Can Case Management Improve Cancer Care?

Jennifer Deagle and colleagues assess the benefits of a pilot scheme to improve aftercare and support for patients living with active or advanced disease.

Abstract

In 2012, Macmillan Cancer Support partnered with 15 NHS health providers in the UK to fund new ways of delivering supportive care to cancer patients in the community. The project grew out of the work commissioned by the National Cancer Survivorship Initiative to find pathways for supporting people with active or advanced disease. In Southampton, a community-based complex case manager was established to test the assumption that the role could improve health outcomes in a group of patients with specific needs. Those with advanced breast or gynaecological disease were case-managed with the aim of improving self-management and wellbeing. The learning from the pilot can be used to inform the argument for building specialist teams in the community, targeted at people under the age of 75, who are living with cancer as a complex chronic disease.

Keywords
cancer, case management, chronic disease, community teams, metastatic cancer, supportive care

THE NATIONAL Cancer Survivorship Initiative (NCSI) (2014) proposed new pathways for improving aftercare and support for people living beyond adjuvant therapy. Research has identified that many patients feel abandoned by health services after initial treatment (Lewis et al 2009). People ask for support with managing the long-term side effects of treatment, returning to work, anxiety and lifestyle changes (NCSI 2014). The number of people surviving cancer has increased but some have recurrent active disease and their illness has been redefined as a chronic disease (Phillips and Currow 2010).

In 2012, Macmillan Cancer Support funded 15 pilot sites throughout the UK, known as the Macmillan One-to-One Pilot, to trial new pathways of care for patients living with active or advanced cancer. University Hospital Southampton NHS Foundation Trust had successfully partnered with the charity in the past, and the hospital culture supported a progressive and proactive approach to developing and testing new pathways of care.

The cancer care team wanted to redesign care pathways for patients with complex progressive disease by piloting the role of a Macmillan complex case manager (CCM), a healthcare professional who would be based in a community team but who would liaise with acute hospital and community palliative care teams. The job description would reflect the work undertaken by other healthcare professionals involved in the case management of patients with complex chronic disease (Ross et al 2011). Holistic needs assessment (HNA) and a risk stratification tool would be used to evaluate patients’ needs and develop supported and integrated care across multiple settings.

The oncology department at University Hospital Southampton NHS Foundation Trust serves a population of two million. Breast cancer accounts for 30% of diagnoses in women, with uterine and ovarian cancers adding a further 5% (Keen and Lennan 2011). In 2010-11, 78% of women with breast cancer lived for ten or more years after diagnosis (Cancer Research UK 2014). These statistics show that staff...
support many people with metastatic breast and gynaecological disease through prolonged periods of illness, exacerbated by repeated cycles of treatment and resulting in death. Ongoing therapies can cause increased morbidity, with periods of severe anxiety and repeated emergency admissions. Reed et al (2012) commented that it was increasingly difficult for oncologists and patients with metastatic breast cancer to be able to identify the ‘final decline’ and therefore make effective use of palliative care services.

Some of the research on breast cancer has been conducted by staff at Southampton, for example, studies on provision and experiences of care (Reed et al 2010, 2012, Foster and Fenlon 2011) and identifying patients’ journeys through the cancer pathway (Reed and Corner 2015). Reed and Corner’s (2015) work in Southampton identified three trajectories of care for metastatic breast cancer patients:

- Ticking over nicely: people who lived for many years with indolent disease and high levels of physical functioning.
- Is there no end to it: a shorter disease trajectory with periods of disease progression and uncontrolled symptoms.
- It is a roller coaster: most typical trajectory, two to five years in length with fluctuating physical function and episodes of crisis.

Patients’ social circumstances play a large factor in their ability to cope with complex illness (Royal College of Nursing 2012). Southampton is a city with increasing areas of deprivation (Southampton City Council 2015). There is a proven link between age, social situation and health deprivation, resulting in poor outcomes with an increase in emergency hospital admissions (Purdy 2010).

Southampton was therefore a logical choice to pilot a role that would support people in gaining self-management skills, increase their sense of wellbeing and decrease use of emergency services.

The World Health Organization (WHO) (2013) addresses the rise in chronic disease with a worldwide action plan for prevention and control that includes case management. It aims to provide effective support to people with chronic disease in the community to improve quality of life and reduce hospital use (Purdy 2010, Ross et al 2011).

