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Abstract

Support for family caregivers is a core function of palliative care. However, there is a lack of consistency in the way needs are assessed, few longitudinal studies to examine the impact of caregiving, and a dearth of evidence-based interventions. In order to help redress this situation, identification of suitable instruments to examine the caregiving experience and the effectiveness of interventions is required. A systematic literature review was undertaken incorporating representatives of the European Association for Palliative Care's International Palliative Care Family Caregiver Research Collaboration and Family Carer Taskforce. The aim of the review was to identify articles that described the use of instruments administered to family caregivers of palliative care patients (pre and post-bereavement). Fourteen of the 62 instruments targeted satisfaction with service delivery and less than half were developed specifically for the palliative care context. In approximately 25% of articles psychometric data were not reported. Where psychometric results were reported, validity data were reported in less than half (42%) of these cases. While a considerable variety of instruments have been administered to family caregivers, the validity of some of these requires further consideration. We recommend that others be judicious before developing new instruments for this population.

Keywords

Palliative care, family carers, family caregivers' instruments, measures, assessment, research

Introduction

Support for family caregivers alongside palliative care patients has been advocated since the inception of the modern hospice movement. The reality, however, is that there are serious shortages in evidence-based strategies to assess and respond to family caregiver needs, and a

limited number of longitudinal studies that have examined the caregiver experience over time.^{1,2} Support for family caregivers is often provided in an ad hoc manner, and hospice assessment tools typically focus on the needs of patients rather than family caregivers.³ Also, family caregivers confronted by significant psychosocial distress should be targeted for interventions. However, a

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suitable means for assessing and measuring distress and wellbeing in this population has not yet been identified.³ Thus at present it is difficult for health professionals to be able to demonstrate that their support for family caregivers is systematic and effective.

In addition to the clinical aspects of family caregiver support, other research-related matters warrant consideration. The challenges of conducting research within palliative care are well documented.⁴ It has also been claimed that few psychometrically sound instruments have been evaluated within palliative care populations,^{5,6} and selecting suitable measures is a common problem.⁷ Furthermore, it is inappropriate to overburden family caregivers with unnecessary self-report questionnaires.

Therefore, clarity is required with regard to the number, focus and quality of family caregiver instruments that have been used in the context of palliative care. Given this background, representatives from the International Palliative Care Family Caregiver Research Collaboration (www.ipcfrc.unimelb.edu.au) and the European Association for Palliative Care's Family Carer Taskforce (www.eapcnet.org/projects/FamilyCarers.html) undertook a systematic review of the literature in order to outline published instruments that have been used with family caregivers of palliative care patients. The purpose of the review was to provide a broad critical appraisal of these instruments in order to guide health professionals and researchers.

Methods

Inclusion criteria

A systematic review of the literature was undertaken to source peer-reviewed journal articles, published in English, that reported the administration of instrument(s) to family caregiver(s) of a person with an advanced, non-curative life-threatening illness (administered either prior to or after the patient's death). An instrument in this context was defined as a tool used to assess or measure some aspects of the family caregiving experience. The term family caregiver was used broadly and included family members (no age restriction) involved in direct or indirect care provision.

Search strategy

(1) Electronic search of articles published in English, in peer-reviewed journals between 1980 and January 2009 of Medline, PsycINFO, CINAHL and PUBMED using any combination of the following search terms: Palliative Care; Hospice; Terminal; End of life; AND bereavement; Caregivers/carer; family caregiver/carer; AND Instrument OR scale OR survey OR measure or inventory.

- (2) The research team identified relevant instruments they were aware of and other key references (including checking reference lists).
- (3) Hand search of Journal of Pain and Symptom Management (1986 to January 2009) and Palliative Medicine (1987 to January 2009).
- (4) Hand search of key palliative care books.^{8–12}
- (5) Websites of key national and international palliative care collaborations (International Association of Hospice and Palliative Care, European Association for Palliative Care and Caresearch: palliative care knowledge network initiative).^{13–15}

Data extraction

The abstracts of these articles were read to detect duplicates and identify articles for full copy retrieval. The instruments and related articles were then reviewed independently by different members of the research team. The data extraction information recorded for each instrument is outlined in Box 1.

