



Research Article

Multi-media Video-based Dementia Caregiving Resources: Appropriateness, Acceptability, Relevancy, and Satisfaction for Family Carers

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Abstract

Background: Dementia caregiving is a highly demanding and a very lonely task faced by family carers. Therefore, caring and supporting older family members of older people with dementia is becoming a major concern in our society. **Aim:** To determine the appropriateness, acceptability, relevancy, and satisfaction of multi-media dementia caregiving resources among family carers who will trial these resources. **Subjects and Methods:** A district elderly centre was approached and convenience sampling was used to recruit 17 family carers to participate in the multi-media video-based caregiving resources (MMVCR) programme. Data for the 17 family carers together with data from the older persons with dementia were obtained. The process of developing the MMVCR was delineated, and a series of 12 mini-videos using different themes with specific examples of cases to share commonly encountered concerns and queries that carers found challenging to manage at home were produced. Additional pictures or images were added for therapeutic effects, and slide shows of key points were summarized and embedded into the videos to emphasize the advice and suggestions provided by the nursing and occupational therapy colleagues. **Findings:** Participants reported that the programme had enhanced their knowledge of dementia caregiving, and the programme was rated highly for appropriateness, acceptability, relevancy, and satisfaction among family carers. **Conclusion:** The findings from this small study provided data to increase awareness, knowledge, and support of the general public towards family carers of older people with dementia. It achieved this by taking the initiative to begin some pilot work to develop dementia resources that were considered to be appropriate, acceptable, relevant, and satisfying to the older family carers.

Keywords: Dementia; Family carers; Multi-media video resources; Hong Kong

Introduction

Dementia caregiving is a highly demanding and a very lonely task faced by family carers of older people with dementia. Indeed, it is not surprising to find that these family carers are already in their old age as well. Therefore, caring and supporting for older family members of older people with dementia is becoming a major concern in our society [1-2]. According to the World Health Organization (WHO) Dementia Fact Sheets [3], around 50 million people worldwide have dementia, and the total number of people with dementia is projected to reach 82 million in 2030. In Hong Kong, dementia is becoming a public health issue, too [4]. The current situation among Chinese older people with dementia is escalating, with a prevalence of 5-8% for the over 65 age group, about 20-30% of older people are aged 80 or above, and 32% for the 85-and-above age group had dementia, with 15.3% for female and 8.9% for male [4-6]. Back in 2012, Yu [7] has estimated that around 333,000 or 11% would be suffering from dementia in 2039 for those aged 60 and above. Therefore, it is expected that as older people continue to live longer, the prevalence of those suffering from dementia is expected to increase. This suggests that more care and attention will be needed by their ageing family members

who need to take care of their older relatives in the community.

Dementia is a chronic syndrome whereby the older person's cognitive functions are progressively deteriorating; and this is accompanied by reduced independence in activities of daily living [5-6]. Family carers are known to experience stress and encounter a number of needs when managing the care of older people with dementia [8-9]. Principally mentioned are needs for information and knowledge, support in managing activities of daily living and instrumental activities of daily living, and management of behavioural and psychological symptoms associated with dementia. Although caring for family members with dementia can be positive, caregiving can be overwhelming and a burden to family carers who need to shoulder the responsibility of care. During the dementia caring journey, uncertainties and lack of confidence with coping and handling matters that concern their older relatives have been revealed by family members in a completed study conducted by the principal author [10]. Indeed, the study found that the challenges of being a dementia caregiver are compounded by the general lack of information and appropriate support to handle dementia as a health condition and issues surrounding dementia care in the longer term. The data also supported that family carers

reported poorer health, and that physical and mental well-being had taken its tolls as the condition of the dementia sufferers had deteriorated to an extent that more intensive care was needed at home. As such, some family members who had to support their older relatives may feel unsupported as they cope with the bulk of caring by themselves in their own homes [11]. These findings are also supported by a very recent report on Working Dementia Caregivers [12] in Hong Kong that sought to identify challenges and needs of more than 188 working adults aged 18 to 60 years. The report stated that an overwhelming 73.7% of working caregivers were exposed to high levels of caregiver stress, with 46.2% having symptoms of depression and 38.6% experiencing family conflict. One main recommendation of the study targets at the provision of accessible information to carers to raise their awareness and enhance knowledge of dementia.

