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Development of home-based care educational programme for the family caregivers of activity limited older people: an educational programme model for community nurses

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ABSTRACT

Background/aim A home-based care educational programme for family caregivers of activity-limited older people was developed and implemented to provide caregiver education and to teach basic caregiving techniques. The purpose of the home-based care educational programme was to improve the caregivers' knowledge, skills and attitudes necessary to perform the caregiving tasks with reduced physical strain.

Methods The educational programme model comprises the knowledge and skills necessary to carry out the caretaking responsibilities of older people, especially those with limited activities. It was conducted as an interventional study recruiting two groups (n=72) as intervention (n=36) and control group (n=36), and the knowledge of the caregivers was evaluated. The teaching sessions were planned considering the adult educational learning theories and guided by a developed educational handbook.

Results The pre and post mean±SD knowledge scores of the intervention group (43.78±12.41; 89.78±5.61) showed a significant difference (p<0.001), whereas the pre and post knowledge mean±SD scores of the control group (50.69±17.90; 51.43±17.79) showed no significant improvement (p>0.05). The difference between the pre-test and post-test between the two groups was significant (p<0.0001).

Conclusions At the end of the educational programme, participants valued the opportunity that they received, and the assessment of knowledge before and after the programme showed an improvement in caregivers' knowledge. The study suggests conducting home-based or community-based health education programmes for caregivers of older people with limited activities, with the involvement of responsible healthcare professionals and leaders.

caregivers are reported to encounter numerous difficulties and challenges in providing care.⁶

In this paper, a family caregiver in the context of older people is defined as a person who assists a family member or friend aged 65 years or older who needs help with their daily living activities due to a prolonged illness or memory problem.⁷ Family caregivers often need direction and guidance when caring for disabled older people with limitations in daily living activities.⁸ The informal caregivers of such older people experience restrictions on their personal lives since they lack time to devote to leisure activities, fulfil family requirements and be with their families and friends.⁹ Naylor *et al* showed that caregiver education programmes to improve skills in decision-making and in improving community contacts can develop caregivers' competencies to meet their own needs along with the needs of their care recipients.¹⁰ Further, awareness programmes conducted in caregivers' homes helped the caregivers to provide good support for acutely ill older people.¹⁰ Educational interventions are reported to reduce the care burden of caregivers,¹¹ which highlights the benefits of implementing community-based programmes and in-home educational programmes targeting caregivers. If such educational programmes are conducted by healthcare professionals, they will very likely help the caregivers to make appropriate decisions, solve problems and provide a foundation for developing and improving skills towards caregiving.¹² Moreover, in addition to knowledge, caregiver training should include aids on simple nursing tasks, skills of lifting and moving and assistance in activities of daily living, which may reduce the burden of care and improve the quality of care.¹³

However, when considering home-based caregiving in Sri Lanka, there is minimal involvement of nursing care professionals, although it is well-established in other countries. Further, there are lack of education programmes available and no available studies conducted on caregiver education programmes to improve the knowledge of caregivers of activity-limited older people. Thus, this study was conducted to develop a home-based care educational programme towards improving the caregivers' knowledge, skills and attitudes necessary to perform the caregiving tasks with reduced physical strain.

INTRODUCTION

Since the overall prevalence of disability, functional limitations and inability to perform self-care activities increase with advancing age,¹⁻³ population ageing challenges society with the collective responsibility for taking care of older adults.⁴ The number of older adults with unmet needs for quality living is projected to increase exponentially, and this will lead to an increased demand for formal (paid) or informal (family and friends) caregivers.⁵ Although family-based caregiving of older people is the socially and culturally accepted norm in Sri Lanka,



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METHODS

The development of the home-based care education programme for caregivers

The need-based educational programme was developed for family caregivers. It comprises knowledge and skills necessary to carry out the caretaking responsibilities of older people, with activity limitations. This educational programme was developed by the author of this manuscript using the results of the cross-sectional and qualitative studies conducted to find the highly prevalent unmet needs (positioning, lifting and moving, transferring, performing exercises, nutrition, elimination, performing self-care activities), perceptions of the older persons with unmet needs in caregiving and the knowledge requirement and caregivers' experiences (physical, psychological, social and environmental (safety) needs/problems, a requirement of the knowledge and supportive assistance).

