# Are cancer helplines effective in supporting caregivers? A systematic review

Leila Heckel[1], Natalie Heynsbergh[1*], Patricia M Livingston[1]

[1] Deakin University, Geelong, Victoria 3220, Faculty of Health, School of Nursing and Midwifery, Australia.

*Corresponding author at: Deakin University, Faculty of Health, Geelong, Victoria 3220, Australia

Tel.: +61 04 3368 5206, email: n.heynsbergh@deakin.edu.au

**Online Resource 1** Cancer helplines and caregivers: Data extraction sheet for the descriptions of cancer caregivers using cancer helplines

| First author, year, country | Study design and aims | Helpline service, participants and sample size | Characteristics of users/calls | Reasons for calling and topics discussed | Outcome/satisfaction |
|---|---|---|---|---|---|
| Boltong 2017 [26]<br>AUS (UK, USA) | Qualitative, descriptive<br><br>To examine the rationale, experiences and outcomes of caregivers and patients who called cancer helpline services in Australia, the UK, and the US | Three cancer helpline services:<br>Cancer Council Victoria CIS (AUS)<br>Cancer Research UK's CIS (UK)<br>American Cancer Society's National CIS (USA)<br><br>Total sample:<br>30 Caregivers and patients with cancer – unrelated, no dyads (10 per helpline service)<br><br>37% caregivers<br>(63% patients) | Gender:<br>73% Female (n=8)<br>27% Male (n=3)<br><br>Age:<br>Mean age: 53 years | Reasons for using helpline:<br><br>Cancer information<br>(not understanding what the cancer diagnosis meant, stunned and confused)<br><br>Not knowing what to do<br>(lost) | Experiences and benefits of using helpline:<br>Questions were answered, helping the caregiver understand their situation, provision of expert knowledge, helpful in providing information, advice and referrals to other services, information and advice at the time when needed<br><br>Impact of using CIS<br>Knowledge as power (confidence and competence in communicating with healthcare team) |
| Boudioni 1999 [27]<br>UK | Retrospective comparison of cancer incident data and population data with first-time helpline users<br><br>Calls from 1 April 1995 to 31 March 1996 | Cancer BACUP Information Service<br><br>Total sample:<br>16 955 first-time callers<br><br>44% relatives/friends<br>(56% patients) | User type:<br>First time users<br><br>Age:<br>Combined data only | | |
| Boudioni 2004 [28]<br>UK | Comparison of helpline caller data and the general population<br><br>Data collection at the time of call over a 5-week period: 13 July 1998–14 August 1998 | Cancer BACUP Information Service<br><br>Total sample:<br>552 callers to the helpline<br><br>55% relatives/friends<br>(45% patients) | | | Compared to the general population:<br>7% of relatives and friends lived alone (20% of patients)<br>Fewer male relatives/friends lived alone<br>89% females over pensionable age living in 2 or more person households |

| | | | | | |
|---|---|---|---|---|---|
| | To examine whether living alone is associated with the use of the helpline service | | | | 91% male caregivers (90% female caregivers) lived in 2 or more person households<br>84% male caregivers lived in couple households<br>86% female caregivers lived in couple households<br><br>Differences in enquiries between relatives/friends and patients:<br>6% Hormonal therapy (vs 14% patient)<br>5% Recurrence (vs 10% patient)<br>5% Treatment side effects (vs 13% patient)<br>13% Prognosis (vs 6.8% patient) |
| Bright 2005 [29]<br>USA | Helpline telephone survey<br><br>To obtain information on callers use of internet to source health information | 14 regional helpline services in the US<br><br>Total helpline calls:<br>N=142779<br>33% family/friends<br><br>Total telephone survey<br>N=6019<br>41% family/friends<br>(23% patients) | | | 67% family/friends used PC's<br>81% used internet to obtain health information<br>72% used internet to obtain cancer information<br>40% reported finding most information they needed<br>50% reported the information found as very useful, and 43% as somewhat useful<br>34% called the helpline to discuss information found on the internet, and 67% found calling the helpline very helpful, 24% somewhat helpful<br>46% were very interested in email service, 32% somewhat interested |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | 90% were interested in calling the helpline while on the internet<br>38% were interested in internet moderated chatrooms |
| Browman 1995 [30]<br>Canada | Census survey of telephone contacts to 6 helpline services in Canada over a 4 day period in April 1992<br><br>Comparison of first-time users with other caller populations. To examine underlying emotional support | Helpline services in the Metro Hamilton district in Canada<br><br>Total contacts:<br>N=946<br><br>Contacts analysed:<br>N=158<br><br>23% (n=36)<br>immediate family<br>12% (n=19)<br>friends, relatives<br>(42% patients) | User type:<br>Of the Spouses, 47% were first time callers<br><br>Of family and friends,<br>44% were first time callers | Reasons for calling:<br><br>Immediate family:<br>61% specific service 22% general information<br>8% emotional support<br><br>Friends/relatives:<br>42% specific service<br>26% general information<br>5% emotional support | First-time callers were more likely to be relatives/friends compared to non-first-time callers |
| Byrne 2012 [31]<br>USA | Analysis of calls to the helpline over a 3 year period (2006-2008)<br><br>To assess how often clinical trials were discussed by callers<br><br>To assess associations between caller characteristics and the presence of clinical trial discussions | Helpline service in Miami<br><br>Total calls to CIS:<br>N=283,094<br><br>32% family/friends<br>(26% patients) | Family and friends provided care for people diagnosed with the following cancer types:<br>13% Prostate/other urogenital<br>14% Breast<br>20% Colorectal/other gastrointestinal<br>9% Hematologic<br>4% Skin<br>7% Gynecologic<br>14% Lung/other respiratory<br>5% Head and neck<br>3% Melanoma<br><br>Gender:<br>79% female<br>21% male<br>Race/ethnicity: | | 15.4% family members discussed clinical trials<br><br>Associations between family member characteristics and clinical trials discussions:<br>21% female<br>15% male<br>16% English<br>33% caring for melanoma patients<br>17% non-Hispanic background<br>33% Below 50yrs<br>34% 51-70yrs<br>30% 71+yrs<br>45% College/postgrad education<br>34% Higher income |

