Int J Clin Exp Med 2019;12(8):9738-9746
www.ijcem.com /ISSN:1940-5901/IJCEM0096490

Original Article

Meta-integration of care and burden quality research for Chinese patients with chronic diseases

Xiaoxi Li[1], Yingying Li[2], Jingjing Hu[3], Hui Peng[4], Xuqi He[5], Youxin Kuang[6], Meiqiong Zheng[2]

Departments of [1]Nursing, [2]Haematology, [3]Respiratory and Critical Care Medicine, [4]Traditional Chinese Medicine, [5]Ophthalmology, [6]International Medical Center, Zhengzhou University People's Hospital, Henan Provincial People's Hospital, Henan University People's Hospital, Zhengzhou, Henan, China

Received May 5, 2019; Accepted June 25, 2019; Epub August 15, 2019; Published August 30, 2019

Abstract: Objective: To use meta's analytical method to evaluate the impact of burdens on patients with chronic diseases in China. Methods: Search the PubMed, EBSCO, EMBase, CINAHL, and Cochrane databases with the keywords of "chronic disease caregiver/carer quality of life/China"; search in CNKI, Wanfang database and VIP database with the keywords of "chronic disease" and "caregiver/tender/carer", "quality of life", "qualitative research" and "China"; the search date is up to 1 July 2018. The analysis data of all relevant qualitative research of income is based on the qualitative research quality evaluation (2016) of the JBI Evidence-Based Health Care Centre in Australia, and the results were integrated and analyzed using the meta integration method. Results: A total of 12 related literatures were found out; 40 results were refined and classified into 5 genera, and 2 integration results were synthesized. Integration results 1: adverse effects will be brought to family members' life due to stress and overburden in the process of care. But slowly they have accepted the disease and tried to cope with it over time; finally they get a sense of achivement; integration results 2: due to the fact that patients lack self-care ability, the caregivers are short of professional care skills and facing enormous economic pressures. They are looking forward to helping from local governments and health systems. Conclusion: In the process of care for patients with chronic diseases, support, guidance and encouragement should be given to establish and improve the hospital-community-family-society continuity nursing service system.

Keywords: Chronic disease patients, caregivers, qualitative research, meta-integration

Introduction

Chronic diseases usually refer to non-infectious diseases, which is a general term of diseases caused by long-term accumulation of various factors. It incudes cardiovascular and cerebrovascular diseases, diabetes, malignant tumors, chronic obstructive pulmonary disease, mental disorders and mental illness. Patients' self-care ability will be limited by these diseases. Some patients need to rely on the care of others [1]. The life expectancy of human beings has been increased year by year with the improvement of living standards, and the population aging has become the focus of global attention [2].

With the increase of age, the elderly's function of various organs has obviously declined. According to the relevant survey results, each elderly has an average of 2-3 chronic diseases [3], and the service demand of the caregiver increases. Based on the fact that the medical security system in China is not yet sound, and that Confucian traditional cultural has far-reaching influence on Chinses, family support is still common in China [3]. It requires family members (including children, spouses, etc.) to provide careful attention and long-lasting care services to patients. The physical and mental health of the caregiver has been greatly affected by the long-term and heavy care. As the closest families to the patient, the caregiver not only has to bear the pressure of the patient's illness, but also is responsible for the long-term care [3]. The stress and burden of illness on relatives has also become the focus of more and more researchers. In recent years, in addition to the publication of more relevant quantitative researches, some researchers have used qualitative research methods to study the care and care experience of chronic disease caregivers during the nursing process [4]. Unlike quantitative research, qualitative research is more focused on specific situations and people in specific situations. The purpose of this research is to understand the process of events, situations, experiences and actions and their impact on caregivers [5]. Through qualitative research, we can further explore the feelings and experiences of relatives when they care the patients [6]. The purpose of this paper is to comprehensively analyze and explain the specific care experience of chronic diseases relatives by collecting relevant qualitative findings and combining meta-integration methods.

Method

Research purposes

The burden of Chinese relatives of patients with chronic diseases during the care process.

