

Original Article

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Increased preparedness for caregiving among family caregivers in specialized home care by using the Carer Support Needs Assessment Tool Intervention

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Abstract

Objectives. Family caregivers often feel insufficiently prepared for a caregiving role, experiencing challenges and demands related to care at home that may negatively affect their own quality of life. Supportive interventions have been shown to influence negative effects, but more studies are needed. Therefore, this study aims to explore potential effects of the Carer Support Needs Assessment Tool Intervention on preparedness, caregiver burden, and quality of life among Swedish family caregivers in specialized home care.

Methods. The study had a pre–post intervention design and was conducted at 6 specialized home care services in Sweden. Family caregivers who received the intervention completed a questionnaire, including the Preparedness for caregiving scale, Caregiver Burden Scale, and Quality of Life in Life-Threatening Illness – Family carer version, at 2 time points, baseline and follow up, about 5 weeks later. Data were analyzed using descriptive statistics and Wilcoxon signed-rank test.

Results. Altogether, 33 family caregivers completed the baseline and follow-up assessment. A majority were retired ($n = 26$, 81%) and women ($n = 19$, 58%) and two-fifths had a university degree ($n = 13$, 41%). The family caregivers had significantly increased their preparedness for caregiving between the baseline and follow-up assessment (Mdn = 18 vs. 20, $p = 0.002$). No significant changes were found on caregiver burden or quality of life.

Significance of results. The results add to knowledge regarding the Carer Support Needs Assessment Tool Intervention's potential to improve family caregiver outcomes. Findings suggest that the intervention may be used to improve the preparedness for caregiving and support among family caregivers in specialized home care.

Introduction

There has been a shift in European specialized palliative care with a significant and constant increase of home care services (Arias-Casais et al. 2020) placing family caregivers in a prominent role as providers of care (Ferrell et al. 2018; McDonald et al. 2018; Palmer Kelly et al. 2019; Rowland et al. 2017). Through their unique relationship with the patient, they contribute with personal commitment and valuable knowledge (Carlsen and Lundberg 2018), enabling care at home (Cai et al. 2021a; Khan et al. 2014). The caregiving tasks and demands that follow with this role may, however, result in feelings of burden that negatively influence family caregiver's own health and quality of life (Cai et al. 2021b). It is also known that family caregivers who report having unmet support needs also report poorer quality of life (Norinder et al. 2021).

Preparedness is important in reducing such negative consequences (Henriksson and Årestedt 2013; Holm et al. 2016; Tang et al. 2021). Being prepared for caregiving has been defined as having a perceived readiness for multiple domains of the caregiving role, such as providing physical care, emotional support, and dealing with the stress of caregiving (Archbold et al. 1990). Family caregivers who feel more prepared may experience less burden (Gutierrez-Baena and Romero-Grimaldi 2022; Karabulutlu et al. 2022), and they also tend to report more positive experiences of caregiving with higher levels of hope and reward, as well as quality of life (Henriksson and Årestedt 2013; Rochmawati and Prawitasari 2021).

Family caregivers require sufficient information and education to manage the caregiver role as well as support for themselves to maintain their well-being (Flemming et al. 2019). Supportive interventions have been shown to have positive effects on family caregivers' outcomes (Becqué et al. 2019). One intervention is the Carer Support Needs Assessment Tool Intervention (CSNAT-I): a person-centered intervention enabling family caregivers to identify, discuss, and prioritize their support needs to ensure support tailored to their individual needs. CSNAT-I covers aspects of practical, emotional, existential, and social support needs. The CSNAT-I has been tested in different contexts and populations of family caregivers, for example, among those living with cancer, chronic obstructive pulmonary disease, motor neuron disease, or stroke (Aoun et al. 2015c; Darley et al. 2021; Diffin et al. 2018; Micklewright and Farquhar 2020). The intervention has been found to have positive effect during caregiving: significantly reducing caregiver strain (Aoun et al. 2015c), decreasing distress (Aoun et al. 2015c; Lund et al. 2020), and increasing satisfaction with support (Aoun et al. 2018; Lund et al. 2020). Additionally, it was found to improve mental and physical health in bereavement (Grande et al. 2017), as well as facilitate the grief process (Grande et al. 2017) among family caregivers in a palliative home care context. A study by Toye et al. (2016) found a positive impact on preparedness for family caregivers of older people discharged home from a medical assessment unit, when CSNAT-I was used as part of an overall discharge support package. While Lund et al. (2020) found a significant effect of caregiver distress, they did not find any impact on caregiver strain in their stepped-wedge cluster randomized controlled trial (RCT). Previous studies have been performed in different countries and contexts, and more studies are needed to increase possibilities for an international aggregated understanding of how the intervention can be helpful for family caregivers. Therefore, this study aims to explore potential effects of CSNAT-I on preparedness for caregiving, caregiver burden, and quality of life among Swedish family caregivers in specialized home care.

