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Care requirements of patients with advanced cancer within a specialist centre – moving to person-centered approaches

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Abstract

Despite the prolonged survival of many patients with advanced cancer and the increasing conceptualization of cancer as a chronic illness, care delivery systems within the Australian context continue to manage advanced cancer as an acute illness. Patients living with advanced cancer are managed alongside those with curable cancers in ambulatory models of care that centre on diagnosis, treatment decision-making or post treatment surveillance. Conversely, the needs of people with advanced disease are often complex, requiring high levels of collaboration between providers across acute, palliative and primary care settings in order to move forwards to a more person-centered approach to care.

Aims:

This paper addresses three specific aims:

1. to identify the care requirements and concerns of patients and their carers;
2. to examine the role of out-reach telephone calls as a component of care;
3. to identify the nurse's role in care coordination for patients with advanced cancer.

Method:

Two nurse clinician researchers (CR) managed a cohort of patients with advanced breast (n=12) and gastrointestinal cancers (n=16) over six and nine months respectively. Data were recorded on every interaction between the CRs and the patients, carers and other health professionals. The CRs were interviewed by an independent nurse researcher.

Results:

The symptoms and issues causing concern to patients and/or carers included pain, weakness, gastrointestinal symptoms, managing appointments and dealing with anxiety. The CR played a major role in coordinating care to address these concerns and found out-reach telephone calls facilitated the process.

Conclusions:

Patients with advanced cancer have complex needs and care coordination requirements not routinely met in an acute care setting. Input from a nurse working at an advanced level and the use of out-reach telephone calls can assist in meeting these care needs.

Keywords

Advanced cancer, care requirements, patient needs, outreach phone calls

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Introduction

People with cancer are living longer with around 60% of all Australians living for at least five years after a diagnosis of cancer [1]. In addition to those who are cured of cancer, there is a growing population of survivors living with advanced disease as a result of improved treatment options and disease management. The result is a need to manage cancer as a chronic illness. While this change in conceptualisation is present in both health-related literature [2,3] and in government policy and planning documents (4, [4,5], it is yet to be translated into care system changes. People with advanced cancer continue to be primarily managed in the acute care setting, in part because of the increasing number of new treatment options available. In contrast, other well recognised chronic diseases, such as depression, hypertension and diabetes, are managed increasingly within the primary care setting [6-10].

Evidence-based models of chronic illness care exist and emphasise patient-centred care [11] and self-management, with the aim of empowering both the patient and their caregivers to manage the illness. This is particularly important in the cancer setting where patients with advanced cancer have multiple needs and issues [12] and are primarily managed in an acute care setting but also receive care from health professionals in primary, community and home settings. Despite these complex care requirements, no specific model of care exists for advanced cancer and medical, psychosocial and practical support is mostly clinician-defined. This can result in poor care coordination and sub-optimal support for patients. In addition, communication with families [13] and between various health professionals such as primary care doctors may be inadequate.

In contrast, effective self-management of chronic conditions by patients and carers results in better communication with clinicians, improved self-reported health and lower distress, fewer hospitalisations and decreased health system costs [14]. To facilitate the self-management aspects of cancer care, advanced practice nurses, also known by a variety of other titles including clinical nurse specialists and nurse care coordinators, are increasingly implemented to assist cancer patients and carers by providing education, medical, emotional and supportive care [15,16]. The aim of care coordination is to enhance the patient's experience during illness. In Australia, many dedicated cancer care coordinators are registered nurses, who practice within the context of a multidisciplinary team and are directly involved in care processes and plans to ensure all patient care requirements are arranged and delivered [17].

In addition, nurse-led telephone or out-reach calls to cancer patients have been trialled [18]. These out-reach calls offer an alternative to routine follow-up hospital visits, potentially reducing the burden on outpatient clinic services and negating the need for patients to travel [18-23]. Furthermore, nurse-led telephone interventions provide psychological support, address informational needs [18,24], reduce emotional distress and enhance physical functioning for cancer patients [25]. These studies also suggest interactions by nurse specialists can promote patient self-management and reduce acute service utilisation.