Search strategy

Search the PubMed, EBSCO, EMBase, CINAHL, and Cochrane databases with the keywords of "Chronic disease caregiver/carer quality of life/China"; search in CNKI, Wanfang database and VIP database with the keywords of "chronic disease" and "caregiver/tender/carer", "quality of life", "qualitative research" and "China"; the search date is up to 1 July 2018.

Inclusion standards of literature

Type of study: the type of literature included is qualitative.

Subjects: The primary caregiver of patients with chronic diseases is an adult, and is the main family member of the patient (such as husband or wife, parents, children, mother-in-law, etc.). They have been taking care of the patient for more than 3 months.

Research content: the burden of caregivers.

Excluding standards of the literature

Although the term "qualitative study" is used in the literature, it is fundamentally different from qualitative research.

Quality evaluation of the included studies

Two researchers independently evaluated the quality of the included research literature based on the relevant evaluation principles developed by the JBI Evidence-Based Health Care Center for qualitative research. Then they compare the evaluation results of the two parties. When they have different opinions, the two parties fully discuss and analyze until the opinions are consistent.

Data extraction

Carefully read the full text of the included studies and extract key data from the research, such as research purposes, research methods, and topics, research year, research location, research case, research data collection, and research main result.

Data analysis methods

Repeately read, understand, and analyze the research results using a manual integration method to combine similar results. New categories are formed, and finally the new categories are summarized as the final integration results, which in turn form new concepts and explanations.

Results

Inclusion of research literature

According to the established search strategy and the screening results of the literature search, a total of 1032 articles were detected in the initial inspection. After reading the text, a total of 33 articles related to the subject and research purposes were screened out. After reading the full text of those 33 articles, based on the inclusion criteria and exclusion criteria selected in this study, 12 articles were selected. 8 of them were in Chinese and 4 of them were in English. After the quality evaluation, 12 articles were finally included (Chan WC [7], Zeng L [8], Zhao XP [9], Liu XY, 2015 [10], Qin Y, 2009 [11], Bai JJ, 2006 [12], Zhang R, 2008 [13], Mu FJ, 2012 [14], Wei BY, 2016 [15], Wu YF [16], 2012, Mei YX, 2014 [17], and He J [18]). The basic characteristics of the literature included are shown in **Table 1**.

Quality results of the literature

The quality of the selected literature was evaluated based on the relevant evaluation principles developed by the JBI Evidence-Based Health Care Center for qualitative research

Table 1. Baseline data of the included studies

Study	Year	Location	Case	Methods	Data collection	Main result
Chan WC [4]	2010	Hong Kong	27	Phenomenology	Focus group interview	1 Difficulties in care: bathing, defecation
						2 Physical overdraft
						3 Self-blame, sad
						4 Economic burden heavy
Zeng L [5]	2014	Shang Hai	12	Phenomenology	Semi-structured interview	1 Heavy financial burden
						2 Avoid troublesome others
Zhao XP [6]	2012	Jiangsu	18	Phenomenology	Semi-structured interview	1 Insufficient care capacity: lack of rehabilitation knowledge, blindness of medication, lack of basic nursing skills, unmet need for health information
						2 Physical and mental exhaustion: physical exhaustion, life rhythm disruption, heavy economic pressure, helplessness, weak social support system
Liu XY [7]	2015	Shanxi	10	Phenomenology	Semi-structured interview	1 Lack of knowledge
						2 Lack of communication
						3 Inner worry
						4 Physical strength is not supported
						5 Economic pressure
Qin Y [8]	2009	Guizhou	20	Phenomenology	Unstructured interview	1 Emotional response
						2 The body burden is aggravated
						3 Economic burden is too heavy
						4 Separation from groups and society
						5 Facing the problem of nursing problems
						6 Marriage life satisfaction is reduced
Bai JJ [9]	2006	Guangzhou	12	Phenomenology	Semi-structured interview	1 The mind is overburdened (fear of anxiety, self-blame, sadness, frustration, fear of inferiority)
						2 Careful tasks (excessive physical overdraft/social activities are affected)
						3 Economic burden is too heavy
						4 Lack of care skills
						5 The patient's care problem is difficult (patient difficulty in bowel movement, patient bathing problem, violence)
Zhang R [10]	2008	Beijing	10	Phenomenology	Semi-structured interview	1 The character of the loved one changes and loses the intimacy of the past
						2 Care items are cumbersome
						3 Physical fatigue
						4 Emotional frustration
						5 Uncertainty about the future
						6 Individual time is limited, personal career is frustrated/family. Reduced friend communication
						7 Patient needs to bring satisfaction
Mu FJ [11]	2012	Shanghai	10	Not clear	Semi-structured interview	1 Fear, worry
						2 On the verge of collapse
						3 Economic burden is too heavy
						4 Lack of private time
Wei BY [12]	2016	Shandong	9	Phenomenology	Unstructured interview	1 The pressure on the patient's family after facing the patient's illness
						2 Self-adjustment and support of the patient's family
						3 Face the decision and significance of signing patients DNR (rejecting cardiopulmonary resuscitation)
						4 The feelings of the family members of the patients during the accompanying process
Wu YF [13]	2012	Shanghai	7	Phenomenology	In-depth interview	1 Overburdened
						2 Lose self
						3 Eager to help
						4 Achieve value
Mei YX [14]	2014	Henan	8	Phenomenology	In-depth interview	1 Care for the burden: exhausted, worried

