



Family caregiver ambassador support for caregivers of patients with newly diagnosed hematological cancer: a feasibility study

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Abstract

Purpose This study investigated the feasibility of a one-on-one peer support intervention in family caregivers of newly diagnosed patients with a hematological cancer during initial treatment.

Methods The study was a one-arm feasibility study including family caregivers of newly diagnosed patients with hematological cancer ($n = 26$) and caregiver ambassadors who were family caregivers of previously treated patients as peer supporters ($n = 17$). The one-on-one peer support intervention consisted of three components: a caregiver ambassador preparatory course; 12 weeks of one-on-one peer support, and caregiver ambassador network meetings.

Results Family caregivers reported high satisfaction with the delivery and flexibility of one-on-one peer support and improved in most psychosocial outcomes over time. Telephone and text messages were the most used form of contact between the peers. Caregiver ambassadors reported high satisfaction with the preparatory course and used the available support from the network meetings. No adverse events were reported.

Conclusion One-on-one peer support provided by a caregiver ambassador is feasible and safe in family caregivers of newly diagnosed hematological cancer patients during their initial treatment. Utilizing volunteer caregiver ambassadors has the potential to be a new support model in family caregivers of hematological cancer patients across diagnostic groups within a clinical setting.

Clinical trial registration number NCT04039100, July 29, 2019.

Keywords Peer support · Family caregivers · Malignant hematological disease · Psychosocial · Supportive Care · Feasibility

Introduction

Being diagnosed with a life-threatening hematological malignant disease can be a traumatic experience for patients and their family caregivers [1, 2]. Hematological cancers are most often treated with long-term intensive and toxic chemotherapeutics with a high risk of complications, severe side effects and profound patient symptom burden [3]. Today, treatment is often administered in out-patient clinics, requiring family members to play a crucial role in providing care, symptom management, and support between hospital visits [4, 5]. This can be challenging for adult family caregivers, who must also manage their own stress and worries. Uncertainty about the future and coping with one's own emotions is challenging, eliciting the highest need for support in family caregivers prior to allogeneic hematopoietic stem cell transplantation (Allo-HSCT) [6]. Previous studies showed increased symptoms of depression and anxiety in family

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caregivers of hematological cancer patients [7, 8], with a pronounced need for support at the time of diagnosis and continuously during the patients' treatment [9, 10].

Psychosocial support like peer-to-peer support differs from the support the family caregiver's own social network and healthcare professionals provide [11, 12]. A definition of peer support within a health care context is "the provision of emotional, appraisal, and informational assistance by a created social network member who possesses experiential knowledge of a specific behavior or stressor and similar characteristics as the target population" [13]. Peer support provides health benefits such as enhanced psychological well-being and improved coping, just as exchanging first-hand experiences can facilitate hope and adjustment [12, 14–17]. Peer support also benefits the provider, as helping others can increase self-development and meaningfulness [12, 15].

Overall, psychosocial cancer caregiver interventions show an effect on reducing the burden related to care and role changes [18], but studies show that variations exist in timing, duration, outcome measurements, and type of delivery of support [16, 19]. The findings from systematic reviews indicate that most interventions targeting caregivers are delivered by nurses, as face-to-face skills-training interventions [19, 20]. Few studies have investigated family caregiver peer support during the initial cancer treatment phase [20–22], and no studies examine one-on-one peer support in family caregivers of newly diagnosed patients with hematologic malignancies or, to our knowledge, report on health benefits, acceptance, and satisfaction in caregiver peer supporters.

This study aims to investigate the feasibility of a one-on-one peer support intervention in family caregivers of newly diagnosed patients with a malignant hematological disease during treatment.

Method

Study design

Conducted at the Department of Haematology, Copenhagen University Hospital – Rigshospitalet, this was a one-arm feasibility study comprising a 12-week, one-on-one peer support intervention for family caregivers of newly diagnosed patients with hematological cancer. The peer supporters, called "caregiver ambassadors", were family caregivers of hematologic cancer survivors.

Participants

Two groups of participants were recruited: family caregivers and caregiver ambassadors. The inclusion criteria for both

groups were adults (≥ 18 years) and able to read and speak Danish. Eligible family caregivers were selected by a patient newly diagnosed with a hematological cancer: acute leukemia, malignant lymphoma, or multiple myeloma receiving initial chemotherapeutic treatment, or hematologic patients receiving Allo-HSCT. Eligible caregiver ambassadors were family caregivers of a hematologic cancer survivor in complete remission. Exclusion criteria for both groups were severe cognitive or psychiatric disorders and patient receiving terminal care or admitted to an intensive care unit. For caregiver ambassadors alone, the exclusion criteria were patient relapse and referral to active chemotherapy.

Recruitment

Caregiver ambassadors were recruited from December 2019 to February 2021, identified using patient medical records and recruited at the hospital or by a letter sent to the patient to forward to the caregiver ambassador containing study information and an invitation. Posters and flyers placed at out-patient clinics and advertising via hematologic patient associations were also used. IHN, the primary investigator (PI), gave eligible caregiver ambassadors oral and written information.

Family caregivers were recruited over 9 months by asking patients to select a family caregiver. If they agreed, the PI contacted the family caregivers either in-person at the hospital or by phone and provided oral and written information, or the patient gave their family caregiver written information at home.

All participants provided written informed consent.

Intervention

The peer-to-peer support intervention comprises three components: a caregiver ambassador preparatory course, 12 weeks of one-on-one peer support, and caregiver ambassador network meetings.

Preparatory course

Caregiver ambassadors attended an online preparatory training course carried out by the PI and the project psychologist prior to engaging in peer support. The preparatory course contained two parts: (1) 45-min video information session and (2) 2-h online group session. Furthermore, the caregiver ambassadors received a hardcopy of course material. The video content, inspired by previous peer support training courses [11, 23], covered the peer-to-peer role, psychological issues, and communication skills. The online group session discussed caregiver ambassador experiences and reflections about their previous supportive needs, motivation, and concerns regarding the caregiver ambassador role.

