

Caregiver sample, study design and measured outcomes

First author, date, reference	Study country	One site/ multisite	Sample	Study design	Outcome measure	Questionnaires
Shaw, 2016 [62]	Australia	Multicenter	N=128 gastrointestinal	RCT Two arms: 1) Family Connect telephone intervention (4 calls in 10 weeks after patient hospital discharge) 2) usual care ASSESSMENT: 3 and 6 months	<ul style="list-style-type: none"> - Quality of Life (QOL) - Caregiver Burden - Unmet supportive care needs - Distress 	<ul style="list-style-type: none"> - SF12 - Partner and Caregiver Supportive Care Needs Survey - Caregiver Reaction Assessment (disrupted schedule, financial problems, lack of family support, health impact and impact on self-esteem scales) - Distress Thermometer
Dionne-Odom, 2016 [57]	USA	Multicenter	N=122 lung, gastrointestinal, genitourinary, hematologic	RCT Two arms: 1) Early group: ENABLE III intervention within 60 days of diagnosis 2) Delayed group: 12 weeks later ASSESSMENT: By telephone At baseline, 6, 12, 18, and 24 weeks. After Week 24, data collection every 12 weeks until patient's death, or study completion	<ul style="list-style-type: none"> - Depression - Grief 	<ul style="list-style-type: none"> - CES-D - PG13
Mosher, 2016 [69]	USA	Multicenter	N=106 lung	RCT Two arms: 1) TSM group 2) Education/support group ASSESSMENT: 4 weekly 45-minute telephone sessions 2 and 6 weeks post-intervention	<ul style="list-style-type: none"> - Anxiety - Confidence in their ability to help the patient manage symptoms - Caregivers' self-efficacy for managing their own emotions - Constraints on cancer-related disclosure from the other dyad member - Caregiver burden 	<ul style="list-style-type: none"> - Generalized Anxiety Disorder seven-item scale (GAD-7) - 16-item standard self-efficacy scale - 8-item self-efficacy scale - five-item social constraints scale - Caregiver Reaction Assessment (impact on schedule, caregiver's esteem, lack of family support, impact on health, and impact on finances)

Dionne-Odom, 2015 [56]	USA	Multicenter	N=122 lung, gastrointestinal, breast, hematologic, genitourinary	RCT Two arms: 1) Early (fast track) 2) Delayed (3 months after diagnosis) ASSESSMENT: by telephone once every 6 weeks until week 24 and then every 3 months until patient's death or study completion	- Quality of Life - Depression - CG burden	- CG QOL Scale–Cancer (CQOL-C) - Center for Epidemiologic Study–Depression (CESD) Scale - 14-item Montgomery–Borgatta CG Burden (MBCB) Scale
Chambers, 2014 [71]	Australia	Multicenter	N=336 lung, gastrointestinal, breast, hematologic, genitourinary	RCT Two arms: 1) Single-session nurse-led self-management intervention 2) 5-session psychologist cognitive behavioural intervention ASSESSMENT: Baseline (pre-intervention), 3, 6, and 12 months after recruitment	- Distress - Post-traumatic growth	- Brief Symptom Inventory-18 (BSI-18) - Impact of Events Scale (IES) - Posttraumatic Growth Inventory (PTGI)
DuBenske, 2014 [51]	USA	Multicenter	N=246 lung	RCT Two arms: 1) CHESS + Clinician Report group 2) Internet group ASSESSMENT: - Intervention time: up to 2 years, or 13 months after patient death - Post-test surveys mailed to caregivers: every 2 months during the period of intervention	- Disruptiveness - Caregiver Burden - Negative mood - Caregiver perception of patient's symptom distress	- Caregiver Quality of Life – Cancer Scale (CQOLC) Disruptiveness Subscale - Caregiver Quality of Life – Cancer Scale (CQOLC) Burden Subscale - Short Version Profile of Mood States (SV-POMS) - Edmonton Symptom Assessment Scale (ESAS)
Kinney, 2014 [49]	USA	Multicenter	N=481 colorectal	RCT Two arms: 1) TeleCARE group 2) Control group ASSESSMENT: by telephone Baseline, 1 and 9 months after intervention	- colonoscopy use within 9 months after the intervention	- Risk Behaviour Diagnosis (RBD) Scale