Previous studies have investigated various methods in delivering information to help the family carers, including telephone-delivered psychoeducational intervention [13], using computers and smartphones to develop dementia care education programme [14], and online caregiver training programme [15-16]. Indeed, the provision of timely general information on dementia care rests on the ability of family carers to access information that is appropriate and relevant to meet their immediate concerns. Ultimately, this project has served to develop a series of multi-media video-based caregiving resource for dementia carers. These mini and short videos have highlighted specific caregiving themes that have been identified by family carers themselves to be important aspects of daily caregiving.

Aim of Study

The aims of this pilot study are to develop the multi-media video-based caregiving resources (MMVCR); and, to determine the appropriateness, acceptability, relevancy, and satisfaction of MMVCR among family carers who will trial these resources.

Subjects and Methods

The Caritas-Hong Kong Services for the Elderly, a large non-government organisation providing community and residential services for older people, was approached to gain access to a district elderly centre to recruit the family carers for this study. District elderly centres function as local community centres and provide a range of activities for older people and/or family carers. In this centre, a dementia carers support group existed to enable carers to receive mutual and social support to relieve stress, learn new skills and interests, attend therapeutic groups such as cognitive behavioral or narrative therapy, and participate in professional health talks relating to dementia care, basic psychomotor skills, and health maintenance measures.

Participants

Convenience sampling was used to recruit 17 participants from the dementia carers support group during the COVID-19 pandemic. The inclusion criteria were family carers of older people with dementia of varying severity,

primary caregiver, and participate in the activities at the centre. The only exclusion criterion was when participants declined to participate.

Multi-media video-based caregiving resources (MMVCR)

The focus of the one-year study was to develop the MMVCR and then to integrate them into an activity programme comprising of two 3-hourly sessions that focused on the inputs of nursing and occupational therapy in dementia caregiving. Owing to the instability of the COVID-19 pandemic and the onset of the fourth wave in Hong Kong at the time of project implementation, the original plan to develop the MMVCR and run two sessions was changed to one session that lasted three hours. This led to the need to make compromises to the MMVCR by combining the content of both disciplines, and eventually producing USB for healthcare professionals at the NGO and DVD for family carers to take home for further viewing. Therefore, family carers did not have the extra time between the sessions to reflect on the information obtained from the videos before they evaluated on the MMVCR resources to determine whether the information obtained were appropriate, acceptable, relevant and satisfying in meeting their current caring needs.

To ensure that the content of the MMVCR would closely reflect the real-life experiences of the dementia caregiving journey, family carer representatives were invited from the outset to participate in a focus group interview to solicit their views and specific information they wanted to know about to cope with dementia caregiving. Following data analysis of the verbatim data, the development of the MMVCR were led and compiled by the research team who were health care professionals in nursing, social work, and psychology. Reference was also made to the findings of the principal author's study on family caregiving of older people with dementia [11], particularly with regards to the topics that could be considered in the MMVCR. These are outlined as:

- a) Improving knowledge, skills, and judgment to carry out tasks;
- b) Supporting caregivers in the early identification of problems and managing the care;
- c) Developing psychomotor skills training;
- d) Enhancing emotional and coping skills;
- e) Developing task-specific and problem-solving skills; and
- f) Providing information to understand the community resources.

In preparing the content of the MMVCR, 'multi-media' referred to the inclusion of video-demonstrated teaching, question-and-answer section, slide shows, pictures and e-leaflets of key take-home messages. The entire video production was undertaken by the video crew of retired older people who were members of the multi-media unit of the NGO, and were frequently called upon to help and support the technological and media aspects in a range of activities. To check the validation of the content, consultations with healthcare professionals in dementia care were made, and guest speakers from occupational therapy and nursing were invited to appear on the videos to share their expert advice and experiences. Once the MMVCR were developed, they were further validated by a group of elderly representatives whose

views improved the quality and final production of the resources.

