

Severity of Illness – Implications for Information Management by Patients

Ragnhild HELLESØ^a, Johannes EINES^b, Lena SORESENSEN^c
and May Solveig FAGERMOEN^{a,b}

^a *Faculty of Medicine, Institute of Nursing and Health Sciences, University of Oslo, Norway*

^b *Oslo University Hospital Trust, Research Centre, Oslo, Norway*

^c *Massachusetts General Hospital Institute of Health Professions, Boston, MA, USA*

Abstract. As more and more people are living with chronic diseases, there is a greater need for patients to have access to accurate and reliable information about health in general and their own health care in particular. In this study we explored how patients suffering from chronic heart insufficiency who needed post-hospital home nursing care assessed their need for health information and their use of the health information they received. Fourteen patients were interviewed in their homes one week after their discharge. Using a thematic approach, we identified three main areas: the hospital systems for providing information to patients, how patients processed the information, and how patients managed the information. Next of kin had a significant role in information management for the patient. The patient's condition has implications for his or her ability to manage the information, and therefore it seems important to customize information according to the patient's level of comprehension.

Keywords: Information management, information strategies, chronic heart insufficiency, discharge summary, electronic patient record

1. Introduction

The Norwegian Patient Rights Act gives the patient specific rights with regard to their health information, how they should be informed, and the format in which the information should be presented [1]. Patients suffering from chronic heart failure represent one of the most common reasons for rehospitalization and are recognized as one of the patient groups who most often need inter-organizational care, i.e. they need continued health care after an episode of hospitalization [2, 3]. Although there is little Norwegian data on prevalence, it is estimated that more than 100 000 people of a population of about 4.5 million have chronic heart failure. One third of these patients are hospitalized every year [4]. We know that patients need comprehensive information aimed at self-monitoring, and that for them to successfully manage their disease, many behavioural changes must occur [5][6]. However, the lack of appropriate health information [7], lack of involvement in care, and fragmentation rather than continuity of care impacts the patient's feeling of powerlessness [8-10] and they feel unable to ask questions during their clinical meetings with providers [11]. There is a dearth of studies addressing the information needs of heart failure patients during their post-hospital nursing care.

2. Objectives

The aim of this study was to explore the health information needs and experiences of elderly, chronically ill patients with severe heart insufficiency and their use of the health information that they received.

3. Materials and Methods

This explorative study included patients at a large university hospital in Oslo, the capital of Norway. This hospital has designed a discharge summary, tailored to patients, which includes information from its electronic patient record (EPR) system. The discharge summary is printed out and given to the patient upon discharge.

A convenience sample of patients with heart failure was interviewed. The inclusion criteria were that the patient had been diagnosed with chronic heart insufficiency and needed post-hospital health care at home. During the fall 2007 and spring 2008, 32 patients who fulfilled the inclusion criteria were identified. Ten patients declined to participate and one other patient's next of kin felt the patient was too ill to participate. Although 21 patients consented to participate, seven patients withdrew their consent after their discharge. The condition of another four patients changed dramatically after they had been informed about the study, and they were therefore not included. A total of 14 patients participated in this study.

A unit research nurse identified and informed the patients who fulfilled the inclusion criteria. The same nurse returned later and asked if the patient wanted to participate. In-depth interviews were conducted in each patient's home about one week after they had been discharged. Four of the patients were living with their spouse. When present, the next of kin was also encouraged to describe their experience. Each interview lasted from 30 minutes to one hour.

The study was approved by the regional committee on medical ethics, the research board at the hospital, and the Ombudsman for Privacy in Research. The patients were informed about their rights and the voluntary nature of their participation. The guidelines for the study ensured that confidentiality and anonymity were maintained.

3.1. Analysis

All interviews except one were taped and transcribed. One participant did not allow us to tape-record the interview, but notes were taken. Field notes were taken during each interview, and reflective notes immediately after the completion of all interviews.

A thematic analysis was conducted [12, 13]. Three main themes were identified: 1) systems of information, 2) process of information, and 3) management of information. The text was then organized according to these identified themes and meaning units were then identified within each theme. We referred to Graneheim and Lundman (2004) for guidance during this phase [14]. They define a meaning unit as "words, sentences or paragraphs containing aspects related to each other throughout their content and context" (p. 106). An example of a meaning unit under the theme Systems of Information is "the written information disappeared." A matrix with the themes was made to facilitate the identification of categories and subcategories.