Northouse, 2014 [68]	USA	Multicenter	N=38 lung, breast, colorectal, prostate	<p>Feasibility study All participants received the intervention</p> <p>ASSESSMENT: Web-based program: 3 sessions over a 6 weeks period, each session every 2 weeks to enable patient-caregiver dyads to learn information in a sequential manner</p> <p>T1 (baseline): web-based questionnaires. Dyads logged on to the program and completed sessions together. T2: Two weeks after finishing all three sessions, post-intervention questionnaires</p>	<p>Primary outcomes:</p> <ul style="list-style-type: none"> - Emotional distress - Quality of life <p>Secondary outcomes:</p> <ul style="list-style-type: none"> - Appraisal - Coping resources - Social support - Self-efficacy 	<ul style="list-style-type: none"> - Profile of Mood States (POMS) (short form) - Functional Assessment of Cancer Therapy (FACT-G version 4) - Benefits of Illness Scale - Communication: Lewis Mutuality and Interpersonal Sensitivity Scale - Brief version of the Social Support Scale - Lewis Cancer Self-efficacy Scale
Badger , 2013 [70]	USA	One center	N=70 breast	<p>RCT Two arms: 1) Telephone interpersonal counseling (TIP-C) 2) Telephone health education (THE)</p> <p>ASSESSMENT: 8-week intervention At baseline, immediately after the intervention completion (8-week) and 8-week after completion</p>	<ul style="list-style-type: none"> - Depression - Negative Affect - Stress - Anxiety - Fatigue - Psychological distress - Social well-being - Spiritual well-being - Cancer Knowledge - Social Support 	<ul style="list-style-type: none"> - 20-item Center for Epidemiological Studies-Depression Scale (CES-D) - 10-item negative affect subscale of the Positive and Negative Affect Schedule - Perceived Stress Scale - STAI - Multidimensional Fatigue Inventory - General Symptom Distress Scale - 8-item social well-being subscale of the Quality of Life Breast Cancer - 8-item spiritual well-being subscale of the Quality of Life Breast Cancer instrument - 20-item cancer knowledge measure developed for this study - Perceived Social Support—Family scale

Badger , 2013 [60]	USA	One center	N=52 breast	<p>RCT</p> <p>Three arms:</p> <ol style="list-style-type: none"> 1) Telephone interpersonal counseling (TIP-C) 2) Telephone health education (THE) 3) Videophone interpersonal counselling (VC) <p>ASSESSMENT: By telephone</p> <ul style="list-style-type: none"> - T1: Baseline - T2: intervention completion (after 8-week) - T3: after 8-week from T2 <p>Intervention: 4 sessions in total, every 2 weeks</p>	<ul style="list-style-type: none"> - Depression - Symptom distress - Social well-being - Spiritual well-being - User satisfaction 	<ul style="list-style-type: none"> - Center for Epidemiological Studies-Depression Scale (CES-D) - General Symptom Distress Scale (GSDS) - 9-item social well-being scale - 7-item spiritual well-being scale
Clark, 2013 [67]	USA	One center	N=131 gastrointestinal, brain, head/neck, lung	<p>RCT</p> <p>Two arms:</p> <ol style="list-style-type: none"> 1) structured multidisciplinary intervention arm 2) standard medical care (appointments, referrals to specialists) <p>ASSESSMENT:</p> <p>T1: baseline</p> <p>T2; T1 + 4 weeks</p> <p>T3: T1 + 27 weeks</p>	<ul style="list-style-type: none"> - Quality of Life 	<ul style="list-style-type: none"> - Caregiver Quality of Life Index-Cancer Scale
Chih, 2013 [55]	USA	Multicenter	N=235 lung, breast, prostate	<p>RCT</p> <p>Two arms:</p> <ol style="list-style-type: none"> 1) CHESS - Only: access to an interactive cancer communication system 2) CHESS + Clinician Report: access to an interactive cancer communication system plus an online symptom reporting system (Clinician Report) <p>ASSESSMENT:</p> <p>6 and 12 months after intervention</p>	<ul style="list-style-type: none"> - caregiver negative mood - caregiving burden and preparedness 	<ul style="list-style-type: none"> - Edmonton Symptom Assessment System (ESAS) - Eastern Cooperative Oncology Group Performance Status - 4-item caregiver Preparedness scale, a subscale of Family Care Inventory - 4-item caregiver Physical Burden scale, a subscale of the Caregiver Burden Inventory - subset of negative mood items from the Shortened Version Profile of Mood States (SV-POMS)