| | | | | | |
|---|---|---|---|---|---|
| | | | 96% English<br>80% white<br>89% non-Hispanic<br>Age:<br>25% 40 and younger<br>24% 41–50<br>23% 51–60<br>17% 61–70<br>9% 71–80<br>2% 81 and older<br>Education:<br>7% Less than high school<br>24% High school graduate<br>29% Some college<br>26% College graduate<br>14% Postgraduate schooling<br>Income:<br>12% Less than $20,000<br>16% $20,000–$29,000<br>17% $30,000–$39,000<br>16% $40,000–$59,000<br>23% $60,000–$79,000<br>17% $80,000+ | | |
| Chambers 2012 [32]<br>AUS | Cross-sectional survey, baseline data of a randomized controlled trial (telephone intervention). Inbound calls from patients and caregivers to the helpline services<br><br>To assess socio-demographic variables, anxiety, depression, cancer specific distress, unmet needs, | Helpline services in QLD and NSW<br><br>Total sample:<br>N=690<br>(callers with DT>4):<br><br>49% Caregivers<br>(51% Patients) | Caregiver gender:<br>88% Female<br>22% Male<br>Marital status:<br>21% Married/de-facto<br>79% Not married (single, divorced, widowed)<br>Education:<br>34% Non-tertiary<br>66% Tertiary<br>Income:<br>>20000 19%<br>20000-39000: 28% | | Comparisons: caregiver vs patient<br><br>Demographics:<br>Caregivers were significantly younger than patients<br>Caregivers were more frequently single than patients who were more likely to be married or in a relationship. Caregivers more often had a tertiary |

| | | | | | |
|---|---|---|---|---|---|
| | reasons for calling, post-traumatic growth<br><br>Comparison between patients and caregivers | | 40000-59000: 14%<br>60000-79000: 10%<br>80000+: 23%<br>Person provided care for:<br>21% spouse/partner<br>15% parent<br>5% child<br>4% sibling<br>Anxiety, Depression, Somatization:<br>17.7% somatization<br>31.1% depression 35.9% anxiety | | education and higher income than patients<br>Distress:<br>Caregivers had significantly higher DT scores than patients when calling the helpline (6.98 vs 6.37 mean) and higher IES intrusion scores (20.65 vs. 16.30 mean)<br>Unmet needs:<br>Mean number of moderate/high unmet needs were higher in caregivers (25.11) than in patients (23.13)<br>Patients reported more frequently<br>Psychological needs, whereas caregivers had more health care services and information needs related to the patient<br>Predictors:<br>Higher intrusion predicted more psychological distress and unmet needs<br>Being single predicted somatization<br>Higher DT score and avoidance predicted depression and anxiety<br>Undergoing treatment predicted anxiety<br>Tertiary education predicted higher unmet needs<br>Being younger and higher avoidance predicted post-traumatic growth |

