


Caring for people who take care: What is already done?

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Review Article

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Abstract

Objective. The growing prevalence and impact of cancer on the family system calls for a palliative care approach with the family as the unit of care. This study aimed at providing an overview of the intervention programs that have been developed to offer support to the family caregivers of oncologic patients receiving palliative care.

Method. Sixteen articles were included in the final review, encompassing (i) studies focused on intervention programs with family caregivers of cancer patients in palliative care, (ii) studies including a pre- and post-test evaluation of the intervention program, (iii) and studies whose cancer patients were at least 18 years old.

Results. A great heterogeneity was verified with respect to care settings, number of sessions, outcome measures, or timing of assessment within the reviewed programs. These findings mirrored the complexity of the palliative care approach, which is difficult to standardize. Nonetheless, some interventions with different features accomplished good and sometimes similar results. The studies' main outcomes were clustered in five categories: psychological symptomatology, general quality of life, caregiving role, family relational variables, and bereavement/grief. Moreover, 44% of the main outcomes were psychological symptomatology of family caregivers, with an emphasis toward anxiety and depression. Also shown was a growing emergence of technology use among these interventions.

Significance of results. Results revealed a scarcity of family-oriented programs and lack of certified mental health professionals as interventionists. Future studies and interventions should focus on the positive outcomes of the caregiving experience and must acknowledge the cultural differences when trying to replicate programs. Considering that there is no precise formula for dealing with terminal illness and grief, we submit that family-centered and systemic lenses are excellent approaches for support during this adjustment process. In conclusion, the present study advocates for increased investment in the field, underscoring the importance of family caregivers' mental health.

Introduction

Death and illness are universal experiences among families (Rolland, 2005; Rolland and Walsh, 2005). Considering the challenges presented by cancer-related incidents and the rise of this chronic condition (WHO, 2017), cancer has come to take on a particularly negative representation cross-culturally. An individual receiving this diagnosis, at any stage of the disease, experiences a very stressful event, usually marked by a profound amount of uncertainty (Edwards and Clarke, 2004) for both the patients and their relatives. In fact, when cancer appears, it may have the potent effect of impairing all family members, thus creating or becoming the “family identity” and, consequently, a “we-disease” (Kayser et al., 2007).

Quite often, family caregivers¹ are “wrapped” in a 24 h job of caregiving, and they tend to be increasingly overloaded with tasks related to looking after their loved ones, a duty for which they are often wholly unprepared (Northouse et al., 2010; Northouse, 2012). Empirical studies have pointed to the high prevalence of psychological morbidity among family members of terminally ill cancer patients, namely that of their primary caregivers (e.g., Govina et al., 2015; Areia et al., 2017a, 2018), who end up as “co-suffers” (Northouse, 2012, p. 500). Thus, it is of utmost relevance to care for the people who provide this critical care.

The increased prevalence of cancer in the human population reinforces the need to develop family-centered interventions with a long-term positive impact aiming to help the system throughout the illness trajectory. As defined by the WHO (2002), palliative care aims to improve the quality of life of both patients and their families during a period in which all

¹For the purpose of the present article, a *family caregiver* is someone who takes care of a person suffering from disabling illness. The family caregiver might be either a partner or spouse, or other family member who helps and supports the patient daily, without being paid for this activity.

members must come to terms with a life-threatening illness and seeks to prevent or relieve suffering. Given how palliative care tries to ease the pain, and mitigate the physical, emotional, and spiritual suffering of these patients and their families, it nevertheless requires a multidisciplinary team, able to provide clear and open communication (Salazar, 2017). Although the WHO (2018) has called for the provision of support to family caregivers of palliative care patients, there are still some gaps found in the development of this issue (Lee et al., 2016). The relevance of palliative care in today's society is heightened by a socio-demographic transition to an aging society where people have smaller families, the consequence of which is that there are fewer children (or nieces and nephews) to take care of the older generation and fewer siblings able to provide support to one another (Walsh, 2016b). The latter contributes to an overwhelmed sandwich generation (Relvas, 2006) mainly comprised of women (Walsh, 2016b) in the primary caregiver position.

Hence, this study intends to provide an overview of the intervention programs aimed at supporting family caregivers of cancer patients receiving palliative care to cope with this life-threatening situation. Specifically, we aimed at identifying common practices and approaches adopted in the development and assessment of these programs in order to gain a broader understating of the work already done in this area.

Method

Data sources and literature search

A systematic search of the literature was undertaken using the PsycINFO, MedLine, and PubMed databases on studies published from 2002 to December 2019, inclusively. The WHO's (2002) updated definition on palliative care, which encompassed both the patient and the family as the unit of care, provided the basis for selecting the starting year for our research. The entire process of the present review followed the guidelines advised by PRISMA — Preferred Reporting Items for Systematic Reviews and Meta-Analyses (Moher et al., 2015).

The electronic research combined the following terms in all databases, limited to the abstract and to the English language: ["intervention*" OR "program*" OR "intervention program*" OR "instrument"] AND ["palliative care"] AND ["cancer" OR "oncology*"] AND ["family caregiver*" OR "care*" OR "caregiver*"]. In addition, an examination was performed of the reference lists of the selected articles to identify other pertinent studies for the present review.