Developed content areas for the home-based care educational programme

Aim and objectives of the home-based care educational programme
The aim was to enhance the caregivers' knowledge and skills in performing caregiving tasks with reduced physical strain.

Specific objectives of the developed educational programme are to encourage informal caregivers to:

1. Distinguish between the normal physiological changes of ageing and pathological processes.
2. Improve their knowledge of personal caregiving techniques.
3. Improve their caregiving skills towards handling an older person with limitations in activities.
4. Manage problems related to sleep, nutrition, immobility, bladder, bowel and psychological problems.
5. Assess the risk factors for maintaining safety in homes.
6. Improve the efficiency of performing caregiving tasks without minimum effects of physical and psychological problems for the caregivers.

Content areas of the developed educational programme

- ▶ Physiological changes due to ageing.
- ▶ Meeting the safety needs of older adults.
- ▶ Managing sleep and rest problems.
- ▶ Bladder and bowel problems in older adults.
- ▶ Managing problems with the activities of older adults.
- ▶ Managing self-care deficits.
- ▶ Meeting nutritional and fluid requirements.
- ▶ Medication management.
- ▶ Managing psychological, social and spiritual needs.
- ▶ Self-care needs of the caregiver.

Skill demonstration areas of the educational programme

- ▶ Nasogastric tube feeding.
- ▶ Oral care.
- ▶ Providing bed bath.
- ▶ Morning care.
- ▶ Pressure point care.
- ▶ Hair care.
- ▶ Nail care.
- ▶ Perineal care.
- ▶ Catheter care.
- ▶ Performing range of motion activities/exercises.

Selection of participants

This study was conducted in 2 selected (out of a total of 13) divisional secretariat divisions in the Colombo District in the

Western province of Sri Lanka. The study population was the home-based caregivers of older people over 65 years with limitations in activities living within the selected divisional secretariat divisions in the Colombo District.

The intervention and control group samples consisted of caregivers (N=72) who fulfilled the inclusion and exclusion criteria. There were two groups as intervention and control groups where the developed home-based care educational programme was delivered to the intervention group and the other group was used as the control group. The number of subjects required for each arm in individually randomised trials involving dichotomous outcomes was calculated using an equation.¹⁴ Ten per cent was added to the sample size for non-response (non-availability for the assessment after intervention and if patients will not attend the intervention). The calculated number of caregivers (n=36) for each group was selected from two separate divisional secretariat divisions in Colombo District which are located far from each other to avoid contamination.

Inclusion and exclusion criteria

The caregivers who were caring for older people (65+) with limitations in activities and living in their own homes (informal caregiving settings) for more than 6 months, who provided >35 hours of care per week and who were the primary caregivers of the older person were selected for this study. The caregivers who were unable to participate and provide information due to reduced capabilities of communication were excluded from this study. The caregivers for the intervention and control groups were selected based on the highest level of limitations in the activities of the older people.

Home-based care educational programme schedule, delivery and evaluation

Enrolment of the study participants was done a week before the intervention. During the first encounter with the caregivers, the nurse-teacher facilitator (NTF) explained the intervention process and obtained their informed written consent. The caregivers in the intervention group were informed of the date and time of the educational programme to be conducted at their own homes. The most convenient time and location for the caregivers was decided. The NTF initially assessed the learning requirement of the caregivers based on their existing knowledge/experience and planned for the sessions as the facilitator. The baseline knowledge of the caregivers in both intervention and control groups was assessed using the self-administered questionnaire developed by the NTF before the intervention. The participants in the control group received standard caregiving without any form of educational intervention. The developed educational programme was delivered by the NTF to the intervention group.

Home-based care educational programme delivery model

The home-based care educational programme was conducted with the overall goal being to improve the knowledge of the caregivers of older people with limitations in activities. The study designed and tested a four-session educational programme that met weekly for 3 hours. Each session follows a similar pattern to provide structure. All sessions were conducted in Sinhala language as all of the caregivers were Sinhalese. Initially, the NTF motivated caregivers to ask for clarifications related to their caregiving problems and needs and then based on the needs assessment educational sessions were planned. The NTF presented the information related to the topic and demonstrated how to perform the caregiving tasks related to the session

