

Adaptation and validation of the Chinese Version of the Carer Support Needs Assessment Tool for Family Caregivers of Cancer Patients Receiving Home-Based Hospice Care

Sijia Zhou

Shenzhen People's Hospital

Qianqian Zhao

Southern Medical University

Huimin Weng

Shenzhen People's Hospital

Ning Wang

Southern Medical University

Xia Wu

Southern Medical University

Xinxin Li

Southern Medical University

Lili Zhang (✉ zhanglilisum@163.com)

Southern Medical University Nanfang Hospital

Research article

Keywords: Family caregivers, cancer, support needs, palliative care, validation, hospice care, Carer Support Needs Assessment Tool, translation

Posted Date: February 25th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-257717/v1>

License:  This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Abstract

Objectives: The study objectives were to adapt and validate the Chinese version of the Carer Support Needs Assessment Tool (CSNAT).

Methods: Cross-cultural adaptation of the original CSNAT for a Chinese setting was performed according to Brislin's translation guidelines. A pilot study was conducted with 15 Chinese family caregivers of cancer patients receiving hospice home care. A cross-sectional survey of 205 family caregivers was conducted from December 2018 to May 2019 at a home-based hospice care institute in Shenzhen, China. The validation procedure comprised the establishment of (1) content validity by a group of six experts; (2) face validity by 15 family caregivers; (3) criterion validity by calculating Spearman's correlations between the CSNAT and caregiving burden, caregiving preparedness and quality of life scales; (4) internal consistency using Cronbach's alpha.

Results: The CSNAT demonstrated good face validity and good content validity (index = 0.98). CSNAT scores showed clear positive correlations with caregiving burden and negative correlations with preparedness for caregiving and quality of life. Internal consistency was high (Cronbach's alpha = 0.899).

Conclusions: The Chinese version of the CSNAT is a valid instrument that is appropriate for identifying needs of family caregivers of cancer patients in home-based hospice care.

Background

Cancer is a major public health concern worldwide and its incidence and mortality rates have rapidly increased in recent years.¹ Cancer affects both patients and their caregivers, as family members, relatives and friends undertake important care work and emotion management.² Cancer caregivers often report higher levels of burden and distress than those caring for frail older people or individuals with other diseases such as diabetes.³ This is especially the case when cancer patients reach the end of life, as most patients prefer to die at home.⁴ Their family caregivers therefore face more duties and responsibilities such as physical care, symptom management, emotional support and daily housework.⁵ Owing to this considerable burden, many caregivers have unmet needs. If their needs are not addressed, they may experience reduced quality of life and greater distress.⁶ International guidelines recommend that caregiver needs should be assessed and a program for caregiver support should be developed.⁷ Therefore, it is important to assess and provide support needs to family caregivers, thus alleviating their caregiving burden and improving the quality of life of the whole family.

Sklenarova et al.² have suggested that strong predictors of caregiver needs remain to be identified; therefore, the specific needs of caregivers may need to be assessed individually. Professionals can only provide tailored assistance to this important group of persons if they can identify their specific care requirements. Thus, a comprehensive, effective and practical assessment tool is needed to achieve this goal. The literature shows an increasing interest in assessing cancer caregivers' needs using various

instruments.^{8,9} However, these instruments are too lengthy and so are inappropriate for caregivers of end-of-life patients who are psychologically stressed and have complex support needs. The Carer Support Needs Assessment Tool (CSNAT) is a brief evidence-based tool developed by Ewing and Grande to identify family caregivers' support needs for end-of-life care research and practice.^{10,11} It contains 14 items on two dimensions: Support to enable the carer to provide care and Direct support for the carers themselves. Generation of the CSNAT items was based on focus group discussions and interviews with 75 bereaved carers.¹⁰ The tool has been subject to rigorous validation testing and has demonstrated good face, content and criterion validity.¹² Additionally, Alvariza et al.¹³ demonstrated that the Swedish version of the CSNAT showed sound psychometric properties. The feasibility and validity of the scale were examined in a recent German study.¹⁴ As a practical tool, the CSNAT intervention facilitates comprehensive, evidence-based assessment and support for family caregivers in palliative care. Aoun et al.¹⁵ reported that the CSNAT intervention substantially reduced caregiver strain and workload. To the best of our knowledge, there is no such tool in China, and there are no reports on the translation of the CSNAT into Chinese and its application in China.