Data collection

The project was approved by the Research and Ethics Committee at the author’s affiliating institution (Caritas Institute of Higher Education, Ref. no. HRE200129). Before data collection, preparation work and site visits were conducted. Preparatory work included designing a questionnaire to collect the participants’ current dementia caregiving situation and knowledge level, and programme effectiveness before and after watching the MMVCR. Open-ended questions were included to collect appreciations, satisfaction, feedback and suggestions for improving the programme. Videos were prepared for easy viewing and involved combining the 12 mini-videos into two parts, with part 1 composing of an introduction to caregiving for dementia clients, and part 2 focusing on behavioural incidents faced by family carers whilst providing daily care. Around one week before data collection, a site visit was made to the centre to check the appropriateness of the venue, provide briefing to staff about the rundown for data collection, check the computing and audio-visual systems, and measures for upholding social distancing and standard precautions owing to the COVID-19 pandemic. A project team meeting was arranged to finalize the arrangements and confirmed the flow of the programme on the day.

On the day of data collection, the research assistant administered information sheet and consent form to the participants. Voluntary participation, rights to withdraw, and rights to answer or refuse any questions were reiterated. Written informed consent was obtained from family carers to indicate their understanding of the study. Staff were available to help participants who required assistance to read the forms. The participants were informed that their views would be kept confidential and would not affect the services they were currently using at the centre. Participants were given the first set of questionnaire with 17 questions to collect the demographic information on the caregiver and older person (12 questions) and baseline data regarding the self-rated score in the level of agreement or disagreement on their current caregiving situation and knowledge level on dementia using a five-level Likert scale (5 questions). This was followed by the delivery of 12 MMVCR, with a short break arranged between the sixth and seventh videos for the participants. A second set of questionnaire was distributed to each participant to collect self-rated scores in the changes in knowledge level on dementia (5 questions) and opinions and effectiveness of the programme (10 questions). Before the participants left, verbal opinions about the design of the DVD were also collected.

Data analysis

Descriptive statistics were conducted including mean, standard deviation, range of possible scores, and actual maximum and minimum scores. Comparison statistics were conducted to examine the differences of scores for pre-post evaluation of the programme. All the analyses were conducted by using the statistical software SPSS version 26.0.

Results

Profile of carers

Although more than 20 participants had enrolled, some of them did not show up on the day owing to the COVID-19 pandemic. Of 17 family carers who participated in this study, four were males and 13 were females. Five were in the late 50 years old, one son-in-law was 47 years old, and the remaining carers ranged from 65 to 89 years. Only 24% of the participants received tertiary education, 41% received secondary education, 29% completed primary education and 6% had no education. Among the carers, 77% had at least one chronic illness, and 35% had 3-5 chronic illnesses. Although 88% of participants claimed to be primary caregivers, only 71% of them lived together with the older person with dementia in the same household.

Profile of older person with dementia

The older people with dementia, who were being cared for by the carers, were aged from 61 to 97 year, with an average age of 82.5 years. The majority of them were female older persons (65%) and 58.8% of them had three to four children. Apart from the service used at this community centre, older persons also used other community services including enhanced home and community services (n=4), elderly home (n=2), and day care centre (n=3).

MMVCR

A series of 12 mini-videos was produced using different themes with specific examples of cases to share commonly encountered concerns and queries that caregivers found challenging to manage at home. Additional pictures or images were added for therapeutic effects, and slide shows of key points were summarized and embedded into the video to emphasize the advice and suggestions provided by the nursing and occupational therapy colleagues. Bearing in mind that time was at a premium for carers, videos were deliberately short and concise to deliver a clear message for them to take home. The total duration of all 12 videos was approximately one hour. Table 1 displays the two-part content of the MMVCR and figure 1 is the cover page of the DVD/USB.

Part 1: Introduction to caregiving for dementia clients	
1.	Introducing the dementia caregiver project
2.	Understanding dementia in older people
3.	Dementia and caregivers stress
4.	Dementia and community care support
Part 2: Behavioural incidents whilst providing daily care	
5.	Case 1: Dementia and day care centre
6.	Case 2. Dementia and foul language
7.	Case 3. Dementia and psychotic medication
8.	Case 4. Dementia and tissue paper
9.	Case 5. Dementia and forgetfulness
10.	Case 6. Dementia and personal hygiene
11.	Case 7. Dementia and wandering behaviour
12.	Case 8. Dementia and toileting habits

Table 1: Content of the MMVCR.



