

The Effect of Online Supportive Program on Care Burden of Parents of Children with Leukemia: A Randomized Controlled Trial

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Abstract

Background: Parents of children with cancer, especially leukemia, face many emotional and physical challenges, which can lead to chronic stress, anxiety, and depression. The online interventions have been recognized as an effective way to support parents in difficult situations.

Aim: The present study was conducted with aim to evaluate the effects of an online supportive program on the care burden of parents of children with leukemia.

Method: This randomized controlled trial study was conducted in 2020 on 76 parents of children with leukemia hospitalized in the oncology department of Dr. Sheikh Hospital in Mashhad, Iran. The parents were randomly divided into two groups: intervention and control (n=38 per group). The parents in the intervention group had access to an online support program via WhatsApp for one month. The parental caregiving burden was measured using the Zarit Caregiver Burden Scale. The data were analyzed using SPSS software (version 20) and descriptive statistics, Kolmogorov-Smirnov, independent t, paired t, and chi-square tests. $p < 0.05$ was considered significant.

Results: The mean care burden scores before the intervention did not differ significantly between the two groups ($p = 0.061$). The mean parental care burden score in the intervention group before the intervention was 45.63 ± 4.44 , which decreased significantly to 42.81 ± 5.07 after the intervention ($p < 0.015$). However, the mean care burden score for the control group before the intervention was 43.94 ± 3.17 and after the intervention was 45.13 ± 4.50 , showing no statistically significant difference ($p < 0.164$). After the intervention, the care burden decreased significantly in the intervention group compared to the control group ($p < 0.05$).

Implications for Practice: Regular supportive programs can be developed and implemented for the main caregivers of patients with other chronic diseases and integrated into the health system.

Keywords: Care Burden, Children, Leukemia, Nursing Support, Online Support, Parents

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Introduction

Cancer is the second leading cause of death in children worldwide (1). Remarkable advances in medical technology in the last few decades have led to a decrease in the death rate of children suffering from cancer (2). Despite medical advances that have positively changed the prognosis of pediatric hemato-oncologic diseases, cancer remains a “life-changing experience” for parents (3). Family members, as the closest caregivers of a child with cancer, usually face a lot of social, psychological, and emotional challenges as they do not have enough information about the diagnosis and treatment of cancer or do not know how to care for a sick child at home (4, 5). Research has shown that having a child with cancer can lead to emotional instability, depression, uncertainty, and conflict among family members, especially parents (6). In the psychology literature, the negative consequences of caregiving are described as caregiver burden (7). Care burden refers to a certain degree of pressure and problems expressed by the caregiver or the patient’s family that involves a range of psychological, emotional, social, and economic problems (8). The care burden can make caregivers prone to physical, emotional, financial, and social problems reflected in the caregiver’s reduced well-being (3).

Accordingly, paying attention to the patient’s family is one of the important components of patient care (9). In various studies, the need for information, support, understanding of feelings, and hope have been reported as the basic need of family members of a person with cancer (10). Caregivers need knowledge and skills to perform their caregiving duties, and studies have shown that caregivers who received this information for caregiving had less caregiver burden. Thus, it is necessary to carry out interventions including supportive interventions to meet this need of family caregivers (11).

Common supportive interventions for parents of children with cancer are face-to-face training and telephone follow-up (12). Face-to-face training is one of the most effective ways to influence the learner, where the instructor can provide the opportunity for active learning in real conditions by using effective models based on the learner’s characteristics. However, the mentioned methods have limitations (13). For example, some parents may prefer not to participate in face-to-face training courses due to the unavailability of other reliable caregivers or their unwillingness because they prefer to take care of the child themselves (14). Online social networks are among the new technologies in the field of communication during the last decade, significantly affecting various areas such as education, learning, and social interactions (15). Many studies have shown that parents of children with cancer bear a high care burden (3, 16). A study (2018) in Iran showed that caregivers of cancer patients face many challenges such as ignorance, instability, anxiety, helplessness, confusion, and stress (17). A high care burden may reduce the provision of care to patients and thus aggravate their condition (16). The aggravation of the clinical condition of patients can lead to an increase in the burden of care (16). The studies carried out in this field have mostly investigated the burden of care in different patients and the related factors (3, 18). Most of the interventional studies have used face-to-face techniques (19, 20). Besides, parents, in addition to taking care of their sick child, have other duties such as taking care of other children, working outside the home, etc., and thus they often fail to attend face-to-face programs. Moreover, the use of online social networks has expanded. Therefore, this study was conducted with aim to evaluate the effect of an online supportive program on the care burden of parents of children with leukemia.

