

A qualitative study of the interaction experiences between family caregivers and community nurses for disabled elderly people at home

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Abstract

Background: Family members are currently the main caregivers of the disabled elderly people at home. With declining health and increasing frailty, caregiving of disabled elderly people becomes a task of family caregivers in conjunction with community nurses. Interaction between family caregivers and community nurses can effectively improve the quality of home care for the disabled elderly people. This study aimed to investigate the interaction experiences between family caregivers and community nurses for disabled elderly people at home.

Methods: This research was a qualitative study based on semi-structured interviews. Qualitative data were collected from family caregivers of the disabled elderly and community nurses in Zhengzhou city, Henan Province. Conceptual content analysis and Colaizzi's method was used to generate qualitative codes and identify themes.

Results: A total of 12 interviews were completed, including 7 family caregivers and 5 community nurses. Three themes were identified: 1) Establish a collaborative relationship ; 2) Get professional support; 3) Factors that promote and hinder the interaction.

Conclusions: Findings from this study suggested that the interaction between family caregivers and community nurses will be very beneficial, which will reduce the burden of family caregivers and improve the quality of care for disabled elderly people. Providing a new perspective that we can develop and implement intervention to facilitate positive interactions and bring the highest quality of care to older adults with disabilities.

Introduction

Population aging has become a worldwide phenomenon, and the concern of elderly care is expanding worldwide [1]. The seventh census of population in China shows that there are 190 million people aged 65 or above, accounting for 13.5% of the total population [2]. Due to the decrease of mortality rate and the extension of life expectancy, the number of the elderly is increasing at the rate of 5.96 million per year. It is predicted that by 2050, China's population above 60 years of age may be reach 498 million [3]. With advancing age, it means the continuous degradation of various physiological functions. This population trend also means that the proportion of people with mental or physical disabilities who are unable to carry out activities of daily living increases [4]. According to statistics, by 2019, there will be more than 40 million disabled and semi disabled elderly people in China, which is expected to reach more than 60 million by 2030 and 96 million by 2050 [5].

“Disability” is an integrative concept that represents the state of incomplete self-care due to various reasons such as old age, disease or physical and mental disorders [6, 7]. With the aging of population, the care problems caused by the increase of the disabled elderly have become increasingly prominent. Most of the disabled elderly are more vulnerable to the pressure brought by the new environment due to the

influence of traditional ideas and physical weakness and aging [8, 9], and are unwilling to choose an unfamiliar environment outside the family and community [10, 11].

To meet the needs of the disabled elderly, the government advocates and encourages home-based care [12]. Both family caregivers and community nurses play an important role in the care of the disabled elderly at home. Their mutual cooperation can effectively improve the quality of home care for the disabled elderly [13]. In the context of home-based care, engagement of community can not only meet the demands of the disabled elderly who are eager for stay-at-home, but also help families provide life care and ensure the quality of care for the disabled elderly [14]. Compared with institutional elder care, community participation in home-based care has the advantages of low cost and high efficiency, which make the demand for community care services of the disabled elderly continue to increase [15]. At present, the family members, with children and spouses as the main body, are still the main providers of home care for the disabled elderly [16]. With the increase of age and disability, the care needs of the disabled elderly at home also increase [17]. However, the trend of family's centralization and miniaturization leads to the decrease of available care manpower in the family [18]. In addition, the burden of long-term care and the lack of time and energy further weaken the function of current care manpower; furthermore, family caregivers are generally deficient in professional caring knowledge and tools, which can not satisfy the requirements of technical care services, resulting in the deficiency of care workforce and ability, which directly affects the quality of care for the disabled elderly [19, 20]. Therefore, in the process of home care for the disabled elderly, the support provided by the family is very limited, and it is difficult to fully realize the long-term care for the disabled elderly. The family's demand for the assistance of long-term professional care from the community is also growing [21].

