Role of GPs in breast cancer-related arm morbidity care

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Abstract

Background: This paper addresses a gap in the literature on breast cancer-related arm morbidity care regarding clinician responsibility for the management of women's treatment-related arm morbidity needs. Using a qualitative research method, the authors spoke to general practitioners (GPs) about their perceptions, knowledge and experiences of breast cancer-related arm morbidity, and what role, if any, they thought they should or could play in this facet of women's breast cancer-related care. *Methods:* The study utilised qualitative, in-depth semi-structured interviews. Interviews lasted approximately 30–45 minutes and were audio-taped. Digital audio files were transcribed verbatim and analysed thematically. *Results:* GPs are prepared to engage in the care of patients with breast cancer-related arm morbidity. However, several gaps were noted in GPs' knowledge and understanding of these conditions, and the majority of GPs did not examine their patients specifically for signs of arm morbidity. *Conclusions:* There are a number of gaps in GPs' knowledge, understanding and experiences with breast cancer treatment-related arm morbidity, and there is a need for education about the complex nature of this condition. GPs are well positioned to improve the care that women living with arm morbidity need to receive. *Declaration of interest:* None.

Key words

Breast cancer
Arm morbidity
General practitioners (GPs)
Continuing care

Although one in nine women in Canada will develop breast cancer some time during their lifetime (Canadian Cancer Society, www.cancer.ca/), increasing numbers of women are living longer following treatment for this disease due to the success of early detection programmes and improvements in treatment modalities (Ugnat et al, 2005; Vivar and McQueen, 2005; Grunfeld et al, 2006). Consequently, many survivors are faced with a series of survivorship and health-related quality of life issues, including breast cancer treatment-related side-effects that result in upper body morbidity and disability.

As one of the most upsetting and misunderstood complications associated with the treatment for breast cancer, breast cancer-related arm morbidity can profoundly impact the daily lives of those afflicted (Kwan et al, 2002; Armer et al, 2004).

As one of the most upsetting and misunderstood complications associated with the treatment for breast cancer, breast cancer-related arm morbidity can profoundly impact the daily lives of those afflicted (Kwan et al, 2002; Armer et al, 2004). Taken together, the most common of the impairments may include any one or combination of the following:

- Numbness of the axilla or lateral chest wall
- Reduced range of motion (ROM) of the shoulder
- Painful lymphoedema (LE), which can affect the chest wall, armpit, wrist, fingers, and hand, often leading to some form of functional impairment (Kwan et al, 2002; Poole and Fallowfield, 2002; Dawes et al, 2008).

Especially pernicious is the incurable and sometimes late emerging morbidity of LE, which can occur months or even decades after treatments have ended (Thomas-MacLean et al, 2005; Kudel et al, 2007; Ahmed et al, 2008). Breast cancer-related LE is a serious medical condition and may be associated with limb heaviness and reduced mobility, impaired limb function, discomfort,

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chronic pain, and disability (Badger, 1988), and can predispose patients to such life-threatening complications as cellulitis and occasionally lymphangiosarcoma (Harris et al, 2001; Chachaj et al, 2010).

Incidence rates for LE vary considerably in the literature and have been reported to range from 2–83%, depending on the measurement tool used (Armer et al, 2003; Hayes et al, 2005; Hayes et al, 2008; Cheifetz, 2010). Estimating the incidence of LE is especially difficult because its aetiology is complex, and researchers remain unaware of all the factors that contribute to its development (Thomas-MacLean et al, 2005). Similarly, diagnostic criteria often vary between clinicians, and consensus has yet to be reached regarding a clear definition of LE (Harris et al, 2001; Armer et al, 2003; Cheville and Tchou, 2007), including the standardisation of measurement protocols (Armer et al, 2003; Armer and Stewart, 2005; Hayes et al, 2005). Recent literature reveals that postoperative LE is often under-diagnosed by healthcare professionals (Warren et al, 2007), and in one study by Delon et al (2008), arm LE was not noted by either researcher or patient in approximately one-third (36%) of their sample (n=133) until a calculation of arm volume (i.e. a 5% of increase in arm volume as an indicator of LE) was performed.

It has recently been argued that the implementation of less invasive surgical techniques such as sentinel lymph node dissection (SLND) and more targeted and refined radiation methods have resulted in the significant reduction of the incidence of breast cancer-related LE (McLaughlin et al, 2008; Helms et al, 2009). Although treatment-related morbidity associated with SLND is reduced, LE remains a clinically relevant complication (Helms et al, 2009; Goldberg et al, 2010), as does morbidity after surgery in the form of pain and functional compromise (Cheville and Tchou, 2007; McLaughlin et al, 2008 Helms et al, 2009). The acceptance of SLND among Canadian surgeons has increased since 2001, but it has yet to be accepted as the standard of care in Canada (Quan et al, 2008), and many patients continue to receive full axillary biopsy, especially if SLND results are positive or inconclusive (Cantin et al, 2008).

Since the predominant focus within the literature on breast cancer treatment-related arm morbidity has been on LE, research on other treatment-related arm morbidities such as chronic pain and arm and shoulder limitations is sparse and remains underdeveloped. The few studies that do exist indicate that both arm pain and shoulder restrictions are common, and can have a significant impact on survivors' quality of life, both in the short and long term (Kwan et al, 2002; Dawes et al, 2008; Thomas-MacLean et al, 2008; Nesvold et al, 2010).