Methods

Study design and context

This intervention study had a pre–post design and was conducted between October 2020 and January 2022, at 6 specialized home care services in 3 geographic locations in Sweden, including urban, suburban, and rural areas. The services provided care for patients with life-threatening illnesses, including patients with palliative care needs. The services provided 24-h care, with varying numbers of home visits, depending on each patient's needs. Physicians, registered nurses, occupational and physical therapists, and social workers were part of the team in all services. The study was approved by the Swedish Ethical Review Authority (No. 2020-00133, 2021-01935).

The Carer Support Needs Assessment Tool Intervention

CSNAT-I has been thoroughly described in earlier publications (Alvariza et al. 2018; Ewing et al. 2015; Horseman et al. 2019); an updated description is available at <https://csnat.org/>. It provides a person-centered approach and consists of 2 parts: a validated assessment tool (CSNAT) that is structured around support domains and a 5-stage person-centered process (Fig. 1). Each stage is facilitated by health-care professionals (in this study by nurses)

but is caregiver-led. The CSNAT process starts with an introduction of CSNAT-I to the family caregiver, and the CSNAT (the tool itself) is given for completion. Then the family caregiver considers and prioritizes the domains for further discussion. An assessment conversation takes place between the caregiver and the health-care professional, which focuses on the prioritized domains. This stage is vital to explore individual support needs in each of the prioritized domains and what supportive inputs the caregiver would find helpful. In the fourth step, a shared action plan is formulated and documented containing identified individual needs and agreed supportive inputs. Lastly, a continuous review of the action plan is required as caregivers' needs change over time. In the present study, the CSNAT version 2, with 14 support domains, was used (Ewing et al. 2013).

Procedure, participants, and data collection

After having received written and oral information about the study, heads of departments approved participation and designated nurses to participate and deliver the intervention. Due to the Covid-19 pandemic, the services were able to designate fewer nurses than initially expected. This resulted in a total of 12 nurses, 1 to 3 per service. Those nurses were then contacted by the researchers for further information, and written consent was obtained. The nurses underwent a digital training, provided by 2 of the researchers, to learn how to use CSNAT-I. Training consisted of a 30-minute video, based on the original CSNAT-I online toolkit (<https://csnat.org/>). The video also included reflective questions to facilitate the learning process. In addition to the video, nurses were given written information and an accompanying PowerPoint presentation with instructions on how to work with the intervention. During the study, one of the researchers was in continuous contact with the nurses and digital meetings were arranged to provide opportunities to discuss issues concerning training in using CSNAT-I. These meetings aimed to ensure that nurses had a full understanding of how to deliver the intervention as intended.

After training, the designated 12 nurses asked spousal caregivers to participate in the study, as they often are the primary caregiver and provide more care and support than other family caregivers. It is also well known that spousal caregivers often report being more burdened. Inclusion criteria was being a spousal caregiver to a person with life-threatening illness receiving specialized home care at one of the included home care services. A spousal caregiver was defined as being a spouse or partner, living together with the patient. Participants had to be ≥ 18 years and able to read and understand the Swedish language. Spousal caregivers will from herein be referred to as family caregivers throughout the manuscript to be consistent and facilitate readability. Before family caregivers were contacted, the patient was asked for approval. Written and verbal information about the study was then provided to the family caregiver with a request for participation.

Family caregivers who had accepted participation were requested to answer questionnaires at 2 time points. A total of 70 family caregivers answered a questionnaire at baseline and returned it along with a written consent form. After completed intervention, a follow-up questionnaire was sent to the family caregiver and 33 finished and returned it. Attrition occurred primarily because the patient deteriorated significantly in their illness and 19 (27%) died before the intervention was completed.