One-on-one peer support

The PI individually matched family caregivers with a caregiver ambassador using these criteria: (1) similar patient diagnosis and/or treatment, (2) family relation to the patient (spouse/partner, parent, adult child, or sibling), (3) life stage (e.g., retired or children at home), (4) age, and (5) gender.

Caregiver ambassadors were instructed to make initial contact with their family caregiver to introduce themselves and establish an incipient relationship. During the 12-week intervention, the frequency of contact was set at approximately weekly based on family caregivers' preferences and needs. Duration and delivery of contact was based on family caregiver preferences, e.g., telephone, text, e-mail, or face-to-face. Conversation topics were based on family caregivers' individual needs, although caregiver ambassadors could introduce topics, they considered relevant. Caregiver ambassadors supported only one family caregiver at a time and were asked to report weekly on contact frequency, type, duration, and topics discussed.

Network meetings

Optional caregiver ambassador network meetings, held at regular 6–8-week intervals to provide support and supervision, were conducted online facilitated by the PI and the psychologist. Furthermore, caregiver ambassadors could exchange experiences and discuss issues related to their ambassador role [24]. Encouraged to contact the PI with any concerns, caregiver ambassadors could also request individual supervision from the psychologist.

Data collection and outcomes

Primary outcome

Feasibility was assessed by acceptability (recruitment, attrition, and retention rates, and satisfaction), practicability (intervention attendance and time including frequency, contact forms and communication, and preparatory course and network meeting attendance), safety, and support (adverse events, utilization of individual support, and contact to PI) [25, 26]. Participant demographic data were collected electronically at baseline via REDCap [27]. Feasibility data were collected by continuous monitoring stored in an Excel database during the study. Electronical surveys via REDCap were used to assess caregiver ambassadors' satisfaction with the preparatory course, and family caregivers' satisfaction with peer support on a five-point Likert scale was obtained via telephone evaluations 1–2 weeks following the intervention.

Secondary outcomes

Secondary outcomes in both family caregivers and caregiver ambassadors were collected electronically at three time points (T) via REDCap: T1, baseline; T2, 12 weeks (end of intervention); and T3, 24-week follow-up. The Hospital Anxiety and Depression Scale was used to assess psychological well-being [28]; Short Form Health-Related Quality of Life Questionnaire 36 (SF-36) [29] for health status and quality of life (QOL); Caregiver Roles and Responsibilities Scale (CRRS) [30] for caregiver burden and QOL; Pittsburgh Sleep Quality Index (PSQI) [31] for sleep quality; and General Self-Efficacy Scale [32] for perceived coping. All questionnaires have demonstrated good performances and are valid and reliable instruments, commonly used in research [28–32].

Statistical analysis

Since a sample size of 30 is recommended for feasibility trials, our sample sizes were 30 family caregivers and 20 caregiver ambassadors, the former because caregiver ambassadors could support more than one family caregiver during the intervention [33]. Categorical variables for demographic characteristics and primary feasibility outcomes were summarized using numbers and percentages. Subscale scores were computed using official scoring manuals and reported as mean and standard deviation. Paired *t*-tests were used to analyze changes from T1 to T2 or T3. All unadjusted *p*-values < 0.05 are mentioned, but we emphasize the study's exploratory nature and the risk of false positive findings. REDCap was used to collect survey data [27]. Statistical analyses were carried out using R.

Ethical considerations

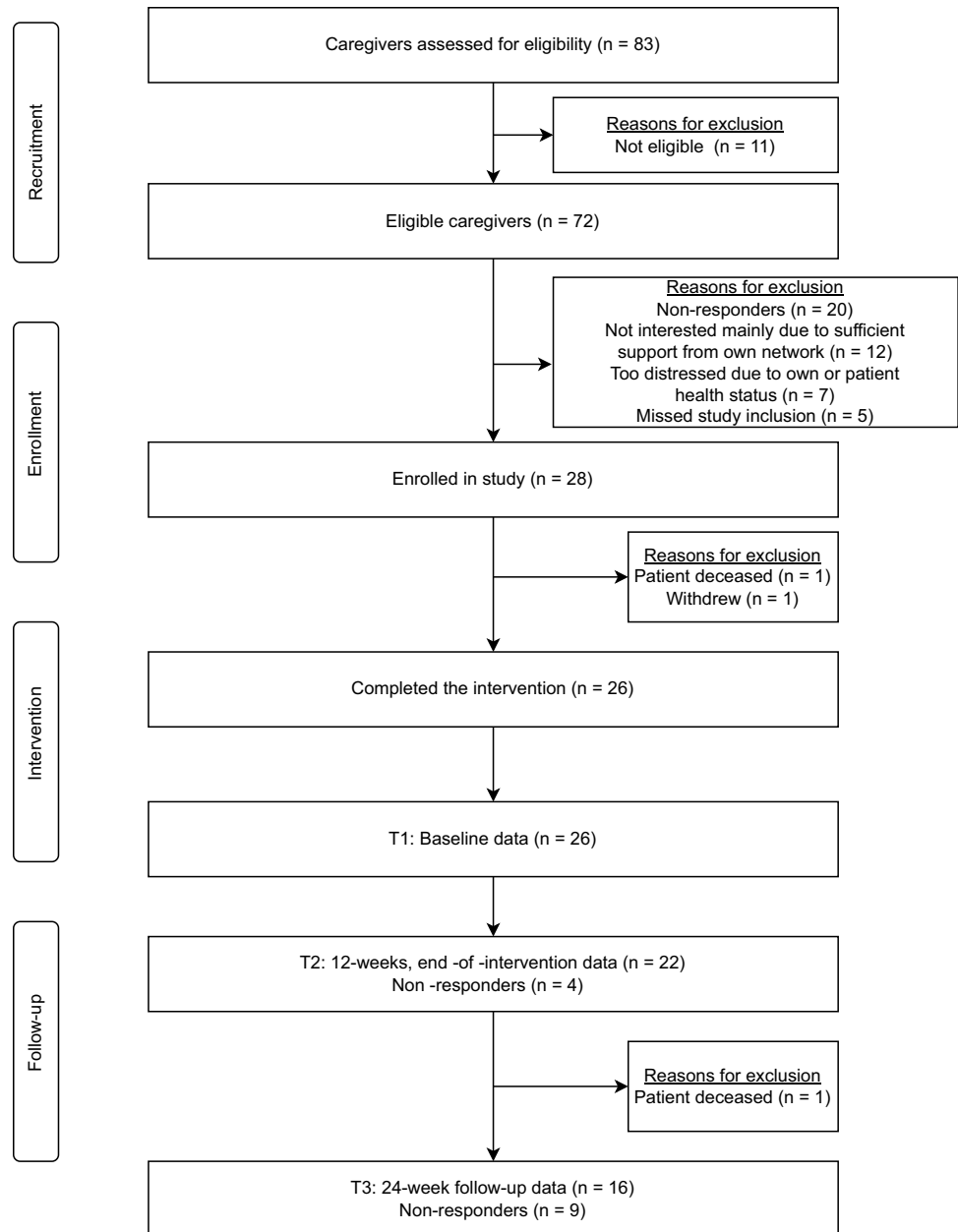
The Danish Data Protection Agency (file no.: P-2019–303) approved the study, which was carried out in accordance with the Helsinki Declaration and registered at ClinicalTrials.com (NCT04039100).

