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ORIGINAL ARTICLES

# Patients' participation in end-of-life care: Relations to different variables as documented in the patients' records

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## ABSTRACT

*Objective:* Patients' participation in care is crucial for assuring patients a high quality of care based on values such as autonomy. The patients are supposed to be actively involved in care and treatment, even though these situations are complex, as in the context of end-of-life-care. The aim in this study was to identify demographic and health-related variables' relation to patients' participation during the last three months in life as documented in patients' records.

*Method:* The population in the present study consists of 229 patients from 49 municipalities in a county in Sweden. Data were collected from all available documentation about deceased patients who were  $\geq 18$  years of age at the time of death and who had received healthcare services during the last 3 months of their life.

*Results:* This article demonstrates patients' participation in end-of-life care as it was noted in the patients' documentation. Demographic variables such as age, gender, and residence did not differ between those who participated and those who did not. Patients with dementia and disorientation were separated from those who were not disoriented. There was no information about the wishes of the patients with dementia and disorientation and they were not described as participating in care and treatment. Cognitive intact patients were participating significant more often. These patients had also more symptom describes in the records. These results can indicate that a patient's participation depends upon either the patient's cognitive capability or the healthcare professionals' competence to communicate and provide adequate documentation regarding patients' participation at end-of-life. The documentation about the participation of patients with cognitive dysfunction is poor and needs further investigation, to achieve the goal of dignified end-of-life care for all patients.

*Significance of results:* The results of the presents study call attention to the importance of finding innovative solutions to make patients with cognitive dysfunction involved in their care and treatment at end-of-life. Improvement of documentation showing patients' involvement in care is necessary, as is a discussion of how healthcare professionals can assure patients a high quality of care at end-of-life even if patients voices are not heard.

**KEYWORDS:** Documentation, Disorientation, End-of-life care, Participation, Patients', symptom/problem

## INTRODUCTION

Patients' participation in care seems to be important for ensuring that patients receive high quality care based on certain values, such as autonomy. Patients

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are supposed to be actively involved in care and treatment, even though such situations are often complex, especially in the context of end-of-life care (Singer et al., 1999; Steinhäuser et al., 2000; Schroder et al., 2006). In Sweden today, the fact that patients have the right and autonomy to make their own choices makes it necessary for healthcare professionals to collaborate with them (SFS, 1982, p. 763). Studies investigating patients' participation in end-of-life care are rare, because of ethical and methodological reasons such as exposing these patients for stressful research (Ingleton & Seymour, 2001; Hudson et al., 2005). Patients' participation in care and treatment forms a foundation for dignity, by creating feelings of confidence and comprehension, and allowing them to maintain a sense of control (Eldh et al., 2004).

Patient participation means a person's involvement in their own life situation. It includes making choices even when one cannot perform certain activities alone. Patients' own will, personal goals, motivations, and roles are important for providing quality of care according to World Health Organization's definition of patients' participation (World Health Organization, 2001). Participation includes the concepts of taking part, being included and/or engaged in an area of life, being accepted, or having access to the necessary resources (Cahill, 1998).

The interaction between healthcare professionals and a patient, concerning the type and extent of care and treatment she/he wishes, is a crucial aspect of patient participation. Patient participation is dependent upon what the healthcare professional knows about the individual's wishes, so that she/he can make it possible for the patient to collaborate in clinical decisions based on values such as autonomy. Patients must be adequately informed by healthcare professionals to make it possible for them to participate in different healthcare situations (Sahlberg-Blom et al., 2000; Bottorff et al., 2000; Sainio et al., 2001). A patient's wishes and needs are supposed to be documented in their medical and nursing records and should correspond to what type of healthcare the patient really wants, which may not be what they actually received (SFS, 1993:20; SFS, 1982:763)

There is a growing consensus that patients' participation in care (i.e., daily life choices as well as decisions about medical procedures) needs to be boosted even in the end-of-life care. Despite the fact that patients are enthusiastically encouraged to participate in this type of care, there is a need for a broader research field, which addresses this issue as well as decision-making about different medical treatments. It is important to acquire considerably more knowledge about the circumstances surrounding patients' participation in care at the end-of-life, since this

has been shown to have a marked influence on dignity and well-being at this time of life (Chochinov, 2006; Randers & Mattiasson, 2004). The aim of this study was to identify demographic and health-related variables' relation to patients' participation during the last 3 months of life, as documented in patients' records.