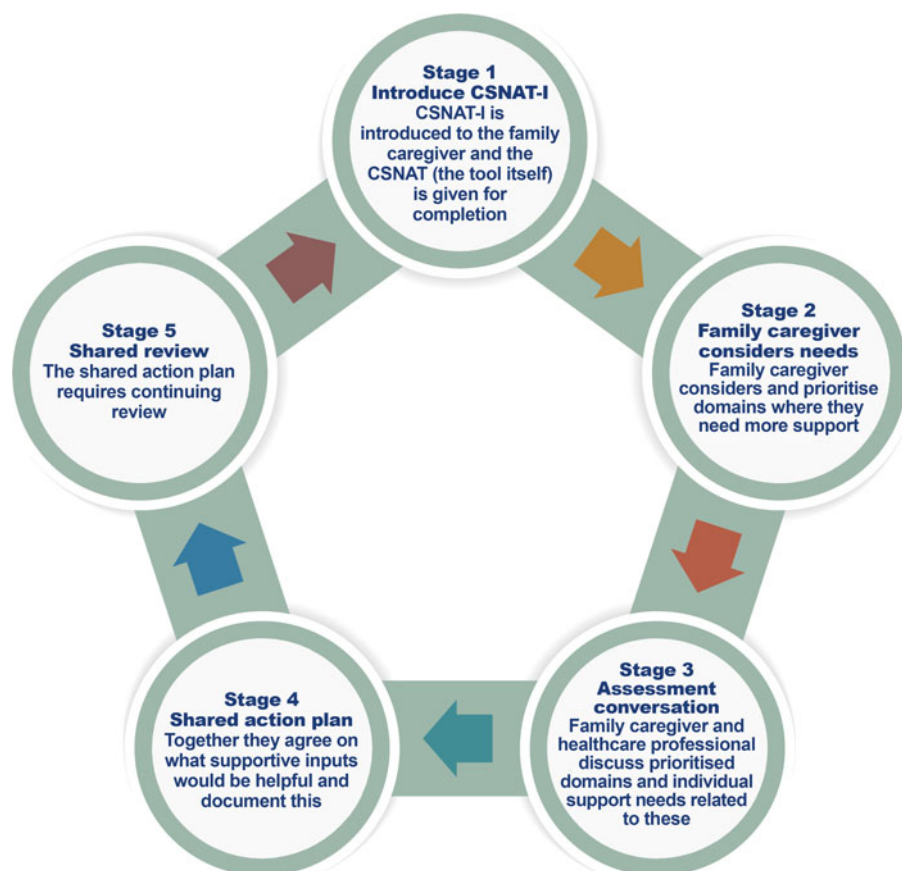


Figure 1. CSNAT-I process

Questionnaires

The questionnaires consisted of demographic questions such as gender, age, education, single items about their own health-care contacts, as well as validated instruments:

Preparedness for caregiving scale

The preparedness for caregiving scale measures caregivers' perceived preparedness to provide care and consists of 8 items (Archbold et al. 1990). The response format is a 5-point Likert scale, ranging from "Not at all prepared" (0) to "Very well prepared" (4). The responses are summed into a total score with a possible range between 0 and 32. A higher score indicates higher preparedness. The instrument has demonstrated good measurement properties in the context of palliative care (Henriksson et al. 2012, 2015).

Caregiver burden scale

The caregiver burden scale measures self-perceived burden and consists of 22 items divided into 5 subscales: general strain, isolation, disappointment, emotional involvement, and environment (Elmståhl et al. 1996). The items are answered on a 4-point Likert scale ranging from "Not at all" (1) to "Often" (4), where higher scores indicate greater caregiver burden. The subscale scores are calculated by summarizing the item responses and dividing that sum with the number of items. Thus, the subscales have a possible score range between 1 and 4. The instrument was developed in the context of care of persons with stroke (Elmståhl et al. 1996).

Quality of Life in Life-Threatening Illness – Family Carer Version

The Quality of Life in Life-Threatening Illness – Family Carer Version (QOLLI-F) v.2 measures quality of life of family caregivers of a person with life-threatening illness and consists of 17 items (Cohen et al. 2006). One item is about overall quality of life, and remaining items are divided into 7 subscales: environment, patient condition, the carer's own state, carer's outlook, quality of care, relationships, and financial worries. The response format is an 11-point numeric rating scale (range 0–10), with descriptive anchors at the ends, higher score implying higher QOL. The responses in each domain are summed and divided with the number of items, giving a possible score range between 0 and 10; higher scores reflect better quality of life (Cohen et al. 2006). The content validity and response processes of the QOLLI-F has shown to be satisfactory among Swedish family caregivers to patients in palliative care (Axelsson et al. 2020a).

