowledge to be able to participate in the planning of his/her care	85	63.5	22.4	14.1
Personnel should take time to give the patient answers to the questions he/she had	86	58.1	25.6	16.3
The patient should be informed at the "right" time for him/her by the personnel	85	57.7	29.4	12.9
Planning and decision-making				
Personnel should try to learn what expectations the patient has for his/her care	86	65.1	19.8	15.1
Personnel should take into account the patient's suggestions regarding care	84	51.2	28.6	20.2
Personnel should know if the patient has any special obstacles/problems that limit good care and rehabilitation	87	50.6	28.7	20.7
Personnel should try to learn what capabilities the patient believes he/she has for care	84	48.8	35.7	15.5
Motivation and encouragement				
Personnel should give the patient hope	84	53.5	29.8	16.7
Personnel should encourage the patient to try/learn new things even when the patient is hesitant or reluctant	86	52.4	30.2	17.4
Personnel should help the patient set realistic goals for different skills	86	50	26.7	23.3
Personnel should motivate the patient	87	46	34.5	19.5
Personnel should be able to propose to the patient when it is time to try something new in care based on their clinical experience	84	39.3	36.9	23.8
Involvement of family				
Relatives should be given the opportunity to take part in care planning, if the patient so wishes	79	38	15.2	46.8
The patient should be asked if he/she wishes to have a relative participate in care planning	85	37.6	23.5	38.9
Relatives should be given the opportunity to take part in planning meetings if the patient so wishes	88	36.4	16.9	46.7
Relatives should be given the opportunity to take part in special meetings for relatives if the patient so wishes	80	36.3	20	43.7

Table 6. Background variable groups' means and Mann–Whitney U or Kruskal–Wallis test for domains of participation for importance ratings (M, SD, Mdn, p)

Demographic variable	Domain of participation (Scale of FI-PPRQ)				
	Respect and integrity Mean total = 4.11	Planning and decision-making Mean total = 4.05	Information and knowledge Mean total = 4.33	Motivation and encouragement Mean total = 4.05	Involvement of family Mean total = 3.91
