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Title: Patients' understanding of palliative care, is the information good enough? A literature review and audit of information provision.

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ABSTRACT

Background

Early access to palliative care can improve symptoms and reduce hospital admissions. In the UK, many palliative care referrals are made in the last weeks and days of life indicating that barriers to timely integration exist. This study aims to understand barriers to timely integration of palliative care for cancer patients and establish the current level of patient information provision.

Methods

This research involved three stages: 1) Literature review to identify barriers to referral; 2) Audit of patient information resources available in adult oncology services across Yorkshire and Humber; 3) Critique of the identified information resources

Results

The literature review identified patient misconceptions about palliative care as a barrier to engagement with palliative care services. Our regional audit of patient information resources found information about palliative care is not widely available to cancer patients and the information provided does not address misconceptions reported in the literature.

Conclusions

We identified a need to improve the information for cancer patients that addresses known misconceptions about palliative care and to make this widely available in oncology departments. This information could facilitate earlier integration of palliative care alongside oncology management by improving understanding of when and how palliative care may benefit them.

Keywords: Palliative Care; Information Needs; Information Provision; Perceptions; Integration; Transition

INTRODUCTION

Specialist palliative care is defined as ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual’ (World Health Organisation, 2018). In the United States, the average time between a palliative care referral and death is approximately 72.5 days (Blackhall et al., 2016). However, within routine clinical practice in the UK, palliative care clinicians report that many referrals are made in the last weeks and days of life. A recent audit of 5,613 patients referred to specialist palliative care services in Leeds found the median interval between referral and death to be 37 days. This figure indicates that barriers to timely integration of palliative care exist in our region.

For patients with advanced cancer, several randomised controlled trials have shown that early access to palliative care services can improve symptoms, reduce acute hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care, including exercising the choice to die at home (Rabow et al., 2004, Brumley et al., 2007, Bakitas et al., 2009, Temel et al., 2010, Zimmermann et al., 2014). Cancer patients who have later or no contact with palliative care tend to receive more aggressive end of life care including receiving chemotherapy close to death, as a

result these patients have a higher risk of dying from treatment related complications (Karim et al., 2015).

In order to facilitate more timely integration of palliative care, it is important to explore the potential barriers that may exist to referral. It has been reported that there is a high level of unmet information needs amongst the palliative care patient population (Harrison et al., 2009) therefore we set out to determine whether some of these knowledge gaps relate to information about the purpose of palliative care and how patients can benefit from it. The aim of this paper is to try and understand the existing barriers to timely integration of palliative care for cancer patients and establish the current level of patient information provision regarding palliative care.

METHODS

There are three distinct phases to this study exploring barriers to referral to palliative care: 1) Literature review; 2) Audit of patient information 3) Critique of patient information. The literature review was conducted as part of a scoping exercise to focus the direction of future research projects. The review highlighted particular issues of interest around patient information which were investigated further in the audit. Ethical approval was not required for the project.

Literature review

We conducted a literature review to identify potential barriers to referral to palliative care for cancer patients. The search was conducted in between May and July 2016 in

PubMed. Subject headings and keywords used in the search included: cancer; palliative care; supportive care; barriers; referral; integration. The search was restricted to papers published after 2000 as it was felt papers published before this time would no longer reflect current referral practices.

Patient information audit

An audit of patient information resources across the Yorkshire and Humber region was conducted during July 2016 to ascertain what information if any, was available to cancer patients regarding palliative care services. All National Health Service Trusts providing adult oncology services were contacted within the Yorkshire and Humber Clinical Research Network of the National Institute of Health Research. Oncology services within each trust were surveyed including in-patient units, day units, outpatient clinics and hospital Palliative Care Teams. Lead nurses or managers were the point of contact for each trust or department. They were asked to describe what palliative care information they have available and how and when such information resources were distributed to patients. They were also asked to provide copies of information available.

Critique of information resources

From the literature search, a list of criteria against which to judge the content of the information materials was developed. The content of the leaflets were then reviewed to see how well they matched with this criteria.

