

Title: Role of the General Practitioner in caring for metastatic breast cancer patients
– a survey of patients' perspective.

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Abstract:

Introduction

There is little published data on the patient's perspective of the role of their general practitioner (GP) in caring for women with metastatic breast cancer (MBC).

Aims

The primary objective was to identify strengths and weaknesses in the management of MBC patients by GP's, from the patients' perspective.

Methodology

A quality assurance project was conducted where 124 MBC patients completed a 37-item questionnaire regarding the existing role of their GP. Patient demographics, aspects of the GP's practice, disease and treatment factors were assessed.

Results

Of the patients studied, 83% regarded their GP as a valued member of the healthcare team. However only 8.1% reported palliative care or psychosocial support being discussed by their GP, with Advanced Care Planning (ACP) infrequently discussed.

Conclusion

Our findings indicate that GPs are closely involved in many MBC patients' ongoing care. Further research is necessary to understand the low rate of GP participation in managing palliative and psychosocial needs, as well as their role in assisting patients in ACP.

Introduction

Breast cancer is the most common cancer diagnosed in women in Australia, and while patients with metastatic breast cancer (MBC) are living longer, current treatments are generally not curative and are aimed at effectively managing symptoms and optimising quality of life¹. Patients with MBC under the care of a medical oncologist (MO) receive systemic treatments aimed at tumour reduction with the intent of symptom palliation and prolongation of survival. Beyond tumour-directed drug therapy, there is a necessity to provide support for the patient's physical functioning, psychological and emotional consequences of metastatic disease, and social and inter-personal difficulties which may exist. Many MBC patients experience fluctuating periods of disease control on treatment, and ultimately the impact of disease progression when treatment-resistance develops. Thus, patient needs are complex and the role their general practitioner (GP) plays, is important².

This quality assurance project was developed to assess how patients viewed their GP's role in the management of their MBC. The aim was to identify the strengths and weaknesses, as seen by MBC patient, regarding care provided by their GP. This would then enable areas in care to be improved with the goal of optimising delivery of care to MBC patients.

Eligibility criteria

Key inclusion criteria for the project included patients diagnosed with MBC under the care of the senior author (AC) during the study period, English regarded as their first language, access to Medicare-funded services and provision of written consent.

Participants with an anticipated life expectancy of less than 3 months and those newly located to their place of residence in the preceding 4 weeks were excluded.

Method

Consecutive MBC patients were approached and following consent, patients completed a 37-item questionnaire, addressing their experiences with access to their GP, provision of palliative, psychosocial and medical advice, and the level of communication between their GP and MO perceived by the patient. Patients were able to provide a comment on areas of improvement. Patient and disease characteristics were obtained from a prospective database managed by the senior author. The goal of the project and acquisition of consent from patients was undertaken by the BCRC-WA Advanced Breast Care Nurse (ABCN). Patients were given the option to complete the questionnaire at the project site or at their residence. Data review and analyses was conducted by all authors.

Statistical analysis

The results of the questionnaire were collated as frequency tables. Variables including patient age (≤ 60 years vs > 60 years), time since MBC diagnosis (progression free survival (PFS) ≤ 5 years vs > 5 years) and current treatment regimen (intravenous chemotherapy with or without anti-HER2 or bone targeted agents, oral chemotherapy, oral biological treatment (OCB), endocrine therapy or nil). Chi-squared and Fisher's exact test (Prism9) were used to assess for statistical significance with p value < 0.05 .

