Introduction

Over 9.9 million new cases of dementia are diagnosed each year worldwide, equating to 1 new case every 3.2 s. In addition, the number of people living with dementia worldwide in 2017 was nearly 50 million. In Taiwan, 3,310,000 people are aged 65 years or older and more than 271,000 people are estimated to have dementia. Specifically, this equals 1 in 12 people aged 65 years or older and 1 in 5 people aged 80 years or older receiving a diagnosis of dementia in Taiwan. Care for people with dementia can be provided at home in the community or in a care home to a resident. Among the various caregivers available, families will always play a central role in addition to support from formal professional care services. A relevant study indicated that more than 90% of people with dementia live in their own homes and are cared for by informal caregivers, mainly their spouses and adult children. Neurologists observed and indicated that approximately 2 million individuals in the family are affected by people with dementia who live at home. However, because of a lack of formal support systems for these family caregivers, their requirements are often not identified or fully understood by healthcare professionals. Family caregiving can affect the mental and physical health of the caregiver, inducing conditions such as depression, anxiety, stress, and emotional difficulties and can cause economic harm, including loss of income and employment opportunities.

Dementia leads to a progressive decline in memory and other cognitive functions, causing increased dependence during daily activities. However, the experiences and requirements of family caregivers of people with dementia considerably vary among individuals because every caregiver and every care recipient are unique. Caregivers

Abstract

Background: This report describes a protocol for determining the barriers and requirements of family caregivers for people with dementia. The perspectives of healthcare professionals, family caregivers, and dementia patients will be collected and analyzed to construct a support model of requirements.

Methods: An in-depth interview and care diary will be adopted during Phase I. Subsequently, the Delphi technique will be conducted to transform opinions from participants into a group consensus. In total, 38 participants are expected to be recruited from the outpatients of the neurology, psychiatry, geriatrics, and family medicine departments of a medical center in central Taiwan. Five domains are to be examined systematically in terms of the barriers and requirements of family caregivers for people with dementia: (1) knowledge of dementia and care skills to cope with problem behaviors; (2) medication and comorbidity management; (3) family relationships and psychological support; (4) resources and benefits; and (5) education and skills training.

Conclusion: Overall, the proposed protocol will construct a support model of requirements for family caregivers, which is expected to provide healthcare professionals, family caregivers, researchers, and policymakers with more concise information and insights into associated problems.

Keywords
Dementia, family caregiver, barriers, supporting model of requirements

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have reported many positive aspects to caring for someone with dementia such as significant gratification, reciprocal relationship, strengthened relationship between family caregiver and other family member, family caregivers’ characteristics changed from pessimistic to optimistic and from soft to strong, and family caregivers perceived themselves as uplifted. Family caregivers have the abilities to explore effective solutions on encountering barriers during the caregiving process. Meanwhile, numerous studies have indicated negative experiences during the caregiving process. For example, the demands of caring for a person with dementia often surpass the emotional, financial, personal, and social resources of the caregiver. The factors that contribute to caregiving burden have been reported to be associated with cultural beliefs, caregiver personalities, perceived resources, and feelings of situational overload, resentment, fatigue, and relational deprivation. Clearly, with regard to the rapid growth of Taiwan’s aging population, authentic guidance for healthcare professionals and providers to identify care requirements, as well as enhance support and services for family caregivers, is urgently required. The overall conceptual research structure is presented in Figure 1.

1. What barriers are identified during the process of caring for a family member with dementia?
2. What requirements are identified or foreseen during the caregiving process among the primary family caregivers and healthcare professionals?
3. What are the themes extracted from the findings that will be used as indicators to construct the support model of requirements?

**Methods**

A mixed methodology will be adopted (Figure 2). The methods are divided into two phases, the details of which are given below.

