What influences referrals within community palliative care services? A qualitative case study

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ABSTRACT

Evidence suggests that the utilisation of community palliative care services varies considerably according to different patient characteristics. Most literature describes this variability, but does not address why such differences exist. Exploring the processes underpinning referral making rather than simply describing the outcomes of referrals may further our understanding of this variability. The aim of this article was to investigate the influences on referral decisions made within community palliative care services. A qualitative case study strategy was adopted, studying three Primary Care Trusts in England, UK. Data collection used multiple methods (interviews, observation and documentary analysis) from multiple perspectives (including general and specialist palliative care professionals, patients, managers and commissioners). Two core influences on the way health care professionals made referral decisions are identified. First, their perception of their own role in providing palliative care; autonomous professionals make independent judgements about referrals, influenced by their expertise, workload, the special nature of palliative care and the relationship they develop with patients. Second, their perception about those to whom they may refer; professionals report needing to know about services to refer to, and then make a complex judgement about the professionals involved and what they could offer the referrer as well as the patient. These findings indicate that many more factors than an assessment of patients' clinical need affect referrals within community palliative care services. It appears that personal, inter-personal and interprofessional factors have the potential to shape referral practices. Practitioners could be more explicit about influences on decision making, and policy makers take account of these complex influences on referrals rather than just mandating change.

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Introduction

Provision of palliative care to patients in the community is complex, requiring more skills than any one professional can reasonably be expected to provide. Consequently, teamwork is important (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002). However, professionals often work not in formal teams, but as a 'web of loosely connected services and individuals' (Corner, 2003). Referral processes are crucial to team formation. Most services depend on referrals to operate, and referral processes are important to understand because of their impact on access and service utilisation (Bestall et al., 2004).

Background

One body of literature investigates patients' access to and use of community palliative care services. Much of this research identifies which patients are least likely to

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access services. Older people, those from minority ethnic populations, unmarried people, economically disadvantaged, those without home carers, those with haematological or brain tumours, or with diseases other than cancer are less likely to be referred to or use specialist palliative care services (Ahmed et al., 2004; Burt & Raine, 2006; Grande, Addington-Hall, & Todd, 1998). Such studies usually describe variability in access and utilisation, but most are retrospective, use routine data, and are not designed to explore causes of variability (Grande et al., 1998). Studies rarely explore the contexts of care, and how these contexts affect referrals and service use.

There are many possible explanations for variability, including different patient needs (Burt & Raine, 2006), or patient attitudes towards referral and care (Catt et al., 2005). One possible explanation is referrer variability.

Previous research identifies three issues which appear to affect referrer variability in palliative care: (a) the influence of palliative care knowledge and skills on referral; (b) prognostication; and (c) the effect of professionals' personal feelings about palliative care and their role in its provision.

Awareness of the existence of services does not guarantee referrals (Gochman & Bonham, 1988; McKenna, Keeny, & Nevin, 1999). A professional's own lack of knowledge or skill may trigger referral (Aitken, 2006; Bradley et al., 2002), or may hamper recognition of its necessity (Bestall et al., 2004). Receiving palliative care training appears to facilitate referrals (Friedman, Harwood, & Shields, 2002; Schim, Jackson, Seely, Grunow, & Baker, 2000).

Difficulties in determining prognosis have been identified as a referral barrier, as it is difficult to predict when a patient may require increased or specialist services (McNeilly & Hillary, 1997; Schockett, Teno, Miller, & Stuart, 2005; Weggel, 1999). Professionals may deliberately delay the discussion of hospice or palliative care services until a late stage in the patient's illness (Becker, 2004). Doctors can feel that they are giving up on patients when a hospice referral is made (Friedman et al., 2002), or be uncomfortable with discussing hospice or palliative care (McNeilly & Hillary, 1997). A further barrier is that those providing 'general' palliative care can feel that they are providing a good standard of care without referral to specialist services (Fellowes, Goodman, Wilkinson, Low, & Harvey, 2003; Schim et al., 2000).

Referrer issues may therefore be part of the explanation for service use variability. However, these studies are limited. They have mainly been conducted in the US, frequently they only study the referral behaviour of doctors who make formal hospice referrals, rather than other professionals (McGorty & Bornstein, 2003), and commonly examine only referrals to specialist palliative care services.