The study aim was therefore to translate the CSNAT into Chinese, to develop a culturally adapted version of the CSNAT for a Chinese-speaking context and to test its psychometric properties in China. A validated Chinese version of the CSNAT would be a useful tool for clinical policymakers and practitioners to identify support needs. The establishment of supportive input for family caregivers of end-of-life cancer patients should be based on family caregivers' needs and preferences.

Methods

Procedure

The study involved three stages: 1) translation of the CSNAT into Chinese, 2) cultural adaptation of the tool through a pilot study and expert committee review and 3) evaluation of the psychometric properties of the Chinese version of the CSNAT.

Translation of the CSNAT

After permission was obtained from the CSNAT developers to translate the original tool into Chinese, the translation was performed according to Brislin's translation guidelines.¹⁶ A forward translation was conducted independently by two bilingual translators and group discussions were used to reach a consensus on a combined version. Without reading the original CSNAT, two different bilingual experts independently performed a backward translation of the Chinese CSNAT into English to establish semantic equivalence. The two back-translations were then reviewed by the research group. Finally, all the translators participated in a proofreading test, and an initial Chinese version of the CSNAT was established.

Cultural adaptation of the CSNAT

The Chinese version of the CSNAT was reviewed by a panel of experts comprising two oncologists, two palliative care specialists and two psychological experts. They assessed the relevance of each item to the tool, and rated items from 1 (not relevant) to 4 (highly relevant). They also provided comments and suggestions about the tool. Subsequently, we conducted structured interviews with 15 family caregivers of cancer patients receiving home-based palliative care and 5 medical staff in the hospice care institution to seek their opinions on the tool items. They were asked whether each question was too difficult to understand or to answer. We also sought their suggestions for more appropriate phrasing of the questions if necessary. On the completion of the above steps, the final Chinese version of the CSNAT was established.

Psychometric analysis of the Chinese version of the CSNAT

Participants and data collection

Using a convenience sampling method, a cross-sectional study was conducted from December 2018 to May 2019 at a hospice care institution in Shenzhen, Guangdong, China. Participants were the primary family caregivers of end-of-life cancer patients. End-of-life cancer is defined as the presence of advanced metastases or estimated life expectancy of less than 6 months. Inclusion criteria were as follows: (1) over 18 years of age; (2) able to read and write Mandarin Chinese; (3) lives with the patient; (4) willing to participate in the research. Exclusion criteria were as follows: (1) having mental illness; (2) having an employment relationship with the patients. Researchers and participants conducted face-to-face assessments of support needs, and caregivers filled out additional questionnaires when they came to register at the hospice institute or when medical staff visited the patient's home. Before the study was conducted, participants were given verbal and written explanations of the purpose and design of the study. It was emphasized that their participation was voluntary, that they could withdraw from the study at any time and that their responses would be anonymous and confidential. After this procedure, caregivers who agreed to participate provided the researcher with their written informed consent.

Instruments

General Information Questionnaire

Sociodemographic and clinical data were collected using a self-report General Information Questionnaire. The questionnaire contained items on gender, age, relationship with patients, religious beliefs, type of residential area, occupational status, educational level, marital status, economic status and number of caregivers. The questionnaire also recorded the following patient clinical data: age, gender, type of cancer, metastasis, awareness of the disease, and whether patients had recently experienced pain, nausea, vomiting or difficulty breathing.

Carer Support Needs Assessment Tool

The 14 CSNAT items assess physical, practical, social, financial, psychological and spiritual support needs of cancer patient family caregivers during end-of-life care. Each item is scored from 0 to 3: a score

of 0 indicates 'no need'; 1 indicates 'a little more'; 2 indicates 'quite a bit more'; and 3 indicates 'very much more.' Higher scores represent higher levels of need for help.

Preparedness for Caregiving Scale (PCS)

The PCS was originally developed by Archbold et al.¹⁷ in the USA for use among family caregivers of frail older persons living at home, but has been used to assess caregivers' preparedness to provide palliative care.¹⁸ The PCS was translated into Chinese in 2016. It consists of eight items; each item is rated on a five-point Likert scale ranging from 'not at all prepared' (0) to 'very well prepared' (4). The total score ranges from 0 to 32; higher scores indicate more preparedness. Cronbach's alpha for the PCS was 0.81 in the present study.

