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Can Participation in Documentation Influence Experiences of Involvement in Care Decision-Making?

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Abstract: *Introduction:* Patients have the right to influence the care they receive, but their wish to participate in care decision-making is unclear.

Aim: This study investigates whether participation in nursing documentation influences patient participation in care decision-making, mastery, self-esteem, empowerment and depressive feelings among adult in-patients with chronic disease.

Materials and Methodology: Adult patients (n=39) with chronic diseases were randomized. The intervention group participated in nursing documentation. Upon departure, patients filled in questionnaires about participation in care decision-making, mastery, self-esteem, empowerment and depressive feelings.

Results: The majority of the patients preferred a collaborative or passive role regarding care decision-making. Lack of knowledge was one reason for non-participation. Having been diagnosed more than five years previously meant stronger empowerment.

Conclusion: It is a challenge for nurses to find strategies to assess patients' wishes regarding participation in care decision-making. Nurses must support patients' knowledge of their disease and empowerment.

Keywords: Care decision-making, empowerment, knowledge, nursing documentation, participation, well-being.

INTRODUCTION

Trust and respect between the nurse and the patient is important for patient participation in care decision-making. Both parties need to have a sense that there are positive benefits associated with the patient being active in the decision-making process [1, 2]. Patient participation is described as the patient obtaining information and knowledge with the aim of increasing understanding of physiology, the disease and the treatment, which in turn may influence self-care ability. The patients share their experiences, symptoms, and knowledge of the disease with the nurse. Thus it is important that the patient is considered an individual and an important member of the care team, not as a symptom or a disease [3]. Increased patient participation in nursing care could be considered particularly important in patients who are suffering from chronic diseases. Patients with chronic disease need a functional self-care regime to cope with their disease and its effects on their daily life [4].

Nurses have an important role in finding methods to support patients' self-care in order to empower them to be as independent as possible [5, 6].

Nurses often strive for increased patient participation in nursing care to achieve mutual care goals. The National Board of Health and Welfare in Sweden states that patients should have the right to influence the care they receive and to participate in their care plans and treatment [7].

Brownlea (1987, p. 605) defines participation as follows: "Participation means getting involved or being allowed to become involved in a decision-making process or the delivery of a service or the evaluation of a service, or even simply to become one of a number of people consulted on an issue or a matter" [8].

Patient participation in nursing may influence clinical decision-making aiming to obtain suitable care. Nurses can facilitate patient participation by informing the patient about his or her care. Patients who have an insight into their situation can be more involved in care decision-making and thus increase their autonomy and integrity. Since there are individual differences in patients' preferences regarding participation in care decision-making, it is important that nurses find out to what extent the patient wants to be involved in the decision-making with regards to their care [3, 6]. Patients' preference to be involved in care decision-

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making could also vary depending on the type of care and decision. Each time a decision is to be made, nurses need to assess the patients' wish for involvement [9]. The patients' age may also influence the wish to participate in care decision-making [10]. Ekdahl, Andersson and Friedrichsen [10] found that many elderly patients defined patient participation as receiving information about care and treatment. The patients felt that they had to ask for information and in many cases they wanted to leave the decision-making to the physicians and the nurses. Even though patients did not particularly wish to take part in the decision-making, they wanted information and felt that receiving information made them involved in their care.

Jansson, Pihlhammar and Forsberg [11] found that patients whose care was based on care plans were more satisfied with their care and had a shorter length of stay in the hospital compared with patients whose care was not based on care plans. Further, patients' adherence to the care plan influences patient satisfaction with care, increases patient empowerment, comprehension and confidence. Thus it is important for nurses to find different strategies to involve the patient in the care process [12, 13]. One strategy to achieve participation in care decision-making is to involve the patient in establishing his/her care plan, but there are individual differences as to the extent to which patients wish to participate in care planning [6, 9].

