

Qualitative Research

Patient, general practitioner and oncologist views regarding long-term cancer shared care

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Abstract

Background. The rising incidence of cancer and increasing number of cancer survivors place competing demands on specialist oncology clinics. This has led to a need to consider collaborative care between primary and secondary care for the long-term post-treatment care of cancer survivors.

Objective. To explore the views of breast and colorectal cancer survivors, their oncologist and GP about GPs taking a more active role in long-term cancer follow-up care.

Methods. Semi-structured interviews using a thematic analysis framework. Respondents were asked their views on the specialist hospital-based model for cancer follow-up care and their views on their GP taking a greater or leading role in follow-up care. Researcher triangulation was used to refine the coding framework and emergent themes; source triangulation and participant validation were used to increase credibility.

Results. Fifty-six interviews were conducted (22 patients, 16 oncologists, 18 GPs). Respondents highlighted the importance of GPs needing specialist cancer knowledge; the need for GPs to have an interest in and time for cancer follow-up care; the GPs role in providing psychosocial care; and the reassurance that was provided from a specialist overseeing care. A staged, shared care team arrangement with both GPs and specialists flexibly providing continuing care was found to be acceptable for most.

Conclusion. Collaborative care of cancer survivors may lessen the load on specialist oncology clinics. The findings suggest that building this model will require early and ongoing shared care processes.

Keywords: Breast cancer, cancer care, colorectal cancer, continuity of care, family health, multidisciplinary care, primary care.

Introduction

Cancer is a leading cause of death worldwide. In Australia, it is the second leading cause of death and accounted for 30% of deaths in 2016 (1). Successful treatments have resulted in a steady decrease in mortality, and effective screening programmes have resulted in an increase in incidence. Long-term cancer care involves surveillance for recurrence, preventive care, management of comorbidities and psychosocial support (2). The growing number of cancer survivors presents a challenge for both specialist cancer services and general

practice and is driving a reconsideration of existing models for long-term care. The management of chronic conditions has become an important part of the daily workload of general practice, making general practice well situated to providing continuing shared care.

Previous studies have found highly discordant views between patients, cancer specialists and/or GPs about the role that primary care should play in long-term follow-up care (3–8). Patients expected that cancer specialists would continue surveillance for both new and recurrent cancers, while their GPs would be involved in the management of

comorbidities and prevention. For some cancers, research has found that primary care follow-up had comparable outcomes (9–11). In Australia, patients had a strong expectation of continued care by their specialist but an openness to increased involvement of their GP (12).

This study investigated the attitudes and beliefs of cancer patients, their GPs and surgical, radiation and medical oncologists, regarding the long-term follow-up care for patients with no current evidence of disease recurrence. The aim was to explore the feasibility and acceptability of greater involvement of GPs in cancer follow-up care in Australia. While there is some information available in the literature on patient and provider preferences in cancer follow-up (12), this study was unique in that GPs and doctors framed their views on follow-up in reference to the actual patients involved in the study.

Methods

The overall study was a qualitative collective instrumental case study (13), which allowed for detailed investigation both within and across cases, informed by an interpretivist constructionist paradigm (14). This paper focuses on the results within groups (patients, GPs or oncologists).

The research was conducted at the Prince of Wales Hospital (POWH) Cancer Centre, which is a tertiary hospital service that provides specialist medical and radiation oncology services and multidisciplinary cancer care. In the case of early breast and colorectal cancer, patients are treated with permutations of surgery, chemotherapy and radiation therapy determined on an individual basis. Patients requiring combined or sequential treatments for their cancer are typically followed up by all specialists involved, mainly to manage side effects of treatment and to look for loco-regional and metastatic recurrence. Follow-up visits are more frequent in the first 2 years ranging from 3 to 6 monthly then 6–12 monthly thereafter. Effort is made to alternate reviews between the various specialists involved, but this is not strictly codified.

Participants and recruitment

Purposeful sampling was employed. Oncologists from the POWH Cancer Centre were first invited by letter from the chief investigator. A letter was then sent from the consenting oncologist to their eligible patients asking them to participate. Patients needed to be ≥ 18 years of age, have completed active treatment for breast and/or colorectal cancers and have no current evidence of disease. At the completion of their interview, patients were asked if they agreed for their GPs to be invited. If they agreed, their GPs were then invited by letter. All participants gave full written informed consent.

Data collection

Semi-structured interviews were conducted face-to-face or by telephone according to the preference of the respondent, at a location convenient for them, between April 2014 and August 2015. Respondents were asked their views on the hospital-based model for cancer follow-up care and about GPs taking a greater or leading role in follow-up care. An outline of the topics covered in the interviews is provided in Box 1. Interviews were audio recorded with consent.