Terminal Cancer Care Load Scale

The Chinese version of the Cancer Care Load Scale was validated by Zhang et al.¹⁹ based on a survey of 186 advanced cancer family members. The scale is mainly used to measure the burden of family members of end-of-life cancer patients. It comprises 17 items measuring physical and mental burden, life burden, economic burden and spiritual burden. Each item is rated on a five-point Likert-type scale, ranging from 'not at all' (1) to 'always' (4). The total score ranges from 17 to 85; higher scores indicate a higher level of caregiving burden. In this study, Cronbach's alpha for this scale was 0.93.

- **item Short-Form Health Survey (SF-12)**

The SF-12 was originally developed from the SF-36, which was widely used to assess self-reported health-related quality of life in various populations.²⁰ The SF-12 consists of 12 items on eight dimensions. The scale includes two summary scores: a physical component summary score and a mental component summary score. Higher scores indicate better quality of life.

Karnofsky Performance Status Scale (KPS)

The KPS was developed to measure patients' functional status. Possible scores range from 0 to 100 with a standard interval of 10. Higher KPS scores indicate better function.²¹

Statistical analysis

The study database was established by two researchers using EpiData 3.1. Statistical analysis was performed using SPSS version 22.0. Descriptive statistics were used to describe participant personal characteristics and family caregiver needs. Content validity was assessed by six experts using a four-point rating scale: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, 4 = highly relevant. The scale content validity index (S-CVI) was calculated as an average of the item content validity index (I-CVI) for all items on the CSNAT. The I-CVI was calculated as the number of experts giving a rating of 3 or 4, divided by the number of experts. Content validity indices were rated as acceptable when I-CVI and S-CVI/Ave were respectively at least 0.78 and 0.90.²² Face validity was evaluated by 15 family caregivers

and 5 medical staff. The test of criterion validity assesses to what extent tools or measures of two constructs that theoretically should be related are in fact related. To evaluate criterion validity, Spearman's rank correlation was used to investigate the relationships between CSNAT items and preparedness for caregiving, caregiving burden and caregiver quality of life. We hypothesized that greater need for support, higher caregiving burden and low preparedness for caregiving would be associated with lower quality of life and poorer patient physical function. Internal consistency was calculated using Cronbach's alpha coefficient to determine the reliability of the tool.

Ethical considerations

Ethical approval was obtained from the ethics committee of the Shenzhen People's Hospital (approval no. LL-KY-201910) and permission to conduct the study was obtained from the Palliative Care Institute. All participants were notified of the research purpose and procedures and that they had the right to choose to participate or withdraw from the study at any time without penalty. All participants provided written informed consent and data confidentiality was guaranteed.

Results

Participant characteristics

A total of 218 family caregivers were invited to take part in the study. Five refused to participate because of high distress levels or inadequate time. Thirteen invalid questionnaires were excluded. Data for the remaining 205 caregivers were included in the analysis. The mean age of participants was 46.43 years (standard deviation = 11.33); 53.2% were women and 46.8% were men. Participant demographic characteristics are shown in Table 1.

Table 1
 Caregiver characteristics and patient clinical information (n = 205)

Variables	n	(%)
Caregiver		
Gender		
Male	96	46.8
Female	109	53.2
Relationship to the patient		
Spouse/partner	75	36.6
Son/daughter	108	52.7
Brother/sister	4	2.0
Friends	2	1.0
Daughter-in-law or son-in-law	16	7.8
Age (years), mean (46.43) SD (11.33)		
18–40	68	33.2
41–60	111	54.1
>60	26	12.7
Type of residential area		
City	156	76.1
County	9	4.4
Town	26	12.7
Village	14	6.8
Marital status		
Unmarried	20	9.8
Married	172	83.9
Widowed	1	0.5
Divorced	12	5.9
Occupational status		
Employed	106	51.7
SD: standard deviation; KPS: Karnofsky performance status.		