The collaboration between family caregivers and community professionals' can effectively improve the mental health level of the disabled elderly [22]. Other studies have shown that the establishment of professional community medical and nursing service institutions can take over the care of the disabled elderly when their families can not take care of them, so as to avoid their worries [23, 24]. On the other hand, professional community service institutions can ensure the disabled elderly to seek medical treatment at the first time in case of physical discomfort or emergency, and reduce the treatment risk of the disabled elderly [25]. Community medical staff provide professional and refined services. Family caregivers can replace professionals, provide less technical informal care services. Family caregivers and community nurse coordinate and cooperate, which enable the disabled elderly to live in their familiar environment and receive professional care services [26]. The interactive relationship between community nurses and caregivers provides caregivers with a good way to vent their bad emotions and gain emotional support. Studies have shown that community nurses have established a stable trust relationship with them during continuous family visits, and that caregivers are willing to open up to their difficulties and dissatisfaction, and proactively express their various emotional and social needs [27].

The effective interaction between family caregivers and community nurse is very important in the process of caring for the disabled elderly at home. However, the previous studies on the interaction relationship between family caregivers and medical staff mostly focused on aging service agencies and hospitals,

and did not pay much attention to the contexts of family caregiving in community settings[28–30]. Therefore, this study aims to explore the interactive experience of the two people in caring for the disabled elderly at home from the perspective of family caregivers and community nurses, so as to provide reference significance for future related research.

Methods

Study design and setting

This was a qualitative research study based on semi-structured interviews [31]. Qualitative data were collected from family caregivers and community nurses of home-based disabled elderly people in Zhengzhou, Henan Province, China. All participants provided written informed consent.

Aim

This study aimed to investigate the interaction experiences of family caregivers and community nurses in the process of caring for disabled elderly people at home.

Participants

We finally interviewed 7 family caregivers and 5 community nurses based on the following eligibility criteria. The family caregiver should be: 1) aged ≥ 18 years old; 2) be the family members of the disabled elderly and taking care of the elderly as the main caregiver for more than 3 months. The community service employees should be: 1) aged ≥ 18 years old; 2) the service and management personnel of relevant institutions in the community who often have direct contact with the elderly and provide door-to-door services; 3) having been engaged in community service for more than one year. Exclusion criteria included cognitive disorders, unwillingness to participate or to complete the interview and vacationers and temporary employees.

we recruited participants through purposive samplings from the Community Health Services Center in Zhengzhou City, Henan Province. Firstly we contacted the community nurses and interviewed them after consent. After the interview, community nurses led us to find family caregivers of disabled elderly people who met the inclusion criteria within their jurisdiction. Explain the purpose and significance of the study, and ask if they were willing to participate in the interview. The study has been approved by the ethical review committee of Zhengzhou University (ZZUIRB2021-15).

Data collection

Two primary authors conducted semi-structured interviews with participants in June 2022. One author served as the main interviewer who conversed with participants and the other author was responsible for recording and time management.

Interviews were conducted at Community Health Services Center and family caregivers' homes. Prior to the interview, we introduced the research content and purpose, as well as confidentiality protections, to

participants. They signed an informed consent form if they agreed to participate and granted us permission for recording. The average interview duration was 30 min. The content of interviews included participants' demographic characteristics (i.e., gender, age, highest education level, and living status) and interaction experience, through the following questions. Finally a total of 12 interviews were completed, including 7 family caregivers and 5 community nurses.

Analyses

Two researchers agreed to end the participant recruitment process when no novel information seemed to emerge from participant interviews. Interview records were stored on a secured device to fully protect the privacy of participants. The audio-taped interview will be listened repeatedly and transcribed verbatim. Two investigators will use Colaizzi phenomenological analysis method to work on the data analysis[32, 33]. Before the formal analysis, the interviewees will be coded with letters A-H to process personal sensitive information such as their names. Then Colaizzi phenomenological analysis method is used to extract the effective content, code, classify and simplify the relevant content, extract the theme and return to the interviewees for confirmation, and finally refine the interview theme. The qualitative data analysis focuses on interactive experience of the disabled elderly family caregivers and community nurses.