Here, we present the outcomes of an exploratory participant observation study of patients with advanced cancer at an acute specialist cancer hospital in Australia. The overall objective was to understand the concerns and care requirements of people affected by advanced cancer and their health professionals. The aims of the study were:

1. to identify the care requirements and concerns of patients and their primary carers;
2. to examine the role of out-reach telephone calls as a component of care, and
3. to identify the nurse's role in care coordination for patients with advanced cancer.

This paper provides insight into the complexity of care required by and provided to patients with advanced cancer and those close to them and highlights the critical role of care coordination in meeting patient needs.

Method

An exploratory participant observation study was undertaken to establish the care coordination needs of patients with advanced breast or gastrointestinal (GI) cancer. Two specialist nurse clinician-researchers (CR) worked as care coordinators and were each responsible for the care of one of the two patient cohorts. The CRs recorded the type, frequency and reasons for interactions between the patients, their family and the treatment team and CRs. The data were augmented by individual interviews with the CRs conducted by an independent nurse researcher. The CRs were asked to discuss their role in the care of patients with advanced cancer.

The study was approved by the Human Ethics and Research Committee at the Peter MacCallum Cancer Centre, Melbourne, Australia.

Recruitment

Patients were eligible for the study if they had an advanced, incurable breast or GI cancer and were identified by their treating team as having multiple, complex issues and needs. Patients were informed about the study during an outpatient appointment and if they gave informed consent were introduced to the relevant CR. Data collection occurred over six and nine months respectively for the breast and GI patients, commencing in October, 2007.

Data collection

Data were recorded on every interaction between the CRs and the patients, family members and/or carers and other health professionals both within the hospital and in the community using specifically designed data collection forms. Data on the physical, psychosocial and practical issues and concerns of both patients and carers were recorded, together with the actions performed by the CRs to facilitate a resolution of issues and concerns. The length of the interactions between the CR and patient/family member was also recorded.

Out-reach telephone calls to patients and carers were made by the CRs five to seven days prior to scheduled outpatient appointments to identify any issues that required interventions or investigations before attending the hospital. Calls were also made one to two days after commencement or change in treatment or when symptoms required close monitoring. The reasons for the out-reach call, length of call and outcome or required actions were all recorded on specifically designed forms by the CRs.

Results

Patient Characteristics

The patients with breast cancer (n=12) ranged in age from 31 – 72 years (mean 51.5). The patients with GI cancers (n=16) were slightly older (range 37–82 years, mean 63.6) and tended to have shorter survival times. Three women with breast cancer lived alone and did not identify a family member or support person while three patients with GI cancer lived alone but had an identified support person.

Disease Characteristics

A range of GI cancers were represented in this sample including neuroendocrine tumours, oesophageal, pancreatic, colorectal and gastric cancers. Most GI and one third of breast cancer patients were initially diagnosed with metastatic disease with the remainder diagnosed with early disease at the beginning that subsequently recurred. Nine patients died during the data collection period (n=8 GI, n=1 breast). The demographic and disease characteristics of the study patients are outlined in Table 1.

Physical Symptoms

A range of physical symptoms were self-reported by patients during data collection with pain, weakness and fatigue, and GI symptoms the most frequently discussed with the CR. (see Table 2)

Frequency and mode of contact with patients

A total of 501 contacts were made between the 28 patients, their carers and the CRs (see Table 3). One GI patient received all his contacts with the CR over the phone as he lived in rural Victoria and was too unwell to travel to Melbourne. There was no carer initiated contact for six patients with breast cancer and nine with GI cancer. The length of time spent on patient contacts from both groups ranged from 1 - 90 minutes (mean 12.6 minutes with breast patients and 11.5 minutes with GI patients). The recorded time spent with patients reflects the actual "direct contact time"; not including time spent by the CR following-up on issues and needs (indirect patient care).

