

Research Article

Semi-structured Interview to Analyse Needs of Family Caregivers for People with Dementia

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Abstract

Background: Globally, our population is aging. The prevalence of dementia increases dramatically with advancing age. Caring for a person living with dementia affects different people in different ways.

Objectives: In response, this research study was conducted to explore the role, needs and stress of family caregivers (FCGs) for people with dementia as a means of understanding their experience of caring. The study also targeted to identify coping strategies employed by FCGs and explore positive aspects of the caring relationship in relation to their quality of life, information needs, day care and respite care, and emotional support.

Methods: To measure individuals' uniqueness and their specificity in their care-giving experience, this study employed qualitative research design, through semi-structure interview (SSI) as research methods to explore the grounded theory on role, needs and stress of caregivers. The needs of caregivers were documented under their continuum of care: seeking understanding, stabilization, preparation, implementation and adaptation.

Results: Twenty FCG were recruited through purposeful sampling. Results indicated caregiving to dementia is a very demanding task both mentally and physically. Two main categories were formulated from the data: the impact of caring and the need to support their caregivers' role. The need to develop understanding of the effectiveness of specific health and social care interventions showed as highly important.

Conclusion: Individuals' perspectives need to be integrated into future service planning and decision-making processes. Suggested strategies from FCG' perspectives that can potentially alleviating their care stress would be illustrated.

Keywords: dementia, caregivers, semi-structure interview

Introduction

Dementia is a global and progressive degeneration of cognitive, emotional and behavioral functions associated with age [1]. Rapid demographic ageing will soon lead to large increases in the numbers of persons with dementia in developing countries [2]. Like other advanced countries, Hong Kong is facing the challenges of an ageing population, decreased fertility and increased longevity [3,4]. The proportion of elderly people is projected to reach 26.5% of the population by 2031 [5]. The prevalence of dementia increases dramatically with advancing age and the number of

people with dementia is projected to increase from 105,000 in 2010 to 273,000 by 2036 that is a 160% increase [6]. Local press even labelled as “dementia tsunami”. Many FCGs choose to care for their relatives whom suffered from dementia at home for as long as they can [7]. Because of gradual decline in cognitive health and function of older adults with dementia, the challenge faced by local caregivers deserved more attention in healthcare policy planning [8]. In our local context, spouse as the main family caregiver had been raised from 137,590 in 2001 to 221,766 in 2011 [9]. With this increasing population of aging, the importance of spouse and other family members as the caregiver is important in maintain the level of care.

All people with dementia experienced certain degrees of functional impairment. However, not all the people living with dementia need to be cared for [10]. All over the world, the family has been the cornerstone of care for relative with dementia [2]. FCGs form the backbone in caring older adults with dementia in the community [10-15]. Theoretical background has been established on caregiving tasks varied with degeneration of dementia care recipients [1,2,16,17]. For example, during the early stage of dementia, caregivers may focus on the tasks related to learning about the disease, making plans for future needs and supervising, discussing and organizing household, financial and legal responsibilities. During the moderate stage of the disease, with increasing responsibilities for management of the household and arrangement of personal and medical care, caregiver tasks may increasingly focus on assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) as well as monitoring and reporting changes of health states and reactions to treatment [18,19].

With progression of the condition, the amount and intensity of caregiving would increase for FCGs. Moreover, there were plenty of evidence in showing FCGs can easily burn out if their pressures in caring for persons with dementia are not assuaged. It is essential to address the needs of caregivers in managing their own stress and maintain their own physical health [20]. Moreover, when caregiver is distressed, the likelihood of nursing home admission rises sharply [21]. This will be further alarmed by the phenomenon of aging caregivers [9]. Caring for a person living with dementia affects different people in different ways [7]. Therefore, it is very important to properly address individuals’ needs of caregivers. It is even more important to look into their specific role, needs and stress in caring. Moreover, to identify individuals’ coping strategies and explore positive aspects of caring.

Qualitative research out-weighted quantitative counterpart for its ideal suitability in exploring experiences and perspectives of caregivers’ qualitative research has been used to examine these experiences for other health-care related conditions [22]. Moreover, it can generate qualitative data through the use of interview questions. This allows the respondent to talk in some depth, choosing their own words. This helps the researcher develop a real sense of a person’s understanding of a situation. Furthermore, qualitative methods have increased validity because it gives the interviewer the opportunity to probe for a deeper understanding, ask for clarification & allow the interviewee to steer the direction of the interview

Methods

In this study, qualitative research method through SSI has a specific way to understand the phenomenon in providing care-giving for older adults with dementia, by using a circular process as approach as shown in figure 1 [23]. This quantitative research studies started with a theory of care stress in FCGs [20]. Higher levels of care recipient behavior problems were more consistently related to poor caregivers’ health than were care receiver impairment and intensity of caregiving. Older in age, lower socioeconomic status, and lower levels of informal support were related to poorer health. Two objectives emerged from this theory, qualitative studies have as a starting point a priori assumptions of individual differences of care stress in FCGs, then guided by data collection and analysis in order to come up with a theory of stress in caregivers [24].