Results

Demographic characteristics

In this qualitative study, the interviews were conducted in June 2022. Following the principle of data saturation, data collection was ceased once saturation was achieved. Finally a total of 12 interviews were completed, including 7 family caregivers and 5 community nurses. The demographic information for the each participants is illustrated in Table 1 and Table 2.

Table 1
demographic information of family caregivers(N = 7)

number	gender	age	Relationship with the disabled elderly	Time of caring (year)	Degree of disability of the elderly
F1	male	66	son	4	moderate
F2	female	73	daughter	6	moderate
F3	male	82	spouse	5	severe
F4	female	63	daughter	3	severe
F5	male	79	spouse	3	moderate
F6	female	59	daughter	5	severe
F7	male	50	son	3	mild

Table 2
demographic information of community nurses(N = 5)

number	Gender	age	Education level	position	Years worked in community
N1	female	59	junior college	Senior nurse	30
N2	male	34	College degree	Senior nurse	10
N3	female	28	College degree	nurse	5
N4	female	33	College degree	nurse	9
N5	female	36	junior college	Senior nurse	15

After the interview, the recording data of seven disabled elderly family caregivers and five community nurses were transcribed in time, with a total transcription time of 240min. The data were analyzed according to Colaizzi's seven-step analysis of phenomenological data were analyzed repeatedly. Based on the data collection and thematic analysis, three overarching themes and seven subthemes were identified. The theme framework is as follows (See Table 3 for major themes and sub-themes):

Table 3
Themes and sub-themes.

Themes	Sub-themes
1. Establish a collaborative relationship	Mutual communication Availability of community nurses
2. Get professional support	Spiritual consolation Information sharing Practical behavior help
3. Factors that promote and hinder the interaction	Factors that promote the interaction Factors that hinder the interaction

Theme1: Establish a collaborative relationship

Mutual communication

Most family caregivers said they hoped to increase the frequency of communication with community nurses. Caregiver F2: "I don't have much contact with community nurses, and they seldom come here. If only they could come here often." Some caregivers also said that although they wanted to get information from medical staff, they gave up communication for fear of disturbing and bothering community nurses. Caregiver F1: "we also know that people (community nurses) are very busy. Generally, I don't want to give people trouble. Sometimes when I can't help it, I will take the initiative to call them." At present, the communication form between caregivers and community nurses is mainly telephone help, and caregivers hope to have a variety of communication forms with community nurses to achieve effective communication. Caregiver F7: "if the community can visit more, or hold more lectures in the community, this form of face-to-face communication is better."

Availability of community nurses

Some family caregivers said they could get professional help from community nurses and were satisfied with this. Caregiver F3 said, "the nurses in the community are very good and responsible. The stomach tubes inserted by my wife are all made by the community nurses. It's inconvenient for me to go upstairs and downstairs. They let me sit and wait and help me go through the formalities. Thanks to them, others dare not expect anything." However, some caregivers said that the help and resources available from community nurses were limited and could not meet their needs. Caregiver F6: "I really hope the community can send nurses to take care of him for me a little, and let me have a rest and catch my breath.". Other caregivers said that the duration of services provided by community nurses each time was very limited, and in-depth communication was not possible. Caregiver F4: "They (community nurses) seem to have a lot of things to do. They just leave after asking a few questions. They don't have time to

sit down and chat with me, but I really need information and help. I really hope someone will spend more time explaining it to me."

Theme2: Get professional support

Spiritual consolation

Caregivers expect to communicate with community nurses as much as possible about the disease. Caregiver F5: "there is a community nurse who is very good. She often asks her about some diseases by phone. She has a good attitude and is very grateful to her." The interaction between the two will bring a positive experience to the caregiver. Caregiver F2: "it's good to interact with the community nurses, and their encouragement enhances my confidence in care." When the caregivers' efforts are affirmed and praised by the community nurses, the caregivers will get self satisfaction and sense of honor, which will help to provide better care for the disabled elderly. Interviewee F3: "a while ago, when the community nurse came to change the gastric tube, she also praised me for taking good care of my wife. I was very happy and proud."