Arm morbidity that results in long-term disability can jeopardise the economic security of survivors and their families through loss of earnings and job-related health insurance (Steiner et al, 2004).

Research that has addressed the impact of breast cancer on patients' quality of life demonstrates that treatment for the disease significantly impairs and intrudes upon paid and unpaid (domestic) work, leisure and sporting activities, family life, and other social relationships (Thomas-MacLean et al, 2005; Quinlan et al, 2009). Arm morbidity that results in long-term disability can jeopardise the economic security of survivors and their families through loss of earnings and job-related health insurance (Steiner et al, 2004). However, the effects of breast cancer treatment-related arm morbidity on daily living and quality of life have yet to be thoroughly documented, despite the large numbers of women who are dealing with long-term survivorship issues (Thomas-MacLean et al, 2008; Sagen et al, 2009).

Despite the continued prevalence of breast cancer-related arm morbidity, it remains unclear which clinicians are responsible for the diagnosis, treatment and management of women's arm morbidity needs, and to the best of the authors' knowledge, there are no studies that have addressed this issue. However, findings from the literature on follow-up and supportive care of breast cancer survivors suggest that responsibility for the treatment and management of women's arm morbidity may be well beyond the purview of breast cancer clinicians who, in Canada, are the primary clinicians responsible for women's after-treatment care. Overwhelmed by a national shortage of oncologists, and facing rising numbers of long-term cancer survivors, Canadian oncologists spend an average of six minutes with their patients (Beaver and Luker, 2005). Many have reported that they feel overburdened and frustrated by the growing rate of early breast cancer patients in need of continued follow-up care. This type of care typically involves the following: taking the patient's history, a physical examination and annual mammography to detect recurrent and new primary breast cancers, and counselling for the psychosomatic sequelae of a diagnosis of and treatment for breast cancer (Grunfeld et al, 2005).

General practitioners (GPs) and breast cancer treatment-related arm morbidity care

There may be a role for general practitioners (GPs) to play in addressing this gap in the management of women's treatment-related arm morbidity care. Although GPs have not traditionally played a formal role in breast cancer follow-up (as this remains the domain of breast cancer specialists whose services are more expensive than that of GPs), several studies indicate that the role they have played has been an important informal one (Grunfeld et al, 2006; Grunfeld et al, 1999a; 1999b).

There are now a number of studies, including randomised trials that have demonstrated that effective follow-up cancer care can be delivered by non-oncologists such as GPs (Grunfeld et al, 1995; 1996; 1999a;1999b). Findings from these and other studies indicate that:

- GP follow-up is acceptable to the majority of patients and patients prefer a single care provider to support and counsel them (Grunfeld et al, 2006)
- The family GP is the obvious clinician to assume this role because of his/her existing relationship with the patient and their family(Vinkel, 1995; Dahler-Eriksen et al, 1998)
- Breast cancer follow-up with a family GP is likely to be more convenient for patients and less costly (Grunfeld, et al, 2006)
- GPs report that they prefer to take on a more active role in breast cancer follow-up care (Paradiso et al, 1995; Worster et al, 1996).

Although these studies do not address the issue of breast cancer-related arm morbidity as part of follow-up, there is a role that GPs can play in the management of women's breast cancer-related arm morbidity needs. As providers of preventative healthcare services (Gray et al, 2002), GPs deal with symptom-based problem-solving in their daily practice (Nissen et al, 2006). Given that arm morbidity symptoms such as LE can develop any time after initial treatment, women will likely present first to their GPs rather than to breast cancer specialists during routine physical examinations (Thomas-MacLean et al, 2005). As a result, GPs are in a position to examine and monitor patients for early as well as latent signs of LE, which could potentially minimise acute morbidity and decrease the likelihood of permanent sequelae (Thomas-MacLean et al, 2005).

Yet, research shows that arm morbidity care and information is limited, and in some instances is non-existent (Gray et al, 1998; Collins et al, 2004; Thomas-MacLean et al, 2008). A Canadian study (Thomas-MacLean et al, 2005; 2008; 2009; 20101) on arm morbidity has consistently shown that for the majority of the respondents, information about, and treatment for arm morbidity was not discussed or received. Similar findings were noted by Collins et al (2004), who reported that although some women were provided with information on LE and what to expect in arm usage, other women felt unprepared, or felt 'dumped' by the hospital and wanted to know what was occurring in their bodies. Among this group of women was the common sentiment that doctors/oncologists offered little in the way of general information or potential complications.

Using a qualitative research method, the authors spoke to GPs about their perceptions, knowledge and experiences of breast cancer-related arm morbidity, and what role, if any, they thought they should or could play in this facet of women's breast cancer-related care.

