**Understanding the demand and unmet need of providing psychological cancer care in the community**

**Abstract**

**Background:** Cancer policy has long called for improved access to psychological care for people with cancer and their carers. **Purpose:** This mixed-methods evaluation aims to explore some of the views of primary and community healthcare professionals in London on their provision of psychological care for people with cancer and their carers. It explores their opinions of what they are currently doing, and what they would like to do more of. **Method:** An exploratory sequential design was used in surveying and interviewing primary and community care staff in London about their cancer care work. Interviews were analysed from a phenomenological perspective. **Results:** 92 questionnaire responses were received (RR=31%), and 7 interviews were conducted. Respondents wanted to offer more psychological care, including peer support groups. Further training in this area was identified as necessary. Care for family and carers was reportedly lacking; this group had perceived unmet needs. GPs’, District and Community Nurses’ provision of bereavement care was reported to be reactive, variable across London and without clear structure or protocol. **Conclusions:** Respondents identified that psychological care for people with cancer and their carers isn’t meeting demand and requires better resourcing. Psychological care was suggested to be a driver of secondary workload.

**Key words:** cancer, psychological care, bereavement, carers, workforce policy, workload, primary care

**Introduction**

In 2004, NICE released guidelines on “Improving Supportive and

Palliative Care for Adults with Cancer”. A key recommendation of this was to “ensure that all patients have access to appropriate psychological support.” It also recognised the unmet needs of carers and recommended the development and implementation of services that specifically focus on the needs of carers during people with cancer’s (PWC) life and in bereavement (NICE, 2004). Services available for carers and families were described as “poorly developed”. Fifteen years after the release of these guidelines, the psychological needs of PWC and their carers are still being repeatedly identified as unmet.

Ten years after treatment, 54% of people with cancer suffer from at least one psychological issue (Macmillan, 2013). Those living with cancer are most commonly affected by psychological distress during their first year after diagnosis, however, it is well documented that this is experienced from presentation of symptoms, whilst undergoing treatment and during survivorship (Gao et al., 2010). As a result of a cancer diagnosis, three quarters of people experience anxiety (Macmillan, 2012). Only 44% of these people receive support, information or treatment for this (Macmillan, 2012). The identification and treatment of psychosocial issues for PWC is reportedly commonplace in primary care, however data on this is limited (Pascoe et al., 2004; Shipman et al., 2002). Screening PWC for psychological problems is not routine, and care is most commonly self-referred, despite literature suggesting the necessity of screening (Sanjida et al., 2018). When the emotional and psychological needs of people with cancer are left untreated, their use of community health services, hospital and visits to their GP increase (Carlson et al., 2004). PWC and their caregivers should be able to expect that all health care professions that they come into contact with have a basic understanding of their psychological needs (Kings Fund, 2016). However, there is a group of people living with cancer, who have unmet needs and would benefit from improved access to psychosocial resources (Armes et al., 2009). The psychosocial consequences of cancer and its treatments and the impacts on mental health are well-known to be a continuing neglected area of care, neither given the funding or the priority it deserves (TCST, 2018). Furthermore, in recent years financial pressures have made it more difficult to access mental health services (Kings Fund, 2017).

Carers and families of PWC experience vicarious psychological distress (Thomas et al., 2002; Ferrario et al., 2004). Murray (2010) suggests that family carers also experience the multidimensional illness of PWC. This vicarious psychological distress has been described as “profound” and can be particularly prevalent in carers’ “emotion work”, where carers try to manage the emotions of the PWC as well as their own (Thomas et al., 2002). Emotional and psychological distress is also experienced after the death of a PWC, and can be long-term (Ferrario et al., 2004). Evidence suggests that family and carers play a crucial role in managing PWC symptoms at home and experience a substantial emotional, social and financial strain (Ullgren et al., 2018; Ferrario et al., 2004). 67% of carers experience anxiety and 42% depression. Over three quarters of this group do not receive any support (Macmillan, 2006). Additionally, psychological morbidity has been shown to be substantially higher in carers than the general population (Grande et al., 2018). Many carers report not receiving information about caring at home and potential treatment side-effects or support from health and social care, although much of this could be easily made available through online support and local resources (Macmillan and NHS, 2018). Carers and PWC alike require varying levels and types of psychological support and information, this care must be tailored and appropriate for individuals’ different needs. Ensuring caregivers' needs are assessed is part of the top ten quality markers for end-of-life care (UK Department of Health, 2009). Despite this, there is a dearth of evidence-based strategy to guide health care professionals in supporting caregivers whilst they are providing care and after death (Hudson et al., 2012; Zwahlen et al., 2008).

