

VIEW FROM THE OBSERVATORY

Viewing patient need through professional writings: a systematic 'ethnographic' review of palliative care professionals' experiences of caring for people with cancer at the end of life

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Aim: A systematic review of palliative care professionals' written accounts of caring for people with cancer who are knowingly facing death; in order to provide another source of evidence on patients' needs.

Methods: Systematic review methodology was utilised to locate published 'reflective narratives' (not original research) written by palliative care professionals from a variety of disciplines and institutional settings, which focused on the experiences of caring for patients with cancer as they approached their death. The search strategy yielded 2224 texts which were reduced to a

dataset of 202 after the application of the inclusion/exclusion criteria. A quantitative analysis was conducted on the full data set and a qualitative analysis was performed on a selected sub-sample.

Main results: Professionals identify a wide range of needs of people with cancer at the end of life. They write particularly forcefully about: patient autonomy; choice and control; access to information; and full participation in decision-making about patient care. However, closer examination of the texts demonstrates that professionals may also have fixed expectations about: management of patients' emotion; over emphasise choice and control; lack recognition of power in the patient-professional relationship; and tend to homogenise patient needs.

Conclusions: The research raises questions about professionals' interpretation of patient needs and suggests that the care received by people with advanced cancer is still firmly framed within biomedical culture and the social organisation of medicine, which struggle to acknowledge individual autonomy and meet the diversity of individual end-of-life needs.

Keywords: Cancer, patients, palliative, autonomy, diversity

A recent study conducted in the International Observatory on End of Life Care at Lancaster University, UK was commissioned by the national charity, Macmillan Cancer Relief. Its aim was to explore the idea of what might be learned when we look in a systematic way at some of the more reflective writings that have been produced by those who care for people who are knowingly facing death. To date, systematic reviews in palliative care have focused on evidence synthesis deriving from the meta-analysis of data generated through research studies. This project took as its focus the 'experience' of professional carers, as evidenced through their written accounts and broader reflections on care-giving in a variety of settings and where the focus of attention is upon patients and clients who are knowingly facing death.

It is now well established that the expansion of palliative care provision for people with advanced cancer has been characterised by an attempt to adopt a multidimensional

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PROGRESS IN PALLIATIVE CARE

Table 1. The four strands of the search strategy

Electronic databases	Medline, CINAHL, Web of Science, ASSIA, JSTOR, Worldcat, CareData, Lexis-Nexis, Historical Abstracts, The Wellcome Library
Key journals (hand and electronically searched)	<i>Journal of Palliative Medicine, European Journal of Palliative Care, International Journal of Palliative Nursing, Mortality, Journal of Palliative Medicine, Progress in Palliative Care, British Medical Journal, Journal for Alternative Medicine, British Homeopathic Journal, Speech and Language Therapy in Practice, Physiotherapy Theory and Practice, Complementary Therapies in Nursing and Midwifery, The Hospice Journal, Supportive Care in Cancer</i>
International Observatory on End-of-life Care archives, database and library	Included electronic searches of the IOELC database which contains journal articles, books and edited collections. Hand examination of library section ‘Narratives, personal experiences, biographies and autobiographies’; Cicely Saunder’s papers; Dr Robert Twycross’s papers; <i>Hospice Bulletin</i> and a variety of hospice newsletters and annual reports
Internet search	Sites used as entry points: <www.macmillan.org.uk>; <www.cancerresearchuk.org>; <www.cancercharities.com>; <www.cancercare.org>; <www.cancernursing.org>; <www.palliativecarenursing.net>; <www.aosw.org> (Association of Oncology Social Work); <www.ons.org> (Oncology Nursing Society); <www.csp.org.uk> (Chartered Society of Physiotherapy); <www.osteopathy.org.uk> (General Osteopathic Council); <www.acupuncture.org.uk> (British Acupuncture Council); <www.cot.co.uk> (British Association of Occupational Therapists).

approach to end-of-life care, which incorporates the physical, social, psychological and spiritual. Through the work of those in the hospice movement and in supportive and palliative care, improvements have been made in the relief of pain and in the delivery of sensitive and appropriate care; from this, some of the taboos that surround death in modern culture have been challenged (1–3). Yet, despite this, death and dying can remain uncertain and frightening for people with cancer and it has been argued that this has been exacerbated by the secularisation, individualisation and medicalisation of social life in ways that create further uncertainty and anxiety about human mortality (3–5). McNamara (2) makes it clear that how we approach dying and what we consider to be a ‘good’ death can have different meanings when considered from the perspectives of the patient, the family and palliative care professionals. A recent UK study suggests that health professionals’ definitions of a good death can be at variance with the patient’s ideal (6). The purpose of the review reported here was to investigate the written stories that health professionals tell about their experiences of caring for people with advanced cancer who are coming to the end of their lives. We wanted to know if these narratives could give a better understanding of the needs and views of people with cancer as they approach death.