Data analysis

Interviews were transcribed verbatim and imported into NVivo (15) Version 10, a programme that assists with coding and data organization. Emergent themes were identified using Braun and Clark's thematic analysis framework (16). The coding framework and dominant emergent themes were then reviewed by the research team to

Box 1. Outline of patient, general practitioner and oncologist interview schedule

Patients

- Experience of current follow-up strategy
- Views on hospital, specialist-led follow-up
- Views on who is the best provider to provide follow-up care
- Views on primary care led follow-up
- Demographics

GP/oncologist

- Role/perceived goals of cancer follow-up
- Experience of current follow-up strategy
- Views on hospital, specialist-led follow-up
- Views on who is the best provider to provide follow-up care
- Views on primary care led follow-up
- Demographics

identify differing or additional insights or meanings, which informed the subsequent analysis. Although data saturation (17) was reached within the first few interviews within each patient, GP or oncologist group, recruiting continued until the number of individual GP–patient–oncologist cases was closer to the target of 20. MFH reviewed a random cross section of 20% of the interviews, and any differences in interpretation between the two coders were resolved by consensus. Participant validation (member checks) for a random cross-sectional sample of 20% of the interviews was also carried out (a process whereby a summary sheet of the themes and the coded interviews were taken back to the participants who were then asked to verify if the analysis had accurately represented their views).

MC was a participant in the study and was excluded from all stages of coding and analysis so as not to influence the findings.

Results

Participation

A total of 82 participants were approached; 67 agreed to participate, 11 were excluded, leaving 56 participants. A breakdown of the participant recruitment is shown in Table 1; participant demographics are provided in Tables 2 and 3.

Perception of general practitioners' current role in cancer follow-up care

Several patients felt that GPs were generalists, and their role was not to deal specifically with their cancer, but their health more holistically:

He actually just receives the letters and the reports from my referring specialist and then he knows how to control my other problems, my blood pressure and my general health... Breast and colorectal cancer patient #1

A common view from GPs was they played an important role in holistic care, particularly in regards to psychosocial support:

...for us the follow-up is to see the impact it's had on them not just physically but psychosocially, their family, their relationship, particularly with cancer such as breast where sometimes there is

Table 1. Participant recruitment, 2014–2015

	Invited	Refused/away	Agreed	Excluded	Included
Oncologist	24	7	17	No eligible patients 1	MO: BR 2, CR 3 SO: BR 3, CR 5 RO: 3
Patient	37	Refused 3 Overseas 2	32	Ineligible 2 Too sick 1 Not needed ^a 7	BR 8 CR 12 BR and CR 2
GP	21	Refused 3	18	0	18

BR, breast cancer; CR, colorectal cancer; MO, medical oncologist; SO, surgical oncologist; RO, radiation oncologist.

^aNot needed because data saturation had been reached and enough patient–GP–oncologist cases had been recruited.

Table 2. Patient demographics, 2014–2015

	Male	Female	Total
Cancer type			
Breast	0	8	8
Colorectal	7	5	12
Both	0	2	2
Total	7	15	22
Age			
40–49	1	0	1
50–59	0	5	5
60–69	2	6	8
70–79	4	3	7
80–89	0	1	1
Total	7	15	22
Years since diagnosis			
2	0	3	3
3	3	4	7
4	2	3	5
5	1	2	3
>5	1	3	4
Total	7	15	22
Highest level of education			
Yr10	1	7	8
Yr12	1	3	4
TAFE certificate or diploma	0	1	1
Bachelor degree	2	3	5
Postgraduate	3	1	4
Total	7	15	22
Main occupation			
Homemaker	0	3	3
Administration	2	1	3
Self-employed	0	1	1
Professional	2	1	3
Retired	3	9	12
Total	7	15	22

TAFE, Technical and Further Education.

significant surgery that happens that may well impact psychological on many women and I think we can provide a good support role there... General practitioner #5

Most participants agreed that GPs currently only had a minimal role in cancer care. This was more by omission than design on the part of the cancer specialists and/or patients:

...[the GP] has given me the referral and that's it...and maybe after the specialist give one letter to her to see, you know my history or something he said, no more. Colorectal cancer patient #2