Selection of studies

Expanding the electronic search, Mendeley was used to merge the results and to remove any duplicates. The following inclusion criteria were applied throughout the review: (i) studies focused on intervention programs with family caregivers of oncologic patients receiving palliative care; (ii) studies that included a pre- and post-test evaluation of the intervention program presented (i.e., evaluation before and after the intervention), and (iii) studies whose cancer patients were adults (were at least 18 years old). In contrast with previous reviews which examined these intervention programs (e.g., Hudson et al., 2010), we did not restrict our search to intervention programs with particular approaches (e.g., psychoeducational, family-centered), nor occurring during specific phases of the disease [e.g., chronic, terminal (Rolland, 2018)],

recognizing the importance of the onset of the care before the end-of-life stage (Klop et al., 2018).

In the initial stage of review, the first author examined the titles and the abstracts of 2,344 works, of which 2,234 were excluded. After this first step of the screening process, 110 records were identified as potentially relevant, according to the previously defined inclusion criteria. There were some primary excluding categories, mainly individual-focused (e.g., emphasizing medical treatments or symptoms; patient-focused intervention; more focused on health professionals), whereas others were more diseased-focused (e.g., pediatric palliative care; patients with other conditions; general descriptions of palliative care).

In the second screening, the first two authors independently appraised the full texts of the selected records, identifying 13 studies that met the inclusion criteria. Furthermore, three studies (Manne et al., 2004; Kissane et al., 2006; Northouse et al., 2007) were added from the bibliography list of those selected from the second screening. In cases of disagreement between the two authors, consensus was reached after debate. Furthermore, an inter-rater agreement was calculated. Cohen's kappa coefficient showed a strong agreement between the two first authors ($\kappa = 0.807$; McHugh, 2012). Figure 1 depicts the flowchart of the study selection process.

Results

The entire process of review yielded 16 studies, presenting one intervention program each. These studies were conducted worldwide: seven in the United States, three in Australia, two in Denmark, and one study each in Canada, London, Germany, and Singapore. Publication dates ranged from 2004 to 2019, with five studies published between 2004 and 2007, five between 2012 and 2015, and seven between 2016 and 2019.

Participants' and programs' main features

From 16 records, 6 were exclusively involved with family caregivers, and 10 comprised the dyad patient-caregiver. These caregivers were mainly women, except for three studies (Manne et al., 2004; Northouse et al., 2007; Mowll et al., 2015) which included couples, and mainly Caucasian, considering studies reporting this information ($n = 8$), except for one conducted in Singapore in which most participants were Asian (Leow et al., 2015). Furthermore, in ten studies, the main participant caregiver was the patient's spouse/partner.

Regarding the studies only with family caregivers, four presented individual intervention programs and two described group interventions (Manne et al., 2004; Fegg et al., 2013). Within the studies with the patient and the caregiver, one presented an individual intervention program (Sun et al., 2015), eight reported dyadic interventions,² and one intervention was reported with the whole family (Kissane et al., 2006).

Thirteen studies were randomized controlled trials (RCTs). The selected studies were clustered in categories according to the type of intervention, based on what was described in each article about the intervention: there were six with a more psychosocial approach, four psychoeducational, four family-centered, and two existential approaches.

²When we are referring to "dyadic intervention," we are describing interventions with both the patient and the family caregiver, which is likely to be, but not necessarily, a couple.

