**Uncovering the hidden workload of providing cancer care in the community**

**Abstract**

**Purpose:** The role of primary and community care in cancer care in the UK is not explicitly defined. The exact nature of the workload to do with people with cancer is unclear. This evaluation aimed to explore some of the workforce’s opinions of what cancer care they do that goes unrecorded or unrecognised. **Method:** An exploratory sequential design was used in surveying and interviewing primary and community care staff in London. Interviews were analysed from a phenomenological perspective. **Results:** 92 survey responses were received, and 7 interviews carried out. An estimated 13% of all patients seen by respondents had a cancer diagnosis, 3% had a suspected cancer. Interviews revealed that systems in place didn’t allow for full capture of cancer care workload. In particular, the knock-on effects of the unpredictability of cancer was noted and people presenting with vague potential cancer symptoms were reported. Relationship building with people with cancer and their families was unrecognised, essential work. Expectations of specific cancer knowledge created a workload burden. **Conclusions:** There is an opinion of primary and community workforce that there is hidden, unrecognised work in cancer care. Efforts to record and recognise this workload could improve cancer care delivery and coordination.

**Key words:** cancer care; workload; workforce policy; primary care; community care

**Introduction**

It is evident that primary and community care workload is rising, however the nature and content of the workload has not been explicitly defined (Hobbs et al., 2016; Thompson and Walter, 2016). Furthermore, the difficulties in accurately measuring the work of GPs in particular has been emphasised (HCHC, 2016). There have been consistent increases in consultation rates in recent years in English primary care providers, including GPs’ and nurses’ consultation durations and patient facing clinical workload. Data on the direct clinical workload of general practitioners and practice nurses in primary care has shown that “the number of consultations per patient per year in English primary care rose by roughly 10% between 2007–08 and 2013–14” (Hobbs et al., 2016). Comprehending and determining what this increase in workload is comprised of, is essential in potential improvement of care provision. Likewise, different professions gaining insight into other members of the workforce’s workload and challenges, for example nurses of GPs and vice versa, is important in sharing best practice and improving care delivery. This study aims to elucidate some of the workload involved in caring for people with cancer in primary and community care that goes unrecorded and unrecognised.

The role of primary and community care in the care of people with cancer (PWC) is currently not well defined (Adams et al., 2011). In fact, there is little data on the volume and nature of primary care activity in the UK (Hobbs et al., 2016). There is evidence of variation in clinical primary care practice in the UK (Swann et al., 2018). Additionally, a distinct lack of communication and collaboration between primary and secondary care has been highlighted in the literature in cancer care and reportedly identified by patients (Johansson et al., 2000; Farquhah et al., 2005; Stegmann et al., 2019; Adams et al., 2011). Consequences can include underutilisation of available services and “invisible” work being carried out that is unseen to patients in need (Puts et al., 2018; Roorda et al., 2014).

There is a workload of people who present to primary and community care with symptoms and with a suspected cancer, but who transpire to not have a cancer. This is a workload related to cancer, but to who and where it is attributed is unclear (Hamilton, 2010). Furthermore, GPs in particular are judged on their diagnostic performance in people who do have cancer, and not on those who do not (Hamilton, 2010). There has been little literature on the area, and the number of people who present to primary or community care with a suspected but not realised cancer in the UK has been largely undocumented (NICE, 2015).

**Implications for practice:**

Primary and community care workforces in England can be made up of GPs, Nurses, direct patient care staff and administrative/non-clinical staff amongst others (NHS Digital, 2019). Gaining insight into primary and community care’s involvement in cancer care is essential in understanding the make-up of the workload of cancer in cancer services. A clear understanding is necessary for capacity building and improvement of service delivery. A clarification of roles and the availability of services within primary and community care could enable better communication between primary and secondary health care providers and an improved holistic delivery of care (Stegmann et al., 2019**;** Price and Majeed, 2018). While primary care and cancer care resources are variable between the four nations of the UK, this evaluation serves as an exploration of the views of a small group of the primary and community care workforce in London.

**Methods**

**Study Design**

This exploratory 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. As part of a larger study of soft system modelling (Checkland, 1989) of cancer services in London, a focus group was held with primary health care staff in London. The focus group was of GPs, and registered Nurses on their involvement with PWC. The focus group results, as well as a review of literature in the area revealed that some of the work they do in cancer care goes unrecorded and unrecognised. This was the motivation for this evaluation.