| | | | | | |
|---|---|---|---|---|---|
| Darrow 1998 [33]<br>USA | Random sample survey of helpline callers in 1996 over a 5-week period<br><br>To evaluate overall satisfaction with call | Total sample:<br>N=2489<br><br>Sub-sample analysed:<br>N=298 (Only those who wanted help coping with cancer<br><br>67% significant others (21% spouse/partner,<br>16% parent, 11% friend/co-worker, 19% other family)<br>(33% patients) | | Reasons for calling:<br>Seeking coping information | Satisfaction:<br>83% were satisfied with service<br>65% found helpline staff very knowledgeable<br>77% found helpline staff completely trustworthy<br>62% found printed material very helpful, 76% read all or most of the printed material<br>Impact:<br>98% shared information received with others incl. health professionals<br>42% recommended the helpline to others<br>80% stated information received helped them adjust to the illness<br>85% felt more knowledgeable<br>69% felt more reassured about the situation<br>39% stated the information received helped find support in the community |
| Davis 2004 [34]<br>USA | Second phase of a randomized controlled trial (pre-post test, two-arm design) conducted at the helpline in the period of March – July 2001<br><br>To assess self-assessed breast cancer risk, breast cancer worries, and breast cancer screening behaviour in callers to the helpline | National Cancer Institute helpline service, Northern California<br><br>Total sample: N=392<br>55% Relative/friends<br>45% general public | Combined data only | Combined data only | Female relatives/friends of cancer patients were more likely to be in mammography maintenance than females of the general public |

| | | | | | |
|---|---|---|---|---|---|
| Davis 1998 [35]<br>USA | Random survey of helpline callers during a 5-week period in 1996<br><br>To assess the satisfaction and impact of treatment and clinical trial information<br><br>Comparison of treatment group with clinical trial group in terms of satisfaction and impact | Total sample: N=2489<br><br>Subsample: N=932<br>Cancer treatment calls: n=579<br>53% family/friends<br>(47% patients)<br><br>Clinical trials calls: n=353<br>54% family/friends<br>(46% patients) | | Reasons for calling:<br>Treatment information<br>Clinical trials information | Combined data only for satisfaction and comparison of cancer treatment group vs clinical trials group<br><br>Patients were more likely to report that the information provided was helpful in making a treatment choice than family/friends |
| Dean 2007 [36]<br>UK | Questionnaire survey of callers using the helpline service during January-March 2007<br><br>To identify the needs and profile of callers and to assess their satisfaction with the service | Breast cancer helpline<br><br>Total survey sample: N=193<br><br>14% Spouse/family/friend<br>(86% patients) | Combined data only | Combined data only | Combined data only |
| Ekberg 2014 [37]<br>UK | Qualitative interviews with 32 cancer helpline callers between November 2010 and May 2012<br><br>To examine callers' perception of using the helpline service | Five major cancer helplines in the UK<br><br>Total sample: N=32<br><br>31% family/friend<br>(69% patient) | Gender: 80% female 20% male<br>Cancer types:<br>Lung, melanoma, stomach, brain, neck, bile duct, bladder, bowel, mesothelioma, esophageal, kidney | | Caregiver perception of helpline service:<br>Positives:<br>Service is anonymous, important resource to gather information,<br>service is filling the support gap<br>Negatives:<br>Call handler lacked empathy, was too formal or blunt, preferred to speak to someone who had gone through similar experience, felt information was delivered in a non-supportive way, service not available during evening hours |

| | | | | | |
|---|---|---|---|---|---|
| Fennell 2016 [38]<br>AUS | Retrospective audit of calls to the helpline between 16 April 2009 and 16 April 2013<br><br>To determine how patients differ from caregivers who call the helpline | Cancer Council Helpline in South Australia<br><br>Total sample: 10940<br>47% caregivers<br>(53% patients) | User type:<br>21.5 % repeat user<br>Gender:<br>83% female<br>17% male<br>Age:<br>53% were 50 and above,<br>47% were aged below 50 years<br>Location/Remoteness:<br>88% resided in major city/inner regional areas<br>12% resided in outer regional/remote/very remote areas<br>Call duration:<br>19.53 min (mean)<br>Levels of distress:<br>Distress level (0-10):<br>6.36 (mean) | Most common topics discussed by caregivers: 44% Emotional, psychosocial issues<br>37% Treatment management 32% Counselling<br>27% Practical issues<br>25% Family, partner issues | Differences between caregivers and patients:<br>Compared to patients, caregivers were more likely to be female<br>below 50 years of age, to call regarding metastasized, widespread, advanced, terminal or unknown stages, to request general information, information on diagnosis, and/or psychological, emotional support<br><br>Compared to caregivers, patients were more likely to be male, over 50 years of age, to call regarding early/localized disease, in the treatment phase, a second primary, in remission, stable or in survivorship phase, to seek advice on treatment and management and/or practical issues<br><br>Caregivers were more likely to find the helpline number via a friend/relative, the media, internet or phone book compared to patients (health professional, cancer Council resource, used number before)<br><br>Caregivers were more distressed than patients |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | 63% of caregivers required follow-up care (73% of patients)<br>Only 7% of caregiver and 8% of patients received a referral |
| Freimuth 1993 [39]<br>USA | 3 Studies to minimize the knowledge gap between white and African American<br>Study1: Call records to the helpline services to explore characteristics and motivations for information seeking<br>Study2: 54 in-depths interviews with African American callers recruited from 5 helplines<br>Study3: random digit dial survey of 600 African Americans to assess cancer knowledge, attitudes and trust in information sources | Various cancer helplines in the US<br><br>Total sample: (N=10000)<br>50% White<br>50% African Americans<br>Study 1:<br>33% Family/friends<br>(21% white, 12% African American)<br><br>(18% patients - 11% white, 7% African American) | Combined data only | Combined data only | Combined data only |
| Hawkes 2010 [40]<br>AUS | Consecutive calls to helpline service from patients and caregivers during September-December 2006<br><br>To assess feasibility of routine distress screening and triage by helpline operators | Cancer Council Queensland Helpline service<br><br>Total sample: N=341<br><br>35% Caregivers<br>(65% Cancer patients) | Age, gender, work status:<br>Caregivers were more likely to be younger, female (89%), work casual part time (14%) or be involved in full time home duties (22%), less likely to be unemployed, permanently ill, disabled, unable to work (8%), or retired (21%)<br>Cancer types enquired:<br>Lung (15%)<br>Liver (12%)<br>Brain (9%)<br>Phase/stage of cancer trajectory: | Caregiver's problem list:<br>27% family issues 27% practical problems 71% emotional issues | Caregivers versus patients:<br>Caregivers were 4 times more likely to report a distress level of => 4 than patients<br>Caregivers were more likely to be anxious. Emotional problems were associated with increased distress |