Table 1 Session outline and timetable

Activity	Time duration
Welcome	10–15 min
Implore questions/problems that have been experienced since the previous session	
Physiological aspects of the care recipient condition	15–20 min
Discuss normal and abnormal age-related changes and adaptations	
Providing education related to the identified areas	30–45 min
Mostly the areas related to self-care activities, pressure ulcer prevention, managing problems related to sleep, nutrition, immobility, bladder, bowel and psychological problems, medication management	
Break	5–10 min
Discuss and identify the existing burden of the caregiver	10–15 min
Current physical, psychological, social and spiritual needs of the caregivers	
Role changes and safety problems	
Need-based skills application session	
Demonstrate the technique	15–30 min
Practice the technique (the caregiver will demonstrate the technique in return)	30–45 min
Feedback and summation	5–10 min
Check and provide answers to unanswered questions	
Introduce the topic for the next session	

topic. During each session, NTF allows the caregiver to follow the technique and re-demonstrate the skill for assessment. The NTF helped them to correct their caregiving actions and gave constructive feedback. After conducting the educational session, the NTF allowed the caregiver to ask questions and let them clarify their doubts, further clarifications as the subject expert. After that the caregiver reflected on the learnt concepts and compared the knowledge enhancement, the NTF let them finalise the caregiving areas that they wanted to perform for the older person. NTF distributed the developed educational handbook based on the content areas of the developed educational based programme to the caregiver. During all four sessions, the NTF carefully listens to the caregiver and addresses their problems. A typical session format is presented in [table 1](#). The knowledge levels of the caregivers in both groups were assessed after 6 months by using the same questionnaire.

Data analysis

Data analysis of the intervention component was performed after checking the normal distribution of data using the Shapiro-Wilk normality test, visual inspection of the histograms, normal Q-Q plots and box plots. The test showed that the outcome variables were not normally distributed, and hence, the study used non-parametric tests (Mann-Whitney U test and paired Wilcoxon signed-rank test) to compare the mean scores between and within groups. χ^2 analysis with Fisher's exact test and Mann-Whitney U tests were performed for the categorical and continuous variables, respectively, to determine the baseline differences of sociodemographic characteristics, activity level and morbidity status of older people in two groups and found that there were no real differences ($p>0.05$) between the two groups.

Patient and public involvement

Randomly selected home-dwelling older persons fulfilling the inclusion criteria living in defined administrative localities were invited to participate in the data collection process, based on a predefined questionnaire. Information about the research study was communicated to the selected subjects verbally and in writing, conforming with good ethical norms. The research questions, study design and outcome measures were developed with the engagement of health and non-health personnel

working in the public sector of Sri Lanka. Patients and members of the public were not involved in the study design, the data analysis or the preparation of this manuscript. The published results, conclusions and recommendations will be disseminated to the participants and their families via the respective administrative office.

RESULTS

Sociodemographic characteristics of the caregivers

The mean age of the caregivers was 55.75 ± 12.9 years, ranging from 27 to 85 years. The majority were female (80.6%, $n=58$), who had lived with the older person in the same house (87.5%, $n=63$) and were married (89.1%, $n=64$). The caregiver was the spouse in 36.1%, son/daughter in 33.3% and son/daughter-in-law in 15.3%. Of the 72 caregivers, 93.1% ($n=67$) were the sole caregivers and caring for only one activity-limited older person at home. There was no statistically significant difference in the sociodemographic factors between the participants of the two groups ($p>0.05$).

Impact of the intervention on the knowledge of the caregivers

This study found that caregivers in the interventional group achieved a higher score in the level of knowledge than the control group. The levels of knowledge of caregivers before the intervention showed no significant difference between the intervention (43.78 ± 12.41) and control (50.69 ± 17.90) groups ([table 2](#)). However, the mean knowledge score showed a significant improvement in the intervention group 6 months after the commencement of the intervention (89.78 ± 5.61 ; $p<0.001$), whereas the control group showed no significant improvement (51.43 ± 17.79 ; $p>0.05$) ([table 2](#)). The difference between pre-test and post-test between the two groups is significant ($p<0.0001$). Thus, the educational intervention conducted based on the developed home-based care educational programme, along with the developed educational handbook in this study, has made a positive impact by improving the knowledge among the caregivers of activity-limited older people.

Table 2 Comparison of the pre-test and post-test knowledge scores of caregivers between and within the intervention and control groups

	Intervention	Control	P value (between groups)
Pre-test, mean (SD) (n=36)	43.78 (12.41)	50.69 (17.90)	0.074
Post-test, mean (SD) (n=36)	89.78 (5.61)	51.43 (17.79)	0.000

*P values <0.05.