In the UK, case management has been targeted at the older frail population, and people with heart failure, diabetes or chronic obstructive pulmonary disease (COPD). Ross et al (2011) stated that only 2% of the population with chronic disease meets the criteria to necessitate referral to a CCM.

Their report presented mixed results about the effectiveness of case management in improving patients’ lives. Ross et al (2011) argued that correct targeting of resources is crucial for success but that it can be difficult to identify appropriate recipients.

Case management succeeded only if patients were identified before they began to experience repeated emergency admissions. Their report also noted that not all patients would accept preventive care.

University Hospital Southampton NHS Foundation Trust did not have systems in place to easily identify people who were struggling in any way. Referral systems to other care providers were reactive in nature and dependent on the professional who was interacting with the patient. To develop new lateral referral systems, the CCM met the clinical nurse specialist (CNS) teams each week. It was agreed that patients who had telephoned the hospital team, or presented at outpatients, with an ongoing issue that could not be speedily resolved would be referred to the CCM. Oncologists, GPs and community nurses were also encouraged to identify patients who required support.

To better identify patients’ concerns, the CNS teams increased use of the HNA, as part of the NCSI (2014) action plan. Patients could complete the HNA at home, or while waiting in outpatients, and then discuss the result with their CNS. The CNSs used the results to complete a risk stratification assessment, which had been developed in Southampton by the community matrons and adapted for the cancer population. Patients were referred by the clinician for support with whatever symptoms were causing them distress. Referral criteria were driven by patients’ interpretation of their experience and need for support.

Further development of the risk stratification assessment (Table 1) enabled staff to identify who would require a weekly visit, fortnightly support or monthly review. The CCM offered emotional and psychological support, advice on benefit claims, physical assessment, rapid access to the acute oncology service (AOS), teaching on self-management strategies to minimise side effects of chemotherapy and radiotherapy, nursing care, mobility equipment and referral to other teams.

After the first year, the pilot was expanded. Discussions with the community matrons and nurses for people aged over 75 led to agreement that cancer patients already known to them would remain in their care, with the CCM providing specialist input as required. The pilot’s geographical area was enlarged to match the population served by the oncology department. The breast oncology clinics were reconfigured to enable all women with secondary breast cancer to be seen in a dedicated clinic. A weekly meeting with the oncologists,
Table 1  Risk stratification assessment and scoring tool

<table>
<thead>
<tr>
<th>Key domains</th>
<th>Assessment criteria</th>
<th>Additional information</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has had high-risk contact</td>
<td>Seen by a health or social care professional in past two weeks and assessed to be at risk of admission to hospital or hospice over the next two months, or of frequent contact with clinical nurse specialist (CNS) or acute oncology service (AOS)</td>
<td>If possible, confirm with more than one health or social care professional</td>
<td>2</td>
</tr>
<tr>
<td>Receiving chemotherapy</td>
<td>Side effects of treatment, such as anaemia, intractable nausea and vomiting, neutropenia</td>
<td>Assessed with Sheffield Profile for Assessment and Referral to Care (SPARC) or other tool. May have completed chemotherapy recently</td>
<td>2</td>
</tr>
<tr>
<td>Uncontrolled symptoms(^1)</td>
<td>Including anorexia, breathlessness, constipation, fatigue, mood disturbance, nausea, neurological symptoms, pain, reduced mobility and/or sleeplessness</td>
<td>Assessed or scored using SPARC or other assessment tool</td>
<td>2</td>
</tr>
<tr>
<td>Increasing requirement for social support</td>
<td>Open cases with repeated re-referral in six-month period</td>
<td>Disease may have progressed. Treatment plan may have changed</td>
<td>1</td>
</tr>
<tr>
<td>History of high resource usage(^2)</td>
<td>One or two admissions in last month One or more attendances at emergency or AOS department in previous month. Frequent CNS contact Three or more primary care consultations in last month</td>
<td>Monthly report to be provided on unscheduled hospital attendances or admissions</td>
<td>2</td>
</tr>
<tr>
<td>Increasing requirements</td>
<td>Reduced ability to self-manage</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Functional support</td>
<td>Motivational and emotional issues that severely limit usual activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uncontrolled clinical indicator</td>
<td>Persistent uncontrolled symptoms for one week after intervention Side effects of treatment, such as anaemia, intractable nausea and vomiting, neutropenia</td>
<td>Intervention, such as drainage of ascites, pleural effusion, pain management, assessment, medical or nursing intervention, may be required</td>
<td>1</td>
</tr>
<tr>
<td>Medication score(^3)</td>
<td>More than four medications</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

