Supporting Self-care and Collaboration in Stroke Care through Information and Communication Technology

Nadia DAVOODYa,1, Sabine KOCHa, Ingvar KRAKAUb, Maria HÄGGLUNDa

aHealth Informatics Centre, Karolinska Institutet, Stockholm, Sweden
bDepartment of Medicine, Karolinska Institutet, Stockholm, Sweden

Abstract. Teamwork, patient participation and involvement of informal caregivers are growing necessities in health and social care as an increasing amount of patients suffer from multiple long-term conditions requiring care from many care providers and professions. Currently, information and communication technology (ICT) remains designed for use within one healthcare organization, and focus on the work of one individual profession rather than supporting collaborative, inter-professional teamwork including patients and informal caregivers. This paper therefore explores some of the problems different actors involved in a stroke patient’s care process face, which will have an impact on how ICT should be designed to support collaborative, inter-professional teamwork including patients and informal caregivers. This paper therefore explores some of the problems different actors involved in a stroke patient’s care process face, which will have an impact on how ICT should be designed to support patient participation, ensure continuity of care and improve communication and collaboration. Methods: Nine interviews with healthcare professionals were performed in the early phases of a socio-technical design approach to identify problems prior to design of an integrated care and rehabilitation plan. Result: Lack of collaboration and supporting tools hinders health and social care professionals from obtaining a holistic view of the patient care process. Poor patient participation and insufficient interaction between health and social care providers and patients confirm the need for tools to improve teamwork and to meet patients and informal caregivers’ information and communication needs.

Keywords. Information system, patient participation, stroke, continuity of patient care

Introduction

Teamwork, both within and between healthcare organizations is an increasing necessity and has the potential to improve care outcomes, and to have a positive impact on patient care [1]. Studies also advocate patient participation [2, 3] and indicate that improved health outcomes are associated with increased patient involvement [4, 5]. Currently, there is however limited support for collaboration, leading to fragmentation and poor continuity of care [6]. It is therefore crucial to design appropriate Information and Communication Technology (ICT) [7, 8]. Shared care planning has been suggested as one such tool [9, 10]. The main purpose of our research is therefore to examine how a tool for care and rehabilitation planning used by patients with chronic or long-term illnesses should be designed to improve collaboration, patient participation, autonomy

1 Corresponding Author. Nadia Davoody, PhD student; Health Informatics Centre, Karolinska Institutet, Berzelius väg 3, 17177 Stockholm, Sweden; Email: nadia.davoody@ki.se
and self-care. In this paper, focus is on describing the underlying problems in stroke care that motivate the redesign and introduction of improved ICT.

1. Methods

A socio-technical design approach focusing on the joint optimization of technical and social aspects of a system is used [11, 12]. User centered design is also applied to meet the necessary local requirements as well as the user needs [13].

Stroke care is chosen as the clinical context of our research since stroke patients often have different degrees of disabilities (physical, cognitive and psychosocial) and require multi-professional care, ranging from acute and specialist neurological care to subsequent long-term rehabilitation and homecare. Initial data collection consists of a number of interviews (n=9) with a stroke coordinator (SC, n=1), general practitioners (GP, n=2) and districts nurses (DN, n=6) in primary care. Further interviews with other health and social care professionals, as well as patients and relatives, are planned and the results will be triangulated with other qualitative methods such as observations and focus group meetings to provide conclusions that are more valid [14]. Qualitative content analysis will be used to analyze data collected through interviews, observations and focus group meetings.

2. Results

Based on interviews with health care professionals, the research group identified several improvement areas in the care process of stroke patients that can be supported through ICT. According to the interviews “since stroke team, social care workers, and primary care professionals have their own care and rehabilitation planning process for stroke patients and no team gets involved in the other ones, a holistic view of the patient care process and a common vision of a patient’s treatment are missing” (DN1). An additional problem according to the interviews is that “the municipality has no responsibility for the health care information despite the fact that stroke patients who receive care at home usually have a need for both healthcare and social care resources and their cooperation” (SC). Lack of patient participation and poor interaction between patients and/or informal caregivers and families with health care professionals are other weak points identified in the stroke care process.

These results confirm that there is a need of tools to improve collaboration between different actors involved in stroke patients’ home care and to meet patients and informal caregivers’ information and communication needs. Health care professionals also describe the need for a tool that supports patients in self-care and secondary prevention; “such a tool could provide more information to patients and remind them to perform activities in order to reduce the risk of a second stroke” (GP2).

In this project, focus is on insufficient collaboration between actors involved in the care process of stroke patients, inadequate continuity of care, poor patient participation and lack of informal caregiver involvement in the care process. A prototype, ‘My care plan’, will be developed that will be a tool for care and rehabilitation planning as a means to improve collaboration between patients and healthcare staff and a tool to enable long-term reporting and monitoring of an individual's health status.
3. Discussion

The project is in the early stages of needs analysis, and the direction of developed prototypes may shift as a deeper understanding of problems and socio-technical aspects emerges. We do however believe that the main issues, i.e. improved multi-professional collaboration and inter-organizational teamwork and improved participation of patients and family carers, will remain stable.

Other challenges that the project faces are the adaption of the tool ‘My care plan’ to individual stroke patients’ physical and cognitive impairments. Patient privacy and autonomy and other ethical considerations are also challenges that will be addressed in the project: who should have access to patient information, how can patients control access rights, and how are relationships between patients and informal caregivers affected by these types of systems?

The main focus of this research is however on producing new knowledge about how care of stroke patients is provided today and an improved understanding of how it can be supported using ICT. The project will also support health and social care providers to gain a better understanding of patients’ information and communication needs, homecare processes and other care providers' roles in relation to these stroke care processes. Most importantly, the project will provide important knowledge about how a tool for care and rehabilitation planning should be designed to support long-term inter-organizational collaboration in patient-centered health and social care.

Reference


