

# A systematic review of instruments assessing dimensions of distress among caregivers of adult and pediatric cancer patients

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## ABSTRACT

**Objective:** Caregivers of cancer patients face intense demands throughout the course of the disease, survivorship, and bereavement. Caregiver burden, needs, satisfaction, quality of life, and other significant areas of caregiving are not monitored regularly in the clinic setting, resulting in a need to address the availability and clinical effectiveness of cancer caregiver distress tools. This review aimed to determine the availability of cancer caregiver instruments, the variation of instruments between different domains of distress, and that between adult and pediatric cancer patient populations.

**Method:** A literature search was conducted using various databases from 1937 to 2013. Original articles on instruments were extracted separately if not included in the original literature search. The instruments were divided into different areas of caregiver distress and into adult versus pediatric populations. Psychometric data were also evaluated.

**Results:** A total of 5,541 articles were reviewed, and 135 articles (2.4%) were accepted based on our inclusion criteria. Some 59 instruments were identified, which fell into the following categories: burden ( $n = 26$ , 44%); satisfaction with healthcare delivery ( $n = 5$ , 8.5%); needs ( $n = 14$ , 23.7%); quality of life ( $n = 9$ , 15.3%); and other issues ( $n = 5$ , 8.5%). The median number of items was 29 (4–125): 20/59 instruments (33.9%) had  $\leq 20$  items; 13 (22%) had  $\leq 20$  items and were psychometrically sound, with 12 of these 13 (92.3%) being self-report questionnaires. There were 44 instruments (74.6%) that measured caregiver distress for adult cancer patients and 15 (25.4%) for caregivers of pediatric patients.

**Significance of results:** There is a significant number of cancer caregiver instruments that are self-reported, concise, and psychometrically sound, which makes them attractive for further research into their clinical use, outcomes, and effectiveness.

**KEYWORDS:** Cancer caregivers, Informal caregivers, Systematic review, Caregiver instruments, Caregiver tools

## INTRODUCTION

Cancer is a disease whose illness trajectory varies according to tumor site and grade (Aslett et al., 2009). The symptoms, treatments, and level of care needed by the cancer patient parallel this, and their disease course may range from a sudden and rapid decline to

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a prolonged course filled with sudden deteriorations in condition. Informal caregivers are expected to take on many roles: medical and financial decision maker, patient advocate, and care provider (National Cancer Institute, 2015). Moreover, in contrast to other diseases, cancer caregivers' tasks involve patients who enter the survivorship phase, including the psychological burden related to the possibility of disease recurrence. At the same time, the normal daily grind of their lives as well as that of the other family members they are already caring for continue, which exponentially increases their workload. The relationship between the patient and caregiver also plays a pivotal role, with a poor preexisting relationship as well as disagreements and conflicts within the family complicating care and decision making (Siminoff et al., 2006; Fried et al., 2003).

As the patient's illness becomes recurrent or terminal, caregivers are expected to provide increased care due to the decline in functional status and greater symptomatology. Caregivers have been found to report low quality of life and other health scores, even when compared to cancer patients (Weitzner et al., 1999a,b; Sales, 1992; Cameron et al., 2002; Glajchen, 2009; Kim & Given, 2008). Physical, psychosocial, and financial complications occur, including insomnia (Hearson & Clement, 2007), fatigue (Teel & Press, 1999), cardiovascular disease (von Kanel et al., 2008), increased mortality (Christakis & Allison, 2006), increased rates of anxiety and depression (Given et al., 2004), and intensified feelings of fear and hopelessness (Dumont et al., 2006). In addition, due to the time-consuming aspect of caring for patients with advanced cancer, social isolation is likely to occur. Adequate social support, financial security, and work stability can offset this social impact (National Cancer Institute, 2015). Financial distress occurs due to accumulating copayments, insurance deductibles, travel costs, home care service expenses, and lost wages (National Cancer Institute, 2015; Glajchen, 2009; Yabroff et al., 2007). Early referral to palliative care has been shown to help improve the physical and psychological well-being of both patients and caregivers as well as enhance family satisfaction (Casarett et al., 2008; Gelfman et al., 2008). Spirituality has also been found to act as a safeguard against caregiver distress by helping caregivers gain a new perspective from the cancer experience and alleviate hopelessness, resulting in improved well-being (Ward et al., 1996; Kim et al., 2007).

Applebaum and Breitbart (2012) recently reviewed available interventions for informal caregivers, ranging from psychoeducation to complementary and alternative medicines. The majority of these interventions have shown benefits for informal caregivers. However, caregiver distress is still not monitored

regularly, resulting in a need to address the availability of clinically applicable and effective caregiver tools that screen and detect any distress early on, which promotes more timely implementation of these interventions.