**Total score**

Score 6 or 7: monthly review by complex care manager (CCM). Primary care contact and monitoring required, low risk of hospital admission, or emergency department (ED) or AOS attendance, low immediate clinical or social care needs.

Score 8-10: fortnightly review by CCM. Multiple health and social care needs, medium risk of hospital admission, or ED or AOS attendance, medium clinical/social care needs.

Score 11-12: weekly support by CCM, multiple health and social care needs, high risk of hospital admission, or ED or AOS attendance, immediate and intensive clinical/social input.
CCM and CNS teams reviewed any patients for whom there was concern. The meeting improved oncologists’ confidence in the level of support patients received from the CCM. Relationships were also developed with the AOS team to enable faster discharge and appropriate use of the AOS facility.

Findings
The CCM role was targeted at the 2% of patients with chronic disease who needed high-level support (Ross et al. 2011). Over 32 months, 204 patients agreed to join the pilot, of whom 97 were people with metastatic breast disease (four men) and 107 were women with gynaecological disease. In total, 9% (n=18) of patients declined further support after the first visit, echoing Ross et al’s (2011) findings that not everyone wants to receive support. As their health deteriorated, 45% (n=92) of patients were referred to the palliative care team.

A caseload of 30 was held at any one time, with a maximum of five patient visits a day. The part-time nature of the role restricted the number of patients the CCM could support, and patients were discharged between one to nine months after referral. It was not possible to follow up, at home, everyone who was admitted to hospital and the CNS teams offered telephone support. Few referrals were received from the GP and community nursing teams. Many of the patients reported that they rarely saw their GP as all their care was provided by the hospital. This finding was reflected in Corner’s (2008) work on addressing the needs of cancer patients.

The age of patients referred did not match the expectations generated by research that most would be older, as shown in Figure 1. Only 36% (n=74) of patients referred were 70 years or older. The Southampton experience of age distribution in referrals was echoed throughout the One-to-One Pilot (Macmillan Cancer Support 2015).

Figure 2 shows reasons for referral. Review at home by the CCM was used by clinicians to reduce possible hospital admissions.

Anxiety has been identified as a significant area of concern for people with breast cancer (Savard et al 2006, Hasson-Ohayon et al 2010, Vodermaier et al 2011). Of referrals, 26% (n=53) were for anxiety. The debilitating effects of severe anxiety and the effects of the CCM on use of health services are described in the case study opposite. The patient’s name has been changed to preserve her anonymity.

Another study on anxiety in all cancer patients noted the interaction of anxiety with increased emergency admissions (Walker et al 2014). A study by the London School of Economics demonstrated that due to poor funding of services in the community, many patients with anxiety were not able to access the support they required (Layard et al 2012).

Many patients had cancer as one of several comorbidities requiring the use of multiple health teams (Macmillan Cancer Support 2015). Patients made little use of the community nursing service or practice nurses. Two patients were treated by practice nurses for diabetic review and three others for wound dressings. These findings may reflect the fact that older patients identified as requiring complex care remained with community matrons.
As the service progressed and care planning became more efficient, 51% (n=104) of patients stayed on the caseload for four weeks or less. Patients who improved received support from voluntary sector services or by telephone from their CNS. During the pilot, patients who had been discharged as stable returned for further supportive care as their disease progressed.

An attempt was made to collect patient satisfaction data through a postal questionnaire. Due to a poor response rate it is not possible to provide an analysis of how patients perceived the pilot. However, managers received several complimentary letters about the service from patients.

Discussion
Cancer is now defined as one of four main chronic diseases, along with diabetes, heart failure and COPD (WHO 2013). Many patients with cancer struggle to accept and identify themselves as people who are living with an ongoing illness.