| | | | | | |
|---|---|---|---|---|---|
| | | | 42% were caring for a patient who had undergone surgery in the past 6 months | | |
| Heckel 2017 [41]<br>AUS | Retrospective audit of calls to the cancer helpline by family/friends during the period of January 2010 – December 2012<br><br>To investigate demographic characteristics and psychosocial support needs of family/friends contacting the service | Cancer Council Australia 131120 services (incl. all Australian state and territory helplines)<br><br>Total calls: N=202697<br><br>21% family/friends | User type:<br>84% first contacts<br>16% repeat users<br>Gender:<br>81% female<br>19% male<br>Age:<br>23% < 40 years<br>45% 40-59 years<br>32% 60+<br>How found out about the service:<br>32% Cancer Council (staff, event, educational material)<br>20% media<br>18% internet<br>11% health professionals<br>10% telephone book<br>6% family/friends<br>3% community organization<br>SES status:<br>19% low<br>40% middle<br>41% high | Topics discussed:<br>22% treatment and management 26% psychological, emotional support<br>52% diagnosis, prevention, practical issues | |
| Heidrich 2003 [42]<br>USA | Structured questions to callers to the North Central cancer helpline to determine feasibility of educational interventions regarding pain and QOL with people calling the service | North Central cancer helpline, located at the University of Wisconsin Comprehensive Cancer Center in Madison<br><br>Total sample: N=306<br><br>Pain substudy (n=205)<br>50% family/friends (50% patients)<br>QoL substudy (n=101)<br>100% family/friends | Mean age:<br>52 years (pain study),<br>50 years (QoL study)<br>Gender:<br>Female<br>85% (pain study)<br>83% (QoL study)<br>Male<br>15% (pain study)<br>17% (QoL study)<br>Phase/stage of cancer trajectory:<br>New diagnosis, no treatment | Reasons for calling: (QoL group)<br>81% feeling anxious<br>71% feeling depressed<br>68% difficulty sleeping<br>63% concerns of how to provide emotional support to patient<br>62% getting information on course and prognosis of disease<br>61% having physical symptoms | Feasibility of conducting telephone-delivered interventions using cancer helpline:<br>Yes responses to question regarding joining future study:<br>89% caregivers in pain study<br>86% of caregivers in QoL study |