Statistical analysis

Descriptive statistics were used to present the sociodemographic and study variables, mean and standard deviations for continuous variables, median and quartiles for ordinal variables, and frequencies for categorical variables. Given the ordinal nature of data, based on the self-reported instruments, the Wilcoxon signed-rank test was used to identify changes in preparedness for caregiving, caregiver burden, and quality of life between the baseline and follow-up assessments. The level of statistical significance was set at $p < 0.05$. All statistical analyses were carried out using Stata 17.0 (StataCorp, College Station, TX).

Table 1. Sample characteristics ($n = 33$)

Age (years), mean (SD) [min-max]	68.6 (8.3) [39-81]
Sex, n (%)	
Female	19 (58)
Male	14 (42)
Education, n (%)	
Primary school	8 (25)
High school	11 (34)
University	13 (41)
Missing data	1
Occupation, n (%)	
Employed	5 (15)
Retired	26 (81)
Other	1 (3)
Missing data	1
Sought health care due to relative's illness, n (%)	
No	24 (75)
Yes	8 (25)
Missing data	1
Visited curator or psychologist due to the relative's illness, n (%)	
No	20 (63)
Yes	12 (37)
Missing data	1
Offered professional support, n (%)	
No	10 (31)
Yes	22 (69)
Missing data	1

Results

Family caregiver characteristics

The final sample included 33 family caregivers who received CSNAT-I and completed both the baseline and follow-up assessment, about 5 weeks later. Their mean age was 68.6 (SD = 8.3) years. A majority were retired ($n = 26$, 81%) and women ($n = 19$, 58%), and two-fifths had a university degree ($n = 13$, 41%). Most family caregivers had been offered professional support from the health care before CSNAT-I ($n = 22$, 69%) was delivered. About one-fourth ($n = 8$, 25%) of the family caregivers had sought health care for themselves and more than one-third ($n = 12$, 37%) had visited a curator or psychologist on their own due to the patient's illness (Table 1). The patients were diagnosed with cancer ($n = 28$), chronic obstructive lung disease ($n = 2$), heart failure ($n = 1$), and neurological diseases ($n = 2$).

Potential intervention effects

Preparedness for caregiving

The family caregivers reported significantly higher levels of preparedness at the follow-up compared to the baseline assessment ($p = 0.002$) (Table 2).

Table 2. Preparedness for caregiving, Caregiver burden, and Quality of life among family caregiver after completed CSNAT-I ($n = 33$)

Study variables	Baseline Mdn (q1-q3)	Follow-up Mdn (q1-q3)	p -value ^a
Preparedness for caregiving	18 (15-20)	20 (17-22)	0.002
Caregiver burden			
General strain	2.4 (1.8-2.6)	2.3 (1.8-2.6)	0.740
Isolation	2.7 (2.0-3.0)	2.7 (2.3-3.0)	0.362
Disappointment	2.2 (2.0-2.6)	2.2 (1.8-2.6)	0.633
Emotional involvement	1.7 (1.0-2.3)	1.7 (1.0-2.0)	0.247
Environment	1.7 (1.5-2.3)	1.7 (1.3-2.0)	0.029
Quality of life			
Overall quality of life	6.0 (5.0-8.0)	6.0 (5.0-8.0)	0.645
Environment	9.0 (7.5-10.0)	9.0 (7.5-10.0)	0.706
Patient condition	5.0 (2.0-8.0)	6.0 (3.0-8.0)	0.505
Carers own state	6.6 (5.6-8.6)	6.6 (5.6-9.2)	0.585
Carers outlook	6.0 (5.0-8.0)	6.0 (5.0-8.0)	0.554
Quality of care	9.8 (8.7-10.0)	10.0 (9.0-10.0)	0.425
Relationships	9.8 (8.7-10.0)	10.0 (9.0-10.0)	0.742
Financial worries	10.0 (10.0-10.0)	10.0 (9.0-10.0)	0.909

^aMann-Whitney U test.

Caregiver burden

Descriptively, family caregivers reported lower caregiver burden regarding general strain, disappointment, emotional involvement, and environment at the follow-up assessment compared to the baseline assessment. In contrast, they reported higher level of isolation at the follow-up. The only change that was statistically significant was found in environment ($p = 0.029$) (Table 2).