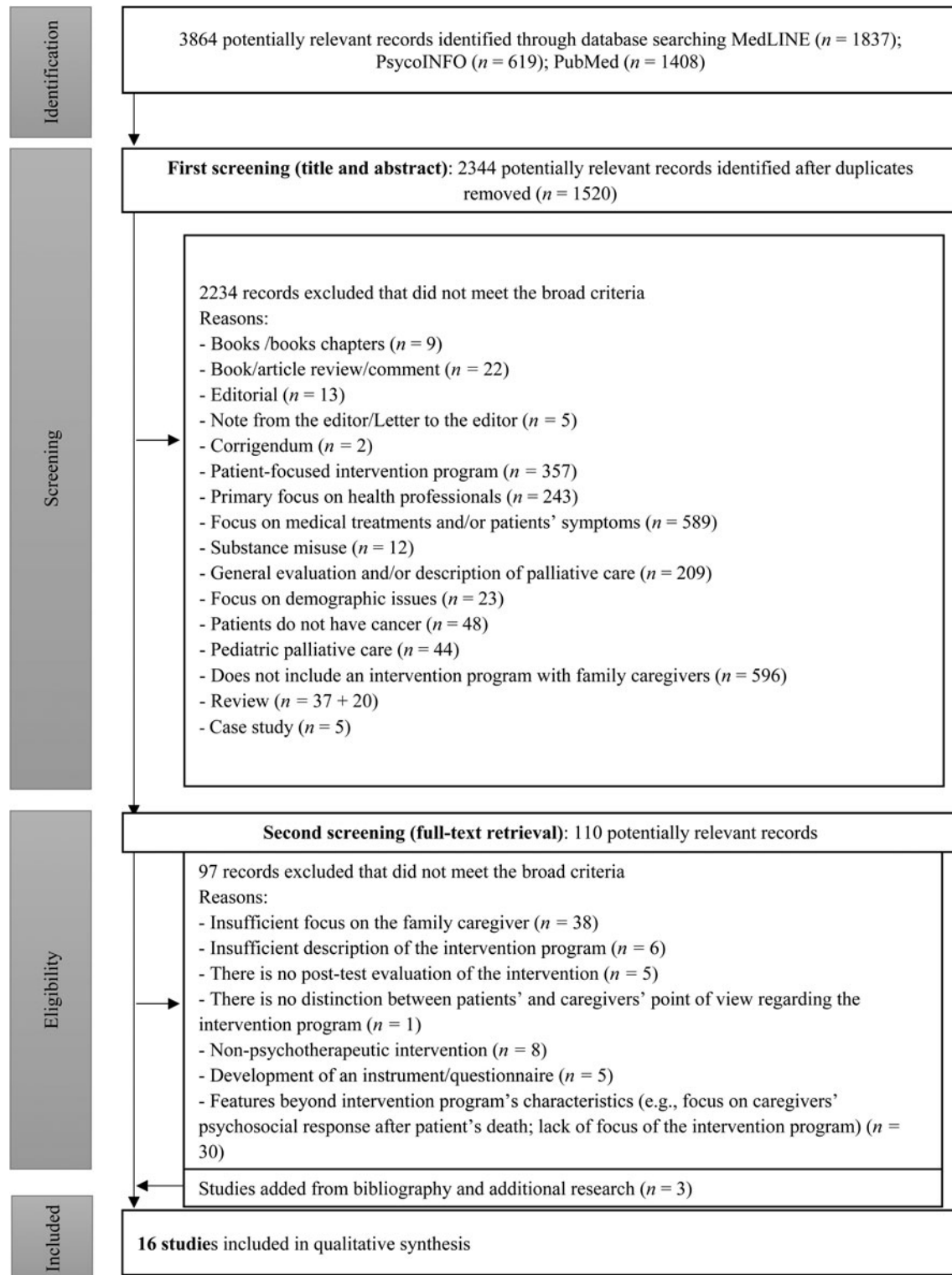


Fig. 1. Flowchart of the review process.

Who conducted the intervention?

Nine programs had nurses as one of the professionals conducting the intervention, being the only interventionists in five of them. Mental health professionals were among the professionals conducting five studies, being the only interventionists in three (Fegg et al., 2013; Badr et al., 2015; Mowll et al., 2015).

Specifically, one study was led by family therapists (Kissane et al., 2006).

For how long and how were they delivered?

With respect to the length of the intervention program, Mowll et al. (2015) described the briefer two-session intervention,

whereas Kissane et al. (2006) advocated four to eight sessions across 9–18 months for which a manual was published (Kissane and Bloch, 2002) with guidelines to conduct the therapy. The latter was the only intervention with the whole family, working with at-risk families, previously selected based on the Family Relationships Index (FRI).

Five studies included six sessions (Manne et al., 2004; Walsh et al., 2007; Fegg et al., 2013; Badr et al., 2015; Ammari et al., 2018). Ten studies reported manualized interventions (i.e., manuals were developed to include the guidelines) or interventions following structured guidebooks/checklists (e.g., Manne et al., 2004; Walsh et al., 2007; Mowll et al., 2015; Schenker et al., 2018). In addition to the intervention itself, five programs (Hudson et al., 2005; Fegg et al., 2013; Badr et al., 2015; Leow et al., 2015; Sun et al., 2015) comprised supplemented material to provide to the participants (e.g., manuals, guidebooks, videos).

Some interventions involved follow-up moments that were not only meant for its efficacy assessment. Leow et al. (2015) described two follow-up phone calls and an invitation to an online social support group. Zimmerman et al. (2019) offered professional support available 24/7 between each appointment and follow-up moments, both in-person and by telephone, meant to address family's needs, symptomatology control, future planning, and other pressing matters over the course of the illness. In turn, the intervention detailed in Schenker et al. (2018) included, if needed, bereavement interviews to the family caregivers 1–3 months after the patient's death, and, similarly, in the intervention of von Heymann-Horan et al. (2018), there were one/two sessions offered after the death of the patient.

Most of the intervention programs were in-person, except in five studies: the intervention of Badr et al. (2015) was telephone-based, whereas Hudson et al. (2005), Nguyen et al. (2018), and Northouse et al. (2007) featured a combination of in-person and telephone calls. Lastly, in the Washington et al. (2018) program, the family was given the option of receiving the intervention by telephone, via web-based videoconferencing, or by any combination of the two.

Pre-/post-test assessments

Self-report measures were predominantly used to assess pre-/post-test effects of the caregivers' outcomes. However, some programs also relied on interviews (e.g., Zimmermann et al., 2019) and/or focus groups (e.g., Hudson et al., 2005). Table 1 presents a summarized description of each intervention program included in the review and the programs' main goals and outcomes (i.e., variables assessed or indicators to evaluate interventions' efficacy — e.g., depression, closeness).

Main outcomes and results of the intervention programs

There were some primarily assessed outcomes, namely depression or anxiety. Nevertheless, the instruments used to measure them varied (e.g., instruments to measure depression — cognitive items from the Beck Depression Inventory, Depression Anxiety Stress Scales, Hospital Anxiety and Depression Scale, and others).