Commissioning recommendations in London state that primary and community care should have easy access to psycho-oncological services in secondary care, but recent mapping has revealed inequities in service provision with some areas having no access. Bereavement and pre-bereavement care is “currently not clearly commissioned across London.”(Macmillan and NHS, 2018). The need for the development across all cancer services of a psychologically minded culture has been called for (London Strategic Clinical Networks, 2015; Macmillan and NHS, 2018). Collaborative working with secondary and third sector providers, through Improved Access to Psychological Therapies (IAPT) is an area for further development in cancer care, in particular upholding community care’s responsibility in offering this care for those with limited mobility or who are housebound (London Strategic Clinical Networks, 2015). Further exploration of the workforce’s views on what care is currently being missed in this area is needed.

59% of respondents in the latest National Cancer Patient Experience Survey of 2017 said that doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home (NCPES, 2017). Of trusts in London, the trust with the lowest score had only 39% of respondents (specifically with breast cancer) answering affirmatively. These figures suggest that there is a significant number of PWC who do not believe that those that are caring for them at home are receiving the necessary information from health services to provide best care. This inevitably will have consequences for both PWC and their carers themselves in terms of knock-on care.

This evaluation aims to explore the views of primary and community health care professionals on their provision of psychological care for both PWC and their families and carers. It reveals some of the workforce’s opinions on what they are currently doing, and what they would like to be able to do more of.

**Methods**

**Study Design**

This service evaluation used mixed-methods. An exploratory sequential design was used to explore the initial views of primary care staff before conducting the questionnaire and interviews. An exploratory sequential design was chosen to ensure the views of the group were heard, before developing the specific area of inquiry. As part of a larger study of soft system modelling (Checkland, 1989) of London cancer services, a focus group was carried out with primary healthcare staff in London. The focus group included GPs and registered Nurses and was on the work they are involved in with people with cancer. The outcomes of the focus group, as well as a review of literature in the area revealed that some of the work in cancer care they carry out goes unrecorded and unrecognised. This was the motivation for this evaluation.

A previously validated self-completed questionnaire was devised, based on a previous evaluation of the work left undone in oncology nursing (Leary et al., 2013; Leary et al., 2018; Stewart et al., 2018). It included questions on caseload related to cancer, overtime, care for carers and bereavement care, as well as open-ended questions. It was distributed through Health Education England’s weekly London newsletter and was accessed through an online link. Participants were invited to interview at the end of the questionnaire. Participant information sheets were given to respondents that expressed an interest in interview, and participants were contacted up to two times to arrange an interview. Informed consent was obtained by all those that took part. The interview guide is available in Figure 1. Using mixed-methods enabled respondents to reflect and expand on their questionnaire answers in interview, and to gain both breadth and depth in the area of inquiry. The order of data collection aided recruitment and facilitated further discussion.

**Framework**

A descriptive phenomenological framework underpinned the secondary analysis of the interviews. Phenomenology is concerned with gaining insight into and exploring personal experiences and perspectives of individuals in relation to a certain phenomenon. In this case, the perceptions of primary and community staff’s work in cancer care. Phenomenology examines subjective human experience and Husserl’s foundational writings on the philosophy gave rise to the descriptive phenomenological approach, which describes and gains a picture of the current or naturally occurring situation (Cohen, 1987; Lopez & Willis, 2004). It seeks to understand rather than explain respondents’ views and to gain depth rather than to draw any generalisations. Phenomenology acknowledges subjectivity of the researcher but asks that this is set aside (bracketed). In this way analysis of results includes description, reduction and identifying essence (non-sensorial objects that are portrayed through experience sharing) (Giorgi et al., 2017).