Results

The survey was conducted from December 2018 through to September 2019. Over this 10-month period, 99% (124 out of 125) of patients approached for the survey, provided written consent. The median age of respondents at the time of study entry was 63.6 years (range 30.6 to 90.7). Table 1 shows that over two-thirds of patients had metastatic recurrence following an early breast cancer diagnosis with a median

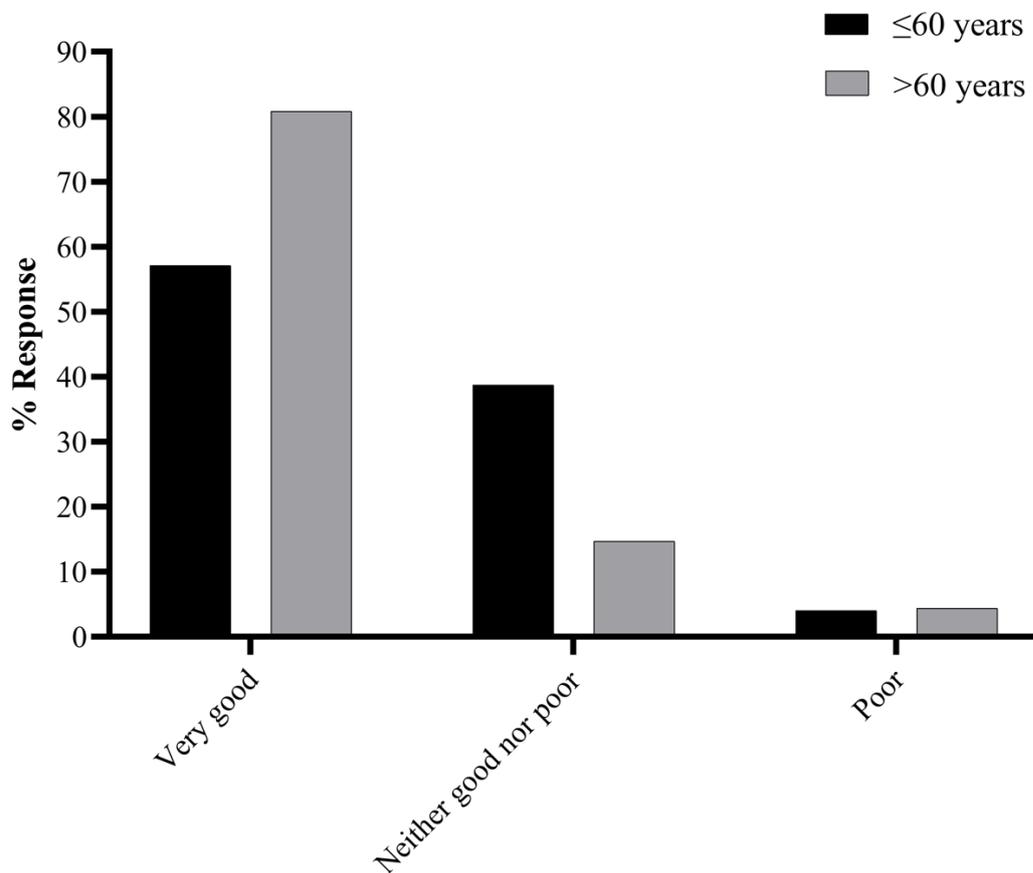
disease-free interval of 61.3 months (range 7 to 327). Of the 31% of patients who were diagnosed with de novo MBC, the median PFS at time of the survey was 48 months (range 15 to 285).

Table 1: Demographics of patients included in the study questionnaire

Patient Characteristic	n (%)
Patients	124
Study period	5/12/2018 to 16/9/2019
Recruitment period	9 months
Age, median	63.6
Age range	30.6 to 90.7
Progression Free Survival (PFS) median (m)	56.6
Progression Free Survival range (m)	4.9 to 320.9
Stage at diagnosis	
Early Breast Cancer (EBC)	86 (69.4%)
Metastatic Breast Cancer (MBC)	38 (30.6%)
Disease status	
De Novo	86 (69.3)
Metastatic recurrence	38 (30.7)
PFS de novo median (m)	48
PFS de novo range (m)	15 to 285
PFS metastatic recurrence median (m)	61.3
PFS metastatic recurrence range (m)	7 to 327
BC type	
Hormone receptor positive	72 (58.1%)
HER2 receptor positive	46 (37.1%)
Triple Negative	7 (5.6%)
Treatment Type	
IV Chemo	25 (20.2%)
Anti-HER2	37 (29.8%)
Oral Chemotherapy / Biological therapy	41 (33.1%)
Oral Endocrine therapy/ Nil	21 (16.9%)
Age	
50y less	21 (16.9%)
50y-60y	29 (23.4%)
60y-70y	36 (29.0%)
70y more	38 (30.6%)

