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The complexity of non face-to-face work with patients affected by metastatic breast cancer and their carers. The ‘hidden consultations’ of the clinical nurse specialist

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A B S T R A C T

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Introduction: Survival rates in breast cancer have risen in the last 30 years. Almost one third of those diagnosed will go onto developing metastatic breast cancer which is becoming a long term condition in cancer care. In 2006 429,000 new cases of breast cancer were recorded across Europe. In recent years treatment for metastatic breast cancer in the UK has moved to the ambulatory setting meaning non face-to-face contact, for example through telephone consultation, has become a vital method of management.

Method: A prospective study conducted over a 1-month period at a London Trust. Data was collected by two clinical nurse specialists on incoming calls using Excel and a bespoke interrelational structured query database. These data were then mined using standard data mining techniques.

Results: The study collected 28 days of data. 229 patient and carer telephone contacts were recorded across the Trust. Most calls were from patients (62.5%). Incoming calls resulted in the delivery of 1282 interventions, a mean of six interventions per call (range 1–8) and clustered into four areas: meeting information needs (29%), symptom management (26%), psychological/social issues (33%) and other issues (12%). The incoming telephone work accounted for 63 h which represented 30% of the total working time of the clinical nurse specialist. Calls primarily originated from patients who were in the follow-up phase (43% of calls), a group usually thought to prefer self management.

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Introduction

Survival rates for breast cancer have been improving for 30 years in the UK (Office of National Statistics, 2008) and across Europe (Verdecchia et al., 2007) as more women are being successfully treated than ever before (CRUK, 2005).

Although improving survival rates due in part to increased awareness, earlier detection and improved therapies for primary breast cancer it is estimated that approximately 1/3 of women will go on and develop metastatic breast cancer (O’Shaughnessy, 2005). Breast cancer is the most common female cancer in Europe, it is estimated that in the year 2006 there were 429,900 new breast cancer cases and the number of deaths from breast cancer was 131,900 (Ferlay et al., 2007).

Metastatic, secondary, advanced and stage IV breast cancer are all terms used to describe breast cancer when cells from a primary

breast tumour metastasis from the breast to other parts of the body via the blood or lymphatic system, most commonly in the bones, liver, lung and brain (Booth, 2006). Once a diagnosis of metastatic breast cancer (MBC) is made the disease is no longer considered curable and treatment selection is aimed at controlling symptoms, maximising quality of life and prolonging survival. No globally accepted standard exists for meeting these goals and treatment patterns vary according to region (Roche and Vahdat, 2010). However over the last decade, advances in more effective and better tolerated therapies for MBC have extended life expectancy (Johnston and Swanton, 2006). Clinical interventions and treatment modalities for MBC are variable with the majority capable of being delivered on an outpatient basis (Findlay et al., 2008).

The needs of women with MBC are complex (Aranda et al., 2005; Vilhauer, 2008; Svenson et al., 2009). Having contact with a key person who has the specialist knowledge and understanding of the complexities associated with MBC can help reduce anxieties and promote coping (Mackie and Warren, 2011).

Clinical nurse specialists who care for metastatic breast cancer patients have been described by the UK charity Breast Cancer Care (2008) as having value as they assume the role of the “key worker”

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(DH, 2007) providing management and continuity of care, applying specialist knowledge and skill to manage physical, psychological and social morbidity, co-ordinate complex care, meet unmet information needs, prevent unscheduled admission to hospital and support patients in clinical-decision making (NCAT, 2010).

In The UK the Clinical Nurse Specialist (CNS) has been described as a nurse who demonstrates a high degree of professional competence and advanced practice in a specialized field of nursing (Trevatt and Leary, 2009). The role and its value have been recognised by the Department of Health (England) as pivotal to cancer care (Department of Health, 2007; NCAT, 2010) and in national studies seen as valuable to patients (Department of Health, 2010).

The clinical nurse specialist (CNS) in secondary breast cancer (SBC) is an innovative and an emerging role that has many facets (Breast Cancer Care, 2008). The aim of the role of the CNS SBC is to promote seamless care, to alleviate suffering caused by the disease, treatment or the distress of cancer.

As the key contact and care manager for patients receiving treatment as an outpatient, the CNS SBC acts as the main link between the community; patients, carers (including health care professionals) and the hospital based teams. In recent years treatment in the United Kingdom for MBC has moved to the ambulatory setting. With patients spending less time physically attending treatment centers contact between patients and CNS SBC is often non face-to-face making telephone contact an essential means of connection and communication.

