



Understanding and Supporting Informal Cancer Caregivers

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Opinion statement

Informal caregivers invest a significant amount of time and effort to provide cancer patients with physical, psychological, information, and social support. These challenging tasks can harm their own health and well-being, while a series of social-ecological factors may also influence the outcomes of cancer caregiving. Several instruments have been developed to help clinicians and researchers understand the multi-dimensional needs and concerns of caregivers. A growing body of evidence indicates that supportive interventions including psychoeducation, skills training, and therapeutic counseling can help improve the burden, information needs, coping strategies, physical functioning, psychological well-being, and quality of life of caregivers. However, there is difficulty in translating research evidence into practice. For instance, some supportive interventions tested in clinical trial settings are regarded as inconsistent with the actual needs of caregivers. Other significant considerations are the lack of well-trained interdisciplinary teams for supportive care provision and insufficient funding. Future research should include indicators that can attract decision-makers and funders, such as improving the efficient utilization of health care services and satisfaction of caregivers. It is also important for researchers to work closely with key stakeholders, to facilitate evidence dissemination and implementation, to benefit caregivers and the patient.

Introduction

With socioeconomic transitions and an increasingly aging population, cancer burden is increasing rapidly. Global cancer statistics show that over 19 million

people were newly diagnosed with cancer in the year of 2020, and that this number is expected to rise to 28 million in the coming two decades [1]. Cancer

and its treatments can cause various adverse effects that affect quality of life of patients and can result in extensive care needs [2]. Due to limited resources, the current formal health care system cannot cater to all domains of cancer care needs [3]. Therefore, informal caregiving becomes an important asset for supporting patients throughout cancer survivorship or into palliative care.

The persons who engage in informal caregiving are mainly the family members, relatives, friends, or neighbors of patients. They provide physical, emotional, social, and financial supports to meet the complex care needs of cancer patients without compensation [4••]. A scoping review of 19 studies indicates that informal caregivers spend much time and energy in taking care

of cancer patients, equivalent to a monetary cost of over \$2000 per month [5]. Having an informal caregiver is associated with better coping capabilities and healthier lifestyle habits in cancer patients [6]. However, many caregivers perceive that they are not well prepared to navigate through the challenges brought by cancer caregiving [7]. Previous reviews have highlighted the importance of understanding the unmet needs of informal cancer caregivers and developing appropriate strategies to improve their well-being [3, 8, 9••]. In this paper, the latest evidence regarding the role, function, experience, and unmet needs of informal cancer caregivers has been reviewed, as well as the innovations in measurements and interventions to inform future practice and research.

Role and function of informal cancer caregivers: juggling multiple and complex roles

Caregivers are essential coordinators in facilitating communication between cancer patients and health professionals [10, 11••] and seeking information to support decision-making in treatment [12•, 13, 14] after the receipt of a cancer diagnosis. In family-centric communities, caregivers, especially spouses and family caregivers, usually serve as gatekeepers and buffers in disclosing the cancer diagnosis to alleviate the fear and shock of the patient [14–16]. They also may act as the key treatment decision-makers for cancer patients [16, 17]. Parents who bear the primary responsibility for treatment decisions for pediatric or adolescent patients with cancer also feel responsible for seeking cancer- and treatment-related information and evaluating the information credibility [18, 19].

Once complex and long-lasting cancer treatment is initiated, caregivers often need to provide care that requires certain professional skills, (such as administering oral medications, managing inserted catheters, and providing nutritional support [11••, 20]), which are crucial for improved patient outcomes. Caregivers may also take on the task of fundraising if patients face financial difficulties caused by cancer care [11••, 21]. When cancer patients experience psychological distress and adverse effects associated with cancer and the corresponding treatment, caregivers would be responsible for providing emotional support, managing symptoms, and assisting with daily activities [11••, 14, 21–23]. They may also need to substitute the role of the patient in doing housework and caring for dependent children, especially if the patient experiences functional decline [14]. After completing treatment, caregivers are responsible for helping the patient return to the “new normal” of life, study, or work [14, 24] and maintain cancer surveillance [25]. In end-of-life care, family caregiver effort is key to supporting cancer patients die at their preferred place of care [26].