The findings of the Southampton pilot demonstrate that few patients under the age of 75 used or received support from community teams, who were not well configured to meet the complex needs of younger people. Only housebound patients may receive a visit from a community nurse. Practice nurses have a task-orientated list to undertake each day, making it difficult to perform holistic assessments.

Case study
Amanda was diagnosed with breast cancer in her early fifties and had chemotherapy before surgery. She found the experience traumatic, requested early clinic appointments on five occasions and self-referred to the acute oncology service (AOS) four times.

After surgery, Amanda was well for a year. Pulmonary and bony metastatic disease was then diagnosed. Further chemotherapy continued for seven months and Amanda self-referred to AOS on eight occasions.

The complex care manager (CCM) became involved in Amanda’s care and carried out 15 home visits over eight months. During this time Amanda’s use of emergency services reduced to one self-referred admission to AOS, one GP admission to AOS and one CCM admission to AOS.

Amanda’s care was transferred to the palliative care team as her health continued to decline and she died two months later.

### Table 2 Possible interventions offered by different nursing teams

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<th>Patient’s situation or needs</th>
<th>Interventions by different professionals</th>
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<tbody>
<tr>
<td></td>
<td>Hospital clinical nurse specialist</td>
</tr>
<tr>
<td>Severe anxiety and use of out-of-hours services</td>
<td>Limited session in outpatients</td>
</tr>
<tr>
<td></td>
<td>Refer to counselling</td>
</tr>
<tr>
<td>Struggling with activities of daily living after chemotherapy</td>
<td>Referral to rapid response team (RRT)</td>
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<tr>
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<td>Telephone review</td>
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<tr>
<td>Recent admission with ongoing morbidity</td>
<td>Limited session in outpatients</td>
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<tr>
<td></td>
<td>Telephone review</td>
</tr>
<tr>
<td>Carer exhaustion or safeguarding concerns</td>
<td>Limited session in outpatients</td>
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<tr>
<td></td>
<td>Refer to cancer charities for support</td>
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The rise of specialist nursing teams and community matrons has fragmented services and led to deskilling of the general workforce (Reed et al 2012).

Patients with diabetes, heart failure and COPD all have their own community specialist teams. Table 2 sets out needs that different healthcare professionals, including a community cancer nurse, might be best placed to respond to for patients with advanced cancer aged under 75.

The community nurse employed as the CCM was not a cancer CNS but was able to meet all the requirements of the role. It is the authors’ opinion that it would be possible to build a community cancer team to manage patients across all tumour groups.

Implications for practice
People under the age of 75 are living for longer with advanced cancer and face a gap in care in community services. The drive to transfer services for cancer patients from the acute to the community sector has not replicated the delivery of specialist community care to people who have other chronic diseases: heart failure, diabetes or COPD. Cancer care provision is still hospital centric. Some cancer patients, who could be treated by the GP with a yearly consultant review, are still returning to hospital for monthly denosumab injections. When future care is transferred to the GP, these patients will lose support from hospital-based CNS teams and face a larger gap in care.

If commissioned do not choose to fund supportive teams in the community for cancer, how can nurses support these patients? Workloads and task-focused delivery of care have made implementing the NCSI (2014) action plan difficult. HNA, as developed by the NCSI (2014), can be completed by patients at home, and the results discussed with a health professional at a later appointment. Macmillan offers free courses to health professionals to provide supportive care (Macmillan Cancer Support 2014).

Conclusion
The Southampton one-to-one pilot aimed to test the assumption that a CCM could improve health outcomes in a specific group of patients with advanced cancer and complex needs. The pilot demonstrated a reduction in hospital admissions and use of social care, and the groups of people requiring support that had been identified by previous research. People were referred with debilitating anxiety, pain, nausea, fatigue, social concerns and relationship difficulties. More than 50% of patients were supported to be able to return to independence through self-management. Other patients were encouraged to discuss their treatment options and consider a new definition of palliative care. The pilot demonstrated that most patients with chronic disease who required help were aged under 70 and excluded from referral to local community teams by locality guidelines. The pilot’s demonstrated improved outcomes are negated by the absence of local funding.

The needs of patients with complex advanced cancer should be prioritised and funded by commissioners in the same manner as those of patients with the other three chronic diseases identified by WHO (2013).

References