						2 Different attitudes: bad fate, responsibility, role adaptation, belief
						3 Positive experience: mother and child are intimate, mother and child are companionship, fullness
						4 Need support: family support, medical help, social support
He J [15]	2016	Beijing	10	Phenomenology	Semi-structured interview	1 Individual time is limited, personal career is frustrated, reduced friend communication
						2 Self-adjustment and support of the patient's family
						3 Economic burden is too heavy
						4 The feelings of the family members of the patients during the accompanying process

(**Table 2**). According to the results of the quality evaluation, only 12 studies indicated that they have adopted the method of qualitative research, and have not elaborated the relevant philosophical basis of the research. So it is still not clear whether the philosophical foundations and methodologies selected by the 12 studies are consistent. In the process of qualitative research, researchers played an important role in the research process. But the 12 studies did not describe the cultural background and personal value of the researchers, nor did they describe the mutual influence between researchers and research. So the above research lacks detailed introduction to the researchers. In addition to the philosophical foundations and researchers, these studies were well evaluated in other areas. Therefore, all of these 12 studies were eventually included.

Meta-integration results

New categories: By repeatedly reading, understanding, analyzing and interpreting the 12 studies included, the researchers extracted 40 clear and accurate results, classified the similar items of the results, and then obtained 5 new categories (**Figure 1**). Category 1: Caregiver's great physical and mental stress; Category 2: Trouble in caring and caring ability; Category 3: Economic pressure; Category 4: Self-adjustment and social assistance; Category 5: A sense of accomplishment. Through the continuous analysis and understanding of the included research results, the classification are reintroduced and re-integrated (**Figures 2-6**).

New integration results: After integrating several studies, the meta-integration results of this study indicate that the caregiver experience of patients with chronic diseases presented a dynamic changing process, which can be divided into three stages: despair-adaptation-sense of accomplishment (**Figure 7**). Despair: In the long-term care for patients, the caregiver bears a huge burden on the body, mind and economy. They aslo suffer reduced life satisfaction, lack of care knowledge and skills, enhanced sense of guilt and fear of death. They desire for professional help. Adaptation: with the increase of care time, the caregiver gradually learns to authorize and effectively adjust the psychological balance. Physical and mental exhaustion are reduced. Sense of accomplishment: The caregiver gradually establishes a relationship of attachment to the patient. Effective care can give the caregiver a sense of satisfaction and happiness.

In the caring process of patients with chronic diseases, caregivers bear enormous economic pressures and the are short of professional skills. They expect care and support from the family, community, society and government (**Figure 8**).