Quality of life

Descriptively, family caregivers reported no change in quality of life regarding overall quality of life, environment, and caregiver's outlook at the follow-up assessment compared to the baseline assessment. Higher levels of quality of life were reported at follow-up regarding distress related to the patient's condition, own state, quality of care, and relationships. In contrast, lower levels of quality of life were reported at follow-up regarding financial worries. None of these changes were statistically significant (Table 2).

Discussion

The present study aimed to explore potential effects of the CSNAT-I on preparedness for caregiving, caregiver burden, and quality of life among family caregivers in specialized home care. The results showed that family caregivers reported significantly higher levels of preparedness at the follow-up assessment. No significant changes were found for caregiver burden (except environment) or quality of life. Nevertheless, descriptively, family caregivers reported a lower caregiver burden in all subscales except isolation and higher levels of quality of life regarding distress related to the patient's condition, their own state, and aspects related to the quality of care at the follow-up assessment compared to the baseline assessment.

The significantly higher levels of preparedness for caregiving after the use of CSNAT-I, shown in the present results, can be compared with the results in a recently published meta-analysis including 11 studies about various intervention programs for family caregivers (Bilgin and Ozdemir 2022). The review concludes that interventions exerted a beneficial impact on the preparedness to care among family caregivers of persons with a life-threatening illness. Interventions delivered by nurses were more effective compared to interventions conducted by an interdisciplinary team. Nurses are suggested to be best suited to provide coordinated support to family caregivers (Grant and Ferrell 2012). They are often described being an important resource for practical and emotional support to help family caregivers to continue their caregiver role (Grant and Ferrell 2012; Li *et al.* 2000). A recent meta-analysis indicates that interventions, including self-care support, psychosocial education, and support education, exerted a beneficial impact on preparedness for caregiving (Bilgin and Ozdemir 2022).

The level of preparedness for caregiving seems to be related to the sociodemographic characteristics of the participants (Bilgin and Ozdemir 2022). For example, the level of preparedness to care has shown to increase with the number of female participants. Importantly, the review shows that family caregivers independent of age often report having difficulties in simultaneously carrying out their daily work and their caregiver roles, and thus need training to feel sufficiently prepared to manage their situation. In addition, it should be recognized that the patients had a progressing life-threatening illness, which might contribute to the need for family caregivers to prepare for new situations and demands continuously during the illness. Preparedness for caregiving in a palliative care context has earlier, in interviews, been described as an ongoing process, involving recognizing the seriousness of the situation, coping with a challenging situation, and planning for the inevitable loss (Holm *et al.* 2015). Preparing was not a linear process and would often have to be restarted, as changes in the patient's condition took place over time and family caregivers were forced to prepare for additional contingencies. Preparing for caregiving was closely related to family caregivers preparing for the death of the patient and their experience of grief. Research has shown that severe pre-loss grief is significantly associated with distress, low preparedness, and little communication during caregiving (Nielsen *et al.* 2017). The present study is the first to demonstrate increased preparedness for caregiving as a result of CSNAT-I. Indeed, the intervention is designed to assess and address the individual needs of the family caregiver, continuously throughout the patient's care, which increases the potential to help them prepare for new emerging situations, emotions, and demands as the patient deteriorates.

Family caregivers have previously expressed appreciation that CSNAT-I conversations focused on their specific life situation and their individual needs, priorities, and solutions (Aoun *et al.* 2015a; Kisch *et al.* 2022). Furthermore, nurses have reported that CSNAT-I enabled them to be able to provide more timely, individualized support (Aoun *et al.* 2015b). Finally, while learning to use CSNAT-I, nurses have experienced that their assessments and supportive input shifted from being reactive to being more proactive (Norinder *et al.* 2022). Their support altered from "ad hoc" contacts toward scheduled, trustful conversations, with a more collaborative approach and shared responsibility between them and the family caregivers.

The present study found no significant changes on caregiver burden of CSNAT-I (except for environment) or on quality of life. Lower level of caregiver burden, in terms of environment, may be due to the inclusion on the CSNAT of domain/question enquiring