Depression and anxiety, included in seven and six of the studies, respectively, along with the quality of life, were presented in eight studies. As for depression, five studies reported positive outcomes for this variable (Kissane et al., 2006; Fegg et al., 2013; Badr et al., 2015; Leow et al., 2015; von Heymann-Horan et al., 2018), suggesting that their interventions may have the potential to decrease its levels. In turn, three studies verified the opposite: there was not a significant reduction in levels of depression (Walsh et al., 2007;

Ammari et al., 2018; Washington et al., 2018). Furthermore, anxiety declined significantly in four studies after the application of the intervention program (Fegg et al., 2013; Badr et al., 2015; von Heymann-Horan et al., 2018; Washington et al., 2018), but negative results were reported in the studies of Walsh et al. (2007) and of Ammari et al. (2018). In fact, the last study verified that there was a tendency for relatives in the intervention group to present poorer outcomes than controls over time. No significant results were shown in the study of Hudson et al. (2005), which simply pointed to an overall decrease in anxiety in both groups (control and intervention groups). With regard to quality of life, there were five studies showing improvements in this domain after the interventions (Northouse et al., 2007; Fegg et al., 2013; Leow et al., 2015; Sun et al., 2015; Nguyen et al., 2018; Zimmermann et al., 2019), and three that did not (Walsh et al., 2007; Ammari et al., 2018; Washington et al., 2018).

Furthermore, caregiver burden and distress were assessed in four and six studies, respectively. Burden diminished in two studies (Badr et al., 2015; Sun et al., 2015), whereas distress diminished in three (Kissane et al., 2006; Northouse et al., 2007; Sun et al., 2015). In the study by Manne et al. (2004), in which distress was the focus, benefits were not observed in this matter.

Concerning the role of professionals during these interventions, within the four studies conducted by a multidisciplinary team that included nurses, two reported effectiveness of the programs, as quality of life (Sun et al., 2015; Nguyen et al., 2018), distress and burden improved after the intervention (Sun et al., 2015) along with preparedness (Nguyen et al., 2018), anxiety and depression, in comparison to the control group (von Heymann-Horan et al., 2018). Moreover, out of five interventions delivered only by nurses, only one reported that the effect of the intervention was less than expected (e.g., over time poorer outcomes, mainly in terms of emotional well-being, were verified; Ammari et al., 2018) and another one considered that future studies should investigate the small effect of the intervention on depression and quality of life, although feasibility was greatly supported (Washington et al., 2018). From the studies encompassing mental health professionals ($n = 5$), all considered that the interventions led to the expected outcomes, being that one of them focused important experiences related to caregiving (e.g., posttraumatic growth, coping; Manne et al., 2004). Moreover, the study conducted by family therapists showed high to moderate efficacy (e.g., greater reduction of general distress over 13 months and a substantial decline of distress and depression; Kissane et al., 2006), whereas the one conducted by part-time carer advisors failed to support its main hypothesis, which was that “a brief intervention by a carer advisor would reduce psychological symptoms in distressed informal carers” (Walsh et al., 2007, p. 145).

Is it all bad?

Despite the emotional toll, some family caregivers reported that the intervention included positive contributions: it promoted personal strength, spiritual growth, and appreciation for life (Manne et al., 2004), it increased their competence, had an impact on the perceived rewards, and underlined the likely positive aspects related to caregiving (Hudson et al., 2005), such as perception of preparedness for caregiving (Nguyen et al., 2018). Schenker et al. (2018) did not achieve feasibility (which was assessed through enrollment, intervention completion, and 3-month outcome assessment rates), even though acceptability and perceived effectiveness were moderate. However, patient and caregivers described both positive experiences (e.g., extra support; someone