RESULTS

Literature search

The literature search identified a number of barriers to palliative care referral. The barriers could be divided into three key areas: health professional, patient and service level barriers (Barton, 2014). Health professional barriers related to their own beliefs but also their perceptions of how patients' view palliative care. Some health professionals felt that by referring patients to palliative care, they would be abandoning them (Charalambous et al., 2014). Some of the barriers that health professionals mentioned related to their perception of patient views of palliative care. They often delayed a palliative care referral as they felt patients would be reluctant to stop active treatment (Miyashita et al., 2008). Health professionals were concerned that the patient would lose hope if they received a palliative care referral (Le et al., 2014) or that patients' negative attitudes of palliative care would prevent them from accepting a referral (Miyashita et al., 2008).

The majority of health professionals acknowledged the importance of early referral and supported the idea (Johnson et al., 2011) but in reality patients were often referred at the end of life (Charalambous et al., 2014). There was no agreement about when early referral should be, some suggestions included when the patient was diagnosed with advanced cancer, when they start opioids, disease progression, no chance of a cure, after multiple readmissions or if they have uncontrollable symptoms (Johnson et al., 2011). Patients were usually referred for the management of complex physical symptoms (Walbert et al., 2016) or after an acute episode (Johnson et al., 2011). Health

professionals felt palliative care needed to be more integrated into oncology practice and most supported a model where the two services ran concurrently (Ward et al., 2009, Chasen et al., 2015). Some health professionals felt that changing the name of the service to supportive care would make them more likely to refer at an earlier stage (Wentlandt et al., 2012, Wentlandt et al., 2014, Hui et al., 2015). Others were supportive of the name change but did not think it would have any impact on the numbers of referrals (Rhondali et al., 2013). Health professionals supported the name change because they felt palliative care was synonymous with hospice and end of life whereas supportive care was associated with treatment and the management of symptoms and side effects (Fadul et al., 2009). Many health professionals reported very little training in palliative care, those health professionals with the least amount of training were less likely to refer patients to palliative care (Walbert et al., 2016).

The literature exploring patient related barriers to palliative care referral is more limited than that available for health professionals. Many patients receive limited information from clinicians regarding palliative and end-of-life care. A survey of cancer patients found that only 30% of patients with life expectancy of less than six months had received information about end of life care (Beernaert et al., 2017). Another survey reported that only 25% of advanced cancer patients receiving palliative treatment knew about palliative care, of those patients not receiving palliative care, just five per cent were aware of it (Zafar et al., 2016).

Palliative care patients have identified a need for more written information about the role of the specialist palliative care service (Tomlinson et al., 2012). Many patients had misconceptions regarding the role of hospices and Macmillan nurses (Randall and Wearn, 2005) and the breadth of services that palliative care could offer (Tomlinson et al., 2012). Many patients reported gaps in their knowledge regarding hospice care, the services they provide and which patients would benefit from it. It was often assumed that hospice care was for patients at the very end of their life (El-Jawahri et al., 2017). The misconceptions reported by some studies suggest that palliative care should be explained in more detail when it is first introduced (Randall and Wearn, 2005). Patients felt they would benefit from receiving more information about hospice care and what it has to offer (El-Jawahri et al., 2017). Despite agreement about the need for information, opinions differed as to when would the optimum time for patients to receive this information (El-Jawahri et al., 2017).

A number of service delivery issues were mentioned as barriers to palliative care referral. In some cases, health professionals felt that palliative care services were not sufficient to meet patients' needs (Beernaert et al., 2015). The lack of clear referral pathways often meant that health professionals were hesitant in making a referral as they were unsure of the steps they should follow (Keim-Malpass et al., 2015). In some cases, palliative care services were simply not available (Charalambous et al., 2014) or the available palliative care service was not sufficient to meet the level of demand

therefore only patients in serious need of palliative care support would be referred (Ward et al., 2009, Keim-Malpass et al., 2015).

One of the most striking results from the literature review was the lack of understanding expressed by patients about palliative care and its' purpose. This led us to conduct an audit of patient information regarding palliative care within our geographic region.