Impact of caregiving on informal cancer caregivers

Since caring for cancer patients is often difficult, caregivers can experience caregiver burden and have unmet needs in terms of time constraints, self-development difficulties, physical health problems, social isolation, emotional distress, and economic issues [27, 28]. To cope with such stressful conditions, caregivers need informational, practical, psychosocial, and financial support from health professionals, other family members, social networks, non-governmental organizations, and/or government agencies [29–33]. Additionally, partner or spousal caregivers may also have information and communication needs with regard to sexual health [34, 35] and fertility [34, 36]. High levels of unmet need can exacerbate caregivers' burden of cancer caregiving and jeopardize their psychophysiological function [37] and quality of life [28, 38, 39]. Heavy caregiver burden may foster unhealthy behaviors such as alcohol [40, 41] and drug [40] use, which can increase the risk of developing metabolic syndrome including high levels of nonfasting glucose and triglycerides, low level of high-density lipoprotein, high blood pressure, and abdominal girth [42]. Caregiver burden and the depressive symptoms associated with caregiving can negatively affect the physical and mental health as well as quality of life of those they care for [43, 44].

Nevertheless, caregiving for cancer patients may also bring positive outcomes. Bloom and colleagues found that some caregivers of adults with cancer expressed more positive emotions than negative ones in their journal entries on online social media [27]. Caregivers often highlight the rewarding experience of caring and the joy of normal daily life [11••, 27, 45]. The relationship between caregiver and patient may become more intimate due to a grateful experience of mutual support [34]. These positive aspects of cancer caregiving were found to be associated with greater personal growth [46] and higher sense of happiness compared to the general population [47]. Additionally, fear of cancer recurrence may promote the caregivers own adherence to cancer screening [48].

Recent longitudinal studies employing either quantitative or qualitative designs showed that although the caregiver burden and unmet needs tend to vary over time, they may persist throughout the cancer illness and caregiving trajectory [49, 50•, 51•]. Caregivers who have substantial caregiver burden and psychological distress before the initiation of treatment are likely to experience higher levels of caregiver burden and psychological distress after termination of chemotherapy [49, 52]. According to a longitudinal qualitative study, family caregivers constantly worry about the prognosis of the patient throughout the course of chemotherapy, which causes anxiety [50•]. With the passage of time, caregivers gain more experience and skills for cancer caregiving [50•], and their information needs tend to be met to a certain extent [51•]. However, due to the emerging adverse effects of treatment and the often the progression of cancer, caregivers may need continuous support from the oncology team [50•]. Their financial burden can continue throughout the course of cancer treatment [50•, 53]. They may experience a strong sense of loneliness throughout the treatment journey [54].

If cancer treatment becomes ineffective, caregivers are likely to develop negative emotions such as shock, regret, frustration, and guilt [55]. They might

be hostile to health professionals if they feel that the prognosis of the patient and comfort care options were not realistically discussed [55, 56]. Some caregivers who have erroneous expectations about the benefit of treatment may wish to continue with more chemotherapy, while some may face a dilemma between supporting the preferences of the patient and their own opinion [55, 57]. Caregivers may have more positive memories if they perceive that what they have done has fulfilled the wishes of the patient, despite the experience of emotional difficulties during the end-of-life transition [55, 56]. Although most caregivers will gradually return to normal life after the death of the patient, some may experience severe post-loss distress, which can result in higher levels of anxiety and depression [58–60]. Parents of children who have died of cancer are likely to experience post-loss distress and prolonged grief symptoms due to regret and unfinished business [61]. Bereaved family caregivers also tend to have a lower quality of life compared with the general population [58, 59].

Factors influencing informal cancer caregiving

The impact of cancer caregiving on caregivers can be influenced by several factors. A literature review classified the factors into four domains: caregiver-related (e.g., gender, age, and socio-economic status), patient-related (e.g., age, health status, and quality of life), the caregiver-patient dyadic (e.g., relationship between caregivers and the cancer patient), and caregiving-related factors (e.g., perceived caregiver burden) [9••]. A growing body of research in recent years demonstrated the mechanisms of these factors in informal cancer caregiving and added knowledge regarding factors beyond the four domains, such as the caregiver-oncologist relationship, organizational support, and social norms. Given that informal cancer caregiving involves extensive interactions between stakeholders and their environment, the review by McLeroy and colleagues employed a Social-Ecological Model [62] to explain the factors associated with informal cancer caregiving. According to this model, factors influencing outcomes of informal cancer caregiving can be divided into intrapersonal, interpersonal, institutional, community, and policy factors (Fig. 1).