| | | | | | |
|---|---|---|---|---|---|
| | | | 20% (pain study)<br>34% (QoL study)<br>New diagnosis, current treatment<br>48% (pain study)<br>37% (QoL study)<br>Post-treatment<br>9% (pain study)<br>8% (QoL study)<br>Recurrence<br>22% (pain study)<br>21% (QoL study)<br>Other<br>1% (pain study)<br>0% (QoL study) | 58% worrying how the cancer will affect future plans<br>56% getting information about cancer<br>53% feeling lonely<br>52% feeling angry | |
| Hughes 2011 [43]<br>AUS | Distress Thermometer (DT) and problem list (PL) use in CIS callers during the period of September – December 2006<br><br>To assess acceptability of DT and PL administration at 13 11 20 service by callers | Cancer Council Queensland helpline service<br><br>Total sample: N=666<br><br>44% Caregivers<br>(56% Patients) | Median call duration:<br>23 minutes<br><br>Median distress rating:<br>(0-10): score of 6<br><br>Problem List:<br>22% practical<br>17% family<br>55% emotional<br>1% spiritual<br>21% treatment<br>12% symptoms<br>21% other | | Administration of DT and PL was acceptable with some barriers to overcome for operators.<br>Median call duration was longer when DT + PL was used compared with non-usage (23 vs 10 minutes)<br>Tool used by operators:<br>90% by 6 operators<br>100% by 3 operators<br>74-77% by 3 operators<br>Reasons for not applying the tool:<br>Time or context restrictions, reason for calling was incongruous with DT screening, caller was unreceptive/too ill, communication difficulties, operator forgot to use the tool<br>Callers responses to the tool:<br>94% completed the tool |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | 6% non-responders<br>Reasons for not responding:<br>43% Unable to describe distress (put a number to it)<br>18% became distressed and were unable to complete the tool<br>Others (not feeling well, called to obtain information material, wanted to get off the phone) |
| Jefford 2005 [44]<br>AUS | Audit of calls to the CIS over a six year period from 1997 - 2003<br><br>To describe the information and support needs of callers and the response of the service to these needs | Cancer Council Victoria helpline service<br><br>Total contacts: N=42029<br><br>17% family/friends (12% immediate family, 5% extended family)<br>(17% patients) | Age:<br>Immediate family (approximately)<br>35% <30 years 30% 30-39 years 20% 40-49 years 15% 50-59 years 5% 60+ years Extended family 35% <30 years 35% 30-39 years 20% 40-49 years 10% 50-59 years 3% 60+ years<br>Mean call duration: 12minutes<br>Cancer type enquired about: Breast cancer | Reasons for calling:<br>Immediate/extended family:<br>70%/80% treatment management<br>50%/50% diagnosis<br>50%/50% psychological emotional support<br>30%/20% recurrence, progression<br>25%/30% practical issues<br>25%/30% prevention, risk factors<br>25/20% side effects<br>25%/30% general information | |
| Klikovac 2015 [45]<br>Serbia | Call audit of contacts to the national helpline in the period of October 2010 until April 2011<br>To assess caller characteristics and reasons for calling/topics discussed | First national helpline in Serbia, providing psychological support to cancer patients and their families.<br><br>Total sample: N=2748<br><br>25% Family, friends, relatives<br>(66% patients) | | | |

| | | | | | |
|---|---|---|---|---|---|
| La Porta 2007 [46]<br>USA | National User Survey conducted between November 2003 – March 2004<br><br>10-min telephone survey of first-time helpline users to assess outcomes and satisfaction with the service. | National Cancer Institute's (NCI's) Cancer Information Service (CIS)<br><br>National sample: N=2485<br><br>43% family/friends | User type:<br>100% first time users<br><br>Combined data only | Combined data only | Levels of Satisfaction:<br>96% (family/friend) 95% (spouse)<br>very satisfied/satisfied<br>89% (both family/friend, Spouse) expectations were met/exceeded<br>91% (both family/friend and spouse) operator was very knowledgeable/knowledgeable<br>85% (family/friend) 83% (spouse)<br>had significant trust in information provided<br>Impact of helpline contact on knowledge:<br>43% reported significant knowledge increase (36% somewhat)<br>Impact of helpline contact on competence:<br>72% more confident in ability to seek information<br>60% more confident in actively participating in treatment decisions |
| Lechner 1996 [47]<br>Netherlands | Postal survey to callers of the helpline over a period of 4 weeks in October 1993<br><br>To evaluate the experience and impact of the Dutch national cancer information helpline | Cancer helpline of the Dutch Cancer Society<br><br>Total sample: N=532<br><br>37% family/relatives<br>(46% patients) | Age:<br>Mean age: 43 years | | Evaluation of the telephone:<br>Accessibility, approachability, appropriateness, and pleasantness were rated positively with mean scores ranging from 0.94 to 1.45 (from scores -2 to +2)<br>Evaluation of information:<br>Clarity, usefulness, amount, and overall quality were rated positively with mean |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | scores ranging from 0.79 to 1.43 (from scores -2 to +2)<br>Evaluation of communication skills:<br>Sincerity, respect, amount of attention, expertise, supportiveness, reassurance, ability to put themselves into the callers situation were rated positively with scores ranging from 0.81 to 1.91 (from scores -2 to +2)<br>Satisfaction:<br>Combined data only<br>Impact on anxiety:<br>Combined data only<br>Impact on expectations:<br>Combined data only<br>Predictors for satisfaction and impact:<br>Best predictor for satisfaction: information received<br>Best predictor for impact on anxiety:<br>Educator's communication<br>Best predictors for impact on expectations met:<br>Information received, communication skills |
| Linehan 2017 [48]<br>AUS | Inbound calls to the cancer helpline between 12 May – 18 July 2014<br><br>Survey to test the validity of the Distress Thermometer (DT) as a measure of changes in distress after a cancer | Cancer Council South Australia helpline<br><br>Total sample: N=100<br><br>37% family/friends<br>(63% people diagnosed with cancer) | | Survey including DT, DASS-21, questions regarding comfort in using DT<br><br>Assessment points:<br>At the start of call<br>At the end of call<br>When completing the survey | DASS-21 scores at time of survey completion:<br>Average anxiety scores (0-3) and depression scores (0-4), both in normal range.<br>Anxiety and depression scores correlated significantly with DT scores<br>Changes in DT scores: |