In addition, the instruments were categorized according to common areas of focus. The process for this entailed: (1) identifying the specific purpose for each instrument; (2) allocating instruments to similar areas of focus; (3) developing broad categories based on these areas; (4) reviewing allocations of instruments; and (5) labelling categories more specifically and developing an operational definition for each.

After the initial data collection phase, the reviewers reports were independently cross-checked and items for

Box 1. Data extraction information for each instrument

1. Instrument name and abbreviation
2. Developer(s) and key reference(s)
3. Selected references reporting psychometric evaluation of the instrument
4. References which reported psychometric evaluation *in the palliative care context*
5. Specific focus of instrument (what the authors purport it measures)
6. Brief description (number of items, response format, number of subscales)
7. Administration method (self report, clinician administered, other, unknown)
8. Population originally developed for
9. Translated into another language (yes, no, unknown)
10. Reliability reported in the context of caregivers in palliative care (Type of reliability and Reliability Co-efficient)
11. Validity reported in the context of caregivers in palliative care (yes, no and comment)
12. Availability (instrument included in key reference)

clarification were discussed and resolved at a face-to-face meeting.

Results

The electronic search of the databases produced between 200 and 350 articles in each database. Abstract review yielded 110 articles that appeared to meet the inclusion criteria. Examination of full versions of these articles identified 62 instruments that were administered to family caregivers of persons with an advanced, non-curative life-threatening illness.

The primary focus of the instruments and associated descriptors were: satisfaction with service delivery (appraisal of quality of service provided by health professionals) $n = 14$; psychiatric disorder (depression, anxiety or other disorder) $n = 6$; quality of life (perceived satisfaction with life) $n = 6$; needs (perceived supportive care needs) $n = 5$; grief and bereavement (angst associated with death or of the carer's relative/friend) $n = 5$; burden (psychological and/or social impact of the carer role) $n = 4$; preparedness/competence (perceived readiness and/or skill level associated with carer role) $n = 3$; family functioning (degree to which the carer's family functions harmoniously) $n = 3$; and other $n = 15$ (variety of foci).

The list of instruments and associated selected information from the data extraction process is presented in Tables 1 to 3. Assessment of family caregivers' perceived satisfaction with health care service delivery was the most common area of instrument development and is outlined in Table 1.^{20–36} Other common areas of assessment and measurement are detailed in Table 2 and included psychiatric disorders, quality of life, needs, burden, preparedness and bereavement.^{37–79} As detailed in Table 3, 15 of the 62 instruments focused on several areas of inquiry.^{80–93} In all three tables an asterisk indicates whether a copy of the instrument was published alongside the key article. This is reported in order to provide an indication of the availability of the instrument.

Approximately three-quarters (77%) of all articles that reported use of a family carer instrument within the context of palliative care also reported some reliability or validity data. In all these cases a test for reliability, for example Cronbach's alpha, was reported. However, in only 42% of cases was an exploration of validity reported.

Less than half (43%) of the instruments were originally developed for palliative care contexts. Typically, in these circumstances the focus was on family carers whose relative was receiving palliative care services or who had received these services (bereaved family carers). The overwhelming majority of instruments (89%) were designed to be administered

via self report. The mean number of items for all instruments was 25.3.

In approximately one-quarter (24%) of cases it was reported that the instrument had been translated into another language. Nearly half of cases (48%) had a full version of the instrument available in the key reference(s). We attempted to discern whether the instrument was developed for clinical and/or research purposes; however, this information was available in only a few cases.