4. Results

A total of 32 patients fulfilled the inclusion criteria, but 13 women and five men did not participate for various reasons. Fourteen patients were interviewed, eight women and

six men, mean age 79.6, range 71-93. Four had their spouse present during the interview. All patients had had several prior hospitalizations. The 18 patients who did not participate had a mean age of 83.0, range 70-93 years.

4.1. The system of information

The hospital used a combination of oral and written communication to inform the patients during their hospital stay. Oral information varied along a continuum from one-way communication to a dialogue between the patient and the health care provider. Occasionally a family member was present, but the patients in the present study said that they thought that the hospital had no routines for involving next of kin. The information was sometimes given in an imperative form, such as “you have to take this pill” or “you have to stop using this medicine”. Patients also experienced that health care providers had conversations “above my head” and felt they were not included in discussions concerning their own health care situations. “They [the providers] spoke Latin above my head”, are an example of patients' statements.

Written information, i.e. the discharge summary designed by the hospital and/or standard written information about heart diseases, was handed to the patient at his/her discharge. Prior to discharge, oral information from the physicians was periodically given, usually in connection with an examination or during the daily rounds. Sometimes the physician had a conversation with the patient on the day of discharge; however, not all patients felt that they had been given additional information before discharge. Furthermore, patients generally thought that physicians, not nurses, were responsible for giving information to the patients. One patient stated that “the nurses don't do that [give information]”, another that the nurses “are not allowed to do that.” However, it became clear that the nurses also informed patients regularly, but that patients did not regard this as information. Situations where nurses provided information to the patient were related to specific tasks and interventions: “I got clear information [when they come with the medication].” The nurses also informed the patient when he or she needed a specific treatment. Apparently, the patients did not regard these instructions as information.

The content of information varied and covered a broad range of themes. The level and details of the information differed with respect to the time frame, from situation-specific information at the hospital to a more overall and long-term perspective. The expressions that patients used to describe the information they had received were in lay terms, such as “they spoke about the water I had in my body.” Lack of information about their health condition, prognosis and future concerned some of the patients. Patients reported that when they received information they were often not in a position to absorb it due to the severity of their disease at that time, as illustrated by this quote: “I was so ill and weak that I could hardly manage to listen to the provider's information”.

4.2. The process of information

Two categories were identified within this theme: what the patients did with the information, and their comprehension of the received information.

Even if the patient summary was designed for the patient, we found that it was more the exception than the rule that the patient actually read the summary. Nearly all of the patients reported that they handed the information over to either their next of kin or to their providers, i.e. their homecare nurse or their physician. Patients experienced that

neither the homecare nurses nor their physician had received sufficient information about them.

The degree to which the patient understood the information varied on a continuum from low to high. The level of comprehension was influenced by personal attributes, such as problems in remembering the information or reading difficulties; some patients were too fatigued to focus on information, and some were frightened and anxious due to their poor state of health. Others stated that the information was unclear: "I don't understand everything." Their problems resulted in difficulties in managing changes in their medication regimes and also in following up recommendations for improving their health care and for preventing rehospitalization. Problems in management of their medication and activities of daily living were also the reasons why they needed nursing care at home. Patients who reported a high level of understanding often had a family member who had helped them by translating the written information to their level of understanding.

4.3. Information management by patients

We found that the patients used two completely different strategies with regard to information management: some stated explicitly that they wanted information and others were reluctant to receive information. Patients who said that they did not want too much information also said that they felt the information could worsen their situation and this frightened them. Other patients took an active approach to obtaining the information they wanted. Such patients said they wanted the information because they found it helpful. Even if they did not always understand the information, they had a positive attitude toward receiving information: "I always ask for the summary. Even if I don't understand everything, I find it useful to read."

For all the patients, it was important that somebody helped them to manage the information to ensure that prescriptions and recommendations were followed up, because they were too exhausted to do it themselves. The role of the next of kin in the information management became evident. On the other hand, the patients usually had a strategy for how much the next of kin should be involved in the information management. They struggled between having control over their own situation and being dependent on others.

5. Discussion and conclusion

The patients who participated in this study had severe heart failure; they were frail and needed nursing care in their homes. It was clear that the information received by these was neither sufficient nor appropriate, which made it difficult for them to understand it or to manage their daily health situation. They were dependent on family members to manage the information.