A previously validated self-completed questionnaire was utilised, 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, educative and professional development, 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 informed consent was obtained by those that did take part. The interview guide is available in Box 1.

**Framework**

A descriptive phenomenological framework underpinned the secondary analysis of the interviews of the evaluation. 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 allowed 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:** The evaluation was subjected to review from the NHS Ethical Committee Health Research Authority (HRA). It was reviewed proportionately and deemed that the evaluation did not require HRA ethical approval.

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.

**Findings**

**1. Results of questionnaire:**

Questionnaire completion:

The questionnaire was sent to an estimated 300 people (RR=31% n=92). 95.6% of respondents completed the open-ended free text questions. Therefore, we were able to gain a depth and variety of written answers.

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. Findings are therefore broken down into these four groups.

**Questionnaire open ended quantitative answers**

**Estimation of people with cancer workload**

Respondents were asked to estimate the number of patients they see each week, and of those how many had a diagnosis of cancer (even if they were not treating them for a cancer related issue). We then asked respondents how many people they suspected may have cancer and were referring them for diagnostic tests. These questions enabled us to gain an average estimate of the percentage of patients with a confirmed or suspected cancer.

Answers are divided into the largest respondent groups. For GPs, (including partners, salaried, locum and portfolio GPs) 11% of their patients per week had a diagnosis of cancer and 3% had a suspected cancer diagnosis. 12% of Advanced Nurse Practitioners’ patients had cancer and 3% had a suspected cancer. District nurses encountered the highest percent of patients with a cancer diagnosis as these were 35% of all patients they see in a week and 7% had a suspected cancer. GPs were further broken down into partners and salaried GPs: 10 and 14% respectively of patients had cancer diagnoses and 3 and 2% had suspected cancers. Combining all answers from all primary and community staff, 13% of all patients seen had a cancer diagnosis, and 3% had a suspected cancer. These results are illustrated in Figure 1.

**2. Results of Interviews:**

**Interview completion:**

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.

**Themes**

**1.Un-recordable work**

The interviews revealed that the systems used by primary and community staff did not allow them to capture the entirety of their workload. This made the documentation of work that was carried out difficult.

*“The time that it takes to make the referrals, chase up GPs: things like that aren’t necessarily documented.”* ***- District Nurse***

*“I think the amount of support we give isn’t something that you can necessarily document: account for…a lot of the support...is the bit that’s difficult to capture.”****– District Nurse***

*“The systems**that we use don’t allow us to capture that information, it doesn’t allow us to put time aside for those sorts of things on our computer systems. So we do it but it’s not visible.”* ***– District Nurse***

Furthermore, one GP thought that this has led to an underestimation of workload for primary care:

*“I think GPs are underestimated in what they do and how much they do: not just GPs: primary care. And I think a lot of it is hidden and a lot of it is not recognised by NHS England. It is just assumed that it will be done without, actually, taking real consideration as to how much time it takes to do these things and to do these things properly.”* ***- GP Partner***

Psychological care frequently came up from different professional groups when asked about “unrecorded” or “hidden” work:

*“Psychological listening is the main one. I mean, you can’t write that down…explaining the stages that they’ll go through after the diagnosis. Really, just speaking to them and just making them aware of what is available and who to contact.”****– ANP***

*“There’s a lot of the psychological element that isn’t picked up and it’s hard to quantify that, and it’s harder also to put a monetary value on that, so that goes unnoticed but I don’t think that there’s an ongoing debate about that, but I think it’s recognised that it goes unnoticed.”****- GP Locum***

**2. Working outside of contract hours**

Two GPs brought up that they would plan to see PWC before their lunch break, or at the end of their work day, as they knew they would spend more than the allocated appointment time with them, and to prevent delaying later appointments:

*“It is not a ten minute consultation but we don’t seem to be able to do anything about that, so it just knocks on to the entire surgery. I will try and predict when these people are coming in and put them at the end of my clinic so then I can spend longer with them and just eat into my lunch time because then I don’t have to rush and worry about everyone else waiting.”* ***– GP locum***

*“I tend to bring patients in at lunchtimes, just to discuss what’s going on. To have a bit longer. This time is not recorded; this time is my own time for patients.”* ***- GP Partner***

Both DNs also brought up frequently working outside of contracted hours for many reasons.