Intrapersonal factors

It is well documented that female caregivers are more likely to develop mental health problems and caregiver burden compared to male caregivers [9••, 63•]. However, male partners or husbands of female cancer patients who hold the norms of masculinity and face the dilemma of expressing emotional distress are also likely to develop high levels of caregiver burden and depressive symptoms [34, 64]. The negative side of masculinity in the context of cancer caregiving may lead to a higher risk of unhealthy behaviors, such as smoking and binge drinking, in male caregivers [41].

Age of the caregiver is another important factor relevant to cancer caregiving outcomes [9••, 63•]. Caregivers of younger age may have high levels of unmet need regarding caregiving skills training than those at older age due to less caregiving experience [65]. Younger caregivers are more prone to develop psychological symptoms, while older caregivers are more likely to experience physical health problems [9••, 63•, 66]. However, a recent study conducted in



Fig. 1. The social ecological model of factors influencing informal cancer caregiving

Italy found that compared with younger (age < 65 years) caregivers, elderly (age \geq 65 years) caregivers experienced higher burden of personal development when supporting cancer patients at the end-of-life, which may be associated with a pessimistic perspective on future life [67]. This indicates that the mental health of elderly caregivers should not be overlooked.

The socioeconomic status of caregivers such as education, occupation, and income are also significant intrapersonal factors that may influence cancer caregiving outcomes [9••, 63•]. Studies indicated that full-time employment and lower educational level can predict greater anxiety and depression in caregivers [68]. However, other recent studies found that higher income and educational level were significantly associated with greater caregiver burden and lower quality of life [21, 28]. This implies that caregivers are facing difficulty in balancing career and cancer caregiving, which can affect their social and psychological well-being [69]. A secondary analysis of data from the Improving Communication in Older Cancer Patients and Their Caregivers (COACH) study suggested that the negative effect of lower education level on caregiver burden was particularly prominent among caregivers who were from rural areas [70]. The lower educated caregivers would have more unmet needs in palliative care and during bereavement [30].

Other identified intrapersonal factors are the coping strategies, self-efficacy, and resilience of caregivers [60, 71]. Maladaptive coping by caregivers is associated with a poorer health profile in cancer survivorship and end-of-life care [68, 72] and prolonged grief symptoms in bereavement [72, 73]. Caregivers with decreased self-efficacy and resilience experience a higher level of caregiver burden, more depressive symptoms, and lower quality of life [64, 71, 74]. In contrast, caregivers with greater self-competency and sense of meaning, may have a more stable mental status despite increased caregiving hours [75].

Interpersonal factors

Since informal caregiving is a dyadic process, the relationship between caregiver and cancer patient is an essential determinant for caregiving outcomes. Being a spousal caregiver is associated with greater psychosocial and financial unmet needs and higher distress [76, 77]. Spousal caregivers with higher marital satisfaction usually have better mental well-being when providing care to the patient [78, 79]. However, an insecure attachment between spousal caregiver and patient may prevent them from using common dyadic coping, and result in impaired quality of life [80]. Lack of effective communication regarding cancer- and caregiving-related concerns was found to be common between caregivers and cancer patients [36, 81, 82]. This is a significant predictor for depressive symptoms in caregivers during caregiving and after the death of the patient [83].

The functional performance of the patient and the demands of care have significant impact on caregiver burden and quality of life [84, 85]. Younger age of cancer patients was found to be associated with greater personal strain and depressive symptoms in caregivers [90, 86]. In addition to caring for cancer patients, the presence of more dependent young children in the family needing to be cared for also predicts higher burden and distress in caregivers [87].

Cumulative evidence has shown that social support from friends and other family members predicts lower caregiver burden and better physical and mental health [60, 63]. This may be attributed to the reinforcement of resilience of caregivers by social support [88]. Spousal support and family functioning are important determinants of financial burden and stress-related symptoms in parents of pediatric patients with cancer [89, 90]. Quality of life of caregivers was found to be associated with posttraumatic stress symptoms in childhood cancer survivors, and this relationship was mediated by posttraumatic stress symptoms of caregivers [91].