Discussion

The scientific significance of meta-integration

The production of scientific evidence needs to be evaluated, integrated and re-evaluated, which is based on evidence-based nursing. And we are now in the physiological-psychological-social medical model. In order to promote the development of holistic nursing, nursing decision makers and researchers must pay full attention to the physical, psychological, social and moral health of human beings [19, 20]. This also means that evidence-based nursing should incorporate both quantitative and qualitative research results. Meta-integration, as a research system method to fully explain

Table 2. Quality evaluation results of the included studies

Evaluation principle	Is the philosophical foundation consistent with the methodology?	Is the methodology and data collection method consistent?	Is the methodology consistent with data analysis?	Whether the methodology is consistent with the interpretation of the results?	Does it explain the situation of the researcher from the perspective of cultural background and values?	Whether to explain the influence of the researcher on the research, or the impact of the research on the researcher?	Is the subject typical? Whether it fully represents the research object and its viewpoint?	Does the study comply with current ethical norms?	Does the conclusion come from the analysis and interpretation of the data?
Chan WC [4]	Not mentioned	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Zeng L [5]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Zhao XP [6]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Liu XY [7]	Not mentioned	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Qin Y [8]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Bai JJ [9]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Zhang R [10]	Not mentioned	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mu FJ [12]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Wei BY [12]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Wu YF [13]	Not mentioned	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Mei YX [14]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes
He J [15]	Not mentioned	Yes	Yes	Yes	No	No	Yes	Yes	Yes

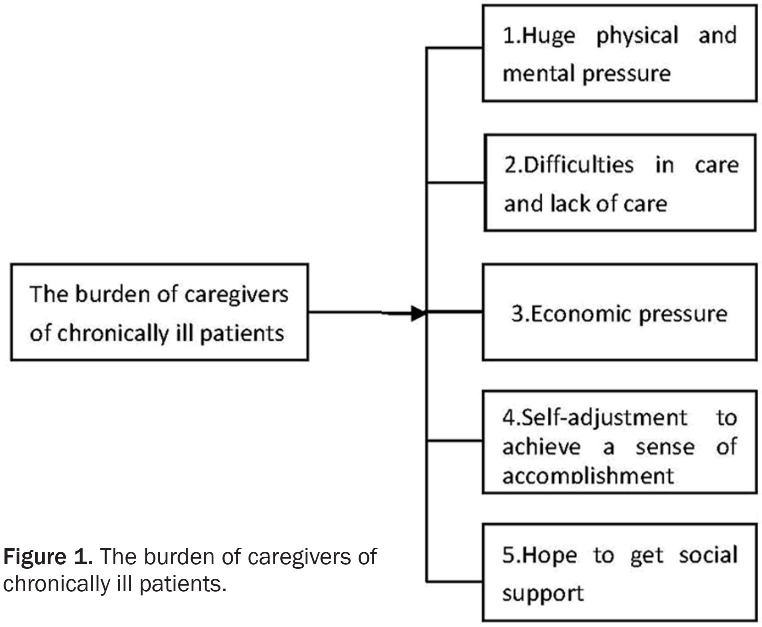

Figure 1. The burden of caregivers of chronically ill patients.