*“I think most people go the extra mile, near enough every day.”* ***– District Nurse***

*“Gosh, our nurses will do a whole lot of things that they’re not supposed to do, you know, they’ll go back and take a patient’s dog for a walk after hours and that kind of thing.”* ***– District Nurse***

**3. Referring for suspected cancer: vague symptoms**

Interviews revealed that primary and community care were frequently seeing people with vague symptoms of potential cancer. This made up a substantial workload in determining where and what to refer for.

Initiatives were being piloted in London to help guide diagnoses of these people with vague symptoms. These include an app “C the Signs” and multi investigation disciplinary centres which help guide cases with unclear cancer symptoms, to consider certain referral pathways. “C the signs” was described by a GP (Partner) as “*It’s brilliant. It’s fantastic*.”

“*We have the multi investigation and disciplinary centres like MDCs where you can send them in if you are unsure of what type of cancer it is.”****- GP Locum***

Two GPs reported that when they weren’t sure about a patient’s symptoms they would ask for advice from primary care colleagues or bring these cases up at “significant event meetings”.

*“You’d get an opinion from a local colleague.”* ***- GP Partner***

Interviews with GPs revealed that sometimes a referral was made when there were no clear symptom for cancer, but that the GP “had a feeling” that there could be a cancer. This was enabled through a “clinical concerns box” on the two week wait referral. This was described with great positivity, as it was a way of acknowledging GPs’ overview and understanding of a patient’s history, and enabling referral for patients who didn’t fit into set boxes of symptoms.

*“We know these patients, we’ve seen them for years so then we are able to say, something is not quite right, I can’t put my finger on what it is but something isn’t quite right.”* ***- GP Locum***

Knowing when to refer was described as down to a combination of experience and intuition. It was very hard to define what this work is, and to put an allocated time or value to this on the available systems.

*“If we just feel somebody’s unwell and there’s something not quite right, just sometimes, it’s just intuition: there’s nothing specific – we’ll go back to the GP.”* ***- District Nurse***

**4. Positive relationship building and overview**

An area of cancer care in primary and community services that was hidden in the respondents’ opinions was the relationships that they build with PWC and the continuity of care that they offer. They also described the overview that they have of the patient, their history, and sometimes knowing their families.

*“We see the whole picture and there isn’t really anybody else that does that, and we have an understanding of family interactions and we might be seeing other family members as well, and I think that’s probably not captured anywhere. I think that’s the important thing, that they’re not just patients with cancer, but our job is to look at them a bit more holistically and I don’t think that’s captured really.”* ***- GP Salaried***

The relationships they build with PWC were perhaps further enabled by being able to offer care in the person’s home, and from building long-term relationships with their families over time.

*“I have met this person before, I know quite a lot about him...of the frail elderly I’ve quite often come across them before… there’s quite a lot of local knowledge which is quite nice.”* ***- Care Navigator***

*“The advantage of people in their own houses is that they’re a bit more relaxed, they know a bit more about what’s going on. We also get to meet the carers and the husbands and the wives.”* ***- Care Navigator***

*“Most of the district nurses know their area inside out and back-to-front and they know their patients.”* ***- District Nurse***

**4A Family and Carer**

Cancer care was reported as wide-encompassing and not limited to the person with cancer, but their family, friends and carers. Knock-on effects were experienced by these people at many different stages:

*“It sounds silly but it can be the husband or wife; it could be the daughter, son, grandchildren, the person’s children; it’s the dog; it’s the cat; it’s the neighbour down the road. It’s whoever is there all need that care.”* ***- District Nurse***

*“We see vicariously indirect results of cancer as well.”* ***– GP Salaried***

A DN described the delivery of complex care to PWC whilst managing and respecting the needs and wants of families or carers:

*“They need a lot of support and advice. Different people need different things. Different people cope in different ways. So some people, we go in and we do absolutely everything; some people, they want to help us, and some people just don’t want to do anything at because they feel completely overwhelmed by the whole situation. And that can change on a daily basis as well. So you can never assume that what was right yesterday is right today: you have to always go in with a new pair of eyes every day.”* ***- District Nurse***

Another area of hidden workload to do with cancer was identified as bereavement care for families and carers of PWC. This was reported as difficult to access and took up substantial time in trying to locate, or alternatively resorting to offering verbal advice to people without structured training in the topic.