Variables	n	(%)
Unemployed	42	20.5
Sick leave	18	8.8
Retired	39	19
Family monthly income (RMB)		
High income	42	20.5
Upper middle income	65	31.7
Medium income	63	30.7
Low income	25	12.2
Extremely low income	10	4.9
Educational level (years)		
Primary school(1–6)	13	6.3
Junior high school(7–10)	55	26.8
Senior high school(11–14)	53	25.9
College level or above(> 15)	84	41.0
Religious beliefs		
No	162	79.0
Yes	43	21.0
Number of caregivers		
one	63	30.7
two	100	48.8
three or more	42	20.5
Patient		
Gender		
Male	120	46.8
Female	85	53.2
Age (years), mean (63.6) SD (13.57)		
18–40	8	3.9

SD: standard deviation; KPS: Karnofsky performance status.

Variables	n	(%)
41–60	75	36.6
61–80	97	47.3
>80	25	12.2
Type of cancer		
Lung cancer	60	29.3
Colorectal cancer	41	20.0
Pancreatic cancer	20	9.8
Hepatic cancer	16	7.8
Reproductive system cancer	14	6.8
Gastric cancer	13	6.3
Breast cancer	12	5.9
Head and neck cancer	13	6.3
Esophageal cancer	5	2.4
Others	11	5.4
Metastasis		
Yes	204	99.5
No	1	0.5
Whether patients with unknown diagnosis		
Fully understand the condition	107	52.2
Understand the diagnosis is not clear prognosis	41	20.0
Not knowing the diagnosis at all	57	27.8
KPS score		
20	18	8.8
30	22	10.7
40	90	43.9
50	54	26,3
60	15	7.3

SD: standard deviation; KPS: Karnofsky performance status.

Variables	n	(%)
70	6	2.9
SD: standard deviation; KPS: Karnofsky performance status.		

A total of 89.3% family caregivers reported that they needed more support regarding knowing what to expect in the future and 82.4% caregivers reported that they needed more support with managing their relative's symptoms. More than 60% of caregivers reported that they wanted more support regarding knowing who to contact, understanding the illness, having time in the day for themselves, dealing with their feelings and worries, and obtaining practical help in the home. Only 39.5% needed support with their own health, and 22.9% needed support regarding their beliefs or spiritual concerns (Fig. 1).

Content validity

The responses of the six experts produced item-level CVIs ranging from 0.83 to 1; the scale-level CVI was 0.98, indicating that the CSNAT had good content validity. The experts felt that all main issues were covered and they also offered specific feedback on wording and presentation. For example, in relation to item 9 (equipment to help care for your relative), one expert suggested adding information about the equipment (e.g., a wheelchair or oxygen machine). However, after consideration of the original author's purpose in developing the scale and further discussion with the expert group, this suggestion was not adopted. This item does not refer solely to the type of equipment in use; rather, it reflects a broad domain that includes support needs relating to information about equipment, advice on what equipment may be useful, training to use equipment and reassurance that the equipment is being used correctly. Another expert suggested that item 12 (practical help in the home) was not clear, as it did not specify the nature of the help (i.e., help from medical staff or other family members?). After consulting the author of the original CSNAT, we added an explanation of this item. This clarified that the item referred to help to manage housework or help around the home, and could encompass help from various sources, not just family members.

The analysis indicated that all the CSNAT items were used by the family caregivers in the study; none were redundant (Fig. 1), which is important. Although only a small percentage of family caregivers wanted more support with beliefs and spiritual concerns, this still represented 46 caregivers. A final optional question asked family caregivers if there were any additional issues they needed help with that were not addressed in the 14 items. Only 20 (5.8%) caregivers expressed an additional need that was not fully covered by the CSNAT, but these needs were strongly related to the existing CSNAT items: help providing emotional support to the patient, help to relieve the patient's cancer pain, help to hire professional and attentive care workers, help with antitumor drugs and mediation methods, and economic help. It is possible that family caregivers just wanted to re-emphasize that they needed support in these areas. Thus, we concluded that the existing CSNAT items comprehensively covered family caregiver support needs.