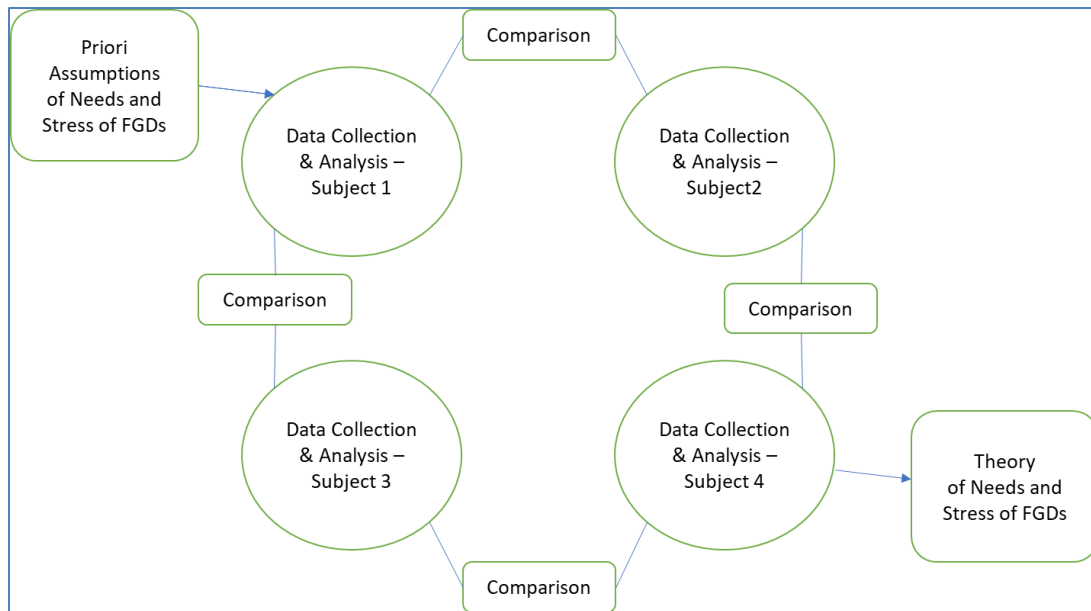


Figure 1: Qualitative Research Design of Semi-structure Interview.

1. What are the needs, stress level and mental health of FCGs, and how mental well-being of them may change over the course of changing cognitive function and functional impairment of older adults with dementia?
2. How far current caregiver program may address the training needs, their mental well-being, and whether such program could promote care outcomes?

Conducted conversation with one subject at a time, the SSI employed open-ended questions, often accompanied by follow-up why or how questions. With the use of sessional-based 60-minutes SSIs to explore how FCGs understand the caring phenomenon and construct meaning from their experience. About one hour is considered a reasonable maximum length for SSIs in order to minimize fatigue for both interviewer and respondent.

FCGs for older adults with dementia were recruited via purposeful sampling between January 2018 to May 2019 from four district-based activity centres for older adults. FCGs should be age-ranged from 65 to 80 years, and their relatives should have a diagnosis of dementia in their medical history under the ICD-10 criteria for dementia which was diagnosed by a psychiatrist. Individual efficacy in care-giving would be screened by the Chinese Version of the Revised Caregiving Self-Efficacy Scale (C-RCSES) [4]. The 27-item C-RCSES was validated to assess self-efficacy amongst FCGs, which contains five factors: a) self-efficacy for responding to problematic behaviors; b) self-efficacy for obtaining support; c) self-efficacy for management of the household, personal and medical care; d) self-efficacy for regulating mood related to caregiving; e) self-efficacy for gathering information about symptoms, treatment, and healthcare. Exclusion criteria for participation in this project were any major neurological illness, any psychiatric disorder, or a known history of substance abuse.

Participants were included after informed consent was obtained. Approval was given by the local research ethics committee and the study was conducted according to the Declaration of Helsinki. Three trainer interviewers with at least five years of dementia care experience participated in the interview process. All interviewers had a paper-based interview guide that could follow. Discussions might diverge from the interview guide. All interviews were tape-recorded and a panel of social worker whom having at least 10 years of dementia care experience transcribed these tapes for analysis.