Table 3. Provider demographics, 2014–2015

	Medical oncologist	Radiation oncologist	Surgeon	General practitioner	Total
Gender					
Male	3	2	8	8	21
Female	2	1	0	10	13
Total	5	3	8	18	34
Age					
40–49	2	2	5	2	11
50–59	2	0	1	11	14
60+	1	1	2	5	9
Total	5	3	8	18	34
Practice type					
Public hospital	5	3	8	0	16
Private practice	0	0	0	17	17
50:50 public and private	0	0	0	1	1
Total	5	3	8	18	34
Training					
Australia	5	3	8	14	30
Overseas	0	0	0	4	4
Total	5	3	8	18	34
Years practicing					
6–10 years	1	0	4	2	7
11–20 years	2	2	1	1	6
>20 years	2	1	3	15	21
Total	5	3	8	18	34
Cancer specialty					
Breast	2	2	3	0	7
Colorectal	3	1	5	0	9
Total	5	3	8	0	16
Most recent oncology training					
<2 years	0	0	0	2	2
3–5 years	0	0	0	1	1
6–10 years	1	1	4	0	6
11–20 years	2	1	2	1	6
>20 years	2	1	2	4	9
No training	0	0	0	10	10
Total	5	3	8	18	34

So I wouldn't say the GPs at the moment are particularly involved except for the fact that we write to them with all the information. So they are never kept out of the loop but they are not a part of the review process. Radiation oncologist #6

Several GPs stated they felt disconnected from the cancer follow-up care process, and feeling that there was a lack of continuity of care:

My role for many of these patients including [Name] is pretty non-existent really...she had her breast cancer 2012, her

follow-up was with her specialist and it's unlikely that I will have any involvement in the post-acute treatment stage. She'll be mostly seeing her specialist until the specialist says you don't need to see me anymore, and then the follow-up, which is five years down the track, might be the GPs role. So we're not really involved. General practitioner #13

Perception of specialist's current role in cancer follow-up care

Most patients and cancer specialists felt that specialists had an important ongoing role in surveillance of patients' cancer and monitoring the long-term effects of treatment. For both breast and colorectal cancer patients, there was a strong bond between patient and their cancer specialist that some participants were reluctant to attenuate:

...you've often got quite a good bond after five years or so of treatment, of knowing one another: and to break that is always difficult and I think that's why we tend to follow patients more than we need to amongst other reasons... Radiation oncologist #7
Well I feel comfortable with Professor [Name] because, you know, from the start he was the one who really—you know, I went from GP who sent me to him straight and then, you know, you start to feel comfortable with your doctor and I feel comfortable with him and I would like to keep doing with him. Colorectal cancer patient #15

Views on general practitioners taking a greater role in cancer follow-up care

There were mixed views on the GP taking a greater role. Both breast and colorectal cancer patients valued the reassurance they got from a specialist looking after them especially in surveillance for cancer recurrence:

I take great confidence in the fact that they are specialists in their field. I mean [GP] is fantastic, don't get me wrong, she's great, but it does just give me incredible confidence when I see them and they give me the all clear. I really do like that a lot. Breast cancer patient #17

However, some patients felt that GPs did not have the adequate training or knowledge to do cancer follow-up:

If it was so easy there would be no oncologists, all GPs would give treatment. But oncologist is a specialist. Breast cancer patient #9

Others stated they would be more comfortable with seeing their GPs for follow-up tests as long as they had adequate training:

I'm sure they would train the GPs to know what they're looking for so I wouldn't have a problem going to a GP if that was the case. It wouldn't worry me. Breast cancer patient #18

Patients also recognized that certain aspects of follow-up care were routine and could be dealt with in general practice:

...after the first couple of sessions when I realised...that it's a blood test and a quick examination, I'd have no problem with that being delegated to a GP. Colorectal cancer patient #16

Although some patients and GPs stated they would be happy to be transferred to the care of their GP after some years, the preference was for GPs to become involved in addition to specialists, not instead of.

GPs, for their part, recognized they lacked training, protocols and access to oncology teams. However, they were happy to be part

of a broader multidisciplinary team providing ongoing care as long as they were given adequate support:

It really it has to be a joint effort between the GP and the- not that we're included in the initial decision about what therapeutic agents are needed to be used, but I do think we need to be included in the overall program. I think that would be really, really good for us, and the patient. General practitioner #5

Some oncologists felt that it was possible for GPs to take on a role in some of the more standardized aspects of long-term cancer follow-up care:

I think the combination of doing check-ups like this could be very regimented in the sense that there is really no necessity in my mind, apart from obviously having colonoscopies which have to be done by specialists. But the process of checking up on a person, asking how they're going, doing a physical examination, ordering a CT scan and reading or reviewing the results are not something that you really need, in my view, a specialist to be doing. Medical oncologist #13

Although having GPs take on a greater role in follow-up could alleviate some of the time pressures for oncologists, most oncologists believed that patients should still be reviewed by an oncologist, but less frequently:

I think people would still need some oncology follow-up but maybe less frequently...getting GPs involved would be helpful. Get them engaged a bit more. They probably should still be followed up by a medical oncologist, I would've thought, but maybe less frequently...I really think 12 months is appropriate. Surgical oncologist #9

All groups (patients, GPs and oncologists) recognized that GPs were time poor and that GPs would need to have an interest in cancer care if they were to take on a greater role in follow-up cancer care.