Planned Communication

Out-reach Phone Calls

Twenty six out-reach calls were made to patients with breast cancer (range 0 – 5) over six months while 99 calls (range 0 – 16) were made to GI patients over nine months. One patient with breast cancer initiated constant contact with the CR and therefore did not receive an out-reach call and one patient from the GI group transferred his care to another hospital and so was not followed up.

When interviewed both CRs reported making more out-reach calls than originally planned (pre appointments and following a change in treatment or symptom profile) particularly to the GI patients during the quite rapid deterioration at the end of life. Despite the volume of out-reach calls the CRs saw this as a time efficient and practical way of monitoring patients, identifying problems and intervening or coordinating support services.

Psychosocial needs were often identified during the out-reach calls. These needs required the CR to engage in therapeutic communication through active listening, eliciting and responding to emotional cues, and providing reassurance and support. Referrals to social work or psychology were also made when necessary. The CR for the patients with breast cancer said: *"patients often said they could ask me things that they would not burden the doctor with"*.

Calls or communication from patients and family

The number of GI patient/carer initiated contacts with the CR (n=60) was higher than the breast cancer patient/carer initiated contacts (n=40), however women

Table 1: Patient Demographics

		Patients with breast cancer (n = 12)	Patients with GI cancers (n = 16)
Gender	Male	0	11
	Female	12	5
Marital status	Married	5	12
	Single	3	2
	Divorced	2	0
	De Facto	1	1
	Widowed	1	1
Employment Status	Full Time	3	1
	Part Time	0	1
	Not working/Sick leave	4	6
	Home Duties	4	2
	Retired	1	6
Place of residence	Metropolitan	10	9
	Rural	2	7
Presence of disease	Metastasis present at diagnosis	4	14
	Early stage/local disease at diagnosis	8	2
Time to metastatic disease	< 2 years	2	0
	2-5 years	3	0
	> 5 years	3	2
Site of Metastatic disease*	Bone	9	2
	Liver	6	13
	Brain	3	0
	Lung	5	3
	Adrenal	1	0
	Spleen	0	1
	Nodal/omental/mesenteric	0	1
Number of metastatic sites	1	7	12
	2	0	4
	3	3	0
	4	2	0
Treatment at recruitment**	Surgery	2	0
	Chemotherapy	4	10
	Biphosphonate therapy	8	0
	Herceptin	2	0
	Hormonal therapy	7	0
	Radiotherapy	1	2
	Palliative care	0	6

*Many patients had metastatic disease in multiple sites
**Many patients were receiving multimodal treatment at time of recruitment

with breast cancer used email more frequently (n=16 versus n=3). The patients with breast cancer tended to contact the CR when they needed advice or clarification about their care plan, but at the same time knew where and how to access support themselves. The CR said *"I think these women have learnt to navigate their way around the system themselves and know where and how to access supports, they didn't need me for that"*. While the data shows GI patients did self initiate contact with the CR some tended to wait for the nurse to call them, even when they had a problem *"When I asked why he hadn't phoned me when the pain got worse he said he didn't want to bother me and besides he knew I would call in the next day or so"* (GI CR).

Patient practical, informational and psychosocial concerns

Patients reported 17 different practical and psychosocial concerns. The most common practical concern related to managing appointments which was raised by 20 of the patients on 47 occasions. Feeling anxious was the most common psychological concern, which was raised by 25 of the patients on 111 occasions. Other emotional concerns, such as fear, worry and ability to cope with the situation were raised on 24 occasions by nine patients from the GI group. The most common

Table 2: Symptoms reported by patients

Symptom	Patients with breast cancer (n=12)	Patients with GI cancers (n=16)	No. of times reported
Pain	11	12	117
Weakness/Fatigue	7	14	96
GIT Symptoms[1]	8	14	120
Respiratory Symptoms (dyspnoea, cough)	3	7	34
Cardiac Symptoms (palpitations, swollen limbs)	4	5	26
Neurological Symptoms (dizziness/drowsiness/confusion)	4	7	34
Restlessness/panic attacks	1	1	6
Mouth/teeth problems	3	3	10
Rash/skin problems	2	3	12
Insomnia/sleep disturbance	5	3	13
Miscellaneous[2]	5	9	63

[1] GIT symptoms include constipation, diarrhoea, abdominal symptoms, nausea and vomiting, dysphagia, anorexia/weight loss, jaundice

[2] Miscellaneous symptoms include alopecia, fever/sweating, shoulder problems, potential infection, urinary symptoms, hormonal symptoms, decreased mobility and bleeding/haemoserous ooze.