**Phase I: review literature on the barriers and requirements for family caregivers using a qualitative process of evaluation**

A systematic review of the literature will be performed to answer the first research question and will be gone through to identify the overarching themes in both qualitative and quantitative studies on PubMed, EBSCOhost, Academic Search Premier, and CINAHL with full text and Airiti Library (in Chinese). The search terms will be “dementia,” “family caregiver,” “healthcare professional,” “barrier,” “requirement,” “supporting model,” or “supporting methods” or “supporting strategies.” The literature search will be limited to peer-reviewed, full-text articles published both in English and in Chinese traditional. Date of publication will be limited to be between 2007 and 2017. Peer-reviewed, reported primary research articles will be included. Abstracts and personal views will be excluded.

Subsequently, an in-depth interview with purposive sampling methods will be employed to ensure a wide variety of respondents. Qualitative interviews provide the mechanism of gathering rich data from a purposive sampling of individuals who have experienced the phenomenon of interest to the researchers to reach an understanding of this phenomenon what it is and how it is perceived, explained, and experienced. An interview guide will be developed collaboratively by the research team. Questions reflect the broader literature regarding knowledge of dementia and care skills to cope with problem behaviors; medication and comorbidity management; family relationships and psychological support; resources and benefits; and education and skills training. Open-ended questions will be constructed to lead the discussion. Participants will be asked to express their thoughts, opinions, and experiences beyond the questions specifically asked which are relevant.

The purposive sampling methods will be used here due to a diverse opinion of experts from three groups. Participants of healthcare professional will be approached via emails, phone calls, or the recommendation of Division leaders. The participants of family caregivers and care receivers will be recruited via outpatient clinics after discussion with the physicians. Family caregivers will be asked to provide a care note from the care receivers, the information on which will include a brief history of diagnosis, records of disease development from the past year, and special events or difficulties encountered by family caregivers. Care notes are to be taken every 2 weeks for a month by family caregivers. The purpose of care notes from family caregiver is to gain more details from the daily routines, ways of living, and probably the
sudden problems that both family caregiver and people with dementia have encountered. In addition, care notes here may provide additional information as mostly participants will be interviewed once or twice. To answer the second research question, every participant from each of the three groups will be interviewed once or twice, the results would be investigated, and themes would be extracted from the findings. These results will be used for the Delphi questionnaires.

**Phase II: the Delphi technique**

A Delphi method aims to reach consensus among experts through rounds of structured questionnaires. To answer the third research question, the themes extracted from interviews will be transferred systematically as guiding principles for the Delphi technique. In Phase II, the Delphi technique will be conducted to transform opinions from participants into a group consensus. The Delphi technique aims to identify practical views from healthcare professionals regarding barriers and requirements that they consider important for the process of caregiving. The guiding principles of Delphi questionnaires will retrieve from the results of qualitative data which are collected from interviews at Phase I. The Delphi questionnaires will cover five domains, including (1) barriers of family caregivers, (2) knowledge of dementia and coping skills for problem behaviors, (3) medication management and clinical support, (4) social resources and benefits, and (5) education and training. Before disseminating the list of guiding principles to experts, items will be reviewed and amended by two experts in the field of dementia care for critical reflection. The feedback provided by the experts on the revised list will be discussed by the research team. The list will be adjusted accordingly based on the feedback. It is possible that the new domains will be added into the questionnaire apart from the above five domains when important information is addressed from the interviews.

Participants who agreed to join the processes of consensus will receive Delphi questionnaires via emails. The first round will aim to generate a list of indicators that participants consider should be reported when describing the barriers and requirements of care people with dementia at home. In the first round, the participants will be presented with the statements identified from the results of interviews in accordance with the above five categories. The participants will be asked to rate whether each statement will be related to the five categories in terms of barriers and requirements of care people with dementia on a three-point scale: 1 (relevant), 2 (not relevant), and 3 (relevant after revision). The initial draft survey will be pilot tested by two staff members from the research team who will not be involved in the Delphi. Pilot testing contributes to minimize potential personal bias and publications. It also determines the clarity of wording, layout, and the time taken to complete the survey.