Northouse, 2013 [59]	USA	Multicenter	N=302 lung, colorectal, breast, prostate	RCT Three arms: 1) Brief (3-session) 2) Extensive (6-session) intervention 3) Control group (usual care) ASSESSMENT: Baseline: prior to intervention Post-intervention: 3 and 6 months from baseline	Primary outcome: - Quality of Life Intermediary outcomes: - Appraisals of illness/caregiving - Uncertainty - Hopelessness - Coping - Healthy Behaviour - Interpersonal relationships - Self-efficacy - Communication - Dyadic support - Risk for distress	- Functional Assessment of Cancer Treatment (FACT-G) - Appraisal of Illness or Appraisal of Caregiving Scales - Mishel Uncertainty in Illness Scale - Beck Hopelessness Scale - Brief Coping Orientations to Problems Experienced scale - Scale to assess activities (e.g., exercise, nutrition, adequate sleep) - Lewis Cancer Self-efficacy Scale - Lewis Mutuality and Interpersonal Sensitivity Scale - Social Support Questionnaire - 77-item RFD
Hogberg, 2013 [63]	Sweden	One center	N=6 haematological	Feasibility study ASSESSMENT: Individual interviews were conducted 4 months after recruitment	- experiences of having access to the web-based communication function - Question of what prevented or allowed the use of web-based communication for support	The interviews were analysed by a content analysis
Scott, 2013 [50]	Australia	One center	N=13 early stage cancer	Feasibility study ASSESSMENT: by semi-structured interviews. 6 modules (released sequentially each week) Post-treatment: 1 week Follow-up: 3 months after programme completion	- Negative affect - Distress - Quality of Life - Programme engagement - Qualitative feedback	- 21-item Depression Anxiety Stress Scale - 17-item Posttraumatic Stress Disorder Symptom Scale-Self Report - EORTC QLQ-C30: Functional subscales of Physical, Emotional, Social, Role and the Global QOL scale
Stern, 2012 [48]	Canada	One center	N=12 breast, lung, bowel, prostate, kidney, brain	Feasibility study ASSESSMENT: Length of exposure to home telehealth: 3.5 months (range: 2 weeks – 6 months)	A) Enhanced access to care: - Ease of access to a health care professional - Reassurance with visual access to care - Enhanced access to pain and symptom management B) Usability of the home telehealth system: - Lack of integration of nursing services - Inappropriate timing of the	Qualitative analysis conducted on - data from interviews (caregivers, patients and tele-nurses) - direct observations (families engaged in video-based communication with tele-nurses) - computerized nursing documentation. All interviews were audio recorded and transcribed verbatim

					<ul style="list-style-type: none"> - intervention - Lack of portability of the equipment - Technical challenges - Ease of use of the equipment 	
Namkoong, 2012 [58]	USA	Multicenter	N=285 lung	<p>RCT Two arms:</p> <ol style="list-style-type: none"> 1) CHESS group: access to the CHESS website as well as a laptop computer and Internet access. 2) Control group: usual care, a laptop computer with Internet access if needed, and a list of high-quality patient-directed lung cancer and palliative care websites (e.g., cancer.gov and alcase.org) based on clinician recommendations. <p>ASSESSMENT: Pre-test surveys prior to randomization Post-test surveys: every 2 months after receipt of the intervention for two years</p>	<ul style="list-style-type: none"> - Caregiver comfort using the Internet - Caregiver perception of patient's symptom distress - Bonding: universality, group cohesiveness, informational and emotional support - Appraisal and Problem-focused Coping Strategies - Active behavioural coping - Seeking instrumental support 	<ul style="list-style-type: none"> - 5-item bonding scale - Brief Cope questionnaire
Schover, 2012 [53]	USA	One center	N=186 prostate	<p>RCT Three arms:</p> <ol style="list-style-type: none"> 1) [3-month waitlist (WL)] 2) 3-session face-to-face format (FF) 3) an internet-based format with email contact with the therapist (WEB1) 4) second internet-based group (WEB2) was added to further examine the relationship between web site usage and outcomes <p>ASSESSMENT: At baseline, post-waitlist, post-treatment, and at 3-, 6-, and 12-</p>	<ul style="list-style-type: none"> - Erectile dysfunction - Female sexual function - Emotional distress - Relationship satisfaction 	<ul style="list-style-type: none"> - International Index of Erectile Function (IIEF) - Female Sexual Function Index (FSFI) - Brief Symptom Inventory (BSI-18) - abbreviated Dyadic Adjustment Scale

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Zulman, 2012 [65]	USA	Multicenter	N=38 lung, colorectal, breast, prostate	Feasibility study 4 focus group and usability testing.	5 core modules: - Family involvement - Optimistic attitude - Coping effectiveness - Uncertainty reduction - Symptom management	Transcripts of the recorded groups were analysed by two members of the content team to identify themes and representative quotes.
Badger, 2011 [64]	USA	Multicenter	N=70 prostate	RCT Two arms: 1) Telephone interpersonal counselling (TIP-C) 2) Health education attention condition (HEAC) ASSESSMENT: By telephone T1: Baseline T2: T1 + 8 weeks T3: T2 + 8 weeks Intervention: 4 calls in total, every 2 weeks	- Depression - Positive and Negative Affect - Symptom distress - Fatigue - Social well-being - Spiritual well-being - Social Support	- 20-item Center for Epidemiological Studies-Depression Scale (CES-D) - 20-item Positive and Negative Affect Schedule - Perceived Stress Scale (PSS) - Multidimensional Fatigue Inventory - 8-item social well-being modified subscale of the Quality of Life Breast Cancer - 8-item spiritual well-being subscale of the modified Quality of Life Breast Cancer instrument - Perceived Social Support—Family scale (PSS-FA)
Porter, 2011 [61]	USA	Multicenter	N=233 lung	RCT Two arms: 1) Caregiver-assisted Coping skills training group (CST) 2) Education/support group ASSESSMENT: By telephone T1: Baseline T2: post-treatment immediately after intervention's completion T3: T2 + 4-month Intervention: 14 telephone-based sessions	- psychological distress - caregiver strain - self-efficacy for helping the patient manage symptoms	- Profile of Mood States-B (POMS-B) - Caregiver Strain Index (CSI) - Chronic Pain Self-Efficacy scale (modified version)