GP Patient relationship

Many patients reported a good relationship with their preferred GP (92%), with 70 patients continuing to see the same GP from prior to their MBC diagnosis. The GP was regarded as a valued member of the healthcare team by 83.1% of patients; and 92.7% of patients felt that their needs were met at their last GP visit. Figure 1 shows that patients >60 years of age reported a more positive experience in the provision of ongoing supportive care with 81% viewing their care as 'very good' compared to 57.1% of younger patients.

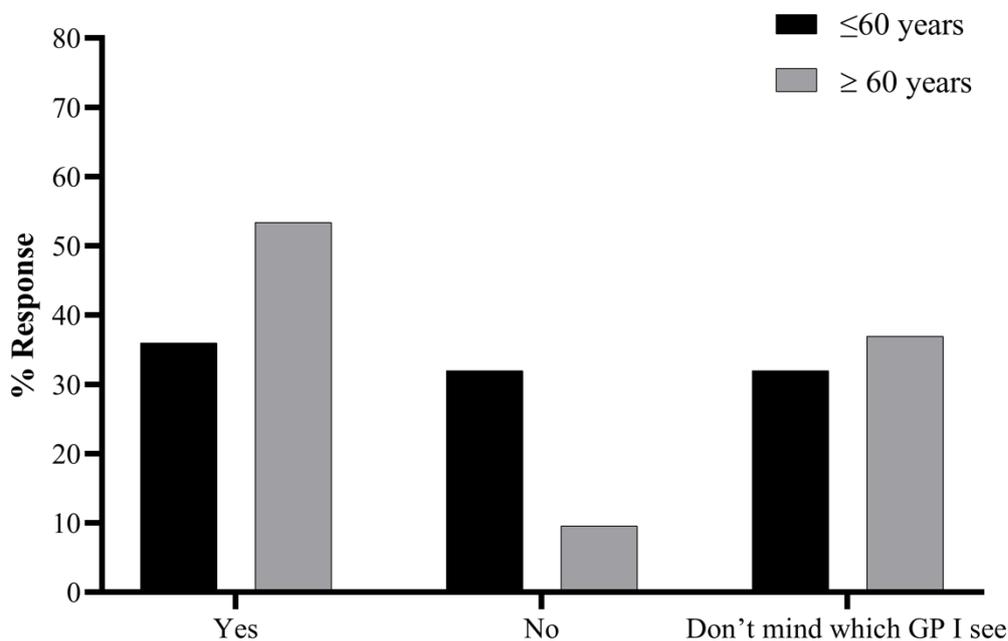


Fisher's exact test p value <0.05

Figure 1: Overall patient experience in provision of ongoing supportive care by GP in MBC patients ≤60 and >60 years of age.

