

ORIGINAL RESEARCH

Patient participation – to what extent? A survey of patients' perspectives

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Abstract

Objective: The past decades have seen an increasingly patient-centred approach to healthcare delivery, with emphasis on patients' participatory role. Patients understand the participatory role as being provided with relevant information, opportunity to give their opinion on potential treatments, involvement in discussions about their condition, or involvement in the decision-making process. Patients' wishes for participation vary considerably. The aim of this study is to explore patients' assessment of the importance of, preferences for and experience of participation.

Methods: A cross-sectional cohort study was conducted. Inpatients and outpatients with diabetes, heart failure or haematological cancer admitted to a hospital in Denmark (N = 1736) received a questionnaire. The results are described by proportions and analysed by Pearson's chi-square test.

Results: The questionnaire was returned by 1173 patients (68% response rate) of whom 89% found participation very important. The same proportion perceived adequacy of information, 90% expressed a preference for consultation in decision-making and 51% wanted to leave the decisions to staff. Seventy-two percent experienced participation. However, 54% of the respondents who received adequate information and 51% of those who wanted to be consulted did not prefer to make decisions themselves. Sixty percent of the respondents reported a mismatch, as they did not want participation but had nevertheless been involved by staff.

Conclusions: Patients find participation of great importance, they feel adequately informed and prefer being consulted in decision-making while they do not necessarily want to make the decisions themselves. We found considerable variation in patients' level of preferred participation and a mismatch between levels of preferred and received participation.

Key words

Patient participation, Survey designs, Decision-making

1 Introduction

The past two decades have seen an increasingly patient-centred approach to healthcare delivery, with increasing emphasis on an active and participatory role for patients.

International research has shown that patient participation can lead to better compliance^[1], increase patient satisfaction and motivation to stay in treatment^[2] and contribute to better patient safety^[3] and treatment outcomes^[4, 5].

No unambiguous definition of patient participation has been established, but patients generally understand the role of participant as one in which they are provided with relevant information, are able to give their opinion on potential treatments, are involved in discussions about their condition, and involved in the decision-making process ^[6].

Knowledge may be considered as a precondition for participation as patients are not in a position to meaningfully express preferences about their conditions and potential treatments unless they have received adequate and appropriate information ^[7]. Likewise, options for participation referred to as patients' being able to give their opinion and being involved in discussions, may be considered a precondition for participation in decision-making ^[8]. Although knowledge and options may be considered as preconditions it may not necessarily predict a preference to decide on treatment.

The study had two aims: to investigate the association between perceived adequacy of information and the wish to be consulted in decision-making and the preferred level of participation; and the association between patients' preferences and perception of participation.

2 Methods

The study was designed as a cross-sectional questionnaire survey. Data were collected from 17 April to 12 June, 2009.

The study included all inpatients and outpatients of 18 years or older with diabetes, heart failure or haematological cancer admitted to the university hospital of Odense in the Region of Southern Denmark from 1 August, 2007, to 1 April, 2009. It was a condition that they were able to read and understand Danish.

The inclusion criteria were met by 1736 patients, of whom 16 were deemed ineligible due to unknown address, or death. A letter of invitation with a pen-and-paper questionnaire was sent to all participants; if no response was obtained within two weeks, a reminder with a new copy of the questionnaire was dispatched. The first questionnaire was sent out between 3 weeks and 20 month after contact with the hospital.

Data on age, gender, diagnosis and total number of diagnoses were harvested from the hospital's patient administration system. Demographic data on level of education, employment status and marital status were collected via the questionnaire (self-reported). Respondents also reported duration of diabetes, heart failure or haematological cancer (months or years) and whether they were in treatment for more than one disease.

The survey was based on a larger 117-item questionnaire concerning patient care pathways. One of its themes was patient participation, which was covered by 22 questions, from which five questions concerning the in-hospital setting were chosen for this survey: 1) the perceived adequacy of information, 2) preferences for participation (two questions), 3) attitude to importance of participation, and 4) the perceived participation. All questions were replied in the light of the patient care pathway that is various consultations and not on the latest consultation. The questionnaire was developed with inspiration from a qualitative study ^[9] and previously conducted patient satisfaction surveys. A pilot test was performed, followed by minor adjustments, as a validated patient care pathway questionnaire with relevant themes was not found. Responses were scored on a five-point Likert scale, including an Undecided response option.

2.1 Perceived adequacy of information

The respondents were asked if they had received adequate information, with the following response opportunities: 1) *Yes, to a large extent*; 2) *Yes, to some extent*; 3) *No, only to a lesser extent*; 4) *No, not at all*.

2.2 Preferences for participation

To assess their preferred role of participation, the respondents were asked two questions: whether they wanted to be consulted when decisions about their treatment were to be made, and whether they considered it to be in their best interest that staff made the necessary decisions. The response options were: 1) *Strongly agree*; 2) *Agree*; 3) *Neither agree nor disagree*; 4) *Disagree*; 5) *Strongly disagree*.

2.3 Importance of participation

The following response opportunities were given concerning the attitude to the importance of patient participation: 1) *No importance*; 2) *Little importance*; 3) *Some importance*; 4) *Great importance*.