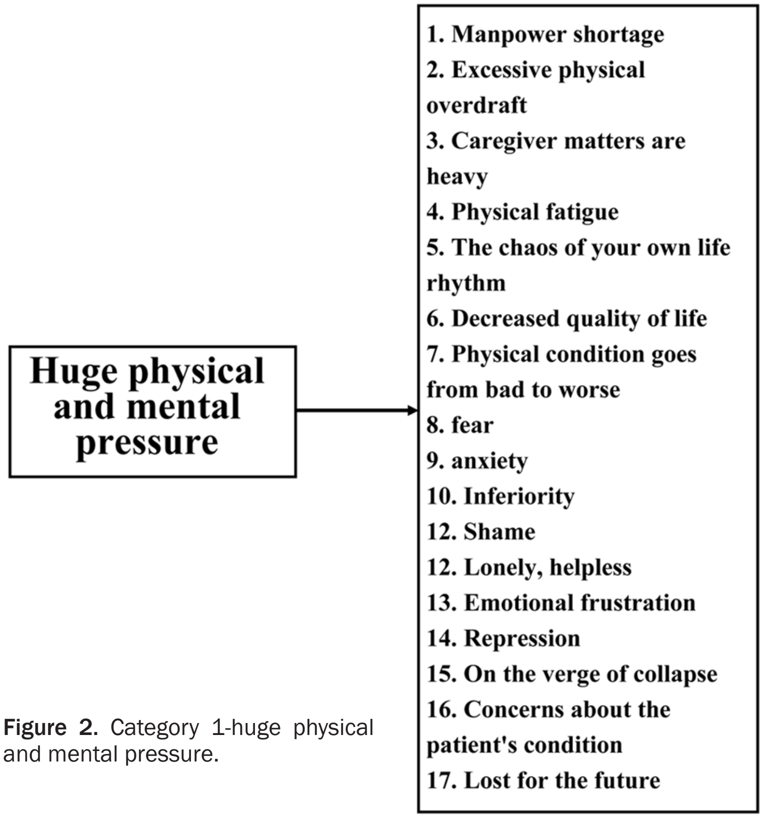

Figure 2. Category 1-huge physical and mental pressure.

the qualitative of phenomena, is based on the premise of fully understanding the philosophical thoughts of each primitive qualitative research and its methodology [21]. Meta-integration deepens the connotation of concepts, effectively promotes qualitative research results and perfectly interprets the definition of care. It can make corresponding judgments and treatments on existing or potential human health problems [22]. In this study, 12 studies were obtained through rigorous screening. They were evaluated, understood, analyzed, summarized, integrated into 40 results and formed into 5 categories. And finally 2 integrated results were obtained, hopping to further provide ideas of care experience for caregivers of chronic diseases.

Meta-integration results

Analysis of the research results of various researchers shows that the psychological pressure and huge sacrifice of the patient's relatives are the most significant care experience. Even if the caregiver finally gets help and support on the spiritual level, it is just the ultimate sublimation of spiritual realm of the caregiver after tremendous efforts, huge sacrifices and self-adjusting throughout the care process. The chronic diseases inherently require high-load and long-term care activities. If the patient care activity is completely or mainly responsible by relatives in the family, the long-term care activities are accompanied by the deterioration of the patient. The nursing relatives will certainly bear tremendous psychological pressure and sacrifice experience during the nursing process. After adjustment and change, the spiritual realm of the nursing relatives has been gradually sublimated. This is also the adaptation that the nursing relatives can gradually present during the care activities within the family. This change is worthy of recognition and admirable.

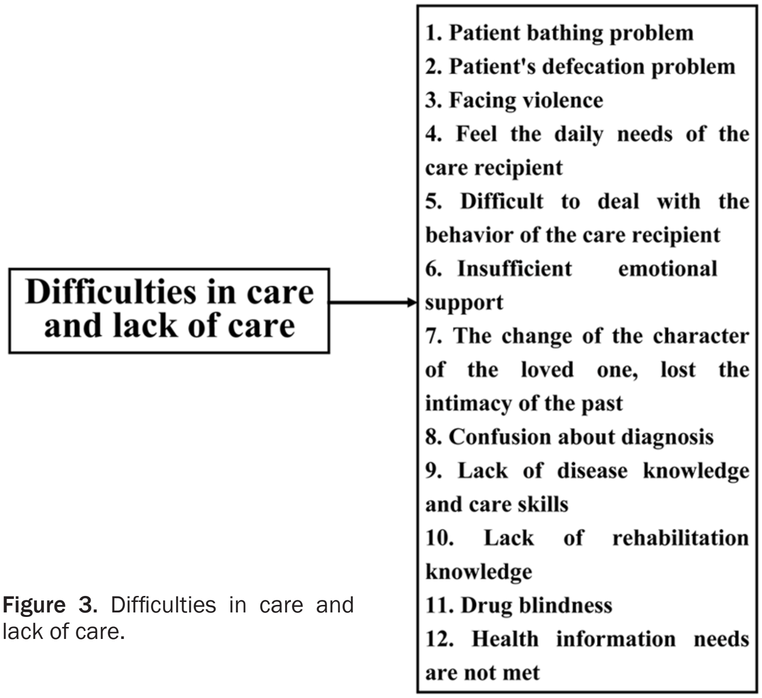

Figure 3. Difficulties in care and lack of care.

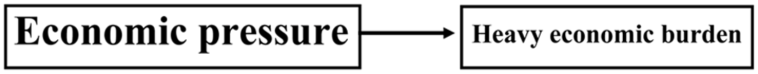

Figure 4. Economic pressure.