	Mean (SD) Median <i>p-value</i>	Mean (SD) Median <i>p-value</i>	Mean (SD) Median <i>p-value</i>	Mean (SD) Median <i>p-value</i>	Mean (SD) Median <i>p-value</i>
Healthcare unit					
Hospital services	3.9 (0.8) 4.0 4.4 (0.6) 4.4	3.9 (0.8) 3.9 4.3 (0.5) 4.5	4.2 (0.6) 4.3 4.5 (0.5) 4.5	4.0 (0.7) 4.0 4.2 (0.6) 4.2	4.0 (0.9) 4.0 4.1 (0.9) 4.4
Appointment services	<i>0.002</i> * <i>M-W U</i> † 1075.5	<i>0.023</i> * <i>M-W U</i> 1157.0	<i>0.09</i>	<i>0.239</i>	<i>0.193</i>
Gender					
Women	4.3 (0.7) 4.4	4.1 (0.7) 4.3	4.4 (0.5) 4.5	4.1 (0.6) 4.0	4.2 (0.8) 4.3
Men	4.0 (0.8) 4.0 <i>0.045</i> * <i>M-W U</i> 690.5	4.0 (0.7) 4.1 <i>0.536</i>	4.2 (0.6) 4.3 <i>0.165</i>	3.9 (0.7) 4.0 <i>0.224</i>	3.7 (0.9) 3.5 <i>0.006</i> * <i>M-W U</i> 562.5
Age					
≤ 49 years	4.5 (0.6) 4.9	4.5 (0.4) 4.6	4.5 (0.5) 4.8	4.2 (0.8) 4.3	4.4 (0.8) 4.5
50–64 years	4.5 (0.4) 4.6	4.4 (0.5) 4.5	4.6 (0.5) 4.8	4.3 (0.6) 4.2	4.3 (0.6) 4.5
65–79 years	3.9 (0.8) 4.0	3.9 (0.6) 3.8	4.2 (0.6) 4.5	3.9 (0.6) 4.0	3.9 (0.8) 4.0
≥ 80 years	4.0 (0.8) 4.0 <i>0.021</i> * <i>K-W</i> ‡ 9.731	3.8 (0.8) 3.9 <i>0.002</i> * <i>K-W</i> 14.506	4.3 (0.6) 4.1 <i>0.060</i>	3.9 (0.7) 4.0 <i>0.190</i>	4.0 (0.7) 3.5 <i>0.029</i> * <i>K-W</i> 9.022
Education level					
Primary	4.0 (0.7) 4.0	4.0 (0.7) 4.0	4.2 (0.6) 4.4	4.0 (0.7) 3.9	3.8 (1.0) 3.8
Secondary	4.1 (0.7) 4.2	3.9 (0.8) 3.8	4.3 (0.6) 4.3	4.0 (0.6) 4.0	3.8 (0.9) 4.0
Tertiary	4.2 (0.9) 4.4 <i>0.419</i>	4.2 (0.6) 4.3 <i>0.478</i>	4.3 (0.5) 4.5 <i>0.658</i>	4.2 (0.7) 4.2 <i>0.283</i>	4.2 (0.8) 4.3 <i>0.171</i>
Marital status					
Single	4.3 (0.8) 4.3	4.3 (0.6) 4.5	4.5 (0.4) 4.5	4.1 (0.8) 4.2	4.2 (0.7) 4.3
Married	4.2 (0.7) 4.2	3.9 (0.6) 4.0	4.2 (0.6) 4.0	4.1 (0.6) 4.2	3.8 (0.9) 3.8
Divorced, separated	4.1 (0.8) 4.2 3.9 (0.8) 4.0	4.2 (0.6) 4.4 3.8 (0.8) 3.8	4.5 (0.5) 4.8 4.2 (0.7) 4.4	4.0 (0.8) 4.0 4.0 (0.6) 3.9	3.9 (0.8) 4.0 3.7 (1.0) 3.8
Widowed	4.6	4.8	4.3	4.2	4.2
Other	<i>0.604</i>	<i>0.249</i>	<i>0.430</i>	<i>0.762</i>	<i>0.522</i>
Appointment visits[§]					
Five or more	4.7 (0.6) 5.0 3.9 (0.9) 4.0	4.3 (0.7) 4.6 3.9 (0.8) 3.9	4.4 (0.8) 4.6 4.3 (0.5) 4.3	4.7 (0.6) 4.9 4.0 (0.7) 4.0	4.4 (0.7) 4.6 3.8 (1.0) 4.0
1–4 visits	4.2 (0.6) 4.4	4.2 (0.6) 4.3	4.4 (0.6) 4.5	4.0 (0.6) 4.0	4.0 (0.8) 4.0
None	<i>0.064</i>	<i>0.108</i>	<i>0.418</i>	<i>0.193</i>	<i>0.441</i>