Patient Information Audit

The audit was conducted across 12 NHS Trusts, including a total of 20 hospitals, 16 inpatient wards, 12 outpatient units, 12 day units and 12 palliative care teams. Over the four week audit period, one hundred per cent response rate was achieved.

Table one provides details of the hospital sites within the 12 trusts that provided access to written patient information leaflets about palliative care. Eleven of the 12 palliative care teams had a written information leaflet. However four teams did not routinely use the leaflet, with three reluctant to distribute the information as fearful the terminology used in the leaflet may cause distress to some patients. These teams preferred to provide verbal explanations of their services. In total, just four trusts had palliative care information available outside the palliative care setting. Information was provided in the inpatient ward at one trust, two trusts provided leaflets in their day units and a further trust provided the same leaflet on their outpatient ward and day unit.

Ten of the 12 NHS trusts had a dedicated area on the intranet, available to health care professionals, detailing the palliative care service available. Four had a downloadable patient information leaflet on the intranet site. Across the trusts, there was better availability of information about palliative care within the palliative care setting.

Critique of information resources

The content of information leaflets available in the oncology settings were evaluated (Table 2) to determine the extent to which they covered the information needs identified in the literature review. Two of the four information leaflets provide a definition of palliative care and three describe the aim of palliative care. Palliative care is described as providing care and support across all aspects of a persons' life. None of the leaflets explain how palliative care is integrated with the existing oncological care that patients are receiving or give an indication of a point in the disease trajectory when palliative care might be appropriate. Only one leaflet explains how a patient could be referred to palliative care and what happens at the point of referral. None of the leaflets cover all areas of information considered to be important in a palliative care information leaflet.

Discussion

Current literature supports the concept that early integration of palliative care is an essential component in the management of patients with advanced cancer (Rabow et al., 2004, Brumley et al., 2007, Bakitas et al., 2009, Temel et al., 2010, Zimmermann et al.,

2014). Despite this, our literature review identifies several barriers to its successful integration. The literature exploring patient related barriers identifies two broad themes; misconceptions on what palliative care is and a lack of understanding of the role and breadth of services available (Tomlinson et al., 2012). The lack of information available to patients about palliative care and their unmet information needs was clearly evident in the literature which led us to conduct an audit of patient palliative care information in our geographical area.

Our regional audit of patient information resources found that patient information relating to palliative care is not widely available to cancer patients. Our audit showed that less than 13% of all in-patient units, 7% of outpatient departments and 25% of chemotherapy day units had written information available to patients regarding palliative care. Despite this, over ninety percent of palliative care teams surveyed said that information leaflets had been produced but that they were not in routine circulation. Our audit shows that although information resources exist within the Trusts, they are often only distributed to patients after they have received a palliative care referral.

We suggest that in order to heighten patient awareness of palliative care services and to address some of the misconceptions about the role of palliative care (Tomlinson et al., 2012), information leaflets should be more readily available in oncology outpatient departments, chemotherapy day units and in patient settings. The provision of such information is likely to increase patient understanding about palliative care and help

initiate discussions about its role in their care which may facilitate more timely integration of palliative care.

Our review of the content of patient information resources identified shows considerable variation exists. The majority fail to describe the referral process and what to expect when referred. None of the information leaflets explain that palliative care can be integrated alongside oncology care. Patient and health professionals' understanding of this concept is key to achieving an integrated service where patients can receive appropriate palliative care input alongside cancer treatment (Von Roenn et al., 2013). It is evident from the literature identified that it is not only patients who have misconceptions about palliative care. Some health professionals believed that starting palliative care would mean the end of active treatment but in practice, that is not necessarily the case. There appears to be a need for health professional education to help improve understanding of the different models of palliative care provision and how these can be integrated within existing patient pathways. In Japan, a regional palliative care programme has shown benefits in improving physicians' knowledge (Kizawa et al., 2015). Other research has suggested that training of oncologists is crucial in ensuring the integration of palliative care (Wentlandt et al., 2012, Charalambous and Silbermann, 2012). The provision of appropriate patient information could help to not only address the patient barriers, but also help address some of the other identified barriers by

facilitating the communication process with health professionals and opening up the referral process so it is both patient and health professional led.