Results

Participant characteristics

A total of 26 family caregivers and 17 caregiver ambassadors were included and participated in the intervention (Figs. 1 and 2). Acute leukemia was the most frequent patient diagnosis in both groups. Nearly half of the patients in the family caregiver group were undergoing Allo-HSCT (46.2%), and two-thirds in the caregiver ambassador group had undergone HSCT (70.6%). Most participants were females in both

Fig. 1 Family caregiver flow-chart on recruitment, enrollment, and intervention



groups, which had a similar mean age of 53.2 in the caregiver group and 54.9 in the caregiver ambassador group. Most participants in both groups were either the patient's spouse or partner (family caregiver: 61.5%; caregiver ambassadors: 70.6%) (Table 1).

Acceptability

Of 83 potentially eligible patients and family caregivers, 19 declined participation due to lack of interest, sufficient support from own network, not wanting to involve others in their personal life, or feeling too distressed. Twenty family caregivers did not respond to the invitation delivered

by the patient, and 11 were excluded based on inclusion/exclusion criteria. Of the 28 family caregivers enrolled, 26 completed the 12-week peer support intervention (Fig. 1).

Of 77 potentially eligible caregiver ambassadors, 53 declined participation, mainly by not responding to the invitation or due to lack of interest. Of the 24 caregiver ambassadors enrolled, 17 completed the one-on-one peer support intervention, nine of whom were matched, not simultaneously, with more than one family caregiver. Two caregiver ambassadors were excluded prior to the preparatory course; three were excluded prior to being matched and two due to lack of a suitable match (e.g., patient

Fig. 2 Caregiver ambassador flowchart on recruitment, enrollment, and intervention