However, many caregivers said that at present, the focus of community nurses is the disabled elderly, and there is a lack of attention and care for caregivers. Caregiver F1: "everyone thinks this is what I should do. It's normal to take care of my father. Who has paid attention to me?". Caregiver F5: "to be honest, no one has paid attention to me. I'm not a patient. It's good to help my wife." Because caregivers have been under high psychological pressure for a long time, they have heavy psychological load and can't be released. Therefore, caregivers urgently need some psychological counseling and psychological counseling to relieve caregivers' pressure and maintain their good emotional state. F3: "I can't sleep well day and night. Alas, I have to get up three or four times at night to change her diaper pad. The doctor told me that I had to turn her over for two hours. If she doesn't turn over, she will get bedsores. I always have a bad rest, which makes me be particularly irritable and annoying. I tell her, but she doesn't understand and can't communicate at all."

Information sharing

Most of the family members of the disabled elderly are not medical personnel, and they want to get more information about home care. F1: "I take care of the elderly at home. I need to know more about what I can and can't do." The content and form of information provided need to meet the individual needs of caregivers. F4: "I think there should be some written or video materials instead of simple oral information, and the professional terms should be avoided, which should be easy to understand, so that we older people can understand." Caregivers are not only eager to acquire care knowledge, but also hope to provide an information exchange platform for health consultation. For example, caregiver F6: "I think we can set up a wechat group. We can consult in it if we have problems. Everyone can see that sometimes what we ask is that everyone is common, which is equivalent to resource sharing. If you have nothing to do, look more in the group and communicate with everyone. Some people always ask the same question, and they

really don't understand it. Nurses can go to their home to communicate face-to-face and teach them by hand. I think it's very good."

Practical behavior help

The health status of disabled elderly people determines that they should often go to relevant medical institutions. However, due to the lack of opportunities to communicate with the outside world, the family caregivers of the disabled elderly are socially isolated; Secondly, it is difficult for caregivers to take the elderly to see a doctor alone. Therefore, how to see a doctor and how to refer to a caregiver is a difficult problem, which requires community nurses to coordinate hospital visits. N2: "if the patient needs treatment, we can bring the doctor to the door to give him a preliminary diagnosis to see if he needs to be hospitalized. This saves him tossing back and forth." F3: "every time my father is uncomfortable, I have to go everywhere to the hospital to register and find a hospital bed. It's not convenient to take him out. If only they could contact and coordinate for me." F2: "now the days of stay in major hospitals is very short. If we want to continue hospitalization for observation and conditioning, we must transfer to other hospitals, but the transfer is very troublesome. I really hope someone can help us contact and transfer hospitals."

Disabled elderly people often suffer from long-term chronic diseases, so they need long-term condition monitoring, such as measuring blood pressure, blood glucose, vital signs, etc., but some family caregivers are not competent for this task. Caregiver F5 mentioned that "if someone regularly measures blood pressure and blood glucose for the elderly at home, free or at a lower cost, we need it very much. Then I hope they can help us see if the medicine is right." Most of the family members have no care experience, and will feel at a loss in the face of patients' diseases and disease-related complications. They hope to obtain nursing related knowledge related to rehabilitation. F1: "if only the community nurse could come to his home to massage him and help him recover, or I didn't do much. I want to learn, but I don't know who to learn from. Let the child find information on the Internet to learn so, and I don't know whether it's professional or not." F4: "I really hope that professional nurses can come home to have a look at what we are doing well or not, and how the elderly are recovering, whether they eat properly or not, and whether their stools are abnormal. Give me some guidance."