The objectives of our systematic review were: to determine the availability and adequacy of caregiver tools that were developed for cancer caregivers; to identify variations in the available cancer caregiver tools regarding different domains of distress, including such physical and psychosocial factors as caregiver needs, burden, and quality of life; and to identify the cancer caregiver tools that have been created for and utilized in the adult and pediatric populations.

## METHODS

We conducted a literature search of all articles pertaining to tools for caregivers of cancer patients. During the initial search, restrictions were not placed in terms of language or publication type.

We employed the following databases to obtain relevant studies for this review (the original search was conducted up through October of 2013):

- MEDLINE (1946–present)
- EMBASE (1947–present)
- CINAHL (1937–present)
- Scopus (1996–present)
- PubMed ePubs (until October 2013)

We retrieved all articles through the strategy listed in Supplementary Appendix A for the MEDLINE search. The same strategy was adopted for the other databases. The methods and results section of each article were reviewed to determine if any reliability and validity tests had been conducted. In addition, we checked for references that might lead to further research on that tool to identify if reliability and validity were measured. See Tables 1–5 for details on the included studies.

An article was included if the instrument cited was designed specifically for caregivers of cancer patients to ensure that the instrument was originally designed with cancer caregiver distress in mind. If an instrument was created for a different population, including cancer patients but not caregivers, it was excluded. Since we intended to capture the whole caregiver experience, there were no restrictions set on the area that a tool assessed. Since there may be differences in the patient–caregiver relationship in the pediatric and adult cancer populations, we included instruments that measured caregivers of

**Table 1.** Instruments focusing on caregiver burden

Instrument name	Purpose/focus	Domains/sections	Original population	No. of items	Reliability/validity
<b>Adult Patients</b>					
<b>*Brief Assessment Scale for Caregivers (BASC) (Glajchen et al., 2005)</b>	<b>Caregiver burden</b>	<b>Negative personal impact, positive personal impact, other family members, medical issues, concern about loved one</b>	<b>Caregivers of patients with chronic illness (cancer 55%, neurological 15%, psychiatric 12%)</b>	<b>14</b>	<b>Yes (<math>\alpha = 0.70</math>)/yes (construct)</b>
<b>*Caregiving Consequences Inventory (CCI) (Sanjo et al., 2009)</b>	<b>Family members' perceptions of caregiving consequences</b>	<b>Four reward domains (mastery, appreciation for others, meaning in life, reprioritization); one burden domain</b>	<b>Bereaved family members of cancer patients</b>	<b>16</b>	<b>Yes (<math>\alpha = 0.78-0.93</math>)/yes (construct)</b>
Appraisal of Caregiving Scale (ACS) (Oberst et al., 1989)	Caregiver burden	Harm/loss, threat, challenge, benign	Family members of cancer patients receiving radiotherapy	53	Yes (0.72–0.91)/yes (content)
Cancer Caregiving Tasks, Consequences and Needs Questionnaire (CaTCoN) (Lund et al., 2012)	Caregiver tasks, consequences and needs	Caregiving tasks, caregiving consequences, caregiver needs	Caregivers of cancer patients	41	Not found
Care Task Scale–Cancer (CTS–C) [Taiwan] (Chen et al., 2007)	Caregiver tasks	Accompany patient and monitor care, substitutive care for social and general affairs, communication and emotional care, mobility maintenance care	Spouse caregivers of cancer patients	37	Yes ( $\alpha = 0.83-0.88$ ) test–retest (0.92–0.94)/yes (construct)
Caregiver Assistance Scale (Cameron et al., 2002)	Caregiver assistance on ADL, iADL	None identified	Caregivers of advanced cancer and stroke patients	17	Yes ( $\alpha = 0.87$ )/not found
Caregiver Reaction Assessment Scale (Given et al., 1992)	Reactions of various groups of caregivers and changes in reactions over time	Caregiver esteem, lack of family support, impact on finances, impact on schedule, impact on health	<i>Exploratory portion:</i> caregivers of elderly patients with dementia/Alzheimer's or various physical impairments/ <i>Confirmatory portion:</i> caregivers of cancer and Alzheimer's/dementia patients	24	Yes ( $\alpha = 0.91$ )/yes (construct)
Caregiver Self-Efficacy Scale (CaSES) (Ugalde et al., 2013)	Caregiver self- efficacy	Resilience, self-maintenance, emotional connectivity, instrumental caregiving	Caregivers of advanced cancer patients	21	Yes ( $\alpha = 0.73-0.94$ )/yes (convergent, divergent)
Caregiver's Communication with the Patient about Illness and Death (CCID) (Bachner et al., 2008)	Caregiver communication with the patient about illness and expected death during the terminal stage	None identified	Caregivers of cancer patients	8	Not found/yes (convergent, divergent)
Caregiving Impact Scale (CIS) (Cameron et al., 2002)	Caregiver's experience of lifestyle interference	Health, diet, employment, active recreation, passive recreation, finances, relationship with partner, sex life, family relations, other social relations, self-expression/improvement, religious expression, community and civic involvement, household responsibilities	Caregivers of patients with incurable cancer	14	yes ( $\alpha = 0.87$ )/Not found
Demand-of-Illness Inventory (DOI) (Haberman et al., 1990)	Impact of disease	Physical symptoms, personal meaning, family functioning, social relationships, self-image, monitoring symptoms, treatment issues	Family of mothers with breast cancer, diabetes, and fibrocystic breast changes	125	Yes ( $\alpha = 0.96$ )/yes (construct, discriminant)