In summary, there is considerable description of variability in palliative care service use, but less research exploring why this may be happening. One explanation which warrants further exploration is the influence of referrers and their behaviour on access to and utilisation of palliative care services. There is an absence of published research investigating in detail the reasons given, and factors influencing a professional's decision to refer a patient to particular palliative care services, provided by generalists and specialists.

The study

Aim and definitions

This paper describes the influences on referral practices of health care professionals providing community general and specialist palliative care services.

For present purposes, 'community care' means care delivered within the patient's home, or in a non-hospital setting while the patient remains living at home. Generalist palliative care is that provided by those not specialising in palliative care provision. Specialist palliative care is provided by those with additional expertise and training. Referral is defined as the process of sending a patient from one practitioner to another for care and may be formal or informal.

Research strategy

Referral processes may be complex and context dependent, so a multiple case study research strategy was adopted (Walshe, Caress, Chew-Graham, & Todd, 2004; Yin, 2003). The case was defined as 'those services providing community general and specialist palliative care to patients registered or residing within a specified Primary Care Trust'. Primary Care Trusts (PCTs) are the organisations in England responsible for commissioning and/or providing most community health services. Three cases (PCTs A, B and C) were studied, selected on the basis of the different ways specialist community palliative care services were provided, thus allowing an exploration of the same phenomenon in a diversity of situations (Mariano, 2001). Table 1 presents some features of the three cases.

Choice of data sources

Data sources included interviews with key staff within case study sites, with health care professionals making and receiving palliative care referrals, and with patients receiving palliative care services. Other data sources included observations of team meetings, documentary evidence such as service directories, palliative care policies, protocols and strategies, and patient related documents such as case notes and referral forms.

Sampling and recruitment

Professionals were invited to participate either because they were 'key informants' who could provide information about palliative care services and their contexts, or because they were professionals who made or received palliative care referrals. Key informants and some health care professionals likely to have pertinent information were selected purposively from staff lists (Coyne, 1997; Heckathorn, 1997). Respondents were asked to suggest other potential informants, to identify relevant documents for analysis, and to suggest opportunities for observation of meetings. Letters of invitation were sent, and non-responders followed up by letter and telephone. Recruitment of professional participants ceased either when no new themes emerged from data analysis within that case, or all possible

Table 1
Contextual information describing elements of the cases studied

Case study	Description of area served	Population served (thousands)	Socio-demographic features of the area	Average annual cancer deaths (as a proxy for palliative care need)	Specialist palliative care provision within PCT area
A	Industrial town	100–120	Predominantly white. 70% of wards in top 30% of deprived wards in country	310–330	Small voluntary hospice. Community specialist palliative care nurses, Hospice at home and Marie Curie nursing services. Consultant in palliative medicine.
B	Industrial town	250–270	90% white 40% of wards in top 30% of deprived wards in country	640–660	Large voluntary hospice. Consultant in palliative medicine. Community specialist palliative care nurses, cancer coordinating service, Marie Curie nursing service.
C	Urban area	130–150	70% white 100% of wards in top 30% of deprived wards in country	210–240	Community specialist palliative care nurses.

informants within the case had been approached (Morse, 1994).

Each participating health care professional was asked to identify a patient to be interviewed, who was in the palliative phase of any illness and who had recent experience of referral. This method of recruitment was designed to maximise opportunities to interview those with relevant experiences. However there was a risk of recruiting those patients professionals thought may reflect well on their own services.

Open-ended interviews were conducted at a place of the respondent's choosing, and while flexible and conversational, had some focused questions. Because of the iterative nature of the study, the interview guide changed, but Box 1 presents a list of general topics covered. Detailed contemporaneous field notes were made after interviews and observations. Audio-recordings of interviews were fully transcribed. Interviews and observations were conducted by one researcher (CW) a qualified nurse with community palliative care experience. Data were collected in 2003–2004 (PCTs B and C) and 2004–2005 (PCT A).

Approval was obtained from NHS and University research ethics committees and NHS research governance approval was obtained. Participants were assured that their comments would be anonymised and we disguise the identities of the three PCTs.

Data analysis

Data collection and analysis occurred iteratively. Initial analytical insights informed further data collection and caused amendment of initial theoretical propositions (Yin, 1999). Theoretical propositions are used within case study strategies to guide the design of research steps according to their relationship to the literature, policy issues or other sources (Yin, 2003). Propositions focus attention on what should be explored in the study but can also reflect researcher's intuitions (Mariano, 2001). The aim is not grand theory, but to have a sufficient theoretical blueprint to guide study design, data collection and analysis. Theoretical propositions are iteratively amended, in a way which has been compared to the constant comparison used in grounded theory (Cowley, Bergen, Young, & Kavanagh, 2000). The iterative refinements and amendments to theoretical propositions then becomes the main vehicle for generalising the results of the case study (Yin, 2003). Four initial propositions were initially developed, derived primarily from literature (Box 2).