DISCUSSION

The major unique feature of this home-based care educational programme is the flexibility that permits the participants to establish the teaching priorities and content areas according to the needs of the caregivers. Similarly to this fact, a study conducted by Zarit mentioned that the interventions that can be changed based on the needs assessment and including operational treatment plans according to the needs are better accepted than the fixed treatment protocols.¹⁵ Therefore, the present study found that the nurses who use this can assess the caregiver's needs and determine the teaching and skill demonstration areas to be included in the sessions. In addition, the educational programme was conducted by a registered nurse who had 10 years of experience as a university lecturer and teaching experience, especially in gerontological nursing. As a limitation, in certain situations, the session outlines and timelines were different due to the caregivers' capabilities and their needs. However, it was predicted by the NTF and it can be considered as another unique feature of this educational programme since the programme was planned to deliver based on need-based assessment which is an essential requirement for home-based caregiving. This can be justified by Zarit since it is mentioned that more individualised treatment protocols can reduce the gap between the researcher and the clinical personnel and having multiple treatment components in various combined ways also would support the caregivers with caregiving problems.¹⁵

This study found that caregivers in the interventional group achieved a higher score in the level of knowledge than the control group. Others have applied interventions to improve caregiver knowledge.^{16 17} However, only a few conducted interventional studies with the guidance of an educational handbook like in our study. Hence, the present study recommends conducting educational interventions using training videos and booklets with simple educational pictures, as such strategies will effectively increase the knowledge of older people.¹⁸ Therefore, providing a support system to caregivers of older people with limitations in activities would facilitate them to perform well, which will also play an important role in the delivery of integrated care.¹⁹ On further consideration of the educational aspects, previous studies found that nurses conducting educational sessions to promote the health of older people were effective, as these interventions provided a safe environment, increased knowledge and improved capacity for self-care.²⁰ A study conducted by Lindolpho *et al* emphasises that nurses would be the key elements in developing interventions to improve the knowledge of caregivers.²¹ Some researchers suggest that such interventions would provide necessary knowledge on basic human needs and help required in adapting to life changes by fulfilling biological, psychological, social, cultural and spiritual needs.²² Capacity-building of caregivers on feeding, nutrition, bathing, mobility and transportation, safety needs and appropriate techniques for transferring are essential,^{22 23} and were addressed in the present study as well. Therefore, when considering this study, the caregiver educational programmes that use the developed educational material would help improve the knowledge related to caregiving of their caregivers. Nevertheless, conducting educational programmes

for family caregivers is a new area deemed essential for capacity-building programmes that would uplift the caregiving aspects in Sri Lanka.

This study has several management implications for health-care leaders looking to improve caregiver support and education within their institutions. Study highlights the importance of conducting home-based care educational programmes customised based on the teaching priorities and specific needs of caregivers. Therefore, healthcare leaders should prioritise the recruitment and continuous professional development of nursing staff who can lead such educational initiatives since the nurses with skills and knowledge can significantly improve the quality and effectiveness of caregiver training programmes. Regarding resource allocation for educational materials, the study highlighted the effectiveness of using an educational handbook and suggests that healthcare leaders can allocate resources to develop and distribute such educational materials to support caregiver training programmes. In addition, the current study highlights the importance of educational programmes for family caregivers as a key component of capacity-building in Sri Lanka, as this can lead to improved care outcomes for older adults.

CONCLUSION

This study concludes that conducting the developed home-based care educational programme along with written guidelines improves the knowledge of caregivers of older people with activity limitations. The study suggests conducting home-based or community-based health education programmes for caregivers of older people with limitations in activities, with the involvement of responsible healthcare professionals, with parallel amendments to the relevant policies that have a potential for suitable public health initiatives, which would help in enhancing the knowledge of caregivers of older people. Further, the findings from this study provide a pathway for healthcare leaders to enhance caregiver education and support through needs-based training programmes. Healthcare institutions can improve the quality of care provided to older people with activity limitations and support caregivers in their roles.

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Data availability statement Data may be obtained from a third party and are not publicly available. The datasets generated and/or analysed during the current study are not publicly available as this study protects the participants' privacy but are available from the corresponding author on reasonable request.

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