Family Appraisal of Caregiving Questionnaire for Palliative Care (FACQ-PC) (Cooper et al., 2006)	Family's appraisal of caregiving	Caregiver strain, positive caregiving appraisals, caregiver distress, family well-being	Family caregivers of a relative with cancer	25	Yes ( $\alpha = 0.73-0.86$ )/yes (construct)
Family Decision-Making Self-Efficacy Scale (Nolan et al., 2009)	Family member confidence in making decisions	Being a surrogate, choosing treatments, accepting palliative care, meeting spiritual needs, maintaining family harmony, and communicating with health professionals	ALS (gradual decline) and pancreatic cancer (rapid decline) caregivers	26	Yes ( $\alpha = 0.91-0.95$ ) test-retest ( $r = 0.96$ )/yes (content)
Family's Difficulty Scale (FDS) (Ishii et al., 2012)	Family's difficulties in caring for cancer patients at end of life at home	Burden of care, concerns about home care doctor, balance of work and care, patient's pain and condition, concerns about visiting nurse, concerns about home care service, relationship between family caregivers and their families, funeral preparations	Family's caring for cancer patient at end of life at home	29	Yes (0.73-0.75)/yes (convergent, divergent)
Parental Cancer Questionnaire (Levesque & Maybery, 2014)	Adult children's experience of having a parent with cancer	Positive changes, affective impact, caregiver strain	Adult children of parents with cancer	53	Yes (0.87-0.91)/yes (convergent/discriminant)
Psychological Well-Being Scale for Caregivers (PWS-C) (Wu et al., 2010)	Screen for psychological distress among family caregivers of advanced cancer patients in a palliative care unit	Social support, life meaning, emotional distress, caregiving inadequacy, hospital care	Family caregivers of advanced cancer patients in a palliative care unit	11	No (0.63-0.86 [hospital care]) test-retest (0.47-0.89)/yes (concurrent)
Prostate Care Questionnaire for Carers (PCQ-C) (Sinfield et al., 2009)	Experience of carers for men with prostate cancer	Carer experience when the patient is undergoing testing, when getting the diagnosis and making the treatment decision, during treatment, discharge and monitoring	Carers for men with prostate cancer	64	Yes ( $\alpha = 0.80-0.89$ ) test-retest (0.52-0.83)/yes (content)
Suffering Scale of Family of Patients with Terminal Cancer [Korean] (Kang, 2011)	Family suffering	Economical distress, loss of meaning in life, feeling of social isolation, emotional distress, burnout, guilty feeling, physical discomfort	Family of patients with terminal cancer	29	Yes ( $\alpha = 0.93$ )/not found
<b>Pediatric Patients</b>					
*Parental Worry and Attitudes Toward Childhood Cancer (Duran, 2011)	Measure negative attitudes of parents toward their child's cancer after treatment completion	Perseveration of parental worry (factor 1), psychosocial losses (factor 2)	Parents of childhood cancer survivors	11	Yes ( $\alpha = 0.91$ , factor 1; $\alpha = 0.76$ , factor 2)/yes (content)
*Psychosocial Assessment Tool (Kazak et al., 2001)	Psychosocial risk in families for elevated distress in caring for a child with cancer	Family resources, social support, child knowledge, child emotional and behavioral concerns, marital and family problems, family beliefs	Families of newly diagnosed pediatric oncology patients	20	Yes ( $\alpha = 0.83$ ) test-retest ( $r = 0.78-0.87$ )/yes (content)
*Psychosocial Assessment Tool 2.0 (Pai et al., 2008)	Psychosocial risk in families for elevated distress in caring for a child with cancer	Family resources, social support, child knowledge, child emotional and behavioral concerns, marital and family problems, family beliefs	Families of children with cancer	15	Yes ( $\alpha = 0.81$ )/yes (content, criterion)