Face validity

Face validity was examined with family caregivers and palliative care staff. Fifteen family caregivers of terminal cancer patients were asked to participate in the pilot study; nine women and six men aged 25–62 years. The interview results indicated that the CSNAT was easy to complete. Participants felt that the tool gave them more opportunities to communicate with health care providers and express their emotions. However, 14 participants felt that item 4 (legal issues) was difficult to understand. This item reflected the cultural background. In China, legal disputes between families are rare, as the culture emphasizes peace and harmony. Thus, after consulting experts, we removed this reference to legal issues. In addition, we also asked five health professionals (two doctors, two nurses and one social worker) to give their opinion about the instrument. They all felt that all items were easy to understand and relevant to family caregivers. This tool therefore helps to generate conversations between health professionals and family caregivers, promotes deeper communication between them, encourages professionals to listen to family caregivers' needs, and prompts them to provide as much help as they can to caregivers. This is one of the development requirements for hospice care.

Criterion validity

Criterion validity refers to whether a tool or measure is related to an outcome. Higher burden and lower quality of life are normally seen as outcomes of unmet needs and are related to preparedness.^{23,24} However, preparedness can be both a precursor and an outcome of support needs.

Table 2 shows the relationship between CSNAT items and scores on preparedness for caregiving, caregiver burden, caregiver quality of life and patients' functional status. With the exception of insignificant correlations regarding the symptom management support need, all other CSNAT items had significant weak to moderate negative correlations with preparedness for caregiving (all $P < 0.01$). All items had significant weak to moderate negative correlations with family caregiver quality of life (all $P < 0.05$), but had significant weak to moderate positive correlations with caregiving burden (all $P < 0.01$). In addition, there were weak significant negative correlations between patients' functional status and the following CSNAT items: knowing who to contact ($P < 0.01$), overnight and daytime breaks ($P < 0.01$), symptom management ($P < 0.01$), dealing with worries ($P < 0.05$), personal care ($P < 0.05$) and equipment needs ($P < 0.05$). These items were all related to the deterioration of the patient's physical condition.

Table 2

Criterion validity: correlations between CSNAT items and preparedness for caregiving, caregiver burden, caregiver quality of life and patient functional status (n = 205)

Carer Support Needs Assessment Tool Items	Preparedness for Caregiving	Caregiver Burden	Quality of Life	KPS
Understanding your relative's illness	-0.207**	0.181**	-0.154*	-0.003
Having time for yourself in the day	-0.230**	0.279**	-0.192**	-0.189**
Managing your relative's symptoms	-0.110	0.269**	-0.236**	-0.205**
Your financial or work issues	-0.255**	0.251**	-0.161*	-0.135
Providing personal care for your relative	-0.240**	0.263**	-0.291**	-0.147*
Dealing with your feelings and worries	-0.340**	0.322**	-0.321**	-0.155*
Knowing who to contact if you are concerned	-0.277**	0.333**	-0.238**	-0.239**
Looking after your own health	-0.341**	0.339**	-0.393**	-0.067
Equipment to help care for your relative	-0.243**	0.274**	-0.226**	-0.159*
Your beliefs or spiritual concerns	-0.200**	0.199**	-0.187**	-0.086
Talking with your relative about his or her illness	-0.355**	0.208**	-0.153*	-0.126
Practical help in the home	-0.259**	0.413**	-0.321**	-0.110
Knowing what to expect in the future	-0.188**	0.205**	-0.151*	-0.108
Getting a break from caring overnight	-0.336**	0.352**	-0.330**	-0.206**
The total of CSNAT	-0.395**	0.468**	-0.360**	-0.222**
CSNAT = Carer Support Needs Assessment Tool.				
Significant Spearman's rank correlations, two-tailed test,*P-value < 0.05; **P-value < 0.01.				

Reliability

Cronbach's alpha for the whole tool was 0.899. The two CSNAT dimensions had Cronbach's alphas of 0.808 and 0.831, respectively (Table 3). A high level of internal consistency was achieved.

Table 3
Internal consistency of the CSNAT (n = 205)

Dimensions	CSNAT items	Cronbach's alpha coefficient
Support enabling the family caregiver to care	Understanding your relative's illness	0.808
	Managing your relative's symptoms	
	Providing personal care for your relative	
	Knowing who to contact if you are concerned	
	Equipment to help care for your relative	
	Talking with your relative about his or her illness	
	Knowing what to expect in the future	
Support in relation to their own well-being	Having time for yourself in the day	0.831
	Your financial or work issues	
	Dealing with your feelings and worries	
	Looking after your own health	
	Your beliefs or spiritual concerns	
	Practical help in the home	
	Getting a break from caring overnight	
CSNAT: Carer Support Needs Assessment Tool.		