## METHOD

### Design and Study Sample

A retrospective review of death certificates, medical records, and nursing records comprise the foundation for population-related information. The population in the present study consists of 229 patients from 49 municipalities in the County of Västra Götaland in Sweden. The number of deaths in the county was 15,869 persons (7,733 males and 8,136 females), during 2001. Data were collected from all available documentation about deceased patients, and the inclusion criteria were: people who had died in the County of Västra Götaland during 2001, aged  $\geq 18$  years at the time of death, and who had received healthcare services according to the Health and Medical Service Act, during the last 3 months of their life.

Two hundred and eighty individuals were chosen as a primary sample. The first selection was made in proportion to size (PPS), i.e., proportional to the number of death incidents in 10 municipalities within the actual county. The next step, a random selection of individuals from chosen municipalities, was made in PPS. Two extra municipalities were included in the sample to ensure sufficient representation and guard against an underrepresentative sample from the county. Twenty-five individuals were excluded because medical and/or nursing records were inaccessible. Eighteen were excluded due to having died from sudden death, accidents, or suicide. Eight were excluded because no healthcare services had been employed during the last 3 months of life. The final study sample consisted of 229 individuals.

### Data Collection

Before the data were collected, a tool, based on the framework by Donaldson and Field (1998) and by Stewart et al. (1999), was developed. This framework emphasizes problems relating to quality as well as to healthcare indicators. One of these quality indicators focuses on patients' participation in different decisions during the end-of-life phase and was used as a foundation for selection of the data in this study. Patients' participation in everyday life, place of

care, pain relief, medical examinations, and treatments were domains used in the protocol as a base for data collection. The four domains developed from a pilot study, in which all records from 20 deceased patients were examined. The protocol was first pretested and the results from these pretests led to revisions, improvements, and retesting of the items, until an inter-rater agreement reliability of >85–95% was reached. All data regarding demographic and clinical characteristics relevant to the patients' last 3 months of life were collected. The collection described occurrence of different variables in the medical and nursing records. Descriptions in the patients' records showing participation was identified from texts articulating the patients' will and wishes. The actual data were noted in the protocol after reading all of the patients' medical and nursing records as well as their death certificates. All available healthcare documentations during the patients' last 3 months were examined according to demographic and health-related variables.

### Ethical Considerations

The Helsinki Declaration was followed in this study (Helsinki, 2004). The Ethical Committee, University of Gothenburg approved the project (Ö633-02).

### Statistical Analysis

Two groups were compared; patients who were described as participating in care and patients whose records lack such information. These two groups are described by using frequencies. Comparisons between the groups are assessed with the Fishers exact test. Univariate analyses were performed in a first stage to select the most relevant variables in relation to the patients' participation. All variables that

showed a  $p$  value  $<0.1$  were included in the multiple linear logistic regression models and this model was used to assess which of the variables were predictive of patients participating in care. The significant main effects in the multiple linear logistic regression models were assessed using the backward stepwise method. This method starts by filling the full model, including all variables, and then removes unimportant variables one at a time until all those remaining in the model contribute significantly. Unless otherwise specified, all tests were two-tailed, and a  $p$  value of  $<0.05$  was judged as significant. The Hosmer and Lemeshow test was used for assessing goodness-of-fit (Hosmer et al., 1997)

### RESULTS

In this study the mean age among the patients was 80 years; half of them residing in private homes and the other half in residential care facilities. One hundred five (46%) of the included patients were female and 124 (54%) were male. One hundred and thirty-two (58%) of the patients were described as participating actively in their healthcare. Patients' participation as documented in their records varied from occurring only in one situation to occurring in several situations during the last 3 months of their lives. In 97 (42%) of the patients' records there were no descriptions found about the patient's own will and wishes. No significant differences were found between the two groups regarding age, gender and residence (Table 1).