Over the last 30 years, palliative care professionals have been inspired to write about their experiences of caring for people with cancer at the end of life. Until the early 1960s and in the absence of more formalised research, such writings comprised the majority of published work on care of the dying within the literature of the caring professions. Doctors have been prominent in the production of such material, but nurses, social workers, chaplains and others have also made important contributions. It was

Cicely Saunders’ concept of ‘total pain’, distilled out of the experience of representing the suffering of hundreds of dying patients in a steady stream of writings in the early 1960s, that did so much to push forward our understanding of suffering at the end of life. Indeed, it can be argued that this narrative approach proved a much richer source of innovative ideas and thinking in ‘terminal care’ than the results of work classified as research.

This extensive genre of writings merits close attention as another source of knowledge or ‘evidence’ about current issues in the care of those with cancer who are approaching death. A major purpose of the research reported here is, therefore, to assist in making sense of the type of ‘knowledge’ that is created by professional writings about the views and needs of people with cancer at the end of life.

METHODS

Our research combined systematic review methodologies with qualitative data analysis methods. The study had different goals to those of a standard systematic review which usually aims to summarise research evidence. This project was not concerned with primary research but sought instead to locate systematically professional writings on caring for people with cancer at the end of life. These writings were to comprise personal reflections, case studies, expert opinions and other comments derived from direct experience of caring for patients. We suggest that such an approach can be thought of as a systematic ‘ethnography’ of professional writings. Most ethnographic data are based on observation of what people are saying and doing but Silverman (7) argues that the ethnographic analysis of written accounts is an important facet of

Table 2. Inclusion/exclusion criteria

Field	Include	Exclude
Professions	All who provide care	
Literature focus	Writings which focus upon the views and needs of patients	Writings which are NOT about views and needs of patients, <i>e.g.</i> debates on drug regimens
	Writings which draw on the experiences of caring for patients (including case-study writing)	Writings which report on primary research; reviews of research; writings about bereavement; and writings about the impact of caring on the professional
Disease	Writings about cancer patients	Writings which are not specifically about cancer patients
Illness status	Writings on people with cancer approaching death	Writings on people with cancer NOT approaching death
Language	Written in English	Not written in English
Date	1975 onwards	Before 1975

understanding the social settings in which people act. The first two stages of the project (search strategy and inclusion/exclusion criteria) followed standard systematic review methodology (8). The final stage (data analysis) utilised both quantitative and qualitative data analysis techniques to derive aggregated and interpretative findings.

The first stage of the systematic review process was devised to locate different sources of published and unpublished literature written by a range of health professionals who, in a variety of institutional settings, care for people with cancer at the end of life (Table 1). Literature reporting on primary research was excluded.

The combined elements of the search strategy yielded 2224 citations. The second stage of the systematic review process applied selected inclusion/exclusion criteria to this body of literature. These criteria evolved as the researchers entered different phases of the search strategy (Table 2).

The inclusion/exclusion criteria were employed as a tool of guidance rather than as an absolute filtering mechanism. Determining the relevance of particular writings to the project aims was often a reflexive process and the steps involved were fluid and iterative. The primary focus of decisions regarding inclusion/exclusion was the question of whether the professional narrative contained direct information about the needs and views of cancer patients knowingly facing death. We also encountered difficulties ascertaining the profession of the author. In many cases, it was unclear if the authors were academics or professionals caring for people with cancer, or both. In some cases, the material was multi-authored, and the writers had a variety of nationalities or the multi-authored papers were from a 'mixed' group or team of professionals. As a result of these complexities, the inclusion/exclusion criteria were applied in a series of stages (Table 3).