Theme3: Factors that promote and hinder the interaction

Factors that promote the interaction

Some caregivers said that the participation of community nurses in the care of disabled elderly at home was low, and the participation of community nurses should be increased. F2: "it seems that taking care of the elderly is my task alone. Community nurses rarely participate in it, and the service content they provide is particularly little. They come occasionally, that is, taking blood pressure or something, and notifying the elderly to have a physical examination every year." Other caregivers said that community nurses should be more active in the home care of the disabled elderly. F5: "only when we take the initiative to seek help will they come over, and the service provided is not particularly timely. They seldom

take the initiative to come over, and I feel unfamiliar with them. If community nurses can often come to see the transformation, I think our relationship will be better." In addition, community nurses and family caregivers should be tolerant of each other, reduce conflicts, take the health of the disabled elderly as the common goal, and actively promote cooperative relations. F7: "community nurses will be more objective and rational from the perspective of a medical staff. But as a family member, from the perspective of my relatives, I think about how to reduce the pain of the elderly and recover faster. However, our ultimate goal is for the health of the elderly, but our views and positions are different."

Factors that hinder the interaction

Poor physical condition or low collaboration of family caregivers lead to inadequate care. N1: "An old man died here in October last year, who was bedridden for a long time with diabetes and needed a gastric tube. His daughter bought a gastric tube online to save money and inserted a gastric tube for the old man. But she was not professional like us. At that time, she inserted the trachea, and then the old man had lung infection. Their family waited for a long time before calling me over. We went to her house to find that the old man was very seriously infected." In addition, there are insufficient community nurses in the health management of the disabled elderly, and the professional quality of community nurses is uneven. N3: "we don't have full-time community nurses for the health management of the disabled elderly. If there are, it will be better. Community nurses also have a weak grasp of the professional knowledge of the disabled elderly. The quality of personnel should be improved and training should be strengthened." N2: "we have to take charge of several areas alone, including physical examination for the elderly and follow-up of diabetes and hypertension. Many of them take the initiative to come to us for door-to-door service. Usually, we don't visit many times, and sometimes he doesn't exactly follow what you say when telling his family members. We can't stare at it every day. There's no way."

Discussion

With the deepening of aging population degree, long-term care for disabled elderly has become a challenging problem gradually. On the one hand, the disabled elderly hope to stay at home [11]; Nevertheless, due to the weakening of family function and the limited support family providing [10], it is difficult to fully realize the home-based long-term care for the disabled elderly, which eventually leads to the increasing demand for community care [21].

Family caregivers and community-based care service can combine the advantages of both good family care and community professional services [26]. Some studies have shown that creating a positive and friendly social environment can promote the positive interaction between family and community, effectively improve the quality of care for the disabled elderly at home, and reduce the burden of family and society [34–36].

Studies have reported the importance of the quality of social interactions between family and formal care providers in residential care settings, and less is known about such relationships in community-based care settings in which the majority of disabled older adults [37, 38]. We conducted semi-structured

interviews with community nurses and family caregivers of disabled elderly to collect information regarding their experiences and attitudes toward interaction. Based on the data collection and thematic analysis, three overarching themes: Establish a collaborative relationship, Get professional support; Factors that promote and hinder the interaction.

Collaboration is one of characteristics of social interaction between family caregivers and community-based service providers [39]. If family caregivers are able to build a collaborative and reciprocal relationship with the community caregivers, which will enable them to better provide care for the disabled elderly people, while reduce the burden on the family caregivers [40]. And being well connected can enhance this collaborative relationship between family caregivers and community nurses [41]. However, at present, caregivers have access to limited the help and resources of community nurses, and no building good collaboration relationship. Other family caregivers said community nurses often had very limited time of services provided to unable to communicate deeply with them. Therefore, caregivers hope to increase the frequency of communication with community nurses, as well as provide multiple forms of communication to achieve effective communication [42].