The interviews were one-off semi-structured qualitative interviews that were audio recorded. Interviews were carried out by telephone. Interview questions covered participants’ personal experiences and views of their involvement in cancer care, and sought to gain a deeper understanding of their lived experience. Respondents were only interviewed once, and this could be challenged from a phenomenological perspective to limit respondents’ opportunity to clarify their understanding of their experiences. However, interviews were carried out post- questionnaire, and enabled respondents to reflect on their questionnaire answers, in particular their free-text responses.

**Analysis**

This is secondary analysis of data.The questionnaire quantitative data was summarised using descriptive statistics in Excel. Interviews were transcribed and then Thematically Analysed (Braun and Clarke, 2006) using NVivoTM (Version 10, QSR International). Identifying thematic moments is frequently used in phenomenology (Morse, 1990; Holloway, 2005, Vaismoradi et al., 2013). Descriptive integration was used to merge the quantitative and qualitative data to make comparisons and for deeper understandings to emerge. Methods triangulation ensured rigour and enabled testing of consistency in the different data sources (Patton, 1999).

**Ethics:**

This was subjected to review from the NHS Ethical Committee Health Research Authority (HRA). It was reviewed proportionately and considered to be an evaluation.

Participants were provided with a participant information sheet prior to 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.

**Results**

**1. Questionnaire**

**Results of questionnaire:**

**Questionnaire completion:**

The questionnaire received 92 responses out of 300 (RR=31%). Completion rate was 100% and 95.6% completed the free-text questions. Responses were received from GPs (partners, salaried, trainee, locum, portfolio) (35), Practice Nurses (5), Community Nurses (6), District Nurses (17), Advanced Nurse Practitioners (22), Health Care Assistants (2), Advanced Clinical Practitioner (1), Care Navigators(2), Clerical and Admin Staff (2). Ten or more completed questionnaires were received from: General Practitioners (Partner), General Practitioners (Salaried), District Nurses (SPQ), Advanced Nurse Practitioners.

**1. Additional services needed**

Respondents were asked what additional services they would like to offer to people with cancer if money and time were no object. The majority of answers referred to psychological care. Responses identified the need for patient peer support groups and suggested “open days” in community services for PWC to meet other people. More counselling and support was suggested for PWC and their families and carers.

*“Group workshops, patients are often less anxious in a familiar setting. Care for the carers”* ***– ANP***

*“Psychological support for cancer patients and carers within primary care”* ***– GP (Partner)***

*“Pre-bereavement counselling” –* ***Community Nurse***

 *“Counselling services or counselling training for nurses, we have great communication skills and ability to listen and support but sometimes feels inadequate”* ***- District Nurse (SPQ)***

*“Mental health support in practices”* **– GP (Partner)**

 *“Just more time to be more regularly supportive, and also to the families of affected patients”* ***– GP (Partner)***

**2. Bereavement care**

Respondents were asked about their provision bereavement care or after-care for families and carers. Answers between and within professions varied, however the consensus of GP answers was that bereavement work wasn’t an explicitly defined part of their job, but that they either made a proactive effort in particular cases, or patients initiated this. Of answers from GPs to this question (n=29), 25% reported not being involved in bereavement care at all.

*“Only if they come to see me because they need help”* ***– GP (Salaried)***

*“When people come to me. There is no proactive support”* ***– GP (Partner)***

GPs bereavement and pre-bereavement work was described as helping people with positive attitudes towards living with cancer and acceptance of death, psychological help, medication and arranging time off work.

District and community nurses were the group that reported the most regular bereavement work in the form of bereavement visits and phone calls with families and carers. The structure of this work seemed to vary across London, most commonly starting with a bereavement visit following death, followed by either a phone call after one month, and continuing as requested, or an additional follow-up bereavement visit between 6-12 months after death. The visits seemed to include signposting 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 (SPQ)***

*“We normally do a follow up visit to ensure the family members are coping with the recent loss and to sign post 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 patient’s lives till this point. The remaining spouse then not only has to deal with a death but frequently then has no visitors.”* ***- District Nurse***

ANPs also noted the lack of structured protocol in these cases.