Table 3 Stages of inclusion/exclusion application

	Process	No. citations excluded	No. citations for inclusion
Stage 1	Search strategy	–	2224
Stage 2	Preliminary application of the criteria by reading citation title and abstract only. (Many citations excluded because outside remit of review, <i>e.g.</i> not cancer)	1666	558
Stage 3	Application of inclusion/exclusion criteria by second researcher reading title and abstract only	242	316
Stage 4	Application of inclusion/exclusion criteria to full text (online or hard copy)	36	280
Stage 5	Final application of inclusion/exclusion criteria by two researchers reading full article/book	78	202

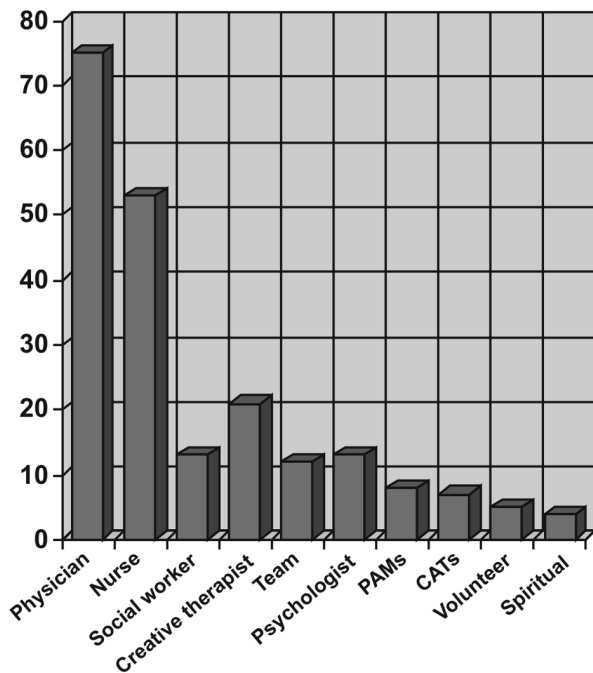


Fig. 1. Writings by professional group (n = 202). Creative therapist = art, music and drama therapists; Team = multi-professional authored texts; PAMs = professions allied to medicine (occupational, speech and physiotherapists).

After the inclusion/exclusion criteria were applied in full, a total of 202 pieces of writing were selected for the data analysis stage of the research. There are no set guidelines about the best ways to review a dataset of 202 professional writings of this type. We were conducting a primary data analysis of professional narratives and not a meta-synthesis or secondary analysis which would form part of a conventional systematic review. Our data set was, therefore, subject to two levels of interrogation: (i) a quantitative analysis of all 202 papers; and (ii) a content analysis and thematic qualitative analysis on a randomly selected sub-sample (n = 64) of the different professional groups. Analysis of the sub-sample enabled an in-depth investigation. In addition, a group of service users participated in the research by commenting on a small sub-set of the professional writings.

RESULTS AND DISCUSSION

Professional, geographical and time patterns

Physicians and nurses wrote the greatest number of the texts (63%) in the dataset. Figure 1 illustrates the distribution of the 202 writings across professional groups. The distribution reflects the range of professionals working with people with cancer at the end of life which includes, for example, occupational therapists and physiotherapists as well as less mainstream professional groups such as aromatherapists, art and music therapists, massage therapists and homeopaths.

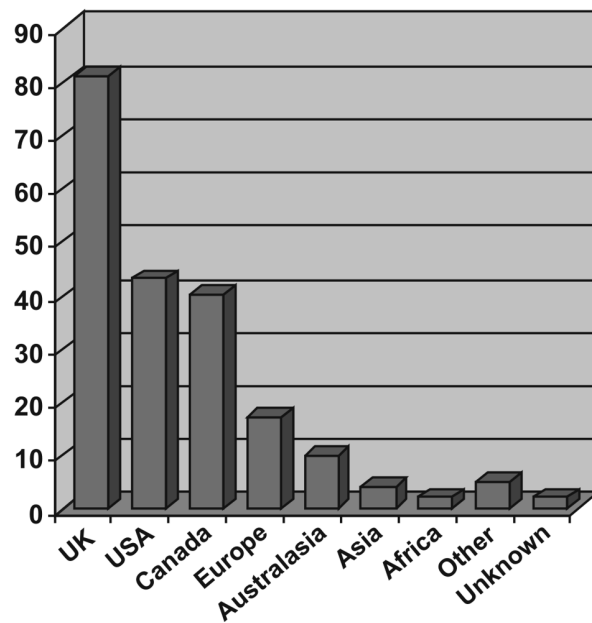


Fig. 2. Writings by geographical area and country (n = 202).