Box 1. Topic guide for interviews

Mapping palliative care within the PCT

Public processes of palliative care (policies, procedures, referral criteria etc.)

Sources of referral

Processes of referral

Referring onwards

Influences and relationships

Background and experience

Box 2. Initial theoretical propositions

Proposition 1. Professional roles and responsibilities are constantly re-negotiated around the care needs of individual patients.

Proposition 2. Caring for palliative care patients is 'special' and the status this confers on professionals affects the referral choices they make.

Proposition 3. Professionals have a sense of ownership and responsibility towards palliative care patients, and this affects their gate keeping role in referral to and work with other professionals.

Proposition 4. The culture and context of individuals, teams, and organisations providing palliative care will affect referral patterns.

The analysis followed a 'horizontal logic' with analysis within cases preceding cross-case comparisons (Kohn, 1997). Framework analysis techniques were used to facilitate within and across case analysis and cross-case pattern matching (Ritchie & Spencer, 1994). An initial thematic framework was developed from the theoretical propositions and data collected, and systematically applied to the data, with changes made to reflect data collected. This was facilitated by use of NVivo® 2.0 (QSR 2002) for indexing and charting. Charts were developed for each major thematic grouping, for each case study, to facilitate within case analysis. Cross-case analysis was facilitated by examining similarities and differences between and across cases, using the developing theoretical propositions as a pattern matching tool.

Tactics used to enhance rigour included using numerous evidence sources, establishing a chain of evidence using NVivo to track data, peer debriefing with members of a research advisory group (including fellow researchers and palliative care professionals), supervision including reading of transcripts, independent identification of key themes, critical comment on interpretations, the identification of sufficient data extracts to support themes, and systematically relating concepts through use of theoretical propositions, supported in more than one case study site (Darke, Shanks, & Broadbent, 1998; Riege, 2003).

Findings

Fifty-seven in-depth interviews were conducted, supported by observational data from six meetings and analysis of 13 case notes and 84 other non-patient specific documents such as referral forms and protocols. Documentary evidence is not presented here, as it does not illuminate the influences on professional referral practices. Most interviews lasted 1–2 h, although a few interviews were shorter. Table 2 summarises respondent information.

The findings presented result from the cross-cases analyses. While there were many differences between sites, for example in service provision patterns, pattern matching analyses across the cases revealed common influences on referral behaviour and practices. Data extracts are identified by the participant's professional affiliation (DN – district nurse, GP – general practitioner, SD – specialist palliative care doctor, SN – specialist palliative care nurse, AH – allied health professional, KI – key informant e.g. commissioner). Study site codes have been removed to protect anonymity.

Professionals' perceptions of their own roles in palliative care

A number of issues appeared to affect professionals' constructions of themselves as palliative care practitioners and in turn their palliative care referral practices: a sense of autonomy and self-management; patient ownership; giving patients choices; expertise in palliative care; workload; and impact of the perceived status of palliative care work.

Autonomy and self-management

Autonomy can be defined as the exercise of considered, independent judgement to effect a desirable outcome (Keenan, 1999). Study participants frequently refer to such independent judgements about role and referral practices:

> 'I can basically do what I like with my time, so long as I meet my target that I have set myself, you know.' (SN8)

Participants appear actively to dislike constraints on their perceived autonomy such as protocols or procedures:

> 'People are very good at giving us protocols and telling us what to do, um, which I think you know, it undervalues us … that's my job, that's why I'm paid a lot of money, that's why I've had a lot of training, is to do that triaging, that managing risk, deciding where people are to go.' (GP7)

This sense of autonomy appears to give flexibility to respond to and make referrals in an independent manner, without necessarily making reference to others, often facilitated by the isolated contexts within which community professionals can work (Griffiths, 1996).