The differences between the groups in the first investigation showed that patients described as participating in end-of-life care had significantly more neoplasm, musculoskeletal disease, and other symptoms or problems (pain, sleeplessness, fatigue,

**Table 1.** Demographic variables for the total number of deceased patients comparing the group of patients participating with the group that were not described participating. P-value shows the significant differences between the groups

Variables	Total (%) N = 229 (100%)	Participating in End-of-life care (%) n = 132 (58%)	Not participating in end-of- life care (%) n = 97 (42%)	p-value Fishers exact test (2-tailed)
<b>Age</b>				
Mean	79.9	79.5	80.4	0.618 <sup>a</sup>
<b>Gender</b>				
Male	124 (54.1)	67 (50.8)	57 (58.8)	0.229 <sup>b</sup>
Female	105 (45.9)	65 (49.2)	40 (41.2)	
<b>Residence</b>				
Private home	115 (50.2)	71 (53.8)	44 (45.4)	0.230 <sup>b</sup>
Residential care facilities	114 (49.8)	61 (46.2)	53 (54.6)	

<sup>a</sup>t-test; <sup>b</sup>Fishers exact test.

feeding problems, nausea/vomiting, urinary incontinence, anxiety, depression, ankle swelling, diarrhea, and various degrees of deterioration) than the group that did not participate. They also had more hospital-based inpatient care and care in private homes. Patients not described as participating had significantly more mental disorder (dementia and cognitive impairment) and disorientation regarding time,

room, or person. Table 2 shows all these variables for the total number of deceased patients, with the group of patients that participated compared with the group that did not participate.

In the next investigation odds ratios and 95% confidence intervals were made and are presented to illustrate the relation between significant predicting variables and the patients' participation (Table 3).

**Table 2.** Health Related variables for the total number of deceased patients participating or not participating at the end-of-life

Variables	Total (%) N = 229 (100%)	Participating in end of life care (%) n = 132 (58%)	Not participating in the end of life care (%) n = 97 (42%)	p-value Fishers exact test (2- tailed)
<b>Physical function</b>				
ADL dependent	109 (47.6)	66 (50)	43 (44.3)	0.424
<b>Cognitive function</b>				
Disoriented to time, room, and/or person	70 (30.6)	34 (25.8)	36 (37.1)	0.081
<b>Chronic diseases</b>				
Circulatory disease	151 (65.9)	87 (65.9)	64 (66.0)	1.000
Neoplasm	82 (35.8)	55 (41.7)	27 (27.8)	0.037
Mental disorder	65 (28.4)	30 (22.7)	35 (36.1)	0.037
Endocrine and metabolic disease	61 (26.6)	39 (29.5)	22 (22.7)	0.290
Respiratory disease	34 (14.8)	23 (17.4)	11 (11.3)	0.259
Musculoskeletal disease	34 (14.8)	26 (19.7)	8 (8.2)	0.023
<b>Symptom/problem</b>				
Pain	192 (83.8)	123 (93.2)	69 (71.1)	0.000
Dyspnea	139 (60.7)	84 (63.6)	55 (56.7)	0.338
Sleeplessness	75 (32.5)	55 (41.7)	20 (20.6)	0.001
Fatigue	174 (76.0)	114 (86.4)	60 (61.9)	0.000
Feeding problem	119 (52.0)	82 (62.1)	37 (38.1)	0.000
Nausea/vomiting	105 (45.9)	76 (57.6)	29 (29.9)	0.000
Urinary incontinence	130 (56.8)	91 (68.9)	39 (40.2)	0.000
Anxiety	130 (56.8)	99 (74.9)	40 (41.2)	0.000
Condition of deterioration	155 (67.7)	102 (77.3)	53 (54.6)	0.000
Depression	57 (24.9)	48 (36.4)	90 (9.3)	0.000
Ankle swelling	85 (37.1)	57 (43.2)	28 (28.9)	0.028
Skin irritation/ulcer	84 (36.7)	55 (41.7)	29 (29.9)	0.073
Cough	57 (24.9)	38 (28.8)	19 (19.6)	0.124
Wheezing	69 (30.1)	43 (32.6)	26 (26.8)	0.384
Difficulty in swallowing	53 (23.1)	31 (23.5)	22 (22.7)	1.000
Loss of weight	55 (24.0)	37 (28.0)	18 (18.6)	0.118
Constipation	55 (24.0)	37 (28.0)	18 (18.6)	0.118
Diarrhea	54 (23.6)	40 (30.3)	14 (14.4)	0.007
<b>Where care was provided</b>				
Hospital-based inpatient care	144 (62.9)	92 (69.7)	52 (53.6)	0.018
Hospital-based outpatient care	134 (58.5)	81 (61.2)	52 (53.6)	0.223
GP services	136 (59.5)	77 (58.3)	59 (60.8)	0.786
Residential care services	123 (53.7)	75 (56.7)	50 (51.5)	0.503
Private homes	67 (29.3)	47 (35.6)	20 (20.6)	0.018
<b>Technologies</b>				
Urinary catheter	107 (46.7)	59 (44.9)	48 (49.5)	0.504
Oxygen treatment	86 (37.6)	52 (39.4)	34 (35.1)	0.581
Artificial liquid treatment	86 (37.6)	54 (40.9)	32 (33.0)	0.269



