

Why you should read this article:

- To acknowledge the psychological care needs of people living with cancer and their families and carers
- To understand why there are unmet needs for psychological cancer care in the community
- To gain insight into the views of primary and community healthcare professionals on provision of psychological cancer care

Understanding the demand and unmet need for psychological cancer care in the community

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Citation

Lawler J, Leary A, Lofton L et al (2020) Understanding the demand and unmet need for psychological cancer care in the community. *Cancer Nursing Practice*. doi: 10.7748/cnp.2020.e1680

Peer review

This article has been subject to external double-blind peer review and has been checked for plagiarism using automated software

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Conflict of interest

None declared

Accepted

6 December 2019

Published online

February 2020

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Abstract

Background Cancer policy has long called for improved access to psychological care for people living with cancer and their carers. However, the psychological effects of cancer and its treatment remain a neglected area of care.

Aim To explore the views of primary and community healthcare professionals in London on their provision of psychological care for people living with cancer and their families and carers.

Method In this service evaluation, an exploratory sequential design was used to survey and interview primary and community care staff in London about their cancer care work. Descriptive integration was used to merge the quantitative data from the questionnaires and the qualitative data from the interviews to enable comparison and analysis.

Findings Questionnaire responses were received from 92 staff and seven interviews were conducted. It was identified that participants wanted to offer more psychological care, including peer support groups, and that further training in this area is necessary. Participants also reported that care for family and carers was lacking. GPs' and district and community nurses' provision of bereavement care was reported to be not only reactive, but also variable across London and without clear structure or protocol. Psychological care was suggested to be a driver of secondary workload.

Conclusion Psychological care for people with cancer and their carers in primary and community care settings is not meeting demand and requires increased resourcing in terms of funding and time.

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Keywords

bereavement, bereavement support, cancer, carers, end of life care, families, living with and beyond cancer, mental health, patients, professional, psychological care, survivorship

Background

In 2004, the National Institute for Health and Care Excellence (NICE) published guidance on palliative care for adults with cancer. An important recommendation of this guidance was that all patients should have access to appropriate psychological support. The guidance also recognised the unmet needs of carers and recommended the development of services focusing on the needs of carers during their relatives' lives and in bereavement.

Furthermore, services for carers and families were described as 'poorly developed' in many parts of England and Wales (NICE 2004).

Many years after the publication of this guidance, the psychological effects of cancer and its treatment remain a neglected area of care that is not given the funding or priority it requires, and the psychological needs of people living with cancer and their carers are still not being met (Transforming Cancer Services Team for London (TCST) 2018).

Needs of people living with cancer

People living with cancer are most commonly affected by psychological issues in the first year after diagnosis, but it is well documented that such issues are experienced from presentation of symptoms to survivorship (Gao et al 2010).

Ten years after treatment, 54% of cancer survivors still experience at least one psychological issue (Macmillan Cancer Support 2014). As a result of their cancer diagnosis, three quarters of people living with cancer experience anxiety, but less than half of them (44%) receive support, information, advice or treatment for this (Macmillan Cancer Support 2006).

The identification and treatment of psychosocial issues for people with cancer is reportedly commonplace in primary care, but data on this has been found to be limited (Shipman et al 2002, Pascoe et al 2004). Screening people living with cancer for psychological issues is not routine and care is most commonly self-referred, despite the literature suggesting that screening could be beneficial (Sanjida et al 2018). When the emotional and psychological needs of people living with cancer are left untreated, their use of community healthcare services, hospital and visits to their GP increase (Carlson and Bultz 2004). Many people living with cancer have unmet needs and would benefit from improved access to psychosocial resources (Armes et al 2009), but in recent years financial pressures have made it increasingly challenging for them to access mental health services (Robertson et al 2017).

Needs of families and carers

Families and carers of people living with cancer experience vicarious psychological issues (Thomas et al 2002, Rossi Ferrario et al 2004). Among carers, 67% experience anxiety and 42% experience depression, with three quarters of these carers not receiving any support (Macmillan Cancer Support 2014). Murray et al (2010) suggested that family carers share many aspects of the illness experience of people living with cancer.

Vicarious psychological distress can be particularly prevalent in 'emotion work', where carers attempt to manage the emotions of people living with cancer as well as their own (Thomas et al 2002). Emotional and psychological distress is also experienced after the death of the person who had cancer and can be long term (Rossi Ferrario et al 2004).

