

# Associations between support needs and preparedness among family caregivers in palliative home care

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## Abstract

**Background:** Family caregivers take on substantial caregiving responsibilities and report unmet support needs of their own when caring for a person with life-threatening illness. **Aim:** To explore self-rated support needs and their association with preparedness for caregiving among family caregivers in specialised palliative home care. **Methods:** Family caregivers of patients with life-threatening illness were recruited. Family caregivers completed questionnaires at baseline and 4 weeks later, including the Preparedness for Caregiving Scale and the Carer Support Needs Assessment Tool. Descriptive statistics and linear regression analyses were performed. **Results:** Family caregivers' ( $n=153$ ) support needs varied over time across several domains. Unmet needs were associated with lower baseline preparedness for caregiving, but a greater improvement in preparedness over time. When needs were met, family caregivers showed a significant improvement in their sense of preparedness. **Conclusions:** Support needs and preparedness for caregiving are closely related. Addressing support needs is important to enhance preparedness.

**Key words:** ● family caregiver ● life-threatening illness ● palliative care nurse ● palliative home care ● preparedness for caregiving ● support needs

Life-threatening illness can bring physical, psychological, social and spiritual challenges for patients and families (World Health Organization, 2020), and many patients wish to be cared for and die at home (Pinto et al, 2024). Family caregivers play a pivotal role in palliative home care often assuming substantial responsibilities for both supportive and medical caregiving activities (Matthys et al, 2022). Family caregivers are both providers of support to patients, but they also have their own support needs (Alvariza et al, 2018).

Therefore, their needs often encompass both the demands of caregiving and their personal wellbeing (Nysaeter et al, 2024). Many family caregivers experience a need for practical, emotional, social and existential support (Chua et al, 2020), and having these

needs effectively met can provide reassurance and validation in their role (Aoun et al, 2017). Palliative care relies on multiprofessional teamwork to ensure family caregivers' needs are met. Of the care team members, nurses are often the ones who spend the most continuous time with family caregivers and patients, which enables them to build rapport that can form the basis for support (Moran et al, 2021).

An important aspect of supporting family caregivers is promoting their ability to prepare for their role as caregivers. Preparedness for caregiving refers to a family caregiver's perceived readiness and confidence for the tasks and emotional demands of caregiving (Archbold et al, 1990; Dal Pizzol et al, 2024). To enhance preparedness for caregiving, supportive nursing interventions can be

effective (Becque et al, 2019). Nurses support family caregivers by providing relevant information and guidance on caregiving, which helps address their needs and contributes to feeling prepared (Karabulutlu et al, 2022).

### Aim

The overall aim was to explore self-rated support needs and their association with preparedness for caregiving among family caregivers in specialised palliative home care. To address this aim, four research questions (RQs) were outlined:

1. What support needs are reported by family caregivers, and how do these vary over time?
2. What are the associations between family caregivers' support needs and their preparedness for caregiving?
3. What are the associations between family caregivers' support needs and changes in their preparedness for caregiving?
4. To what extent does having support needs met affect changes in family caregivers' preparedness for caregiving?

### Methods

#### Design and study context

This prospective study was based on data from a randomised controlled trial (RCT) evaluating a web-based intervention for family caregivers. The purpose of the intervention was to improve family caregivers' preparedness for caregiving and is described in detail elsewhere (Bauman et al, 2025).

The study was approved by the Swedish Ethical Review Authority (No. 2022-02218-02 and 2022-06623-02), and registered at ClinicalTrials.gov (No. NCT05785494).

Participants were recruited through five specialised home care services in the Stockholm region. The majority of patients cared for within these services have life-threatening conditions and palliative care needs. The services are multidisciplinary, with registered nurses as the largest professional group, with a central role in planning care, working closely with patients and family caregivers.

#### Sampling and procedure

To be included in the study, participants were required to be family caregivers of patients with a life-threatening illness and palliative care needs. Both patients and family caregivers had to be  $\geq 18$  years, and family caregivers were required to be able to communicate

in Swedish.