Table 1. Summary of the main characteristics of the selected studies

Author(s), year (country)	Type of Program RCT	Participants			Sessions			Main FCG's Outcomes
		Target participants	Health professionals	Setting	Structure (How long and how)	Pre-/post-intervention assessments	Main Goals	
Manne et al. (2004) (US)	Psychoeduc. RCT	FCG	Radiation oncologist; nutritionist; psychologists; social worker	Cancer center	Six-week group intervention	Baseline; 1 month after intervention	To provide information; to help the stress management; enhance good communication and intimacy; talk about survivorship issues.	Distress; coping; personal growth; communication
Hudson et al. (2005) (Australia)	Psychoeduc. RCT	FCG	Nurses	Home-based	Two sessions; Phone call between sessions; Guidebook and audiotape	Baseline; five weeks from baseline, (by mail); eight weeks following the patient's death (at home)	To enhance FCG support: providing information on the caregiving role; focusing on their needs; reinforcing palliative care's role; identifying resources; finding meaning; self-care.	Preparedness; competence; rewards; anxiety; self-efficacy
Kissane et al. (2006) (Australia)	Family-centered RCT	At-risk families (whole-family)	Family therapists (social workers)	Hospice; home-based	4–8 sessions (90') across 9–18 months; three phases: assessment, intervention; termination	Baseline; 6 and 13 months after patients' death	To reduce the morbid effects of grief within at-risk families: enhancing the functioning of the family (e.g., cohesion, communication).	Psychosocial functioning; family functioning; distress; depression; social adjustment
Northouse et al. (2007) (US)	Family-centered RCT	Patients; FCG (Couples)	Masters-prepared nurses	Home-based	Three 90 min home visits and two 30 min telephone sessions, spaced two weeks apart	Baseline; 4, 8, and 12 months	To improve appraisal variables, coping resources, symptom distress, and QOL.	Communication; hope; coping, uncertainty; QOL; symptom management; distress
Walsh et al. (2007) (London)	Psychosocial RCT	FCG	Part-time carer advisors with experience in community nursing and social work	Home-based	Six weekly visits	Baseline; 4, 9, and 12 weeks after randomization; Brief, semi-structured interviews at the final follow-up	To reduce symptoms of anxiety, depression, carer burden, and intensity of grief reactions; to improve QOL and satisfaction with care.	Caregiver distress; strain; quality of life; satisfaction with care; bereavement
Fegg et al. (2013) (Germany)	Existential behavioral therapy RCT	FCG	Behavioral therapists	Hospital-based	Six group sessions (22 h); CD to practice mindfulness at home	Baseline; pre-treatment, post-treatment, follow-ups after 3 and 12 months	To reduce psychological distress and improve QOL: implementing mindfulness; activating resources; finding meaning; promoting self-care; stress management; saying goodbye.	Severity of symptoms (somatization, depression and anxiety); QOL; positive and negative affect

Badr et al. (2015) (US)	Psychosocial RCT	Patients; FCG	Interventionists — master's degree in mental health counseling	Telephone-based	Six weekly dyadic telephone sessions; Home-work assignments; Tailored manuals divided into six sections	Recruitment; baseline; follow-up (week 8)	To improve patients' and FCG's QOL: focused on self-care, stress, coping, symptom management, autonomy, communication, problem solving, enhancing relationships.	Psychological functioning; caregiver burden; autonomy; competence; relatedness
Sun et al. (2015) (US)	Psychosocial	Patients; FCG	Nurses, doctors, social worker, chaplain, dietitian, physical therapist, members of the research team	Cancer center	Weekly care meetings; FCG: four educational sessions (physical, psychological, social, and spiritual domains); self-care plan; manual to FCG	Baseline; FCGs at 7 and 12 weeks; Patients at 6 and 12 weeks	To decrease FCG burden and psychological distress; to improve FCG and patients' QOL (physical, psychological, social, spiritual domains)	QOL, caregiver burden, caregiving skills preparedness, psychological distress
Mowll et al. (2015) (Australia)	Psychosocial	Patients; FCG (Couples)	Clinical psychologists	Hospital; home-based	Clinical interview; two weeks after: face-to-face semi-structured interview at home	Baseline; eight weeks; Post- intervention semi-structured interview	To promote communication about living with advanced cancer.	Communication
Leow et al. (2015) (Singapore)	Psychoeduc. RCT	FCG	Nurses	Home-based; hospice	One 1 h session; Video clip; two follow-up phone calls (at weeks 3 and 6); Invitation to an online social support group	Baseline, weeks 4 and 8 (after the intervention); two post-test surveys: by phone	To enhance FCG's QOL: helping to cope with stress, frustration, depression, anticipatory grief; improving patient-FCG communication; increasing FCG's social support; activating community resources; managing patient's death.	QOL; social support; stress; depression; self-efficacy; closeness; rewards; knowledge
Washington et al. (2018) (US)	Psychosocial RCT	FCG	Nurses	Web-based videoconferencing or telephone	Three sessions (one week apart) [digitally audio-recorded]	Baseline; day 15; day 30; day 60	To analyze the impact of problem-solving therapy on FCG's anxiety, depression, and QOL.	Anxiety; depression; QOL
Ammari et al. (2018) (Denmark)	Family-centered RCT	Patients; FCG	Nurses	Home-based	Six home visits (three-week interval).	Baseline; 16 and 24 weeks	To improve measures of HRQoL of patients and FCG, to reduce anxiety and depression, and prevent unnecessary hospital admissions.	Health-related QOL; anxiety; depression
Schenker et al. (2018) (US)	Psychosocial RCT	Patients; FCG	Specialty trained palliative care physician	Cancer center	First session; Before each visit — patients: "what would you most like to discuss with your supportive care doctor today?"; assessed	Baseline and 3 months	Focused on: relationships; illness understanding; preferences and concerns; needs; social/financial/	Caregiver burden; mood symptoms (distress, anxiety, depression); preparedness for

(Continued)

Table 1. (Continued.)