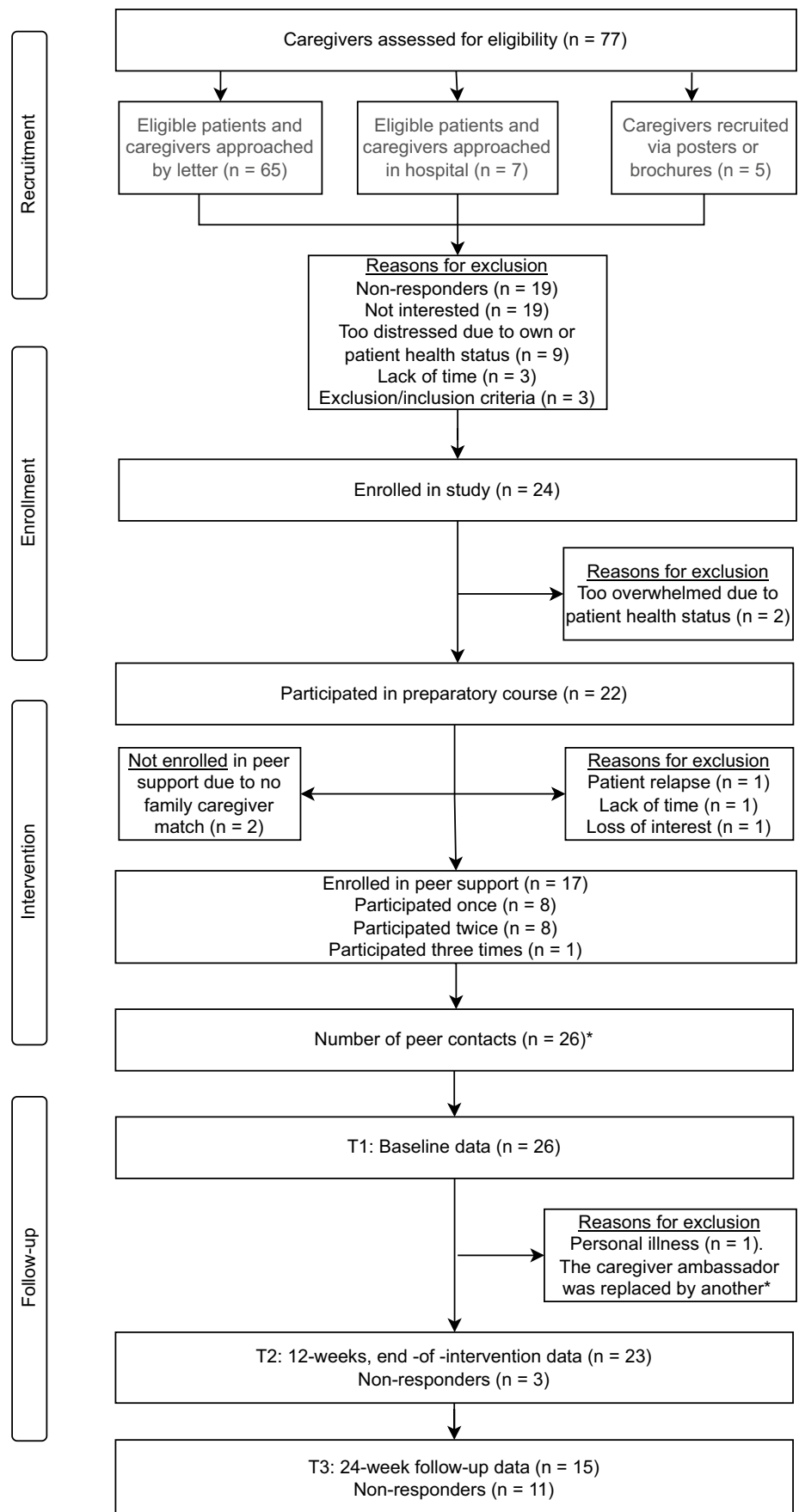


Table 1 Demographic and clinical characteristics of study participants

Characteristics	Family caregivers (<i>n</i> =26)	Caregiver ambassadors (<i>n</i> =17)
Gender, female <i>n</i> (%)	20 (76.9)	11 (64.7)
Age, mean (range)	53.2 (26–80)	54.9 (24–74)
Education, <i>n</i> (%)		
High school diploma	1 (3.8)	0 (0.0)
2-year college	9 (34.6)	3 (17.7)
4-year college	11 (42.3)	3 (17.6)
Master's degree or higher	5 (19.2)	11 (64.7)
Occupation, <i>n</i> (%)		
Employed	16 (61.5)	13 (76.5)
Unemployed	1 (3.8)	0 (0.0)
Retired	4 (15.4)	3 (17.6)
Student	1 (3.8)	1 (5.9)
Leave of absence	4 (15.4)	0 (0.0)
Relation to patient, <i>n</i> (%)		
Spouse or partner	16 (61.5)	12 (70.6)
Parent	7 (26.9)	2 (11.8)
Child	2 (7.7)	2 (11.8)
Sibling	1 (3.8)	1 (5.9)
Children at home, <i>n</i> (%)	7 (26.9)	6 (35.3)
Marital status, <i>n</i> (%)		
Married or cohabitating	25 (96.2)	16 (94.1)
Single or living alone	1 (3.8)	1 (5.9)
Diagnosis, <i>n</i> (%)		
Acute leukemia	13(50)	6 (35.3)
Lymphoma	7 (26.9)	4 (23.5)
Myeloma	2 (7.7)	3 (17.6)
Other	4 (15.4)	4 (23.5)
Allo—HSCT, <i>n</i> (%)	12 (46.2)	12 (70.6)
Years post diagnosis, <i>n</i> (%)		
1—2 years		3 (17.6)
2—3 years		3 (17.6)
3—4 years		3 (17.6)
> 5 years		8 (47.0)

Allo-HSCT Allogeneic hematopoietic stem cell transplantation

diagnosis). One caregiver ambassador was excluded during the intervention and replaced by another (Fig. 2).

Family caregivers and caregiver ambassadors were generally satisfied with the intervention. Most family caregivers (75%) would highly recommend the intervention to others, and 25% would most likely recommend it to others, but with some reservations (Table 2).

Most family caregivers (*n*=22) reported a high level of satisfaction (Likert: 4–5), and *n*=2 reported a lower level of satisfaction (Likert: 3) (Table 2). The reasons for the lower level of satisfaction among family caregivers were

insufficient contact, patient trajectories differed greatly (e.g., complications or disease progression), or poor timing of the intervention.

During the study, four preparatory courses were held. Caregiver ambassadors were encouraged to submit course evaluations electronically and anonymously; 73% responded. Overall, satisfaction was high, as was the degree of role preparation (Table 2). Reasons for dissatisfaction were technical challenges (e.g., poor internet, connection fails (*n*=6), and lack of in-person contact (*n*=6).

Practicability

Twenty-one caregiver ambassadors divided into groups of 3–7, participated in the preparatory course (Table 2). One caregiver ambassador did the course by telephone due to technical issues. Family caregivers and caregiver ambassadors had 389 contacts, 15 on average between peers. All peers used text message, which was the most frequent type of contact (*n*=275, ranging from 2 to 49), then telephone calls (*n*=90, ranging from 0 to 11). Only five dyads had face-to-face contact during the intervention, with a total of 13 contacts (ranging from 1 to 8 contacts per dyad). Caregiver ambassadors spent an average of 18 min weekly providing peer support (Table 2).

All topics of discussion between the family caregiver and the caregiver ambassador were grouped into eight categories by the PI. More than one topic was often discussed during a single contact. The most frequent categories were related to disease and treatment (*n*=61) and the family caregivers' emotional reactions (*n*=46) (Table 2).

All but one of the six caregiver ambassador network meetings were held online with both the PI and psychologist present. Fourteen caregiver ambassadors attended one or more meetings. Reasons for not attending were, e.g., other responsibilities, work, patient care, forgetfulness, or supervision not requested.