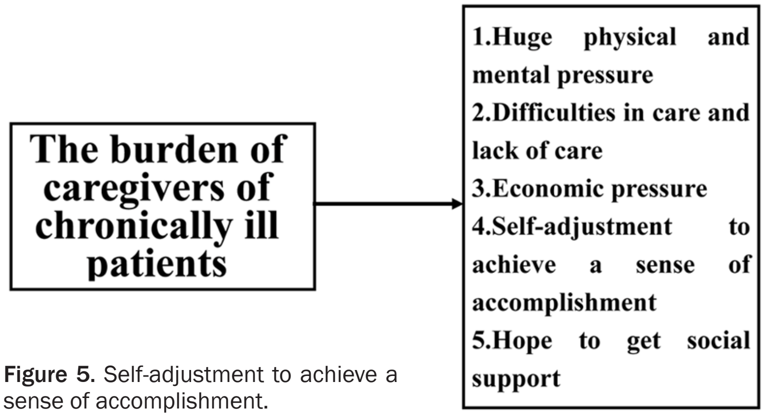

Figure 5. Self-adjustment to achieve a sense of accomplishment.

Comparison with quantitative research results

The results of this study are basically consistent with the results of quantitative studies by comparison with quantitative research results. By collecting, collating, and analyzing the relevant care behaviors of the primary caregivers for Alzheimer's patients, Josep M et al. [23] found that caregivers are not able to fully guarantee patient's safety. They are lack of relevant nursing knowledge to help patients recover, which is consistent with the fact that the study's caregivers are facing with "difficult disease care". From the related research results of psychological burden status and family care of chronic disease caregivers, Cond [24], Cil Akincil [25] and others found that caregivers often need to bear a moderate psychological and stress burden. Long-term care for the patient every day eventually leads great pressure to caregiver's body and mind. This result is highly consistent with the results of the "physical fatigue" and "psychological stress" of the caregiver in this study. However, the positive results of "self-adjustment and seeking for help" and "psychological motivation and acquisition" in this study did not appear in the results of previous quantitative studies. We can see that qualitative research plays great role in analyzing the experience of caregivers. Therefore, in the later study of experience process, it is recommended that the qualitative research method should be treated as the main method or the qualitative research should be put in the quantitative research.

Recommendations

Due to the limited human resources and family economic conditions of the hospital, most patients choose to go home or go to the community for post-rehabilitation. From the literature retrieved, we found that the utilization rate of community health services is low, and most of the patients' families do not understand the function of the community. This often means that the patient's family will bear the full responsibility for taking care of the patient alone [26]. Interviews with caregivers show that lack of rehabilitation knowledge and care skills is the common problems of caregivers, and they are eager to

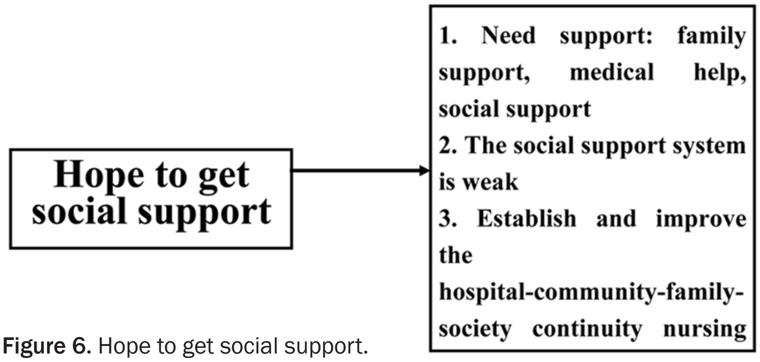

Figure 6. Hope to get social support.

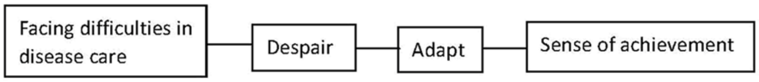

Figure 7. Meta-integration results 1.