Ownership

'Ownership' of a patient may give an advantage to a particular professional in relationship to the claims of others, and with regard to issues such as decision making on patients' behalf (Dan-Cohen, 2001). In this study,

Table 2
Participants interviewed (and invited to participate)

Case study site	General palliative care services	Specialist palliative care services	Key informants	Patients	Total
A	5 (12) DNs 3 (21) GPs 1 (1) nurse practitioner	4 (5) specialist nurses	1 (1) commissioner	1	15
B	3 (34) GPs 4 (8) DNs 1 (1) AHP	3 (4) specialist nurses 2 (2) AHP 1 (1) specialist doctor	1 (1) commissioner	4	19
C	5 (12) DNs 6 (28) GPs	3 (3) specialist nurses 1 (1) AHP 1 (1) specialist doctor	1 (2) manager 1 (1) senior DN	5	23
Total	28	15	4	10	57

DN = district nurse, GP = general practitioner, AHP = allied health professional (physiotherapist, occupational therapist, social worker, dietician). The numbers in brackets indicate the numbers in each group invited to participate.

ownership concepts appear bound to the interrelated issues of responsibility for, and relationship building with, patients. Doctors tend to have a sense of responsibility for patients:

> 'Well, I'm a consultant, so it's a traditional pattern of working that you would expect from any consultant, in the sense of having overall responsibility for all patients who come in under hospice services.' (SD1)

Nursing staff have a sense of ownership gained through building relationships with patients. The importance of 'knowing the patient' is clear from others' research (Luker, Austin, Caress, & Hallett, 2000; May et al., 2004), and is confirmed in this study. The issues of who can be responsible for patients, and how this can affect referral and care decisions for that patient can be complex. It can involve staff negotiating between those with different senses of ownership and responsibility to achieve what they feel is best care for the patient:

> 'If someone is at home they are the responsibility, the key person, the key team really is the GP and the district nurse, um, if someone is in here [hospice] then I am responsible for them, and I make the decisions … but when they go back home they go back to the GP, and sometimes if the Macmillan nurse may go and see somebody at home' (SD2)

Giving patient's choices

Giving patients information to make choices about their care is a current policy imperative (Department of Health, 2006; NICE, 2004). Health care professionals talk about the importance of patient choice, operationalising choice as asking patients about preferences regarding referrals:

> 'So we do the initial nursing assessment and take it from there basically and then we let the patient decide what they want. So some patients will say yes they want us to go back, others will want us to ring them, others want no contact and they will contact us. Sometimes they say oh well you decide, but we always put the ball back in their court and say "no it's your decision, what do you want?".' (DN3)

Generalists report offering access to care irrespective of their own assessment of what is required. However, observational data also revealed choices being made by health care professionals without consultation with the patient:

Notes from observation of team meeting

Location: GP surgery. Present: two GPs, district nurse. Apologies sent from Community Macmillan nurse. Meeting length: 60 minutes. Meeting frequency: weekly. Meeting purpose: to discuss patients and make referrals. No formal referral made to DN during meeting.

'Then discussed a patient with uncertain diagnosis, initiated by GP. Recently discharged from hospital. He has rung to request GP visit. DNs know of him from previous care episode, but no recent care input. DN suggests she will visit day after GP – no reference to patient choice, or assessment of GP, but she was quite pushy that this was what she would do, even when questioned by GP as to why this was so.'

Patients' choices may not be informed by an awareness of the way services work and their options. Patients and professionals are aware of these dilemmas:

> 'I don't really think patients understand what people's roles are really, particularly with Marie Curie and Macmillan and, you know the district nurses … so there is a misunderstanding of what the roles are and what people do.' (SN1)
>
> 'I wouldn't know what services were available, you know what I mean, I've just accepted the services that have been offered … I don't know whether I had any expectations really, I just didn't have any information about district nurses at that time.' (P5)

During clinical conversations in palliative care, patients often adopt passive roles and tend not to engage in important decision making (Clover, Browne, McErlain, & Vandenberg, 2004). Choices should be informed by appropriate knowledge of services and patients' likely roles in decision making. Otherwise, it may be that a strategy intended to empower patients actually restricts access to services.

Expertise in palliative care

Key to referral processes is a self-assessment of professionals' own capabilities and limits of expertise, and judgement of the expertise of the person to whom they are referring. Where respondents feel they could offer expertise to patients or where they perceive others could not offer considerable additional expertise, then referrals appear less likely to take place:

> 'We've got quite a lot of experience so it's only when I think that people feel that it's getting beyond them, and beyond me, and beyond everybody else's expertise that we think, "right, actually now I think we need to ask somebody's else's help and advice".' (DN6)

Perceptions of expertise appear to affect referral practices, with those who feel themselves to have sufficient expertise in a particular area reporting that they are less likely to refer to specialists.