Continued

Table 1. Continued

Instrument name	Purpose/focus	Domains/sections	Original population	No. of items	Reliability/validity
Care of My Child With Cancer (CMCC) (Wells et al., 2002)	Time and effort associated with caring for a child with cancer	None identified	Primary caregivers of children with cancer	28	Yes (0.93) test–retest (0.90)/yes (content, construct)
Family Illness Beliefs Inventory (FIBI) (Kazak et al., 2004)	Cancer-related beliefs	Treatment-related suffering, death and devastation, caregiver competence, connection, finding meaning	Parents of children with cancer	41	No/no
Life Situation Scale for Parents (LSS–P) (Enskar et al., 1997)	Parents' experiences	Care, well-being, social life, preparedness	Parents of children with cancer	37	Yes ( $\alpha = 0.82$ )/not found
Parental Coping Strategy Inventory (PCSI) (Yeh, 2001)	Parental coping	Learning, struggling, interaction with patient, interaction with spouse, interaction with healthy sibling, emotion support, information support, actual support, maintaining stability, maintaining an optimistic state of mind, searching for spiritual meaning, increasing religious activities	Parents of children with cancer	48	Yes (0.71–0.88)/yes (construct)
Pediatric Inventory for Parents (PIP) (Streisand et al., 2001)	Assess stress among parents of children with a critical illness	Medical care, communication, role functioning, emotional functioning	Parents of children with a critical illness, childhood cancer	42	Yes (construct)/yes ( $\alpha = 0.95–0.96$ )

\*Self-report instruments with  $\leq 20$  items, positive reliability, and validity.

**Table 2.** Instruments focusing on caregiver needs

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/validity
<b>Adult Patients</b>					
<b>*Family Inventory of Needs (Kristjanson et al., 1995)</b>	Caregiver needs	Importance of family care needs, fulfillment of care needs	Families of advanced cancer patients	20	Yes ( $\alpha = 0.83$ )/yes (construct, content)
<b>**Palliative Care-Needs Assessment Tool (PC-NAT) (Waller et al., 2008)</b>	Patient and caregiver needs determined by health professionals	Patient well-being, ability of caregiver/family to care for patient, caregiver well-being	Health professionals treating advanced cancer patients and their caregivers	18	Yes (interrater)/yes (face, content)
Caregivers Needs Scale (Longman et al., 1992)	Caregiver needs	Personal care, activity management, involvement with healthcare, work, interpersonal interaction, finance	Caregivers of cancer patients undergoing treatment	90	Yes ( $\alpha = 0.80$ )/not found
Carer Support Needs Assessment Tool (CSNAT) (Ewing & Grande 2013)	Caregiver needs	Support to enable the carer to provide care, direct support for carers	Caregivers for patients at end of life, including cancer	50	Not found/yes (face, content, criterion)
Family Inventory of Needs-Husbands (Kilpatrick et al., 1998)	Husband's information needs	Surgical care needs, communication with doctor, family relations, diagnosis/treatment specifics, husband's involvement	Husbands of women with breast cancer	30	Yes ( $\alpha = 0.91-0.93$ )/yes (content)
Family Needs Assessment (FNA) (Tringali, 1986)	Caregiver needs	Cognitive, emotional, physical	Family members of cancer patients in three different phases of illness (initial treatment, recurrent disease, follow-up treatment)	53	Not found/yes (content)
Home Caregiver Need Survey (Hileman et al., 1992)	Caregiver needs	Psychological, informational, patient care needs, personal, spiritual, household	Home caregivers of cancer patients	90	Yes ( $\alpha = 0.85-0.97$ )/yes (construct, content)
Needs Assessment of Family Caregivers-Cancer (NAFC-C) (Kim et al., 2010)	Caregiver needs during survivorship phase	Cognitive/informational, communication, daily activity, emotional, financial/legal, medical, social/relationship, spiritual needs	Cancer caregivers	27	No/no
Needs Assessment Tool-Caregivers (NAT-C) (Mitchell et al., 2010)	Caregiver needs	Information, practical support, personal health and well-being, relationships, meaning	Cancer caregivers	33	No/no