Table 3: Frequency and mode of contact with patients

	Patients with breast cancer (n = 12)	Patients with GI cancers (n = 16)
Total number of contacts	186	315
Mean per patient (range)	16 (3-26)	20 (2-42)
Face-to-face	72	88
Telephone to patient/carer*	58	160
Telephone from patient	21	25
Telephone from carer	3	32
Email to patient/carer	16	0
Email from patient/carer	16	3
Number of days with multiple contacts with the same patient(s)	27^	44^^

*Includes planned out-reach calls and unplanned or unscheduled calls

^Range of contacts with one breast patient in one day 2-5

^^ Range of contacts with one GI patient in one day 2-4

informational concern was a desire for clarification about the treatment options which had been discussed with the oncologist, which was raised by 19 of the patients on 80 occasions. See Table 4 for detail.

Carer practical and psychosocial concerns

Six different practical issues and five psychosocial concerns were raised by patients' carers (see Table 5). Carers were most commonly concerned about their ability to deal with patient symptoms and their own anxiety. Differences in the concerns raised by the two groups of carers were noted and possibly related to differences in the prognosis of the breast and GI patients. Carers of patients with GI cancers expressed concerns about decisions relating to the need for hospitalisation, their ability to provide all support required, dealing with finances and arranging transport. These issues were not raised by the carers of the women with breast cancer.

Clinician researcher actions

Most interactions with the patients and/or their carers required subsequent action by the CR. Seventeen different types of actions were performed by the CR with the number of actions carried out across the study totalling 1064. Provision of supportive medication and symptom management advice, liaison with hospital staff, managing appointments and checking on how patients and carers were managing at home were the most frequent actions performed. All actions were required by GI patients while five actions were not required by the

Table 4: Patient practical and psychosocial concerns

Issues		No. of Breast Patients (from n=12)	No. of GI Patients (from n=16)	No. of times reported
Practical	Clarification and management of appointments	8	12	47
	Dealing with medications	4	6	28
	Obtaining results of blood tests and investigations	2	5	25
	Managing financial concerns	4	2	20
	Managing at home	2	6	11
	Caring for venous access devices	1	4	8
	Managing complimentary and alternative therapies in conjunction with standard treatments	1	2	7
	Arranging accommodation	0	3	4
	Managing co-morbidities	1	0	2
Psychosocial	Feeling anxious	12	13	111
	Clarification of treatment options as discussed with specialists	9	10	80
	Emotional issues such as how to cope, fear and general worry	0	9	24
	Concerns about family carers	5	3	17
	Desire to know prognosis	4	6	13
	Concerns regarding quality of care being provided	3	3	9
	Dealing with uncertainty	0	3	7
	Meaning of palliative care and implications of palliative care involvement	1	2	4

Table 5: Carer practical and psychosocial concerns

Issues		No. of Breast Carers (from n=9)	No. of GI Carers (from n=16)	No. of times reported
Practical	Managing patient symptoms	2	9	52
	Obtaining results	4	6	30
	Managing appointments	2	6	15
	Ability to provide support	0	2	3
	Arranging transport	0	2	2
	Managing financial concerns	0	1	1
Psychosocial	Dealing with own anxiety	5	9	62
	Having end of life discussions with the patient	1	5	14
	Meaning of palliative care and implications of palliative care involvement	1	4	11
	Discussing whether or not the patient required a hospital admission	0	3	6
	Psychological health of the patient	0	1	5

patients with breast cancer (Table 6). A number of actions, such as arranging transport, rearranging or making appointments, faxing referrals, booking procedures (e.g. ascetic taps and blood transfusions) were administrative in nature and did not require nursing expertise. On average each patient required 38 actions with a range of 2-42 across the total period they were enrolled in the study.