Likert scale: 5 = extremely important, 4 = very important, 3 = important, 2 = slightly important, 1 = not at all important † The Mann–Whitney U test (M-W U) is used when comparing two groups

‡ The Kruskal–Wallis test (K-W) is used when comparing more than two groups

§ Number of healthcare appointment services visits in the past year * Significant at $p < 0.05$

SD = standard deviation

Table 7. Background variable groups' means and Mann–Whitney U or Kruskal–Wallis test for domains of participations for experience ratings (M, SD, Mdn, p)

Demographic variable	Domain of participation (Scale of FI-PPRQ)									
	Respect and integrity		Planning and decision-making		Information and knowledge		Motivation and encouragement		Involvement of family	
	Mean total = 3.83		Mean total = 3.45		Mean total = 3.68		Mean total = 3.37		Mean total = 2.81	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Median	<i>p-value</i>	Median	<i>p-value</i>	Median	<i>p-value</i>	Median	<i>p-value</i>	Median	<i>p-value</i>	
Healthcare unit										
Hospital services	3.7 (1.0)	4.0	3.3 (1.0)	3.4	3.6 (1.0)	3.8	3.4 (0.8)	3.4	2.9 (1.3)	3.0
Appointment Services	4.0 (0.6)	4.0	3.6 (0.8)	3.8	3.8 (0.7)	4.0	3.3 (0.9)	3.4	2.8 (1.3)	2.5
	<i>0.287</i>		<i>0.135</i>		<i>0.249</i>		<i>0.956</i>		<i>0.765</i>	
Gender										
Women	3.9 (0.9)	4.0	3.3 (1.0)	3.6	3.8 (0.9)	4.0	3.4 (0.9)	3.5	2.9 (1.3)	2.6
Men	3.8 (0.9)	4.0	3.5 (0.8)	3.5	3.5 (0.8)	3.5	3.4 (0.8)	3.3	2.7 (1.3)	2.5
	<i>0.842</i>		<i>0.661</i>		<i>0.096</i>		<i>0.789</i>		<i>0.605</i>	
Age										
≤ 49 years	3.3 (0.9)	3.2	3.3 (1.0)	3.3	3.5 (0.9)	3.4	3.2 (1.0)	3.3	3.1 (1.2)	3.4
50–64 years	4.0 (0.7)	4.0	3.6 (0.8)	3.5	3.7 (0.7)	3.8	3.6 (0.8)	3.3	3.1 (1.2)	3.0
65–79 years	3.9 (0.8)	4.0	3.6 (0.7)	3.8	3.8 (0.8)	4.0	3.2 (0.8)	3.4	2.8 (1.3)	2.8
≥ 80 years	3.9 (1.0)	4.2	3.1 (1.0)	3.0	3.6 (1.0)	3.6	3.4 (0.9)	3.4	2.4 (1.4)	2.0
	<i>0.139</i>		<i>0.207</i>		<i>0.777</i>		<i>0.762</i>		<i>0.473</i>	
Education level										
Primary	3.8 (0.9)	4.0	3.5 (1.0)	3.3	3.7 (1.0)	3.7	3.5 (0.8)	3.5	2.8 (1.5)	2.3
Secondary	3.5 (0.9)	3.6	3.1 (0.9)	3.0	3.4 (0.8)	3.5	3.2 (0.8)	3.2	2.6 (1.0)	2.5
Tertiary	4.1 (0.7)	4.2	3.7 (0.7)	3.8	3.9 (0.7)	4.3	3.4 (1.0)	3.6	3.0 (1.4)	3.0
	<i>0.013 *</i>		<i>0.117</i>		<i>0.055</i>		<i>0.297</i>		<i>0.527</i>	
	K-W 8.631									
Marital status										
Single	3.8 (0.9)	3.8	3.4 (1.0)	3.0	3.8 (0.8)	3.9	3.3 (1.0)	3.2	3.2 (1.4)	3.5
Married	4.1 (0.6)	4.1	3.5 (0.8)	3.8	3.7 (0.6)	3.9	3.6 (0.8)	3.9	2.8 (1.1)	2.5
Divorced, separated	3.8 (0.8)	4.0	3.7 (0.8)	3.9	3.7 (1.1)	4.0	3.3 (0.8)	3.2	3.1 (1.0)	3.0
Widowed	3.6 (1.0)	4.0	3.2 (1.0)	3.3	3.5 (1.1)	3.8	3.3 (0.8)	3.2	2.2 (1.4)	1.8
Other	3.4		3.4		3.7		3.8		3.3	
	<i>0.521</i>		<i>0.480</i>		<i>0.975</i>		<i>0.366</i>		<i>0.119</i>	
Appointment visits[§]										
Five or more	4.7 (0.3)	4.7	3.0 (1.8)	2.5	4.1 (0.7)	4.0	4.1 (0.6)	3.9	3.5 (1.2)	3.5
1–4 visits	3.7 (0.9)	4.0	3.4 (1.0)	3.5	3.6 (0.9)	3.8	3.4 (0.8)	3.5	2.8 (1.3)	2.5
None	3.9 (0.9)	4.0	3.5 (0.8)	3.8	3.7 (0.8)	3.8	3.3 (0.9)	3.2	2.8 (1.3)	2.5
	<i>0.058</i>		<i>0.723</i>		<i>0.640</i>		<i>0.167</i>		<i>0.570</i>	

Likert scale: 5 = always, 4 = often, 3 = sometimes, 2 = seldom, 1 = never † The Mann–Whitney U test (M-W U) is used when comparing two groups ‡ The Kruskal–Wallis test (K-W) is used when comparing more than two groups § Number of healthcare appointment visits in the past year

* Significant at $p < 0.05$ SD = standard deviation

Discussion

This study evaluated primary healthcare clients' perceptions of the importance, and their experience, of participation in care using the FI-PPRQ. The results show that clients perceived participation as very important, consistent with the results of earlier studies (Lindberg et al., 2013b; Tobiano et al., 2016). The experiences of participation varied from very good to poor. Prior studies also revealed such individuality and variability of experiences. Similarly, shortcomings were detected (Aasen, Kvangarsnes, & Heggen, 2012; Malmgren, Törnvall, & Jansson, 2014). This study echoes previous studies indicating that measuring patient participation is important, especially from a patient perspective. Experience of participation is valuable because it improves the quality of care and can strengthen patients' potential to engage and take responsibility for their own healthcare (Luhr et al., 2017). These aspects are particularly vital in primary healthcare to meet challenges posed by growing numbers of people with chronic health conditions (Organisation for Economic Co-operation and Development, 2016; World Health Organization, 2008).