Institutional factors

The schedule of health care service was identified as a significant institutional factor. In recent qualitative studies, caregivers expressed that they felt distressed if professional support was not available in time for managing the deterioration of the patient [110, 92]. Poorly organized home care services caused a sense of insecurity in caregivers [92]. Long waiting times and lack of a comfortable environment during clinic visits can amplify unpleasant caregiver emotions [93].

Lack of attention and communication regarding the well-being of caregivers from health care teams is another important institutional factor that should be considered. Several caregivers considered that health professionals focused entirely on patients and ignored their concerns [34]. They might become angry if realistic information on the prognosis of the patient was not provided by the

health care team [55]. On the contrary, effective communication between caregivers and health professionals can improve the experience of caregivers end-of-life care for cancer patients and reduce decision regret [94].

Community factors

Inconvenient transportation and unbalanced geographical distribution of medical resources in the community are barriers for obtaining professional and non-professional support, which would increase burden and sense of insecurity [11••, 92, 95]. Financial and instrumental support from non-governmental organizations in the community (e.g., churches, charities, and philanthropies) can partially alleviate economic burden and practical issues of caregivers [11••, 96, 97].

Policy and environmental factors

Governments of high-income countries such as Australia [97, 98], Canada [96, 99], and Norway [92] can provide financial compensation for informal caregiving, that can attenuate the financial difficulties of cancer patients and caregivers. However, caregivers may experience undesired anxiety or insecurity if an application for governmental compensation is cumbersome and slowly processed [92]. Caregivers in low-income countries usually face financial and resource constraints due to the lack of support from the government [11••, 23, 100].

The recent coronavirus disease 2019 (COVID-19) pandemic has placed an additional burden on caregivers. COVID-19 can increase the concerns of caregivers about ongoing treatment and care for the patient [101, 102]. Nevertheless, some parents of childhood cancer survivors considered that the isolation experience during active anticancer treatment allowed them to better respond to the epidemic [103]. Several caregivers worried that the COVID-19 epidemic might affect psychosocial well-being of the patient [101, 104]. Furthermore, the “lockdown” and isolation in response to the COVID-19 epidemic can also affect social support and income [101, 103]. This can result in negative emotions such as loneliness, uncertainty, anxiety, and fear [102]. Numerous caregivers expressed a stronger sense of responsibility for the patient [102] and attached importance to efforts by the government and health professionals to support them [102, 103].

Innovations in outcome measurements for informal cancer caregivers

Literature reviews [105–106, 107••] have summarized commonly used assessment tools specific to informal cancer caregivers, which can help health professionals and researchers gain a comprehensive understanding of unmet needs and quality of life of caregivers regarding daily activity, health care services, information, personal well-being, employment and social security, communication, family support, and financial issues (Table 1). More recently, an array of new outcome measurements [108–116] have been developed for assessing the expanding domains of unmet needs, burden, quality of life, and associated factors in caregivers (Table 1). However, these instruments are still in the stage of preliminary testing and require further verification in larger and more diverse populations.