With the goal of addressing some of the identified gaps in arm morbidity care, the authors' research project was part of a larger initiative that seeks to determine the information needs and media preferences of clinicians involved in the management of these conditions. The objective is to develop a model for knowledge translation around arm morbidity after breast cancer by drawing directly upon the perspectives of clinicians involved with follow-up care to provide them with the latest research findings and best care practices. However, as it remains unclear which healthcare professionals are responsible for the management of women's breast cancer-related arm morbidity needs, the authors conducted a preliminary study to determine if this was an aspect of care that GPs were interested in providing. The authors also sought to discern GPs' knowledge, understanding and experiences with breast cancer-related arm morbidity. A second, similar study was also conducted with breast cancer specialists (i.e. general surgeons, radiation and medical oncologists).

Using a qualitative research method, the authors spoke to GPs about their perceptions, knowledge and experiences of breast cancer-related arm morbidity, and what role, if any, they thought they should or could play in this facet of women's breast cancer-related care. To the best of the authors' knowledge, there are no studies that have addressed the role of GPs in the management of women's breast cancer-related arm morbidity care.

Methods

The focus was on the interpretive, on 'people's own written or spoken words and observable behaviour' (Bogdon and Taylor, 1975). In keeping with this research tradition, the intent was to capture the subtleties and complexities of GPs' perceptions, experiences and knowledge of breast cancer-related arm morbidity. The collection and analysis of the data was informed by the inductive grounded methodology of Glaser and Strauss (1967) and Strauss and Corbin (1994), a general methodology for developing theory that is grounded in data that is systematically gathered and comparatively analysed. Also known as the constant comparative method, theory is generated initially from the data, or if an existing grounded theory is elaborated on and modified as new data is carefully compared against it.

Procedure

Following ethics approval by the University of Saskatchewan's Research Ethics Board, telephone interviews with 12 GPs from across the province of Saskatchewan were conducted. One hundred GPs were invited to participate in the study, through letters (sent by mail and fax) and phone calls. Of the 100 GPs contacted, 12

agreed to participate in the study. Reasons provided for being unable to participate included:

- Lack of time to do the interview
- Lack of interest in the study topic
- Too few breast cancer patients
- Lack of patients presenting with breast cancer-related arm morbidity.

Of those who participated, four practitioners were from rural-remote locations (population <5,000), four were from mid-sized urban centres (population <36,000), and four were from large urban centres (population >175,000). Six practitioners were male and six were female. Seven GPs had 20 or more years' experience, five had 15 years' experience or less; years of experience ranged from 2.5–41 years in the sample overall.

Interviews were semi-structured rather than open-ended because the authors were interested in exploring specific questions regarding GPs' perceptions, knowledge and experiences of arm morbidity. However, prompts and follow-up questions were also employed to elicit breadth and depth in participants' responses (Breakwell, 1995), thereby allowing the participants the opportunity to reveal in their own words (Bogdan and Taylor, 1975) their experiences with and understanding of breast cancer-related arm morbidity. The interview questions addressed two over-arching concerns. The first was to glean an understanding of GPs' knowledge of (i.e. formal and/or experiential) and experiences with treatment-related arm morbidity to understand what their related information needs might be, as this was unknown. The second focus was to determine GPs' information media preferences (i.e. websites, emails, journals, podcasts, knowledge brokers, etc) and practices, in order to develop a model for knowledge translation that would aid in the transfer of research findings into clinical practice so that women's arm morbidity needs could be appropriately managed. This paper focuses on the first concern, therefore the relevant interview questions are:

- How many breast cancer patients are you currently seeing?
- With what types of arm morbidity concerns are women presenting?
- How do you respond when a woman presents with arm morbidity?
- How do you rate your knowledge of arm morbidity?
- Have you received any information on arm morbidity?
- Do you see GPs as having a role to play in arm morbidity treatment and care?

Interviews were audio-taped after written informed consent was obtained and lasted 15 to 30 minutes. Audiotapes were transcribed verbatim and the transcripts were read and reread in their entirety by the first author to discern similarities and differences within and between the transcripts, and to identify recurrent themes and sub-themes among the participants' accounts. Discussions with the second author verified the emergence of these thematic categories, as well as agreement on their similarities and applicability.

All identifying information was removed from the data and pseudonyms were attached to all transcript files. Written data were kept in locked cabinets in locked offices at the University of Saskatchewan. Audio, transcript and data analysis computer files are kept on a password-protected computer. Participants did not receive any honoraria for their participation in this study.

Results

This section focuses on GPs' perceptions and knowledge (formal and informal) of arm morbidity, their existing arm morbidity monitoring practices, and reasons why family practitioners thought they should (or should not) be involved in the management of women's breast cancer-related arm morbidity care.

GPs' perceptions of breast cancer-related arm morbidity

What emerged from GPs' responses were a series of assumptions and perceptions about the nature, prevalence and severity of arm morbidity. The majority of GPs reported that they were aware that arm morbidity could take a range of forms, and reported that they were seeing this among a number of their breast cancer patients. However, this majority also reported that, although they had patients who were presenting with some type of treatment-related arm morbidity, the actual numbers of women who were affected by these conditions was limited, as was the severity of their morbidity:

> *I don't have anyone right now that is having too much trouble. Just with some tightness... As far as LE, I don't have too many that are struggling with that.* (How about range of motion and pain?) *Um, yeah again, I haven't had too many people complain about that.*
>
> (female, large urban, 15 years)

Among the types of arm morbidity that women were presenting with, it was acute LE rather than pain, numbness or range of motion limitations that most physicians referred to:

> *Oh yeah, for sure, pain and physical restrictions. I certainly see that. I guess I'm thinking of LE in terms of acute swelling of the arm, yeah.* (So the women are still continuing to present with pain and …) *Oh yeah, and restrictions, I see that.*
>
> (female, mid-size urban, 27 years)

Popular among the majority of GPs was the perception that the prevalence of arm LE was on the decline due to recent innovations in breast cancer treatment modalities (i.e. SLNB, breast conserving surgery), including the view that the acute nature of the condition eventually lessened in severity or dissipated over time:

> *As to how much LE they have, for most of them it's transient, gone in a few weeks, and the odd one has long-term problems with LE.*

You don't see that very often, they don't do the radical mastectomies any more so most often it's either lumpectomy, but it's all due to how many nodes they take. (Are you seeing patients who have had SLNB, or is it still axillary?) *Uh-huh. That's the state of the art here now isn't it?*

(male, mid-size urban, 30 years)

Not only was treatment-related arm morbidity perceived as uncommon by the majority of GPs, the negative impact of arm morbidity on the lives of their patients was also regarded as relatively inconsequential by some. One physician stated that even among his (older) patients who were experiencing definite arm morbidity problems, the impact of the morbidity on daily living and on their quality of life was superficial and relatively negligible:

Some of my older breast cancer patients who have been around for a long time, some of them have LE problems. Some have definite arm problems, but it is usually related to the fact that they can't comb their hair properly and things like that. And it's the non-dominant arm, so it's not quite so much the problem as the other one.

(male, mid-size urban, 41 years)

This same practitioner also regarded the effects of arm morbidity as minimal when situated within the larger context of dealing with breast amputation and living with a potentially life-threatening disease. He remarked:

I hate to say this but I don't think of it (arm morbidity) *as kind of a major issue you know? I think though when you've dealt with the fact that you've lost a breast and you're dealing with a potentially fatal disease process that I think the arm problems tend to be relegated to the sort of second tier of concerns.*

Some participants viewed the responsibility for arm morbidity care to reside with such cancer care specialists as nurse and lymphoedema specialists, physio and occupational therapists, oncologists and/or surgeons.

I mean the cancer clinic must deal with it (arm morbidity issues), *oncologists must deal with it quite a bit. I was just going to say that I really do find that it is probably the surgeons who give the most advice to patients about that because they are mentioning that this you know may be a concern.*

(female, large urban, 15 years)

GPs' formal knowledge of breast cancer-related arm morbidity

GPs were also asked to rate their clinical knowledge of breast cancer-related arm morbidity. It was clear from the physicians' responses that this formal knowledge was shaped and informed by the assumptions about arm morbidity that are addressed in the previous section. Only two physicians rated their knowledge of arm morbidity as above average or better.

Those GPs who rated their knowledge of arm morbidity as poor or average, attributed it to a lack of experience with patients who presented with arm morbidity. Several of these same GPs also mentioned that because of the (perceived) rarity of arm morbidity issues among their breast cancer patients, it was not a topic that they approached their colleagues about:

(My knowledge is) *not good, but to be honest, since I've been here it hasn't been much of an issue so I don't think I could rate myself at all. I haven't actually had to discuss it with any other GPs around here and nobody's brought it up so maybe the doctors don't see it as a huge problem.*

(female, mid-size urban, 2.5 years)

Nor, was breast cancer-related arm morbidity a topic that physicians researched:

I would say mine was about the same as everybody else because I haven't gone and specifically read up on it.

(male, rural/remote 14 years)

On the other hand, GPs who rated their knowledge of arm morbidity as good or as above average, did so because of their experiences with patients who presented with arm morbidity:

Yeah, probably a little bit more knowledgeable than the average person because I've done a fair amount of sports injuries kind of things, plus the previous experience at the cancer clinic where it was something to look for in every woman who had radiation.

(female, large urban, 22 years)

Interestingly, there was one GP who rated his knowledge of arm morbidity as poor despite his many experiences with patients who presented with these conditions, because his knowledge was only based on practice. He remarked:

Just not great, it's just from experience. Back in (home country) *I worked with quite a few mastectomy patients when I was a military doctor. Then I had some experience in my private practice there. I had interesting experiences from them, so nothing more formal than just experience.*

(male, rural/remote, 21 years)

GPs were also asked if they had received media information (e.g. pamphlets, directives, clinical guidelines, emails, or podcasts) about the treatment and management of breast cancer treatment-related arm morbidity. All but one of the physicians reported that they had not received, nor could recall receiving, information about breast cancer treatment-related arm morbidity .

Not that comes to mind, it's hardly ever mentioned to be honest with you… I don't remember any CME or you know other sources of information coming through the system.

(male, rural/remote, 26 years)

However, one GP did reflect that because he was unaware of breast cancer-related arm morbidity as a clinical problem, there was the possibility that he may have received information about the condition(s) but chose to

ignore it because of its perceived rarity and irrelevance to his family practice. He said:

> *Not that I'm aware of or can remember. You know I think also when one is not aware of these problems and you receive literature you are like, 'well this is so rare. Why would I bother reading this?' Perhaps something has come across my desk but I cannot remember that at all.*
>
> (male, rural/remote, 14 years)

GPs' arm morbidity monitoring practices

GPs were asked if they were 'proactive' in monitoring their breast cancer patients for arm morbidity (i.e. purposefully checked for signs and symptoms of arm morbidity and/or if they asked patients if they were experiencing arm problems or if they had any related concerns), or if they took a more 'reactive' approach and waited for their patients to mention any arm morbidity issues they might be experiencing. Several approaches were noted among the responses.