Workload issues

Professionals' perceptions of their own caseloads and workloads affect the way they make and respond to referrals. District nurses in particular find it hard to refuse referrals, and so use strategies to cope with what are sometimes onerous workloads by juggling the timing or frequency of visits. Time constraints mean that referrals to other services could be both to relieve the workload of the referrer, and to ensure that the patient got enough time to address their needs:

> 'We just felt that because palliative care is so personal and so emotional that we don't always have the time facility to provide that.' (DN9)
>
> 'I know the district nurses have less and less time to do anything other than physical things.' (GP10)

'Can sit down and chat more than we can because we don't have the time to do that, we have got other nursing things like dressings and insulins or whatever, whereas the Macmillan nurse would sort of have, spend a bit more time with those patients which we probably wouldn't be able to do.' (DN14)

Lack of time may be a convenient way to explain avoiding patients. There is evidence that many professionals lack the skills to communicate effectively with patients (Gysels, Richardson, & Higginson, 2004; de Haes & Teunissen, 2005; Maguire, 1999), and that one reason for avoiding in-depth communication is the time that it would take were psychological issues revealed or strong emotions displayed (Maguire, 1999). There may be undisclosed reasons for time being cited as a reason for referral to others, with not only the reality of a stretched service triggering referrals, but also concerns about having sufficient skills to provide time-consuming and difficult psychological care to patients.

Status of palliative care work

Caring for patients requiring palliative care appears to be a priority, with respondents describing incidents where they extend their normal range of caring behaviours, and talk about their passion for palliative care patients:

'We're all passionate about our palliative care patients, and we're all protective of them.' (DN3)

This could be important to referral behaviour, with professionals anxious to retain care of a group of patients because of the significance given by their own and other professionals to providing care for those who are dying.

Working with other professionals in palliative care

The impact on making and accepting referrals on professionals' perceptions of others with whom they work is explored below. Three main issues are examined: knowledge of other services, negotiating team roles and maintaining professional relationships, and judging other professionals.

Knowing about other services

A key factor in referral decision making is professionals' appraisal of how much they understand about the work of fellow professionals and services. Respondents describe poor understanding of how other professionals work; acknowledge the variability in how different professionals approach their work in palliative care; and tailor referrals to fit with what they know about colleagues' work.

For many respondents, work in the community is unseen, conducted unobserved in patients' homes, which can lead to a poor understanding of others' roles (c.f. Griffiths et al, 2007):

'I think it's all about learning each other's roles, because if you don't have a clear understanding you tend not to refer, because you don't understand what they're doing, so what are they going to do that I can't do?' (SN2)

When an individual's approach to their role is understood, then the response to a referral could vary to reflect the interest, ability, and predicted response of the person from whom they receive the referral:

'If you know that you have got other professionals who perhaps don't provide the same standard of care as other professionals do, or other people that you work with, then that might give me cause for concern as to whether that patient (a) has been assessed properly, or (b) has had their needs met. In which case I might prioritise that over and above somebody that I know has got a good district nurse if you like going in. In fact I would prioritise that above, if I had two referrals, one with a good district nurse that I knew and trusted, and I knew she could cope, and one that was crap basically, then I know which one I would go to first.' (SN8)

Negotiating team roles and maintaining professional relationships

Many respondents indicate that they believe they deliver the best possible palliative care to patients when they work as part of a well functioning team:

'I think the best care for patients is that which is palliative partnership, and as they're at home for the majority of their lives with their illness, that's where their care has to be provided, but it has to be skilled and experienced and appropriate care.' (SD1)
'the fact is that we work very closely together and there is traditionally a nurse/doctor, north/south divide isn't there in most specialties, but this is one in my limited experience where I find a result … we are very much an integrated team.' (GP2)

Formal or informal referrals between health care professionals appear key to the formation of networks of professionals working together in community palliative care services. The provision of specialist palliative care in particular is 'by invitation only' and specialists are mindful of their status as supplementary health care professionals, whose presence is negotiated with the generalists:

'I suppose it's a bit more challenging as a palliative medicine doctor, because we don't just need to decide what to do, we need to convince somebody else to do it … because there's no point me seeing them, offering advice if they're [generalist] not going to follow it.' (SD2)

This caution appears well founded, as there are generalists who are sceptical about some of the benefits of specialist palliative care, and nervous about what the involvement of specialist palliative care services could mean for their own involvement with patients. Those working in specialist palliative care appear aware of the concerns of generalists with whom they work:

'Some of my more enthusiastic colleagues in dealing with patients at this stage in their life would perhaps fear or think about not wanting us to take over, and, but I've, because I know who those GPs are, I think we would tend to, I

hope we could have a negotiated sort of shared care approach to their patients' care.' (SD1)

Caution is also shown in meetings, with care taken to involve generalists in initial care, rather than involving only specialist colleagues:

Notes from observation of team meeting

Location: Hospice. Present: consultant (chair), SpR, 2 medical officers, 2 community Macmillan nurses, hospital Macmillan nurse, staff nurse from hospice (all specialist palliative care staff). Meeting length: 45 minutes. Meeting frequency: thrice weekly. Meeting purpose: to discuss patients and referrals. Three referrals made during meeting. Referrals received by Macmillan nurses not discussed as 'too numerous'. Focus clearly on hospice, determined primarily by medical staff.
Extract from notes: 'The discussion then moved to an in-patient who will be discharged home tomorrow. The background and medical history of the patient was discussed in detail amongst the in-patient nurse, consultant and other medical staff. A referral was made to the community Macmillan nurse (present at the meeting). However, it was clear that the community Macmillan nurse would not visit or assess the patient, despite the knowledge of the patient she had gained at the meeting, but would wait for feedback from district nurse before any referral would be activated'.

This action appears to re-affirm the importance of the generalist provider to the specialist. There is a strong sense that referrals to specialist palliative care services are optional for patients. Such referrals are carefully negotiated, recognising that the role of the specialist is essentially additional and advisory. Professionals appreciate that efforts need to be made to build relationships which facilitate their own working practices, and the social cohesion of the 'team'. Each professional is judged on the basis of their current and past interactions, and they are mindful that the successful referral and care of future patients could depend on their negotiation of good current relationships:

'That is relationships and personalities, which GP I am dealing with, and that is down to negotiating, but unfortunately it's not negotiating on a professional level is it. It is about personalities. The minute I falter, he is going to say no and that's that…. Well, mention your name and it's "oh her again, I don't want to know". A lot of it is about knowing your own GPs and chipping away and knowing how far you can go in one telephone conversation and think right, I've gone too far now, we'll just finish this and I will maybe ring back with a different tack next week.' (SN6)

Thus, the care of a current patient could be affected in order to maintain and enhance a professional relationship.

Judging other professionals

Referrals to others are often predicated on a critical judgement of the individual professional's past performance, rather than the service provided per se. A distinct notion of individuals as 'good' or 'bad' professionals is often discussed. General practitioners are particularly judged on

the basis of their responsiveness, communication skills and the respect they show towards other professionals:

'The GPs in this area are not particularly responsive to nurse demands. It doesn't matter for what… there is two of them that I will ask, and know I will get, but the rest of them it depend on what mood they are in, how busy they are or whatever.' (DN9)

Thus, the label of "good" or "bad" doctor does not necessarily relate to medical knowledge, but to how willingly they acquiesce to nurse requests. In this manner, doctors have the power to disrupt or legitimate the nurses' capacity to manage patient care. District nurses are judged on the basis of their working practices:

'I'll refer to the DN team, and I'll say, can you go out and assess this patient for wound care, and if the team leader is involved there's psychological support also, and if they feel okay at that, but, but the story so far has been that the psychological support has been largely ignored.' (SN1)

Comments about specialist professionals highlight issues of elitism and the impact of their expertise.

'I think they [specialist palliative care nurses] were completely rigid in their ideas of how specialist palliative care was, they were the elite, and you know, they would do what they wanted.' (SN1)

What appears critical is the relationship which exists between professionals. Such judgemental attitudes colour a lot of the discussion regarding professional relationships, working patterns and the way referrals are made. Having a negative view of the personality, working patterns, or competency of someone adversely affects the likelihood of making a referral.

Discussion

Throughout data collection and analysis theoretical propositions were constantly interrogated, and new propositions developed (Yin, 2003). Three overarching final theoretical propositions are presented (Box 3), relating to the core issues of making and receiving referrals within community palliative care services, and the context within which these referral decisions occur.

Proposition 1: Referrals are made following a complex appraisal of the referral situation, not purely a patient's clinical need.

An assumption of rationality and equity in referral appears to underpin much of the research reviewed earlier; that those who have equal need will be equally referred for care. However, this study shows that the factors which affect referral in community palliative care services are complex, and often personal to the referrer. Patient characteristics appear less important to referrers. Referrals are therefore not 'rational' in the sense of being overtly based on clinical need.