Safety and support

No adverse events were reported. One caregiver ambassador spoke individually with the psychologist, but not about anything directly related to the role as peer supporter. Eleven caregiver ambassadors contacted the PI (Table 2), primarily about challenges in reaching their family caregiver or feeling unsure about whether their family caregiver found the support valuable.

Secondary outcomes

Family caregiver results indicated improvement in most sum scores over time (Table 3). The SF-36 mean score on the mental health subscale improved from T1 to T2 (change:

Table 2 Feasibility outcomes

Acceptability	Total <i>n</i>	<i>n</i> (%)
Caregiver ambassador training course attendance	22	21 (95.8)
Caregiver ambassador overall satisfaction with preparatory course		
Very high	19	3 (15.7)
High	19	16 (84.2)
Caregiver ambassador assessment of relevance of training course part 1		
Very high	18	10 (55.5)
High	18	8 (44.4)
Caregiver ambassador assessment of relevance of training course part 2		
Very high	19	12 (63.1)
High	19	7 (36.8)
Caregiver ambassador satisfaction with role preparation		
Very high	19	7 (36.8)
High	19	12 (63.1)
Family caregiver satisfaction with the provision of support		
Highly recommend to others	24	18 (75)
Most likely recommend to others, but with reservations	24	6 (25)
Likert scale 4—5	24	22 (91.7)
Likert scale 3	24	2 (8.3)
Practicability		
Caregiver ambassador network meeting, attendance	17	14 (82.3)
Contact frequency ^a	26	389 (15)*
Delivery form		
Telephone	26	90 (23.1)
Text message	26	275 (70.7)
E-mail	26	11 (2.8)
Face-to-face	26	13 (3.3)
Duration of support	26	18 (3–54)**
Themes addressed during peer support ^b		
Reactions from family/network	26	30 (7.7)
Role challenges	26	33 (8.5)
Diseases and treatment (e.g., side effects)	26	61 (15.7)
Emotional reactions	26	46 (11.8)
Everyday life	26	38 (9.8)
Coping with uncertainty	26	36 (9.2)
Communication with patient and professionals	26	27 (6.9)
Practical advice (e.g., diet and social care support)	26	27 (6.9)
Safety and support		
Caregiver ambassadors meeting individually with psychologist	17	1 (5.8)
Caregiver ambassador contacts with PI during intervention		
< 2	17	6 (35.2)
≥ 3	17	4 (23.5)

FC family caregiver; *PI* primary investigator

^aThe number of contacts was measured from self-reported data

A contact was defined as a communication that resulted in a response

*Total number of contacts (average per dyad)

**Minutes per week, average (minimum–maximum)

^bThe number of themes was measured from self-reported data

Table 3 Patient-reported outcomes in family caregivers

Variables	Baseline (n=26)		12-week end of intervention (n=22)		24-week follow-up (n=16)		Baseline to 12-week end of intervention (n=26)		Baseline to 24-week follow-up (n=26)	
	n	mean (SD)	n	mean (SD)	n	mean (SD)	n	Change	n	Change
HADS										
Anxiety (0–21)	23	8.6 (4.3)	21	7.7 (4.7)	14	5.6 (3.2)	20	-0.35	14	-1.42
Depression (0–21)	23	6.3 (4.8)	21	5.5 (4.1)	14	3.6 (4.2)	20	-0.35	14	-0.72
CRRS										
Support and impact (0–24)	21	16.7 (3.6)	21	15 (4.5)	14	14.8 (4.5)	18	-1.27	13	-2.93
Lifestyle (0–44)	21	25.3 (7.3)	21	26.1 (6.5)	14	29.3 (8.1)	18	0.96	13	2.64
Emotional well-being (0–36)	21	20.6 (7.3)	21	23.7 (6.2)	14	27 (8)	18	3.5	13	3.61
Self-care (0–24)	21	19.3 (3)	20	19 (3.5)	14	20.7 (2.8)	17	-0.34	13	0.69
Financial well-being (0–24)	21	18.9 (4.8)	21	19.8 (4.3)	14	17.6 (6.4)	18	0.42	13	-1.33
Jobs and career (0–28)	11	20.3 (5.6)	10	20.9 (4.1)	7	23.7 (3.5)	8	-0.87	6	0.5
Total (0–152)	21	100.8 (20.2)	20	102.9 (20.5)	14	109.3 (24.8)	17	2.95	13	2.67
GSE										
Average score (1–4)	21	2.1 (0.6)	21	2 (0.8)	14	2.3 (0.5)	18	0.027	13	0.001
PSQI										
Duration (0–3)	22	1 (0.9)	20	0.6 (0.7)	15	0.9 (1.1)	19	-0.26	14	0
Disturbance (0–3)	23	1.5 (0.5)	20	1.2 (0.4)	14	1.2 (0.4)	19	-0.21	14	-0.21
Latency (0–3)	23	1.4 (0.9)	20	1.2 (1)	14	1.3 (1.1)	19	-0.1	14	-0.07
Day dysfunction (0–3)	23	1.4 (0.8)	21	1.1 (0.6)	15	1.4 (0.9)	20	-0.2	15	0.26
Efficiency (0–3)	22	1 (1.2)	19	0.9 (1.1)	15	0.6 (1)	19	-0.05	14	-0.21
Sleep quality (0–3)	23	1.4 (0.8)	21	1 (0.6)	15	1.1 (0.8)	20	-0.35	15	-0.13
Need Meds (0–3)	23	0.2 (0.5)	21	0.3 (0.8)	15	0.5 (0.9)	20	0.2	15	0.26
Total (0–21)	22	7.9 (4.1)	17	6.9 (3.3)	14	7.1 (4.5)	17	-0.64	13	0.07
SF-36										
Physical functioning (0–100)	24	84.8 (19.5)	22	85.4 (17.6)	15	87.6 (14.2)	21	0.21	15	1.25
Role emotional (0–100)	25	39.3 (24)	22	35.6 (26.9)	15	20.6 (26.9)	22	-3.4	15	-12.7
Mental health (0–100)	25	53 (21.1)	22	62.7 (16.2)	15	71.7 (21.7)	22	9.77	15	14
Role physical (0–100)	24	22.7 (26.8)	22	29.1 (26.8)	15	18.8 (25.3)	21	9.62	15	-1.66
Bodily pain (0–100)	25	83 (25.1)	22	80.1 (24.2)	15	83.8 (20.7)	22	-3.63	15	-3.16
General health (0–100)	25	53.4 (16.3)	22	54.4 (13.1)	15	56.6 (11)	22	0.51	15	1.58
Social function (0–100)	25	69 (27.7)	22	73.3 (21.2)	16	85.9 (27.3)	22	3.4	16	11.77
Vitality (0–100)	25	40.2 (22.5)	22	48.6 (21)	15	60 (24.4)	22	5.96	15	11.25