Author(s), year (country)	Type of Program RCT	Participants			Sessions			Main FCG's Outcomes
		Target participants	Health professionals	Setting	Structure (How long and how)	Pre-/post-intervention assessments	Main Goals	
					symptom burden and distress; FCG: caregiver burden and distress; Follow-up intervention visits: monthly for the first 3 months; as needed after; Some cases: bereavement interviews for FCG 1–3 months after patient's death		caregiver burden; resources; future.	death and complicated grief
Nguyen et al. (2018) (US)	Psychoeduc.	Patients; FCG	Nurses; research staff	Community-based setting	Three sessions; 1–2 semi-structured follow-up calls	Telephone assessments: baseline; 1 and 3 months	To improve patient QOL and healthcare utilization; to decrease distress; to improve FCG QOL and preparedness; to diminish burden and distress.	QOL; distress; preparedness; caregiver burden
von Heymann-Horan et al. (2018) (Denmark)	Existential-phenomenological RCT	Patients; FCG	Nurses; doctors; psychologist; specialized palliative care team	Home-based	Home conference; Needs-based care based on national guidelines; Intervention: two-sessions; monthly needs-assessment and/or needs-based sessions; After patient's death: 1/2 closing sessions	Patients and FCG: three days before randomization and four times after randomization (weeks 2, 4, 8, and month 6); Caregivers: five times after the patient's death (week 2, months 2, 7, 13, 19)	To decrease distress in patients and FCG (dyad as the unit of care): helping dyads to adapt flexibly; identifying rigid aspects of their worldview.	Anxiety; depression
Zimmermann et al. (2019) (Canada)	Family-centered RCT	Patients; FCG	Specialist palliative care physician and a registered nurse with palliative care certification	Outpatient PC clinic	Initial consultation; Monthly sessions (or more) for 4 months; Possibility of telephone follow-up	Baseline; at each clinic visit	To improve QOL through the early identification and treatment of physical, psychosocial, and existential concerns.	QOL; decision-making; future planning; satisfaction with care; support; symptom management

Note. FCG, family caregiver; QOL, quality of life; PC, palliative care; Psychoeduc., Psychoeducational; RCT, randomized controlled trial.

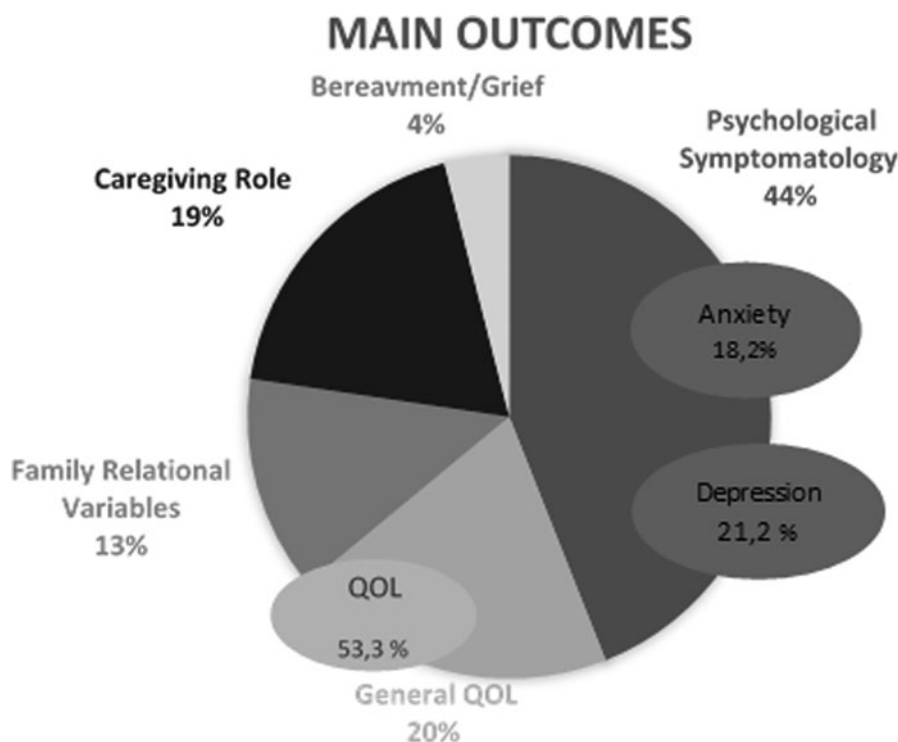


Fig. 2. Main focus of the outcomes of the measures.

to listen and to provide information about the process) and negative experiences (e.g., spending too long at the cancer center; long travel times) with early specialty palliative care (Schenker et al., 2018). Additionally, the importance of marital communication was found to be enhanced in the intervention of Mowll et al. (2015) (e.g., having insight into each other's feelings).

Lastly, apart from the mainly assessed outcomes, others were involved among the included programs, detailed in the last column of Table 1. From those, grief/anticipatory grief and bereavement are highlighted due to their low frequency. The latter was addressed, for instance, in the study of Kissane et al. (2006) which appeared to protect against pathological grief, broadly speaking. Likewise, Zimmermann et al. (2019) discussed preferences surrounding end-of-life care and resuscitation. The graph in Figure 2 represents the main outcomes assessed, clustered in five categories. It should be noted that the General Quality of Life category encompasses not only Quality of Life (QOL) but also well-being, hope, and satisfaction with life and with care, which also contribute to the global feeling of the quality of life.

Discussion

The present study aimed to provide an overview of the intervention programs developed to support family caregivers of cancer patients in palliative care since 2002. A vast heterogeneity of the programs included in this review was noted, namely with regard to care settings, dosage (i.e., number of sessions), outcome measures, or timing of assessment (Hui et al., 2018). This is likely to reflect the lack of consensual and effective guidelines for these kinds of interventions. Undoubtedly, palliative care is complex and multidimensional, which makes it difficult to standardize (Hui et al., 2018). Thus, comprehending the extent to which the illness, the individual, the family life cycles (Rolland, 1987) and even the healthcare setting are intertwined is a vital issue impacting all clinical interventions in this scope.