Evidence suggests that families and carers have an important role in managing people with cancer at home and experience substantial emotional, social and financial strain (Rossi

Ferrario et al 2004, Ullgren et al 2018). Additionally, psychological morbidity has been shown to be substantially higher in carers than in the general population (Grande et al 2018).

Many carers report not receiving information about caring at home or support from health and social care services, although much of this information could be made available online and locally (TCST 2018). It has also been identified that there is a lack of evidence-based strategy to guide healthcare professionals in supporting carers while they are providing care and after a bereavement (Zwahlen et al 2008, Hudson et al 2012).

In the 2018 National Cancer Patient Experience Survey (NCPES) (2018a), 60% of respondents said that 'the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home'. Among NHS trusts in London, the trust with the lowest score for that question had only 36% of respondents (all cancer types) answering affirmatively (NCPES 2018b). These figures suggest that there is a significant number of people living with cancer who do not believe that their carers receive the information they need from healthcare services.

Service provision inequities in London

In London, commissioning recommendations state that primary and community healthcare professionals should have easy access to psycho-oncological services in secondary care, but mapping has revealed inequities in service provision, with some areas having no access to such services. According to TCST (2018), bereavement services are 'currently not clearly commissioned across London', leading to inequality in their provision, and they have called for the development of a psychologically minded culture across all cancer services.

Collaborative working with secondary care and third-sector providers through the Improving Access to Psychological Therapies (IAPT) initiative is an area for further development, in particular to maintain community services' responsibility in offering psychological cancer care to people with limited mobility and those who are housebound (London Strategic Clinical Networks 2015). Exploration of the workforce's views on what care is being missed in this area is needed.

Aim

To explore the views of primary and community healthcare professionals in London on their provision of psychological care for people with cancer and their families and carers.

Method

Study design

This service evaluation used a mixed-methods approach and an exploratory sequential design. Initial views of primary care staff had been identified via a focus group, before questionnaire data were collected and interviews were conducted. The exploratory sequential design ensured that the views of participants were heard before the area of enquiry was defined.

As part of a larger study of soft-system modelling (Checkland 1989) of London cancer services, a focus group had been carried out with seven primary care staff. The focus group included GPs and nurses, who discussed their work with people with cancer. The outcomes of the focus group, as well as a review of literature on the subject, revealed that some of the cancer care work carried out by primary care staff goes unrecorded and unrecognised. This was the motivation for conducting the service evaluation. The outcomes of the focus group provided guidance for constructing the interviews.

A previously validated self-completion questionnaire was devised based on a previous evaluation of the work left undone in oncology nursing (Leary et al 2014, 2018, Stewart et al 2018). The questionnaire explored topics such as cancer-related caseload, overtime, care for carers and bereavement care, and included free-text questions. It was distributed through Health Education England's (HEE) weekly London newsletter, which was emailed to 300 people, and was accessed via an online link.

At the end of the questionnaire, respondents were invited to take part in an interview. Those who expressed interest received an information sheet and were contacted up to two times to arrange the interview. The interviews were one-off semi-structured qualitative interviews that were carried out by telephone and audio recorded. They covered participants' views of their involvement in cancer care and sought to gain a deeper understanding of their lived experience. Box 1 shows the interview questions.

The area of enquiry was defined as an exploration of the views of primary and community healthcare professionals on their provision of psychological care for people with cancer, and their families and carers. The mixed-methods approach enabled participants to reflect and expand on questionnaire responses in the interview, and the researchers to gain breadth and depth in the area of enquiry. The order of data collection aided recruitment for the interviews.

Data analysis

This was a secondary analysis of data. Quantitative questionnaire data were

summarised using descriptive statistics in Excel. A descriptive phenomenological framework underpinned the secondary analysis of the interview data. Phenomenology is an approach that is used to gain insight into personal experiences and perspectives of individuals in relation to a certain phenomenon. Husserl's foundational writings on phenomenology aided the development of the descriptive phenomenological framework, which provides an understanding of a current or naturally occurring situation (Cohen 1987, Lopez and Willis 2004). It seeks to understand rather than explain, and to gain depth rather than draw any generalisations. Phenomenology acknowledges the subjectivity of the researcher but asks that this is set aside. The analysis of findings includes description, reduction and identifying essence (Giorgi et al 2017).