Respect and integrity and information and knowledge were the best-achieved domains. This is significant, as mutual respect and information processing have been found to be the basis for patient participation. Importantly, however, every fifth respondent felt that personnel had treated them rarely or never as a unique individual. Individual and holistic encounters are considered to be essential for the experience of patient participation (Thórarinsdóttir & Kristjánsson, 2014). In addition, 40% felt that personnel sometimes, rarely, or never had time to answer their questions. The lack of time as a barrier to participation was apparent in several previous studies (Tobiano et al., 2015; Henselmans, Heijmans, & Rademakers, 2015). However, previously reported patients' experiences indicate that the possibility of posing questions is integral for participation, as it enables information processing in a way that is generated by the clients' own needs (Thórarinsdóttir & Kristjánsson, 2014), and sufficient time and high-quality interaction with a professional are associated with higher patient activity and satisfaction with care (Wong, Peterson, & Black, 2011).

Furthermore, there were moderate averages for the domains of planning and decision-making and motivation and encouragement, but clear deficiencies were also detected. Almost a quarter of respondents felt that personnel rarely or never helped them set realistic goals for different skills. This would be an important task (Wressle et al., 2002) especially for patients undergoing rehabilitation, but also for frequent attenders of healthcare services. According to the results, attention should also be paid to the involvement of family, which was deemed the weakest domain. This is likely partly due to the fact that the participation of family members is less established in primary healthcare appointment services as compared to hospital care. However, family should be involved whenever the patient and his/her close ones so wish.

This study's findings suggest that clients' demographics are related to their perceptions of participation. There were some statistically significant differences between groups, but the small sample size could have affected the fact that not all actual differences were statistically significant. For importance ratings, it was found that clients of appointment services, women, and those under 65 years old perceived respect and integrity as most important; clients of appointment services and those under 65 years old perceived planning and decision-making as most important; while involvement of family was most valued by women and those under 65 years old. It seems that during appointment services visits, clients tend to have slightly different preferences than they do in wards. Moreover, age and gender seem to affect perceptions, as noted earlier (Fröjd et al., 2011; Kolovos et al., 2016). Foss and Hofoss (2004) found that female patients pointed to the importance of being treated as a whole person and taken seriously, while male patients focused more on receiving the correct medical treatment. Previously, younger and highly educated people were detected as being more active and also as feeling more confident in healthcare encounters (Henselmans, Heijmans, & Rademakers, 2015). In this study, highly educated clients perceived respect and integrity as being realized more often than did the less educated clients, but there were no significant differences in any scale for importance. The FI-PPRQ provided information about the central aspects of participation. Importance ratings allowed clients to depict their personal preferences, while experience ratings

allowed them to manifest their perceptions of the degree to which the conditions and requirements for participation are actually provided in healthcare contexts (Lindberg et al., 2013b). This questionnaire can also help personnel monitor and tailor care to individual clients' unique needs. Healthcare professionals have considerable scope for supporting patients through their actions and inviting them to participate and assume an active role in their care given their capabilities (Thórarinsdóttir & Kristjánsson, 2014). Previous studies suggested that it is not just professionals' responsive attitudes toward patient participation; there is also a need for adequate staffing, and both professionals (Malfait, Eeckloo, & Van Hecke, 2017) and patients would benefit from proper education (Henselmans, Heijmans, & Rademakers, 2015; Luhr, 2017). Patient participation is also considered to entail an active patient role in encounters with healthcare providers. This instrument does not measure this action dimension, preferred or actual, and this represents a challenge for future research.

Several methodological considerations should be taken into account. The sample was not representative of the larger study population because it was a convenience sample. The sample size was small, but was probably sufficiently large for a pilot study. One known effect on the sample size was the limited number of clients who met the study inclusion criteria in the units involved during the data collection period. It was not possible to calculate the overall response rate for the total sample or analyze the comparability of non-respondents and the final sample due to the anonymity of responses. However, the respondents did seem to reflect the wider target population in terms of age, gender, and education profile. To ensure that the respondents' assessments accurately reflected their perceptions of patient participation during care, they completed the questionnaire immediately after their care periods, thus minimizing recall bias.

Conclusion

The results indicate that most primary healthcare clients find participation highly important, but their experiences of participation varied; both individual and situation-specific differences were observed. To maintain high-quality healthcare, it is essential to measure clients' participation. Further research is needed to examine client

experiences in more versatile (varied) settings using mixed methods. It is also important to deepen our understanding of participation as an ethical principle.

Acknowledgments: The authors would like to thank Dr. Ari Voutilainen, University of Eastern Finland, for applying his expertise in statistical research methods in a review of this study, and Dr. Jeanette Melin, University of Gothenburg, for her collaboration to the study. We also thank all the health professionals, translators, and clients who participated in this study for their collaboration and invaluable contributions.

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