Table 1. Outcome measurements for informal cancer caregivers

Outcome measurement	Domains	No. of item	Psychometric property	Reference
Needs/unmet needs				
Supportive Care Needs Survey for Partners and Caregivers (SNCS-P&C) ^a	Health care service needs; psychological and emotional needs; work and social needs; information needs	40	Internal consistency: $\alpha = 0.88-0.94$ Face validity: yes Content validity: yes Construct validity: yes	[105]
Cancer Support Person's Unmet Needs Survey (SPUNS) ^a	Information and relationship needs; emotional needs; personal needs; work and finance; health care access and continuity; worries about the future	78	Internal consistency: $\alpha = 0.93-0.98$ Test-retest reliability: 0.70 Face validity: yes Content validity: yes Construct validity: yes	[105]
Needs Assessment of Family Caregivers-Cancer (NAFC-C) ^a	Importance of the need: psychosocial, medical, financial, and daily activity unmet needs; How the need has been fulfilled	27	Internal consistency: $\alpha = 0.56-0.86$ Test-retest reliability: 0.70 Construct validity: yes Predictive validity: yes	[105]
Health Care Needs Survey (HCNS) ^a	Psychological needs; information needs; patient care needs; personal needs; spiritual needs; household needs	90	Internal consistency: $\alpha = 0.85-0.97$ Content validity: yes Construct validity: yes	[105]
Cancer Survivors' Partners Unmet Needs (CaSPUN) ^a	Relationships; information; partner issues; comprehensive care; emotional support	42	Internal consistency: $\alpha = 0.94$ Test-retest reliability: 0.60 Face validity: yes Content validity: yes Construct validity: yes	[105]
Comprehensive Needs Assessment Tool for Cancer-Caregivers (CNAT-C) ^a	Health and psychological problems; family/social support; health care staff; information; religious/spiritual support; hospital facilities and services; practical support	41	Internal consistency: $\alpha = 0.79-0.95$ Content validity: yes Construct validity: yes	[105]
Cancer Caregiving Tasks Consequences and Needs Questionnaire (CaTCoN) ^a	Caregiving workload; attention from health professionals on caregiver well-being; personal growth; privacy concerns; support from health professionals; information from health professionals; quality of information and communication from health professionals; social activities; peer support with other caregivers	72	Internal consistency: $\alpha = 0.65-0.95$ Face validity: yes Content validity: yes Construct validity: yes	[105]

Table 1. (Continued)

Outcome measurement	Domains	No. of item	Psychometric property	Reference
Need Assessment of Family Caregivers-Bereavement to Cancer (NAFC-BvC) ^b	Reintegration: finding meaning, understanding the system, social relationships; Managing the loss: tangible support, family relationships, personal health care	20	Internal consistency: $\alpha = 0.76-0.90$ Test-retest reliability: 0.31-0.58 Construct validity: yes Predictive validity: yes	[108]
Caregiver burden				
Caregiver Reaction Assessment (CRA) ^a	Impact on schedule; caregiver esteem; family support; impact on health; impact on finances	24	Internal consistency: $\alpha = 0.57-0.91$	[106]
Family Difficulty Scale (FDS) ^a	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 caregivers and their families; funeral preparations	29	Internal consistency: $\alpha = 0.73-0.75$ Test-retest reliability: 0.75-0.85 Construct validity: yes	[107••]
Brief Assessment Scale for Caregivers (BASC) ^a	Negative personal impact; positive personal impact; other family members; medical issues; concern about loved one	14	Internal consistency: $\alpha = 0.70$ Construct validity: yes	[107••]
Zarit Burden Interview-7 (ZBI-7) ^b	Unidimensional caregiver burden	7	Internal consistency: $\alpha = 0.83$ Inter-rater reliability: 0.51 Construct validity: yes Construct validity: yes	[109]
ZBI-1 ^b	Unidimensional caregiver burden	1	Construct validity: yes	[109]
Quality of life				
Caregiver Quality of Life Index-Cancer (CQOLC) ^a	Not reported	35	Internal consistency: $\alpha = 0.91$ Test-retest reliability: 0.95 Content validity: yes Construct validity: yes	[107••]
CareGiver Oncology Quality of Life (CarGOoL) ^a	Psychological well-being; burden; relationship with health care; administration and finances; coping; physical well-being; self-esteem; leisure time; social support; private life	29	Internal consistency: $\alpha = 0.55-0.90$ Test-retest reliability: 0.40-0.80 Face validity: yes Content validity: yes Construct validity: yes	[107••]
Caregiver Roles and Responsibilities Scale (CRRS) ^b	Emotional health and well-being; lifestyle; support and impact; self-care; financial well-being	41	Internal consistency: $\alpha = 0.75-0.92$ Test-retest reliability: 0.91 Face validity: yes	[110]

Table 1. (Continued)