After approval from the home care service managers, patient records were screened to identify eligible patients. A research coordinator sent written study information to eligible patients, along with a letter of information for a family caregiver of the patient's choosing. The letter was followed by a telephone call from the research team during which patients received verbal information and gave permission for a family caregiver to be contacted. Patients also provided written consent, confirming that their age and diagnosis could be retrieved from their medical records. Once the patient had given permission, the family caregiver was contacted by phone, gave verbal consent and received online questionnaires. The overarching RCT included data collection at three time points: baseline, after 4 weeks and after 8 weeks. The present study used data from the baseline and the 4-week follow-up assessments. Participants provided written consent when completing the baseline questionnaire. Recruitment took place between October 2022 and December 2023.

### Measures

The questionnaires included sociodemographic questions, such as gender and age, along with the Preparedness for Caregiving Scale (PCS), the Carer Support Needs Assessment Tool (CSNAT), RAND-36 for health status, and the Quality of Life in Life-Threatening Illness-Family Caregiver version (QOLLTI-F).

PCS is designed as a unidimensional measure to assess family caregivers' self-perceived preparedness for caregiving (Archbold et

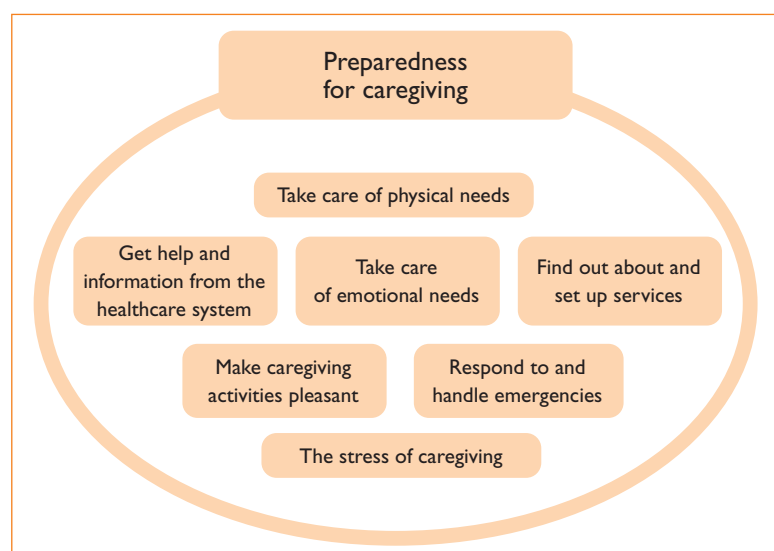


Figure 1. Aspects of the preparedness for Caregiving Scale

al, 1990). The scale comprises eight items that cover various aspects of caregiving (Figure 1). Each item is self-rated on a five-point Likert-type scale ranging from Not at all prepared (0) to Very well prepared (4). According to scoring instructions, the responses are summed to a total score with a possible range of 0–32, with higher scores reflecting greater self-perceived preparedness. The Swedish version has shown evidence of validity and reliability (Henriksson et al, 2012). In the present sample, internal consistency was high (Cronbach’s alpha=0.92).

The CSNAT was used as a research tool to identify the support needs of family caregivers. CSNAT comprises 15 broad support domains, divided into the enabling domains, i.e., support to be able to provide care to the patient, and the direct domains, i.e., support needs for the family caregiver’s own health and wellbeing (Table 1) (Ewing et al, 2013). The items are formulated as questions concerning self-perceived practical, emotional, existential and social support needs.

Each question refers to whether more support is needed with the response categories ‘No more support’, ‘A little more support’, or ‘Much more support’. Each of the 15 CSNAT domains was dichotomised by grouping responses ‘No more support’ to indicate no support needs, and ‘A little more support’ and ‘Much more support’ to indicate support needs. The Swedish version has shown evidence of validity and reliability (Alvariza et al, 2018).

To describe participant characteristics, family caregivers’ health status and quality of life were assessed using the overall health item from RAND-36 (Hays et al, 1993) and the overall item from the QOLLTI-F (Axelsson

et al, 2020), respectively. The RAND-36 item is part of the general health dimension and uses a five-point scale ranging from Excellent (1) to Poor (5), whereas the QOLLTI-F item belongs to the overall dimension and uses an eleven-point numeric rating scale with anchored extremes, Very bad (0) and Excellent (10).

**Statistical analyses**

Missing data in the PCS were imputed using each participant’s median score, given that missing item responses did not exceed 25% (i.e., ≤2 items). Of 1224 reported values, five were missing across four participants and were imputed.