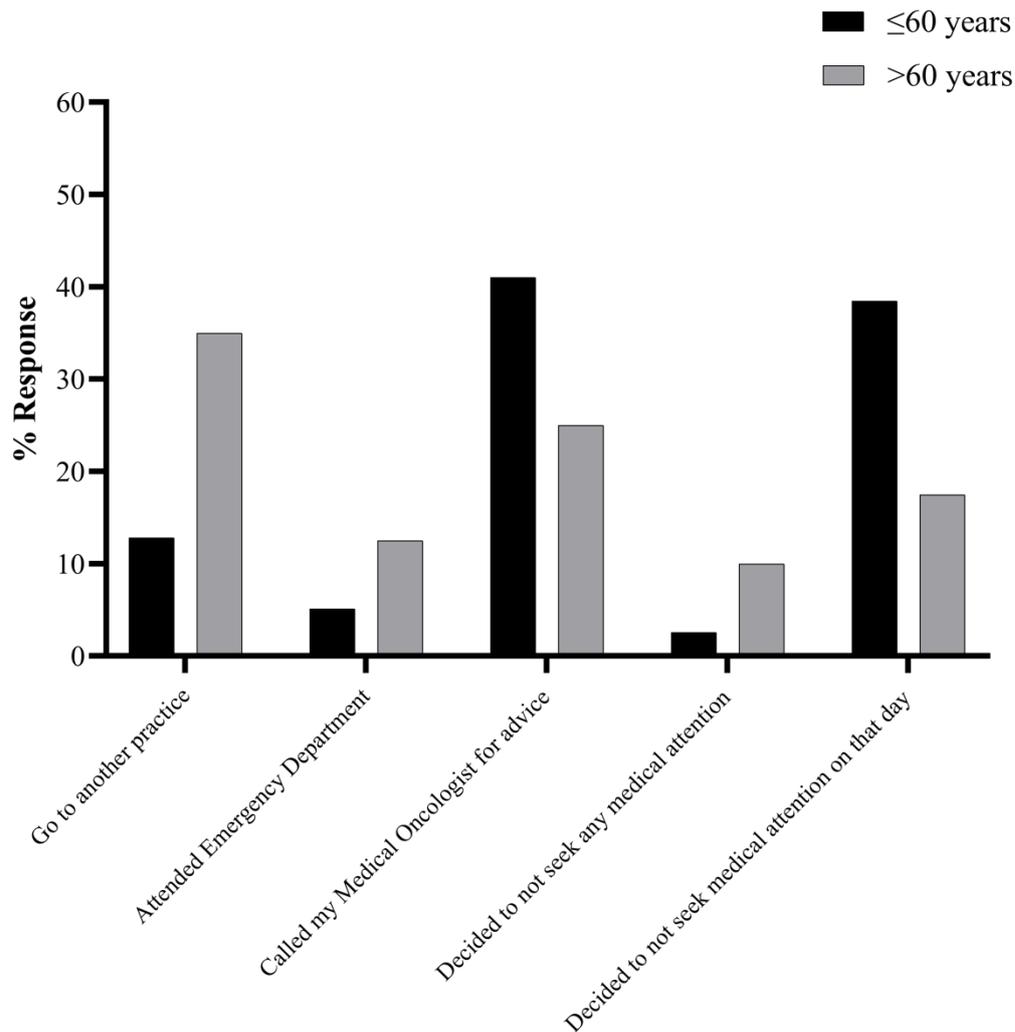
Accessibility to GP

Overall, 57% of patients had a GP who they had seen regularly prior to their breast cancer diagnosis. In the event of needing an urgent appointment, 95% were able to be seen within a week, with 48.4% being able to see their GP on the same day and 46% being able to see their preferred GP. Patients aged over 60 years were more likely to be able to see their preferred GP for an urgent appointment compared to younger patients (54% vs. 36% respectively), as shown in figure 2. In the event of not being able to see any GP at the time of an urgent medical need (n=79), patients aged >60 years were significantly more likely to go to another GP practice, attend an emergency department or not seek medical attention at all, whilst patients ≤60 years were more likely call their MO for advice as shown in figure 3 (p=0.016).



Fisher's Exact Test p value <0.05

Figure 2: Comparison of age of MBC patients (≤60 vs >60 years) and ability to see preferred GP for an urgent appointment.



Fisher's exact test p value <0.05

Figure 3: Action taken by MBC patients (≤60 years vs >60 years) when unable to see any GP for an urgent appointment.

Subsequently, apart from urgent appointments, only 1.6% of patients surveyed visited their GP at least once a week following their diagnosis of metastatic breast cancer, with a majority of patients (70.2%) seeing their GP occasionally. The type of treatment patients were on (chemotherapy, endocrine, anti-HER2 or biological agents) at the time of the survey did not impact on the responses with respect to any of the

questions relating to seeing preferred GP for urgent appointment, timeframe of seeing their GP or choice of an alternative health care provider (data not shown).

