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Feature Article

Meaning in stroke family caregiving: A literature review

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ABSTRACT

Meaning plays an important role in stroke family caregiving. Understanding meaning facilitates the development of effective interventions that support stroke family caregivers. However, knowledge about this subject is fragmented and sparse. This review fills this knowledge gap by examining existing findings regarding meanings in stroke family caregiving. Specifically, a search of seven databases and a manual search produced a total of five articles for review. Embedded in the lived experience of caregivers, meanings in stroke family caregiving were interpreted as a physical, psychological, and social suffering; an obligation resulting from moral ethics, religion doctrines, others' expectations, and social norms; and a subjective choice based on love, hope, and a sense of reciprocity. However, the detailed process of how and when caregivers identify meaning in caregiving needs further exploration. To gain a full picture of meaning in caregiving, more studies should be conducted among stroke family caregivers from different cultural, economic, and social backgrounds.

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Introduction

Interest in caregiving issues is growing along with the increasing attention on the aging population and chronic illnesses.¹ A large number of family members become family caregivers who provide support to their loved ones who are older, sick or disabled.² As one of the leading causes of death and disability in the world, stroke exerts a significant effect not only on patients but also on family caregivers.^{3–5} A large body of research examines the burdens and negative consequences of stroke family caregiving.^{1,4–6} However, evidence also indicates that caregivers can perceive benefits in their caregiving experience, such as an increased satisfaction to life, a feeling of being needed and appreciated, and the development of a positive attitude toward life.^{7,8}

The issue on the differences between family caregivers who adapt and thrive under demanding circumstances and those who report a compromised well-being has attracted the attention of numerous researchers.^{9–11} A number of researchers have tried to explore this topic by exploring meaning in caregiving.^{9–11} Meaning in caregiving has emerged from the coping and adaptation literature with the potential to explain some of the variations in caregiver outcomes.¹² The individual differences in the meanings perceived through caregiving may lead to different

reactions to caregiving and thus result in different caregiving consequences.^{9–11,13} Farran et al¹⁴ found that the absence of meaning in caregiving may result in despair and hopelessness. Caregivers who fail to find meaning in caregiving may endure anxiety and depression and develop a low self-esteem. By contrast, caregivers who are able to find positive meaning in caregiving and derive something positive out of it could reinforce their desire to provide care.¹⁵ Konstam et al¹⁶ suggested that finding positive meaning in caregiving is the key to understanding well-being among caregivers of patients with Parkinson's disease and is a source of empowerment.

Efforts have been made to uncover the meaning in caregiving among caregivers of patients with long-term illnesses, such as dementia,^{17,18} cancer,^{19,20} and HIV.²¹ However, given that stroke family caregivers usually assumed their roles suddenly and with barely enough preparation, their caregiving experience and perceived meaning may be different from those of caregivers of people with other chronic illnesses. Therefore, an understanding of the meaning in caregiving among stroke family caregivers is needed to inform the development of individualized interventions that effectively support stroke family caregivers.

This review was aimed at exploring the meaning in caregiving among stroke family caregivers. The objectives were to summarize the studies related to the purpose of this review published from 2000 to 2015; to identify reported meanings in the caregiving experiences of family members looking after stroke survivors; and to make recommendations for future research in this area of inquiry.

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Table 1
Quality assessment for qualitative studies.

Criteria	Bäckström and Sundin ²⁵	Wallengren et al ²⁶	Wallengren et al ²⁷	Bäckström et al ²⁸	Kitzmüller et al ²⁹
1. Is there a clear connection to an existing body of knowledge/wider theoretical framework?	1	1	1	1	1
2. Are research methods appropriate to the question being asked?	1	1	1	1	1
3. Is the description of the context for the study clear and sufficiently detailed?	1	1	1	1	1
4. Is the description of the method clear and sufficiently detailed to be replicated?	1	1	1	1	1
5. Is there an adequate description of the sampling strategy?	0	0	0	0	0
6. Is the method of data analysis appropriate and justified?	1	1	1	1	1
7. Are procedures for data analysis clearly described and in sufficient detail?	1	1	1	1	1
8. Is there evidence that the data analysis involved more than one researcher?	1	0	0	0	1
9. Are the participants adequately described?	1	1	1	0	0
10. Are the findings presented in an accessible and easy to follow manner?	1	1	1	1	1
11. Is sufficient original evidence provided to support the relationship between interpretation and evidence?	1	1	1	1	1
Agreed total score	10	9	9	8	9

Maximum possible score 11 and minimum 0.