Discussion

The purpose of our study was to translate the CSNAT into Chinese, and assess this tool's validity and reliability in hospice home care with 205 family caregivers of terminal cancer patients. The findings indicated that the Chinese version of the CSNAT has good content, face and criterion validity, similar to the original English version and the Swedish version of the tool.^{12,13} Our study provides preliminary evidence of the internal reliability of the Chinese version of the CSNAT. The CSNAT is not a questionnaire, but a communication tool to open up discussions with healthcare practitioners about different broad domains of family caregiver support needs. As the CSNAT captures the multidimensional and individual nature of family caregivers' support needs its construct validity has not been tested.

The content validity of the Chinese CSNAT was reviewed by an expert panel and was based on expert ratings of item relevance. The results showed that all items on the Chinese version of CSNAT were considered appropriate and relevant. Both item-level and scale-level CVIs showed that the CSNAT has satisfactory content validity.

Face validity is very important, as it determines whether the tool can be used in practice. Qualitative feedback on the acceptability of the tool and its items was obtained from family caregivers and medical staff. Generally, there were no major changes; only a few problems were amended. To adapt the tool to the Chinese cultural background, we deleted the reference to legal issues in item 4; however, all items were retained. The response rate was high; nearly 97% of family caregivers participated in our research and interviews. Participants reported that the tool was brief, comprehensive and helpful. The survey made them feel that the medical staff cared about them and were allowing them the opportunity to express their needs and tell their stories.

The relationship between CSNAT items and caregiving burden, caregiving preparedness and quality of life scales indicated good criterion validity. There was also some correlation between CSNAT items and patient functional status; family caregivers require more support if patient physical condition is poor. These findings indicate that the tool has reasonable criterion validity.

Although the original developer of the tool does not recommend reliability testing, in our opinion, the main use of the CSNAT is to assess the support needs of family caregivers. Internal consistency reflects the interrelatedness of items on a scale and is a measure of whether all items assess the same construct. The CSNAT demonstrated a high level of internal consistency; Cronbach's alpha was 0.899 for the whole tool, and at least 0.808 for both dimensions.

The findings indicate that, as a screening tool, the CSNAT can effectively assess the support needs of family caregivers in a hospice home care setting. The family caregivers in this study had similar support needs. The most frequent support need was associated with knowing what to expect in the future regarding patient care, a finding similar to that reported in a UK study.¹² The second most frequent support need was patient symptom management, especially pain management. One systematic review showed that pain management is the most obvious problem faced by family caregivers in end-of-life caregiving.²⁵ The least-mentioned support need was spiritual support, which reflects the religious and cultural background in China. Family caregivers generally expressed more need for support in caring for patients than for support for themselves.

In conclusion, the CSNAT is a valid and reliable tool that can be used in hospice care settings in China to identify supportive care needs of family caregivers of cancer patients.

Limitations

There are several study limitations. First, the convenience sampling method may have caused sampling bias. Second, the data collection was only conducted in one hospice care institute, so the results may not

be generalizable to other institutions. Third, the test–retest reliability of the CSNAT was not examined.

Conclusions

We translated and validated a Chinese (Mandarin) version of the CSNAT from the original English version. Our findings show that the CSNAT is suitable for assessing the support needs of family caregivers in home-based hospice care, and that the tool has good validity and reliability. The advantages of the CSNAT are its short format, ease of use in practice and comprehensive content. Our findings suggest that the CSNAT is a useful tool for healthcare providers to assess the support needs of family caregivers of end-of-life cancer patients in home-based hospice care in China.

Declarations

Funding

Southern Medical University Nursing Research Special Youth Project (K1022234)

Competing interests

The authors declare that they have no conflict of interests.

Ethical approval

The institution's review board (LL-KY-201910) approved this study.

Consent for publication

All participating patients provided written informed consent.

Ethics approval and consent to participate

Ethical approval was obtained from the ethics committee of the Shenzhen People's Hospital (approval no. LL-KY-201910) and permission to conduct the study was obtained from the Palliative Care Institute. All participants were notified of the research purpose and procedures and that they had the right to choose to participate or withdraw from the study at any time without penalty. All participants provided written informed consent and data confidentiality was guaranteed.