Figure 1: Cover page of DVD/ USB.

Current dementia caregiving situation and knowledge level

Table 2 displays the mean scores of the five questions on the level of agreement towards current dementia caregiving

situation and knowledge level. In general, the family caregivers rated their caregiving situation and knowledge level higher after watching the MMVCR. The mean scores range shifted from between 2.94-3.12 before watching to between 3.24-4.12 after watching the MMVCR.

	Statements	Mean scores before watching	Mean scores after watching	Percentage increase
1.	I have knowledge, skills and judgment to carry out tasks.	2.94	3.65	24%
2.	I have support in early identification of problems and managing the care.	3.12	3.71	19%
3.	I have good emotional and coping skills.	3.00	3.71	24%
4.	I have developed task-specific and problem-solving skills.	2.94	3.24	10%
5.	I have information to understand the community resources.	3.00	4.12	37%

Table 2: Percentage change in the self-rated score of carers on current caregiving situation and knowledge level before and after MMVCR.

This indicated that the participants considered their current dementia caregiving situation and knowledge level have improved after receiving the MMVCR. In the statements reflecting the carers' current dementia caregiving situation, the score of the statement 'I have information to understand the community resources' rose sharply by 37%. The increase of self-rated score in understanding the community resources implied that the carers may have felt more confident and less desperate about where to source for help and have aroused their understanding about where to go to find dementia care support in their district. However, there were less than 20% increase in the statements relating to developing task-specific

and problem-solving skills (10%) and having support in early identification of problems and managing care (19%). This may imply that the multimedia resources may not be able to effectively distinguish between how carers develop specific skills to handle problems, as well as supporting them in the early identification of problems and managing the care.

Programme effectiveness

Figure 2 shows the mean scores of 10 items to determine the effectiveness of the programme.