Further detail about the CR's actions was identified during the interviews. Both CRs described their role in broad terms as including problem solving, acting as a resource person and point of contact within the hospital. They believed their existence and actions benefited patients and their carers by facilitating the journey through the health system. One said *"I think the patients liked having someone within the hospital who 'knew their story' and who was interested in them as individuals as well."*

Table 6: Clinician researcher actions.

Actions	Frequency of action	
	Breast Patient (n=12)	GI Patient (n=16)
Provision of supportive communication or reassurance to patients or family members	120	130
Arrange another time to check on patient and/or carer (includes hospital appointments and outreach calls)	62	160
Liaise with clinicians and hospital staff	77	110
Providing advice on managing symptoms, nutritional requirements, medications	50	63
Making, changing, cancelling and clarifying appointments*	31	48
Seek clarification of issues discussed with clinicians during previous appointments	22	17
Booking, organising and copying investigations (eg; blood tests)*	9	19
Making a referral to an allied health professional at the hospital	16	9
Organise a hospital admission (Inpatient and day patient stay)	4	14
Advise to go to GP	3	11
Making a referral to a community palliative care service	0	12
Liaise with GPs about a change in condition or treatment	6	6
Organise transport for a future hospital appointment e.g. ambulance*	0	8
Discussing the benefits and draw backs of venous access devices	0	5
Making a referral to the hospital based palliative care consultancy service	0	4
Making a referral to a generalist community nursing service	0	3
Miscellaneous^	27	19

^ Miscellaneous: organising scripts, accommodation and wound dressings, sending out written resources

*Actions that do not require nursing input

The care coordination role performed by the CR also benefited the medical staff and assisted in the provision of quality cancer care as illustrated by one CR who said *"I don't know how he* [the medical oncologist] *followed up blood results, arranged treatment times, transport and all the extra support services before me and this project because he certainly doesn't do all that now."*

Discussion

This paper addresses three aims: to identify the care requirements and concerns of patients with advanced breast and GI cancer as well as those of their primary carer, to examine the role of out-reach telephone calls made by the CR, and to understand the role of the nurse in the care coordination of patients with advanced cancer. The results highlight the value of having a nurse in a coordination role who is able to identify and address the 'support gaps' that exist for patients being treated for advanced cancer in a specialist centre.

The role of the CR in this study was established as a specialist or advanced practice role. Such roles are increasingly promoted as appropriate and necessary for the provision of specialised cancer care [26,27]. Advanced roles have been successful for women with gynaecological cancers recovering from surgery and undergoing chemotherapy as measured by symptom and support outcomes, dissemination of information, and coordination of referrals and resources [28]. They have also been successful in radiation oncology multidisciplinary teams as evidenced by the provision of direct patient care, involvement in specialized procedures, and conducting initial and/or follow-up visits [29]. A structured review of the literature on specialist nursing roles in chronic disease management such as diabetes, coronary heart disease and chronic obstructive respiratory disease also concluded that nurses in such roles impact positively on care coordination, quality of life and functionality and self care [30].(

The existing nurse co-ordinator (NC) roles at the study hospital, upon which the CR role was modelled, traditionally focus on patients newly diagnosed with cancer and on those with early stage disease receiving first line treatment. This focus evolved because many of these roles were funded by surgical and radiotherapy services resulting in the development of close working relationships between the nurse and surgeon/radiation oncologist. In contrast, patients with persistent, recurrent or metastatic disease remain somewhat invisible within the health care system despite the substantial growth in numbers [10]. This seems to be a problem in both the US [10] and Australia where it is nearly impossible to identify the number of people living with advanced cancer as a central database containing such detail does not exist.

In the study hospital patients with advanced cancer are only brought to the attention of the NC when problems or issues are identified by other team members. This can be partially explained as a result of the absence of standard and routine work processes for linking patients with advanced disease to a designated NC. Yet research by Aranda and colleagues [31,32]found that women with advanced breast cancer, who had high initial needs and then received interventions by breast care nurses had reduced emotional and psychological needs over time suggesting routine identification of such patients is required and would be beneficial.