In line with this “complexity,” the range of possible professionals leading the interventions should be discussed, despite our findings suggesting that different health professionals manage to achieve similar good results. According to the literature on the population living the crisis, chronic, remission, recurrent, and terminal phases of cancer (Areia et al., 2017b), some of the most prominent family caregivers' needs having general information about the patient's condition, treatment and care, having support from healthcare professionals, and being assured of the patient's comfort. Accordingly, “information” is a key factor to decrease family caregivers' psychological morbidity (Areia et al., 2017a), which could be provided by different professionals accompanying the case. By contrast, family-centered interventions are expected to be delivered by qualified and expert professionals in the field, such as family therapists or other mental health professionals. Nonetheless, only one of the included studies with this approach met these expectations, with the other two family-centered approached interventions conducted by nurses. Despite the great value of these last professionals in palliative care, attention should be made when choosing the most well-suited practitioners to conduct an intervention program of such complexity.

Although most interventions were delivered in-person, there seems to be an increased trend that relies on available technologies, namely telephones, to lead these programs. The increased use of technologies in our globalized world appears to offer some advantages when dealing with the emotional and physical toll on family caregivers, allowing individuals to remain in the comfort of their own homes yet still feel that they are being “taken care of.” Also, the current COVID-19 pandemic has shown that videoconferences have come to stay, which emphasizes their increasing role in the future. Nonetheless, we have to consider the demographic features of our target population before developing intervention programs sustained mostly in technology.

Furthermore, as seen in Figure 2, 44% of the main outcomes were referred to the psychological symptomatology of the family

caregivers, stressing the lack of attention paid to the positive experiences of caregiving. The absence of research that incorporates this scope skews the perceptions of this practice, hindering the access to positive experiences that might emerge with the caregiving, such as the positive daily relationships, feelings of accomplishment, reward, personal growth, and the meaning of this role (Li and Loke, 2013). Sometimes, families who experienced crisis reported that something positive came out of the suffering and despair (e.g., enriched and more affectionate relationships) (Walsh, 2016a). Likewise, there were scarce interventions pertaining to the bereavement period either in the intervention itself or among the follow-up assessments. Considering the complex tasks involved in a family's mourning process (e.g., shared acknowledgement of the death; reorganization of the family system; attempts to ascribe meaning to the loss) (Walsh, 2016b), it would be expected that more interventions recognized the importance of helping families throughout this process.

Moreover, previous research (Northouse et al., 2010; Areia et al., 2020) reveals that none of the intervention programs was found to be translated into languages other than those they were originally developed in. Thus, they were not applied in different countries nor cultures, which would have provided enriching information regarding the strengths and weaknesses of each of those programs.

However, there were positive findings stemming from this review as well. Primarily, although not being part of the inclusion criteria, RCTs prevailed within the studies. The increment of this type of design aimed at eliminating selection and confounding biases (Moher et al., 2010), to assure the reliability of the studies and correspondent results. Besides, multiple outcomes were assessed, related to the negative (e.g., anxiety, distress), and even positive impact (e.g., rewards, well-being,) which were clustered into the five categories mentioned in the Results section (cf. Figure 2). This enriched our work by showing the diversity of outcomes that can emerge from the experience of caring, presenting the most explored variables (e.g., psychological morbidity) along with those which would benefit from greater investigation (e.g., anticipatory grief). In addition, some of the described interventions managed to attain their goals, benefiting family caregivers' symptomatology and well-being. Hence, despite the seeming lack of guidelines to conduct intervention programs with family caregivers of cancer patients in palliative care, it is possible to develop effective interventions with different approaches (i.e., psychoeducational; family-centered). Also, six out of 16 studies were published in the last 2 years, which suggests an increased interest in the field, as well as greater insight into the importance of the family caregivers' mental health across these periods.

Evidence from the present review also identified advantages and drawbacks concerning the inclusion of the sole family caregivers or both the family caregiver and the patients in the intervention. On the one hand, the literature (Northouse et al., 2010) points to interventions that include only the relatives of people living with cancer as allowing them to focus better on their own role as caregivers (Hudson et al., 2005; Leow et al., 2015), as well as to openly share feelings without fear of hurting the loved one. The low number of interventions working exclusively with family caregivers sustains the lack of support given to this population to help them deal with their emotional distress (Northouse, 2012). On the other hand, the inclusion of the dyad appeared to be important, for instance, to promote greater insight into each other's needs (e.g., Schenker et al., 2018) and feelings. Due to the lack of healthy communication patterns, patients' needs or preferences are often not considered (Goldsmith et al., 2016), which is another benefit of

the presence of the patient–family caregiver dyad. Besides, there is an interdependence between patients and family caregivers (i.e., patients' negative feelings affect their relatives, and the inverse) (Northouse, 2012), reinforcing the need “to treat” the family as the unit of care (e.g., WHO, 2002). Finally, the present work stresses the lack of interventions with the whole family, since only one of the included programs (Kissane et al., 2006) takes into account all members of the family household.