Reasons for GP visit

The most common reasons for patients seeking an appointment with their GP were for routine health checks (38.9%) and prescriptions (26.5%), with only 8% of patients indicating an emergency medical consultation as the reason for seeing their GP. At the time of the survey, 53.2% of patients reported pain as a symptom that they experienced. These patients reported their GP as being solely responsible for pain management (15%), MO for 36% and both GP and MO for 47%.

The survey identified that 85% of GP's would rarely or never order additional tests in relation to MBC management. In the situation where GPs requested additional investigations, patients reported being aware that their GP communicated with their MO (25%), did not communicate with their MO (27%) or were unsure (47.8%).

Patient Management Plan

Two-thirds of patients reported that their GP was up to date about their breast cancer management plan, and at the most recent last GP visit 71% of women had confidence and trust in the care and advice that was provided by their GP. Importantly, 76.6% of patients felt that during their recent visit(s) with their GP, they were happy with their level of involvement in decisions about their care. However, 91% of the patients did not feel that their GP recognised or understood their psychosocial needs.

Palliative Care, Advance Care Plan and Advance Health Directive

Overall, 19 patients reported that their GP provided palliative care support (15%), whilst the remainder of patients stated either no or uncertain of GP palliative care support

(21% & 57.3%, respectively). Less than 5% of patients were unclear what palliative care support was. Patients were asked if they had completed an Advance Care Plan (ACP) and/or Advance Health Directive (AHD). Only 10 patients (8%) had completed an ACP and/or AHD and of the latter only 2 had requested their GP to be involved as a witness. Subsequently 48% of patients responded that they did not want to receive any additional information regarding ACP.

Discussion

Prolonging survival is a key goal for MBC, but this must be done whilst optimising cancer-related symptoms and minimising treatment-related toxicities³. Furthermore, as many MBC patients experience complex care needs, multidisciplinary care is imperative for these patients. Thus, the GP's role is regarded as an integral component of care, which requires a good relationship between the patient and their GP¹. In 2005, a quarter of GP's were not willing to provide palliative care⁴. However, the response to changing practice has advanced in recent times and studies have demonstrated that GPs now receive core education in patient needs, including physical and psychosocial aspects of care. This has resulted in a majority of GP's now considering themselves as important members of the palliative care team⁴.

Furthermore, there is little published data on the role and nature of GP involvement in the care of women with MBC^{5,6}. Therefore, this survey was aimed at assessing the patient's perspective regarding medical, psychosocial, and palliative care provision by their GP. The identification of gaps in provision of care for MBC patients by their GP would potentially enable interventions to be developed, with the goal of improving the delivery of patient-centred care.

As discussed in our results, we found that the vast majority of MBC patients surveyed had a good relationship with their GP and regarded their GP's involvement in MBC care as being important. We did however identify a difference in patient-reported supportive care from their GP based on the patient's age, with just over half of the younger patients reporting very good supportive care from their GP as compared to 80.8% of older patients.

Over the course of a patients' MBC disease, they may experience a significant amount of physical and emotional distress, including treatment side effects, disease related symptoms, the need for complex decision making, and being confronted with their own mortality ^{7,8}. The fear of the unknown can also be very distressing and severely debilitating. This not only affects the patient's quality of life but has also been shown to negatively impact progression of cancer, with chronic distress being correlated with promoting metastases ⁹. It is therefore important that attention is given for physical functioning issues, psychological and emotional consequences of metastatic disease, as well as social and inter-personal difficulties that may exist ⁶.

The results did show that patients were able to obtain appointments with their preferred GP for general consults, however only 48.4% were able to obtain same-day appointment for an urgent consultation and less than half of the patients were able to see their preferred GP. As a result, more younger patients chose to either call the MO or go to another practice; whilst there was a significantly higher likelihood that older patients elected to attend an emergency department. Of some concern was the finding that 17.5% chose not to seek any medical attention on that day, while 10% did not seek any medical attention at all. We did not specifically assess the impact on the outcome of the urgent medical problem in those who were unable to see their GP, but there is potential concern that awaiting review in an emergency department may not

have been necessary and it is possible that a lack of medical review could have led to greater symptomatic distress and thus poorer quality of life.