**5. Interaction with secondary care**

Problems with interactions with secondary care were frequently brought up in the interviews. A lack of structured communication between secondary and primary care meant that information was sometimes relayed through the patient, and miscommunications were common.

*“Getting information back is very poor, so communication back from secondary care is renownedly terrible and it doesn’t come directly into our system, letters are delayed in getting to us, so I will get the patients to write down what the doctor is telling you, what they’ve excluded, then I don’t have to wait for that letter.”* ***- GP Locum***

*“I get delayed in being told someone has a cancer diagnosis and the patient is telling me, not the doctor, so I think that is not great.”* ***- GP Locum***

GPs in particular mentioned the need for improved communication and coordination with secondary care. Problems with the timing of receiving information from oncologists was frequently mentioned.

*“I think better and more timely communication between us and their oncologist. Often you get letters a couple of months down the line when it’s not current or relevant anymore which isn’t helpful.”* ***- GP Salaried***

Furthermore, advice from secondary care for GPs themselves was an important part of improved coordination. GPs wanted there to be someone, or something to go to when they were unsure about a PWC’s symptoms.

*“I know that maybe as a source of information I’m not always clear, what are the expected side effects of certain treatments. So if a patient comes to me with a problem, is that a side effect, I don’t know, I’m not an expert, where can we go to find information on different types of treatment and what might be an expected side effect.”* ***- GP Salaried***

*“It’s more just a support for me I think that would really help, because people don’t fit in these neat boxes and you want to be able to ring someone and say this patient was last seen at this time or they had this treatment or can you help them. You just want a co-ordination in there.”* ***- GP Locum***

5A **Administrative work**

A lack of communication with secondary care was also reported to result in large amounts of sometimes unnecessary and hidden administrative work. Accessing necessary information about a person with cancer was reported as time consuming:

*“I spend I would say hours of my time ringing, trying to get hold of the secretaries...if I’m not sure whether someone fits a two week box or if I’m following up regarding their investigation or results, again email is just so helpful if there is an email specifically for each cancer, for each trust, that would be brilliant.”* ***- GP Locum***

Work that primary care thought should be done by secondary care but was being asked of them was also an example of a workload that was difficult to account for, for example taking regular bloods during chemotherapy. Although this was recognised as meaning that patients did not need to go into secondary care for bloods to be taken, it meant that results were coming back to primary care, and not the patient’s oncologist. This resulted in time being spent making sure the results were sent to the correct oncologist, and not being able to take action on results quickly. A GP (salaried) noted that they sometimes didn’t understand the significance of the results requested by secondary care, and they would feel stressed and anxious if they could not get hold of the oncologist who requested the tests.

*“So there’s lots of going in between and back and forth between secondary and primary.”* ***- GP Salaried***

One DN, who’s area of work was split over two CCGs reported difficulties and unnecessary administrative work due to the CCGs wanting different things, and operating differently. Another brought up time spent on administrative tasks such as contacting GPs and secondary care for information about a patient. This was not easy to document and account for:

*“It’s the little things like ringing the GPs and trying to get hold of them or trying to get hold of specialist people, trying to get through to hospitals: that sort of thing is probably not captured very well.”* **- District Nurse**

**6. Unpredictability**

The unpredictability of caring for PWC, and the effect this had on workload was brought up. Planning of time and resource allocation also proved difficult.

*“Because we’re dealing with frail people, it doesn’t take much for them to deteriorate...You can’t always predict when people are going to die. We try our best to but the human spirit is a wonderful thing and doesn’t always abide by the rules*.” ***- District Nurse***

*“Cancer patients can be very unpredictable, therefore can have a massive impact on the service for other patients and colleagues. I spent 5 hours with a patient a few days ago - could not get their symptoms under control. This meant some of my other visits had to be reallocated to colleagues.”* ***- District Nurse***

*“Acknowledging that it might be that you’re going into wound care but, actually, because it’s a cancer patient, it may take a lot longer because they’ve got other issues going on.”* ***- District Nurse***