There was also a recognition that holistic and psychosocial care was important for cancer follow-up care, and this may not be adequately addressed in some specialist care:

It would be nice, I suppose, to get someone to say, 'How's the rest of everything going?'....Everyone assumes that somebody else is doing it. Breast and colorectal cancer patient #20
I'm not sure that the hospital follow-up necessarily takes into account psychological issues. I think with some services at the time of the cancer diagnosis and initial treatment, but I think in follow-up, that's probably not followed-up. General practitioner #17

...oncology specialists are not necessarily ideal in handling many of the non-malignant issues that might arise in somebody who's been through cancer treatment; psychosocial issues, lifestyle issues. And so there's kind of areas in which an oncologist would be very good at dealing with follow-up, and there are actually areas where they're suboptimal. Medical oncologist #3

Women come in with problems having sex or men having erectile dysfunction...That's what they truly want to discuss with you but you don't have the time for them. You just say something like, 'Oh well you don't have your prostate cancer any more. It's just one of the side effects I mentioned.' It's hardly satisfactory. Medical oncologist #12

Main factors needed for a shared care/integrated care model for cancer follow-up care.

Participants identified a number of requirements for shared care to be safe and effective. These included defining agreed roles for the GPs, having clear protocols and plans for care, and having systems that allowed for shared care as discussed below.

Defined roles in cancer follow-up care

Specialists identified that defined roles would be needed upfront in accordance with patient, GP and oncologist expectations. Rather than being disconnected from patients during their active cancer treatment, GPs would be seen to have a continuing role throughout the process. Having this explicit would allow much greater acceptance by all involved:

...I think if we were to say to patients from the outset...this is the diagnosis, this is the treatment you're going to have and then after that...your GP will be your first point of contact going forward. It needs clear expectation-setting from the outset rather than from the end of treatment...the end of treatment is a really challenging time for patients...if they knew that was something that was always on the cards, and they knew that there was support both for them and the GP in that process, they'd be more willing to take it up. Medical oncologist #16

Having roles defined upfront, would ensure that all parties knew what was expected from them. It would also help address misconceptions that GPs were not competent and had no role to play or that patients were being relegated to poorer quality care by being seen by their GPs.

Protocols for cancer follow-up care

GPs and specialists felt that specific protocols were needed to assist GPs to provide optimal care and to provide a safety net in case of recurrence or other serious event:

...to maintain levels of care delivery it would have to be set in some sort of a protocol, perhaps a little bit like anti-natal shared care. So that's another example where you know it's standard routine stuff and most of the time nothing happens, but occasionally something does happen...I think protocols give a framework and a guideline for best practice. So I think in the scope of that then I think you know general practice definitely could be intimately involved in the actual follow-up process. General practitioner #7

Unlike other chronic conditions, there was a strong view that specific cancers were infrequently seen in general practice and this meant that more patient-specific follow-up protocols and plans needed to be written by cancer specialists for each patient. Routine elements of follow-up care could be performed by the GP, but the overall responsibility for the patient would remain with the cancer specialist who was expert in their tumour type and its treatment:

Well I would see [shared care] working the same way that it works for, let's say, antenatal shared care, in which there's a protocol, some of the consultations are done with the GP, some consultations are done at the hospital, and so that means that the patient doesn't have to always go to the hospital for follow-up, it could be done in the GP setting organising tumour markers for instance or CTs if they are required at different stages of their follow-up care...a protocol should be started, even with forms or some kind of template that we could fill out and say okay this has been sent to the hospital now, the patient's had, let's say, two more markers or whatever and a colonoscopy or, look, I don't know, and then if that gets sent to the specialist or the oncology department so somebody would review that and say, yes fine. General practitioner #11

Specialists retaining ownership or responsibility for their patients also ensured that patients were readily able to be sent directly into secondary care without having to go back through the hospital emergency department:

...they would need a very clear path that if something came up that they could immediately then call back on the specialist service. Medical oncologist #13