There are several reasons why nurses have problems involving patients in the care. One reason could be the nurses' competence level which can be a problem for both new, inexperienced nurses as well as for experienced nurses. The nurses may lack the insight that they have to encourage patient participation, and they could also be unaware of the need to work and plan for it [12]. The patients' knowledge about care and treatment, as well as their interest in participation in care decision-making varies. The patients' ability to communicate this knowledge and interest affects how nurses involve them in care decision-making [14]. Another reason could be that nurses feel threatened as professionals by expert patients who have much knowledge about their disease. This can be a particular problem for nurses with less experience as their role in relation to patients with extensive knowledge of their disease has not been clearly defined [4]. The organization and work environment could influence patient participation negatively, one example being lack of continuity. The more time the nurse and patient spend together, the more likely it is that they will develop the kind of relationship where the patient feels confident being involved in the clinical decision-making process [5, 12].

Discrepancies between patients' preferred and actual roles with regards to participation in care decision-making are common, irrespectively of the patients' wishes concerning participation [15].

Evaluation of patients' preferences regarding their role in clinical decision-making and nursing care thus seems to be difficult [15, 16]. The aim of this study was to investigate whether participation in nursing documentation influenced patient participation in care decision-making, mastery, self-esteem, empowerment and depressive feelings among patients with chronic disease.

MATERIALS AND METHODOLOGY

Design

This study has an experimental, randomized design. Data was collected between September 2008 and January 2010. All nurses at the ward were informed about the study and the study design at nursing meetings several times before the intervention started to assure reliability. The authors were at the ward twice a week to support and remind the nurses on the design of the study. According to power analysis, 80 patients (power 80% and $p < 0.05$) were ideally needed to conduct the study, since the smaller the measured effect expected, the larger the sample is needed to obtain distinctive results [17]. Thus 80 patient information letters describing the study were prepared and patients who were admitted to a medical ward were consecutively asked by the nurses to participate in the study if they matched the inclusion criteria. The patients who chose to participate were randomised either to a group participating in nursing documentation or to a control group, depending on the content of the patient information letter. Therefore the study was blinded and nurses could not ascertain which patient information letter the patient received.

The study intervention meant that during their stay in the ward, the patient participated in the nursing documentation together with their nurse. General health status, care goals, and care plans were documented by the nurse and the patient together. The documentation was completed daily. The patients received a printed copy of his/her nursing record and documentation was changed according to the patients' comments utilizing documentation standards. The nurses used a laptop computer to complete all nursing documentation, to facilitate patient presence and direct documentation in the patient record. However, in some cases when the patient was isolated because of a contagious disease this was not possible. In these cases, a discussion took place between the patient and the nurse and a printed copy of the patient record was given to the patient for corrections.

Data Collection

The study environment was a medical ward with patients who had the following chronic conditions; diabetes, inflammatory bowel diseases, liver disease, coronary artery disease and chronic obstructive pulmonary diseases. Inclusion criteria were living with the chronic disease for more than one year, ability to read and write Swedish, and no established or observed cognitive problems. Seventy patients were asked to participate, of whom 24 declined participation. They did not have to declare any reason for non-participation. Some questionnaires were not returned and some questionnaires were not completed accurately ($n=5$). A total of 41 patients filled in the questionnaires. Two questionnaires were submitted without recognition of belonging to the intervention group or control group. Therefore, these questionnaires were excluded and the total sample was 39.

Questionnaires

Upon departure, a demographic sheet, a Likert scale with five response categories for rating present well-being and the following questionnaires were used:

The Control Preference Scale (CPS), developed to measure how clinical decisions are made among patients with life-threatening disease was used. It consists of two questions, one about the patients' preferred role and one about the patients' actual role in clinical decision-making. Both questions are followed by five statements about the degree of control the patient wishes to have on his/her care, ranging from an active role *via* a collaborative role to a passive role. The CPS asks the patient to select the statement closest to their preferred role in treatment decision-making to find discrepancies between patients' preferred and actual roles in clinical decision-making [18]. The CPS can also be used to ascertain a patient's preferred role in the nurse-patient relationship, as modified by Florin *et al.* (2006) [16]. The CPS has acceptable reliability and validity [16].