*“Not formally.”* **– Advanced Nurse Practitioner**

*“Support as needed.”* **– Advanced Nurse Practitioner**

*“Yes but generally only for regular patients or opportunistic”* **– Advanced Nurse Practitioner**

**2. Interviews**

**Results of interviews**

Seven interviews were carried out with GPs (3) (one partner, one salaried, and one locum), District Nurses (2), Advanced Nurse Practitioner (1) and Care Navigator (1).

A table of the interview themes can be found in Table 1.

**1. Psychological care**

Being able to offer time to PWC to talk through their concerns, providing social prescribing links and psychological care repeatedly came up as an area that primary and community care staff would like to do more in:

***“****Psychological care**it would probably be the same for both the cancer patients and the not 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.”* ***– ANP***

*“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”* **– GP Locum**

*“More social prescribing: having social prescribing facilities within CCGs. 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***

This psychological care also extended to the families, friends, and carers of people 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 her sister is not my patient but 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.”****– GP Salaried***

*“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***

An ANP reported difficulty in knowing and finding out where to signpost people who were affected by the diagnosis of a cancer.

*“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.”* ***- ANP***

Signposting to relevant and available services was an area that was reported as time consuming and difficult. GPs noted that they spend significant time in finding available support services to PWC and their families and carers. The services recommended varied from psychological support, helpdesks and support groups to general advice or social groups. All three GPs interviewed said that there was no set list of resources that they would refer to and that their signposting was often guided by contacts or previous knowledge of resources. This was an area of cancer care that was suggested as potentially being easily improved with a more structured set-up. Moreover, many of the services GPs wanted to recommend to their patients were not available, or resources were stretched and patients faced waiting lists.

*“When they’ve just had a diagnosis of cancer or 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.”* ***- GP Locum***

*“It’s always hard to keep up with what is available. So I think a big role for GPs is signposting.”* ***- GP salaried***

**2. Bereavement care**

Work associated with caring for those who were bereaved was reported varyingly. All three GPs interviewed commented that there was no plan in place for bereaved people (from any illness not just specifically cancer). This meant that GPs spent a lot of time trying to find available care and this was sometimes hard to find, or difficult to access:

*“There is no practice policy**for that, that’s just what individual GPs do I guess.”* ***– GP Salaried***

*“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**

One GP reported*: “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.”* ***– GP Locum***

This lack of care for bereaved people for the first six weeks was explained by the belief that six weeks of grieving is natural, and after this time if people were seeking help, then a bereavement service would be offered to them.

GPs felt as though they were offering bereavement and psychological care without having specific training in it.

*“We spend a lot of our time providing psychological support when actually we’re not experts in this”* ***- GP Locum***

A District Nurse talked of a ‘three visit’ rule for those who are bereaved in order to keep within constrained budgets and staffing shortages:

*“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***

**Discussion**

The findings in this evaluation would suggest that psychological care is a driver of secondary workload for PWC and their carers. Respondents identified that they did not have enough time, the appropriate training or resources available to offer the psychological care that PWC needed. Furthermore, being able to find relevant services to signpost PWC to when they couldn’t provide this care, was difficult and created a workload burden. This concurs with literature in the field (Shipman et al., 2002). NCPES currently has no questions that relate to patients’ experience of psychological or emotional care (2017). As is well-evidenced in the literature, this is an incredibly integral part of cancer care; a question in NCPES to understand patients’ experiences of this form of care could be beneficial. Additionally respondents identified families and carers that required psychological support, and bereavement (including pre-bereavement) care, as an area they believed they were lacking in provision of and were dissatisfied with the level of care they were providing. In a 2016 Macmillan and YouGov survey of 892 UK carers of PWC, emotional support was the largest type of further support that was wanted, with 22% of respondents identifying that this would be beneficial (Macmillan, 2016). GP surgeries were identified as the top preferred source of support (41%).