This research reports on complex referral patterns between generalists and specialists, doctors and nurses, in a way which has rarely been addressed (O'Donnell, 2000). While palliative care is seen by many providers as 'special', such that referral patterns may differ within this field, this

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Box 3. Final theoretical propositions

Proposition 1. Referrals are made following a complex appraisal of the referral situation, not purely a patient's clinical need.

This appraisal takes account of

- The needs of the referring professional, including their emotional capacity, expertise, time available, and interest in palliative care.
- The health care professionals' interpretation of patient preferences, including an appraisal of their fears about referral.
- The clinical needs of the patient. Formal reasons for referrals are framed by reference to a bio-psycho-social model of care, although there is no 'absolute' definition of clinical need in palliative care which triggers a referral.
- An appraisal of the professional/service to whom the referral is made, including what they can offer to the referring professional in terms of time, expertise or teamwork, and a judgement about their previous input with patients.
- The relationship with patients and carers which can create a sense of ownership that restricts or facilitates referrals.

Proposition 2. Referrals are acted upon following an appraisal of both referral information and the person making the referral.

This appraisal takes account of

- A judgement about the knowledge, skills, expertise and interest of the person making the referral.
- Any potential need to compensate for perceived gaps in care.
- An interpretation of the perceived appropriateness of the referral.

Proposition 3. Referral decision making is influenced by factors which affect the professionals' perspectives about their work.

- A sense of autonomy, self-determination or the independence of clinical judgement allows professionals to make referral judgements independently, not necessarily according to local or national policies.
- An individual's interpretation of and approach to their role is more important than the role itself in determining referral patterns.
- Maintaining a relationship with fellow professionals to facilitate future care and referrals can be as important as care of current patients.
- Palliative care is 'special' and 'important' work which allows usual approaches to care to be suspended.
- Specialist palliative care services involvement with patients is not mandatory, and so their use is carefully negotiated.

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research may provide insights useful to practitioners or researchers in other areas. There is evidence of variable, often unexplained referral behaviour in fields such as general practice (O'Donnell, 2000) and mental health (Hull, Jones, Tissier, Eldridge, & Maclaren, 2002). It has been shown, for example, that referrals to community mental health teams vary according to relationship styles between the teams and referring GPs (Hull et al., 2002). Such factors influencing referrals may be important in other health care areas.

Proposition 2: Referrals are acted upon following an appraisal of both referral information and the person making the referral.

The operation of these theoretical propositions demands that professionals work from a position of relative independence or autonomy when exercising professional judgement. To act upon a personal assessment of whether referral is needed requires the person to have the capacity and authority to make such a decision. Whether such referral choices are then perceived as 'good' or 'bad' depends on the differing perspectives of the referrer and others, not necessarily an explicit, agreed notion of what might be right or wrong. Judgements about referrals are not necessarily made on an appraisal of patient experience or outcome, but more commonly on the impact of such referrals on professional's practice. In this way, professionals are enacting policy in practice – in essence acting as 'street-level bureaucrats' (Lipsky, 1980). Lipsky (1980) argues that front line public servants exercise power by making and implementing policy, whereby the routines they establish and the devices they invent to cope with uncertainties and work pressures effectively become the policies they carry out. General practitioners have been identified as 'street-level bureaucrats', exercising individual clinical judgement rather than following central guidance (Checkland, 2004; McDonald, 2002).

Proposition 3: Referral decision making is influenced by factors which affect the professionals' perspectives about their work.

The concept of team appears very important within palliative care, with a clear assumption that teamwork will bring about more efficient and effective work and consequently that patients will receive better care (Farrell, Schmitt, & Heinemann, 2001). This assumption appears to underpin much of the Gold Standards Framework, a strategy to improve practice based palliative care (Thomas, 2002). However, there is little evidence to support this, either in the wider general literature (NICE, 2004), or within this study. Professionals perceive themselves to be providing a good quality of palliative care both when they work as part of a team, and when there is no team approach. This may be both because professionals feel it is not necessary to supplement the care they offer, and because teamwork requires effort which they may not feel able to give. Teamwork and collaboration can be difficult at times (Henneman, Lee, & Cohen, 1995), and are affected in this research by autonomous working practices, negative appraisals of some fellow professionals, lack of understanding of the work of others, and a lack of team resources. These are likely to be major obstacles to teamwork or collaboration. Such obstacles can be seen as private or individual challenges to public activities. Individual professional

autonomy and judgement is essentially a private activity, whereas teamwork is essentially a public activity. It is argued that health care is increasingly corporate (public) rather than individualised (private) (May, 2007), but that professionals find ways to resist increasing regulation, or create areas where they can continue to provide private, autonomous practice (Armstrong, 2002). It may be that palliative care is an area where individual, autonomous care is accepted or tolerated, despite the ideological importance of teamwork. Partnership or teamwork may be an important solution to particular problems, but may not be the only or best solution for the individual or the organisation.