Discussion

Our systematic review of the literature identified 62 instruments that have been administered to family caregivers of palliative care patients. As a general comment, we found it difficult in many instances to find specific information from some articles, particularly in those that focused on the development and/or evaluation of a new instrument. Hence we encourage authors and editors of journal articles to ensure that relevant information is explicitly outlined. Without this detail it makes it difficult to select suitable instruments for clinical and research purposes.

Less than half (43%) of the 62 instruments were developed specifically for family caregivers within palliative care. We contend that, where pertinent, generic measures are relevant for this population. The generic measures approach allows for comparison with other populations. If, for example, an instrument for psychiatric caseness is needed, it should not require adaptation to the palliative care context because the criteria for caseness should not be affected by the nature of this specific population.

Approximately one-quarter of articles did not report psychometric data related to the use of the instrument within the context of palliative care. Where psychometric data were reported, validity data were reported in less than half (42%) of these cases and reliability was reported via Cronbach's alpha. While this form of reliability is based on the internal consistency of the items comprising the measure, there were only six instances of test-retest reliability.

It would be important to establish instruments' sensitivity to change over time in situations where measurement of more stable constructs is required, such as when determining the effectiveness of interventions. However, in situations where the instrument is designed, for example, to ascertain carer needs based on a 'one-off' assessment, then internal consistency may be more relevant.

Many of the instruments *appeared* to have been developed for research purposes as opposed to clinical use. The instruments developed for research purposes may be more suited to scientific inquiry of a particular

Table 1. Instruments focusing on family carer satisfaction with service delivery ($n = 14$)

Instrument name	Original developer(s) & original key reference(s)	Select reference(s) reporting psychometric evaluation within palliative care	Population originally developed for	Number of items	Reliability (Type)/ Validity (Type): reported in the context of palliative care	Sample size
Care Evaluation Scale (CES)	*20	20	Family members of patients who had received specialized inpatient palliative care services	28	Yes (α 0.98)/ Yes (convergent)	854
Carer satisfaction with palliative care	21	21	Family carers of patients recently died after palliative care	89	Yes (α 0.68–0.84)/ No	355
Families evaluation on management, care and disclosure for terminal stage cancer patients	*22	22	Family members of patients with terminal stage cancer	21	Yes (α 0.50–0.70)/ Yes (convergent)	146
FAMCARE Scale	*23	23 24	Family members of cancer patients	20	Yes (α 0.93–0.95)/ Yes (criterion)	30
F-Care Perceptions Scale	25	26	Family members of advanced cancer patients in different settings	Unsure	Yes (α 0.86)/ No	72
Family Perception of Care Scale (FPCS)	*27	27	Family members of patients who resided in a long-term care facility	27	Yes (α 0.96)/ No	203
Good Death Inventory (GDI)	*28	28	Bereaved family members	54	Yes (α 0.71–0.94)/ Yes (concurrent, discriminant & content)	189
Home care study questionnaire – caretaker version	29	29	Chronically and terminally ill patients and their families	42	Yes (α 0.50–0.85)/ Yes (discriminant & convergent)	111
Need Satisfaction Scale	30	30	Family members of patients in a hospice or conventional care setting who are dying or have died from cancer	18	Yes (α 0.74–0.84)/ Yes (content & criterion)	100
Scales for evaluation of end-of-life care in dementia	31	31	Family caregivers of deceased dementia patients	33	Yes (α 0.78–0.90)/ Yes (construct)	156
Views of informal carers – evaluation of services (VOICES)	32	NI	Bereaved family caregivers	158	No/No	N/A
After-death bereaved family member interview	33 34	34	Bereaved family members of patients who died in a hospice, nursing home or hospital	118	Yes (α 0.58–0.87)/ Yes (criterion & construct)	156
Family Assessment of Treatment at End of Life (FATE) Survey	35	35	Next of kin, primary contact and power of attorney of patients who died in Veteran Affairs medical centres	32	Yes (α 0.91)/ Yes (discriminant)	309
Satisfaction Scale for Family Members Receiving Inpatient Palliative Care (Sat-Fam-IPC)	*36	36	Primary caregivers of cancer patients who received palliative care	34	Yes (α 0.98)/ Yes (construct & convergent)	850

* = Copy of the instrument within key reference(s); NI, nil identified.