Although the information summary that patients received when they were discharged from the hospital was customized and intended for the patient, it also served as an information source for both home care nurses and the patient's GP. This study revealed that patients often felt responsible for ensuring that their nurses and physician received sufficient information after their discharge. For this purpose, they used the discharge information. Insufficient information exchange and collaboration across organizational levels in health care is well documented [15-18]. This study shows how patients themselves have to compensate for this insufficiency. Hellesø et al. (2005)

found that it was most frequently the patients who were responsible for informing the health care providers so as to ensure continuity of care [19].

For frail and severely ill persons, it is important to involve the patients' next of kin. The patients in this study stated that it would have been helpful if their next of kin had been present, especially at the time of discharge, but also when oral information was given to them during the hospital stay. However, they experienced that this was not an option. The state of health has implications for how patients can manage the information, and therefore it seems important to customize the information with regard to their level of comprehension.

The patients who consented to participate, however, had a lower mean age than those who were not able to participate. This raises an important question as to how we can approach the oldest and most severely ill patients to learn about their information needs and develop adequate information systems for them.

6. References

- [1] Helse- og omsorgsdepartementet. Nasjonal helseplan. 2006-2010.
- [2] Hofseth C, Norvoll R. Kommunehelsetjenesten - gamle og nye utfordringer: en studie av sykepleietjenesten i sykehjem og hjemmesykepleien. Oslo: SINTEF Unimed; 2003.
- [3] Helse- og omsorgsdepartementet. Fra stykkevis til helt. En sammenhengende helsetjeneste. Oslo; 2005.
- [4] Gullestad L, Madsen S. Moderne diagnostikk og behandling av kronisk hjertesvikt. *Tidsskrift for Den Norske Lægeforening*. 2004;8:1107-10.
- [5] Jaarsma T, Abu-Saad HH, Dracup K, Halfens R. Self-care behaviour of patients with heart failure. *Scand J Caring Sci*. 2000;14(2):112-19.
- [6] Jaarsma T, Halfens R, Tan F, Abu-Saad HH, Huijter H, Dracup K, et al. Self-care and quality of life in patients with advanced heart failure: The effect of a supportive educational intervention. *The Journal of Acute and Critical Care*. 2000;29(5):319-30.
- [7] Holte TO, Bjertnæs ØA, Stavem K. Er det sammenheng mellom sykehusstørrelse og pasienterfaringer. *Tidsskrift for Den Norske Lægeforening*. 2005;125(12):1685-8.
- [8] Efraimsson E, Rasmussen BH, Gilje F, Sandman P. Expressions of power and powerlessness in discharge planning: a case study of an older woman on her way home. *J Clin Nurs*. 2003;12(5):707-16.
- [9] Bull MJ, Luo D, Maruyama GM. Measuring continuity of elders' posthospital care. *J Nurs Meas*. 2000;8(1):41-60.
- [10] Doherty C, Doherty W. Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. *J Nurs Manag*. 2005;13:119-27.
- [11] Rogers AE, Addington-Hall JM, Abern J, McCoy AMS, Bulpitt C, Coats AJS, et al. Knowledge and communication difficulties for patients with chronic heart failure. *BMJ*. 2000;321:605-07.
- [12] Malterud K. Kvalitative metoder i medisinsk forskning: en innføring. 2. utg. ed. Oslo: Universitetsforl. 2003.
- [13] Thagaard T. Systematikk og innlevelse: en innføring i kvalitativ metode. 2 ed. Bergen: Fagbokforlaget 2003.
- [14] Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24:105-12.
- [15] Tjerbo T, Kjekshus LE. Coordinating health care: lessons from Norway. *International Journal of Integrated Care*. 2005;5 (November).
- [16] Hellesø R, Lorensen M, Sorensen L, Normann L, Bang K. Management of Information between Two Nursing Contexts. In: Park H-A, Murray P, Delaney C, editors. *Consumer-Centered Computer-Supported Care for Healthy People*; 2006; Seoul, Korea: IOS Press; 2006. p. 600-4.
- [17] Kvamme OJ, Olesen F, Samuelson M. Improving the interface between primary and secondary care: a statement from the European Working Party on Quality in Family Practice. *Qual Health Care*. 2001;10(1):33-9.
- [18] Gronroos E, Perala ML. Home care personnel's perspectives on successful discharge of elderly clients from hospital to home setting. *Scand J Caring Sci*. 2005;19(3):288-95.
- [19] Hellesø R, Sorensen L, Lorensen M. Nurses' information management across complex health care organizations. *Int J Med Inf*. 2005;74:960-72.

Corresponding author: ragnhild.helleso@medisin.uio.no