2.4 Perceived participation

The following response opportunities were given to elicit responses about the perception of staff consideration for wishes and needs concerning the patient care pathway: 1) *Yes, to a large extent*; 2) *Yes, to some extent*; 3) *No, only to a lesser extent*; 4) *No, not at all*.

We dichotomized responses to the questions about perceived adequacy of information, importance of participation and the question of perceived participation into the top rating versus lower ratings. The data assessing preferences for patient participation were divided into three groups. The results were described by proportions and analysed by Pearson's *chi*-square test using Stata, version 12 software (Stata Corp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP).

The return of a questionnaire, whether fully or only partially completed, was considered to express voluntary consent to participation. Identification by the researcher was precluded as all personal identifiers were removed or disguised during data collection.

The study was approved by the Danish Data Protection Agency and the Regional Scientific Ethical Committees of Southern Denmark.

3 Results

Of the 1720 patients who were included, 68% (1173) returned the questionnaire. The mean age of responders was 62.9 years (SD = 14.9); 62% were male; mean duration of disease 8.3 years (SD = 10.9).

Table 1. Demographic and disease characteristics

	N (%)
Diagnosis	
Diabetes	336 (29%)
Heart failure	412 (35%)
Cancer	425 (36%)
Gender	
Male	722 (62%)
Education	
12 years or less	401 (36%)
Vocational training	456 (41%)
College or university degree	239 (23%)
Employment status	
Retired	704 (65%)
Unemployed	86 (8%)
Employed	275 (26%)
Education	14 (1%)
Marital status	
Widowed or single	334 (30%)
Married or living with a partner	785 (70%)
Treatment for > 1 disease	503 (44%)
Mean age in years (SD)	62.9 (14.9)
Mean duration of disease in years (SD)	8.3 (10.9)
Mean number of diagnoses (SD)	6.2 (4.4)

As Table 1 shows, 36% had 12 years or less education, 26% were in employment, 70% were married or lived with a partner. Forty-four per cent had been treated for more than one disease (mean number 6.2). A diabetes diagnosis was reported by 29% of the respondents, heart failure by 35%, and haematological cancer by 36%.

Compared to respondents, non-respondents were likely to be younger (mean = 61.3 years, $p < .05$) and have more diagnoses (mean = 7.38, $p < .01$). Significantly more non-respondents were diagnosed with diabetes (40%, $p < .01$), and significantly less with heart failure (32%, $p < .01$), or haematological cancer (28%, $p < .01$). The gender distribution in the two groups was comparable.

Table 2. Perceived information, preferences for, importance of and perceived participation

	N (%)
Perceived adequacy of information	1003
Adequate information	980 (89%)
Inadequate information	98 (9%)
Undecided	25 (2%)
Preferences for participation	
<i>The staff making the decisions</i>	1075
Disagree	265 (25%)
Neither agree nor disagree	225 (21%)
Agree	545 (51%)
Undecided	40 (3%)
Want to be consulted when decisions are made	1090
Disagree	26 (3%)
Neither agree nor disagree	65 (6%)
Agree	984 (90%)
Undecided	15 (1%)
Importance of participation	1131
Very important	1006 (89%)
Less important	55 (5%)
Undecided	70 (6%)
Perceived participation	998
Yes	721 (72%)
No	88 (9%)
Undecided	189 (19%)

Of the respondents 89% answered that they received adequate information, 9% deemed it as inadequate, while 2% were undecided (see Table 2).

As regards the responders' preferences concerning participation, 51% wanted to leave decisions to staff, 25% did not want the staff to make the decisions, 21% neither wanted the staff to make decisions nor wanted to do so themselves, and 3% were undecided.

Ninety percent of the respondents wanted to be consulted in decision-making, 3% did not want this, 6% neither wanted nor did not want to be consulted, and 1% were undecided.

Participation was considered very important by 89% of the respondents, whereas 5% found it less important, and 6% were undecided.

Participation was experienced by 72%, where as 9% indicated they had not experienced participation and 19% were undecided.

In investigating for associations, *Undecided* responses were omitted. The analyses showed that 54% of those patients who had received adequate information preferred not to make the decision, while 25% preferred doing so. 21% neither agreed nor disagreed.

Table 3. Associations between preferred participation and adequate information or being consulted about decisions N (%) and associations between preferred and perceived participation, n (%)

	Preferred level of participation			Total
	Prefer making decisions	Neither agree nor disagree	Do not prefer making decisions	
Adequate information				
No	28 (30%)	26 (29%)	26 (29%)	90 (100%)
Yes	222 (25%)	193 (21%)	481 (54%)	896 (100%)
Want to be consulted when decisions are made				
Disagree	5 (20%)	1 (4%)	19 (76%)	25 (100%)
Neither agree nor disagree	3 (4%)	18 (28%)	44 (68%)	65 (100%)
Agree	250 (27%)	205 (22%)	464 (51%)	919 (100%)
	Preferred level of participation		Do not prefer making decision	Total
	Prefer making decisions			
Perceived level of participation				
Yes	169 (29%)		357 (60%)	526 (89%)
No	27 (5%)		37 (6%)	64 (11%)

*Chi-square test: $p = .107$

Of the patients who wanted to be consulted in decision-making, 51% preferred not to make the decisions, whereas 27% preferred doing so, while 22% neither agreed nor disagreed (see Table 3).