Interviews were transcribed and thematically analysed (Braun and Clarke 2006) using NVivo software version 10 (QSR International). Identifying thematic aspects is frequently used in phenomenology (Morse 1991, Holloway 2005, Vaismoradi et al 2013). Descriptive integration was used to merge the quantitative and qualitative data to enable comparison and analysis. Triangulation ensured rigour and enabled the researchers to test consistency between the different data sources (Patton 1999).

Ethics

This service evaluation was subjected to review by the NHS Ethical Committee Health Research Authority. It was subject to proportional review and deemed an evaluation. Potential participants were provided with an information sheet before their involvement and written consent was obtained from all those who took part. Participation was voluntary and participants were reminded that they were free to withdraw at any point. The data were anonymised to maintain participants' confidentiality.

Findings

Questionnaire findings

The questionnaire received 92 responses out of 300 recipients of the HEE newsletter (response rate 31%). The completion rate was

Box 1. Interview questions

1. Can you tell me about the type of work you do for people with cancer?
2. If you can recall your workload last week on a particular day, were you in contact with a person with cancer?
3. Is there any of your work you think goes unrecorded or unrecognised?
4. Are you involved in work to do with preventing cancers and risks of cancers?
5. If time and money were no object, what work would you like to be doing in cancer care that you are not able to do now?

100%, although only 96% of respondents completed the free-text questions. Responses were received from:

- » GPs (partner, salaried, trainee, locum, portfolio) ($n=35$).
- » Advanced nurse practitioners ($n=22$).
- » District nurses ($n=17$).
- » Community nurses ($n=6$).
- » Practice nurses ($n=5$).
- » Healthcare assistants ($n=2$).
- » Care navigators ($n=2$).
- » Clerical and admin staff ($n=2$).
- » Advanced clinical practitioners ($n=1$).

Additional services

Respondents were asked what additional services they would like to offer people living with cancer if money and time were no object. The majority of answers referred to psychological care. Respondents identified the need for patient peer-support groups and suggested 'open days' in community services for people with cancer to meet other people. They also suggested more counselling and support for people with cancer and their families and carers:

'Group workshops, patients are often less anxious in a familiar setting. Care for the carers' (Advanced nurse practitioner).

'Psychological support for cancer patients and carers within primary care' (GP partner 1).

'Pre-bereavement counselling' (Community nurse).

'Mental health support in practices' (GP partner 2).

'Just more time to be more regularly supportive, and also to the families of affected patients' (GP partner 3).

Bereavement care

Respondents were asked about their provision of bereavement care to families and carers. Answers varied between and within professions. The consensus among GPs was that bereavement care was not an explicit part of their job, but that they either made a proactive effort in particular cases or if patients initiated this:

'Only if they come to see me because they need help' (Salaried GP).

'When people come to me. There is no proactive support' (GP partner).

Of 29 GPs who answered that question, around one quarter reported not being involved in bereavement care at all. GPs described their pre-bereavement and bereavement work as supporting people to develop positive attitudes towards living with cancer, as well as acceptance of death, psychological support, medication and arranging time off work.

District and community nurses were the group that reported the most regular bereavement work in the form of visits and phone calls. The structure of this work seemed to vary across London, most commonly starting with a bereavement visit after a death followed by either a phone call after one month, and continuing care as requested, or an additional follow-up visit between six and 12 months after death. The visits seemed to include signposting to support services and collecting any equipment in the home:

'Always provide family with bereavement visit and follow up, their choice of this continues and sometimes not wanted at all' (District nurse).

'We normally do a follow-up visit to ensure the family members are coping with the recent loss and to signpost relevant support agencies if required' (Community nurse).

'Following a patient's death, we always perform a bereavement visit and this is usually the last we have to do with the family, which is sad as we have played a very important part of patients' lives till this point. The remaining spouse then not only has to deal with a death but frequently then has no visitors' (District nurse).

Some advanced nurse practitioners noted the lack of structured protocols for bereavement care:

'Not formally' (Advanced nurse practitioner 1).

'Support as needed' (Advanced nurse practitioner 2).

'Yes but generally only for regular patients or opportunistic' (Advanced nurse practitioner 3).

Interview findings

Seven interviews were carried out with three GPs (one partner, one salaried and one locum), two district nurses, one advanced nurse practitioner and one care navigator. Table 1 shows the themes identified from the interviews and selected participant quotes.

Psychological care

Offering people with cancer time to talk through concerns, and providing psychological care and social prescribing links, repeatedly came up as areas where participants wanted to do more:

'Psychological care would probably be the same for both the cancer patients and the non-cancer patients, which is more care, the thing that is limiting us at the moment is social care' (Care navigator).