Outcome measurement	Domains	No. of item	Psychometric property	Reference
Singapore Caregiver Quality of Life Scale (SCQOLS) ^b	Physical well-being; mental well-being; experience and meaning; impact on daily life; financial well-being	51	Content validity: yes Construct validity: yes Internal consistency: $\alpha = 0.86-0.93$ Test-retest reliability: 0.74-0.89 Face validity: yes Content validity: yes Construct validity: yes	[111]
SCQOLS-15 ^b	Physical well-being; mental well-being; experience and meaning; impact on daily life; financial well-being	15	Internal consistency: $\alpha = 0.75-0.89$ Test-retest reliability: 0.86 Content validity: yes Construct validity: yes	[112]
SCQOLS-10 ^b	Physical well-being; mental well-being; experience and meaning; impact on daily life; financial well-being	10	Internal consistency: $\alpha = 0.48-0.89$ Test-retest reliability: 0.85 Content validity: yes Construct validity: yes	[112]
Associated factors				
Dyadic Communicative Resilience Scale (DCRS) ^b	Keeping pre-cancer routines; creating new routines; communication networks; identity anchors; attractiveness; jokes/humor; feeling of lucky; constructing positivity; foregrounding productive action	47	Internal consistency: $\alpha = 0.77-0.88$ Content validity: yes Construct validity: yes	[113]
Caregiver-Centered Communication Questionnaire (CCCQ) ^b	Exchange of information; relationship with team; emotions; managing care; decision-making	30	Internal consistency: $\alpha = 0.82-0.97$ Face validity: yes	[114]
Family Resilience (FaRE) Questionnaire ^b	Communication and cohesion; perceived social support; perceived family coping; religiousness and spirituality	24	Internal consistency: $\alpha = 0.82-0.88$ Construct validity: yes	[115]
Psychosocial Assessment Tool-Hematopoietic Cell Transplantation (PAT-HCT) ^b	Structure/resources; social support; child problems; sibling problems; family problems; stress reactions; family beliefs		Internal consistency: $\alpha = 0.55-0.88$ Construct validity: yes	[116]

^aOutcome measurements summarized in previous literature reviews

^bOutcome measurements developed in recent years

Innovations in interventions for supporting informal cancer caregivers

Two evidence-based reviews, analyzing a total of 79 randomized controlled trials published between 1983 and 2016, classified supportive interventions for informal cancer caregivers into three categories: psychoeducation, skills training, and therapeutic counseling [117, 118]. These interventions are mainly composed of multiple components covering patient care, family reintegration, and caregiver self-management [117, 118]. The target population of the interventions can be either caregivers per se or, more frequently, caregiver-patient dyads [117, 118]. Alam et al. suggested that the provision of palliative care to both patients and caregivers simultaneously should be considered as the disease and functional status of a cancer patient is closely related to the distress of the caregiver [9••]. Although pooled analysis of supportive interventions indicated significant improvement in caregiver burden, information needs, coping strategies, physical functioning, psychological well-being, and quality of life, the effects were mostly small and short-term [117, 119•]. Moreover, there were discordant findings across the individual randomized controlled trials.

In their scoping review, Samuelsson et al. summarized current supportive care models for informal cancer caregivers and concluded that the high heterogeneity in cancer diagnosis, disease trajectory, and intervention components are key factors that contributed to the inconclusive results of most studies [120••]. A few recent studies tried to address these issues. For instance, in a randomized controlled trial, El-Jawahri and colleagues tested a 6-session psychological intervention (BMT-CARE) in caregivers of patients with hematological malignancies throughout the trajectory of hematopoietic stem cell transplantation. The results showed that, compared with those allocated in the usual care group ($n = 45$), the caregivers in the BMT-CARE group ($n = 42$) achieved statistically significant improvements in all the caregiver-reported outcomes including quality of life, self-efficacy, coping skills, caregiver burden, anxiety, and depression with moderate to large effect size [121].

Previous studies were conducted predominantly with white populations in Western countries, while other ethnic groups have typically been underrepresented. More recent work has attempted to address this issue. For example, a randomized controlled trial of a psychosocial intervention conducted by Badger et al. focused on Latino women with breast cancer and the caregivers and employed a bilingual intervention provider to comply with the language preference of the participants [122]. Another pilot trial used a racially diverse recruitment team to facilitate the recruitment of racially diverse research participants and successfully promoted the participation of African Americans in the study [123].

