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Mapping and understanding specialist cancer and cancer- related helplines in the UK: Executive summary

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Study Investigators

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Executive summary

Background

The University of Southampton undertook a research project funded by Dimbleby Cancer Care (referred to hereafter as DCC). The aim of this research project was to map and understand specialist cancer and cancer-related helplines in the UK.

This research formed part of a larger body of work using Conversation Analysis to explore how cancer helpline calls are structured and accomplished to identify features that are likely to optimise effectiveness (funded by a NIHR personal Fellowship Award (Dr GM Leydon) and a PhD studentship (Ms C Woods)).

Rationale

Helplines are a core feature of the contemporary UK health care system and the importance of them has been acknowledged by the UK Department of Health. With an increasing need for the National Health Service (NHS) to find less costly methods of health care, which can be accessed by large numbers, it is timely to consider the role of cancer helplines. There is a clear demand for telephone based cancer care and as the UK population ages and the number of cancer survivors increase, demand is likely to rise.

There are over 1500 UK helplines in operation, yet we have scant knowledge about the process of delivering and seeking cancer-related telephone help. The literature on face-to face communications identified that sometimes patients do not receive the information or supportive care that they need. Equally, as services increase in number, it may become difficult for service commissioners, existing and start-up helpline organisations, to gain a strategic overview of the cancer helpline landscape to identify gaps in service, points of overlap and possibilities for co-ordination or integration.

This research is aimed to provide a comprehensive and up to date picture on current cancer and cancer-related helpline service provision both in terms of the number of helplines, and the services provided.

An electronic questionnaire survey aimed to provide a national picture as to what specialist cancer and cancer-related helplines exist in the UK, and to better understand what each helpline does in terms of their role and remit and relationship with other helplines, and lastly to understand the challenges they face. Qualitative interviews were undertaken with callers and call-handlers to ascertain their views and experiences of providing and receiving telephone help.

The study strands

The research project comprised three inter-related phases:

- i) A comprehensive identification phase to map UK Cancer and Cancer-related Helplines.
- ii) An electronic questionnaire survey to identify helplines.
- iii) Interviews with callers and call-handlers on cancer helplines.

Key results are presented in the Executive Summary.

Comprehensive mapping exercise

Aims

- i) To identify and map specialist cancer and cancer-related helplines in the UK and services provided to establish current provision.

Methods

Design

The use of online search facilities, cancer/cancer-related helplines and organisations websites and paper based directories were used to identify and compile a database of UK Cancer and Cancer-related Helplines.

Setting

Online search facilities and paper based directories. An excel spread sheet for the compilation and mapping of cancer and cancer-related helpline services.

Participants

Cancer and cancer-related helplines identified by the mapping exercise.

Main outcome measures

A comprehensive database of UK Cancer and Cancer-related helplines and a defined list of organisations identified as eligible to receive the questionnaire survey.

Key results

The mapping exercise identified a total of 152 helplines, of whom 98 were identified as eligible. The survey was sent out to 95 helplines (three helplines determined that they were

ineligible and elected not to participate as they felt that they did not directly deliver a cancer helpline service or their remit was not specifically cancer). Of the 95 eligible helplines that the questionnaire was sent to, 69 completed and returned the survey.

Electronic questionnaire survey

Aims

- i) To establish which specialist cancer and cancer-related helplines exist in the UK.
- ii) To understand the role and remit of each helpline (e.g. caller volume, caller type, caller profile, staff training and supervision).
- iii) To understand the relationship between helplines (e.g. integration and co-ordination of activities).
- iv) To understand the challenges that helplines face.

Methods

Design

An electronic questionnaire survey (administered using Survey Monkey).

Setting

An online questionnaire to cancer and cancer-related helplines identified as eligible via the comprehensive mapping exercise.

Participants

Ninety-five cancer and cancer-related helplines were eligible and were sent a survey and a total of sixty nine helplines completed and returned the questionnaire survey.

Main outcome measures

- Descriptive and statistical analyses of the questionnaire survey results e.g. basic descriptive statistics of the results of all survey questions and further analysis e.g. cross tabulations to assess associations between key variables.
- Production of a UK National Directory of Cancer and Cancer-related Helplines.

Key results

- i) A total of 69 (73%) of the 95 surveyed cancer and cancer-related helplines completed the survey.

Helpline Service Information

- Helplines/organisations provided both cancer specific and cancer-related services.
- Most helplines/organisations were registered charities.
- Donations formed the basis of the main sources of income for helplines/organisations.
- Nearly a third of helplines did not operate a triage system.

Helpline Services offered

- The main capacity in which people used helpline services was as someone living with cancer.
- Signposting and emotional support were cited as the main services offered on helpline.
- Approximately 60% of helplines reported that their helpline did not cover all cancer types.
- Over 70% of helplines had national coverage and served all age groups and nearly all helplines served both genders and all ethnic groups.
- Nearly a third of helplines had a standard voicemail system in place where a message could be left (e.g. a call back facility).
- Approximately 45% of helplines had a geographic helpline number and approximately 13% had a number that was free from landlines and most mobile networks.
- Approximately a third of helplines reported that they had no provision in place for speakers of other non-English languages.
- Over 50% of helplines reported that they had no specialist provisions in place e.g. for callers with hearing, speech/communication difficulties, visual and physical impairment and learning disabilities.