Methods

This randomized controlled trial study was conducted in 2020 on the parents of children with acute lymphoblastic leukemia admitted to the oncology ward of Doctor Sheikh Pediatric Hospital in Mashhad, Iran. The reason for selecting this hospital was the large number of children with acute lymphoblastic leukemia hospitalized. Moreover, the researcher was working as a nurse in the mentioned hospital and this facilitated access to the patient’s parents and communication with them. After obtaining the necessary permission, the names of all candidates were recorded. Then, a list of people who met the criteria to attend the study was prepared. Using a table of random numbers, they were divided into two groups: intervention (n=38) and control (n=38). The inclusion criteria for parents were the willingness to participate in the study and completion of a written consent form, age over 18 years and being the main caregiver of the child, having a 3-8-year-old child with acute lymphoblastic leukemia, daily care of the child at least 2-3 hours, reading and writing literacy, having a smartphone and using the WhatsApp messenger, the ability to join online social networks, having

access to the educational content shared on the online group/channel, willingness to start and continue the treatment for the sick child, and not participated in similar training courses in the past. The inclusion criteria for the child were being between 3-8 years old, at least three months had passed since the diagnosis of the disease, and the child having no neurological or chronic physical diseases. The participants were excluded if they were unwilling to continue cooperating in the study, if the patient passed away or entered into an acute phase of the disease, and if they were absent for more than one day in the training sessions. Based on a previous study and assuming a power of 0.9 and an alpha value of 0.05, as well as a attrition rate of 10%, the sample size was determined to be equal to 40 participants for each group (21). Based on the sample size calculation, it was initially predicted that 40 participants would be included in each group (intervention and control). However, in the present study, 38 participants were placed into each group. Two participants were excluded due to withdrawal from the study. This decision was made to ensure the integrity of the data and the validity of the research results (Figure 1).