Continued

**Table 2.** *Continued*

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/validity
Offspring Cancer Needs Instrument (OCNI) (Patterson et al., 2011)	Unmet needs	Information, family issues, practical assistance, time out, feelings, support (friends), support (other young people)	Young people (12–24 years) impacted by parental cancer	47	Yes ( $\alpha = 0.89$ ) test–retest ( $r = 0.73$ )/yes (construct)
Supportive Care Needs Survey–Partners and Caregivers (SCNS–P&C) (Girgis et al., 2011)	Caregiver needs	Healthcare service needs, psychological and emotional needs, work and social needs, information needs	Cancer caregivers	44	Yes ( $\alpha = 0.88–0.94$ )/partial (construct)
Support Person Unmet Needs Survey (SPUNS) (Campbell et al., 2009)	Unmet needs	Information and relationships, emotional needs, personal needs, work and finance, healthcare access and continuity, worries about future	Principal caregivers of cancer survivors	78	Yes ( $\alpha > 0.90$ )/yes (face, content, construct)
<b>Pediatric Patients</b>					
<b>*Family Inventory of Needs–Pediatrics II (FIN–PED II) (Monterosso et al., 2006)</b>	<b>Caregiver needs</b>	<b>Importance of care needs, extent to which needs were met, need for further information</b>	<b>Parents of children with cancer</b>	<b>17</b>	<b>Yes (<math>\alpha = 0.83–0.98</math>) test–retest (<math>r = 0.74–0.94</math>)/yes (content)</b>
Family Inventory of Needs–Pediatrics (FIN–PED) (Whiteley et al., 1999)	Caregiver needs	Importance of care needs and extent to which needs were met	Mothers of children with cancer	52	Yes ( $\alpha = 0.94$ )/yes (construct)

\*Self-report instruments with  $\leq 20$  items, and positive reliability and validity.

\*\*Healthcare provider administered instrument with  $\leq 20$  items, and positive reliability and validity.

both adult and pediatric cancer patients and divided the instruments by population within the various areas of the caregiving experience.

The authors carried out a study selection to determine that all the articles met our inclusion criteria. Any disagreements about a particular study were resolved by discussion and consensus. Articles that were not studies on caregivers of cancer patients were excluded. Articles about cancer caregivers but with no standardized tools reported were also excluded. Articles that were only published as conference abstracts, research protocols, or theses, with no corresponding published manuscript, were also excluded. Finally, we also excluded articles for which no English translation was available.

The data were then extracted into the following areas of focus: purpose of the tool; dimensions measured; population originally developed for; number

of items; and psychometric data. In order to allow these tools to be implemented in a clinical setting and avoid excessive burden to caregivers and clinicians in completing them, our team chose a cutoff of 20 items. Table 6 summarizes the distribution of tools and their number of items.

### Definition of Burden

The term “burden” has been employed to define the impact on clinical and psychosocial factors within families. In Given’s study on the Caregiver Reaction Assessment Scale, “caregiver burden” was defined as the physical, psychological, social, emotional, and financial problems experienced by family members (including both objective and subjective factors) (Given et al., 1992; Gwyther & George, 1986; Montgomery et al., 1985).

**Table 3.** Instruments focusing on satisfaction with care

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/validity
<b>Adult Patients</b>					
*Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL) (Higgins & Prigerson, 2013)	Caregiver satisfaction with end-of-life care	Prolongation of death, perceived suffering, shared decision making, preparation for death	Caregivers of advanced cancer patients	13	Partial ( $\alpha = 0.52-0.78$ )/yes (convergent)
*FAMCARE (Kristjanson, 1993)	Family satisfaction with advanced cancer care	Information giving, availability of care, physical care, psychosocial care	Family members of patients with advanced cancer	20	Yes ( $\alpha = 0.93$ )/yes (criterion)
Canadian Health Care Evaluation Project (CANHELP) questionnaire (Heyland et al., 2010)	Patient and family satisfaction with end-of-life care	None identified	Patient with advanced, life-limiting illness and their caregivers (including metastatic cancer)	38 items (patient version), 40 items (family caregiver version)	Yes ( $\alpha = 0.69-0.94$ )/yes (construct)
Good Death Inventory (Miyashita et al., 2008)	Evaluate death	10 core domains (Environmental comfort, life completion, dying in a favorite place, maintaining hope and pleasure, independence, physical and psychological comfort, good relationship with medical staff, not being a burden to others, good relationship with family, being respected as an individual); 8 optional domains (religious and spiritual comfort, receiving enough treatment, control over the future, feeling that one's life is worth living, unawareness of death, pride and beauty, natural death, preparation for death)	Bereaved family members of cancer patients	30 (core domains) + 24 (optional domains)	Yes ( $\alpha = 0.74-0.95$ ) test-retest (ICC = 0.38-0.72)/yes (concurrent)
Post Mortem Questionnaire-Short Form (QPM-SF) (Partinico et al., 2014)	Assess home and inpatient hospice care	Integrated home care, hospice, physical care, information, global evaluation, needs	Family caregivers of cancer patients receiving palliative care	37	Yes ( $\alpha = 0.85-0.99$ ) test-retest (ICC = 0.66-0.98)/none found
<b>Pediatric Patients</b>					
None found					

\*Self-report instruments with  $\leq 20$  items and positive reliability and validity.