Metastatic breast cancer patients and carers initiate telephone contact with the CNS SBC for a variety of reasons; symptom management, treatment advice, psychological support and social issues. A study by Breast Cancer Care into the work of SBC CNS's found that 30% of their work activity was done on the phone the vast majority of this work was clinical (27%) (Breast Cancer Care, 2008). Telephone intervention not only deals with issues requiring attention e.g. unresolved symptom control or community referrals but for many patients it enables them to have a more in-depth discussion than is practical during typical clinic visit (Bakitias et al., 2009). The use of nurse-led telephone interventions has also been described as an efficient means of maintaining contact with a large cancer patient group (Cox and Wilson, 2003).

Few studies have been carried out to investigate the nature of telephone contact initiated by cancer patients and their carers with the clinical nurse specialist (CNS) (Twomey, 2000; Moore et al., 2006). No published papers that directly address telephone contact between patients and their carers affected by MBC and the CNS SBC have been found despite a systematic search of the available literature.

Aim

The aim of this study was to examine the complexity of non face-to-face patient interaction using complex interrelational data and then to mine these data to articulate the component parts of the perceived complexity of this work.

Methods

The study was prospective and conducted over a 1-month period as part of a normal service at a London Trust. Data was collected by two CNS's one of whom worked part time thus 1.6 whole equivalents. All patient and carer (partner, family member, friend or health care professional) incoming telephone contact with 2 CNS's in secondary breast cancer (SBC) was recorded using a data collection tool developed by the CNS's on Excel. The tool was completed by the CNS's immediately following contact with a patient or carer.

The tool recorded information about:

- Date
- Patient ID number
- Who initiated the telephone call (patient, spouse/partner, parent, daughter/son, sibling, friend and health professional)
- Stage of the patient pathway (diagnosis, treatment, follow-up, palliative and other)
- Reason for contact
- Duration of call
- Intervention by the CNS SBC

To supplement the CNS SBC data collection tool, the CNS's also prospectively collected data on Pandora which was an interrelational structured query language platform based on mathematical modelling which examines the complex role and activity of the CNS (Leary et al., 2008). Pandora had been customised to record specific data about nurses working in secondary breast cancer for a previous study (Breast Cancer Care, 2008).

Pandora recorded information about:

- Time interval of telephone contact event
- Emotional effort of telephone contact event
- Interventions – Clinical (i.e. physical, social, psychological, spiritual, and referrals) and sub domains of these such as specialist symptom control
- Event form (i.e. clinical expertise, administration, case management)
- Event outcome (i.e. access to key worker, management of symptoms, preventing unscheduled care)

Analysis

The two data sets generated were captured in two systems. One was the Pandora database (Leary et al., 2008) an interrelational structured query database that examined the activity and complexity of the work, the second data set (demographic of caller, stage of pathway etc) was captured on an Excel spreadsheet. These data set were amalgamated and then mined to discover new knowledge using methods described elsewhere (Fayyed et al., 1996; Brodley and Smyth, 1997).

Results

The 1-month pilot study consisted of 28 working days. During this period, 229 patient and carer telephone contacts, incoming calls only, were recorded between the 2 CNS's SBC (1.6 WTE), across both sites of the Trust. The largest contact group were patients, followed by health professionals and then partners, relatives and friends (Table 1).

All telephone contact initiated by health care professionals to the CNS SBC were about a specific patient related issue. In mapping these calls to the patient pathway the highest numbers of calls from

Table 1
Patient and carer initiated telephone contact with the CNS SBC.

Who initiated the telephone call	Number of contacts (<i>n</i> = 229) (%)
Patient	143 (62.5%)
Health care professional	48 (21%)
Spouse/Partner	12 (5%)
Daughter/Son	8 (3.5%)
Sibling	8 (3.5%)
Parent	6 (3%)
Friend	4 (1.5%)

Table 2
Number of patient and carer contacts in relation to stage in patient's pathway.

Stage of patient pathway	Number of contacts (n = 229) (%)
Diagnosis (new SBC)	27 (12%)
Disease progression (treatment change)	28 (13%)
Follow-up (stable disease)	99 (43%)
Palliative	72 (31%)
Other (non SBC and staff support)	3 (1%)

patients and carers was at follow-up (43%), when patients were receiving treatment and their metastatic breast cancer was deemed stable and at the palliative stage (31%) (Table 2).

The total amount of time spent on patient and carer telephone contact was approximately 63 h in this time period of 210 working hours. This amounts to approximately 30% of the CNS SBC working time (i.e. 0.6 and 1.00 × 37.5 h per week). Most contacts lasted 15 min or less (58%) however a third of calls lasted a mean of 20 min (Fig. 1).