| | | | | | |
|---|---|---|---|---|---|
| | helpline call, to measure the impact of a helpline call on callers'<br>distress; comfort using the DT, and the frequency of referral to internal support services | | | | A reduction in mean distress scores over time was observed<br>54% reported a recollected score of >= 6 on the DT at time of calling (Time 1) - only 4 of the family/friends received an internal referral for follow up<br>This percentage dropped to 25% at Time two (end of call) and remained the same at Time 3 (survey completion)<br>Comfort completing or administering the DT:<br>81% of family/friends reported feeling comfortable completing the DT<br>In 82% of cases, the nurses were comfortable administering the DT to family/friends |
| Maibach 1998 [49]<br>USA | Satisfaction survey of a random sample of helpline callers during a 5-week period in 1996, 3 to 6 weeks after initial call<br><br>To assess caller demographics and satisfaction/impact of service regarding prevention and decision making | Cancer helpline service, USA<br><br>Total survey sample:<br>N=2489<br><br>23% family, relatives, friends (77% patients) | Combined data only | Combined data only | Impact:<br>More than 90% of family, friends shared the information received from the helpline with the cancer patient |
| Manning 2002 [50]<br>Northern Ireland | Retrospective analysis of first-time callers to the cancer helpline over an 18 | Cancer information Service (CIS) in Belfast, Northern Ireland | Cancer types enquired by relatives/friends:<br>Breast, Prostate, Lung, Bowel | Topics discussed:<br>20% cancer-related symptoms | |

| | | | | | |
|---|---|---|---|---|---|
| | months period (January 1999 – June 2000) | Total calls: N=571<br><br>46% Relative/friend (21% patients) | | 30% prostate and testicular problems | |
| Marcus 1993 [51]<br>USA | RCT of counselling intervention to promote breast screening in female callers to the helpline | Cancer Information Service, USA<br><br>Total sample: N=1831<br><br>57% family, relative (n=1015)<br>27% patients/survivors (n=488) | Combined data only | | Combined data only |
| Marcus 2002 [52]<br>USA | Retrospective audit of calls to the cancer helpline during the period of 1st June 1998 until 30 May 1999<br><br>To describe the caller types and their topics of enquiry | Cancer information and Counselling Line (CICL) of the AMC Cancer Research Centre in Denver, Colorado.<br><br>Total sample: N=1627<br><br>43% Spouse, partner, relative, friends (27% Patients, survivors) | Phase/stage of cancer trajectory:<br>27% newly diagnosed<br>31% in treatment 6% post treatment (survivorship)<br>24% recurrence, palliative care, hospice | Reasons for calling:<br>51% mentioned psychological concerns during the call<br><br>Topics of enquiry:<br>Combined data only | |
| Meissner 1990 [53]<br>USA | Descriptive analysis of calls to all cancer information services (nationwide sample) in the period of 1983 - 1987<br><br>To examine the information needs of significant others | All cancer information helplines in the US<br><br>Total sample: N=750221<br>25% Significant others (12% patients) | Age:<br>The majority was aged in their 30s and 40s<br>How found out about the helpline:<br>28% health professionals<br>23% written materials, promotions<br>22% telephone book<br>15% other friends, relatives<br>15% TV, radio | Topics discussed:<br>26% Site information<br>13% treatment 12% referral<br>11% counselling<br>10% clinical trials | |
| Morris 2015 [54]<br>AUS | Descriptive analysis of sleep problems and associated factors in patients and caregivers who called the helpline between 11th | Cancer Council Queensland helpline service<br><br>Total sample: N=734 | Gender:<br>84% female<br>16% male<br>Age:<br>18% aged 20-39 | Topics discussed:<br>37% practical issues<br>32% psychological, emotional support | Sleep problems:<br>Insomnia Severity Index (ISI)<br>Insomnia mean (0-28): 11<br>Insomnia prevalence: |