An open-ended question asked the patients if there were further reasons for their non-involvement in care decision-making.

To measure coping ability the Pearlin-Schooler Mastery scale as developed by Pearlin and Schooler (1978)[19], was used. This scale measures individuals' perceived level of control over their lives. The mastery scale is a summative scale ranging from 7, indicating low mastery, to 28 indicating high mastery. The Pearlin-Schooler Mastery Scale is widely used, and has been validated and shown to have high internal consistency, Cronbach α 0.75 [20], and 0.86 [21].

The Rosenberg Self-Esteem Scale was used to measure self-esteem. The scale ranges from 0-30, and includes 10 items with four points ranging from 'strongly agree' to 'strongly disagree'. Scores between 15 and 25 are within normal range; scores below 15 suggest low self-esteem [22]. The scale is widely used, and has been validated, and shown to be reliable in many different contexts [23].

Empowerment was measured using the Swedish Version of the Diabetes Empowerment Scale (Swe-DES), as developed by Leksell *et al.*, (2007) [24]. It was modified to cover all chronic diseases approved by its creator. The Swe-DES consists of 23 items, with four subscales, each measuring the following; subscale 1; goal achievement, subscale 2; self-awareness, subscale 3; stress management, and subscale 4; readiness to change. The scales range from strongly disagree (1) to strongly agree (5) where a higher value indicates stronger empowerment. The instrument has proven internal consistency by a Cronbach α ranging from 0.68 to 0.91 for the subscales, and 0.91 for the total scale [24].

The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure current level of depressive symptoms (20 items) during the past week, ranking items from 0-3 points. Higher scores indicate more depressive symptoms, although this does not necessarily indicate clinical depression [25]. A suggestion is that 28 points or more should indicate depressive feelings [26]. The CES-D is designed to study the relationship between depression and other variables in general population surveys. The CES-D has good validity and the reliability coefficient is α 0.80 [25].

Ethical Considerations

This study was approved by the Regional Ethical Review Board, Linköping, Sweden Dnr: M74-08. Written informed consent was obtained from patients who chose to participate in the study. Participation was voluntary; participants were informed they could end participation at any time and that their care was not influenced by participation in the study.

Data Analysis

Descriptive data was analysed using frequencies, percentages, mean and standard deviations, median and range. The Student t-test was used for age and the number of years since patients had received their diagnosis. The Mann-Whitney U-test was used to find significant differences between the two independent groups. The Chi-square test was used to find associations between independent variables in the sample, and due to the small and unevenly distributed sample size, Fisher's Exact Test was used. The Spearman rank correlation test was used for correlations. When analysing patients' preferred and perceived roles in care decision-making the five factors in the CPS scale were categorised into either an active, collaborative or a passive role, as suggested by Degner *et al.* (1997) [18]. The sample was split into groups according to the patients' preferred and perceived active/collaborative/passive roles. Each role was analysed separately and comparisons were made between the role the patient wanted and the role he/she perceived themselves to have had during their stay in the ward. Since the retirement age in Sweden is 65 years this was chosen as a cut-off for analysing age differences. The sample was divided into two groups: 1) patients who had lived with a diagnosis for less than five years, 2) patients who had been diagnosed more than five years previously. The two groups living with the diagnosis for less than five years and more than five years, respectively, were compared related to the participation role and empowerment. The significance level was set to $p < 0.05$. Analysis was performed using the statistical computer software program PASW Statistics 18 (SPSS Inc).