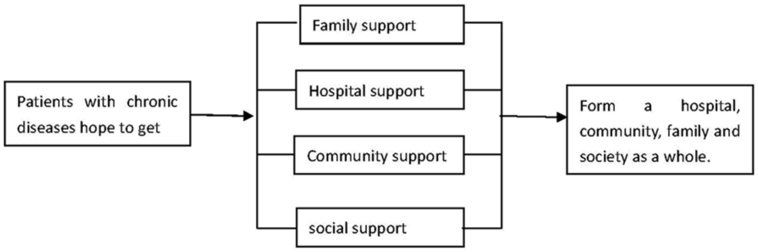

Figure 8. Meta-integration results 2. Note: This paper is a meta-integration analysis of qualitative research. Since the included literatures are all qualitative studies, the results of the included studies are the emotional experience of the caregiver, so no data and related controls are involved.

get professional helps to improve their care ability. It is recommended to establish a incorporated and continuous care model of hospital-community-family. The medical staff can evaluate the willingness, knowledge and skills of the primary caregiver during the hospitalization. According to the assessment results, the training guides the caregivers to learn appropriate nursing skills, and significantly reduces their care pressure and improves the quality of care [27]. At the same time, the government should increase the support for chronic diseases and strengthen the role of the community in the rehabilitation period of patients [28].

Conclusion

During the care process of patients with chronic diseases, the relatives of patients with chronic diseases first need to face the strangeness and difficulty of nursing. It is also accompanied by physical exertion, huge psychological pressure and heavy economic burden. And then through self-adaptation, adjustment and seeking for help from society and the government, they were finally sublimated to satisfaction. The influence of patients with chronic diseases on their family members should be highly valued by the government, medical and health institutions and the public. In the process of care, support, guidance and encouragement should be given to establish an incorporated and continuous care model of hospital-community-family. By increasing the psychological quality and ability to cope with diseases, the physical and mental health of patients with chronic diseases and their families can be guaranteed.

Acknowledgements

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Disclosure of conflict of interest

None.

Address correspondence to: Meiqiong Zheng, Department of Haematology, Zhengzhou University People's Hospital, Henan Provincial People's Hospital, Henan University People's Hospital, No. 7 Weiwu Road, Jinshui District, Zhengzhou 450003, Henan, China. Tel: +86-0371-65580717; E-mail: mqz717y@163.com

References

[1] Pan DX, Qian YJ, Wang CM, Guo Y, Bian Z, Xie KX, Chen LL, Zhang YD and Li QY. Interaction between smoking and indoor air pollution on chronic obstructive pulmonary diseases. Zhonghua Liu Xing Bing Xue Za Zhi 2016; 37: 1444-1449.
[2] Navab E, Negarandeh R, Peyrovi H and Navab P. Stigma among Iranian family caregivers of patients with Alzheimer's disease: a herme-

neutic study. Nurs Health Sci 2013; 15: 201-206.

[3] Rymer S, Salloway S, Norton L, Malloy P, Correia S and Monast D. Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer disease. Alzheimer Dis Assoc Disord 2002; 16: 248-253.

[4] Hsiao CY and Tsai YF. Caregiver burden and satisfaction in families of individuals with schizophrenia. Nurs Res 2014; 63: 260-269.

[5] Costa-Requena G, Espinosa Val MC and Cristofol R. Caregiver burden in end-of-life care: advanced cancer and final stage of dementia. Palliat Support Care 2015; 13: 583-589.

[6] Ikeda C, Terada S, Oshima E, Hayashi S, Okahisa Y, Takaki M, Inagaki M, Yokota O and Uchitomi Y. Difference in determinants of caregiver burden between amnestic mild cognitive impairment and mild Alzheimer's disease. Psychiatry Res 2015; 226: 242-246.

[7] Chan WC, Ng C, Mok CC, Wong FL, Pang SL and Chiu HF. Lived experience of caregivers of persons with dementia in Hong Kong: a qualitative study. East Asian Arch Psychiatry 2010; 20: 163-168.

[8] Zeng L, Zhu X, Meng X, Mao Y, Wu Q, Shi Y and Zhou L. Responsibility and burden from the perspective of seniors' family caregivers: a qualitative study in Shanghai, China. Int J Clin Exp Med 2014; 7: 1818-1828.

[9] Mohammed S, Swami N, Pope A, Rodin G, Hannon B, Nissim R, Hales S and Zimmermann C. "I didn't want to be in charge and yet I was": bereaved caregivers' accounts of providing home care for family members with advanced cancer. Psychooncology 2018; 27: 1229-1236.

