Stroke patients’ post-discharge information needs and actual information provision

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Abstract Information provision to stroke patients and their carers are of great importance. Despite efforts from care providers, studies show that there is still lack of supporting tools and patients and their carers still suffer from unmet information needs. This paper explores the patients’ desired information needs and actual information provision as input for the process of designing a supportive information system to be used by stroke patients post-discharge. Methods: Thirteen interviews with care professionals and three focus group meetings with post-discharge stroke patients were performed. Data were analysed using qualitative content analysis. Results: Patients’ desired information needs differ from actual information provision. Patients seek peer support from other stroke patients and are interested in receiving individualized health information whereas care professionals focus on treatment and risk factors.

Keywords. Stroke, information system, content analysis

Introduction

Rehabilitation plays a significant role in stroke patients’ recovery process. To support stroke patients in their rehabilitation process at home, provision of relevant information is crucial [1, 2]. Despite many attempts to provide information [3], stroke patients and informal carers experience unmet information needs [4]. Studies indicate that better methods of providing information are needed [5]. We have started designing an electronic care and rehabilitation plan aiming to support patients by providing general information about stroke and individualized information about the patients’ care and rehabilitation needs as well as self-management functionality. In order to support integration of such a tool into current care and rehabilitation processes, it is of great importance to investigate the patients’ information needs and the current information provision by care professionals in primary care and home rehabilitation.

1. Methods

Thirteen in-depth semi-structured interviews with open-ended questions with care professionals and three focus group meetings with four post-discharge stroke patients were performed. One-to-one interviews with follow-up questions provided a deep understanding of information provision by each care professional and group dynamic in focus group meetings enhanced data collection regarding patients’ information needs.

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A purposive selection of care professionals consisted of 3 physicians, 5 registered nurses, whereof 2 work mainly in homecare, as well as 4 members of a home rehabilitation team (neuro team), namely one speech therapist, one occupational therapist, one counsellor and one physiotherapist. Focus group participants were a convenience sample recruited through a patient organization. Each interview lasted an average of 1 hour and each focus group meeting 2 hours. Qualitative content analysis was used to analyse the data. Categories were identified and verified by 2 researchers.

2. Results

Table 1 illustrates the stroke patients’ desired information needs and the actual information provision by care providers, and the differences are highlighted.

Table 1. Desired information needs and actual information provision

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3. Discussion

Preliminary results indicate that basing the design of a tool exclusively on either patients experienced needs or care professionals current information provision risks creating a system that is not fully useful to either group. More detailed analysis of the differences are needed, but indications are that patients look for a holistic view of the illness, personalized health information, peer support from other patients in similar situations and coping strategies while care professionals mostly focus on preventive actions. Further research on what implications these differences may have on the design of a supportive e-health tool is needed.

References