RESULTS

In this study, 18 of the 39 patients participated in nursing documentation during their stay in the medical ward. The total sample (19 women and 20 men) had a mean age of 57 ± 21 years. The mean age of the intervention and control groups was 56 ± 21 and 57 ± 20.5 , respectively. There was no statistical difference between the intervention and control group with regard to sex, civil status, education, occupation or living environment (Table 1).

Regarding well-being, 76.2% of the patients in the control group answered that they felt "fairly well" or better, compared to 70.6% in the intervention group, with no significant difference.

No significant difference was found between the intervention and the control groups with regard to patients' preferred and perceived roles in participation in care decision-making (Table 2). The preference for an active, collaborative or passive role in decision-making was not

Table 1. Descriptive Data of the Participants in the Study (n=39), Intervention (n=18), Control (n=21)

	Total Sample n (%)	Intervention Group n	Control Group n	p- Value
Age				
Mean + SD	56.8 ± 20.6	56.2 ± 21.2	57.3 ± 20.6	ns
Sex				
Female	19 (48.7)	8	11	ns
Male	20 (51.3)	10	10	ns
Civil Status				
Married	14 (35.9)	9	5	ns
Co-habitant	7 (17.9)	3	4	ns
In a relationship	1 (2.6)	-	1	ns
Single	12 (30.8)	3	9	ns
Widow/widower	5 (12.8)	3	2	ns
Education				
6 th grade (before 1972)	8 (20.5)	4	4	ns
9 th grade	4 (10.3)	2	2	ns
High school graduation	18 (46.2)	8	10	ns
University	6 (15.5)	4	2	ns
Other education	3 (7.7)	-	3	ns
Occupation*				
Work, full-time	8 (20.5)	4	4	ns
Work, part-time	4 (10.3)	2	2	ns
Unemployed	2 (5.1)	1	1	ns
Student	3 (7.7)	1	2	ns
Early retirement	3 (7.7)	1	2	ns
Retired	17 (43.6)	8	9	ns
Living Environment*				
Rural	6 (15.4)	2	4	ns
Village	8 (20.5)	3	5	ns
City	21 (53.8)	10	11	ns
Metropolis	3 (7.7)	2	1	ns

*Missing data from one-two patients.

affected by sex or educational level or by whether the patient had been in the intervention or the control group.

Patients who preferred to be active were significantly more active than those who did not wish to be active ($p < 0.05$). Patients who preferred a collaborative role had it more often than those who did not want such a role ($p < 0.05$). Patients who preferred to be passive were passive more often compared to patients who did not want to be passive ($p < 0.001$). A significant correlation was found between preferring a certain role in care decision-making, and having this role ($p < 0.001$, $r = 0.69$). There was a significant correlation between well-being and wanting to be passive in care decision-making ($p < 0.05$, $r = 0.60$). Most of the patients who had perceived themselves as being active in care

decision-making were found in the intervention group ($p = 0.083$).

The preferred role in decision-making was not related to the number of years the patient had been diagnosed with the disease. Exceptions included patients over 65 years of age, where those who had been diagnosed less than five years previously had a more passive role in the decision-making process. Patients over 65 preferred to leave decision-making to their nurses to a greater extent than the patients under 65 years of age ($p < 0.05$).

Patients were asked to give reasons for not being involved in care decision-making. Ten patients responded and two themes could be identified; trust in the physician and lack of knowledge regarding the disease. Two patients

Table 2. The Patients' Rating of their Preferred and Perceived Level of Participation in Care Decision-Making

	Intervention Group		Control Group		Total Sample	
	Preferred Role n (%)	Perceived Role n (%)	Preferred Role n (%)	Perceived Role n (%)	Preferred Role n (%)	Perceived Role n (%)
Active role	1 (5.6)	1 (5.6)	5 (23.8)	3 (14.3)	6 (15.4)	4 (10.3)
Collaborative role	10 (55.6)	6 (33.3)	9 (42.9)	7 (33.3)	19 (48.7)	13 (33.3)
Passive role	6 (33.3)	9 (50.0)	7 (33.3)	9 (42.9)	13 (33.3)	18 (46.2)
Missing	1 (5.6)	2 (11.1)	-0(0.0)	2 (9.5)	1 (2.6)	4 (10.3)

*Some patients did not answer all questions, leading to missing values.

stated that they thought care decisions were the physician's responsibility.

