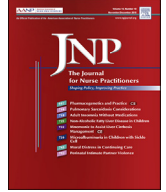




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Mobile Application-Based Education to Improve Family Caregivers' Readiness: Feasibility Study

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A B S T R A C T

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Family caregivers often lack preparation to provide care at home to manage symptoms for patients with life-limiting illnesses. Nurse practitioners can be instrumental in enhancing caregiver readiness by educating relatives about symptom management. Mobile application (app) health education provides one solution. We evaluated the acceptability and initial effectiveness of mobile app health education intended to improve caregiver readiness among 50 family caregivers. Caregiver readiness was measured using the Caregiving Index before and after the 30-day intervention. Mobile app health education improved the caregiver readiness for the intervention group. Our findings demonstrate feasibility and acceptability for delivering education to family caregivers through a smartphone app.

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Introduction

The number of patients with life-limiting illness (LLI) increases globally every year, placing a marked burden on society and the health care system.¹ Despite advances in medical technology, patients with LLI still suffer significantly, particularly from the multiple symptoms they experience.^{2,3} Most patients with LLI prefer to be cared for at home, assisted by their relatives as informal caregivers. However, many family caregivers feel unprepared, lack knowledge, and have limited sources of information that collectively serve as obstacles in the provision of palliative care for patients at home.⁴

Family caregivers' readiness can be enhanced by providing education on how to manage symptoms at home. Nurse practitioners (NPs), particularly those in primary care and ambulatory care settings, have an important role in improving family caregivers' readiness. NPs can support family caregivers by educating them about the patient's illness and treatment plan, including how to manage adverse effects. This supportive education may help reduce anxiety, improve coping, reduce decision conflict, promote patient autonomy, and improve experiences for patients and family caregivers. Health education can also enhance patients' independence in self-care, including self-monitoring and gaining solution skills about their health problems.⁵

Various media solutions can be used by NPs and other health care professionals to provide education for family members caring for patients at home, including mobile applications (apps).⁶ Educational interventions delivered through mobile apps can provide information, including videos to support and facilitate behavioral changes in the treatment of LLI disease.⁷

Mobile app-based education has the potential to improve caregiver readiness by providing timely appropriate health information to assist family caregivers in addressing patients' symptom management.⁸ Mobile app-based education can provide guidance, information, and encouragement to patients and family caregivers without restrictions on place or time.⁹ Results of a 2020 scoping review of mobile app-based education to manage symptoms in patients with cancer at home, show the benefits of smartphone app-based education include improved family caregivers' knowledge of monitoring symptoms, symptom management, and adherence to the treatment plan.¹⁰ Other benefits include promotion of health behavioral change and improved monitoring of physiological indicators of the disease state for patients and family caregivers. Mobile apps have the potential advantages for family caregivers such as increasing readiness, reducing stress, and increasing access to communicate with nurses, thus having the potential to improve the quality of life of family caregivers.¹⁰

Mobile apps have been used in many countries, particularly in Western countries, to increase available resources for family caregivers. The mobile apps have various features, including videos, modules, cultural integration, and avatars.¹¹⁻¹⁴ Literature searches have found no studies on the development of mobile app health education, especially in symptom management in Indonesia. In Indonesia, patients' spouses or close relatives generally become informal caregivers,¹⁵ especially for patients with LLI diseases. Yet, one study conducted in Indonesia identified that the caregiving readiness of family caregivers in suburban Indonesia was very low.¹⁶ The researchers developed a smartphone app, named *My Semah*, to provide health education on symptom management and self-care. The mobile app is available for use and can be