This unpredictability also had a knock-on effect in acquiring appropriate care:

*“The hospices are often a little bit wary of frail elderly people, because again the cancer may be something that they’re dying with rather than dying of, and it’s just very unpredictable, is the person dying or not.” –* ***Care Navigator***

**7. Cancer knowledge and accessing cancer information**

All GPs interviewed said that having specialist cancer knowledge was increasingly becoming more expected of them, and that it was not possible to keep up to date with different treatments and side effects:

*“This is something else we’re pushing back to secondary care, saying, ‘You’ve got to give us clear guidance as to what to do.’ Because we’re not oncologists; we’re not neurologists; we’re not specialists: we’re generalists.” -* ***GP Partner***

*“There’s a lot of expectations that, ‘Oh, the GP can do this’, ‘The GP can do this.’ But, actually, there’s no allocated resource or time for the GPs to do this.”  -* ***GP Partner***

*“A lot of the time I’m not very up to date with my chemotherapy regimes, so I don’t know if that’s attributable to the chemotherapy that they’ve had or if this is something new and what the process is, how long it takes for them to get better.” -* ***GP Locum***

Patients were coming to GPs with side effects from treatment that they did not know about. This was a hidden part of GPs’ workload where they spent time researching different cancer treatments:

*“Sometimes, the patients will come to us with random side effects which we don’t know about.” - GP Partner*

*“I will end up trying to Google it because I don’t know” - GP Locum*

**Discussion**

**Limitations**

This was a secondary analysis of data from a larger evaluation. Therefore questionnaire results are limited to three questions that focused on the estimation of PWC workload. The results are not generalisable or representative of other groups and purely provide insight and depth in to the small group of individuals in this evaluation’s experiences of providing cancer care. There is a risk of oversimplifying these views at this scale.

**1. Referring for suspected cancer: vague symptoms**

Most PWC present with symptoms first to a non-specialist (Mendonca et al., 2016). Patients often present to primary care with low positive predictive value symptoms. High diagnostic difficulty may also be linked to common symptoms that may not be immediately recognised as a potential symptom of cancer (Lyratzopoulos et al., 2014). Patients diagnosed with cancers characterised by non-specific symptoms are thought to be at risk of more pre-referral consultations and longer primary care intervals although evidence for this is limited (Mendonca et al., 2016; Swann et al., 2018); these findings may point towards this being the case. Respondents reported that people presenting with vague symptoms that may be related to a cancer diagnosis made up a substantial workload. Respondents in this evaluation reported that they appreciate the acknowledgement of their expertise and overview of patients in work streams that supported these vague diagnoses such as the “clinical concerns box” on two week wait referrals. This highlights the need for flexibility in caring for PWC who don’t always fit into rigid boxes. It is well recognised that clinical intuition has diagnostic value (NICE, 2015). Perhaps there is an extra workload caused by these "intuition" referrals (by a lack of allowances for this within systems) and if so, is that workload causing a negative effect (i.e. it comes back with a non-cancer diagnosis and time has been spent on test/analysis) or is it potentially causing a positive effect (earlier diagnoses). Recent implementation of ‘one-stop-shop’ multi-specialist diagnostic services for patients with unexplained symptoms and clinical guidelines covering many different symptom presentations will likely improve times to diagnoses. Recognition of diagnostic difficulties and the necessity of investigating vague symptoms are needed to fully understand the drivers of multiple consultations (Lyratzopoulos et al., 2014).

**2. Systems unable to record all workload related to cancer care** - **unpredictability**

This evaluation revealed some but not all areas of work related to cancer that are not able to be recorded using current systems. The effect of the unpredictable nature of cancer on workload has not been explored in the literature. This is something that was identified in this evaluation as difficult to record with the current systems in place and resulted in additional contributions to workload. In particular the knock-on effects of time spent with PWC for other patients has rarely been touched upon. Efforts to expand systems to record different forms of workload could increase accuracy of workload estimation and potentially be used to ease pressures.