Table 2. Instruments focusing on: family carer: psychiatric disorders; quality of life; needs; bereavement; burden; preparedness and family functioning ($n = 33$)

Instrument name	Original developer(s) & original key reference(s)	Select reference(s) reporting psychometric evaluation within palliative care	Primary focus	Population originally developed for	Number of items	Reliability (Type)/ Validity (Type): reported in the context of palliative care	Sample size
Beck Depression Inventory (BDI)	*37	38	Depression, Anxiety & Psychiatric	Patients with mental health problems	21	Yes (α 0.884)/No	96
Brief Symptom Inventory (BSI)	39	40	Depression, Anxiety & Psychiatric	Adolescents and adults	53	Yes (α 0.93)/No	31
10 Item Center for Epidemiologic Studies Depression Scale (CES-D) Short Form	41 42 *43	NI	Depression, Anxiety & Psychiatric	General population	10	No/Unclear	N/A
Hamilton Depression Rating Scale (HDRS)	44	NI	Depression, Anxiety & Psychiatric	Patients already diagnosed as suffering from affective disorder of depressive type	21	No/No	N/A
Hospital Anxiety and Depression Scale (HADS)	*45	46	Depression, Anxiety & Psychiatric	Patients in non psychiatric hospital clinics	14	Yes (α 0.84–0.89)/No	106
The structured clinical interview for DSM-IV-R (SCID)	47	NI	Depression, Anxiety & Psychiatric	Psychiatric patients (SCID-P) or non-patients (SCID-NP)	Unsure	No/No	N/A
Quality of Life in Life-Threatening Illness – Family carer version (QOLTTI-F)	*48	48	Quality of life	Family Caregivers of cancer patients receiving palliative care	16	Yes (α 0.86)/Yes (construct)	149
The Medical Outcomes Study 36-item Short Form (SF-36)	*49	NI	Quality of life	General population, plus specific disease groups	36	No/No	N/A
Caregiver Quality of Life Index-Cancer (CQOLC) scale	50	51	Quality of life	Family caregivers of patients with cancer	35	Yes (α 0.87)/Yes (convergent)	239
Quality of Life (QOL)-Family Caregiver Tool	52	NI	Quality of life	Family caregivers of cancer patients	27	No/No	N/A
Quality of Life Scale (QOLS)	53	54	Quality of life	Healthy population (United States)	16	Yes (α 0.88)/No	1912
Caregiver Quality of Life Index (CQLI)	*55	55	Quality of life	Caregivers of cancer patients receiving hospice care	4	Yes (α 0.76–0.88)/Yes (face)	68
Caregiving at Life's End Questionnaire	56	56	Needs	End-of-life family caregivers	Unsure	Yes (α 0.67–0.94)/Yes (concurrent)	51

(continued)