Approximately two-thirds of the GPs reported that they did not make it a regular practice to ask patients if they were experiencing any arm morbidity problems, or if they had any related concerns. Several of these GPs were of the mind that if their patients had any issues they would mention it during the consultation. Others reported that they would ask general, open-ended questions that would allow patients the opportunity to bring up any problems or concerns they might be experiencing:

> (Do you ask if there are problems or do you wait for them to mention it?) *Um, usually wait for them to mention it.* (And why wait?) *I would probably ask an open-ended question, you know, are they having any particular problems? But I wouldn't narrow it down to the arm in particular. It's just the way I've always done it so, maybe I should be asking about the arm but I haven't.*
>
> (male, rural/remote, 26 years)

However, concerns about the treatment-affected arm would often arise during the physical examination when certain tests or procedures were performed, thereby bringing the issue of the hand/arm/shoulder to the GP's attention. One GP stated that arm issues would often arise when trying to take blood pressure:

> *It is probably them mentioning it to tell you the truth. It tends to come up because most people you are doing blood pressure on it and so you don't do blood pressure on those arms. So then that often leads to you looking at the arm or at least commenting on their arm.*
>
> (female, large urban, 15 years)

Approximately two-thirds of the GPs reported that they did not make it a regular practice to ask patients if they were experiencing any arm morbidity problems, or if they had any related concerns.

Even if the majority of GPs did not ask their patients directed questions about treatment-related arm morbidity, there were several who reported that they did check for particular bodily markers or signs like radiation tattoos or swelling (as an indication of LE or of recurrent disease), and for limited range of motion if they noticed the patient was having functional problems. However, as in the case of the GP cited below, these examinations were often limited in scope, and monitoring for arm morbidity was often not the central focus of the examination:

> *Now I do check the axilla and if they seem to be having any problems getting their arms up above their head for a breast examination I ask them, other than that I tend not to focus on that.*
>
> (male, rural/remote, 41 years)

Among the remaining third of the sample were those who reported that they made it a regular practice to ask their patients about any arm morbidity problems or concerns: 'No no, I ask them if they've had any problems with swelling' (female, large urban, 27 years). However, surveillance of arm morbidity was often limited to a short period following surgery, or was later addressed if a patient presented with a symptom or complaint, but would not be monitored across the long term:

> *I think I would routinely ask about that, you know in the months fairly soon after the surgery. I probably wouldn't think to ask about it five years later or whatever.*
>
> (female, large urban, 25 years)

Role of GPs in arm morbidity follow-up care

Given the gap in care regarding which group of clinicians are responsible for the treatment and management of breast cancer-related arm morbidity, the authors asked GPs if this was a role appropriate for their practice. All but two of the practitioners responded in the affirmative. Several reasons were offered regarding why GPs should or could be involved in this aspect of women's breast cancer-related continuing care.

For a number of practitioners, GPs had a role to play in women's arm morbidity care because of the holistic nature of primary care:

> *Oh absolutely! Oh definitely.* (And could you elaborate on why?) *Um, it's a specialist field of course, the operation and the treatment of the cancer, but I think it's very important for a patient even going through something like this to maintain a very healthy relationship with a primary care provider. Because that is the person or team whose not just going to look after the arm, it's much broader than that. This is the person who looks after my general ailments, even my problems at home, my psychological problems and everything. So, I think the primary care worker is the one that stands in the first range for this and should be the one geared and well equipped to deal with it.*
>
> (male, rural/remote, 21 years)

GPs also had a role to play in arm morbidity care because of the relatively short-term duration of breast cancer follow-up. This meant that treatment-related complications or long-term side-effects such as arm morbidity would eventually become their responsibility:

Oh yeah, we clean up the pieces, clean up the aftermath. Ultimately, in the immediate post-op period the surgeons are really quite good about dealing with any complications, but the long term of course, the GPs look after the lion's share of it.
(male, mid-size urban, 30 years)

One GP remarked that not only were family practitioners more than capable of learning how to treat and manage women's arm morbidity, but it was also an aspect of women's continuing care that is beyond the mandate of breast cancer specialists, whose focus should be on the treatment and eradication of breast cancer:

I think we are primary because when you go to the specialist for breast cancer, that's what the oncologist is worried about. When you present with LE, they really don't want that because they know there is very little they can do and it distracts from the bigger work that they are doing. When they've got to try and save a woman's life they can't spend hours with a patient who is complaining about LE. So I think that they should defer to us and allow us to treat that because we can learn about it as much as they can and this isn't their mandate. So I think if anybody should be responsible for it, it should be us.
(male, rural/remote, 14 years)

Among GPs that had practices in remote and rural localities, all saw themselves as being the logical and primary clinician to oversee the management and treatment of women's arm morbidity needs because of the difficulties (i.e. cost, time, and inconvenience) associated with accessing specialist health care in these communities.