**Table 4.** Instruments focusing on caregiver quality of life (QoL)

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/ validity
<b>Adult Patients</b>					
*Caregiver Quality of Life Index (McMillan & Mahon, 1994)	QoL	Emotional, social, financial, physical	Primary caregivers of cancer patients in hospice	4	Yes ( $\alpha = 0.76-0.88$ )/yes (content, construct)
*Family Pain Questionnaire (FPQ) (Ferrell et al., 1993)	Measure family caregivers' experience with and knowledge about cancer pain	None identified	Family caregivers of cancer patients	13	Yes ( $\alpha = 0.81$ )/yes (content)
*Quality of Life in Life-Threatening Illness–Family Carer Version (QoLLTI–F) (Cohen et al., 2006)	QoL	Carer's own state, relationships, carer outlook, quality of care, patient condition, finances, environment	Caregivers of cancer patients receiving palliative care	16	Yes ( $\alpha = 0.86$ )/yes (content, construct)
CareGiver Oncology Quality of Life questionnaire (CarGOQoL) (Minaya et al., 2012)	QoL	Psychological well-being, burden, relationship with healthcare, administration and finances, coping, physical well-being, self-esteem, leisure time, social support and private life	Caregivers of cancer patients	29	Yes (0.72–0.89, except private life 0.55)/yes (construct, convergent)
Caregiver Quality of Life Index–Cancer (Weitzner et al., 1999a)	QoL	None identified	Primary caregiver of cancer patients	35	Yes ( $\alpha = 0.91$ )/yes (content, construct, convergent, divergent)
City of Hope QoL Scale–Family Version (Ferrell et al., 1991)	QoL	Physical, psychological, social, spiritual	Family caregivers of cancer patients	37	Yes test–retest (0.89) internal consistency ( $\alpha = 0.69$ )/not found
Quality of Life–Family Caregiver Tool (QoL) (Ferrell et al., 1999)	QoL	Physical, psychological, social, spiritual	Family caregivers of cancer patients	27	Yes ( $\alpha = 0.69$ ) test–retest ( $r = 0.89$ )/yes (concurrent)
<b>Pediatric Patients</b>					
Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module (Varni et al., 1999)	QoL of parents and family functioning	6 subscales measuring parents' self-reported functioning (physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry); 2 subscales measuring parent-reported family functioning (daily activities, family relationships)	Parents/guardians of children with cancer in active therapy aged 2–18 years	95	Yes (test–retest 0.81–0.96)( $\alpha = 0.73-0.89$ )/yes (construct)

Continued

**Table 4.** *Continued*

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/validity
Varricchio-Wright Impact of Cancer Scale–Parents (VWICS–P) (Wright, 1993)	QoL	None identified	Parents of children with cancer	Not found	Yes ( $\alpha = 0.67–0.87$ )/yes (construct, content)

\*Self-report instruments with  $\leq 20$  items, and positive reliability and validity.

### Definition of Need

“Caregiver needs” have been defined as needs related to state of health and state of healthcare that are not being met (Hudson et al., 2010; Hileman & Lackey, 1990).

### Definition of Quality of Life

The Centers for Disease Control and Prevention (2015) defines “quality of life” (QoL) as a subjective evaluation of both the positive and negative aspects of life. QoL instruments typically measure

psychological, social, and physical well-being but may also include one’s spiritual state.

### Definition of Satisfaction with Care

“Satisfaction” has been defined as the fulfillment of a need or want (Merriam-Webster, 2015). Satisfaction with care has been determined to be a significant factor, as the patient and caregiver will go through multiple aspects of care through the cancer trajectory (diagnosis, treatments, recurrence, survivorship, end of life), as well as the various healthcare specialties to which the patient will be referred.