SD Standard deviation, CI confidence interval, HADS, hospital anxiety and depression scale (14-item measure with higher scores indicating higher symptomatology (cutoff scores > 8 for each item, demonstrating good performances and is a valid and reliable instrument; CRRS, caregiver roles and responsibility scale (a 41-item measure with six subscales assessing the impact of caregiving and caregiver quality of life, with higher scores indicating better quality of life. Preliminary evaluation indicates that it is a valid and reliable instrument; GSE, general self-efficacy scale (10-item measure with higher scores indicating greater sense of self-efficacy, demonstrated to be a valid and reliable instrument; PSQI, Pittsburgh sleep quality index (19-item measure with seven subscales with combined total score, a higher score indicating poor sleep quality (cutoff > 5 for total score. PSQI is a valid and reliable measure; SF-36, short form health-related quality of life questionnaire (36-item measure with eight subscales with higher scores indicating better health and functioning. SF-36 a commonly used and reliable instrument

9.77, $p=0.01$) and between T1 and T3 (change: 14.00, $p=0.02$). Also, the mean SF-36 vitality score improved from T1 to T3 (change: 11.25, ($p=0.003$)). The mean score for HADS anxiety was above the cut-off score (>8) at T1 but improved over time scoring below the cut-off at T3 (change: -1.42 , $p=0.05$). The PSQI mean score on the sleep quality subscale improved from T1 to T2 (change: -0.35 , $p=0.03$). The CRRS mean score on the emotional well-being subscale improved from T1 to T2 (change: 3.50, $p=0.02$). The CRRS mean score on the support and impact subscale, in contrast, declined between T1 and T3 (change: -2.93 , $p=0.03$).

Caregiver ambassador sum scores were maintained overall over time (Table 4). The CRRS mean score on the emotional well-being subscale improved from T1 to T3 (change: 2.07, $p=0.04$). Although the SF-36 mean score on the vitality subscale declined from T1 to T2 (change: -4.82 , $p=0.04$), mean scores were above the cut-off (>50), indicating overall good energy.

Discussion

To our knowledge, this is the first study to investigate a one-on-one peer ambassador support intervention in family caregivers of newly diagnosed hematological cancer patients. Our findings show that it is feasible and safe, and caregiver peer support was acceptable with high satisfaction in both groups, which is in line with studies on peer support in cancer populations [16].

Family caregivers were primarily matched with a caregiver ambassador with a similar diagnosis or life stage, and aligned as closely as possible to their preferences, which may explain the high satisfaction and low dropout rate. Furthermore, studies show that similar age and gender are perceived less important for successful matching [34], while similar experiences and common interests help build reciprocal, trusting relationships [15, 35]. Social comparison processes can explain the benefits of a successful match, suggesting that comparisons aid in interpreting illness encounters, health threats, and disconcerting symptoms [36, 37]. Previous peer support studies in cancer patients highlight that social comparison positively impacts patients' understanding of their current situation and expectations, as well as reassures newly diagnosed patients [14, 15]. However, if experiences are too dissimilar, there is the risk of alienation and poorer perceived support [37]. More research into the key components of matching in peer support is warranted.

In the current study, the provision of caregiver support was individualized based on the needs and preferences of family caregivers. Hence, the delivery format and topics discussed were not predefined, in contrast to other peer studies [16, 21]. Our results reveal that the topics targeted different

support needs in family caregivers, with disease, treatment, and emotional reactions occurring most frequently. The most helpful support in a peer support intervention for caregivers of leukemia patients involves giving information about disease and treatment [10]. Kisch et al. similarly describe different support needs related to the family caregiver's ability to provide care for the patient, and support needs directly related to the family caregiver's own well-being [6]. A recent study found that family caregivers' individual support needs adjusted according to changes during the disease and treatment trajectory, and caregiver responsibilities and time constraints possibly challenging the ability to attend regular support programs [9]. Thus, the one-on-one peer support format is highly suitable to catering to various support needs, also regarding type and frequency of support. Furthermore, a study on patients with colorectal cancer showed that one-on-one peer support is more discrete and less intimidating than a group format [38]. The most common type of communication in the current study was text messages and telephone calls. One possible explanation for fewer face-to-face meetings was the precautions taken to minimize the transfer of infectious diseases to patients, including COVID-19. Likewise, telephone support is preferable in overcoming barriers, including caregiver commitments and transportation related to participation [38]. Peer studies comparing telephone-based and face-to-face support find neither one has clear advantages [16] and that cancer patients prefer both formats [34].