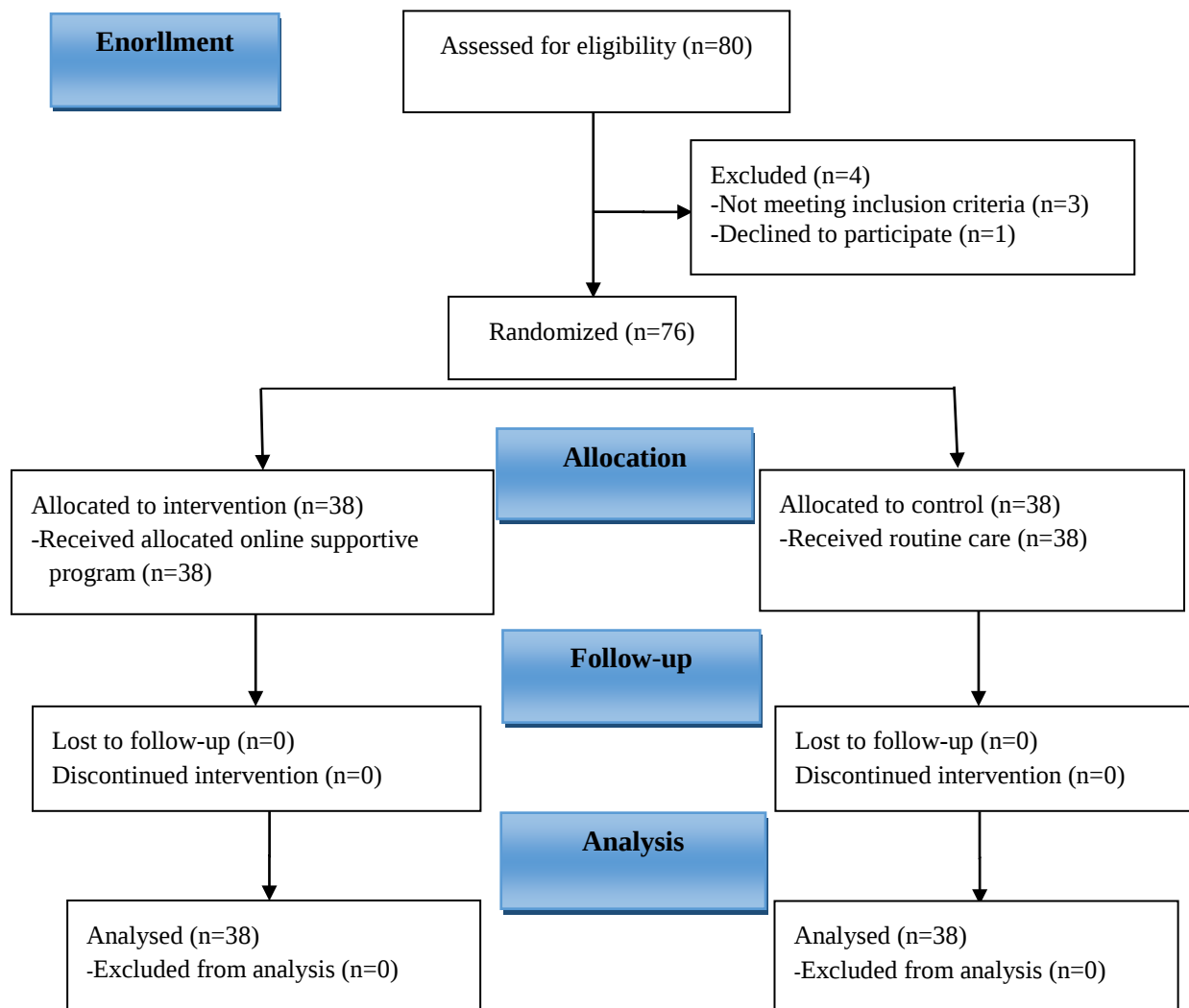


Figure 1. Flowchart of the effect of online supportive program on the care burden of parents of children with leukemia

The participants in the intervention group attended the supportive program held via WhatsApp messenger for one month. The participants in the control group only received the hospital routine support. Routine training in the department included doctor's and nurse's recommendations and presentation of educational pamphlets during discharge. The content of the supportive program was developed after the researcher talked with the parents in the pre-intervention phase to learn about their problems, challenges, and needs. Then, using a random-number table, the children's caregivers were

placed into the intervention and control groups. To prevent the control group from receiving the content of the educational program through interaction with parents in the intervention group and as a result contamination in data collection, first the data were collected from the participants in the control group one month earlier, and then the educational intervention was conducted for the participants in the intervention group. The care management team consisted of five members, including one pediatric hematologist, one clinical nurse, two nursing researchers, and one expert working at Mahak Charity Institute.

After assessing the needs of the patients, the researcher developed the content of the training program based on the literature and with the help of subject-matter experts in various fields (medicine, psychology, social). The sources used included scientific articles, clinical guidelines, and experiences of experts in the field of supporting parents of children with chronic diseases. The researcher worked in this field as a nurse and had relative knowledge of the patients' needs. In the intervention stage, a support group was created on WhatsApp messenger, and the parents in the intervention group were added to it as members. In this group, there was a possibility of two-way interaction between the second author (ZS) and the parents. The intervention was carried out for one month as follows: Presentation of support content based on the different support needs of the caregivers of children with leukemia. The content was prepared in the form of text, audio, video, animation, and image files under the supervision of subject-matter experts and pediatric hematologists. Regarding the different support needs of caregivers of children with leukemia, different educational materials including informational, economic, social, spiritual, and emotional support were prepared.

The training content was gradually presented to the members of the group within one month, two days a week, on Saturdays and Tuesdays at 16:00. The group members discussed the content and materials and shared their experiences. During the one-month intervention, the researcher was online for 2 hours in the morning from 9 to 11 and 3 hours in the evening from 16 to 19 at the times specified in advance and answered the questions asked by the group members, responded to their support needs, and participated in the group discussions. A pediatric hematologist was also a member of the group and handled the parents' medical and treatment issues in the scheduled meetings. Moreover, an expert working at Mahak Charity Institute helped the parents with financial needs. In the virtual group, there were rules to maintain order and respect for the opinions of others. The members were encouraged to ask questions and join discussions. There was an active Q&A session, and the parents could share their experiences and materials. The intended content was uploaded regularly by the group administrator, but the members could also ask their questions and participate in discussions.