Overall, this critical review verified that there is still a gap with respect to the development of programs with this purpose. During the process of review (cf. Figure 1), the main reasons to exclude the retrieved records were the lack of inclusion or focus on the family caregivers, the predominant focus on patients' medical treatments and/or symptoms, and the fact of being patient-focused intervention programs. Stemming from this information, it is likely that the research from the last decade is still primarily “patient-based,” which is in line with previous reviews, sustaining that substantial improvements must be made with regard to the design and rigor of studies in the field (e.g., Hudson et al., 2010).

Given the extent to which cancer impacts families and family caregivers across several domains (e.g., the caregiver's loss of social roles when assuming the caregiver role, isolation, health impairment, financial strain, facing death), it is urgent to help these systems to create meaning underlying the experience of impending loss and the vagueness of the future ahead, fostering continuity between past, present, and future (Rolland, 1994, 2018). Families must avoid being psychologically and/or physically trapped in past traumatic experiences, Walsh (2016b) states, given how a resilience-oriented attitude enables families to heal, thus fostering positive growth out of adversity.

Study limitations, strengths, and future directions

The present study has limitations that might skew some of its results and conclusions. First, the databases selected and the filter of English language on the electronic research might have hidden important research on the theme. Second, we did not draw a distinction within our conclusions based on the studies' features, namely the type of study (e.g., feasibility, efficacy), the size of the samples, baseline values, or others. For instance, although most of the studies were RCTs, there should be caution when interpreting results, given that we did not verify the baseline values measure in each one. If the recruitment of the sample did not consider the initial distress that allowed the detection of change over the process, there is a likelihood of including low distressed participants who might create floor effects (Shields et al., 2012). In addition, most included participants were North American, which could have biased the results because, as expected, cultural differences were already found in previous research (e.g., Kreling et al., 2010).

Despite these limitations, this work managed to provide an updated portrait of the intervention programs that have been developed to support family caregivers of oncologic patients in palliative care. There is a circularity that should be outlined from our findings: the lack of programs focusing the family caregiver, their heterogeneity, and consequent absence of guidelines to conduct these interventions hamper our ability to identify which are, in fact, the most and least favorable ways to intervene. Nevertheless, this review pointed to those which were the main focus of assessment, allowing for greater comprehension with respect to the work that is still to be done. We propose family-centered and systemic approaches considering the proven benefits of working with the

whole family (e.g., Gonzalez et al., 1989; Kissane et al., 2006) and that, when it comes to dealing with chronic and/or terminal illness and grief, “one-size-does-not-fits-all.” We strongly suggest that future studies pay more attention to the positive outcomes of the caregiving role, as positive emotions can have a profound impact during this period. Few studies took place in European countries. Future research should be aware of the cultural differences, which highlights the importance of undertaking these studies worldwide. The almost exclusive use of self-report measures [e.g., Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983)] to assess intervention results meant that qualitative methods were not selected, which could have provided relevant information. In the future, more attention should be dedicated to the family caregivers of cancer patients, with financed research allowing both quantitative and qualitative investigation. Furthermore, and in accordance with the findings of Northouse et al. (2010), the field would benefit from increased teamwork. There is still a lack of unity among professionals, either researchers or clinicians, with respect to working toward the same goal, which is improving the quality of the care provided to the families. Clinical practice and redoubled research efforts are more likely to thrive with a multidisciplinary team approach, which might contribute to reducing burnout among palliative care health professionals (Hui et al., 2018). Moreover, some interventions merge web/online/telephone-based techniques. Future interventions should benefit from technologies in order to be less intrusive (Shields et al., 2012), as they occur during periods of great stress and adjustment for the family system. Finally, we verified that the studies are typically *studies of result*. Yet, we intend to use this review as the cornerstone for the *study of the process* to reach those results, in order to grasp the dynamics of change, which adds a level of relevance to our work.

Conclusions

Much remains to be done concerning intervention with this scope, and significant data is still missing in terms of the cultural context, national financial standing, professionals available, and population needs. Findings of this work demonstrate an effective need to care for the entire family (Del Gaudio et al., 2012), which has become increasingly recognized over the years by the generality of the intervention approaches. It represents an opportunity to adopt an integrated and multisystemic approach not only in the way we look at the existent intervention programs, but also in terms of a hypothetical intervention we might develop.

The need for these effective programs has taken on particular relevance due to the growing prevalence of cancer and families struggling with challenges associated with this condition (Rolland and Walsh, 2005), the growth of the aging population, and the emphasis on quality of life (WHO, 2017). Increasingly important, therefore, is the need to nurture those who are charged with taking care of their sick loved ones. Reaching burnout can trigger family crises (Rolland, 2018), which is why it is of utmost importance to prevent them from succumbing to exhaustion.

To conclude, “There can never be enough support for a caregiver” (Kutner et al., 2009, p. 1103). Accordingly, based on the premise “dying and healing are not incompatible” (Walsh, 2016b, p. 231), we would hope that this work can help to inspire more research focused on supporting family caregivers, in which either problematic areas or the strengths and resources of families are considered, given how the tendency is to focus on what is dysfunctional (Walsh and McGoldrick, 2013).

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