if the family caregivers need support with practical care, assistive devices, or personal care. It may be the case that responses to these domains resulted in processes including prescriptions of assistive devices and/or assistance with personal care, and these inputs are likely to have contributed to reduced burden. However, we did not have access to detailed information on this. Despite the non-significant results, descriptively small improvements were shown in both caregiver burden and quality of life. This could indicate that family caregivers perceived the intervention as supportive and helpful despite a probable deterioration of the patient's illness and increasing demands. As the goal of palliative care is to promote quality of life for patients and their family, approaches to developing supportive interventions for family caregivers are increasing but with varying results. Recent Cochrane reviews evaluating the effectiveness of support interventions for family caregivers show small improvements in their quality of life immediately after taking part in an intervention and little to no effect on caregiver burden (Corry *et al.* 2019; Treanor *et al.* 2019). When measuring quality of life, slightly higher effects were found on different dimensions, measured by subscales (Corry *et al.* 2019; Treanor *et al.* 2019) than when using overall single items (Treanor *et al.* 2019). It could be assumed that it is difficult to promote quality of life and decrease caregiver burden for family caregivers who are in a situation when someone close to them has a life-threatening illness and likely deterioration in their illness during the study period. Also, overall single items may not be sensitive enough to capture the minor changes in small samples, and therefore it can be important to also include the measurements subscales when evaluating interventions, as palliative care is multidimensional (Treanor *et al.* 2019). To date, no study that has evaluated CSNAT-I has showed a potential to positively impact family caregiver's quality of life. Lund *et al.* (2020) included quality of life as a secondary outcome with a two-item subscale assessing overall health and quality of life but found no significant change. Previous CSNAT-I studies have found diverse results on caregiver strain (Aoun *et al.* 2015c; Lund *et al.* 2020), but the present study is the first to explore the intervention's effect on caregiver burden. While there appeared to be a trend toward reductions in caregiver burden and improvements in family caregiver's quality of life within the small sample in the present study, it would be of value to explore any statistically significant effects of the CSNAT-I utilizing these outcomes in a larger RCT.

The overall results in the present study need to be understood in the context of the stressful situation in which family caregivers often live (Ferrell *et al.* 2018). It is known that the situation triggers experiences of pre-death grief related to the coming loss (Axelsson *et al.* 2020b; Coelho and Barbosa 2017). To care for a close person with life-threatening illness can be experienced as existing in uncertainty, focusing on the present, yet trying to prepare for the future and the impending death. Preparing for the future can be possible intermittently but sometimes needs to be completely paused to live fully in the present (Janze and Henriksson 2014). This way of managing can be seen through the dual process model of coping with bereavement (Breen *et al.* 2018; Coelho *et al.* 2020; Stroebe and Schut 1999, 2015). The model establishes a regulatory coping process of oscillating between loss and restoration positions. Before death, family caregivers must prepare for new demands and the patient's impending death. This is a process at an individual level but also together with the patient. This adds further complexity to family caregivers' possibilities to prepare as the oscillation process differs in time between themselves and the patient. They may confront or distract from grieving at different

times, leading to incompatibility, versus grieving intensely at the same time, leading to intensification of suffering (Stroebe and Schut 2015). It is important that health professionals acknowledge the oscillation process and find structured ways of working that enables them to adequately support the family caregivers through the demands of caregiving and the preparation for the future and coming loss. CSNAT-I facilitates nurses in providing proactive support to family caregivers (Norinder et al. 2022) and provides nurses with guidance and structure when discussing with family caregivers about their specific support needs (Aoun et al. 2015b).

Limitations

Even though data were collected from 6 services spread over 3 geographic locations in Sweden, the result may be limited by the fact that it included only family caregivers able to read and understand the Swedish language. Thus, the results cannot be generalized to the wider population in today's multicultural society. Further, the study was conducted during the Covid-19 pandemic, which affected the possibility for the services to designate nurses for intervention delivery, resulting in a small sample. In addition, the study took place at home care services where all patients had advanced illness and a significant minority died before the intervention was completed. A limitation of the study is that no information was collected about how long participants had been in a caregiver role: caregiver time may have impacted the included outcomes.

Although significant effects were found for preparedness, the small sample size may have limited the statistical power to detect changes in quality of life and caregiver burden. Furthermore, a pre- and post-design, without a control group, was used in this study, which limited the establishment of cause and effect; therefore, in the future studies using an RCT design would give more reassurance about the impact of intervention.

Conclusion

This study contributes to further understanding of the CSNAT-I's effect on family caregiver outcomes. The results show that the intervention led to a significant increase in family caregiver's preparedness for caregiving and a slight improvement in caregiver burden and quality of life. Therefore, the intervention can be used to improve the preparedness for caregiving and support among family caregivers in specialized home care. Future research could with advantage focus on other care contexts, such as primary home care (non-specialized). The intervention could also be tested with family caregivers of persons with multifunctional impairments.

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