The qualitative data are used to inform a quantitative first round of the Delphi and then it will be fed back to the participants in a Delphi form through a second questionnaire. After a statistical analysis regarding collective opinions from groups, results from the second questionnaire will assist the formulation of a third quantitative questionnaire. The Delphi process will be ongoing until a consensus is obtained or until the number of returns for each round decreases. Specifically, responses are to be summarized between rounds and communicated.

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**Figure 2. Research process design and participants.**

![Diagram of research process](image)

The diagram illustrates the research process design and participants. Phase I includes literature review, qualitative data collection, and interviews. Phase II involves Delphi technique, pilot testing, and round-by-round analysis. Selected respondents contribute to constructing the support model of requirements.
back to the participants through a process of controlled feedback. After a consensus is reached, indicators cover the above five domains which will be feasible in the position of constructing a supporting model of requirements for family caregivers of people with dementia. In other words, there is an attempt that the five domains or including the new added domains will be used as the characteristics to be able to form a “supportive model” in which the issues of barriers and requirements will be answered.

Table 1. Interview participants.

| Type         | Participants          | Number |
|--------------|-----------------------|--------|
| Group 1      | Primary family caregivers | 10     |
| Group 2      | Dementia patients     | 10     |
| Group 3      | Healthcare professionals | 18     |

Participants

Group 1
Participants will be divided into three groups (Table 1). Group 1 will comprise primary family caregivers who live with the care recipient regardless of age and sex.

Group 2
Group 2 will comprise people who have been diagnosed with dementia. For a complete picture of patients with dementia in terms of necessary support and requirements, people of any age and sex with a diagnosis of dementia (Alzheimer’s disease, vascular dementia, mixed Alzheimer’s and vascular dementia, or other types of dementia) who live in the community (excluding people in institutions receiving 24-h care). Furthermore, people at mild stages of disease progression (mainly people who remain able to express views) selected from outpatient clinics of neurology, psychiatry, and geriatric departments will be included. Those care receivers who are unwilling to participate in interview will be excluded from the study. Groups 1 and 2 will comprise 10 pairs of people with dementia and their primary caregivers, recruited from the outpatient clinics of neurology, psychiatry, and geriatric departments.

Group 3
To gain more complex perspectives upon the issues from different backgrounds of healthcare professionals, group 3 will comprise healthcare professionals including physicians (e.g. neurologic, psychiatric, geriatric, and family medicine physicians), nurses, clinical psychologists, occupational therapists, and social workers. A total of 18 professional healthcare practitioners are selected from the above five healthcare professions, and each profession is expected to recruit 3–4 participants, mainly in the same medical center to participate in interviews. Quantity (e.g. simple size) should not be conflated with quality. Key in thinking about sample size in thematic analysis is recognized that it produces accounts of patterns across the data set. Earlier on, Braun and Clarke provide some broad indicative size recommendation across thematic analysis projects of different scales for reference in which a 15–20 interview sample size is recommended for a larger project (TA data as only a part of the whole project).

Phase II: the Delphi technique
Participant selection relies on a consideration of disciplinary area, target issue, and level of training or experience. Potential participants will be identified from a group of clinicians in the areas of clinical care, geriatrics, psychiatry, dementia education, clinical psychology, and service delivery, due to the attitudes and experiences of clinicians may vary from one to another. This study mainly focuses on the opinions and experiences of the healthcare professionals from the same hospital. Hence, the potential participants of Delphi questionnaires will be mainly approached from the interviewees and agree to join the process of consensus. A total of 10 respondents from the interview group will be purposively sampled to participate in the Delphi method. Because it is heavily dependent on the sample having the time required to commit to the process, those who have agreed to participate must remain involved until the process is completed.

Ethical considerations
This study was approved by the Institutional Review Board (IRB) of China Medical University Hospital (CMUH106-REC1-142) on 5 December 2017. In accordance with IRB requirements, participation will be informed and voluntary to ensure data confidentiality.