**Table 3.** *The significant relations between patients' participation in care and health related variables including 95% confident interval (N = 229)*

Variables	Odds ratio	95% confidence limits	
Depression	3.561	1.592	8.685
Urinary incontinence	3.304	1.716	6.521
Pain	2.971	1.180	7.968
Musculoskeletal disease	2.889	1.140	8.141
Fatigue	2.304	1.041	5.167
Nausea/vomiting	1.932	1.007	3.722
Disoriented to time, room, and/or person	0.471	0.231	0.944

Depression is the most closely related variable for patients participating in end-of-life care followed by urinary incontinence, pain, musculoskeletal disease, fatigue, and nausea/vomiting. Disorientation to time, room or person is negatively connected to patients' chances to participate in care and treatment at the end-of-life. Fifty-nine profiles identified among the 229 patients show the patients' different degrees of probability for participating in care at the end-of-life when a combination of predictive variables occurred. The most typical profile of patient participation in end-of-life care is the one with an estimated probability of 98%, which includes: patients with depression, urinary incontinence, musculoskeletal disease, pain, fatigue, and nausea/vomiting. The lowest probability profile with an estimated probability of 4% is for disoriented patients with no other symptoms/problems and diseases described in the documentation.

## DISCUSSION

Almost 50 % of the medical and nursing records lack any information that described patients' participation in care at the end-of-life. The study showed that these patients were significantly more likely to suffer from dementia and were disoriented to time, location, and/or person compared with the patients who were involved in some way or other in their care and treatment. It is a well-known fact that patients with cognitive dysfunction are one of the most vulnerable groups regarding participation in healthcare, resulting in inadequate information regarding patients' wishes, which may lead to insufficient palliative treatment (Nolan et al., 2005; Aminoff & Adunsky, 2005; Mahon & Sorrell, 2008). To ensure quality of care, it is necessary to assess disoriented patients' wishes, as well as to plan carefully in order to establish special skills, knowledge, and

empathy among the healthcare professionals involved (Eldh et al., 2006; van Thiel & van Delden, 2001). Black and Osman (2005) point out the importance of making a distinction between patients' capacity and competence. Although involvement in care for patients with cognitive dysfunction is problematic, this does not mean that it is impossible, but further investigation is needed to find innovative solutions to this problem, if the necessity of patients' active involvement in care is ever to become a reality for everybody (Holmerova et al., 2007). According to documentation in healthcare records, we found indication that the more problematic patients' situations relate to symptoms/problems, the more they are involved in care and treatments. Some of the most common symptoms/problems for patients at the end-of-life are pain, fatigue, depression, nausea/vomiting, and urinary incontinence (Nordgren & Sorensen, 2003).