Descriptive statistics were used to present participants’ background characteristics, with appropriate measures of central tendency and variability applied according to the level of measurement. A drop-out analysis was conducted to examine potential differences in background characteristics between participants and non-participants. The proportions of family caregivers reporting support needs, or no support needs, across the 15 CSNAT domains at baseline and follow-up were examined using cross-tabulation and a stacked bar chart to illustrate the distribution and variations over time (RQ1).

A series of simple linear regression analyses was performed to examine the associations between family caregivers’ support needs and preparedness for caregiving. In these models, support needs, measured by the CSNAT, were included as an explanatory variable, while preparedness for caregiving, measured by the PCS, served as the outcome variable.

First, associations between support needs and preparedness for caregiving at

**Table 1. The domains of support needs in the Carer Support Needs Assessment Tool**

Enabling support for providing care to the patient		Direct support for the family caregiver	
	Do you need more support with ...		Do you need more support with ...
CSNAT 1	... understanding the patient’s illness	CSNAT 2	... having time for yourself in the day
CSNAT 3	... managing symptoms including medicines	CSNAT 4	... your financial, legal or work issues
CSNAT 5	... providing personal care for the patient	CSNAT 6	... dealing with your feelings and worries
CSNAT 8	... knowing whom to contact when concerned	CSNAT 7	... managing relationships
CSNAT 10	... equipment to help care for the patient	CSNAT 9	... your own physical health concerns
CSNAT 12	... talking to the patient about their illness	CSNAT 11	... your beliefs or spiritual concerns
CSNAT 14	... knowing what to expect for the future	CSNAT 13	... practical help in the home

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**Table 2. Characteristics of the family caregivers**

Background characteristics	All (n=205)	Drop-out analysis		
		Included (n=153)	Not included (n=52)	p-value
<b>Age, M (SD) [min, max]</b>	64.0 (13.1) [19, 88]	64.0 (12.5) [19, 88]	64.3 (14.8) [24, 84]	0.850 <sup>a</sup>
<b>Gender, n (%)</b>				0.648 <sup>b</sup>
Female	128 (62.4)	94 (61.4)	34 (65.4)	
Male	76 (37.1)	58 (37.9)	18 (34.6)	
Did not respond	1	1		
<b>Relation to patient, n (%)</b>				0.839 <sup>c</sup>
My partner	141 (68.8)	104 (68.0)	37 (71.2)	
My parent	47 (22.9)	35 (22.9)	12 (23.1)	
Other*	17 (8.3)	14 (9.2)	3 (5.8)	
<b>Place of birth, n (%)</b>				0.238 <sup>c</sup>
In Sweden	194 (94.6)	146 (95.4)	48 (92.3)	
Outside of Sweden	9 (4.4)	5 (3.4)	4 (7.7)	
Did not respond	2	2		
<b>Education, n (%)</b>				0.369 <sup>c</sup>
Primary school	13 (6.3)	9 (5.9)	4 (7.8)	
High school	47 (22.9)	39 (25.5)	8 (15.7)	
Post-secondary education	20 (9.8)	13 (8.5)	7 (13.7)	
University	123 (60.0)	91 (59.5)	32 (62.7)	
Did not respond	2	1	1	
<b>Employment status, n (%)</b>				0.475 <sup>b</sup>
Working	88 (42.9)	69 (45.1)	19 (37.3)	
Retired	98 (47.8)	72 (47.1)	26 (51.0)	
Other*	17 (8.3)	11 (7.2)	6 (11.8)	
Did not respond	2	1	1	
<b>Sick leave past month, n (%)</b>				0.346 <sup>c</sup>
No	185 (90.2)	141 (92.2)	44 (93.6)	
Part-time	9 (4.4)	8 (5.2)	1 (2.1)	
Full-time	4 (2.0)	2 (1.3)	2 (4.3)	
Did not respond	7	2	5	
<b>Overall health, Md (q1, q3) [min, max]</b>	3 (3, 4) [1, 5]	3 (3, 4) [2, 5]	3 (3, 4) [1, 5]	0.651 <sup>d</sup>
Did not respond	2	1	1	
<b>Overall quality of life, Md (q1, q3) [min, max]</b>	8 (6, 9) [2, 11]	8 (6, 9) [2, 11]	7 (5, 9) [3, 11]	0.287 <sup>d</sup>
<b>Patient's diagnosis, n (%)</b>				0.303 <sup>c</sup>
Cancer	193 (94.1)	142 (92.8)	51 (98.1)	
Non-cancer	12 (5.9)	11 (7.2)	1 (1.9)	