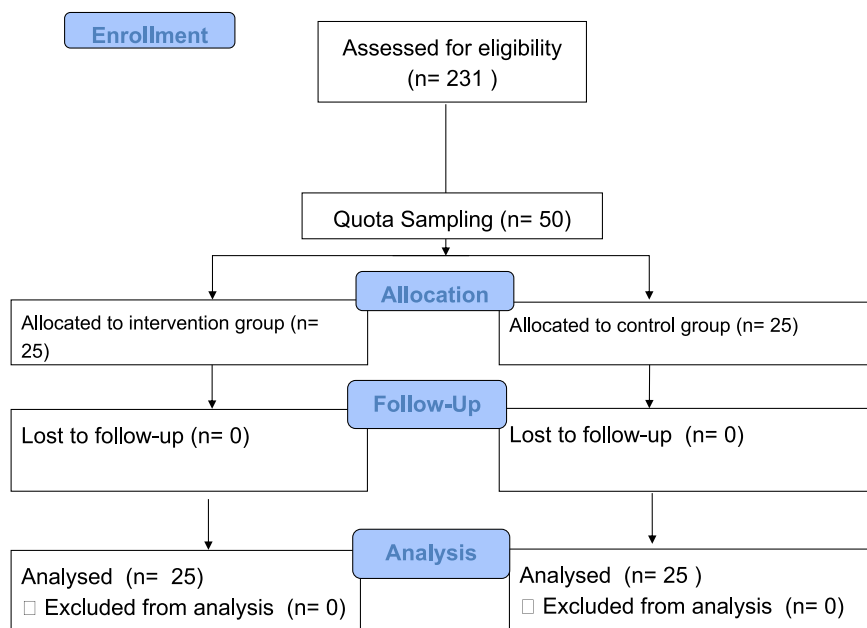


Figure. Study flowchart

downloaded for free in the Google Play Store for smartphones that use the Android operating system.

The current study was a feasibility study to measure the acceptance and initial effectiveness of 30-day mobile app-based education for family caregivers of patients with LLI. The feasibility and initial effectiveness of *My Semah* was determined by evaluating (1) family caregivers' self-reported acceptance and (2) changes in outcomes of caregiving readiness and quality of life after the 30-day intervention.

Method

A single-center study was conducted to assess the acceptability and initial effectiveness of health education using a mobile app. The Universitas Aisyiah Ethics Review Board approved the study protocol (900/KEP-XX/II/2019). The primary end point was the feasibility and outcomes, including caregiving readiness and quality of life. The outcome variables were measured before and after the intervention.

Participants

The study enrolled 50 family caregivers providing care for patients with LLI at home who agreed to participate. The sample included informal caregivers who voluntarily provided care. According to sample size formula, a minimal sample size of 25 in each group was considered adequate to detect changes of a large effect in the outcomes from preimplementation to postimplementation of the intervention, setting the *P* value at .05 and power at 0.8 for an estimated effect size of 0.7.^{17,18}

The family caregivers were divided into intervention group (*n* = 25) and control group (*n* = 25) based on the geographic location of their home (Figure). There was no attrition from either group. Therefore, all 25 participants in the intervention group and 25 participants in the control group were included in the final analysis (Figure). Principal inclusion criteria were being primary caregivers of patients with LLI and having an Android-based smartphone. Exclusion criteria included family caregivers who were diagnosed with LLI.

The researcher screened family caregivers for eligibility. Eligible family caregivers were contacted and provided with a brief overview of the study and participant information sheet before completing consent. After completing the consent, the participants were asked to complete the questionnaires, including the demographic questionnaire, the Caregiving Inventory (CGI) questionnaire to measure readiness levels, and the World Health Organization Quality of Life (WHOQOL-BREF) to measure the quality of life.

Intervention Content

The mobile app, *My Semah*, was developed to address family caregivers' needs. *My Semah* stands for management of symptoms at home. In addition, in Java, where the study was conducted, *My Semah* refers to "my spouse" because most of the family caregivers are the patient's spouse. Several features in the mobile app include (1) my family, (2) self-care, (3) caring for patients, (4) symptom management, and (5) notes. The structured educational content was arranged to achieve the outcome.¹⁹ The mobile app was available via Google Play Store. Participants were asked to access the app using study-specific nonidentifiable credentials. During the study, the application was not accessible to the public. The 30-day smartphone app-based education was delivered by mobile app, and weekly monitoring was conducted by the research monitors via the WhatsApp group.

Instructions to family caregivers about participation expectations included downloading the app at the beginning of the study and exploring the features in the application as they wished during the study period. During the study, the researcher monitored the participants weekly to ensure that participants accessed the smartphone app and understood the education materials. Family caregivers were able to ask questions directly to the researcher or through the WhatsApp group. In the menu of *caring for patients*, there were more specific topics to learn (eg, personal hygiene, nutrition, taking medicine, spirituality, and comfort). In the menu of *symptom management*, the family caregivers were able to learn about the following topics: pain, nausea and vomiting, fatigue, loss of appetite, and dyspnea. In the last menu item, *notes*, participants

Table 1
Characteristics of the Participants (N = 50)