The search strategy aimed to locate international material written in English. As a result, the distribution of the writings by country is, by design, dominated by English speaking professionals from Western industrialised countries. In total, professionals from the UK, US, Canada, Australia and New Zealand wrote 85% of the 202 texts. The distribution of the writings across geographical areas and country is represented in Figure 2.

Since 1975, there has been some change in the authorship of professional writings about end-of-life care. In the 1970s, writings by physicians and nurses dominated. Although physicians continue to write the largest number of articles and books and to publish in the greatest number of journal titles, from the 1990s to the present time we see a wider range of professionals in print. These now include social workers, therapists, chaplains, and other allied health professionals involved in hospital, hospice and community end-of-life care, with a small but definite contribution from alternative and complementary therapists.

Professionally identified patient needs

The results we report here are based upon a content analysis of a selected sub-sample of 64 texts. We found that professionals identify a wide range of needs for people with cancer at the end of life. We grouped these under eight headings: pain and symptom control; information needs; emotional needs; psychological and therapeutic needs; spiritual needs; practical needs; needs from professional practice; and principles of meeting patient needs. As we might expect,

professionals recognised the need for patients to have relief from pain, suffering and symptoms as paramount. For example: 'Mr Zimmer need not die in agony. For most terminally ill patients, pain relief is possible. Yet pain remains a primary concern of these patients and their families' (9) [nurse, 2002]. Pain and symptom control are often the focus of the texts and contributions on these are clearly written to add to professional debates about the most effective treatments. Case-studies are used to illustrate examples where professionals had experienced particular practical, ethical or medical difficulties in controlling pain or easing symptoms.

It was, however, surprising that the professional writings in the sub-sample placed considerable emphasis upon identifying and meeting patients' psychological and therapeutic needs. This is more evident in the material written in the last 15 years than in the earlier accounts. The psychological needs of cancer patients at the end of life are orientated towards helping them to find meaning in death (and thus life). For example:

Jim Brown ... was a man with many good memories, as well as unresolved issues, from the past. Peter Pannett (social worker) has to weigh up whether to take risks that could have disturbed his clients emotional and physical well-being in order to help him die in peace (10) [social worker, 1998].

Palliative care professionals write about the need for patients to accept their approaching 'journey' as one in which they can still live life and develop the self. There is a recurrent emphasis upon the role of professionals in recognising patients' psychological needs regarding any conflict with the self and/or significant others (family, friends, partners, children) so that 'resolution' (usually through 'talking' therapies such as counselling) can occur and the patient can have a peaceful death.

The importance of paying attention to the individual requirements of the cancer patient is a core theme in the over-arching values and approaches to meeting patients' needs which the professionals identify in the sub-sample. Our content analysis found that professionals write particularly forcefully about the need for patient autonomy, choice and control, access to information and full participation in decision-making around patient care. For example:

Patients who are confronted with the autonomy/paternalism dichotomy are often unable to verbalise their needs or wants to their doctors, either because they are intimidated by the doctors' perceived power, or because the doctors lack the time to listen to their concerns. Nurses, however, as patients' advocates, are ideally positioned to assist the patients and their families to clarify their needs and desires (11) [nurse, 2001].

In the remaining sections, some of these issues are explored further using data from the in-depth thematic interpretative analysis of the sub-sample.

Professional expectations about the needs of the dying cancer patient

Social scientists have observed the way in which society and the professionals who work in hospices and palliative care organisations have constructed a purposeful ideology of a 'good death' (1,2). Evidence from the sub-sample of professional writings on caring for people with advanced cancer suggests that the 'good death' is a powerful norm which influences palliative care professionals. While some authors recognise that the good death may not always be possible, it is apparent from the texts that this is an ideal that professional carers continue to pursue. For example, physicians writing in the *British Medical Journal* state: 'In palliative care we aim to provide good symptom control and ultimately a good death' (12).

However, our interpretative analysis of the sub-sample indicates that professionals may have fixed expectations about the ways in which patients with cancer should behave at the end of life and are, in their writings, promoting normative ideals not simply of a 'good death' but of a 'good dying patient'. Our interpretation suggests that the ideal of the 'good dying patient' is particularly strong in two areas – the management and containment of emotion, and the maintenance of choice and control at the end of life.

Managed and contained emotion

The texts we analysed show that professionals, when writing about their experiences of caring for people with cancer at the end of life, may believe that patients are better prepared for death if they display emotions which are contained and controlled, such as quietness and peacefulness rather than anger or frustration. This is demonstrated in the following extracts:

...gave me immense respect for this man who was victim to such a dreadful disease. His quiet dignity and fortitude were inspiring and humbling (13) [nurse, 1998].