[10] Ong PH, Tai BC, Wong WP, Wee LE, Chen C, Cheong A, Fong NP, Chan KM, Tan BY, Menon E, Lee KK, Ee CH, Petrella R, Thind A and Koh GC. Caregivers: do they make a difference to patient recovery in subacute stroke? Arch Phys Med Rehabil 2017; 98: 2009-2020.

[11] Carod-Artal FJ, Ferreira Coral L, Trizotto DS and Menezes Moreira C. Burden and perceived health status among caregivers of stroke patients. Cerebrovasc Dis 2009; 28: 472-480.

[12] Abdullah L, Luis C, Paris D, Ait-ghezala G, Mouzon B, Allen E, Parrish J, Mullan MA, Ferguson S, Wood M, Crawford F and Mullan M. High serum Abeta and vascular risk factors in first-degree relatives of Alzheimer's disease patients. Mol Med 2009; 15: 95-100.

[13] Smith B, Chur-Hansen A, Neale A and Symon J. Quality of life and cholinesterase inhibitors: a qualitative study of patients with Alzheimer's disease and their carers. Australas Psychiatry 2008; 16: 433-437.

[14] Sevilla-Casado M, Ferre-Grau C and Tahta-Haddouch M. [Death anxiety in nursing: experience in supporting of the death and field care]. Rev Enferm 2012; 35: 52-57.

[15] Inci FH and Temel AB. The effect of the support program on the resilience of female family caregivers of stroke patients: randomized controlled trial. Appl Nurs Res 2016; 32: 233-240.

[16] Chen MC, Palmer MH and Lin SY. Creating a conceptual model for family caregivers of older adults intervention research: a narrative review of learned resourcefulness, resourcefulness, and the transtheoretical model. Geriatr Nurs 2018; 39: 521-527.

[17] Kim M, Cho K and Lee W. Community walking training program improves walking function and social participation in chronic stroke patients. Tohoku J Exp Med 2014; 234: 281-286.

[18] Agren S, Evangelista L and Stromberg A. Do partners of patients with chronic heart failure experience caregiver burden? Eur J Cardiovasc Nurs 2010; 9: 254-262.

[19] Adelman RD, Tmanova LL, Delgado D, Dion S and Lachs MS. Caregiver burden: a clinical review. JAMA 2014; 311: 1052-1060.

[20] Akgul N and Ozdemir L. Caregiver burden among primary caregivers of patients undergoing peripheral blood stem cell transplantation: a cross sectional study. Eur J Oncol Nurs 2014; 18: 372-377.

[21] Mei R and Mei X. Screening of skin lesion-associated genes in patients with psoriasis by meta-integration analysis. Dermatology 2017; 233: 277-288.

[22] Branger C, O'Connell ME and Peacock S. Protocol for a meta-integration: investigating positive aspects of caregiving in dementia. BMJ Open 2018; 8: e021215.

[23] Ota K, Arikawa M, Ohashi S, Azekawa T and Matsumoto T. Factors influencing nursing home placement of patients with dementia: a retrospective, single-centre study in Japan. Psychogeriatrics 2019; 19: 111-116.

[24] Conde-Sala JL, Turro-Garriga O, Calvo-Perxas L, Vilalta-Franch J, Lopez-Pousa S and Garre-Olmo J. Three-year trajectories of caregiver burden in Alzheimer's disease. J Alzheimers Dis 2014; 42: 623-633.

[25] Cil Akinci A and Pinar R. Validity and reliability of turkish caregiver burden scale among family caregivers of haemodialysis patients. J Clin Nurs 2014; 23: 352-360.

[26] Bastawrous M. Caregiver burden-a critical discussion. Int J Nurs Stud 2013; 50: 431-441.

[27] Chi DL, McManus BM and Carle AC. Caregiver burden and preventive dental care use for US children with special health care needs: a stratified analysis based on functional limitation. Matern Child Health J 2014; 18: 882-890.

[28] Tramonti F, Bongioanni P, Leotta R, Puppi I and Rossi B. Age, gender, kinship and caregiver burden in amyotrophic lateral sclerosis. Psychol Health Med 2015; 20: 4.