A total of 1281 interventions were generated as a result of the 229 incoming telephone calls made by patients and carers to the CNS SBC. This resulted in a mean of six interventions per call (range 1–8). The nature of these interventions has been clustered (Tan et al., 2006) into 4 broad interventions (Fig. 2). Psychological and social support formed the largest group (33%).

Clustered interventions

- A = Assessing and meeting information needs
- B = Physical assessment/Symptom management
- C = Psychological/Social assessment and interventions
- D = Other

Clustered group A

Examples of meeting information needs and management. The second most common intervention was meeting complex information needs (29%) and this included meeting unmet information needs, clarification regarding disease pathway, results, treatment and side effects.

"Patient who hadn't understood the information given to them during a clinic consultation the previous day" – Clarified in more detail the information given to the patient by the doctor, until reassurance given by the patient that they fully understood their individual clinical situation

"Patient with concerns following confirmation of progressive disease" – Clarification given regarding disease pathway and treatment options available to the patient

"Health Care Professional concerned about patient omitting dose of oral chemotherapy due to side effects" – Level of toxicity assessed and appropriate advice given.

Time interval of calls

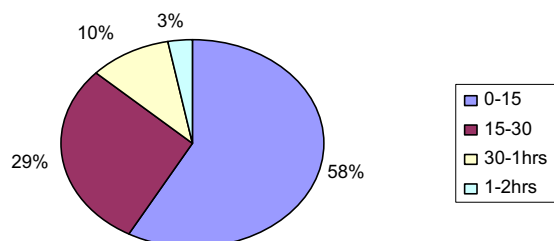


Fig. 1. Time interval of each incoming telephone contact with the SBC CNS n = 229.

Proportion of interventions n=1282

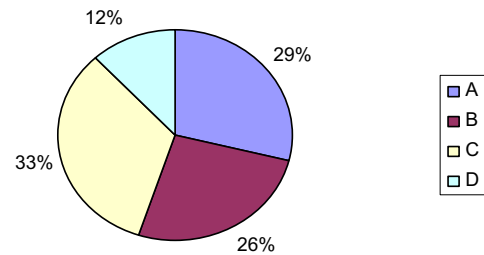


Fig. 2. Proportion of clustered interventions.

Clustered group B

Examples of physical assessment and symptom management. Assessing physical symptoms and symptom management (26%) was another key intervention provided by the CNS SBC. This involved assessment, general and specialist symptom management, rescue work (Silber et al., 1992) recommending care, liaison and coordination with community and allied health professionals.

Specialist symptom management exemplar. "Contacted by patient with ongoing bone pain, that was not responding to several lines of analgesia" – Specialist symptom management coordinated by arranging community palliative care consultant to make a home visit.

Rescue exemplars. "Signs and symptoms of neutropenia identified" – Urgent hospital review arranged.

"Signs and symptoms of central nervous system disease identified" – Urgent hospital review and MRI arranged.

Clustered group C

Examples of psychosocial support and interventions. The types of psychosocial interventions the CNS SBC provided were anxiety management, dealing with distress, crisis intervention, supporting clinical choices and family and carer support.

"Anxiety regarding treatment decisions, the need to change from endocrine therapy and unsure about coping with chemotherapy because of potential side effects" – Explanation given about the aims of palliative chemotherapy.

"Concern from family member about hospital discharge of relative" – Co-ordinating community health care professionals regarding a complex terminal discharge

"a patient in the follow-up phase telephoned as her family aren't coping with her illness and this is impacting on her. Psychological assessment carried out and referral made for psychological support."

Unexpectedly the follow-up phase group with stable disease was the largest group of patients who telephoned in, highlighting the impact SBC has on psychological and social functioning. It is important patients devoid of physical symptoms still need to be assessed as it may be the psychosocial aspects of the disease that are impacting on quality of life and it is vital that psychological assessment is continually assessed.

Clustered group D – other

Finally, the last intervention was 'other' (12%), which commonly included administration tasks such as coordinating out patient

appointments, rationalizing out patient appointments and requesting investigations and medical reports.

Discussion

National data reports 30% of the CNS SBC time is spent on the telephone (Breast Cancer Care, 2008; Leary et al., 2008). This study focused solely on incoming telephone calls initiated by patients and carers (partner, family member, friend and health care professional) to the CNS SBC, which accounted for 30% of their time.

The largest incoming telephone contacts were from patients, illustrating the extent of contact and support required by patients from the CNS SBC when at home.