The trouble is we're 5.5 hours north of (a major city) *and a breast specialist would require 11–12-hour turn-around trip, so it's logistically a family physician. I think the best situation is for family physicians to have a basic knowledge of what to do and then to have the breast cancer surgeons as the backup willing to receive the calls or offer opinions in the time period shortly after the surgery. But, down the line, I think the family doctor is the best because they are the available person.*
(male, rural/remote, 26 years)

... all of the study participants were in agreement that they should be involved in this aspect of care. They have a role to play because of the holistic nature of family medicine, and because of the temporally limited nature of breast cancer follow-up care with specialists.

Although the majority of practitioners reported that they were willing to play a more active role in the treatment and management of women's arm morbidity needs, two saw themselves playing a more limited one. These GPs reported that they preferred to act as advocates or intermediaries for their patients. One GP referred to her role as that of a 'sounding board' for her patients: 'I think just as a sounding board to help them to determine if this is something they should worry about with regards to the arm, so if they're having questions about it' (female, mid-size, 10 years), while another (the practitioner who did not see a role for GPs in arm morbidity care) reported that she referred her patients to those practitioners (i.e. physio, massage and occupational therapists) who were specially trained to treat and manage breast cancer-related arm morbidity.

Discussion

As noted in the authors' review of the literature, research shows that despite recent innovations in treatments for breast cancer, women continue to experience physical and psychosocial consequences of these treatments which can result in functional impairment, disability and pain, and that these can worsen over time. Arm morbidity affects paid work, relationships with family, and leisure activities, including the pursuit of physical activity.

Findings from interviews with GPs show that many may be prepared to engage in the care of patients with arm morbidity, and that there is an appropriate role for physicians to fulfil. There are, however, some gaps in practitioners' knowledge and understanding of these conditions. These include misconceptions regarding prevalence, and that due to recent innovations in treatment and staging protocols, arm morbidity is now a rare event, and is no longer disabling. Other gaps in knowledge include a lack of formal education and training around arm morbidity issues, as well as a lack of awareness about available clinical information (e.g. guidelines, directives and factsheets). GPs did perceive their own knowledge to be somewhat inadequate, based on their limited experience with patients who presented with lymphoedema and chronic pain.

Regarding their arm morbidity monitoring practices, the majority of GPs did not examine their patients specifically for signs of arm morbidity, with some preferring to let their patients set the agenda. The few GPs who routinely enquired about and monitored their patients for signs of arm morbidity tended to do so only for a limited period of time following treatment, despite indications in the literature that conditions such as LE may emerge several years post-treatment.

Despite these gaps in GPs' understanding and management of breast cancer-related arm morbidity, almost all of the study participants were in agreement that they should be involved in this aspect of care. They have a role to play because of the holistic nature of family medicine, and because of the temporally limited nature of breast cancer follow-up care with specialists.

It is clear from the responses of the study participants that GPs have a role to play in the management of arm morbidity care. However, it is also clear that there are a number of gaps (i.e. rates of prevalence and severity of, lack of formal training about) in their knowledge of arm morbidity. There is a need to educate GPs about the complex nature of this condition, including the often subtle ways in which it can present (i.e. as late emerging and being imperceptible to the naked eye), along with its potential impact on quality of life.

Conclusion

As said, this study indicates that there are a number of gaps in GPs' knowledge, understanding and experiences with breast cancer treatment-related arm morbidity, and that there is a need for education about the complex nature of this condition. Despite these difficulties, GPs are well-positioned to help improve the care that women living with arm morbidity need to receive (i.e. because of their existing relationship with patients and their families, and the fact that patients prefer a single care provider), and should endeavour to regularly assess their breast cancer patients for treatment-related arm morbidity regardless of time since treatment. JL

Key points

- Despite recent innovations in treatments for breast cancer, women continue to experience treatment-related consequences that can result in functional impairment, disability and pain that can worsen over time.
- It remains unclear which physicians are responsible for the diagnosis, treatment and management of women's arm morbidity needs.
- There is an appropriate role for GPs to fulfil in the management and care of breast cancer survivors' arm morbidity-related needs.
- However, there are gaps in GPs' knowledge and understanding of breast cancer-related arm morbidity, and there is a need for education about the complex nature of this condition, including the often subtle and imperceptible ways in which it can sometimes present.
- GPs need to regularly assess their breast cancer patients for treatment-related arm morbidity regardless of time since treatment.

References

Ahmed R, Prizment A, Lazovich D, Schmitz K, Folsom A (2008) Lymphedema and quality of life in breast cancer survivors: The Iowa women's health study. *J Clin Oncol* **26**: 1–9

Armer J, Culbertson S, Radina M, Porock D (2003) Prediction of breast cancer lymphedema based on lymphedema and breast cancer questionnaire (lbcq) symptom report. *Nurs Res* **52(6)**: 370–9

Armer J, Fu MR, Wainstock JM, Zagar E, Jacobes LK (2004) Lymphedema following breast cancer treatment, including sentinel lymph node biopsy. *Lymphology* **37(2)**: 73–91

Armer JM, Stewart BR (2005) A comparison of four diagnostic criteria for lymphedema in a post-breast cancer population. *Lymph Res Biol* **3(4)**: 208–17