Getting professional support includes emotional support, information sharing, and practical behavioral support. Family caregivers who perceived higher levels of support reported significantly higher levels of satisfaction with professional providers [28]. Family caregivers, who are mostly non-medical practitioners, want the community to provide an information-sharing platform for health counseling to get more information about the care of the disabled elderly. In terms of practical help, there are still deficiencies in the quality and quantity of services provided by community nurses. As many disabled elderly people suffer from long-term chronic diseases, community nurses should visit regularly to monitor their health status for a long time [43]. Due to the health problems of the disabled elderly, the lack of relevant care skills and heavy burden of caregivers, they are eager to have professional nursing staff to provide services to reduce their burden [44]. Moreover, caregivers also raised the problem of difficulty in seeing a doctor, hoping that community nurses can assist in seeing a doctor. However, community-based service agencies often focus on physical aspects of caregiving, such as the number of hours served and tasks completed, rather than the social or emotional aspects [45]. Caregivers have heavy psychological load and cannot be released under high psychological pressure for a long time [46, 47]. Therefore, caregivers urgently need some psychological counseling and psychological counseling to relieve caregivers' pressure and maintain their good emotional state. Previous studies showed the importance of provider support on the psychological well-being of family caregivers [48]. When the caregivers' efforts are affirmed and praised by community nurses, their self satisfaction and sense of honor will be improved, which will help to provide better care for the disabled elderly.

Factors that promote and hinder the interaction the interaction. At present, the participation of community nurses in the care of disabled elderly at home is low. In the interactions between nurses and family caregivers, nurses usually lack initiative [49]. In order to promote the interaction between caregivers and community nurses, the participation of community nurses should be increased, and community nurses should be more active in the home care of the disabled elderly. Moreover, community nurses and family

caregivers should tolerate each other, reduce conflict, take the health of the elderly as a common goal, and actively promote partnerships [50]. However, there are insufficient community nurses in the health management of the disabled elderly, and the professional quality of community nurses is uneven. There are also some family caregivers with poor physical condition or low cooperation and low attention, resulting in inadequate care. These all will hinder interaction between family caregiver and community nurses. Interventions to facilitate positive interactions such as support and collaboration between family and nursing home care providers have been developed and tested [51]. Such interventions can be adapted for community-based care settings. Family members are more likely to provide a larger share of caregiving tasks in community settings compared to nursing home settings [39, 52].

In light of the implications of the findings of this study, future research could further advance this field by developing interventions to enhance interactions between home caregivers and community nurses to help them to effectively collaborate and support each other. Besides, government and social organizations should create and provide a suitable environment where family caregivers and community nurses can focus on strengthening their interactive relationships to bring the highest quality of care to older adults with disabilities.

Limitations

This was the qualitative study to explore the interaction experiences between family caregivers and community nurses for disabled elderly people at home. We collected the voices and feelings about interaction directly from participants. Despite this study's important contribution to home care of disabled elderly people, two limitations should be mentioned. The conduct of our study has been greatly affected due to the COVID-19. There were some difficulties in recruiting and contacting eligible participants. Therefore, the study had small samples, which limits the generalizability and representativeness. Our sampling method may have resulted in selection and response bias. Family caregivers were recruited via purposive sampling through community nurses. Those participants were more likely to have a better relationship with community nurses. We communicated with community nurses in advance, in order to avoid having their presence which could cause response bias. However, in a few cases, community nurses were present for a portion of the interview, and family caregivers could have felt more inclined to give a positive evaluation of interaction with community nurses.

Conclusion

The interaction between family caregivers and community nurses will be very beneficial, which will reduce the burden of family caregivers and have positive impacts on the disabled elderly people through better care provision. These results inform recommendations for community nursing and home care for the disabled elderly people. And providing a new perspective that we can develop and implement intervention to facilitate positive interactions and bring the higher quality of care to older adults with disabilities.

Declarations

Ethics approval and consent to participate

The methods and protocol for this study were approved by the ethical review committee of Zhengzhou University (ZZUIRB2021-15). This study was performed in accordance with the Declaration of Helsinki. All participants will receive written and verbal information about the aim of the study. All participants gave their written informed consent prior to data collection and anonymity is preserved.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to be the important data of the author's master's thesis, but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests. The study has not been peer-reviewed.

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Author contributions

PG, SW and MN contributed equally to the study. PG, SW, PW and MN were involved in concept and design, acquisition and interpretation of data. PG, DZ and CW contributed significantly to data analyses and manuscript preparation; PG and PW wrote the manuscript; HY, LL and RM helped perform the analysis with constructive discussions. All authors read and approved the final article.

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