Table 2. Continued

Instrument name	Original developer(s) & original key reference(s)	Select reference(s) reporting psychometric evaluation within palliative care	Primary focus	Population originally developed for	Number of items	Reliability (Type)/ Validity (Type): reported in the context of palliative care	Sample size
Family Members' Care Expectations (F-Care Expectations)	²⁵	²⁶	Needs	English-speaking family members of advanced cancer patients in different settings	Unsure	Yes (α 0.88)/No	72
Family Inventory of Needs (FIN)	^{*57}	⁵⁷ ²⁴	Needs	Family members of advanced cancer patients	20	Yes (α 0.83–0.92)/Yes (construct)	1109
Home caregiver need survey (HCNS)	⁵⁸	⁵⁹	Needs	Home based family caregivers of patients with cancer	90	Yes (α 0.71–0.92)/No	55
Spiritual Needs Inventory (SNI)	⁶⁰ ⁶¹	NI	Needs	Patients near the end of life	17	No/No	N/A
Pre-death Inventory of Complicated Grief – Caregiver Version (Pre-ICG)	⁶²	⁶³	Grief/Bereavement	Unable to identify	Unsure	Yes (α 0.76)/No	248
The Texas Revised Inventory of Grief (TRIG)	^{*64}	NI	Grief/Bereavement	Bereaved persons	21	No/No	N/A
Grief Resolution Index (GRI)	^{*65}	⁶⁶	Grief/Bereavement	Widowed women	7	Yes (α 0.89)/No	75
Inventory of complicated grief (ITG)	^{*67}	NI	Grief/Bereavement	Bereaved elderly	19	No/No	N/A
Modified Bereavement Risk Index (BRI)	^{*68}	⁶⁸	Grief/Bereavement	Bereaved family members who had received palliative care	4	Yes (α 0.64–0.80)/No	150
Brief Assessment Scale for Caregivers (BASC)	^{*69}	⁶⁹	Burden	Family caregivers of the medically ill	14	Yes (α 0.58–0.80)/Yes (construct)	102

(continued)

Table 2. Continued

Instrument name	Original developer(s) & original key reference(s)	Select reference(s) reporting psychometric evaluation within palliative care	Primary focus	Population originally developed for	Number of items	Reliability (Type)/ Validity (Type): reported in the context of palliative care	Sample size
Caregiver burden scale (CBS)	*70	40	Burden	Family caregivers of stroke patients	22	Yes (α 0.92)/No	31
Caregiver's Burden Scale in End-of-Life Care (CBS-EOLC)	*71	71	Burden	Family caregivers of palliative care patients	16	Yes (α 0.91–0.94)/ Yes (construct & convergent)	25
Zarit Burden Inventory	*72	NI	Burden	Relatives of the impaired elderly	29	No/No	N/A
The Caregiver Strain Index (CSI)	73 *24	24	Burden	Caregivers of elderly adults who are physically ill and functionally impaired	13	Yes (α 0.84)/ Yes (construct)	100
Caregiver competence scale	*74	75	Competence/ Preparedness	Caregivers of noninstitutionalised patients with Alzheimer's disease	4	Yes (α 0.86)/ Yes (construct)	106
Caregiving mastery	76	75	Competence/ Preparedness	Family Caregivers	12	Yes (α 0.56–0.70)/ Yes (construct)	106
Preparedness for caregiving scale	77	75	Competence/ Preparedness	Family Caregivers	8	Yes (α 0.93)/ Yes (construct)	106
Family APGAR Scale	78	NI	Family functioning	Unable to identify Families	5	No/No	N/A
Family environment scale (FES)	79	NI	Family functioning	Families	90	No/No	N/A
Family relationship index	79	NI	Family functioning	Normal and dysfunctional families	12	No/No	N/A

* = Copy of the instrument within key reference(s); NI, nil identified.

Table 3. Instruments focusing on a variety of family carer issues ($n = 15$)