The data were collected using the Zarit Caregiver Burden Scale at the beginning and one month after the intervention. The participants' data were recorded in a demographic information form including the parent's age, parent's education, child's age, child's gender, place of residence, and length of stay in the hospital. The parental care burden was measured using the Zarit Caregiver Burden Scale. This scale was developed by Zarit et al. (1998) to measure caregiver burden (22). This scale was used to measure the stress experienced by caregivers of patients with physical and mental illnesses. The scale contains 22 items, with responses on a Likert scale including never, rarely, sometimes, most of the time, and almost always, with a minimum score of 0 and a maximum score of 4. The raw scores obtained from the algebraic sum of the items answered by a respondent range from 0 to 88. The validity and reliability of the scale in Iran have been examined and confirmed by Navidian et al. (2008) (23) and Shafizadeh et al. (2019) (24). Its reliability was calculated using the test-retest method in the two mentioned studies as 0.94 and 0.96, respectively. The reliability coefficient of the original version of the scale using the test-retest method was 0.71, and its internal consistency with Cronbach's alpha was 0.91 and 0.93 in the two mentioned studies (23, 24).

The collected data were analyzed with SPSS software (version 20). The Kolmogorov-Smirnov test was used to examine the normal distribution of the variables. The participants' demographic characteristics were checked using descriptive statistics including frequency, mean, and standard deviation. Moreover, the independent samples t-test was used to compare the two groups in terms of their care burden scores before and after the intervention. The paired samples t-test was also used to compare the mean scores for each group in the pre-intervention and post-intervention phases. The chi-square test was used to compare qualitative variables in the two groups. $P < 0.05$ was considered significant.

Ethical Consideration

The study received ethical review approval (IR.BUMS.REC.1398.108) from the Research Ethics Committee of Birjand University of Medical Sciences. The participants attended a briefing session and were informed of the aim of this study and participant's rights. All participants provided written informed consent before they participated in this study.

Results

The mean age of the primary caregivers was 34.10 ± 7.11 years in the intervention group and 36.86 ± 6.99 years in the control group. Other demographic variables are shown in Table 1.

Table 1. Comparing the demographic variables in control and intervention groups

Variable	Group		P-value
	Intervention	Control	
Age of primary caregiver (years)	34.10 ±7.11	36.86 ±6.99	0.092*
Age of children (years)	5.34 ±1.80	5.55 ±1.75	0.607*
Days of hospitalization (days)	27.81 ±7.71	32.15± 15.57	0.128*
Educational level (n%)			
Lower than a diploma	15 (39.5)	14 (36.8)	0.888**
Diploma and associate degree	17 (44)	19 (50)	
Bachelor's degree and higher	6 (15.8)	5 (13.2)	
Gender of children (n%)			
Male	27 (71.1)	25 (65.8)	0.622**
Female	11 (28.9)	13 (34.2)	
Location of residence (n%)			
Urban	27 (71.1)	28 (73.7)	0.798**
Rural	11 (28.9)	10 (26.3)	

*Independent t-test; **Chi-square test

The mean care burden scores of the parents in the intervention and control groups before the intervention had no statistically significant difference ($p=0.061$). The mean care burden scores in the two groups showed statistically significant differences after the intervention ($p<0.039$). The mean burden care scores of the parents in the intervention group before and after the intervention had a significant difference ($p<0.015$). The mean burden care scores of the parents in the control group before and after the intervention were not significantly different ($p=0.164$) (Table 2).

Table 2: Intra and inter-group comparisons of care burden score

Time Group	Before intervention	One month after intervention	Test result
Intervention	45.63 ± 4.44	42.81 ± 5.07	$t = 2.56, p < 0.015^*$
Control	43.49 ± 3.17	45.13 ± 4.50	$t = -1.42, p < 0.164^*$
Test result	$t = 1.90, p = 0.061^{**}$	$t = -2.10, p < 0.039^{**}$	

*Paired t-test; **Independent t-test

Discussion

This study examined the impact of an online supportive program on the care burden of parents of children with leukemia. An online support program for parents of children with leukemia addresses their needs by providing emotional support, reducing the burden of caregiving, and accessing vital information and resources. The program helps parents cope with the challenges of their child's illness through shared experiences and expert guidance. Belgacem et al. (2018) found that the educational program increased the quality of life of patients and caregivers and reduced caregiver burden in the experimental group compared to the control group (25). The results indicated that the care burden scores reported by the parents in the intervention and control groups showed a statistically significant difference after the intervention. Previous studies have generally indicated that parents may face many physical, social, and economic problems in caring for cancer patients (26). Thus, healthcare professionals should be aware of the role of parents when caring for a child with cancer because childcare can be significantly influenced by caregivers. Care burden adversely affects the life of

parents and the reduction of the caregiver's quality of life influence both the quality of care and the patient's quality of life (27).