Patients with disorientation to time, location, and/or person had fewer symptoms documented, which has been shown in several other studies. This means that subsequently, patients with cognitive dysfunction are underestimated regarding symptoms/problems at the end-of-life (Hall et al., 2002; Klinkenberg et al., 2004; Oi-Ling et al., 2005). This could be seen as natural but the problem is that patients with cognitive impairment do not express their wishes in the same way as people who are cognitively unimpaired (Chochinov, 2006). Our results indicate that the documentation lacks important information that might make these patients more involved in their care and treatments.

Inadequate notes in the patients' records could indeed point to a problem in documentation, which is recognized as a discrepancy between patients' expressions and healthcare professionals' descriptions, especially when related to patients with cognitive dysfunction at the end-of-life (Hegarty et al., 2005; Nordgren & Sorensen, 2003). It is important to develop improved standards for documentation, and policies for healthcare professionals, in order to deal with the wishes of patients and to guarantee them quality of care at the end-of-life. Further research related to patients' participation in end-of-life care is necessary, and special attention must be focused on patients with different kinds of cognitive dysfunction.

## Study Limitations

We have chosen to study participation in healthcare through retrospective reviews of medical and nursing records. Findings must be interpreted in the context of the strengths and limitations of such data sources. Studies have shown that there are discrepancies

between the content of patients' healthcare records and patients' self-reported problems. Notes in documentation regarding patients' participation are short and sometimes inadequate (Nordgren & Sorensen, 2003; Hegarty et al., 2005; Kirchhoff et al., 2004). Furthermore, this specific data set represents a combination of subjective symptoms voiced by the individuals themselves, and indicators by professional caregivers.

## CONCLUSIONS

This study demonstrates patients' participation in end-of-life care as it was noted in the patients' documentation. Patients with dementia and disorientation to time, location, and/or person lacked a variety of descriptions in their records about their will and wishes. Cognitively unimpaired patients' problem/symptoms and wishes were described in an extensive way.

These findings demonstrate that descriptions in the records about patient participation were not visible for patients with cognitive dysfunction, as compared with records for those patients who were cognitively unimpaired. Even if involvement in care for patients with cognitive dysfunction is problematic, it does not mean that it is impossible. Further investigation is needed to find innovative solutions to this problem. There is a need for improvement of documentation showing the patients involvement in care, and for a discussion on how to assure patients a high quality care at end-of-life even if patients' voices are not heard.

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## REFERENCES

Hälso- och sjukvårdslagen (SFS 1982:763). [The Health and Medical Service Act] Ministry of Health and Social Affairs in Sweden, 1982 [in Swedish].

Patientjournalagen (SFS 1993:20). [Regulations and advisory instructions on the Patient Record Act] Ministry of Health and Social Affairs in Sweden, 1993 [in Swedish].

Aminoff, B.Z. & Adunsky, A. (2005). Dying dementia patients: Too much suffering, too little palliation. *American Journal of Hospice & Palliative care*, 22, 344–348.

Bottorff, J.L., Steele, R., Davies, B., et al. (2000). Facilitating day-to-day decision making in palliative care. *Cancer Nursing*, 23, 141–150.

Black, K. & Osman, H. (2005). Concerned about client decision-making capacity? Considerations for practice. *Care Management Journal*, 6, 50–51.

Cahill, J. (1998). Patient participation: A review of the literature. *Journal of Clinical Nursing*, 7, 119–128.

Chochinov, H.M. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *Cancer Journal for Clinicians*, 56, 84–105.

Donaldson, M.S. & Field, M.J. (1998). Measuring quality of care at the end of life. *Archives of Internal Medicine*, 158, 121–128.

Eldh, A.C., Ehnfors, M. & Ekman, I. (2004). The phenomena of participation and non-participation in health care: Experiences of patients attending a nurse-led clinic for chronic heart failure. *Archives of Internal Medicine*, 3, 239–246.

Eldh, A.C., Ekman, I. & Ehnfors, M. (2006). Conditions for patient participation and non-participation in health care. *Nursing Ethics*, 13, 503–514.