We also identified key gaps in the palliative care of these patients with 57% of patients being unsure of whether GP's provided palliative care. The Cancer Australia Statement in 2019 "influencing best practice in MBC", states that, it is critical for patients with MBC to have access to multidisciplinary supportive care including, palliative care services, and psychosocial support when needed ¹. Palliative care is a fundamental element of care for patients with MBC and can significantly reduce both physical suffering and emotional distress. Effective palliative care is aimed at minimising the impact of the progressing illness along the disease trajectory, as it includes holistic patient assessment and enabling of interventions tailored to the patient's needs ¹⁰. Subsequently, the principles of palliative care can be applied at any stage of the patient's illness. Thus, to understand the reasons behind our findings, it would be necessary to delve in greater detail as to individual patient's understanding of what palliative care means and to also obtain the perspective from GPs as to how they discuss and manage patients with a palliative intent.

Yoong and Poon (2018) describe cancer pain as one of the most common and problematic symptoms faced in palliative care. It is therefore essential that patients are aware that their GP can play an integral role in managing this symptom. GP's have in-depth longitudinal knowledge and are well placed to provide ongoing holistic pain management support ¹¹. Our survey identified that 45% of women with MBC did not experience cancer pain requiring prescription intervention, but in those who did have pain, their GP was solely or jointly involved in pain management (62% of patients).

The majority of patients reported that their GP rarely or never order additional tests as part of MBC management. Of the 13% that did request additional tests, only 23% of their GP's consulted with the MO. In response to our question as to whether the patient perceived their GP was up to date on their management, two-thirds of patients responded in the negative. To evaluate the significance of this response, it would be necessary to elucidate what aspects of management that the patient was specifically referring to and importantly, to know if the GP similarly perceived a lack of up-to-date appraisal of the patient's condition. This aspect deserves further evaluation as to whether inadequacy lies in suboptimal communication from the MO, the rapidity of management changes related to the nature of the metastatic disease, or the complexity of factors which face the patient and her family in dealing with the illness such that intermittent written correspondence is ineffectual. Druel et al, 2020 demonstrated a correlation between patient's perception of a good relationship between their GP/oncologist and their visit to GPs for cancer-related consultations ⁶. This is however also dependent on the relationship between GP's and MO's. A cross-sectional survey of GP-specialist relationships across 34 countries demonstrated that approximately 60% of GPs in Australia almost always received feedback communication from specialists, while <5% stated never receiving any communication ¹². Potential strategies to improve this area include informal interactions between GP's and specialists via phone or virtual meetings and the role of a specialist advanced breast nurse in being an additional point of contact for GPs.

The survey only posed a general question as to the patient's perspective of their GP's role in meeting their psychosocial needs (“During your recent visit(s) to see your GP, did you feel that he/she recognized or understood any psychosocial health needs that you may have had?”). It is noted that 88% of patients responded that their psychosocial

needs were not addressed. Although the understanding of 'psychosocial' would have been subjective between patients, this result highlights an area in need of attention. Within clinical practice, the emotional side effects of cancer may not always be discussed in as much detail as the physical side effects. Improving this aspect of care provided by the GP and ABCN would likely be significant to the patient and their family's ability to deal with an incurable cancer diagnosis.

The National Comprehensive Cancer Network (NCCN) (2020) state that about a third of cancer patients may experience a significant amount of distress, with only five percent obtaining psychological help. It is therefore important to assess for psychosocial risks as it may affect how patients cope with their cancer and their ability to follow treatment recommendations¹³. The NCCN Distress Thermometer and Problem List can be a useful tool in clinical practice as it measures distress and allows patients to inform their clinician if they have concerns in areas such as practical, family, emotional, spiritual, and physical problems¹³. Furthermore, the specificity of this instrument may enable patients to more easily discuss the emotional consequences of the diagnosis, symptoms, and treatment of cancer. Considering the high prevalence of psychological distress associated with metastatic cancer, the implementation of a 6-monthly psychosocial screen, such as the NCCN, as part of GP interaction with MBC patients, could assist in early identification and interventions that can substantially improve quality of life⁸.