Consistent with other family caregiver intervention studies, our results show that most psychosocial outcomes improved over time in family caregivers [20]. Although sum scores improved over time, they were not comparable to normative data, indicating higher anxiety and poorer well-being than the general population [39, 40]. This highlights the importance of undertaking interventions to improve psychosocial well-being in family caregivers of hematological cancer patients. In contrast, caregiver ambassadors maintained their psychosocial levels, which were equal to or better in many outcomes than normative population data [39]. This reveals an important perspective to be addressed: the caregiver ambassadors in our study are socioeconomically advantaged and a selected group. They may have more resources, higher resilience and cope better than most, an essential precondition to be suited for the role as peer supporter [23]. However, secondary outcome data was missing in both groups, especially at T3, which may have led to biased sum-score estimates.

Several studies describe how helping others benefits peer supporters, positively influencing their long-term psychological recovery by providing new perspectives on their own experiences [12, 15, 41]. Nevertheless, the risk of emotional fatigue or re-traumatization underlines the importance of providing supervision, role preparation, and communication

Table 4 Patient-reported outcomes in caregiver ambassadors

Variables	Baseline (n = 27)			12-week end of intervention (n = 23)/24-week follow-up (n = 15)			Baseline to 12-week end of intervention (n = 26)			Baseline to 24-week follow-up (n = 26)				
	n	mean (SD)	n	mean (SD)	n	mean (SD)	n	Change	95% CI	P-value	n	Change	95% CI	P-value
HADS														
Anxiety (0–21)	24	2.2 (2.6)	21	2.2 (2.2)	13	2.2 (2.4)	19	-0.25	(-1.51–1.00)	0.67	11	0.72	(-1.10–2.55)	0.39
Depression (0–21)	24	1.3 (2.2)	21	1.4 (2.2)	13	0.6 (1.7)	19	0.02	(-0.92–0.96)	0.96	11	-0.18	(-1.90–1.53)	0.81
CRRS														
Support and impact (0–24)	21	15.1 (5.3)	18	15.7 (5.4)	11	15.5 (4.1)	15	0.46	(-1.47–2.40)	0.61	10	0.1	(0.07–4.07)	0.92
Lifestyle (0–44)	21	37.7 (4.9)	18	36.1 (6.8)	11	40.3 (2.4)	15	-0.79	(-4.03–2.44)	0.60	10	3.45	(-0.58–7.48)	0.08
Emotional well-being (0–36)	21	32.7 (4.8)	18	33 (3.9)	11	34.1 (3.6)	15	0.25	(-1.68–2.18)	0.78	10	2.07	(0.07–4.07)	0.04*
Self-care (0–24)	21	20.0 (3.5)	18	19.6 (4.5)	11	21.3 (3.2)	15	-0.2	(-1.63–1.23)	0.76	10	-0.4	(-1.95–1.15)	0.57
Financial well-being (0–24)	21	19.9 (4.8)	18	20.2 (4.5)	11	20.3 (4.8)	15	0.93	(-0.22–2.08)	0.10	10	0.78	(-1.77–3.33)	0.5
Jobs and career (0–28)	15	23.2 (3.3)	15	22.2 (4.5)	8	22.2 (2.9)	10	0.8	(-0.25–1.85)	0.12	5	-0.4	(-2.47–1.67)	0.62
Total	21	125.3 (17.5)	18	124.5 (18.8)	11	131.5 (10.9)	15	0.65	(-4.87–6.18)	0.80	10	6.0	(-1.05–13.0)	0.08
GSE														
Average score (1–4)	24	2.4 (0.5)	20	2.4 (0.4)	12	2.6 (0.4)	18	-0.04	(-0.24–0.15)	0.64	10	-0.003	(-0.32–0.32)	0.98
PSQI														
Duration (0–3)	25	0.3 (0.5)	21	0.6 (0.5)	13	0.5 (0.5)	19	0.26	(-0.007–0.53)	0.06	12	0.25	(-0.03–0.53)	0.08
Disturbance (0–3)	24	1 (0.6)	22	1 (0.4)	13	0.9 (0.3)	19	0.05	(-0.14–0.24)	0.57	11	0.09	(-0.27–0.45)	0.58
Latency (0–3)	24	0.7 (0.6)	21	0.8 (0.8)	12	0.6 (0.5)	18	0	(-0.24–0.24)	1	10	0	(-0.33–0.33)	1
Day dysfunction (0–3)	25	0.3 (0.5)	22	0.5 (0.6)	13	0.3 (0.6)	20	0.15	(-0.07–0.37)	0.18	12	0.08	(-0.10–0.26)	0.33
Efficiency (0–3)	25	0.3 (0.5)	20	0.2 (0.6)	13	0.2 (0.4)	18	-0.05	(-0.32–0.21)	0.66	12	-0.16	(-0.53–0.20)	0.33
Sleep quality (0–3)	25	0.6 (0.5)	22	0.7 (0.6)	13	0.7 (0.6)	20	0.1	(-0.19–0.39)	0.49	12	0.16	(-0.28–0.62)	0.43
Need Meets (0–3)	25	0 (0.2)	22	0 (0)	13	0 (0)	20	0	(-0.44–0.97)	0.43	12	0	(-1.15–1.82)	0.61
Total (0–21)	23	3.2 (1.6)	19	3.8 (2.2)	12	3.2 (1.7)	15	0.26	(-0.44–0.97)	0.43	9	0.33	(-1.15–1.82)	0.61
SF-36														
Physical functioning (0–100)	26	97.5 (3.8)	23	94.8 (10.7)	15	97.7 (3.2)	22	-3.2	(-7.97–1.56)	0.17	15	0.66	(-0.76–2.09)	0.33
Role, emotional (0–100)	26	4.8 (11.3)	23	6.9 (15)	15	1.7 (4.7)	22	1.51	(-6.98–10.0)	0.71	15	-1.66	(-5.24–1.90)	0.33
Mental health (0–100)	26	88.3 (9.2)	23	84.8 (10.9)	15	88 (10.7)	22	-2.95	(-6.68–0.77)	0.11	15	-0.33	(-4.95–4.28)	0.87
Role, physical (0–100)	26	4.2 (7.1)	23	4.9 (10.8)	15	1.2 (2.6)	22	0.47	(-5.19–6.14)	0.86	15	-1.8	(-4.55–0.94)	0.18
Bodily pain (0–100)	26	93.3 (8.9)	23	91.8 (12.1)	15	94.5 (11.2)	22	-1.02	(-6.19–4.14)	0.68	15	0.66	(-6.2–7.53)	0.83
General health (0–100)	26	67.2 (14.1)	23	65.4 (12.3)	15	66 (11.2)	22	-1.3	(-6.39–3.77)	0.59	15	-2.58	(-7.92–2.75)	0.31
Social function (0–100)	26	98.6 (5.4)	23	95.1 (14.5)	15	99.2 (3.2)	22	-3.4	(-10.7–3.88)	0.34	15	0.83	(-0.95–2.62)	0.33
Vitality (0–100)	26	82.2 (11)	23	76.6 (12.7)	15	79.2 (12.6)	22	-4.82	(-9.34–0.30)	0.04*	15	-2.91	(-8.44–2.61)	0.27