There are some limitations to this research. The audit was undertaken in one geographical region and although this included 20 hospitals across 12 NHS Trusts we acknowledge the findings may not be representative of the rest of the UK. We are also reliant on the health professionals we contacted to have provided accurate information. The literature review was a scoping review to inform the direction of future research and as such we did not report the numbers of papers identified, included or excluded. Despite these limitations, the review highlights the lack of patient palliative care information and the lack of research exploring patient views in this area, both of which are being further explored in an NIHR funded research project, which aims to develop a patient decision aid and doctor training to support timely conversations about palliative care.

Conclusion

We identified a need to improve the information for cancer patients that addresses known misconceptions about palliative care and to make this widely available in oncology departments. This information could facilitate earlier integration of palliative care alongside oncology management by supporting patients with the knowledge to

understand when palliative care may benefit them. More research is needed to explore ways to disseminate information about palliative care effectively and sensitively.

Implications for practice

- Robust patient information needs to be created to ensure patients are aware of the purpose and benefits of palliative care
- Information about palliative care needs to be available in the oncology setting
- Making patients more aware of the role and benefits of palliative care should help to facilitate earlier referral by removing many of the misconceptions surrounding palliative care

DECLARATION OF CONFLICT OF INTEREST

The authors declare that there is no conflict of interest

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Table 1: Provision of palliative care information leaflets within different clinical areas across 12 NHS Trusts in Yorkshire and Humber

NHS Trust	Inpatient	Outpatient	Day unit	Palliative care team
1				✓
2				✓
3				✓
4				✓
5				
6				✓
7	✓			✓
8				✓
9				✓
10			✓	✓
11		✓	✓	✓
12			✓	✓

Table 2: Summary of information provided in palliative care information leaflets

Place of distribution	Day unit	Outpatients/Day unit	Inpatient ward	Day unit
Definition of palliative care	Active care and support of people at any stage of progressive illness. Provides psychological/ social/spiritual support for families	Improving quality of life by paying attention to physical, psychological, social and spiritual concerns		
Aims of palliative care	To achieve the best quality of life for patients, their families and carers	To improve the quality of life of people (including carers) affected by serious illness		To provide high levels of advice and support to patients and carers that require input
Specific support and services provided by palliative care	Assess individual needs, symptom management, time to talk through feelings, advice on benefits/ employment, liaising with other teams, planning the future, help to make decisions about the place you wish to be cared for, rehabilitation and fatigue management	Pain control, symptom control, emotional support, spiritual care, carer support, planning future palliative care, end of life care	Opportunity to talk through information given, provide further information, advice on pain or symptoms, help make informed decisions about care, coordinate care and provide links to health professionals, provide specialist nursing advice	
Type of patients who would benefit from palliative care	Patients with life threatening illnesses	Cancer, heart, lung, kidney or neurological diseases		Cancer or other life threatening conditions
Integration of palliative care into patients existing care				
Timing of referral				
Referral process:		Usually ward staff		

who can make referrals		will make the referral		
Referral process: what happens when a referral is made		A member of the team will introduce themselves, assess your problems and offer management suggestions		
Settings where palliative care is delivered	Hospital wards, home, outpatient clinics	Home, hospital, hospice, nursing home	Hospital wards and outpatient clinics	Home, hospice
Description of staff members delivering palliative care	Specialist nurses, doctors, family support worker, physiotherapists, occupational therapists, administrative staff	Specially trained nurses (Macmillan), doctors and a pharmacist	Macmillan clinical nurse specialists and consultants in palliative medicine	Specialist nurses
Description of the wider healthcare team involved in palliative care	Psychology services, outpatient clinics, local hospice, chronic pain team, complimentary therapies		Social worker, pharmacist, dietician, physiotherapist, occupational therapist, chaplain	GP, district nursing team, other community staff, the hospital and the hospice
Palliative care team contact details	Provided	Provided	Provided	Provided
Format of leaflet	A5 8 page booklet	Tri-fold leaflet	A4 three page leaflet	A4 four page leaflet