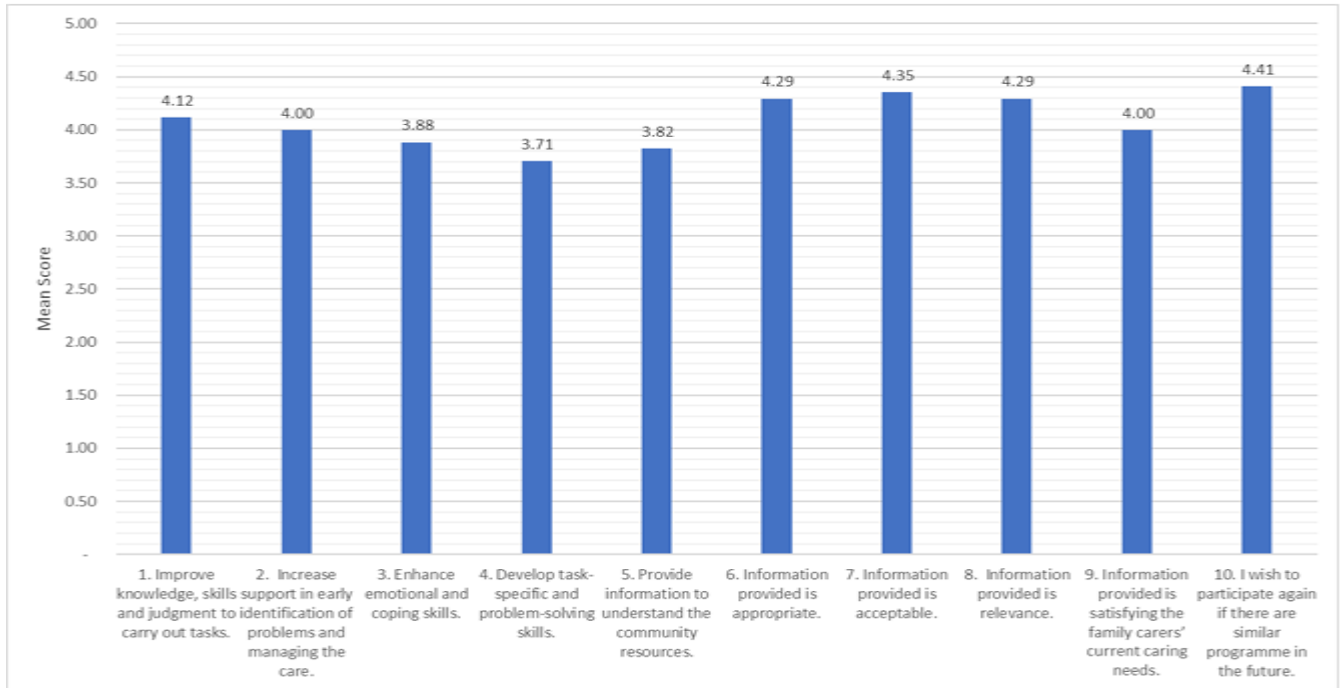


Figure 2: Mean scores of 10 items to determine the effectiveness of the programme.

Overall, the programme was effective in delivering dementia caregiving information and facilitating the family carers' understanding of dementia care. This was indicated by the above-four mean scores in seven out of ten items. The item with the highest score was 'I wish to participate again if there are similar programme in the future', with the distribution of scores ranging between 3 and 5, with the majority choosing 4 (n=8) or 5 (n=8). This had elicited the participants' eagerness to learn more about dementia caregiving in the form of multimedia playing session.

Furthermore, seven out of ten items had mean score higher than four out of five, which indicated that the programme was effective in delivering caregiving-related information to the participants. However, the mean scores of 'develop task-specific and problem-solving skills' scored the lowest, which indicated the programme might be less effective in demonstrating caregiving-related skills to the participants. Table 3 summarizes the scores of the first five items in programme effectiveness.

Improve knowledge, skills and judgment to carry out tasks	Scores ranged between 3 and 5 and peaked at 4, indicating participants' improved knowledge, skills and judgment.
Increase support in early identification of problems and managing the care	Scores ranged between 3 and 5 and peaked at 4, indicating participants' had obtained more support.
Enhance emotional and coping skills	Scores spread between 2 and 5 and peaked at 4, indicating the enhancement of emotional and coping skills.
Develop task-specific and problem-solving skills	Scores ranged between 3 and 5 and peaked at 4. Similar number of participants chose 3 and 4 to show their level of agreeing the statement.
Provide information to understand the community resources	Scores ranged between 2 and 5 and peaked at 4, indicating participants regarded information related to the community resources were provided and their understanding on the community resources have been promoted.

Table 3: Summary score for the first five items in programme effectiveness.

Regarding the items on appropriateness, acceptability, relevance and satisfaction of MMVCR, all the items had high scores. There were:

- For appropriateness, all participants either agreed or totally agreed that the MMVCR was highly appropriate, and gave the score of 4 (n=12) or 5 (n=5). This implied that the video content was highly suitable for the family carers who were mostly over 60-year-old, and targeted at their level of

understanding as the majority of them only received primary or secondary education.

- For acceptability of information, family carers also scored highly with the distribution of scores of 4 (n=9) and 5 (n=7). This indicated that the participants regarded the information provided was acceptable.
- For relevance of information, the distribution ranged between 3 (n=2) and 5 (n=7) and peaked at 4 (n=8). This indicated that the participants regarded the information provided was relevant.

- For satisfaction level, data revealed that the information provided in the MMVCR was able to satisfy the family carers current caring needs, with similar number of participants scoring 3 (n=6), 4 (n=5) and 5 (n=6).

Discussion

The findings from this small study had provided data and a small initiative to raise the general public's awareness of providing knowledge and support to family carers of older people with dementia. It has achieved this by taking the initiative to begin some pilot work to develop a MMVCR programme that was considered to be appropriate, acceptable, relevant and satisfying to the older family carers in the community. This project has brought together the expertise, knowledge and beliefs held by a multi-disciplinary team of healthcare professionals and family carer representatives who have willingly volunteered their time to compile user-friendly dementia caregiving resources. The content of which is packaged into creative and innovative multimedia resource materials that can be used in activity programmes at the community centre, and can be sustained by using the USB and DVD as resources in the different service units for elderly persons of the NGO.