Badger C (1988) A problem for nurses — lymphoedema. *Surg Nurse* October: 14–19

Beaver K, Luker K (2005) Follow-up in breast cancer clinics: reassuring for patients rather than detecting recurrence. *Psycho-Oncol* **2**: 94–101

Bogdan R, Taylor S (1975) *Introduction to Qualitative Research Methods. A Phenomenological Approach to the Social Sciences*. John Wiley and Sons, Toronto

Breakwell G (1995) Interviewing. In: Breakwell GM, Hammond S, Fife-Shaw C, eds. *Research Methods in Psychology*. Sage, London: 232–53

Cantin J, Scarth H, Levine M, Jugi M, the Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer (2001) Clinical practice guidelines for the care and treatment of breast cancer: 13. Sentinel lymph node biopsy. *CMAJ* **152(2)**: 166–73

Chachaj A, Malyszczak K, Pyszel K, Lukas J, Tarkowski R, Pudelko M, Andrzejak R, Szuba A (2010) Physical and psychological impairments of women with upper limb lymphedema following breast cancer treatment. *Psych-Oncol* **19**: 299–306

Cheifetz O (2010) Management of secondary lymphedema related to breast cancer. *Can Fam Phy* **56(12)**: 1277–84

Cheville A, Tchou J (2007) Barriers to rehabilitation following surgery for primary breast cancer. *J Surg Oncol* **95**: 409–18

Collins L, Nash R, Round T, Newman B (2004) Perceptions of upper-body problems during recovery from breast cancer treatment. *Supp Care Can* **12**: 106–13

Dahler-Eriksen K, Nielsen JD, Lassen JF, Olesen F (1998) Shared care programmes — an example of a cooperating healthcare system. English summary. *Ugeskr Læger* **160**: 5021–4

Dawes D, Meterissian S, Goldberg M, Mayo N (2008) Impact of lymphoedema on arm function and health-related quality of life in women following breast cancer surgery. *J Rehabil Med* **40(8)**: 651–8

Del Giudice ME, Grunfeld E, Harvey B, Piliotis E, Verma S (2009) Primary Care Physicians views of routine follow-up care of cancer survivors. *J Clin Oncol* 27(20): 3338–45

Delon M, Wade A, Cooper S, Walls C, McGillycuddy B, Martlew B (2008) Early post-op swelling and its association with lymphoedema. *J Lymphoedema* **3(1)**: 26–30

Glaser B, Strauss A (1967) *The Discovery of Grounded Theory. Strategies for Qualitative Research*. Aldine, Chicago

Goldberg J, Wiechmann L, Riedel E, Morrow M, Van Zee K, Morbidity of sentinel mode biopsy in breast cancer (2010) The relationship between the number of excised lymph nodes and

lymphedema. *Ann Surg Oncol* **17**: 3278–86

Gray R, Fitch M, Greenberg M, Hampson M, Labrecque M (1998) The information needs of well, longer-term survivors of breast cancer. *Patient Educ Couns* **33**: 245–54

Gray R, Goel V, Fitch M, Franssen E, Labrecque M (2002) Supportive care provided by physicians and nurses to women with breast cancer. Results for a population based survey. *Medicine* **10(8)**: 647–52

Grunfeld E, Gray A, Mant D, et al (1999a) Follow-up of breast cancer in primary care vs specialist care: results of an economic evaluation. *Br Med J* **79**: 1227–33

Grunfeld E, Fitzpatrick R, Mant D, Yudkin P, Adewuyi-Dalton R, Stewart J, Cole D, Vessey M (1999b) Comparison of breast cancer patient satisfaction with follow up in primary care vs specialist care: Results from a randomized controlled trial. *Br J Gen Pract* **49**: 705–10

Grunfeld E, Levine M, Julian J, Coyle D, Szechtman B, Mirsky D, Verma, Dent S, Sawka C, Pritchard K, Ginsburg D, Wood M, Whelan T (2006) Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol* **24(6)**: 848–55

Grunfeld E, Levine M, Julian J, Coyle D, Szechtman B, Mirsky D, Verma, Dent S, Sawka, C, Pritchard K, Ginsburg D, Wood M, Whelan T (2006) Randomized trial of long-term follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. *J Clin Oncol* **24(6)**: 848–55

Grunfeld E, Mant D, Vessey M, Fitzpatrick R (1995) Specialist and general practice views on routine follow-up of breast cancer patients in general practice. *Fam Pract* **12**: 60–5

Grunfeld E, Mant D, Yudkin P,Adewuyi-Dalton R, Cole D, Stewary J, et al (1996) Routine follow-up of breast cancer in primary care: A randomized trial. *Br Med J* **313**: 665–9

Grunfeld E, Zitzelsberger L, Coristine M, et al (2005) Job stress and job satisfaction of cancer care workers. *Psycho-Oncology* **14**: 61–9

Hack T, Kwan W, Thomas-MacLean R, Towers A, Miedema B, Tilley A, Chateau D (2010) Predictors of arm morbidity following breast cancer surgery. *Pycho-Oncology* **19(11)**: 1205–12

Harris S, Hugi M, Olivotto I, Levine M (2001) Clinical practice guidelines for the care and treatment of breast cancer: 11. Lymphedema. *CMAJ* **64(2)**: 191–7