No difference was found between the intervention and the control group with regard to mastery or self-esteem. Men in the control group rated themselves as having higher mastery than men in the intervention group ($p < 0.05$).

No statistical difference was identified between the intervention and control group with regards to empowerment. However, patients in the intervention group who had been diagnosed more than five years previously scored higher on the subscales of goal achievement, self-awareness and readiness to change as well as the total SWEDS score, compared with patients who had been diagnosed less than five years previously ($p < 0.05$). Significant correlations were found in the intervention group between having been diagnosed more than five years previously and higher scores on empowerment ($p = 0.005$, $r = 0.80$), especially on the subscales of goal achievement, self-awareness and readiness to change. In the total sample women had a stronger readiness to change compared to men ($p < 0.05$).

The women in the control group had a significantly higher risk of depression compared to the men ($p < 0.05$). High scores on depression correlated with low scores on stress management ($p < 0.01$) in the total sample. No significant difference was found regarding age or number of years with diagnosis in the CES-D scores.

DISCUSSION

Patients with chronic diseases in this study often preferred a collaborative or passive role when offered to participate in the nursing documentation together with their nurse. However, no significant difference was found between the intervention and the control group regarding participation in care decisions.

Nurses need to be aware of that many patients prefer either a collaborative or passive role when offering them the opportunity to be involved in care decision-making. These results concur with the findings by Florin *et al.* [16], who reported that many patients wanted to play a more passive role than the nurses thought. In a recent study of elderly patients with three or more diagnoses, 35% wanted a more active role and 21% a more passive role than they had [27]. This is in contrast to results in a review by Singh *et al.* [28] who reported that most patients, 49%, prefer a collaborative role however 26% preferred to be active and 25% to be passive [28]. Contrasting results challenge nurses to satisfy

patients' wishes to participate in care decision-making. Nurses need to ask the patients what role they prefer and also assess if the patients need more knowledge on participation in care decisions.

However, in our study there was a significant correlation between preferring a certain role and having that role which is in accordance with results reported by van den Brink-Muinen *et al.* [9], who found a significant correlation between importance and involvement in care decision-making. This was the case even when controlling for socio-economic factors such as gender, age and education level, as well as severity of the illness. In addition, the study of elderly patients with three or more diagnoses reported a moderate correlation between the preferred and actual role in medical decision-making among 44% of the patients [27]. However, women in the study by van den Brink-Muinen *et al.* [9] reported less involvement in decision-making than men, which was not confirmed by our study or the study by Ekdahl *et al.* [27]. This was probably due to the relatively small samples that were maybe too small to show any significant differences.

Some patients claimed that they did not have enough knowledge about their disease and treatment to take an active role and participate in care decision-making. This is in line with health care professionals' perceptions of haematology patients' involvement in decision-making. The health care professionals felt that patients had a passive, uncooperative, withdrawn or expert role depending on their knowledge of their disease. Passivity was viewed as a normal behaviour. However, active patients related to information that was not applicable or relevant to their own situation. The expert group, which was unique and motivated, was the smallest group. These patients had relevant knowledge and claimed to be involved in decision-making [14]. It is important that nurses educate patients in order to increase empowerment and mastery, and that they adapt the education to the patients' individual knowledge level. When shifting from a traditional paternalistic standpoint to increased patient autonomy, nurses must support patients in improving awareness of their knowledge about themselves and their bodily reactions [29]. Patients need time, continuity and information to be able to take part in decision-making and to enjoy increased participation [10]. The way information is provided can affect how it is received. However, although health care professionals might think they are empowering patients, subtle messages in their actions and rhetoric can be contradictory, since traditionally the health care professionals are the decision-makers.