Instrument name	Original developer(s) & original key reference(s)	Select reference(s) reporting psychometric evaluation within palliative care	Primary focus	Population originally developed for	Number of items	Reliability (Type)/ Validity (Type): reported in the context of palliative care	Sample size
Beck Hopelessness Scale (BHS)	^{*80}	38	Hopelessness	Patients with mental health conditions	20	Yes (α 0.864)/No	96
Caregiver Assistance Scale (CAS)	81	81	Assistance provided by the caregiver	Family caregivers of advanced cancer patients	17	Yes (α 0.87)/No	44
Caregiver mutuality instrument	77 82	75	Meaning within their relationship	Family caregivers of aged care patients	15	Yes (α 0.83–0.93)/Yes (construct)	106
The Caregiver Reaction Assessment (CRA)	18	75 83	Reactions of family	Family caregivers of persons with physical impairments and Alzheimer's disease	24	Yes (α 0.71–0.81)/Yes (construct)	106 85
Caregiver Self-Efficacy	^{*84}	75	Self care and problem solving	Family Caregivers	14	Yes (α 0.80–0.92)/Yes (construct)	217
Caregiving Impact Scale (CIS)	81 85	81	Caregivers lifestyle impact	Family caregivers of advanced cancer patients	Unsure	Yes (α 0.87)/No	44
Modified Cost and Reciprocity Index (CRI)	86	86	Social networks	Family caregivers of the terminally ill receiving hospice services at home	25	Yes (α 0.68–0.83)/No	70
Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC)	87	87	Impact: burden, family well being and positive appraisals	Family caregivers of people receiving palliative care at home	25	Yes (α 0.73–0.86)/No	160
Family Crisis Orientated Personal Evaluation Scale (F-COPES)	^{*88}	40	Coping behaviours/responses	Families in difficult or problematic situations	29	Yes (α 0.50–0.83)/Unclear	31
General Functioning Scale of the Family Assessment Device (FAD)	89	26	Coping behaviours	Unable to identify	12	Yes (α 0.93)/No	72
The Relative Stress Scale Inventory (RSSI)	^{*90}	NI	Psychological impact	Relatives of elderly demented patients	15	No/No	N/A
The stressful caregiving adult reactions to experiences of dying scale (SCARED)	^{*91}	91	Psychological impact	Primary family caregivers of terminally ill patients	10	Yes (α 0.77)/No	76
Social Support Questionnaire (SSQ) Brief form (6 items)	^{*92}	75	Social support	'Clinical' population	6	Yes (α 0.90)/Yes (construct)	106
Life Orientation Test (LOT)	93	75	Optimism	Unable to identify	12	Yes (α 0.79–0.81)/Yes (construct)	106
Rewards of Caregiving	77	75	Positive aspect of role	Unable to identify	15	Yes (α 0.93)/Yes (construct)	106

* = Copy of the instrument within key reference(s); NI, nil identified.

topic and/or, for example, to testing the effectiveness of interventions for future clinical application. When clinicians are selecting caregiver instruments they therefore need to discern the purpose for which the instrument was developed and subsequently used. In many instances, clinicians are interested in using suitable instruments to assess or measure needs and/or the psycho-social impact of the family caregiver role. This contrasts with examination of an intervention whereby the primary purpose may be to explore the utility and/or effectiveness of the impact or outcome of a new therapeutic approach. These two broad purposes are related; however, they are not the same, and when assessing the utility, appropriateness and validity of an instrument in any given context, this distinction also needs to be considered. What is evident is that clinicians need instruments that are not only psychometrically sound but also relatively brief and easy to administer.

Our review revealed the existence of a considerable number of instruments ($n=14$) that measure family caregivers' satisfaction with service delivery. It appears therefore that development of new instruments that focus on this area of inquiry is not warranted. It should also be noted that although family caregiver satisfaction with health care service delivery has emerged as a key outcome variable for evaluating the quality of care, there are limitations associated with its use as a measure for this purpose.¹⁶

There is also a high number of measures that focus on family caregiver burden ($n=6$), family caregiver quality of life ($n=5$) and family caregiver needs ($n=5$). While there will be circumstances where an existing instrument does not meet the specific needs of clinicians or researchers, we recommend that caution prevail before embarking upon the development and subsequent testing of new instruments. Another option is to modify existing tools; however, we believe that this potentially creates *de facto* new instruments, and the psychometric claims cannot be inherited from their predecessors. It is the responsibility of authors to demonstrate the psychometrics of these new instruments created from old ones.

Although we identified five bereavement instruments that have been utilized with family caregivers of palliative care patients, Agnew and colleagues¹⁷ recent review of bereavement needs assessment tools suggests that more instrument development and psychometric testing is required in this specific area. This work should focus on instruments for clinical application that target family caregivers' grief response/risk during (1) the period from referral to palliative care to early bereavement, and (2) the longer-term post-bereavement period, in order to determine normal versus complicated grief.