Results

Twenty FCGs were recruited through purposeful sampling. 13 male caregivers aged from 62 to 82 (SD=1.75) and 7 female FCGs aged from 72 to 84 (SD=2.34). They shared similar demographic and socio-demographic background. With the application of model of human occupation (MOHO) [25], 10 were high occupational functioning with regular outdoor activities; 10 low occupational functioning and with sedentary lifestyle.

There were identified 5 major themes of experience from SSI in caregiving for older adults with dementia, namely a) seeking understanding, b) stabilization, c) preparation, d) implementation, and e) adaptation.

Under seeking understanding, there were sub-themes on timeliness of diagnosis and stress in diagnostic process generated from FCGs, in which, FCGs with lower socio-economic status showed their marked concern in seeking proper understanding on their journey of caring. In stabilization, FCGs identified with the sub-themes of path to support and getting services. Caregivers showed their concern and initiatives in getting service for their relatives with dementia. In preparation, FCGs started to actual work-out for equipping themselves like by accessing the healthcare system, contacting healthcare professionals and seeking resources. FCGs showed their motivation in planning and acting for future by taking up their care-givers' role more actively. By accommodating changes in life roles by more emphasizing on their care-giving roles, FCGs showed open communication and started to formulate a better network in self-helpings with each other. In our panel discussion, the findings can be grouped to the impact of caring and the need to support their caregivers' role. Several sub-themes and constructs to address different needs of FCGs as shown in Table 1. These themes can address their needs in continuum of care.

Table 1. Findings from Semi-structure Interview on Experience of Caregiving for Older Adults with Dementia

Theme	Constructs	Illustration
Seeking understanding		
Timeliness of diagnosis of cognitive and functional problem	Caregivers wanted timely diagnoses with accompanying education about the disease, its course and management.	Caregiver: "...I want to know if this can be cured or treated... However, it took 18 months in Hospital Authority – the public health sector to see a doctor (psychiatrist) ... our family cannot afford to pay for consultation in private sector..."
Diagnostic process	Assessment process was probing and demoralizing	Caregiver: "...he merely becomes a "strange" person that I never know..." Caregiver: "healthcare professionals showed indifferent to my distress when she was in state of sundowning ..."
	Several caregivers reported that their doctor commented no effective treatment till now is reported.	Caregiver: "A nightmare... and I felt helplessness... when I know the husband that I knew and had been living for my entire life will not be back (starts to cry).
Stabilization		
Active involvement in volitional aspect	Many caregivers and patients reported that their doctors did not discuss next steps of intervention	Caregiver: "Can I help him to do something to delay his deterioration? I asked the doctor... I ran into the problem that they give you the information, ...we don't do that service in our community"
	Sometimes extremely supportive individuals from aged care and dementia support organizations were encountered.	Caregiver: "I cried over the phone for an hour ... and a social worker listened to me ... she says go on, go on talking, they were absolutely wonderful..."
Preparation		
To acquire knowledge and skills in handling cognitive dysfunction and functional dependence.	Accessing the health care system, contacting healthcare professionals and knowing what kind of resources were available	Caregiver: "I start to prepare myself... In properly care for him and myself..."
	Most comments were about not enough detail being given about the memory tests, the diagnosis and, in particular, the progression of dementia	Caregiver: "I would like to know more on the handling techniques for his cognitive function deterioration and functional dependence..."

Implementation		
Role fulfilling with performance integration.	Start to take up role of caregivers actively	Caregiver: "I felt safer in handling his activities of daily living" Caregiver: "I felt I can take up the role of caregiver with a step forward"
Adaptation		
To accommodate and accustom to new role and function	They can handle well with others	Caregiver: "even though I mentioned it to him many times... but I can handle this well without support from other caregivers"
	Open communication, helpful factual information and Empathy.	Care-givers: "We are here to support and guide you through this journey of caregiving"

Researchers indicated caregivers showed good attitude and values in dementia care. However, in SSI, they reported there was a lack of accessibility in seeking the understanding of the disease. Moreover, they indicated high stress and significant mental health issue that also reflected from their reported screenings from the C-RCSES [4]. Higher levels of care recipient problematic behaviour were correlated with the poor subjective health. Older in age, lower socioeconomic status, and lower levels of informal support were related to higher stress and poorer health.

Participants whom need to take care for more functional dependent relative showed marked higher level of distress in their daily living. Furthermore, caregivers showed their concern on deterioration of both physical and mental condition in taking of their demented relatives.