**Table 5.** *Instruments focusing on other aspects of caregiver distress*

Instrument name	Purpose/focus	Domains/sections	Original population	Number of items	Reliability/validity
<b>Adult Patients</b>					
Morbidities Index for Caregivers of Chronic Illnesses (MICCI) (Kim et al., 2013)	Caregiver comorbidities	None identified	Cancer caregivers	40	No/no
Mutual Communal Behaviors Scale (Williamson & Schulz, 1995)	Communal feelings between caregiver and patient	None identified	Cancer caregivers undergoing outpatient palliative radiation therapy	10	Yes ( $\alpha = 0.86–0.88$ ; test–retest = 0.71, 0.67)/not found
<b>Pediatric Patients</b>					
Marwit and Meuser Caregiver Inventory Childhood Cancer (MM–CGI Childhood Cancer) (Al-Gamal et al., 2009)	Anticipatory grief	Personal sacrifice burden, heartfelt sadness and longing, worry and felt isolation	Parents of children with cancer	50	Yes ( $\alpha = 0.95$ )/yes (construct)
Parent Experience of Child Illness (Bonner et al., 2006)	Parent adjustment	Guilt and worry, unresolved sorrow and anger, long-term uncertainty, emotional resources	Parents of children with brain tumors	25	Yes ( $\alpha = 0.72–0.89$ )/yes (construct)
SCREEM Family Resources Survey (SCREEM–RES) (Panganiban-Corales & Medina, 2011)	Family resources	Social, cultural, religious, economic, educational, medical resources	Family caregivers of children with cancer	12	Yes ( $\alpha = 0.80$ )/not found

**Table 6.** Breakdown of number of items per instrument

Number of items	<i>n</i>
<b>1–10</b>	3
<b>11–20</b>	17
<b>21–30</b>	13
<b>31–40</b>	9
<b>41–50</b>	8
<b>51–100</b>	8
<b>&gt;100</b>	1
<b>Total</b>	59

### Definition of Other Aspects

“Other aspects” were defined as any other aspect in caregiving that did not fit exclusively into any of the previous categories, including emotions between caregivers and patients, caregiver comorbidity, and anticipatory grief.

### RESULTS

The database search identified 5,541 articles. These were narrowed down to 135 articles (2.4%) based on our inclusion criteria. All 135 were extensively discussed by the authors, and a consensus was reached. From these we extracted 59 instruments that measured different dimensions of cancer caregiving distress. Instruments that had similar names to other tools were labeled according to their country/region of origin. The abbreviated names of the instruments were also listed. The PRISMA diagram is shown in Supplementary Appendix B.

The instruments were divided into the following categories: burden ( $n = 26$ , 44%); needs ( $n = 14$ , 23.7%); quality of life ([QoL]  $n = 9$ , 15.3%); satisfaction with healthcare delivery ( $n = 5$ , 8.5%); and various other issues ( $n = 5$ ; 8.5%). Among the 59 instruments, 45 (74.6%) measured caregiver distress in adult cancer patients and 15 (25.4%) in caregivers of pediatric patients. Forty-one of the (69.5%) instruments were found to be reliable and valid. The list of instruments and associated information are presented in [Tables 1–5](#).

The median number of items was 29 (4–125). Twenty instruments (33.9%) had  $\leq 20$  items. There were 9 instruments that had  $\geq 50$  items (15.3%). The breakdown of number of items is shown in [Table 6](#). Thirteen instruments (22%) had  $\leq 20$  items and were valid and reliable, 12 (92.3%) of which were self-report instruments. These instruments are denoted in bold and shown first in [Tables 1–5](#).

Of the caregiver burden instruments, 9 of the 26 (34.6%) had  $\leq 20$  items, with 5 (55.6%) being reliable,

valid, and self-report. Eighteen (69.2%) of the tools measured caregiver burden in adult patients. Of the caregiver needs instruments, 3 of 14 (21.4%) were reliable and valid, and had  $\leq 20$  items, with 1 of these 3 (33.3%) requiring administration by healthcare providers. Twelve of the 14 (85.7%) needs instruments measured the caregiver needs of adult patients. Of the instruments measuring satisfaction with care, 2 of 5 (40%) were self-report, reliable, and valid and had  $\leq 20$  items. All instruments for caregiver satisfaction were for caregivers of adult patients. Of the caregiver QoL instruments, 3 of 9 (33.3%) were self-report, reliable, and valid and had  $\leq 20$  items. Seven of the 9 (77.8%) measured caregiver QoL in adult patients.

### DISCUSSION

Our systematic review of the literature identified 135 of 5,541 articles that met our inclusion criteria, with 59 instruments found to be developed initially for caregivers of cancer patients. Some of these instruments were mentioned in multiple articles, thereby explaining the larger number of articles than instruments.