Northouse, 2007 [52]	USA	Multicenter	N=235 prostate	<p>RCT</p> <p>Two arms:</p> <ol style="list-style-type: none"> 1) FOCUS program group 2) Usual care <p>Assessment: Baseline, and 4, 8, 12 months after intervention's completion</p>	<ul style="list-style-type: none"> - Quality of life - Appraisals of illness/caregiving - Uncertainty - Hopelessness - Coping strategies - Self-efficacy - Communication - General symptom distress - Extent to which husbands' prostate-specific symptoms created problems for spouses - Risk for distress 	<ul style="list-style-type: none"> - Medical Outcomes Study 12-item short form (MOS SF-12) - Functional Assessment of Cancer Treatment (FACT-G) - Appraisal of Illness or Appraisal of Caregiving Scales - Mishel Uncertainty in Illness Scale - Beck Hopelessness Scale - Brief Coping Orientations to Problems Experienced scale - Lewis Cancer Self-Efficacy Scale - Lewis Mutuality and Interpersonal Sensitivity Scale - Omega Screening Questionnaire (OSQ) - 4-item spousal version of the EPIC - 77-item RFD
Northouse, 2005 [54]	USA	Multicenter	N=134 breast	<p>RCT</p> <p>Two arms:</p> <ol style="list-style-type: none"> 1) FOCUS program group 2) Usual care <p>ASSESSMENT: Baseline, 3-months after initial phase completion, and 6-months after booster phase completion of the program</p>	<ul style="list-style-type: none"> - Appraisal of illness - Appraisal of caregiving - Uncertainty - Hopelessness - Coping - Quality of life 	<ul style="list-style-type: none"> - Appraisal of Illness Scale - Appraisal of Caregiving Scale - Uncertainty in Illness Scale - Beck Hopelessness Scale - Brief COPE - Functional Assessment of Cancer Treatment (FACT-G) - SF-36
Farnham, 2002 [66]	USA	One center	N=49 bone marrow transplant	<p>RCT</p> <p>Two arms:</p> <ol style="list-style-type: none"> 1) HutchWorld group: computers with access to the Internet and HutchWorld 2) Control group: no access to the Internet in their apartments <p>ASSESSMENT: Baseline, monthly and weekly questionnaires for up to 3 months + debriefing session at the end of the study (feedback on HutchWorld and the study)</p>	<ul style="list-style-type: none"> - Quality of Life - Social support - Internet and web-based program usage patterns 	Not specified

				itself) Participants submitted their questionnaires using a self-addressed envelope		
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Abbreviations

BSI-18: Brief Symptom Inventory-18

CESD: Center for Epidemiological Studies- Depression scale

CHESS: Comprehensive Health Enhancement Support System

CQOL-C: Caregiver Quality of Life Index-Cancer scale

CSI: Caregiver Strain Index

CST: Caregiver-assisted Coping skills training group

ENABLE: Educate Nurture Advise Before Life Ends

EORTC QLQ-C30: European Organisation for Research and Treatment of Cancer Quality of Life Core Questionnaire

ESAS: Edmonton Symptom Assessment Scale

FSFI: Female Sexual Function Index

HEAC: Health education attention condition

GAD-7: Generalized Anxiety Disorder seven-item scale

GSDS: General Symptom Distress Scale

IES: Impact of Events Scale

IIEF: International Index of Erectile Function

MBCB: Montgomery–Borgatta CG Burden scale

MOS SF-12: Medical Outcomes Study 12-item short form

OSQ: Omega Screening Questionnaire

PG13: Prolonged Grief scale

PSS: Perceived Stress Scale

SV-POMS: Shortened Version Profile of Mood States

PTGI: Posttraumatic Growth Inventory

RBD: Risk Behaviour Diagnosis Scale

RCT: randomized controlled trial

RFD: Risk for Distress scale

SF 12: 12-Item Short Form Survey

STAI: State-Trait Anxiety Inventory

SV-POMS: Short Version Profile of Mood States

TIP-C: Telephone interpersonal counseling

THE: Telephone health education

TSM: Telephone-based Symptom Management