With the development of information technology, the provision of supportive interventions for caregivers has gradually shifted from a face-to-face format to telehealth, electronic health (eHealth), or mobile health (mHealth) formats. Previous literature reviews have shown that adopting technology-mediated interventions to facilitate convenient access to supportive resources is feasible,

useable, and acceptable, and that these can improve the interaction between caregivers and the health care team, shared decision making, personal well-being, social support, and dyadic communication and relationship with cancer patients [124–125, 126•]. This is especially crucial for caregivers and cancer patients who have transportation difficulties. A randomized controlled trial demonstrated that a videoconference intervention can significantly relieve distress and anxiety of caregivers, who would otherwise need more than an hour to travel to the residence of the patient [127]. Under the current circumstance of the COVID-19 pandemic, remote supportive interventions may be more suitable for caregivers and patients [127]. However, the optimal content and amount of technology-mediated supportive interventions for caregivers needs to be further determined in future research. Another concern is the digital divide (i.e., the inequities in access to technology) in older adults, minority groups, and residents of low- and middle-income countries, which is regarded as an important barrier impeding implementation of technology-mediated supportive interventions [126•].

Knowledge translation and evidence implementation

The existing supportive interventions for informal cancer caregivers are mostly in the clinical trial stage and implementing these interventions into practice is difficult. By interviewing experts and potential end users of supportive cancer care, Ratcliff and colleagues identified that the essential factors hindering the implementation of research evidence into practice include deviations between the investigated intervention and caregiver/patient needs, lack of well-trained interdisciplinary teams, insufficient funding and time for supportive care provision, and exclusion of caregivers from current health care systems [128••].

To address these barriers, Campbell and colleagues launched a quality improvement program with a designated interdisciplinary team to improve family caregiver identification, documentation, assessment, and needs-based intervention in a tertiary gynecologic oncology clinic. The program managed to increase family caregiver identification and assessment rates from 19% and 28% at baseline to 57% and 60% after eight PDSA (Plan-Do-Study-Act) cycles, respectively, with half of the identified caregivers having received the supportive intervention [129]. Bitz and colleagues shared their experience of integrating a couples-based interdisciplinary supportive care program into the standard of care. Based on the Values-Benefits-Outcomes Model of Engagement, this project has currently served nearly 2000 breast cancer patients and/or their partners and achieved high satisfaction rate among its users [130]. However, the two reports neither evaluated caregivers/patient quality of life and utilization of health care services, nor provided information on cost and cost-effectiveness.

Conclusion and future directions

Informal caregivers spend a large amount of time and energy in caring for cancer patients at the cost of their own health and well-being. Their contributions fill the gaps of cancer care discontinuity in the formal health care system, and this should be fully acknowledged. Understanding the distress and related social-ecological factors that caring brings and providing proactive and cost-effective supportive

interventions to carers are important practice areas. Research evidence suggests that providing psychoeducation, skills training, and therapeutic counseling for caregivers or caregiver-patient dyads can be beneficial. In order to translate current research evidence into routine practice, further research needs to be undertaken. Suggestions for future practice changes and research are shown in Box 1.

Box 1 Suggestions for future practice and research

- Interventions should be designed based on both the real-world needs of caregivers and the practice context.
- When formulating implementation schemes of a supportive intervention, it would be necessary to consider the social-ecological factors that may influence the outcomes and to address modifiable factors.
- Emphasize interdisciplinary collaboration in practice and research to promote intervention provision and evidence dissemination.
- Make full use of new technologies to ensure the cost-effectiveness, sustainability, and equity of the supportive interventions.
- It would be valuable to explore how and why the different supportive interventions work or do not work in caregivers by using realist evaluation theory on the context-mechanism-outcome (CMO) configurations since they are complex interventions.
- Given supportive interventions were found to have a delayed effect on several outcomes in caregivers [117], real-world studies with longer-term follow-up may be able to obtain richer information for decision-making.
- Development of theories specific to guide research and evidence implementation in supporting caregivers is necessary.
- Involve caregivers more in the health care discussions and decision-making, with the permission of the patient, and discuss with caregivers their experiences and challenges.
- Have a referral and support system in place for caregivers that can be easily accessible with few hurdles.
- Address caregiver issues of lack of practical skills, psychophysiological burden, economic support, and work discrimination at both the health care system level and policy level.

Data availability Not applicable.

Code availability Not applicable.

Declarations

Conflict of interest

Prof. Alex Molassiotis reports research grants from Helsinn, outside the submitted work. Mr. Mian Wang has no conflicts of interest to disclose.

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Papers of particular interest, published recently, have been highlighted as:

- Of importance
- Of major importance

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