| | | | | | |
|---|---|---|---|---|---|
| | December 2012 – 26th March 2013 | 32% Caregivers<br>(68% Patients) | 41% aged 40-59<br>36% aged 60+<br>Education:<br>24% tertiary education (undergrad + postgrad)<br>15% Certificate/diploma<br>54% high school education<br>Phase/stage of cancer trajectory:<br>Time since diagnosis:<br>3 months<br>Cancer types enquired about:<br>13% breast<br>6% male urological<br>11% lower GI<br>7% gynecological<br>8% respiratory<br>10% CNS<br>27% other | 14% treatment and management<br>11% general information | 63% had a score of 8 or above on the ISI<br>32% had a score of 15 or above on the ISI (moderate to severe insomnia)<br>Distress:<br>Distress Thermometer (DT)<br>DT mean (0-10): 6<br>83% had a score of 4 or above on the DT<br>Caregivers reported significantly higher levels of distress than patients<br>Insomnia and distress:<br>Greater insomnia level was associated with higher levels of distress<br>Caregivers of breast enquiries:<br>37% had moderate/severe insomnia 75% had DT of 4 or above<br>Caregivers of prostate enquiries:<br>14% had moderate/severe insomnia<br>71% had DT of 4 or above<br>Caregivers of other cancer enquiries:<br>31% had moderate/severe insomnia<br>86% had DT of 4 or above |
| Namboodiri 1993 [55] USA | Analysis of caller data to the helpline regarding tobacco use, mammography, pap test, and clinical trials enquiries during the period of 1986 – 1991.<br><br>To study trends over time | Ohio Cancer information service<br><br>Caregiver data only on clinical trials:<br><br>Over the 5 year period percentage of calls from | Combined data only | Clinical trials | The frequency of enquiries by family/friends regarding clinical trials increased steadily over the five year period |

| | | | | | |
|---|---|---|---|---|---|
| | | family/friends regarding clinical trials ranged from 52%-63% | | | |
| Reiches 1982 [56]<br>USA | Retrospective audit of calls to the helpline from July 1979 – July 1980 | Ohio Cancer Information Service<br><br>Total calls: N=3162<br><br>34% Relatives/friends (14% patients) | Cancer types enquired about:<br>Of those enquiring about:<br>Breast: 26% relatives<br>Colon: 47% relatives<br>Lung: 58% relatives<br>Brain: 72% relatives<br>Leukemia: 61% relatives<br>Hodgkin's disease: 60% relatives | Topics discussed:<br>Of those enquiring about:<br>Causes: 7% relatives<br>Community resources: 34% relatives<br>Screening, diagnosis: 17% relatives<br>Symptoms: 18% relatives<br>Treatment: 57% relatives | |
| Reubsaet 2006 [57]<br>Netherlands | Cross-sectional survey to evaluate the helpline service and caller satisfaction.<br><br>Callers between December 2003 – March 2004 were invited to complete a postal survey | Dutch national Cancer Information Service<br><br>Total sample: N=1128<br>Surveys returned: N=665<br><br>35% relatives, friends (39% patients) | Age:<br>Mean age: 48.5 years | | Satisfaction and impact:<br>Combined data only<br>Predictors for satisfaction and impact (relatives/friends):<br>Best predictor for satisfaction: information received<br>Best predictor for impact on anxiety:<br>Information received<br>Best predictors for impact on expectations met:<br>Information received, communication skills |
| Rimer 1993 [58]<br>USA | Call audit to the cancer helpline from 1983 to 1990<br><br>To assess demographic characteristics of callers aged 60 and over and to examine relationships between younger and older callers | Cancer information helpline in the US<br><br>Total sample:<br>N=206 104<br><br>22% spouses/relatives (25% patients) | Age:<br>27% aged 40-59 years<br>22% aged $60^{+}$ years | Combined data only | |
| Finney Rutten 2006 [59]<br>USA | Call data of family/friends contacting the cancer helpline between 1. | National Cancer Institute's Cancer Information Service (CIS) | Gender:<br>80% female<br>20% male | Reasons for calling:<br>Specific treatment information | Associations between reasons for calling and demographic characteristics: |

| | | | | | |
|---|---|---|---|---|---|
| | September 2002 and 31. August 2003<br><br>To characterize callers information needs<br><br>To summarize differences by demographic characteristics | Total number of calls:<br>N=188 570<br>Subsample analysed:<br>N=83439<br><br>14% Family/friends | Age:<br>39 and below: 27%<br>40-59 years: 47%<br>60+ years: 26%<br>Race:<br>86% white<br>Education:<br>1% Grade school<br>27% Some high school/high school<br>57% college graduate, post-graduate training | General cancer site information<br>Referrals to medical services<br>Support services<br>Psychosocial issues<br>Cancer screening and diagnosis | Gender differences<br>More female than male caregivers inquired about general cancer site information, support services, psychosocial issues, cancer screening/diagnosis, and prevention/risk factors<br>Females more likely to request general cancer site info and to discuss psychosocial issues than males. Males more likely to request specific cancer information.<br><br>Education differences<br>As education levels increased, so did the proportion of calls regarding specific treatment information, referrals to medical services/organizations<br>Frequency of calls about support services where higher in those with less than a high school degree.<br>Caller with higher levels of education more likely to seek specific treatment info, referral to medical services and info about organizations, and less likely to inquire about support services.<br><br>Age differences<br>As age increased, the proportion of calls regarding |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | general cancer site information, support services, referrals to medical services decreased. A greater proportion of older caregivers requested specific treatment information than younger caregivers. The percentage of caregivers calling about psychosocial issues was greatest among those aged 40-59. Older age groups more likely to request specific treatment info, younger age groups more likely to request general cancer site info and info on support services |
| Salako 2016 [60] Nigeria | Descriptive study of call data to three breast cancer helplines over a three months period | Sebeccly Cancer Care & Support Center – three breast cancer helplines in Lagos, Nigeria<br><br>Total number of calls: N=294<br><br>18% Relatives/family (13% patients) | Combined data only | Combined data only | |
| Slevin 1988 [61] UK | Evaluation of the BACUP service through call record forms and postal questionnaires<br>In the period of October 1985 to November 1987 | British Association of Cancer United Patients and their Families and Friends (BACUP) – CIS<br><br>Total number of calls: N=30 000<br><br>39% Relatives/friends (32% patients) | Combined data only | Combined data only | Impact:<br>67% of relatives/friends shared the information received with the patient<br>Overall satisfaction:<br>Combined data only |
| Sanders Thompson 2008 [62] USA | Audit of call data from African Americans who | National Institute of Cancer CIS service | Combined data only | Topics discussed:<br>10% prevention/risk factors | Spouses, relatives, friends were less likely to seek |