Improved information sharing, in real time

The lag time in GPs receiving information on a patient after a specialist visit was identified as an issue by many. Improved information sharing was identified as a crucial component to the model:

A lot of support in terms of electronic support systems and information systems so that information transfer—people could be reassured that information was being transferred effectively and accurately between GP practices and specialist practices, and access to that information for the patient themselves and the nursing leader. Medical oncologist #13

This has implications for electronic health record capabilities and remote access to hospital records by both specialists and GPs:

I think if we can link that up where the specialist will have access to the hospital system, you know from their own private personal computers or computers in their rooms, and then also those information can then be passed on to the GPs in their rooms networked computer, that would be fantastic. Surgical oncologist #15

Discussion

An integrated shared care model has the potential to streamline the follow-up process while taking the burden off the hospital system; prevent duplication of services; increase GPs exposure to cancer cases and correct misconceptions about GPs not needing to be part of cancer follow-up care or currently playing a role; and provide continuity of care for patients, including psychosocial care and management of comorbidities, while reassuring patients that a specialist is overseeing their care.

A unique feature of this study was that patients, specialists and GPs were linked together, which meant that their discussion of follow-up cancer care and shared care was not abstract but very concrete, taking into consideration the capacity and interpersonal dynamics of the real relationships.

A key finding of this study was that cancer patients, their GPs and cancer specialists were mostly comfortable with the idea of GPs being more involved in cancer follow-up care due to the value of the psychosocial and holistic care that GPs provided, but less so with the total transfer of care to general practice. This was because of the reassurance that was provided by having a specialist overseeing patient care, the specific follow-up surveillance and monitoring required for each patient, concerns with the quality of cancer knowledge and training of GPs, time pressures GPs face in general practice and individual GP levels of interest in cancer care. This is consistent with a number of other studies of patients' views of long-term follow-up care in Australia (12,18,19) and overseas (3,5,20,21).

Some GPs felt disconnected from the follow-up care process. Having GPs involved in a model of shared cancer care from the outset would increase GPs exposure to cancer patients. Other GPs lacked confidence in cancer care especially given the relatively small number of patients with a specific cancer type seen by any one GP. A common concern was about having specialist medical support and ready access for the patient back into the hospital system if needed. Having patient protocols and plans written by patients own oncologists would provide the reassurance of a specialist overseeing care.

Strong support for shared care plans initiated by cancer specialists for the long-term care of cancer survivors has been found in other Australian research (4,12).

It is recognized that cancer follow-up care requires, 'the same organized, evidence- and team-based approach that is afforded other chronic conditions in primary care' (22) p. 805. Fundamental to shared care is multidisciplinary teamwork, which assumes a higher level of communication and teamwork between primary and specialist care than is often the case (5). Effective and timely communication between GPs and cancer specialists is essential to coordination of cancer care (23). Where there is good communication, primary care providers are likely to discuss cancer survivorship issues with patients providing an extra layer to support (24), and improve the patient experience (25). Through involvement of primary care, cancer can be managed in conjunction with patients' other needs including co-morbid conditions (26), and patient continuity of care and engagement can be improved (27). However, in the absence of this communication, many primary care providers lack confidence to take a significant role in the long follow-up of cancer survivors (5). Improved communication has been found with electronic health records in integrated health systems overseas (28). This highlights the importance of the need for improved communication channels between primary and secondary care and in real time, and the need for the development of e-platforms to share information between GPs and specialists to better integrate primary and secondary health care in Australia. Primary Health Networks are well positioned in Australia to work closely with cancer services, general practice and software providers redesign providers to redesign cancer pathways cancer pathways and models of care.

Limitations

This study has some limitations. Patients and oncologists were recruited from a single metropolitan hospital, and most patients had GPs who worked in the vicinity. Their views may therefore not reflect the views of patients and doctors in other areas or settings. Participants may also be individuals interested in this topic. However, the results were consistent with findings from previous research indicating (3–6,12,18) that the sample was not biased.

Conclusion

Although some patients and doctors are comfortable for cancer survivors to be transferred to general practice for long-term follow-up care, the preference is for a shared care team approach. The complexity of cancer care leads to a need for a greater degree of tailoring or individualization of care plans and negotiation of roles than is necessary in the shared care of other chronic conditions. This implies a model of care with earlier engagement of GPs as part of the cancer team, GP involvement in risk assessment and care planning, and the development of information and communication systems to support this. There is an opportunity for cancer services and primary health networks to work closely together to develop this.

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Declaration

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Conflict of interest: MC was a participant in the study and was therefore excluded from all stages of coding and analysis.

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