The complexity of power relationships between doctors and nurses and generalists and specialists is highlighted in this study. Nurses report subtle interactions with doctors and the work needed to maintain relationships while achieving their desired aims. Their desire to develop relationships with patients could be seen as a way of nurses achieving superior social knowledge to doctors to address the power relationship between the two professionals. Such interactions are reported in the classic doctor–nurse relationship and negotiated order literature, with reports of nurses exerting influence by manipulating doctors without changing the fundamental asymmetry of the power relationship (Allen, 1997; Speed & Luker, 2006; Stein, Watts, & Howell, 1990; Strauss, 1978; Svensson, 1996).

The relationship between generalists and specialist is also assuming increased importance in palliative care. There is increasing emphasis on the role of generalists in providing community palliative care, and for their expertise to be recognised, supported and extended (Murray, Boyd, Thomas, & Higginson, 2004; Thomas, 2002). A logical extension of the argument that the skills of primary care professionals are well suited to the provision of palliative care is to question what specialist palliative care can add. The popular perception that specialist care is ipso facto superior to generalist care is a powerful one – despite a lack of evidence of difference in processes or outcomes (Fordham, Dowrick, & May, 1998). There are real tensions between an evidence base in palliative care, which almost exclusively looks at the impact of specialist palliative care on outcomes, reinforcing an idea of the superior nature of specialist palliative care, and an increasing clamour from generalists for their role in providing community palliative care services to be recognised. These data highlight the existence of these tensions between generalists and specialists, and the impact these tensions may have on referral practices.

Strengths and limitations of this study

This study is strengthened because it is a study of referrals in context from the perspectives of multiple stakeholders. Such multiple perspectives enable the complexities of referral practices to be examined rigorously. Studying referrals in context allows the identification of similar issues across different cases, enhancing the utility of the findings to others.

The study is limited by the difficulties recruiting some participants, particularly general practitioners who cited workload and time pressures as a barrier to participation. While the numbers interviewed were as expected, this was only after strenuous recruitment efforts. It is not possible to know whether those who participated held different views from those who did not. Patient recruitment was also low, primarily because of professionals' reluctance to involve their patients (Ewing et al., 2004). This limited exploration of the patient perspective.

Recommendations for further research and policy

Research is needed which explores further any relationship between the personal, professional and interprofessional influences on referral practices described here and the evidence of variation in referral to and utilisation of palliative care services. There is an implicit assumption in the research reviewed of equal need among patients with different characteristics. The relationship between referrals and clinical needs of patients is also an issue meriting further exploration. The contribution of generalists to the provision and outcomes of palliative care warrants further exploration. This research demonstrates the importance generalists place on their own contribution to palliative care, yet most research only investigates issues affecting specialist palliative care. Research needs to recognise the complexity of care provision.

Recommendations for referral practices cannot be made from this study. Rather, it is recommended that policy take account of the influences on such practices described here, and recognise that simply mandating referral, partnership, or teamwork is unlikely to change practice. Instead, practitioners should be encouraged to be more explicit about their referral behaviours, attempting to be more open to themselves, other professionals and patients why they are making particular choices. Referral policies need to recognise the breadth of influences on referral, and could explain in more detail local referral expectations such that exceptions to this can be more easily highlighted and debated. Best practice in understanding how to influence professional behaviour should also be attended to. Without such overt awareness and discussion of variability there are potential risks to clinical care, and threats to clinical governance.

Conclusions

This research adds to knowledge by revealing the processes which impact on referral practices, rather than purely the outcomes of referral processes. It demonstrates that understanding referral processes is a key pre-requisite to understanding patterns of service utilisation. It illuminates professional working practices more generally. Issues such as autonomy, patient ownership and the judgement of other professionals may be particularly highlighted in palliative care because of its 'status', but are also likely to be important in ongoing encounters between health care professionals.

Acknowledgements

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