REVIEW ARTICLE (META-ANALYSIS)

Patients' Views on the Impact of Stroke on Their Roles and Self: A Thematic Synthesis of Qualitative Studies

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Abstract

Objective: To synthesize patients' views on the impact of stroke on their roles and self.

Data Sources: PubMed, CINAHL, Embase, PsycINFO, and Cochrane searched from inception to September 2010, using a combination of relevant Medical Subject Headings and free-text terms. This search was supplemented by reference tracking.

Study Selection: Qualitative studies reporting the views of people poststroke. The search yielded 494 records. Opinion articles, quantitative studies, or those reporting somatic functioning were excluded. Thirty-three studies were included.

Data Extraction: Data extraction involved identifying all text presented as "results" or "findings" in the included studies, and importing this into software for the analysis of qualitative data.

Data Synthesis: The abstracted text was coded and then subject to a thematic analysis and synthesis, which was discussed and agreed by the research team. Three overarching themes were identified: (1) managing discontinuity is a struggle; (2) regaining roles: to continue or adapt? and (3) context influences management of roles and self. Regaining valued roles and self was an ongoing struggle, and discontinuity and uncertainty were central to the adjustment process after stroke.

Conclusions: The thematic synthesis provides new insights into the poststroke experience. Regaining or developing a new self and roles was problematic. Interventions targeted at self-management should be focused on the recognition of this problem and included in rehabilitation, to facilitate adjustment and continuity as far as possible in life poststroke.

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Stroke is a major cause of disability worldwide.[1] A stroke may affect physical, cognitive, social, and emotional functioning. Although some empirical studies[2,3] recommend that rehabilitation programs pay attention to the psychological impact of stroke, this does not always happen.[4] Persons with stroke report feeling not ready to manage their daily life when discharged[4] and lacking support to regain former and new roles.[5] Roles are sets of connected behaviors, rights, and obligations related to social status, identity, and self.[6] Self can be described as a cognitive representation a person makes of his/her identity.[7] Identity is the fact of being who or what a person is, and a social identity refers to a collection of roles a person has in the society.[6,8]

Self-management interventions may enable people to manage their lives, roles, and self after stroke.[9] Wilkinson and Whitehead[10] define self-management as "an individual's ability, in conjunction with family, community and health care professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease."[10(p1145)] Three types of self-management for people with

chronic diseases have been identified[11,12]: (1) medical (behavioral) management, which is about dealing with the illness; (2) emotional management, which refers to coping with the emotions associated with the illness and experienced changes; and (3) role management, which is about the way people continue their normal life and regain and maintain roles.[13]

Before designing a self-management program, and tailoring it to the needs of people after stroke, we first wanted to understand the patients' perspectives about the impact of stroke on their roles and self, and how they regained their roles and self after stroke.

Although there are some primary studies about how persons with stroke experience the process of regaining their self and roles after stroke, these have not been systematically reviewed. Syntheses of qualitative research are a well-established form of systematic literature review that draws together findings of qualitative studies to contribute new understandings of patients' perspectives.[14-17] Noblit and Hare[16] published one of the first books about synthesizing qualitative studies in 1988. In a synthesis, findings of single studies with a variety of designs, methods, populations, and time frames are analyzed, synthesized, and integrated with the aim to "attain a level of conceptual and theoretical development beyond that achieved in any individual empirical study."[15(p672)]

A thematic synthesis was performed to gain a better understanding of poststroke experiences of stroke patients.[18] Campbell et al[15] suggest that syntheses of qualitative research give a stronger voice to patients' perspectives than single studies do. Our synthesis addressed the question, "How do persons with stroke view the impact of stroke on their roles and self?"

Methods

The method was a 4-stage thematic synthesis of qualitative studies.[18] The first stage was searching the literature and selecting relevant primary studies. Next, the included studies were subjected to a quality appraisal. The third stage was data extraction. Finally, descriptive and analytical themes were identified that reflected the perceptions of persons with stroke concerning the impact of stroke on roles and self.

Search strategy and selection criteria

Five relevant electronic databases were searched from inception to September 2010. The databases were PubMed, CINAHL, Embase, PsycINFO, and Cochrane. A librarian was consulted to refine the search terms and strategies. The search question was divided into 4 concepts: stroke, role or self, management (of role or self), and the process of adaptation after stroke. The individual concepts have been searched with thesaurus terms (eg, Medical Subject Headings [MeSH]) or free text terms. The index terms for each database were used. Search terms were exploded and combined. The search in PubMed was as follows (appendix 1): (stroke[MeSH] OR stroke OR cerebrovascular accident OR cerebrovascular disease) AND (role[MeSH] OR ego[MeSH] OR self OR role) AND (self care [MeSH] OR self management OR role management OR self management OR self care) AND (adaptation, psychological

[MeSH] OR social adjustment[MeSH] OR emotions[MeSH] OR adaptation OR adjustment OR transition OR transformation OR coping). Searching of cited references was also done. The search term "qualitative" or related terms were not used because each database uses different index terms, which makes it problematic to locate qualitative studies.[19] Selection of qualitative studies was done in the abstract selection by the first 2 authors (T.S., E.C.).

Qualitative studies were included if they contained original data describing the perceptions of persons with stroke on their role, self, and/or the management of these factors. Reviews, opinion articles, quantitative studies, or studies with findings only at the level of body function were excluded. Studies in which the perceptions of the persons with stroke could not be separated from other patient groups were also excluded. When multiple reports of the same study were found, the articles were compared and only selected if each article presented distinct findings, based on different study aims and questions about the same material.

Quality appraisal

The Critical Appraisal Skills Program (CASP) tool[20] for reviewing qualitative studies was used to appraise the methodological quality of the studies. The items, which are, for example, referring to the study aim, study design, data collection, and data analysis, were scored with "yes" or "no," depending on whether the topic was described sufficiently. An additional score of "unclear" was added to differentiate between sufficiently and insufficiently. This resulted in 3 options: 1, $\frac{1}{2}$, and 0. The higher the total score, the better the methodological quality, with a maximum score of 10. The studies were independently appraised by the first 2 authors. Any difference in item and total scoring was resolved through discussion. The purpose of the quality appraisal was to ascertain the methodological quality of the studies included in the synthesis.

Data extraction, analysis, and synthesis

The data extraction stage involved identifying text labeled as "results" or "findings" in the selected studies, and importing this data into Atlas.ti qualitative analysis software.[a] Theoretical perspectives or discussion of findings by primary authors were not extracted. If different client groups were interviewed in the same study, only the findings related to persons poststroke were extracted.

The data analysis and synthesis consisted of 3 steps.[18] First, the extracted text was read as a whole, and meaningful segments in the text were labeled with a free code. Meaningful segments were parts of the text such as quotations or metaphors from participants, and phrases from authors of the primary data, and often consisted of more than 1 line or sentence. Free codes were described by the first author (T.S.) and paralleled the meaning and content of the segments of the primary data. At the next step, the coded meaningful segments were organized into related areas to develop descriptive themes. A descriptive theme was a theme that stayed close to the original meaning of the primary data. Finally, the descriptive themes were discussed, and more abstract and analytical themes were developed. This involved developing interpretations that go beyond the primary studies. Concept mapping supported the discussion and the process of generating the descriptive and analytical themes. The first author (T.S.) performed all steps. The second author (E.C.) served as peer reviewer during the process of coding, and the development of descriptive and analytical themes. The process and content of the steps were regularly discussed with the whole research team.

List of abbreviations:

CASP	Critical Appraisal Skills Program
MeSH	Medical Subject Headings