- The use of email as a supportive communication channel to the helpline was available in nearly all helplines with a growing presence on social networking sites, especially Facebook and Twitter.
- Over 80% of helplines signpost their helpline users to other helplines. Macmillan Cancer Support, Cancer Research UK and Breast Cancer Care were popular helplines for organisations to signpost their users to.

Caller Profile Data

- The general trend in caller demand over the last five years was an increase in calls to helplines.
- Approximately 40% of helplines/organisation did not collect information on the type of caller profile data. If this information was collected, it tended to be based on individual calls.
- The main age profile of callers to the helpline were those in the 26 to 65 age group. Females formed the majority of callers to helplines. The majority of callers to helplines were White British/Irish/Any other White background. The ethnic group that tended to call helplines the least was Black or Black British African or Caribbean group.

Staffing, Training and Development

- Most of the helplines had other 'non-clinical' staff or volunteers working on the helpline. This was followed by nurses and welfare and benefits professionals.
- The main experience for clinical staff working on helplines was previous experience of working within the cancer field. For other helpline staff, the main experience was previous experience of chronic illness and previous experience of working within the cancer field.
- Approximately 65% of helplines reported that their staff received induction training and 60% reported that supervision was available.
- Debriefing sessions were the main kind of formal support reported by the helplines surveyed. This was followed by 'time-out' and formal counselling. Nearly a third of helplines reported that they had no formal system in place.
- Approximately 60% of helplines reported that staff made use of the formal methods of support available to them.

Helpline Monitoring and Assessment

- Over 50% of helplines had no form accreditation in place. Approximately 11% of helplines/organisations reported that they had the Telephone Helplines Association (THA) Quality Standard; a further 13% reported that they had the Information Standard.
- Over 50% of helplines reported that they were aware of the THA and the Helplines Association Quality Standard. Approximately 38% of helplines reported that they were a member of the THA and a quarter reported that they were working towards the THA Quality Standard.

The Future

- Over 50% of helplines reported that they had no planned or anticipated changes in the delivery of their helpline service.
- The main organisational service challenges reported by helplines were technological advances, e.g. the use of the internet, funding, maintaining quality of the helpline service, changes in demand, competition and duplication from other helplines, publicity and service promotion and ambiguity of the service.
- The main operational service challenges included staff recruitment and retention, limited staffing and capacity and availability of time. Training opportunities and managing expectations of callers were also cited to be operational challenges.

Interviews

Aims

To ascertain the views and experiences of callers and call-handlers on cancer helplines on providing and receiving telephone help and support.

Methods

Participants

Participants involved UK cancer helpline callers and call-handlers.

Data collection and analysis

In-depth semi-structured interviews were conducted with the participants either face-to-face or over the telephone. The audio-recorded interviews were transcribed verbatim in preparation for inductive thematic analysis (following the principles of constant comparison), assisted by NVivo 8 software.

Key results

Interviews:

In total 32 helpline callers were interviewed. Of these, 22 were cancer patients, 9 were carers or family members and 1 interviewee was a friend of a cancer patient. There were 25 female, and 7 male caller interviewees. Additionally, 30 call-handlers were interviewed from three cancer helplines with various levels of experience (ranging 10 months to 16 years) and a range of men (n=7) and women (n=23).

Caller interviews:

- Callers were often apprehensive about making their first call to a cancer helpline, but most felt relieved and reassured after making the call.
- Helplines appealed to callers because they could be used at times that were convenient to them, and could be made from the comfort of their home.
- Callers typically reported using a cancer helpline due to time constraints or other limitations with their consultations with other healthcare professionals.
- The most common reasons for calling a cancer helpline were for medical information, emotional support or advice.

- Call-handler manner was important. For example, when callers spoke with a call-handler who was “blunt” or “not empathic” towards them, callers described being dissatisfied with their call, even if they had received the information they were originally seeking.
- Callers described call-handlers as being like ‘anonymous friends’; knowledgeable with the characteristics of a good friend, but also anonymous and detached from the caller’s personal situation.
- Callers described how they viewed the helpline as an anonymous service as being a key advantage of cancer helplines, as they did not always want to burden those in their close social network with their questions or worries.

Call-handler interviews:

- Call-handlers described their core roles on the helpline as information-giving, support, and, for some, advice-giving, and described these roles as often overlapping.
- Call-handlers’ perceptions about giving advice to callers varied among participants – some described advice-giving as outside their remit whilst others reported sometimes providing advice to callers, particularly recalling occasions when they had recommended a caller to visit their doctor. Several call-handlers reported that they experience a blurring of clear boundaries between advice and information-giving
- Most call-handlers interviewed reported that there are tasks that fall outside of the remit of the helpline such as counselling, specialist support for mental health problems and non-cancer related information. Mental health issues were described as particularly challenging.
- Call-handlers also described the difficulties of managing callers’ expectations about the type of service they could offer.
- Other challenges faced by call-handlers involved support-related challenges, including identifying the support needs of callers over the phone, which often varied from caller to caller.
- Call-handlers also reported knowledge-related challenges including keeping up to date with cancer information, and needing a broad knowledge base as well as knowledge on specialist cancers. Most interviewees described feeling that they needed more time for continued development courses and research to keep up to date with cancer policy, information and the research literature.

The full report provides an integrated summary, and recommendations.

The Cancer Helpline Directory can be downloaded for free at:

<http://www.forms.soton.ac.uk/calm/>