One reason for not being involved in care decision-making was trust in the physician, which confirms results by other studies of chronically ill patients who felt that the health care team owns the knowledge, has the experience and thus can make wise decisions about care and medical treatment [10, 30, 31]. Nurses and physicians are usually in charge of care decision-making and it may be easier to give advice based on evidence and experience rather than the patient's own experienced situation [32].

An interesting result was that even though the patients were asked about their relationship to nurses, they said that they felt it was the physicians' responsibility, or that they trusted the physician to make the decisions, when being asked for reasons for non-participation in care decision-making. Perhaps patients do not recognise the differences between medical care, nursing care and self-care. Therefore they may have problems understanding their own role in the care team. This insight supports the need for patients to be involved in decisions that influence and support their self-care. In support of this concept, Chow *et al.* [33] found that patients with a chronic disease need a plan for managing their disease and self-care at home, which could increase the patients' feeling of well-being. Supporting patients to develop their own care plan has also been shown to improve adherence and clinical outcomes [34].

Stronger empowerment was related to having been diagnosed with a chronic disease for more than five years. Perhaps the patients had found strategies to achieve their goals despite the problems their disease might cause in daily life. Patients who have lived with a disease for many years often have a great deal of experience and knowledge about the disease, which could explain the stronger empowerment. However, having a chronic disease does not necessarily increase the desire to participate in care decision-making [31, 35], some patients may prefer not to be responsible and/or have knowledge about the future when living with a chronic disease.

Surprisingly, upon discharge from the medical ward, 25-30% of the patients responded that they had a decreased sense of well-being. Thus, it is important for the health care staff to better explore well-being among patients upon departure. In this study, most patients had a passive role which generates the following reflection; Does partaking in clinical decisions influence the experience of well-being and in turn the health care results among patients with chronic disease?

To show statistical difference between the groups, power analysis indicated that 80 participants would be needed. The small sample probably affected the results and thus possibilities to draw conclusions. Another aspect is the length of stay that influenced partaking in the intervention and in turn may influence the results. In the medical ward the patients were often seriously ill at the time of admission, which might have influenced the number of patients willing to participate. Calne *et al.* [29] argue that vulnerable and ill patients are not always able to make care decisions. Although participation was voluntary, and reasons for not participating were not sought, some patients openly stated that they did not have the energy to participate. Some patients stated that because of the length and severity of their disease they had already participated in many studies and did

not wish to participate again. Due to staff turnover, all patients matching the criteria were not asked to participate. The nurses who carried out documentation together with patients sometimes felt unsure about how to perform this task, since they normally did this on their own. Computers were not brought into the rooms of patients with contagious diseases due to hygienic considerations. In cases where patients were diagnosed with a contagious disease the strategy for patient participation in nursing documentation was changed and the patients only had to approve the entries in the nursing record. Together, these facts could explain the sample size and the weak statistical differences in the results.

CONCLUSION

Patients with chronic diseases preferred a collaborative or passive role in care decision-making, sometimes due to a lack of knowledge of their disease. Therefore, nurses need to acknowledge patients' needs for disease knowledge and individually educate patients according to their wishes. The strategy tested in this intervention - nurses documenting in the nursing record together with the patient - needs to be further evaluated.

CLINICAL IMPLICATIONS

Nurses need to find strategies to involve patients with chronic disease in care decision-making and planning, since this is a way to improve the clinical outcome and strengthen the patients' empowerment and feelings of control over their life situation. By documenting in the nursing record together with the patient, the patient has the possibility to express his/her thoughts directly, which could facilitate care planning.

CONTRIBUTIONS

Study Design (GHF).

Data Collection and Analysis (HV, GHF).

Manuscript Preparation (HV, GHF).

CONFLICT OF INTEREST

There is no conflict of interest concerning this manuscript.

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