Data analysis
This study will adopt the framework of Braun and Clarke to conduct a thematic analysis. Thematic analysis is seen as a foundational method for qualitative analysis as it provides core skills that will be useful for conducting many other forms of qualitative analysis. All interviews will be audio-recorded and transcribed verbatim. Data analysis will be undertaken individually by members of the research team. The analysis will include five phases: In Phase (1), the transcripts will be read and repeated constantly back and forward to search for meanings and identify possible patterns. Notes and ideas for coding will start alongside; in Phase (2), the data set will be coded manually and inductively to apply topical codes. In this stage, researchers will review and open-code
the data set for emergent topics. Highlighters or colored pens will be used to indicate emerging patterns. It is important in this stage to ensure that all actual data extracts are coded and collated together within each code. Data saturation will be reached when further coding is no longer feasible. A draft of the coding scheme with codes and descriptions will be developed; Phase (3) begins by sorting the different codes into candidate themes and collating all the relevant coded data extracts within the identified themes. Candidate themes and subthemes will be formed from initial codes. Some may be discarded when the codes do not seem to belong to anywhere; Phase (4) will involve the reviews and refinement of candidate themes as building a thematic map of the data. The researchers will read all the collated extracts for each theme and think whether they appear to form a coherent pattern. Subsequently, the validity of individual themes in relation to the data set will be considered. Moreover, whether the candidate themes accurately reflect the meaning evidences in the data set as a whole will also be carefully examined; Phase (5) will involve defining and redefining each theme and determine what aspect of the data each theme captures. In the final stage, it will start to think about the names in the final analysis. The researchers will review the conceptual map and domains will be identified from the data as the major themes emerged from the analysis.

Discussion

This study will examine the barriers and requirements of family caregivers for people with dementia. At the end, the support model of requirements will be constructed. Therefore, this study intends to be of academic value and pursues the following contributions and implementation:

1. This is a mixed-method study. Both qualitative methods (e.g. interview, care notes) and quantitative methods (e.g. Delphi technique) are adopted, which is unlike relevant studies that have mainly used quantitative methods.
2. Qualitative research methods contribute to allowing the experiences and voices of participants from a variety of backgrounds to be heard. Participants playing various roles are included to provide a complete spectrum of the issues regarding the requirements of family caregivers for people with dementia.
3. This study includes patients who have been diagnosed with dementia at the mild stage if they are able to express opinions to the interviewer with or without the assistance of caregivers.
4. Results of this study may help practitioners to develop services and interventions required by family caregivers for people with dementia.
5. Results of this preliminary study may provide a strong foundation for further assessing the requirements of family caregivers for people with dementia at a national level.
6. Researchers, educators, healthcare professionals, and government policymakers may benefit from acknowledging the findings from a concise and complete spectrum of current requirements.
7. Several limitations may result from recruiting participants in this study. Patients with dementia and their primary caregivers will be selected from outpatient clinics and may have limited time to talk during medical visits to hospital. In addition, patients with dementia and their primary caregivers may feel unease or have reservations about openly discussing their problems with someone unfamiliar, especially if these problems are considered familial matters. The researcher intends to minimize this limitation by referring to patients’ attending physicians and explaining patients’ concerns in detail; thus, the number and content of interviews with patients with dementia and their primary caregivers may be restricted.

Conclusion

This study will examine the barriers and requirements of family caregivers for people with dementia. A support model of requirements based on the combined perspectives of people with various core roles is expected to be constructed. Unlike most relevant studies, this study will be conducted both qualitatively and quantitatively to allow the voices of representatives of a variety of backgrounds to be heard. Furthermore, healthcare professionals will benefit from the results, using them to further the development of specific services and interventions for family caregivers of people with dementia.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical approval

Ethical approval for this study was obtained from China Medical University Hospital (CMUH106-REC1-142).

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Informed consent

Written informed consent was obtained from all subjects while conducting the study.
**Trial registration**

The trial has been registered at ISRCTN (http://www.isrctn.com/) under ISRCTN-ID: 13505830 on 18 January 2018.

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