\* My child, my friend, or other \*\*Student, unemployed, on parental leave, or other a= t-test; b=Chi-squared test; c=Fischer's exact test; d=Mann-Whitney U test

baseline were examined (RQ2). Second, to assess whether baseline support needs were associated with changes in preparedness over time (RQ3), the same regression models were applied using the difference score between PCS at baseline and follow-up as the outcome variable. Third, to explore whether having support needs met was associated with changes in preparedness (RQ4), dichotomous

variables representing changes in each CSNAT domain were used as explanatory variables. These variables were categorised as 'support needs met' versus 'all others'. As the outcome variable, the difference score between PCS at baseline and follow-up was used.

The level of statistical significance was set to  $P < 0.05$ . All statistical analyses were performed in SPSS, Version 28.0.1.1 (IBM Corp.,

Armonk, NY, USA).

## Results

### *Sample characteristics*

Of the family caregivers who participated in the RCT ( $n=205$ ), 153 completed the 4-week follow-up and were included in the present study. The drop-out analysis of background characteristics revealed no statistically significant differences (Table 2).

Participants had a mean age of 64.0 years ( $SD=12.5$ ). The majority were female (61.4%), caring for a patient with cancer (92.5%), were in a partner relationship with the patient (68.0%), and were born in Sweden (95.4%). A university degree was held by 59.5% of participants, and most were retired (47.1%). Family caregivers' median self-rated overall health was three on the 5-point scale, and median quality of life was 8 on the 10-point scale.

### *Variations in support needs*

Support needs were reported across all 15 CSNAT domains at both baseline and follow-up (RQ1). However, not all family caregivers reported needs at both time points (Figure 2), indicating a variation over time. The support need most commonly reported among the enabling domains was knowing what to expect in the future (CSNAT 14). In this domain, 50% of family caregivers reported needing more support at both baseline and follow-up, which means that the need persisted over time. For 16%, it was reported only at follow-up, meaning it emerged between time points. For 21% of family caregivers, the support need was reported at baseline only, meaning it had been met. A minority (14%) reported not needing more support in this domain at either time point.

The support need most commonly reported among the direct domains was dealing with one's own feelings and worries (CSNAT 6). In this domain, 34% of family caregivers reported needing more support at both baseline and follow-up, which means it persisted over time. For 20%, it was reported only at follow-up, meaning it emerged between time points. For 21% of family caregivers, the support need was reported at baseline only, meaning it had been met. For 25%, no support was needed in this domain at either time point.

### *Associations between support needs and preparedness for caregiving*

In the first step (RQ2), significant negative associations were found between support needs at baseline and preparedness at baseline across almost all CSNAT domains (Table 3). That is, reporting a support need was associated with lower preparedness for caregiving. The only support domains that were not significantly associated with preparedness for caregiving were having time for oneself in the day (CSNAT 2) and providing personal care for the patient (CSNAT 5).

In the second step (RQ3), significant positive associations were found between support needs at baseline and changes in preparedness for caregiving over time. Specifically, reporting a support need, compared to not reporting one, was associated with greater positive changes in preparedness for caregiving between baseline and follow-up. This was observed in eight domains of support needs: managing symptoms and medication, managing relationships, knowing whom to contact, using equipment, addressing spiritual concerns, talking with the patient, knowing what to expect and having a break from caregiving (CSNAT 3, 7, 8, 10, 11, 12, 14 and 15).

In the third step (RQ4), significant positive associations were found between having support needs met and changes in preparedness for caregiving over time. Specifically, that family caregivers' support needs in these domains were met was associated with greater positive changes in preparedness for caregiving, compared to those whose needs were unmet. This pattern was observed for the same domains of support needs as in the second step, with the addition of support needs regarding understanding the illness (CSNAT 1), dealing with own feelings and worries (CSNAT 6), and talking to the patient (CSNAT 12).