SD Standard deviation, CI confidence interval, HADS, hospital anxiety and depression scale (14-item measure with higher scores indicating higher symptomatology (cutoff scores > 8 for each item, demonstrating good performance and is a valid and reliable instrument; CRRS, caregiver roles and responsibility scale (a 41-item measure with six subscales assessing the impact of caregiving and caregiver quality of life, with higher scores indicating better quality of life. Preliminary evaluation indicates that it is a valid and reliable instrument; GSE, general self-efficacy scale (10-item measure with higher scores indicating greater sense of self-efficacy, demonstrated to be a valid and reliable instrument; PSQI, Pittsburgh sleep quality index (19-item measure with seven subscales with combined total score, a higher score indicating poor sleep quality (cutoff > 5 for total score. PSQI is a valid and reliable measure; SF-36, short form health-related quality of life questionnaire (36-item measure with eight subscales with higher scores indicating better health and functioning. SF-36 a commonly used and reliable instrument

training to increase emotional resilience and avoid negative adverse effects in peer supporters [35, 42]. Overall, caregiver ambassadors reported that the preparatory course and network meetings appropriately enhanced their role preparation and performance, which aligns with previous findings [15, 23]. A recurring theme at ambassador network meetings was feeling concerned about whether the family caregiver thought the support was sufficient. Other studies also identify these concerns, which stress the peer supporters' need to feel that their efforts are appreciated and helpful [12, 15, 35]. The strong preparation and support the caregiver ambassadors received in the present study may explain their high satisfaction and low attrition rate.

Methodological considerations

Strengths of this study are the longitudinal design and close monitoring of feasibility parameters and psychosocial well-being in both participant groups, but potential limitations need to be acknowledged. First, due to the uncontrolled design, it is uncertain if changes in the secondary outcome measures were related to the intervention or other factors such as patient improvement. We encountered missing data from non-responders especially at the 24-week follow-up in both groups. Caution should therefore be drawn to the conclusions of the secondary outcomes. The family caregiver recruitment rate was 31%, which is low but comparable to other intervention studies of cancer patients and caregivers with 20–60% recruitment rates [43]. COVID-19 restricted contact may partially explain lower recruitment via patients. Sygna et al. maintain that on-site recruitment by the researcher or healthcare professional is the most effective approach [44]. Alternatively, most caregiver ambassadors were recruited using a recruitment letter, a successful strategy also used in a study of caregivers and seriously ill patients [45]. The intervention components were originally designed to be carried out in-person, especially the preparatory course and network meetings, but due to COVID-19 restrictions these were held online. Overall, the online format functioned well; however, challenges especially regarding participants' technical skills and competencies needs be considered.

Clinical implications

Our results demonstrate the relevance of caregiver peer support for family caregivers of newly diagnosed hematological cancer patients. Utilizing former family caregivers as volunteer peer supporters is a way to provide meaningful support that supplements support from health care professionals, family, or friends. Providing support and education to peer supporters is imperative as these volunteers are not professionals. Our results show that peer support should be

delivered individually with optional forms of contact. Flexibility in delivery and duration of peer support is important for satisfaction as it accommodates the responsibilities of family caregivers. Recruiting family caregivers of newly diagnosed patients requires care, as this group is psychologically overwhelmed, posing the risk that only the most socioeconomically advantaged and resourceful family caregivers accept peer support.

Conclusion

The findings demonstrate that one-on-one peer support is feasible and safe in family caregivers of newly diagnosed hematological cancer patients during initial treatment. Family caregivers improved psychosocial outcomes over time. The flexibility of peer support delivery accommodates individual support needs and preferences. Also, caregiver ambassadors should be trained and supported to ensure their safety and wellbeing. This study's findings demonstrate that caregiver ambassador support can potentially be incorporated as a new support model in family caregivers of hematological cancer patients across diagnostic groups in a clinical setting. Future research should investigate the motivation for volunteering as a peer supporter, especially among caregivers of patients with life-threatening disease, as this area is understudied. Furthermore, examining peer support in other vulnerable patient groups such as palliative or end-of-life care should be considered in future studies.

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Data availability Not applicable.

Code availability Not applicable.

Declarations

Ethics approval The study is approved by the Danish Data Protection Agency (file no. P-2019–303) and registered with the Regional Ethics Committee of the Capital Region of Denmark (file no. 19028619), carried out in accordance with the Helsinki Declaration.

Consent to participate All participants provided informed consent.

Consent for publication All participants provided informed consent regarding publishing their data in this article.

Conflict of interest The authors declare no competing interests.

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