'Just trying to get them an appointment quickly to help them come to terms with their diagnosis or just somebody to talk to about it is... I don't know where to refer them to' (Advanced nurse practitioner).

'I do spend a lot of my time on the psychological element of it, how long are they going to feel like this for and the depression associated with treatment and uncertainty. So there's a lot of the psychological element that isn't picked up and it's hard to quantify that' (Locum GP).

'More social prescribing: having social prescribing facilities within CCGs [clinical commissioning groups]. Because a lot of the stuff is not medical. And actually having a social prescribing link, care navigators, social prescribing, psychological services and, I think, just more resources in primary care: more training' (GP partner).

Interviews suggested that psychological care extended to the families, friends and carers of people living with cancer:

'We see vicariously indirect results of cancer as well. One lady who I see quite regularly, who is a carer for her sister who has got terminal cancer, and even though her sister is not my patient, her primary reason to come to see me is because her mood is very low because she's a carer for her sister who is dying' (Salaried GP).

'I don't know how everybody else does it but I, personally, make sure that whoever is looking after that person is okay, if they've got any questions or any help that they need. Because there's always a lot of focus on the patient but I always make sure that those that are caring for the patient are supported as well' (District nurse 2).

Signposting to relevant and available services was reported to be time consuming, with the advanced nurse practitioner citing issues with finding out where to signpost carers of people recently diagnosed with cancer to:

'This was for the just recent diagnosis or some of them that had just had a family member diagnosed as cancer, but they were the main carer and they wanted the help. I just never knew where to signpost them to. I don't think that exists' (Advanced nurse practitioner).

GPs noted that they spent significant time finding available support services for patients and their families and carers. The services they recommended varied from psychological support, helpdesks and general advice to support groups and social groups. All three GPs said that there was no set list of resources they could refer to and that their signposting was often guided by contacts or previous knowledge. This was an area of cancer care that was suggested as potentially easy to improve with a structured set-up. Moreover, many of the services GPs wanted to recommend to their patients were either not available, or resources were limited so patients experienced waiting lists:

'When they've just had a diagnosis of cancer or are going through cancer treatment it's very tough for them to be motivated to go to the centre, to pick up the resources, to read them and then proactively know where to go' (Locum GP).

Bereavement care

All three GPs commented that there were no set bereavement care plans in place for any illness, including cancer. This meant that they spent a lot of time attempting to find available care, which could be challenging to find or hindered by access issues. GPs felt they were offering bereavement and psychological care without having received specific training:

'There is no set plan. It's entirely practice/physician dependent. Sometimes, I find I'm a bereavement counsellor GP, particularly if I know the patient well enough' (GP partner).

'It is extremely difficult to find a bereavement service. It's a challenge' (GP partner).

'We do have a commissioned bereavement service, but they can't access it for six weeks, so for the first six weeks they are ours' (Locum GP).

This lack of bereavement service in the first six weeks was explained by the belief that six weeks of grieving is natural and that if people sought support after that time, then bereavement care would be offered to them.

One of the district nurses discussed a 'three-visit rule' to keep within constrained budgets and mitigate staffing shortage:

'We do a general bereavement visit, just to see how they're coping. But that's pretty much straightaway. So it's not further down the line. At the minute, we've got a "three-visit" rule' (District nurse 2).

Table 1. Themes identified from interviews and selected participant quotes

| Theme | Participant quotes |
|--|---|
| Psychological care for people with cancer | 'We spend a lot of our time providing psychological support when actually we're not experts in this' (Locum GP) |
| | 'It's always hard to keep up with what is available. So I think a big role for GPs is signposting' (Salaried GP) |
| Psychological care for families and carers | 'There's always a lot of focus on the patient but I always make sure that those that are caring for the patient are supported as well' (District nurse 2) |
| | 'They were the main carer and they wanted the help. I just never knew where to signpost them to. I don't think that exists' (Advanced nurse practitioner) |
| Bereavement care | 'It is extremely difficult to find a bereavement service. It's a challenge' (GP partner) |
| | 'We do have a commissioned bereavement service but they can't access it for six weeks, so for the first six weeks they are ours' (Locum GP) |
| | 'There's no practice policy for that, it's just what individual GPs do I guess' (Salaried GP) |