Although this study was affected by the COVID-19 pandemic, it has managed to develop a series of multi-media video-based caregiving resource for dementia carers, which were short and concise and targeted at their immediate daily caregiving needs for older people with dementia who were living at home. It is also worthy to mention that this study had listened and involved older people and family carers from the outset of the study. Attention is drawn to the close involvement of family carers, and soliciting their caring needs and concerns in the focused group interviews before developing the MMVCR resources. Thereafter, retired older people were invited to be the video crew to help in the production and editing of the MMVCR. Together with healthcare professionals, both older people and family caregivers were approached to solicit views to validate and improve the quality of the final production of the resources. According to Macleod and colleagues [8] who wrote about not being easy for dementia family caregivers to find help that was available, the barriers and facilitators of service use among dementia family caregivers in their study have been addressed in this study.

Although the original plan was to run two sessions instead of one session, the findings revealed that family carers reported that the MMVCR was, on the whole, appropriate, acceptable, relevant and satisfying, and scored relatively high scores of 4 and 5. These mini and short videos highlighted specific and concise caregiving themes and messages that family carers could easily grasp and remember. Indeed, this study had recruited participants who had only received primary and secondary education, with only a few of them completing tertiary education. Therefore, the written content should be simple and visually supported by relevant images that can help to reinforce the message and stimulate memory recall. Indeed, the 12 topics are not exhaustive, but were selected for video-shooting as family carers had mentioned them to be important aspects of daily caregiving in the focused group interview.

In the programme effectiveness, the scores indicated participants' appreciation for producing simple MMVCR that were clear and easy to comprehend. Importantly, findings revealed that they had better understanding on dementia caregiving after watching those videos. Indeed, in the area for improvement, there was a request for more solutions to handle tricky situations of the older people with dementia; that question-and-answer sessions between the participants and the healthcare professionals about the use of the videos after the study has ended could enhance their understanding on the content. Although participants' knowledge of dementia caregiving may have been enhanced, as illustrated in the satisfaction scores, six participants gave the score of hesitant and uncertain about not having the skills and understanding of the community resources to take care of older people with dementia. This uncertainty is also supported by the items 'enhance emotional and coping skills', 'develop task-specific and problem-solving skills' and 'provide information to understand the community resources' which scored above-three and below-four.

In terms of project sustainability, there is a need to refer to the comments for improving the MMVCR initiative. Responses received pertained to items to bring when going outdoors with the relative with dementia, and the DVD production should be uploaded to other social media means so more family members can have access to them and get some help and support to fulfil the demand of being a dementia caregiver. In the light of the pandemic, service providers have found the USB to be useful for carers and have introduced a 'Shopping for Carers Knowledge Library Resource' where carers can borrow the USB to view at home and returning it after the loan period. Alternatively, they were invited to attend specific on-site sessions should they wish to visit the centre to meet other carers and staff members.

Recommendations for this study can include thoughts to the following. If other multimedia resources on dementia caregiving would be produced in the future, attention can be given to provide more practical skills in coping with one's emotions and health condition. It would also be helpful to have more task-specific problem-solving skills whereby family carers can work in cooperation and receive support from healthcare professionals as needed. District-specific information should be made available to further enhance the participants' understanding of the community resources that could be suitable and relevant to them. In terms of the way to deliver the multimedia to the participants, it was suggested by family carers to upload the dementia caregiving materials to websites or social media platform, for instance YouTube. This is because of technology driven interventions appear to be promising for the near future owing to its convenience and ease of access [17]. Utilizing the internet may also accommodate the use of a wider variety of multimedia such as interactive voice response as mentioned in Godwin's and colleagues work [18], and not just confined to videos.

Conclusion

Multi-media resources using simple, short and clear messages have been demonstrated to be effective in conveying concise information to the dementia family carers. Indeed, this study is the start to examining simple measures

that can be user-friendly and accepted by family carers to continue caring for their loved ones at home.

Conflicts of Interest

The authors declare no conflict of interest.

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