As a general comment, we found it difficult to document whether a particular tool was developed for research or clinical purposes. Instead, we included the number of items in each instrument to indirectly illustrate if the tool was too complex or time-consuming to complete during a regular healthcare visit. Among all instruments, about 20% were reliable, valid, had  $\leq 20$  items, and were self-report questionnaires. We believe this is an encouraging number of instruments that are psychometrically sound and, more importantly, that can be applied effectively in a clinical setting. Among these instruments, McMillan’s Caregiver Quality of Life Index appeared to be the simplest questionnaire, with four items measuring a caregiver’s physical, emotional, social, and financial well-being (McMillan & Mahon, 1994). Although interesting for research purposes in understanding the complexities of caregiver distress, lengthy instruments can place a heavy burden on already-stressed caregivers and, likewise, may increase the burden on clinicians in trying to apply these instruments in a busy clinical setting. Self-report instruments may also help decrease the burden on busy healthcare providers, as caregivers are able to complete them without taking time away from providers.

Our review demonstrated a considerable number of instruments measuring caregiver burden ( $n = 26$ ) and caregiver needs ( $n = 14$ ). While Deeken et al. (2003), in their review of self-report instruments for informal caregivers, appropriately identified the

disproportion of quality-of-life tools between cancer patients and caregivers, our search was actually able to identify a higher number of caregiver QoL tools compared to previous literature reviews (Hudson et al., 2010; Deeken et al., 2003). On the contrary, there is a dearth of instruments measuring family satisfaction with care, grief, and bereavement.

We found that there were 44 of 59 (74.6%) adult patient-based cancer caregiver instruments compared to 15 (25.4%) pediatric patient-based cancer caregiver instruments, which is not surprising when compared to overall cancer statistics (Murphy et al., 2013; Howlader et al., 2013; NIH, 2015). Although a statistical analysis suggests that cancer is overwhelmingly a disease of adults, the diagnosis of cancer in a child puts enormous burden on caregivers, so that assessment tools are of great importance in that population (Sargent et al., 1995; Woodgate, 2006; Patterson et al., 2004). Furthermore, there are very specific issues in pediatric caregiving, including the effects of advanced disease on children and adolescents, and those need to be addressed in future research.

One of the limitations of the study is that we did not address tools that were not designed initially for cancer caregivers but can and are being used currently for that population. We believe that the level of complexity of caring for cancer patients may need specifically designed tools to capture their level of distress. There were several valuable tools that were excluded from the final tally. These tools were initially developed for other diseases or for patients, and were then eventually found to be applicable for caregivers as well. Some of these tools included the Zarit Burden Interview, developed for caregivers of dementia patients (Zarit et al., 1980); the Distress Thermometer, initially utilized with prostate cancer patients (Roth et al., 1998); and the Family Relationships Index, initially used in cancer patients and was part of the Family Environment Scale (Edwards & Clarke, 2005). Although not meeting the inclusion criteria for our review, these tools should not be neglected and are particularly valuable in detecting distress for both caregivers and patients with different disease processes.

Another limitation is the choice of 20 items as a cutoff for the instruments, which we based on our clinical experience in using other regular clinical assessment tools, including the Edmonton Symptom Assessment System (ESAS) and the Memorial Delirium Assessment Scale (MDAS). It might be possible that certain lengthier instruments would also be feasible and time-efficient in the clinical setting.

As compared to the reviews conducted by Deeken et al. (2003), Hudson et al. (2010), and Applebaum and Breitbart (2012), our research supports their

findings and also adds more instruments to the list that can be utilized for caregivers of adults and pediatric cancer patients. We also confirmed that there is a significant number of tools that have  $\leq 20$  items and that can be applied clinically. The challenge for the future is how to implement them regularly, improving caregiver care and measuring outcomes in the adaptation of these tools. Since there is no gold standard or real comparison between the different tools, clinical teams will have to determine which of these tools are more suitable to their practice. Ideally, in the future, receiving caregiver feedback will help identify the most effective.

Our review of tools has demonstrated that very few instruments have been incorporated into regular clinical practice. In addition, there are no studies documenting how the use of these tools helps modify clinical and/or health service utilization outcomes. There is also a lack of data on the comparative clinical performance of these instruments. These are all areas where research is needed.

We have found that there are several self-report cancer caregiver distress instruments that are concise, reliable, and valid. Clinical utilization and outcomes measures are certainly important areas for future research.

## SUPPLEMENTARY MATERIALS AND METHODS

To view supplementary material for this article, please visit <http://dx.doi.org/10.1017/S1478951516000079>.

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