The remaining instruments focused on a variety of domains including social support, positive aspects of the role, psychological reactions to the role and impact on caregiver lifestyle. It is also noteworthy that several instruments were multidimensional, for example the Caregiver Reactions Assessment.¹⁸ Hence, we conclude that instruments exist for a broad range of caregiver responses and experiences. However, we did not locate instrument(s) that seemed to comprehensively assist health care professionals to accurately discern (upon commencement of palliative care) the risk of developing psychosocial problems. It would seem worthwhile to pursue the development and testing of a 'triage' type tool for family caregivers.

The overwhelming majority of instruments were administered via self report, and this is pertinent given that subjective reports from caregivers are necessary to gain further insight into the caregiver experience and to discern the level of health support required. Nonetheless, consideration should perhaps be given to other modes of administration. For example, a family caregiver may perceive themselves as highly competent in their role, yet a health care professional assessment may indicate the contrary. This type of incongruence may not necessarily be a disadvantage, as it may provide a basis for dialogue between health professionals and family caregivers and therefore foster a deeper exploration of the caregiver's experience and unmet needs. Also, given the complexities of conducting research in palliative care, consideration should be given to exploring and evaluating the use of instruments via telephone and web-based systems.

Our review showed that the average number of items per instrument was 25. Although family caregivers commonly report benefits from participating in palliative research,¹⁹ future instrument development should attempt to reduce the number of items, particularly as it is not uncommon to administer multiple measures simultaneously.

In terms of the availability of the instrument, in almost half of cases (48%) the instrument was available as a component of the key reference(s) reporting its development and/or use in palliative care. It is assumed that in other situations the instrument is available via a website, or alternatively it is necessary for researchers and clinicians to contact the author directly. We suggest that the latter approach is the least desirable, and support instead making it as easy as possible for people to access the instruments, with clear instructions regarding, for example, whether or not the tool is free of charge and whether it can be adapted.

We also note that approximately one-quarter (24%) of the instruments had been translated into languages other than English. We encourage instrument translation so that participants who cannot speak the main

language of the country in which the research and/or clinical assessment is being undertaken are not excluded. Addressing this issue will assist in reducing bias and enhance generalizability of results. We recommend that forward and backwards translation procedures are used, and that translated instruments are scrutinized for cultural equivalence.

There are several limitations with our review. We did not explicitly interrogate the quality or otherwise of individual instruments, hence we cannot recommend specific measures. This could be the focus of future work. We are aware that in some instances psychometric data may have been published in books rather than journal articles. Also, we did not explore whether the instruments were developed from a sound theoretical framework. Our system for categorizing the focus of instruments did not necessarily capture the specific nature of some measures. Thus we encourage others to explore the full copies of the instruments and related data in order to determine appropriateness for their particular needs. Despite the limitations, the value of the review is the collation and examination of a large number of instruments that have been used specifically in a palliative care context.

Conclusion

Support for family caregivers is a requirement for palliative care service delivery. Health care professionals should therefore have access to reliable and valid instruments in order to accurately assess family caregiver needs, psychosocial impacts of the family caregiver role and the quality of care provided. Researchers also need appropriate instruments to explore the family caregiver experience and examine the utility and effectiveness of the much-needed interventions for this population.

Our systematic literature review revealed that there is a wide variety of existing instruments that are available for use in this population. Gaining more psychometric data would be advantageous, and in a couple of specific areas more instrument development may be needed. However, we contend that clinicians and researchers exercise caution before embarking upon the development of new instruments related to family caregivers of palliative care patients. Furthermore, we advocate that if new instruments are developed for clinical use (or adapted from existing ones), they should ideally be brief and in a conducive format. It would also be prudent for instrument developers to take into consideration the context of changing clinical environments, such as home versus hospital care, and cultural variations. Finally, it would be helpful to both clinicians and researchers if a comprehensive repository of family caregiver instruments was developed and maintained.

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