Implications for practice

- Structured and proactive protocols for psychological cancer care in primary and community care settings are required to provide clarity and standardised guidance
- Consulting people living with cancer and their families and carers is necessary to understand the variety of support they need and when and where it is best provided
- Psychological and bereavement care for people living with cancer and their families and carers requires a higher priority and requires increased resourcing in terms of funding and time

Discussion

The findings of this service evaluation suggest that psychological care for people living with cancer and their carers is a driver of secondary workload. Participants identified that they did not have appropriate time, training or resources to offer the psychological care that people with cancer needed. Furthermore, being able to find relevant services to signpost people living with cancer to was challenging and led to a workload burden. This concurs with literature in the field (Shipman et al 2002, Robertson et al 2017). The NCPES currently has no questions that relate to patients' experiences of psychological or emotional care. As evidenced in the literature, psychological care is an important part of cancer care (Gao et al 2010, Macmillan Cancer Support 2012, 2013), so a question in the NCPES to understand patients' experiences of it could be beneficial.

Participants identified a lack of provision of psychological support, pre-bereavement and bereavement care, and were dissatisfied with the level of care they were providing. In a 2016 survey of 892 UK carers of people living with cancer, emotional support came first among the types of further support that carers thought would be helpful, while GP surgeries were identified as the top preferred source of support (Macmillan Cancer Support 2016). This service evaluation identified that psychological care in cancer requires increased resourcing in terms of funding and time. This may need to be reflected in changes to the current cancer care workforce, with an increase in mental health therapists, counsellors and psychologists based in primary and community care settings.

In 2016, NHS England announced plans to recruit and fund 3,000 new practice-based mental health therapists to address the gap between the supply of and demand for psychological care in primary care, but the percentage of GP surgeries employing a mental health therapist has remained level at 10% (Cogora 2019).

The NICE (2017) quality standard on end of life care for adults includes a statement on bereavement support, which states that people closely affected by a death should be communicated with in a sensitive way and offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences. Despite this, in this service evaluation, bereavement care was described as inaccessible in the first six weeks of bereavement. Participants reported that, since there were no set bereavement care plans, they

spent a significant amount of time searching for appropriate care for the bereaved. Having set bereavement care plans and/or databases of available resources would save them significant time. Furthermore, the findings suggest that healthcare professionals would benefit from receiving further training in bereavement care. This area of work may continue to increase with the rising prevalence of cancer.

The lack of clarity regarding bereavement services is evident in the literature (TCST 2018). The evidence on which GPs and practice nurses can base their bereavement care delivery is limited and the manner in which bereavement care is delivered in primary care settings is unclear and variable (Payne et al 2002, Nagraj and Barclay 2011). Routine proactive care for bereaved people would be a productive preventive measure that is not currently commonplace. GPs' referral decisions for people who have experienced a bereavement may be biased by assumptions regarding patients who are not presenting with abnormal bereavement symptoms (Wiles et al 2002).

Predictive risk factors have been evaluated in carers to identify their psychological needs post-bereavement (Kelly et al 1999, Rossi Ferrario et al 2004). Research has long identified that carers of people with cancer may have unmet psychosocial needs (Soothill et al 2002, Wang et al 2018). However, constraints on primary and community care are resulting in insufficient provision of pre-bereavement and bereavement care (Shipman et al 2002, Hudson et al 2012, Robertson et al 2017).

In this service evaluation, bereavement care was described as reactive, with no set bereavement plans and initiated mainly by the individuals themselves. Efforts to work proactively with predictive models would benefit carers and healthcare professionals, and assist in avoiding potential adverse effects of bereavement and extra workload.

The NICE (2004) guidance recognised that there is no consensus on the services that should be provided to people living with cancer and carers experiencing psychological distress and that, as a result, many of them are not able to access the services they require. One of the recommendations in the NICE (2004) guidance was that staff in contact with people living with cancer should be adequately trained and supervised in screening for distress and offering general psychological support. GPs have an important role in this and nurses are in an optimal position to identify and respond to patients' psychological care needs. The findings of this service evaluation suggest that this recommendation has had limited effects.

Limitations

The findings from this service evaluation provide an insight into the views of a small group of primary and community care staff in London and therefore cannot be generalised. There is also a risk of oversimplifying views at this scale. The questionnaire was distributed through a HEE mailing list and subsequently shared on the Queen's Nursing Institute's Twitter feed, so the exact number of people reached is unknown and the response rate is an estimation.

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