Moreover, it is worthy to note female participants inclined to use avoidance strategies when they encountered conflicts in caring. Collective results from SSIs indicated that mental well-being of FCGs changed over the course of changing cognitive function and functional impairment of older adults with dementia [16]. Moreover, it echoed with literature that younger family caregivers showed poorer outcome in caring [16]. Participants reinforced literature and agreed existing medical services can address the needs of FCGs in a timely manner, and to evaluate existing services for FCGs [26]. However, it was interesting to note that, caregivers deemed the current caregiver program cannot address their specific training needs (e.g. handling the specific temper outburst behavior of their demented relatives), since they shared present trainings are not level specific enough. It indicated different levels of skills training are required depending on the frequency and the extent of their interaction with people with dementia [27]. They suggested for the arrangement of levels of training for different FCGs.

Discussion

Many researchers like to use SSIs because questions can be prepared ahead of time. This allows the interviewer to be prepared and appear competent during the interview. Moreover, SSIs can provide reliable and comparable qualitative data. SSI allow informants the freedom to express their views in their own terms. It is suited for a number of valuable tasks, particularly when more than a few of the open-ended questions require follow-up queries.

Phenomenology was the qualitative research method used in this study to describe how FCGs experience to the phenomenon of stress and needs in caring. Given the stress and needs of FCGs are psychosocial in nature, phenomenologist views both stress and needs as a product of how FCGs interpret the world. In order to grasp the meanings of a person's behavior, this study adopted the phenomenologist attempts to see things from that persons' point of view" [26]. What was this kind of care-giving experience like? What did the experience mean? By the technique of phenomenological reduction, the situation of FCGs were explained, interpreted and described. Individuals' role needs and stress in caring as a means of understanding their experience of caring were noted. FCGs shared their impact of caring and expressed the need to learn how to care for.

Through this SSI study, our findings echoed previous findings that the successfulness in FCGs was identified to be highlight individualized and personalized [28]. Moreover, studies over decades reinforced that knowledge, attitude and

skills of caregivers are crucial parameters of success in community care for dementia [20,29]. Understanding individuals' role and their care experience became increasingly important [30]. Incorporating the health care experience of patients and caregivers in health service planning is important to ensure that their needs are met and that person-centered care is provided [31].

Participants reported existing caregiver interventions have drawn substantially from research on social support and aim to provide different elements of support including emotional (e.g., providing comfort, listening to problems [32,33] instrumental (e.g., providing training in problem-solving [31], informational (e.g., providing information about illness and services [34], and appraisal support (e.g., providing feedback about their caregiving activities [22]. In addition, findings from this study further confirmed support is most beneficial if it is closely matched to an individual's current needs [35]. This reinforces the need to more closely examine caregivers' support needs over time and provide support when and where they need it [33].

Family caregivers' interventions have modest but significant benefits on caregivers knowledge, psychological morbidity, and other main outcome measures such as coping skills and social support [11]. Despite these modest findings, caregivers were frequently satisfied or very satisfied with the interventions, appraised their own coping skills as improved [36], reported that their relationship with the patient had improved and identified helpful training elements [27]. Moreover, it was suggested to enhance quality of care from informal caregivers. In addressing for their stress in caring, FCGs treasured respite care is a short-term community support targeting vulnerable community-dwelling older adults in need of personal or nursing care. At the same time, it serves to provide temporary relief to primary caregivers from continue caregiving responsibilities. However, not every FCGs knew how to apply for such care service.

It is worthy pointing out that Chinese communities tend not to seek help unless they require assistance to manage their relatives at a later stage of the dementia [32,37]. This is one of the main reasons for the difference in findings of caregiver research when compared with Western countries. It is important to point out FCGs may feel reluctant to send their relatives to day care unit/center even a brief period [25]. They even had the misconception about the eligibility for respite care is determined based on the urgency of service needs or the level of impairment of the care recipients.

For the limitation of this study, since SSIs do not consist of closed questions, it may be hard to end them. Some researchers commented it can be time consuming to conduct the interview and analyze the qualitative data (using methods such as thematic analysis). Moreover, employing and training interviewers is expensive, and not as effective as collecting data via questionnaires. For example, certain skills may be needed by the interviewer. These include the ability to establish rapport & knowing when to probe. Furthermore, an interview is a social interaction the appearance or behavior of the interviewer may influence the answers of the respondent. This can be a problem as it could bias the results of the study and make them invalid.

Conclusion

Qualitative research is ideally suited to exploring the experiences and perspectives of patients and FCGs and has been used to examine these experiences for other conditions. This study identifies the areas on the impact of caring and the need to support their caregivers' role. The findings highlight areas of dementia care and services about which FCGs in need. Despite services are available, service providers need to make services accessible to those in need, as FCGs may not be able to access to these services without help. In addressing for the impact of caring, health care professionals should structure their model of service delivery as well as upkeeping their promotional strategies so that service information can reach the targeted groups. Through better understanding on their needs in this project, we develop better caregivers' service to become more easily accessible and effective.

Conflict of Interest

The authors declare that there are no conflicts of interest.

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