The existence of breast cancer specific clinical psychologists, as is the case in our comprehensive breast cancer centre, allows prompt referral of patients – from within the centre or by the patients' GP. The involvement of a clinical psychologist also includes the provision of emotional assessment feedback to the GP, which can further enable the GP to deliver more focussed attention to the areas of need.

Despite the suggested benefits of implementing ACP, the number of patients completing an ACP remains low. Only 8% of patients who completed the survey had completed an ACP or AHD and we believe this is an area that requires more attention. The barriers to initiating and completing an ACP are numerous and it was beyond the scope of this survey to evaluate the cause of such a low rate. Published studies have demonstrated that health professionals reported barriers such as fear of undermining people's positive coping strategies and depriving people of hope by talking about death¹⁴. Therefore, within clinical practice, timing of such discussion may reflect the question, "When is the right time to start the conversation?". When discussing sensitive subjects such as AHD, effective, sensitive communication and a patient-centred holistic approach is required. General practice, where trusted relationships are already formed, might be the optimal location for introducing and promoting ACP¹⁴. It has been reported by Palliative Care Western Australia (PCWA) (2019), that more than 80% of Australians think it is important to document their end-of-life care preferences. In 2019, PCWA developed a specialised website on ACP, called 'You only die once' that also supported a television, radio, and social media campaign to increase community awareness of advance care planning¹⁵. There are several fundamental components within ACP including the understanding of treatment options, understanding of palliative care and the writing of an AHD. It is therefore vital that patients receive holistic information at a time that is right for them. We believe that the GP plays an important role in this area and may be well placed to offer patients guidance and information to plan.

We noted that 50% of patients in this survey did request to receive more information about ACP and AHD. Mann et al (2017) describes that despite the low uptake of establishing an ACP, when completed by patients, it can positively affect end-of-life

care experiences ¹⁴. Their study supports that co-locating facilitators in general practice is an effective method for increasing ACP participation. They recommend incorporating ACP into routine healthcare practices, preferably when the patient is medically stable and has time to reflect on one's values and preferences ¹⁴.

As a result of this survey, a strategy was introduced within our centre whereby all patients diagnosed with MBC are offered an appointment with the ABCN to discuss ACP and AHD. During the initial appointment, patients are provided with key information including hard copies of ACP's and AHD's. The ABCN advises the patient to make a follow-up appointment with their GP or MO to finalise their AHD. With a structured standard operational procedure being implemented, the aim is to reduce patients' and carers' fear of discussing advance care planning, including the taboo subject of palliative and end-of-life care. It would be interesting to assess the rate of ACP and AHD uptake in the future following the implementation of this strategy.

Limitations of the project design

Within the limitations of the survey, we did not specifically seek out the reasons why patients had not undertaken an ACP or AHD. The survey was only carried out at one centre with patients being under the specialist care of one MO. It is likely that broadening the patient population to different health care centres in the public and private setting, metropolitan and rural regions would potentially identify other areas of patient need as it relates to the role of their GP.

Implications/Recommendations of this project

We would therefore recommend that to capture a wider population, surveying more patients, GP's, and MO's could tease out the factors affecting the management of palliative care for patients with MBC. In addition to obtaining a more detailed perspective of the individual patient, it could also be suggested to incorporate additional patient demographics such as marital status, family support, ethnicity, and socioeconomic status to understand the sociocultural factors contributing to complex care needs..

Conclusion

Our project demonstrated that many patients viewed their GP as an important clinician in their treating team, with overall satisfactory access to seeing their GP when needed. The significant findings that warrant more attention in our ongoing research is to improve the access of older patients to their GP in the event of an urgent medical matter, a greater articulation of the palliative management central in the care of patients with metastatic breast cancer, enhanced communication between treating specialist centres and the GP, and further elucidation of the GP's role in planning of ACP and AHD.

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