## Discussion

This study explored variations in reported support needs, and their associations with preparedness for caregiving among family caregivers. Support needs were reported in each CSNAT domain, with variation over time. Furthermore, reporting unmet support needs at baseline was associated with lower initial preparedness for caregiving, but greater positive changes over time. Moreover, family caregivers who reported that their

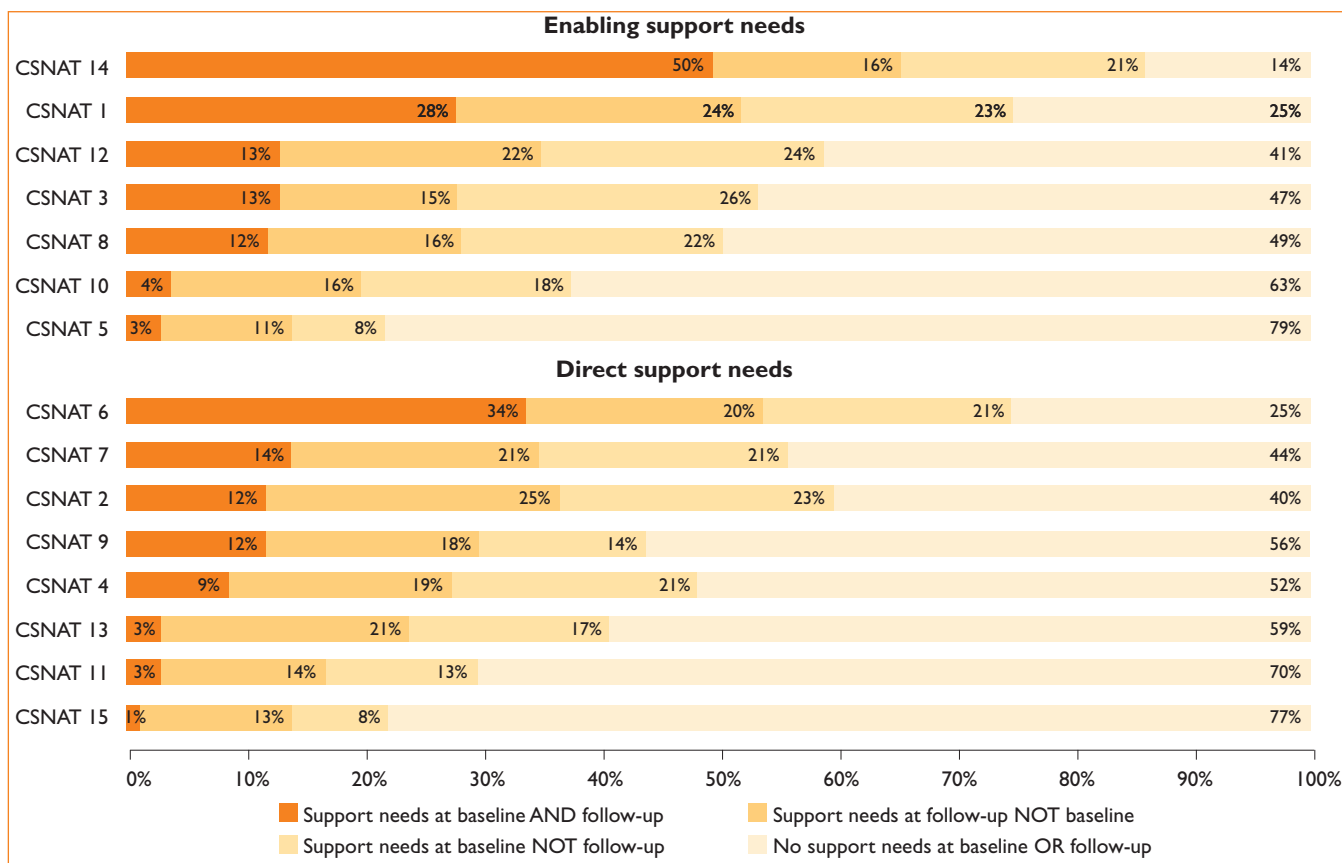


Figure 2. Family caregivers' self-reported support needs at baseline and follow-up