Hall, P., Schroder, C. & Weaver, L. (2002). The last 48 hours of life in long-term care: A focused chart audit. *Journal of the American Geriatrics Society*, 50, 501–506.

Hegarty, M., Hammond, L., Parish, K., et al. (2005). Nursing documentation: Non-physical dimensions of end-of-life care in acute wards. *International Journal of Palliative Nursing*, 11, 632–636.

Holmerova, I., Juraskova, B., Kalvach, Z., et al. (2007). Dignity and palliative care in dementia. *Journal of Nutrition, Health & Aging*, 11, 489–494.

Hosmer, D.W., Hosmer, T., Le Cessie, S., et al. (1997). A comparison of goodness-of-fit tests for the logistic regression model. *Statistics in Medicine*, 16, 965–980.

Hudson, P.A.S., Krisjanson, L.J. & Quinn, K. (2005). Minimising gate-keeping in palliative care research. *European Journal of Palliative Care*, 12, 165–169.

Ingleton, C. & Seymour, J.E. (2001). Analysing qualitative data: Examples from two studies of end-of-life care. *International Journal of Palliative Nursing*, 7, 227–233.

Kirchhoff, K.T., Anumandla, P.R., Foth, K.T., et al. (2004). Documentation on withdrawal of life support in adult patients in the intensive care unit. *American Journal of Critical Care*, 13, 328–334.

Klinkenberg, M., Willems, D.L., van der Wal, G., et al. (2004). Symptom burden in the last week of life. *Journal of Pain and Symptom Management*, 27, 5–13.

Mahon, M.M. & Sorrell, J.M. (2008). Palliative care for people with Alzheimer's disease. *Nursing Philosophy*, 9, 110–120.

Nolan, M.T., Hughes, M., Narendra, D.P., et al. (2005). When patients lack capacity: The roles that patients with terminal diagnoses would choose for their physicians and loved ones in making medical decisions. *Journal of Pain and Symptom Management*, 30, 342–353.

Nordgren, L. & Sorensen, S. (2003). Symptoms experienced in the last six months of life in patients with end-stage heart failure. *European Journal of Cardiovascular Nursing*, 2, 213–217.

Oi-Ling, K., Man-Wah, D.T. & Kam-Hung, D.N. (2005). Symptom distress as rated by advanced cancer patients, caregivers and physicians in the last week of life. *Palliative Medicine*, 19, 228–233.

Randers, I. & Mattiasson, A.C. (2004). Autonomy and integrity: Upholding older adult patients' dignity. *Journal of Advanced Nursing*, 45, 63–71.

Sahlberg-Blom, E., Ternstedt, B.M. & Johansson, J.E. (2000). Patient participation in decision making at the

- end of life as seen by a close relative. *Nursing Ethics*, 7, 296–313.
- Sainio, C., Lauri, S. & Eriksson, E. (2001). Cancer patients' views and experiences of participation in care and decision making. *Nursing Ethics*, 8, 97–113.
- Schroder, A., Ahlstrom, G. & Larsson, B.W. (2006). Patients' perceptions of the concept of the quality of care in the psychiatric setting: A phenomenographic study. *Journal of Clinical Nursing*, 15, 93–102.
- Singer, P.A., Martin, D.K. & Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *Journal of the American Medical Association*, 281, 163–168.
- Steinhauser, K.E., Christakis, N.A., Clipp, E.C., et al. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association*, 284, 2476–2482.
- Stewart, A.L., Teno, J., Patrick, D.L., et al. (1999). The concept of quality of life of dying persons in the context of health care. *Journal of Pain and Symptom Management*, 17, 93–108.
- van Thiel, G.J. & van Delden, J.J. (2001). The principle of respect for autonomy in the care of nursing home residents. *Nursing Ethics*, 8, 419–431.
- World Health Organization. (2001). *International Classification of Function, Disability and Health (ICF)*. Geneva: World Health Organization.
- World Medical Association Declaration of Helsinki (2004). Ethical principles for medical research involving human subjects. *International Journal of Bioethics*, 15, 124–129.