When I asked him why he got so angry, he replied that it was just him. When I asked if he would like to work on this issue, he replied 'asking me to not be angry would be like asking you not to worry' (14) [social worker, 2003].

Terry (mother) quietly asked if she could go back to Jane's (dying daughter) room. We thanked her for the privilege of sitting with her in silence, and we all shared with her our admiration for her courage in making such a difficult decision (15) [physician, 2001].

These extracts suggest that professionals may expect patients (and family members) to manage their emotions so that they are displayed in a restricted manner at the end of life. This subtle norm of equating emotional ‘containment’ with a ‘good dying patient’ is illustrated through different types of professional writing. There are narratives which recount professional experiences of exemplary cases – the quiet, dignified, undemanding, accepting patient – alongside writings about experiences of the ‘problematic’ cases which mark out as ‘deviant’ the patients who are angry, uncontained, unresolved, or ‘in denial’.

Perhaps the pertinent question is whether the ‘excessive’, unhindered display of emotion from patients and their relatives is more psychologically and emotionally demanding for palliative care professionals? Such professionals work in challenging circumstances and it may be that, in an attempt to develop working practices that can be sustained, the ideal of an emotionally ‘self-managed’ patient makes sense.

Maintaining choice and control at the end of life

Our analysis of the sub-sample of writings demonstrates that professionals place a high importance on patient control, choice, decision-making and the provision of information in end-of-life care:

Eleanor showed that she had a clear idea of which factors affected her quality of life. She wanted full control of her life at this time. Information about her cancer helped her with decisions about how she wanted to live it (16) [nurse, 1997].

I only had 2 weeks to come to know her, and new facets of her personality opened up even in the last couple of days. She was in control to the end, and she had her sense of humour to the end (17) [physician, 1999].

Joe had always been independent...Joe was not going to let this cancer beat him. Now that he knows the end of his life is near, Joe still wants some control in his life(18) [nurse, 2001].

As the above extracts indicate, palliative care professionals, in the sub-sample writings, seem to be putting a premium upon individual control and choice in providing care for the dying cancer patient. Individual notions of autonomy, choice and control are often discussed as ethical principles which guide professional practice. The difficulty with this emphasis is that it may be producing an absolute and fixed way to approach providing care for people at the end of life. In other words, it may fail to allow room for the notion that control and choice are not paramount to all people as they face death.

In addition, our interpretation suggests that the prominence given to choice and control may be creating a norm

which reflects the ways in which people from more privileged social and economic circumstances would like their lives to end. The ideal of control and choice as central to providing appropriate palliative care is more likely to ‘fit’ with people from social positions of advantage and for whom exercising control has been part of everyday life – where to live, work, holiday; what to eat; where to send children to school. It may be that a more passive and fatalistic approach to dying is more culturally appropriate to people who are from resource-poor circumstances because it reflects more accurately their experience – that with few resources they have less control over their lives. In fact, Richard Lamerton in his book *East End Doc* makes the interesting connection between social positioning, choice and the experience of dying:

Elegant professional men, accustomed to being their own masters, often find the prospect of a patient dying, or being a patient themselves, alarming. The loss of control involved with incurable illness and dying can be its most frightening aspect (19) [physician, 1986].

Professional–patient relationship

The patient–professional relationship has been recognised as a contentious issue in health care. Patient autonomy and professional control are often contrasted as two incompatible positions. Patient autonomy relies on a range of factors that are outside the control of the patient, and professional control is influenced as much by the professional’s personal belief as professional guidance (20). Although there have been significant changes from palliative care professionals within recent years, patient choice still has to be negotiated within the powerful framework of medicine. McNamara’s (2) work has illustrated the way that patient autonomy at the end of life ‘is always tempered by other aspects of the biomedical, organisational and moral culture of the institutions in which people die’ (p.106).

The professional–patient relationship was central to the sub-sampled writings we analysed. It was acknowledged as a key mechanism in meeting the needs of people with cancer at the end of life. Consequently, a great deal of the sub-sampled literature was devoted to discussing and reflecting upon the difficulties in, and sensitivities required for, communicating with patients. For example, Henteleff, a physician, summarises lessons learnt from a difficult case:

...it is apparent that informing is not a value-free, objective procedure grounded in ‘biomedical’ science; besides honesty about diagnosis and prognosis, there should be honest awareness of bias (21).