Explanatory variable	Preparedness at baseline				Change in PCS between baseline and follow-up				Change in PCS between baseline and follow-up when support needs are met			
	B	95% CI for B	p-value	R <sup>2</sup>	B	95% CI for B	p-value	R <sup>2</sup>	B	95% CI for B	p-value	R <sup>2</sup>
CSNAT 1	-3.595	-5.639, -1.542	0.001	0.076	2.462	-0.274, 5.268	0.080	0.020	4.907	1.244, 8.585	0.010	0.057
CSNAT 2	-0.410	-2.505, 1.711	0.707	0.001	1.542	-1.272, 4.345	0.287	0.007	2.163	-1.181, 5.403	0.196	0.011
CSNAT 3	-5.023	-6.897, -3.145	<0.001	0.141	4.235	1.391, 6.994	0.005	0.057	4.812	1.433, 8.167	0.007	0.060
CSNAT 4	-3.453	-5.512, -1.292	0.002	0.058	3.001	-0.106, 6.151	0.062	0.025	3.187	-0.700, 6.894	0.098	0.022
CSNAT 5	-0.411	-3.265, 2.315	0.773	0.000	1.625	-3.455, 6.477	0.505	0.003	3.387	-2.984, 9.540	0.263	0.011
CSNAT 6	-4.194	-6.121, -2.253	<0.001	0.103	2.303	-0.361, 4.990	0.100	0.018	5.402	1.974, 8.775	0.002	0.065
CSNAT 7	-4.803	-6.855, -2.715	<0.001	0.123	3.464	0.576, 6.259	0.018	0.037	4.160	0.709, 7.583	0.018	0.038
CSNAT 8	-5.600	-7.458, -3.783	<0.001	0.166	5.715	3.019, 8.401	<0.001	0.098	8.000	5.034, 10.952	<0.001	0.149
CSNAT 9	-2.468	-4.620, -0.355	0.025	0.028	1.832	-0.970, 4.681	0.200	0.009	2.698	-0.759, 6.300	0.136	0.012
CSNAT 10	-4.188	-6.511, -1.972	<0.001	0.069	4.535	1.169, 7.876	0.008	0.047	5.254	1.651, 9.088	0.007	0.054
CSNAT 11	-5.071	-7.168, -2.905	<0.001	0.078	5.556	2.286, 9.036	0.003	0.053	5.744	1.954, 9.894	0.004	0.049
CSNAT 12	-5.924	-7.862, -4.027	<0.001	0.193	5.070	2.354, 7.829	0.001	0.081	7.082	3.829, 10.197	<0.001	0.125
CSNAT 13	-2.310	-4.546, -0.040	0.047	0.021	2.586	-0.414, 5.656	0.099	0.015	3.616	0.214, 7.097	0.039	0.025
CSNAT 14	-5.792	-7.886, -3.631	<0.001	0.163	4.363	1.350, 7.416	0.005	0.053	6.773	3.623, 9.908	<0.001	0.101
CSNAT 15	-3.476	-6.113, -0.622	0.013	0.027	4.032	-0.056, 7.632	0.035	0.021	5.211	0.250, 9.113	0.018	0.027

Carer Support Needs Assessment Tool (CSNAT). See Table 1 for details on the 15 domains; Preparedness for Caregiving Scale (PCS)

support needs were met during the 4 weeks demonstrated a significantly greater increase in preparedness during that period compared to those whose needs were unmet.

Knowing what to expect in the future and dealing with one's own feelings and worries were the most common support needs, consistent with previous research (Lund et al, 2022; Gül et al, 2024; Kreyer et al, 2024). In addition to this, the present study showed that in a considerable proportion of family caregivers, these support needs either persisted or emerged over time. This indicates that not knowing what to expect and feeling worried are issues that family caregivers may need support in managing throughout the entire care period.

This study has shown that unmet support needs and lower preparedness for caregiving (both measured at the same time point) were associated across nearly all support domains. This indicates that support needs, encompassing practical, emotional, social and existential domains, are closely tied to preparedness for caregiving. In particular, practical support needs related to providing care are central to family caregivers' sense of preparedness (Zhang et al, 2023), and preparedness is higher among family caregivers who cohabit with the patient and have longer caregiving duration, highlighting the role of relational aspects (Gutierrez-Baena and Romero-Grimaldi, 2022). Having help from family and extended social networks further strengthens family caregivers' perceived support (Milberg et al, 2020), emphasising social support needs. Importantly, both support and being prepared are crucial for family caregivers' motivation and willingness to take on caregiving (Zarzycki et al, 2023). These findings highlight the importance of paying attention to family caregivers' individual circumstances, including their life situation and social network.

In the present study, the unmet baseline support needs that were associated with positive changes in preparedness over time fall within the enabling and direct support domains as described by Ewing et al (2020). This suggests that supporting family caregivers in both caring for the patient and in attending to their own wellbeing can enhance their preparedness for caregiving. Consistent with this, using CSNAT to identify and address family caregivers' individual support needs can improve their preparedness for caregiving (Norinder et al, 2024), highlighting the

importance of repeatedly assessing evolving support needs.