Data availability

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

Code availability

N/A

Authors' contributions

Conceptualization: SJZ, QQZ,LLZ

Data collection and analysis: SJZ,HMW,XW

Writing: SJZ, NW

Reviewing and editing: SJZ, QQZ,LLZ,HMW,NW,XW,XXL

Supervision: LLZ

Acknowledgement

This study utilized the Carer Support Needs Assessment Tool (CSNAT) devised by Dr Gail Ewing and Professor Gunn Grande, copyright © 2009 (version 2.0) University of Cambridge (Centre for Family Research)/The University of Manchester (Division of Nursing, Midwifery and Social Work), All rights reserved. Further information about the CSNAT intervention can be found at the following site:

<http://csnat.org>

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 2018; **68**: 394-424.
2. Sklenarova H, Krumpelmann A, Haun MW, *et al.*. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *CANCER* 2015; **121**: 1513-1519.
3. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *JOURNAL OF AGING AND HEALTH* 2008; **20**: 483-503.
4. Gu X, Cheng W, Cheng M, Liu M, Zhang Z. The preference of place of death and its predictors among terminally ill patients with cancer and their caregivers in China. *Am J Hosp Palliat Care* 2015; **32**: 835-840.
5. Rowland C, Hanratty B, Pilling M, van den Berg B, Grande G. The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliat Med* 2017; **31**: 346-355.
6. Romito F, Goldzweig G, Cormio C, Hagedoorn M, Andersen BL. Informal caregiving for cancer patients. *CANCER* 2013; **119 Suppl 11**: 2160-2169.
7. Hudson P, Remedios C, Zordan R, *et al.*. Guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. *JOURNAL OF PALLIATIVE MEDICINE* 2012; **15**: 696-702.

8. Liu JJ, Liu QH, He HY, *et al.*. Psychometric Testing of the Chinese Version of Supportive Care Needs Survey for Partners and Caregivers of Cancer Patients. *JOURNAL OF CANCER EDUCATION* 2018.
9. Han Y, Zhou Y, Wang J, *et al.*. Chinese version of the Cancer Support Person's Unmet Needs Survey-Sort Form: A psychometric study. *Eur J Cancer Care (Engl)* 2019; **28**: e12963.
10. Ewing G, Grande G. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013; **27**: 244-256.
11. Ewing G, Austin L, Jones D, Grande G. Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach. *Palliat Med* 2018; **32**: 939-949.
12. Ewing G, Brundle C, Payne S, Grande G. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013; **46**: 395-405.
13. Alvariza A, Holm M, Benkel I, *et al.*. A person-centred approach in nursing: Validity and reliability of the Carer Support Needs Assessment Tool. *European Journal of Oncology Nursing* 2018; **35**: 1-8.
14. Kreyer C, Bukki J, Pleschberger S. Development of a German version of the Carer Support Needs Assessment Tool (CSNAT): The process of translation and cultural adaptation. *Palliative & Supportive Care* 2019: 1-6.
15. Aoun SM, Grande G, Howting D, *et al.*. The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One* 2015; **10**: e123012.
16. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine (Phila Pa 1976)* 2000; **25**: 3186-3191.
17. Archbold PG, Stewart BJ, Greenlick MR, Harvath T. Mutuality and preparedness as predictors of caregiver role strain. *RESEARCH IN NURSING & HEALTH* 1990; **13**: 375-384.
18. Hudson P, Quinn K, Kristjanson L, *et al.*. Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliat Med* 2008; **22**: 270-280.
19. Zhang M, Kang X, Lai Q, Zhang C, University XM, Nursing DO. Reliability and validity of Chinese version of terminal cancer care load scale. *China Medical Herald* 2017.
20. Shou J, Ren L, Wang H, *et al.*. Reliability and validity of 12-item Short-Form health survey (SF-12) for the health status of Chinese community elderly population in Xujiahui district of Shanghai. *AGING CLINICAL AND EXPERIMENTAL RESEARCH* 2016; **28**: 339-346.
21. Peus D, Newcomb N, Hofer S. Appraisal of the Karnofsky Performance Status and proposal of a simple algorithmic system for its evaluation. *BMC Med Inform Decis Mak* 2013; **13**: 72.