It was identified in this evaluation that psychological care in cancer needed better resourcing. This may well need to be reflected in changes to the current workforce working in cancer care with an increase in primary and community based mental health therapists, counsellors and psychologists. In 2016 NHS England announced plans to recruit and fund 3,000 new practice-based mental health therapists as part of the growing need for action to address the gap between demand and supply of psychological care. However, it is concerning to note that the percentage of practices employing a mental health therapist has remained level at 10% (Cogora, 2018).

NICE guideline’s quality statement on bereavement care is that “People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.” (NICE, 2011). Bereavement care was revealed to be inaccessible for primary care to offer to those who asked for it for the first 6 weeks of bereavement. There is a group of people requiring care that are unable to receive this care, particularly immediately after a death. This is clearly an area where people are falling through the gaps, and steps should be taken to address this. Furthermore, staff reported that as they had no set bereavement care plan in place (for people affected by the deaths of PWC, or from any disease), they spent a significant amount of time searching for appropriate care for the bereaved. By having a set bereavement care-plan in place, or a structured database of available resources, significant time could be saved for GPs (as one example). Furthermore the findings suggest that bereavement care (including pre-bereavement) is an area that would be valuable for primary and community health care professionals to receive further training or structure in. This may be an area of workload that will continue to increase with the increasing prevalence of cancer. The lack of clarity surrounding bereavement services in evident in the literature (TCST, 2018).

The research base on which GPs and practice nurses can base their bereavement care delivery is limited and the manner in which this care is delivered in primary care is unknown and variable (Nagraj and Barclay, 2011; Payne et al., 2002;). Routine and proactive care for people who are bereaved would be a productive preventative measure that is not currently commonplace. At present, GPs referral decisions for bereaved individuals may be biased by assumed knowledge and prejudice against certain groups of patients that are not presenting abnormal symptoms (Wiles et al., 2002).

Predictive risk factors have been identified in carers to identify their psychological needs post bereavement (Kelly et al., 1999; Ferarrio et al., 2004). However, strains on primary and community care are meaning that pre and post-bereavement care is falling short (Shipman et al., 2002). Research has long identified that carers for PWC may represent a group with unmet psychosocial needs (Soothill et al., 2002; Wang et al., 2018). Informal carer burdens have also been seen to be associated with hospital admission for PWC in their last days, who had chosen to die at home (Jack and O’Brien, 2010). As work in bereavement care was described in this evaluation as reactive, and initiated mainly by the individual themselves, it appears that efforts to work proactively with predictive models would benefit this group with unmet needs, and the health providers themselves, with potential adverse or extra workload avoided.

The 2004 NICE guidelines recognised that no uniform agreements exist on the services that should be provided to PWC and carers in psychological distress, and that as a result, many people are not able to access needed services. Among NICE’s detailed and specific 2004 recommendations, was that staff in contact with PWC should be adequately trained and supervised in screening for distress and offering general psychological support, identifying GPs as having an important role in this. Nurses were seen to be in a key position to be able to identify and respond to patients’ needs for psychological care (NICE, 2004).The findings from this evaluation would suggest that this policy has had limited impact. Respondents identified the need for psychological care to be better resourced, and to have more training and time for this.

**Limitations**

The results of this evaluation give insight in to the views and perspectives of a small group of primary and community care staff and cannot be generalised. There is a risk of oversimplifying these views at this scale. The survey was distributed through a Health Education England mailing list and was subsequently shared by the Queens Nursing Institute’s social media (Twitter). Therefore the exact number of people that the survey reached is unknown, and response rate is an estimation.

**Conclusions**

Improvements in psychosocial care for people with cancer in primary and community care have long been called for and are of significant concern (NICE, 2004; Shipman et al., 2002). The findings from this evaluation would support the current literature base that identifies priority areas that need most attention: psychological care for PWC and their carers, as well as bereavement and pre-bereavement care.

Future Recommendations:

Structured and proactive protocols for primary and community care to follow in these priority areas are needed to provide clarity and standardised guidance. Consulting people with cancer and their families and carers themselves is necessary to understand and recognise the variety of support that is needed and when and where this care is best given. Psychological and bereavement care require better resourcing, and deserve a higher priority in terms of funding and time available to provide this care.

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