Methods

Search strategies

A computerized literature search was conducted from 2000 to 2015. Seven databases were searched: AMED, CINAHL Plus, EMBASE, MEDLINE, PsycINFO, 中國期刊全文數據庫 China Journal Net (CJN), and 萬方數據 WanFang Data. The search terms included stroke AND (caregiver* OR carer* OR caregiving OR caring) AND (meaning* OR meaning-making OR meaning-searching OR meaning-finding OR meaning-seeking). Chinese research terms included (“腦卒中” OR “中風” OR “腦血管意外”) AND (“照顧者” OR “家屬” OR “配偶” OR “子女”) AND (“意義” OR “尋找意義” OR “意義構建”). A manual search was also conducted to identify relevant articles from reference lists.

A stroke family caregiver refers to an unpaid or a not professionally trained caregiver who provides care to a partner, spouse, relative, or friend who suffers from a stroke in the acute, rehabilitation, or chronic phase. All study designs, including the quantitative, qualitative, and mixed-method studies, were included. Studies published in either English or Chinese with a focus on caregivers' experiences, emotions, and responses regarding meaning were included. The exclusion criteria covered (i) the studies that were not peer reviewed, (ii) those with full text that cannot be extracted; (iii) those without primary data or with data for caregivers and care recipients that cannot be clearly stated or separated; (iv) those that focused on one stroke-related condition and excluded general experiences or those that focused on improving service/research instead of reporting the caregiving experience related to meaning.

Quality appraisal

The quality of the articles was appraised with an 11-item rating scale developed by Greenwood et al^{22,23} in their reviews of informal primary caregivers of stroke survivors. The items in the scale were based on the strategies used by Mays and Pope²⁴ in their qualitative research assessment. These items were not intended to exclude articles but were used to systematically investigate and question the content of the papers. Items include, for example, whether the method is suitable for the research question and whether the descriptions of the method and data analysis are sufficiently clear and detailed to be replicated. Table 1 outlines all the items included in the scale. The rating scale is easy to apply and can lead to a close agreement between different critics. The total score ranges from 0 to 11.²² A higher score indicates more quality elements is recorded in the study.²²

Data abstraction and synthesis

The two authors (JZ and DL) independently extracted data from each eligible study. Information about the characteristics of the informants and the methodological characteristics of the studies, such as the study setting, research design, and sampling methods, was described to provide a context for data synthesis.

The data were synthesized by using the thematic synthesis method developed by Thomas and Harden.^{30,31} This method has been used in several systematic reviews that address questions about people's perceptions and experiences.³¹ Thematic synthesis is aimed at achieving analytical abstraction at a higher level by rigorously examining the overlaps and elements that are common among primary studies.^{30,31} Thematic synthesis was performed in the current review to explore the meanings in caregiving among stroke family caregivers. The detailed synthesis process involves three steps: free line-by-line coding of the findings of primary studies, organization of these “free codes” into related areas to construct “descriptive” themes, and development of “analytical” themes.^{30,31} In the first step, the authors (JZ and DL) independently extracted and synthesized study findings using free line-by-line coding to generate codes. The primary studies were read several times to achieve immersion. The participant quotations and text under the “findings” or “discussion” sections of the included studies were extracted. Then, the authors (JZ and DL) independently coded each line of the text according to the purpose of the review. The second step was to organize the codes into descriptive themes. The similarities and differences among the initial codes were discussed and compared by the two authors (JZ and DL). Similar codes were then grouped together and translated into new codes that captured the meanings of the groups of initial codes. New codes were also created when necessary. The agreement upon the new codes between the authors (JZ and DL) resulted in a preliminary synthesis (i.e., descriptive themes) of the meanings in caregiving among stroke family caregivers. The last step was to achieve new interpretations of the meanings in caregiving that went beyond the primary studies. The preliminary findings were reviewed by the authors (JZ and DL) independently to ensure that key data were captured from the included studies. Then, the descriptive themes were abstracted and reinterpreted inductively to produce abstract and analytical themes. Discrepancies were discussed by the authors (JZ and DL), and the analytical themes were agreed upon.

Results

The search identified 646 articles (637 articles through database search and 9 articles from manual search) (Fig. 1). All articles were

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