| | | | | | |
|---|---|---|---|---|---|
| | contacted the helpline in the period of 2000-2004<br><br>To assess cancer information seeking among this population group | Total number of calls:<br>N=408 220<br>Calls from African Americans: N=32 834<br><br>30% relatives/friends (26% patients) | | 47% psychosocial issues | medical referrals, referrals for support services - and were less likely to discuss prevention information but more likely to discuss psychosocial topics |
| Vanderpool 2011 [63] USA | Cancer helpline call data from 2006-2008 to assess calls received from rural-urban areas regarding clinical trials discussions | National Cancer Institute's CISs<br><br>Total calls received:<br>N=283094<br>Geographically coded calls:<br>N=54842<br><br>34% relatives/friends (27% patients) Urban areas:<br>34% relatives/friends (27% patients)<br>Rural areas:<br>37% relatives/friends (30% patients) | Combined data only | Topics discussed:<br>Clinical treatment trials<br>Total: 16%<br>Urban areas: 16%<br>Rural areas: 14% | Family members/friends are 6 times more likely to engage in a clinical trials conversation than other callers (general public, healthcare providers) |
| Venn 1996 [64] UK | Callers to the BACUP cancer information service were invited to take part in a postal survey. Study was conducted over 10 working days in August 1991.<br><br>To evaluate access, reasons for calling, satisfaction with the information and service received | The British Association of Cancer United Patients (BACUP) cancer information service<br><br>Total sample who responded to the postal survey: N=282<br><br>62% relatives, friends (36% patients) | Combined data only | | Perceptions of the information received:<br>Combined data only<br><br>Impact and overall satisfaction:<br>Combined data only<br><br>Predicting impact and satisfaction:<br>For relatives and friends:<br>Emotional impact was predicted by the nurse's perceived communication skills. Overall satisfaction |

| | | | | | |
|---|---|---|---|---|---|
| | | | | | was predicted by the perceived quality of information and the nurse's communication skills |
| Dewing Ward 1998 [65]<br>USA | A random sample survey of callers to the cancer helpline in 1996 conducted over a 6-weeks period<br>to assess satisfaction and impact of the service | National Cancer Institute's CIS<br><br>Total sample: N=2489<br><br>49% relative, friend<br>(51% patients) | Combined data only | Combined data only | Impact:<br>Sharing of information<br>76% discussed telephone information with the patient<br>76% shared printed material with the patient<br>Satisfaction:<br>Combined data only |
| Jefford 2005 [68]<br>AUS | Audit of utility and profile of callers to Australian Cancer Council helplines during months of July, August and September 2001-2003 | Call data collected by the National Cancer Information Service Network (NCISN), including all Australian states (except Northern Territory)<br><br>Total number of calls:<br>N=76000 | Cancer types family/friends enquired about:<br>Colon<br>Prostate<br>Breast Other malignant skin<br>Cervix uteri | | |
| Sutherland 2005 [69] 2005 | Calls to the cancer helpline from 1 January 2003 to 31 December 2004 in which callers discussed diet and nutrition | Calls to the Victorian Cancer Council helpline service<br><br>Total number of calls involving diet, nutrition discussions: N=1918<br><br>36% family/friends<br>43% (patients) | | Topics discussed:<br>by family/friends<br>13% Unproven cancer-related diet and nutrition cancer<br>9% Risk factors/causes<br>8% Early detection<br>6% Food and nutrition programs<br>4% Cancer prevention<br>Resources provided:<br>Printed material sent to family/friends:<br>41% Tips for eating well<br>7% General nutritional guides, cookbooks<br>5% Healthy eating to reduce cancer risk | |