In exploring the level of agreement between preferred and perceived levels of participation, the neither agree nor disagree responses were omitted. We found that 35% had participated in the preferred fashion as 29% of the participants preferred and perceived participation and 6% neither preferred nor perceived participation. However, 65% of the participants reported a mismatch; 5% of the participants who preferred participation said they had not perceived any participation and 60% perceived participation despite their wish not to participate. Overall, no significant association between preferred and perceived participation was found ($p = .107$).

4 Discussion

4.1 Discussion of results

When asked about their preferences regarding consultation in decision-making, 90% of the respondents said they wanted to be asked. With regard to decision-making, 51% preferred to leave this to staff. There is evidence suggesting that haematological patients wish to take less active participatory role (63% passive role) in the decision-making process than those suffering from solid cancer (29.7% passive role) ^[10], furthermore that patients with chronic heart failure has a relatively high wish of being passive (47.8%) ^[11]. These studies are indicating that the type of illness may influence on the participatory role. As the participants in this study represent haematological cancer, diabetes and heart failure, our results are corroborating.

A total of 89% of the respondents indicated they had received adequate information, yet 54% of this group preferred not to make decisions themselves. Hence, the fact is that almost all respondents received adequate information and preferred to

be consulted when decisions were made, only about half the respondents preferred to make the decision. This finding corresponds with those of other studies that have examined the association between preferred participation and adequate information; e.g. a Canadian survey of the general population showing that 96% preferred to be offered choices and to be asked for their opinions, nevertheless, only 52% of the respondents preferred to leave final decisions to their physicians^[12]. A review by Gaston *et al.* found that almost all patients with cancer expressed a desire for full information, but only two-thirds wished to participate actively in decision-making^[13], thus corroborating the findings in Chewning *et al.*'s review that although the majority of patients wanted to discuss options and receive information from physicians, they did not wish to make the final decision^[14].

In our study, 35% of the participants reported a match of their preferred and perceived degree of participation; the remainder, however, experienced a mismatch. Of those 65% reporting a mismatch, 60% did not want to make decisions themselves but nevertheless felt that they had been involved in decision-making and 5% want to make decisions themselves but perceived no participation.

According to a meta-analysis on cancer patient studies, 60% of respondents had the preferred decision-making role while 40% experienced a mismatch^[15]. A cross-sectional study of haematological patients in Australia showed that 44% experienced a mismatch between preferred and perceived degree of participation; of those, 34% had been less involved than they desired^[16]. These results correspond to findings in two reviews concluding that patients want more participation than they had actually experienced^[17, 18]. Yet, we found a higher proportion of patients experiencing a mismatch and furthermore that this mismatch was a result of being involved to a higher degree than desired.

4.2 Discussion of method

The larger survey on which our analysis is based had the overall purpose of assessing coherent patient pathways, with patient participation as a subtheme. The majority of questions therefore focused on patients' pathways rather than on participation. Furthermore 17 questions regarding patient participation was focusing on the setting outside the hospital, which was not the focus of this study.

The questions asked, reflect the patients' position towards patient participation in general more than one experience in a specific consultation; a fact that might result in data being insensitive from the approach of one health professional to another.

The variable concerning "received adequate information" might question the competency and standardization of those providing the education and thereby challenge the patient's understanding of "adequate information". The educators style "approach and attitude" may have impacted the patient's desire to participate and are limitations to the study. Nevertheless, the variable reflects the patients' understanding and is considered a precondition for participation^[7]. The variable "preference for participation" may reflect the approach and attitude of the health care workers who approached the patient in addition to the patients' sincere preference.

A majority of published studies on patient participation are based on the Control Preference Scale^[19] in which responses are divided into active, collaborative and passive roles. In our case, response options for perceived participation were limited to Yes or No (to an active role) and thus offered no option to indicate a collaborative role. Leaving respondents with only two options may have caused a relatively high proportion of mismatches between preferred and perceived degrees of participation.

4.3 Strengths and limitations

Non-respondents were younger and had more diagnoses than the respondents. According to Hubbard *et al.*, younger patients tend to prefer more involvement than older patients although no association between health status and role preferences can be claimed to exist^[17]. The slight underrepresentation of young patients in our study may thus have

contributed to the finding that the majority of respondents preferred staff to make the decisions. On the other hand, our higher-than-normal response rate of 68% (mean of 60%) to mail surveys strengthens our conclusion^[20].

5 Conclusion

This study has demonstrated that participation is very important to patients although there is substantial variation in their preferences regarding decision-making. While almost all patients express perceived adequacy of information and a wish to be consulted about their opinion, they do not necessarily want to make the decisions themselves.

Physicians and health care professionals should therefore assess individual patient preferences concerning information and degree of participation and seek to act accordingly. The found mismatch between preferred and perceived participation may be lowered by aligning expectations to secure better patient satisfaction.

Qualitative studies are recommended to further elaborate the patients' perceptions.

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