Characteristics	Control Group (n = 25)		Intervention Group (n = 25)		P Value
	No. or Mean	% or Min-Max	No. or Mean	% or Min-Max	
Demographic information					
Age, y	43.76	26-63	35	23-52	.01 ^a
Sex					
Male	3	12	10	40	.02 ^a
Female	22	88	15	60	
Education background					
a. No school	1	4	0	0	.00 ^a
b. Elementary school	4	16	0	0	
c. Junior high school	10	40	3	12	
d. Senior high school	10	40	16	64	
e. Bachelor's degree	0	0	6	24	
Patient-related data					
Patient's diagnoses					
a. Diabetes mellitus	5	20	6	24	.22
b. Heart failure	4	16	9	36	
c. Stroke	7	28	5	20	
d. COPD	5	20	1	4	
e. Cancer	4	16	4	16	
Length of caregiving, y	4.76	2-8	5.80	2-15	.82
Patients' dependability					
a. Partial	19	76	21	84	.48
b. Total	6	24	4	16	
Relationship between patients and caregivers					
a. Children	15	60	18	72	.41
b. Spouse	7	28	5	20	
c. Grandchildren	0	0	2	8	
d. In laws	1	4	0	0	
e. Siblings	2	8	.0	0	
Availability of support					
Yes	0	0	2	8	.15
No	25	100	23	92	
Total	25	100	25	100	

COPD = chronic obstructive pulmonary disease; Max = maximum; Min = Minimum

^a $P < .05$.

were able to document symptoms experienced by the patients and drug administration.

We asked 3 experts to evaluate our smartphone app using the Mobile Application Rating Scale (MARS). MARS is a multidimensional, reliable, and flexible application quality rating scale for researchers, developers, and health care professionals.²⁰ The current assessment results showed that MARS had an average of 70.3 of 100 points from all 3 experts.

Measures

The participants completed a set of demographic questions that included age, sex, previous education, availability of support, and length of providing care to the patient. In addition, participants were asked questions related to the patient's data such as medical diagnosis, length of illness, and dependency level. Participants were also asked to complete the outcome variable questions before and after the intervention that included content on caregiver readiness and quality of life.

Permission to use and translate the CGI was obtained before use. The translated and validated CGI that was then used to measure caregiving readiness consisted of 21 items. The reliability score of the Indonesian version of CGI was 0.856.¹⁶ There were 4 domains in the caregiving readiness, including medical information management, caring for the recipient of care (patient), taking care of themselves, and managing the difficult communication and emotions associated with providing care for sick family members.²¹ The readiness score ranges from 1 to 189, where the higher score reflects higher readiness of the family in caring for the patient.

Quality of life was evaluated using the Indonesia version of validated WHOQOL-BREF.²² The tool consists of 26 items and has 4 domains, namely, physical, psychological, environmental, and social support. The intraclass coefficient correlation of these 4 domains was between 0.77 and 0.79.²² The final score ranges from 0 to 100, with higher scores demonstrating better quality of life.

In addition to demographic and outcome variables, the participants were asked about their acceptance of the *My Semah* smartphone app, including effectiveness of the app, limitations of the app, additional information required for the app, and how willing they would be to recommend the app to others.

Results

Sample characteristics of the 50 participants completing the study in the smartphone app-based education (intervention) and control groups, respectively, are presented in Table 1. There were no significant differences on the length of time providing care, patient's level of dependency, and availability of support between groups at baseline. Notably, however, the control group was older (mean age of 43.76 years compared with 35 years for the intervention group; $P = .01$) than that of the intervention group, included more female caregivers (88% compared with 60% for the intervention group; $P = .02$), and had less education ($P = .001$).

At follow-up participants in the smartphone app-based education (intervention) group reported significantly increased caregiving readiness ($P = .001$). There were also significant differences in participants' quality of life in all domains (physical, psychological, social, and environmental) in the intervention group compared with family caregivers in the control group (Table 2).