Hayes S, Battistutta D, Newman B (2005) Objective and subjective upper-body function six months following diagnosis of breast cancer. *Breast Cancer Res Treat* **94**: 1–10

Hayes S, Janda M, Cornish B, Battistutta D, Newman B (2008) Lymphedema secondary to breast cancer: how choice of measure influences diagnosis, prevalence, and identifiable risk factors. *Lymphology* **41(1)**: 18–28

Helms G, Kuhn T, Moser L, Remmel E, Kreienberg R (2009) Shoulder-arm morbidity in patients with sentinel node biopsy and complete axillary dissection — data from a prospective randomized trial. *EJSO* **35**: 696–701

Kudel I, Edwards R, Kozachik S, Block B, Agarwal S, Heinberg L, Haythornthwaite H, Raja S (2007) Predictors and consequences of multiple persistent postmastectomy pains. *J Pain Symptom Manage* **34(6)**: 619–27

Kwan W, Jackson J, Weir L, Dingee C, McGregor G, Olivotto I (2002) Chronic arm morbidity after curative breast cancer treatment: prevalence and impact on quality of life. *J Clin Oncol* **20**: 424–48

McLaughlin S, Wright M, Morris K, Sampson M, Brockway J, Hurley K, Riedel E, Van Zee K (2008) Prevalence of Lymphedema in women with breast cancer 5 years after sentinel lymph node biopsy or axillary dissection: Patient perceptions and precautionary behaviours. *J Clin Oncol* **26(32)**: 5220–6

Nesvold I, Fossa S, Holm I, Naume B, Dahl A (2010) Arm/shoulder problems in breast cancer survivors are associated with reduced health and poorer physical quality of life. *Acta Oncol* **49**: 347–53

Nissen M, Beran MS, Lee M, Mehta S, Pine D Swenson K (2006) Views of primary care providers on follow-up care of cancer patients. *Fam Med* **39(7)**: 477–82

Paradiso A, Nitti P, Frezza P, et al: A survey in Puglia (1995) The attitudes and opinions of specialists,general physicians and patients on follow-up practice. *Ann Oncol* **6**: S53–S56

Poole K, Fallowfield L (2002) The psychological impact of post-operative arm morbidity following axillary surgery for breast cancer: a critical review. *Breast J* **11**: 81–7

Quan M, Hodgson N, Lovrics P, Porter G, Poirier B, Wirght F (2008) National adoption of sentinel node biopsy for breast cancer: Lessons learned from the Canadian experience. *Breast J* **14(5)**: 421–7

Quinlan E, Thomas-MacLean R, Hack T, Kwan W, Miedema B, Tatemichi S, Towers S, Tilley A (2009) The impact of breast cancer among Canadian women: disability and productivity. *Work* **34(3)**: 285–96

Sagen A, Karesen R, Sandvik L, Risberg M (2009) Changes in arm morbidities and health-related quality of life after breast cancer surgery — a five-year follow-up study. *Acta Oncol* **48**: 1111–18

Smith R (1998) Introduction: American Cancer Society workshop on breast cancer treatment-related lymphedema. *Cancer* **83(12 Suppl)**: 2775

Steiner J, Cavender T, Main D, Bradley C (2004) Assessing the impact of cancer on work outcomes. *Cancer* **101(8)**: 1703–11

Strauss A, Corbin J (1994) Grounded theory methodology: An Overview. In: Denzin N, Lincoln Y, eds. *Handbook of Qualitative Research*. Sage Publications, London

Thomas-MacLean R, Hack T, Kwan W, Towers A, Miedema B, Tilley A (2008) Arm morbidity and disability after breast cancer: new directions for care. *Oncol Nurs Forum* **35(1)**: 65–71

Thomas-MacLean R, Miedema B, Tatemichi S (2005) Breast cancer-related lymphedema. Women's experiences with an underestimated condition. *Can Fam Physician* **51**: 246–7

Thomas-MacLean, R, Towers A, Quinlan E, Hack T, Miedema B, Tilley A, Graham P (2009) 'This is a kind of betrayal': a qualitative study of disability after breast cancer. *Curr Oncol* **16(3)**: 26–32

Ugnat A, Xie L, Semenciw R, Water C, Mao Y (2005) Survival patterns for the top four cancers in Canada: the effects of age, region and period. *Eur J Cancer Prev* **14**: 91–100

Vanhuyse M, Bedard P, Sheiner J, Fitzgerald B Clemons M (2007) Transfer of follow-up care to family physicians for early-stage breast cancer. *Clin Oncol* **19**: 172–6

Vinkel A (1995) The general practitioner — an important cooperation partner for cancer patients and their relatives. *Practicus* **100**: 367–8

Vivar C, McQueen A (2005) Informational and emotional needs of long-term survivors of breast cancer. *J Adv Nurs* **51(5)**: 520–8

Warren A, Brorson H, Borud L, Slavin S (2007) Lymphedema: a comprehensive review. *Ann Plast Surg* **56(4)**: 464–72

Worster A, Bass M, Wood M (1996) A willingness to follow breast cancer: A survey of family physicians. *Can Fam Physician* **42**: 263–8