22. Shi J, Mo X, Sun Z. [Content validity index in scale development]. *Zhong Nan Da Xue Xue Bao Yi Xue Ban* 2012; **37**: 152-155.
23. Friethriksdottir N, Saevarsdottir T, Halfdanardottir SI, *et al.*. Family members of cancer patients: Needs, quality of life and symptoms of anxiety and depression. *ACTA ONCOLOGICA* 2011; **50**: 252-258.
24. Hendrix CC, Bailey DJ, Steinhauser KE, *et al.*. Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. *SUPPORTIVE CARE IN CANCER* 2016; **24**: 327-336.
- 2 Chi NC, Demiris G. Family Caregivers' Pain Management in End-of-Life Care: A Systematic Review. *Am J Hosp Palliat Care* 2017; **34**: 470-485.

Figures

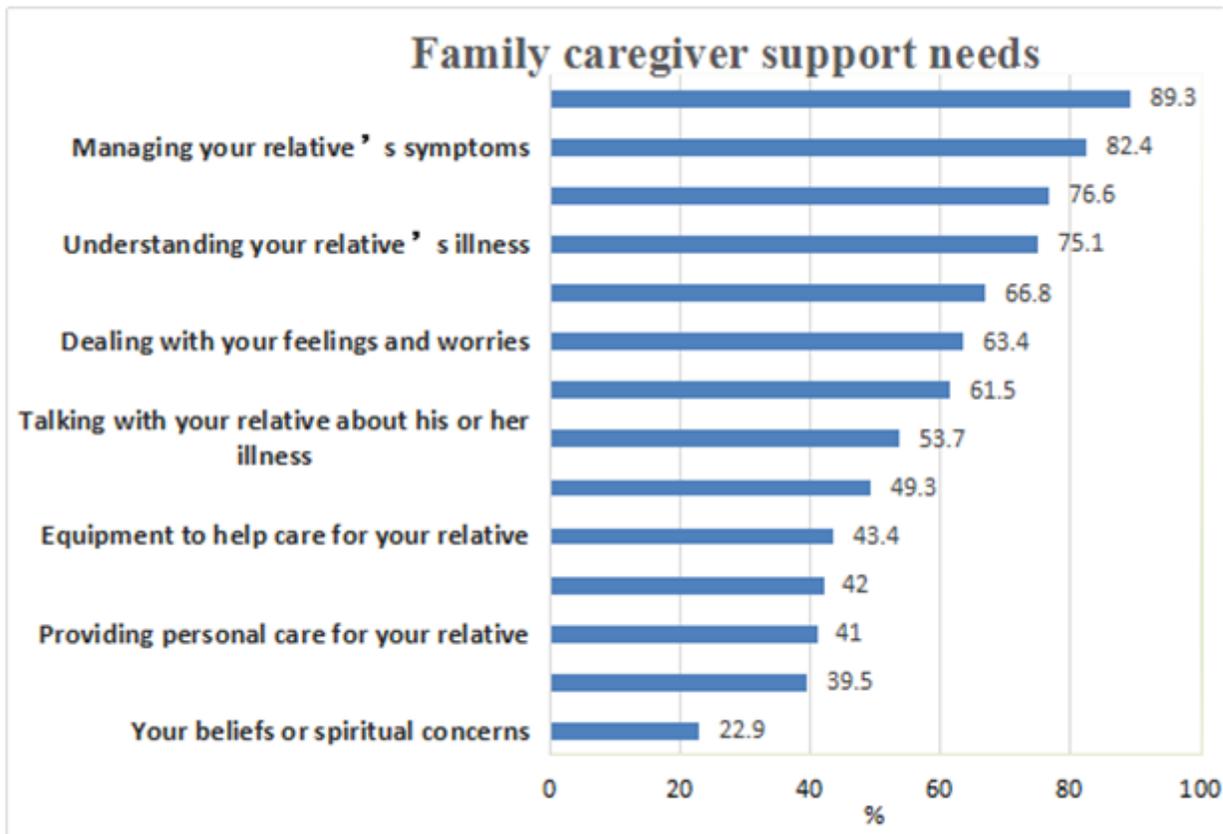


Figure 1

Family caregivers' support needs as assessed by the CSNAT items