Table 2
Caregiving Readiness and Quality of Life

Variable	Time Point	Intervention (n = 25)	Control (n = 25)	P Value
Caregiving readiness	Pretest	69.00 ± 8.636	68.12 ± 6.204	.001
	Posttest	162.32 ± 23.112	71.20 ± 9.513	
Quality of life				.001
	Physical aspect	Pretest Posttest	56.76 ± 8.258 45.60 ± 6.776	
Psychological aspect	Pretest	46.64 ± 4.923	47.16 ± 5.352	.001
	Posttest	65.56 ± 12.616	52.72 ± 9.537	
Social	Pretest	51.80 ± 10.716	51.28 ± 10.147	.001
	Posttest	62.36 ± 13.254	45.88 ± 5.231	
Environment	Pretest	48.88 ± 6.425	49.84 ± 7.004	.001
	Posttest	64.40 ± 9.097	50.80 ± 6.513	

Data are presented as mean ± SD.

Relevant to acceptability of the intervention, participants in the intervention group felt better about providing care to the patients using the *My Semah* app because it helped provide information to support their daily living in caring for their loved ones. Regarding shortcomings of the app, some participants said they sometimes had difficulty in opening the app, noting that there were no images or videos. Participants suggested adding several things to improve the smartphone app, such as materials to care for patients with dementia, and additional features such as health consultations, how to provide emergency first aid to patients, pictures or videos for the treatment of symptoms, and how to connect to the hospital or other health care services. All participants highly recommended the app to others because the app provided information and insight on how to treat patients with LLI.

Discussion

The aim of the current study was to pilot test the smartphone app-based (*My Semah*) educational intervention for family caregivers of patients with LLI and explore the acceptability and initial effectiveness of the app. We found that the 30-day smartphone app-based educational and training program designed to improve self-care and symptom management was effective in increasing caregiving preparedness. Our findings are consistent with previous studies that found mobile app-based education interventions have a beneficial effect in increasing family caregivers readiness.²³ A review of the literature indicates that mobile apps focused on improving knowledge and technical skills resources in family caregivers in palliative care have not been developed.^{12–14} Family caregivers in our study were provided with resources through a smartphone app aimed at enhancing their ability to perform activities for adequate care for patients with LLI. The increasing readiness may be a result of having more information and ability.²⁴

In our study, the smartphone app-based educational and training program was also effective in improving all 4 domains (physical, psychological, social, and environmental) of quality of life for family caregivers. Our results align with findings of previous studies investigating the effect of self-management using the app on the quality of life of patients with cancer.^{25,26} Although in the previous studies the patient populations were different, the health education and training via a mobile app was found to be effective in improving quality of life. NPs, particularly NPs in the primary and ambulatory care settings, have an opportunity to use mobile app-based training and education to improve both family caregivers' and patients' capabilities in symptom management that have the potential to improve quality of life.

Overall, family caregivers who were in the intervention group gave positive feedback. In addition, most of the family caregivers in the intervention group considered the mobile app acceptable and

feasible. The family caregivers' responses to the open-ended acceptance questions provided useful insights, particularly into the strengths of the app and the potential areas of improvement. The strengths of the mobile app included the variety of information for symptom management at home to the family caregivers. In addition, the family caregivers expressed increasing confidence in providing care for the patients. More opportunities to interact with health care services, particularly in emergency situations, was highlighted by family caregivers. Other recommendations by family caregivers included providing more videos and pictorial information and a need for more information related to caring for patients with dementia.

Our study has several limitations. First, the major limitation of our study is the relatively small sample size. However, this study was designed to be a feasibility study to evaluate the initial effectiveness and acceptability of the intervention.

Second, a few of the demographic characteristics of the sample differed between groups at baseline, namely, mean age, percentage of female caregivers, and education level. Thus, it is unknown whether this influenced the differences between groups relative to caregiver readiness or quality of life. Future studies should consider random sampling to enhance representativeness in each treatment group.

Third, the sample consisted of family caregivers living in a suburban area in Indonesia, which limits the generalizability of interventions to family caregivers from different geographic backgrounds. Further research in more diverse populations and settings may provide important insights on the feasibility and acceptability of this mobile app-based intervention.

Conclusion

Our education intervention delivered through a smartphone app, namely *My Semah*, was effective in improving family readiness and quality of life in family members who cared for patients with LLI in their home. Next steps should incorporate family caregivers' feedback provided in our study into an expanded app. Further research is needed to assess the benefits of the smartphone app intervention in a randomized controlled trial with a larger sample size with follow-up beyond 30 days. A larger-scale study could potentially identify which family caregivers would benefit the most from the mobile app-based education and determine the effect of the family caregiver intervention on the quality of care and quality of life of patients with LLI.

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