Our analysis suggests that the professional–patient relationship was commonly presented in the sub-sample

texts as though the patient and professional were on an equal footing. The problems patients may have in negotiating this interaction were seldom discussed:

I felt, as I often do in such circumstances, that we met, not just as doctor and patient, but as one human being face to face with another (22) [physician, 2002].

As this extract suggests, the palliative care professionals rarely acknowledge that they are in a position of authority in relation to patients, and have control over the type of care patients receive. In this sense, they are in a position of power. Consequently, it was unusual to find the author reflecting on the difficulties the patient may have in negotiating the patient–professional relationship because of the power differential between the two parties. In addition, the majority of authors appear not to recognise that as professionals they may also be susceptible to social stereotyping and bias (such as racism, sexism, homophobia, class-based judgements) in their interactions with patients.

Professional homogenisation of patient needs

The links between social inequality and mortality differentials has a long history of documentation in the UK. There has been a multitude of research which demonstrates that how well and how long a person lives is powerfully shaped by social position, such as social class, age, ethnicity, sexuality, and gender (23). Furthermore, there is evidence to suggest that in the process of dying, these differentials remain significant (see 24,25).

It was, therefore, of note that professional authors rarely discuss the implications of social inequalities and diversity for meeting patients' needs and views at the end of life. There are some case-studies which describe patients needing particular attention because of their social circumstances (for example, homelessness, a husband in prison, a mother rejecting the patient's [homo]sexuality, the experience of racism, unemployment). However, these cases are written about apparently 'unusual' individual patients and are not, in the main, used to reflect on the wider impact of social inequalities on professional practice.

This raises questions about why the palliative care professionals' texts in this sub-sample did not have inequality and difference as an integral aspect of their reflections on caring for patients with advanced cancer. Our analysis suggests this has less to do with an unwillingness on the part of health professionals to engage with such issues and is more related to the history and development of palliative care. There are a number of interconnected reasons as to why these issues of inequality and diversity are pushed to the margins of these writings.

First, there is a tendency for palliative care to be seen as humanitarian work (death happens to us all). By such means diversity and inequality are glossed over and the

patient tends to be homogenised. We also identified a propensity in some of the texts for professionals to universalise their own end-of-life preferences to all patients. For example:

I told patients they were going to die, wives what to expect in the final days of their husbands' lives and children that their mother or father had just died. I did not find the work difficult, as in each situation I was able to reflect on how I would want to be spoken to if this were happening to me, how I would want to be nursed if I were lying in that bed, how I would want someone to break bad news to me if they had to (26) [nurse, 2002].

In a few words, I would like this part of my life, an important part, during my last days, to remain mine; still my responsibility and dependent upon my decisions... This is what I believe, and this is more or less what my colleagues believe, and try to carry out in looking after over 400 patients each year (27) [physician, 2000].

Second, the importance of paying attention to the individual means psychological needs become the primary focus; as a result, the impact of social inequalities and diversity on patient needs is pushed into the background. Patient diversity is reduced to personality traits, to coping mechanisms or to psychiatric morbidity and the implications of social inequality and diversity to patient care are rarely acknowledged. For example:

While the principles are clear and universally applicable, each patient is unique and must be responded to in an individual way (28) [nurse, 1989].

...patients with cancer, although they share a similar traumatic experience, do not constitute a homogenous population. Among them may be patients with a psychiatric history (29) [art therapist, 1998].

There was no sustained discussion about the ways in which issues – such as social class, gender, ethnicity, sexuality, family diversity, age – would impact upon professionals meeting the needs of people with cancer at the end of life. The marginalisation of in-depth discussion regarding patient inequality and diversity is indeed a worrying finding because what it suggests is that palliative care professionals may be not be sensitised adequately to the needs and views of people with cancer approaching death who are in less privileged positions, who may be at the margins of mainstream society, or who are least able to secure a 'good death'.

Service-user perspectives on professional writings

Comments from service users who read a small sub-set of the texts, suggest professionals' writings may over-emphasise the ability of the professional to meet patient needs suc-

cessfully. In particular, there were views expressed about the appropriateness of palliative care professionals' attempts to meet 'perceived' psychological needs. In the professional writings, all patients are presumed to have psychological needs, and ones which should be met by health practitioners. The users' observations suggest that this may not always be the case. As one service user stated after reading some of the texts:

I feel that it needs to be remembered that some people whether patients or family members will avoid making a close relationship with the nurses. Reasons could be many... Nurses must be able to sense when a patient is willing and wants to share confidences and when such intimacy would be an anathema to him or her.