Frameworks of typical illness trajectories can be useful in planning broad timeframes and predicting patient needs (Murray et al., 2005). Murray (2005) suggests that cancer, which is commonly characterised by a “short period of evident decline” is broadly predictable in terms of anticipating palliative care needs, however resource constraints particularly in community care limit this. Additionally, Murray’s review suggests that for both the patient and carer, understanding the likely trajectory can be empowering. Furthermore, early prognostic awareness and discussions about palliative care with families and carers has been seen to lead to an increased quality of life for people with lung cancer (Boyd and Murray 2014). It would seem that steps to address or leniency to account for the unpredictable nature of cancer and its treatment would benefit both the patient and the provider. Within this evaluation, district nurses in particular commented on the impact of the unpredictability of delivering cancer care and that acknowledgement and recognition of this could ease pressures.

Additionally, the number of people who present to primary care with a suspected cancer that does not turn out to be a cancer is an area that may warrant further research, as there is little available currently (Hamilton, 2010). For all respondents in this evaluation, an estimated 3% of the people they came into contact with every week presented with symptoms that may be cancer, and they were being referred for diagnostic tests. Of these people some may turn out to have a diagnosis of cancer, and others may not, however recognition of these that do not have cancer as part of the primary and community workload related to cancer is needed. Currently it appears that this workload is not recorded or recognised as attributable to cancer.

**3. Family and carer**

Work that might not immediately be recognised as related to cancer, such as effects on families and carers, was identified in this evaluation of an area of hidden workload. The district nurses in this evaluation noted the challenges of navigating the needs of families and carers and balancing these with the needs of the PWC in their homes. The knock-on effects of a cancer diagnosis, treatment, or death of a loved one were evident as commonly presenting to primary and community care. This concurs with literature in the field (Thomas et al., 2002; Ullgren et al., 2018). Murray (2010) suggests that family carers experience much of the multidimensional illness of the PWC and recommends that they are supported throughout the period of illness and not only in bereavement cases.

In Adams’ 2011 study of six UK primary care practices, GPs’ close relationships with cancer patients appeared paramount to primary care consultations with patients. The interviews with GPs in this evaluation concurred with this, with relationship building and monitoring progress with patients and families an important part of care delivery in cancer. The value of personal relationships between patient and GP are widely recognised (Kearley et al., 2001) and may be associated with patient satisfaction (Williams et al., 1998).

**4. Secondary care interaction and cancer specific knowledge**

Concerns have been raised that there has been little movement towards improving communication between primary and secondary care clinicians despite these changes depending on minimal cost investments such as routine use of email (HCHC, 2016). Additionally the barriers between the two have been recognised for some time and specifically in cancer care (Johansson et al., 2000; Farquhah et al., 2005; Stegmann et al., 2019). Enhancements and streamlining pathways between primary and secondary care have long been called for in cancer care (Price and Majeed, 2018; Sampson et al., 2016, Macmillan, 2016). The lack of communication and barriers to coordinating care between primary and secondary care have been brought up in this evaluation. Respondents reported a repetition of work, an administrative burden and ultimately a lack of continuity of care for PWC. Patient views of the interface between primary and secondary care have been identified as an important indicator of health system performance and continuity of care (Preston et al., 1999). Patients have been reported to pick up on primary and secondary cares’ lack of coordination in their cancer “journey” (Adams et al., 2011). This evaluation adds to the literature base that would support improved coordination and communication between primary and secondary care, in particular in cancer care concerns.

Cancer-specific knowledge was identified by the respondents themselves as an area that may be lacking and that they would like to have more coordination with secondary care in. The Kings Fund recognised in 2018 the need for greater support for primary care staff to have more time and space to develop new skills (The Kings Fund, 2018). The differences between primary and secondary care’s knowledge and practice of caring for cancer survivors have been noted, and primary care practitioners’ confidence in their knowledge of cancer treatments raised (Potosky et al., 2011; Roorda et al., 2014). This is an area that could warrant further research.

**Conclusions**

This evaluation has explored some of the hidden workload of cancer care in primary and community settings. Respondents suggest that current systems in place do not allow sufficient recording of workload, and that there are many areas of care related to cancer that are not formally recognised. These include the unpredictability of cancer progression, diagnosing patients with vague symptoms, knock on family and carer care and an expectation of specialist cancer knowledge, amongst communication problems with secondary care surrounding PWC.

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Figures

**Figure 1.** Estimated number of patients seen per week reported by questionnaire respondents.

Box 1. **Interview guide**

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 was no object what work would you like to be doing in cancer care that you are not able to do now?