The data in this study demonstrated the large number and range of practical and psychosocial issues experienced by both cohorts and the subsequent actions carried out by the CRs. The issues were similar for both groups with almost all patients reporting at least one psychosocial concern which reflects evidence from earlier studies suggesting that many patients with advanced cancer experience psychosocial concerns [33,34]. The high volume of issues reported may reflect the relatively poor performance status of the GI cohort in particular (half of the sample died within the nine months of data collection) and the well developed breast care services which promote a culture of voicing needs and asking for support.

One of the highest volume actions carried out by the CR was the provision of supportive communication and reassurance to both the patient and family member. Most often this meant clarifying results of investigations and the risks and benefits of different treatment options as well as the normalisation of fears and concerns. Such therapeutic interactions need to be tailored to the specific issues faced by people affected by advanced cancer rather than mimicking interactions routinely undertaken with people dealing with a potentially curable disease [35].

The high proportion of patients reporting pain (92% of breast versus 75% of GI patients) and fatigue and weakness (58% versus 88%) reflects findings from other studies [36]. Gastrointestinal symptoms including diarrhoea, constipation, nausea and vomiting were also problematic for the majority of the participants (67% of breast versus 88% of GI patients). This symptom profile, when considered in conjunction with the multitude of psychosocial issues reported illustrates the complex care requirements of patients with advanced cancer and supports the argument for having a specialist nurse available to these patients. Nurses in care co-ordination roles who are attuned to the complex needs of patients and family members are well positioned to identify gaps in care delivery and then develop appropriate interventions [10]. With the growing number of patients living with advanced cancer for considerable periods of time, interventions must incorporate self care where feasible and support for family or friend caregivers when necessary [10].

In addition to care co-ordination provided by specialist nurses, patient care was also enhanced by the structured use of out-reach calls as they were a feasible and effective way to monitor the patients and to reduce the need for the patients to travel to the acute hospital. Other studies of telephone interventions, both in cancer care and in chronic illness care, have shown mixed results in terms of helping patients manage their illness at home. Patients with heart disease were found to require fewer hospitalisations and showed greater adherence to treatment recommendations following a telephone intervention [37-39]. While in a cohort of patients with poorly controlled type 1 diabetes, hospital admissions were not reduced and psychological functioning did not improve but patients rated the calls as helpful [40]. Within a cancer setting Allard [25] showed that a telephone intervention following day surgery for 117 patients with breast cancer reduced emotional distress and enhanced physical functioning and Anastasia [41] describes the benefits of nurse-led telephone management of chemotherapy side-effects when the nurse is highly skilled and familiar with treatment related side-effects. In this study the out-reach calls were deemed important when considered in light of the patients' reluctance to ask doctors all their questions during clinic appointments. Although a degree of caution must be exercised if relying on out-reach calls as a two way means of monitoring patients at home given that some patients chose not to initiate a call when a problem occurred because they knew a call from the CR was scheduled later in the week. Despite this caution this study supports the conclusion reached by Cox and Wilson [42] that nurse-led follow up by telephone was an acceptable, efficient and appropriate means of maintaining contact with a cancer population and provides vital support to vulnerable patients. However, formal evaluation of the effectiveness, long term sustainably and funding options of such out-reach calls within an advanced cancer setting is now required.

In summary, this study has provided significant insight into the range of concerns and issues and the associated complexity of care required by patients with advanced cancer and their carers attending an acute specialist cancer hospital. The issues, needs and concerns experienced by patients and their carers illustrate the diversity of care requirements that require attention by health professionals in order to make the model of care more person-centered. As new biological targeted treatments for cancer begin to fulfil the hope of turning advanced cancer into a chronic disease, there is a clear advantage in having cancer nurses with advanced skills who can effectively assist in the care coordination and management of patients and their carers living with advanced cancer.

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