The issues where the disparity between the professional writings and service users' experiences seemed greatest are: pain and symptom relief; the importance of listening to the patient (communication); how diversity and inequality may mediate the expression and recognition of needs; respecting patient's wishes (patient autonomy); and place of death.

Professional identities and their impact on interpreting patient need

The in-depth analysis of the sub-sampled literature suggests that maintaining a professional identity may be an important factor in motivating professionals to write. It may be that writing is connected to the need for palliative care workers to 'cement' and authenticate their professional identity by reflecting on experiences and through contributing to professional discussions and debates on good practice. The importance of a robust 'caring' professional identity is highlighted in the following extracts:

Despite the tensions that have formed over time, Mr M is one of those patients that make you think 'this is why I went into medicine. This is what it feels like to be a doctor.' The whole process is very rewarding (30) [physician, 2001].

I also recognized my desire to 'do' in the midst of suffering. I wondered what I could say to connect with T, and what I could do to 'help' him. The limit of what I can control seems paled by what is totally out of my control (31) [nurse, 2002].

I kept trying to initiate a conversation and feeling less and less certain as to my usefulness in being there (32) [social worker, 2002].

As these extracts suggest, professionals caring for patients at the end of life place a great deal of importance on being able to carry out their professional duties and in establishing a feeling that they are helping individuals. The

quotes also indicate that a degree of anxiety may arise where the professional role/identity is compromised. What might this mean for cancer patients at the end of life? One of the potential implications is that in maintaining a professional caring identity which relies on the fulfilment of a desire to feel valuable to patients, professionals' own needs may influence the ways in which patients needs are interpreted. For example the 'weight' of medicine on the shoulders of a physician is highlighted in the following extract. Saunders *et al.* state:

To 'do nothing' requires enormous restraint by a doctor, and he or she needs to be sure that they are informed of all the relevant information... Doctors are usually expected to intervene, not only by the patient and family but also by nurses and other doctors (12) [physician, 2003].

In order to improve our understanding of how patients' needs and views are met, we require a better understanding and acknowledgement of professional needs that emerge when caring for people at the end of life.

CONCLUSIONS

We found professionals identify a wide range of needs for people with cancer at the end of life, from symptom control and practical needs, to spiritual and emotional support. In particular, we found that the professional literature places a great deal of importance on providing individualised care for patients, emphasising concepts such as autonomy, choice and control. At the same time, there has been a growing emphasis on individual psychological care and the 'need' for therapeutic intervention.

However, our analysis indicates that professionals write about patients' needs in complex and contradictory ways. On the one hand, the writings stress the importance of patient autonomy, choice and control, and the recognition of patient need. On the other, they suggest that professionals may have a fixed or narrow interpretation of how patients' needs should be met; for example, that patients are better prepared for death if their display of emotions is contained and controlled, marked by quietness and peacefulness rather than anger or frustration.

We also found that the professionals' writings do not consider, in the main, the impact of social inequalities or diversity on patients and patient care. Rather, people with advanced cancer approaching death appear to be 'homogenised' within these writings. In other words, differences relating to social class, gender, ethnicity, age, sexuality and disability are rarely deemed to be significant issues for consideration in meeting the needs of patients. We suggest that social variation among patients is likely to mean they have diverse needs, and this is an important area for future research.

In addition, the writings suggest that professionals do not fully appreciate that patients may have difficulties in negotiating relationships with professionals and in expressing their needs. As the service user 'readers' comments suggest, there may be a gap between what professionals write about patient need, and patients' experiences of their needs being met by professionals.

Our systematic 'ethnographic' review of professionals' writings provides a new and different type of evidence on the needs and views of cancer patients at the end of life. Our analysis suggests that while professionals' writings support patient autonomy, control and choice, their understanding of these are partial, and narrow expectations may place limits on the ways in which patients with advanced cancer approach their end of life. Professional writings of this kind within the palliative care paradigm may be overly influenced by physician discourses, in spite of the increased contribution from other health professionals over the last two decades. Practice, policy and most importantly the care people with advanced cancer receive, are thus still firmly framed within biomedical culture and the social organisation of medicine, which struggles to acknowledge and meet the diversity of individual end of life needs.

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