The results of the present study revealed that the mean score of parental care burden in the intervention group after conducting the online support program was significantly reduced. Accordingly, Wang et al. (2018) assessed the effectiveness of online leukemia care through smartphones (11). Their findings indicated that the information needs of parents in the intervention group were well met. Similarly, the present study demonstrated that supportive interventions can help reduce parental caregiving burden. However, there may be differences in the results of the two studies. The quality of organization, content, process, and ease of use of the supportive intervention in the study may have influenced the findings.

In the present study, the mean burden care score for the parents in the intervention group decreased significantly one month after the intervention compared to their pre-intervention scores. The results confirm the increasing trend of the caregiver burden of parents after their children were diagnosed with leukemia and the effectiveness of interventions in reducing parents' care burden. The study by Wang et al. and the present study highlight the necessity of implementing effective interventions to prevent the progressive increase in care burden or to reduce it in parents of children with leukemia. Wang et al. reported that most of the informational needs of the parents in the intervention group were supported and probably, the quality of organization, content, procedure, and ease of use of the supportive intervention by leukemia caregivers could account for the conflicting findings of the two studies in reducing caregiver burden (11). Hassan et al. (2018) examined the effect of nursing support interventions on the burden and coping strategies of caregivers of children with cancer, and showed that the caregiver burden score in the treatment group decreased from 42.2 before the intervention to 33.7 immediately after the intervention and 25.6 one month after the intervention. In contrast, the caregiver burden score in the control group increased from 44.2 to 46.1 and then to 48.5 (19). Similarly, the present study revealed that supportive interventions can help reduce parental care burden. Overall, the findings from the present study and other studies in the literature highlight the need for effective interventions to prevent or reduce the gradual increase in caregiving burden in parents of children with leukemia. These findings emphasize that support programs should be specifically tailored to the needs of parents and their quality and effectiveness should be continuously evaluated to achieve the best possible outcomes.

In the present study, the mean burden care score for the parents in the control group increased one month after the intervention compared to before the intervention. Pahlavanzade et al (2014) reported that in the control group, the caregiver burden gradually increased during the three time intervals, before, immediately after, and one month after the intervention (26). Accordingly, Davidson et al. (2007) (25) and Belgacem et al. (2013) (28) found that supportive interventions can effectively reduce parental caregiving burden. Conversely, the absence of these interventions leads to increased caregiving burden. In line with these findings, the present study highlighted the importance of supportive interventions in reducing parental caregiving burden. Previous studies have revealed the support needs of parents are mostly informational, emotional, psychosocial, material, and spiritual (27). Arab et al. (2020) conducted a cross-sectional study on the factors influencing the care burden of mothers of children undergoing treatment for acute lymphocytic leukemia in Bam. The results showed a significant correlation between care burden and the availability of social support. Mothers who received less social support experienced more care burden (29). This finding highlights the need for parents to have more support resources to better cope with their caregiving challenges.

The present study provides interesting insights about emerging needs among parents of children with hemato-oncological diseases. Receiving appropriate information after the diagnosis of a child's illness is the first unfulfilled need expressed by parents. In addition, the parents reported that the need to have additional support resources for coping and adaptation was essential (e.g., communication with health professionals, ways to manage the child's physical/emotional symptoms, and practical/emotional support for the sick child). Thus, the evidence from the studies conducted in this field shows the importance of providing continuous supportive care to the healthcare team (30, 31).