This study found that family caregivers whose support needs had been met over the previous 4 weeks demonstrated a significantly greater increase in preparedness for caregiving compared to those whose needs were unmet. This highlights the importance of addressing issues, such as understanding and talking about the illness. This lies at the core of palliative care nursing and is underpinned by a holistic care philosophy (Dobrina et al, 2014). In practice, palliative care nurses support family caregivers through a combination of practical actions, such as education and training, and emotional actions such as addressing fears and uncertainties (Kreyer et al, 2024). Core values of palliative care nursing are presence and holistic care, through which nurses provide support to family caregivers and patients (Dobrina et al, 2014). The ability of nurses to uphold professional values is influenced by social, organisational and policy factors, highlighting the need for tools and interventions to ensure these values are consistently enacted in practice (Becqué et al, 2021). To effectively promote preparedness, it is important to both recognise family caregivers' needs and implement strategies to meet them (Ongko et al, 2023). Altogether, the present findings and prior nursing research point to the important, yet challenging, responsibility nurses carry in supporting family caregivers.

The present study showed that having support needs met was associated with positive changes in preparedness for caregiving, aligning with the theoretical framework on family caregivers' involvement in care presented by Andershed and Ternstedt (2001). This framework outlines three principal needs that shape involvement: knowing (knowledge of illness and symptoms), being (shared time and presence), and doing (practical tasks and caregiving actions). Based on findings in the present study, support needs related to knowing could be interpreted as understanding the illness, knowing whom to contact, and anticipating the future.

Knowledge gained from caregiving fosters preparedness by reducing uncertainty and building a sense of control (Dal Pizzol et al, 2024). Support needs related to being can be interpreted as handling relationships, feelings and worries, addressing spiritual concerns, and talking about the illness. Streck et al (2020) described similar aspects, and highlighted

how family caregivers and patients shape each other's wellbeing through shared presence and relational dynamics. McCauley et al (2021) noted that talking about the illness can give meaning to shared moments. Further, support needs related to doing may include symptom and medication management, assistance with caregiving tasks, use of equipment, and a break from caregiving. When practical demands intensify, family caregivers can feel alone and uncertain about their role as caregivers (Banadinovic et al, 2023).

### Limitations

The family caregivers in this study represent a subgroup from a RCT who chose to participate in a web-based intervention designed to promote preparedness for caregiving, which may introduce selection bias and limit generalisability. Sample size was only calculated for the overarching RCT, and the complete case analysis further reduced the sample. However, a sample of 50 would be sufficient to identify a medium-large effect size ( $f^2=0.15$ ,  $\alpha=0.05$ ,  $\beta=0.2$ , power=0.80). Thus, the sample size is sufficiently large overall to detect associations of this magnitude.

Family caregivers' support needs were dichotomised into 'support needs met' versus 'all others'. A more differentiated categorisation could have added nuance, but was limited by the small number of responses within the original categories. Potential confounders (such as patients' illness duration, family caregivers' prior caregiving experiences and sources of support) were not controlled for and may have influenced the observed associations.

### Conclusions

This study demonstrates that addressing family caregivers' support needs is crucial for promoting preparedness for caregiving. Family caregivers reported support needs across all CSNAT domains, with variation over time. Unmet needs at baseline were associated with lower initial preparedness, but greater increases in preparedness over time, and having support needs met was associated with greater positive changes in preparedness. Given that support needs vary across domains and over time, it is essential to develop ongoing, tailored support that addresses both enabling and direct support domains. Effectively meeting family caregivers' support needs provides an opportunity to increase their preparedness for caregiving. *IJPN*

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### CPD reflective questions

- How do evolving support needs challenge approaches to enabling family caregivers to prepare over time?
- In what ways might addressing both practical caregiving tasks and caregivers' emotional wellbeing simultaneously enhance preparedness more effectively than focusing on one domain alone?
- Considering the study's methodological limitations, how might unmeasured aspects, such as prior caregiving experience or social support networks, influence the relationship between unmet needs and changes in preparedness?

### Key points

- Support needs among family caregivers vary and change over time.
- Family caregivers who have unmet support needs are initially less prepared for caregiving, but show greater improvements in preparedness over time.
- Family caregivers whose support needs are met show a greater increase in preparedness for caregiving than those whose needs are unmet.

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