Increasingly more treatments for MBC are being delivered on an ambulatory care basis due the availability of more oral anti cancer treatments such as endocrine therapies, bisphosphonates, and oral chemotherapy (Findlay et al., 2008). Whilst there are several advantages for ambulatory care, there are well documented concerns from patients and families receiving treatment on an outpatient basis; less health professional involvement, feelings of abandonment and isolation, worries about pill burden and increased potential for drug interactions (O'Neill and Twelve, 2002; Macmillan, 2006; Findlay et al., 2008; Moore and Cobeleigh, 2007).

Ambulatory care includes services provided in the outpatient setting and frequently overlaps with the care provided in the community. 21% of the initiated telephone contacts with the CNS SBC were from health care professionals requiring the expertise and knowledge of the CNS SBC in managing the care of the patient on the community often in connection with patient disease and treatment related problems.

In relation to the patient's disease and treatment pathway the highest numbers of incoming calls made were at follow-up when patients were deemed to be stable. This is an interesting finding as they are a group increasing thought of as desiring little contact and preferring self management strategies. The second largest group of calls made were at the palliative stage when the focus of care transfers from hospital based to community based care. An explanation for this is at the other stages of the patient pathway; at the time of a diagnosis of MBC and subsequent progressions there can be an increase in the number of hospital visits and face-to-face contact with the CNS SBC. An example of a model of care for MBC patients at this Trust is designated MBC only clinics, where before each session a multi professional meeting led by the consultant in charge is held and each patient due to attend clinic will be discussed to help streamline the service provided, to identify and prioritize each patient's clinical and supportive-care needs (Mackie and Doyle, 2010). A key member of the team at this meeting is the CNS SBC who will assess individual patient needs, often giving priority to newly diagnosed, symptomatic MBC patients and those patients where no further hospital based treatment is to be discussed (Breast Cancer Care, 2008).

This study provides insight with regards to the number of interventions generated. The majority of the calls (225) required more than one specialist management intervention. Frequently when patients initiated telephone contact with the CNS SBC discussion can start with a specific enquiry about scan date or an appointment, then subsequent discussion allowed the patient to reveal more in depth concerns than is often feasible during a clinic visit (Lucia et al., 2007; Bakitias et al., 2009). The CNS SBC would use their specialist expertise and knowledge to assess the over-riding nature of the call. The fact that the largest group to access the service were patients with stable disease, and therefore potentially asymptomatic, and the largest intervention group was for psychological and social support highlights the complexity of the disease and how, despite being clinically stable, patients and their carers require ongoing support from the CNS SBC.

The CNS SBC has an understanding of the complexities of all the different treatment options for MBC and is knowledgeable about the cyclical nature of the disease recognizing the continual changing needs of the patient and their families and carers (Burnet and Robinson, 2000; Vilhauer, 2008). As the main key point of contact for patients with MBC, the CNS SBC is at a distinct advantage as they will develop patient-specific knowledge over the course of the patient's disease and treatment trajectory (Wilson and Hubert, 2002). With enhanced knowledge of the individual patient such as illness stage, psychosocial context and approach to self care management, the CNS is well placed and is likely to effectively and independently resolve patient and carer calls through telephone care (Wilson and Hubert, 2002; Cox and Wilson, 2003; Lucia et al., 2007).

This study has demonstrated CNS SBC telephone care/intervention is able to pre-empt complications often before they become crises, access appropriate care via direct referral and redirect patients to the most suitable resources. The CNS has the potential to transform cancer care by guiding patients through the multifaceted systems of health care provision; smoothing care pathways, supporting patients to cope at home and making a contribution to patient experience and safety (NCAT, 2010).

Currently CNS SBC telephone work is not remunerated but with a move to ambulatory care there is an opportunity to formalize against clinical coding and claim remuneration for employing trusts as part of a commissioned pathway. The largest group of patients to access the CNS SBC telephone service in this study was stable which offers the potential to explore the streamlining of this patient groups follow-up appointments as long as they have a "key contact".

Conclusion

This study has offered an insight into the complex nature of non face-to-face work with patients affected by metastatic breast cancer and their carers. Telephone contact is an integral component of the CNS SBC's work. However, compared to face-to-face contact, telephone contact is not formally recognised, therefore is hidden.

Considering the, frequently, in depth and specialist advice required when telephone contact is initiated by patients and carers to the CNS SBC, it is crucial these hidden appointments are formally identified.

Building on this study, further research into telephone intervention work is essential in order to recognize the value and for formalization. Further study to ascertain the outcomes of telephone CNS SBC care/contact would need to be explored such as; the prevention of scheduled and unscheduled care both in the outpatient and inpatient setting, the nature of all out going calls, individual demographics, and whether there is scope for patients with stable disease for substituting selected clinic visits with telephone care.

Competing interests

None.

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