The support program in the present study incorporated all aspects of support. Hence, it reduced the care burden of parents in the intervention group, while no change was observed in the care burden of the parents in the control group. These results confirmed the effectiveness of the intervention implemented in the current study. Similarly, Hassan et al. (2018) reported that after the intervention,

the mean care burden score of the parents in the intervention group was significantly reduced compared to the control group. They found that supportive nursing intervention could decrease the burden on caregivers of children with cancer and, as a result, improve their adaptation by reducing stress (19). Salehi Nejad et al. (2017) investigated the effect of providing web-based health information on the care burden of family caregivers of patients with dementia and showed that the care burden of the participants in the intervention group decreased significantly after the intervention, while no change was observed in the care burden of the participants in the control group (32). These results confirmed the effectiveness of the interventions for providing health information and necessary counseling and training on caring for these patients. The studies on web-based programs for caregivers of chronic patients reported that the caregivers described the use of this method as easy, useful, and practical, and confirmed the positive outcomes on knowledge, attitude, self-efficacy, and feelings of sympathy, and reducing stress and anxiety in caregivers. The caregivers also reported that they felt more confident about their care skills and communication with their patients (32). One of the strengths of the current study was the implementation of a web-based support program.

In an interventional study, Creedle et al. (2012) investigated the effect of training on the care burden of caregivers of cancer patients. The findings indicated that standard training of patients helped to improve the overall health of caregivers, but it did not affect the time spent and the level of difficulty in providing care. The results also did not show a significant change in care burden scores (33), as reported in the present study. Hence, it can be concluded that the nature and content of the support program play an important role in reducing the care burden, and since the program conducted in the present study focused on all dimensions of support (informational, social, emotional, and spiritual support), it was effective in reducing the care burden of parents.

The present study found no significant relationship between the demographic characteristics (the child's age, parental age, the child's gender, parental education, and the place of residence of the family) and the care burden. The researcher believes that the reason for the relative success of the program can be its content, which was designed based on the examination of the problems identified in similar studies and the needs assessment of the caregivers of the patients in this center. Caregiving burden is influenced by several factors, including demographic characteristics. There may be specific characteristics of the population being studied, such as age, gender, or economic status, that make their effects on caregiving burden not observable in this particular group. For example, in certain communities, caregiving burden may be evenly distributed across different groups. Methodological limitations, including small sample sizes or insufficient diversity in demographic characteristics, can affect the ability to identify meaningful relationships.

Holistic nursing care involves paying attention to all aspects of patient care (physical, mental, social, spiritual, etc.) and taking care of the family and caregivers of patients with chronic diseases such as cancer. The training program carried out in this study focused on these issues as much as possible to reduce the care burden of patients. The results of this study showed that the online support program significantly reduced the burden of caring for parents of children with leukemia. These findings emphasize the importance of using new technologies in providing psychological and educational support to parents and this interventional technique can be used as a model for similar programs in the future. The strengths of the study include the use of a randomized design to assign participants to intervention and control groups, the diverse content (text, audio, video, etc.) of the educational program, and the use of an online platform (WhatsApp) to provide easy access and two-way interaction. Limitations of the study include a small sample size during the COVID-19 pandemic and the need for long-term follow-up to assess the lasting effects of the program. The results may not be generalizable to different communities due to cultural and social differences. Moreover, the use of self-report instruments may lead to response bias. Future studies could increase the validity of the results by recruiting a larger sample size and expanding geographical diversity. Moreover, future studies need to track the effects of support programs over time to assess their lasting effects.

Implications for practice

The findings from this study have some implications for training medical students, especially nursing students, nurses, and doctors, in establishing support methods for parents of children with leukemia using social networks and other support-educational methods. Health centers can also organize regular training programs for parents of children with chronic illnesses, including leukemia. These programs

can include workshops, counseling sessions, and support groups that help parents better cope with their caregiving challenges. Given the success of the online program conducted in this study, health centers could create similar platforms such as webinars and discussion groups to provide advice and support to parents of such children. Establishing interdisciplinary collaborations between physicians, psychologists, social workers, and nurses can help provide a comprehensive and integrated approach to supporting parents. This collaboration can include holding joint meetings, exchanging information, and coordinating service delivery. Increasing public awareness about the challenges of parents of children with chronic illnesses and the importance of social supports can help attract more resources and support from the community.

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Conflicts of interest

The authors declared no conflict of interests.

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Authors' Contributions

H.S, Z.S., and S.B. contributed to the design and implementation of the research. H.K.M, Z.S verified the analytical methods. H.S., S.B., and S.A.V. supervised the findings. H.S. and S.B. drafted the manuscript with support from H.K.M and S.A.V. All authors discussed the results and contributed to the final manuscript.

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