



Queensland University of Technology
Brisbane Australia

This is the author's version of a work that was submitted/accepted for publication in the following source:

[Fox, Jennifer, Windsor, Carol, Connell, Shirley, & Yates, Patsy](#)
(2016)

The positioning of palliative care in acute care: A multiperspective qualitative study in the context of metastatic melanoma.

Palliative and Supportive Care, 14(03), pp. 259-268.

This file was downloaded from: <https://eprints.qut.edu.au/89081/>

© Copyright 2015 Cambridge University Press

Notice: *Changes introduced as a result of publishing processes such as copy-editing and formatting may not be reflected in this document. For a definitive version of this work, please refer to the published source:*

<https://doi.org/10.1017/S1478951515000917>

TITLE PAGE

a. Full Title

The positioning of palliative care in acute care: A multi perspective qualitative study in the context of metastatic melanoma

b. Names and affiliations of all authors

Jennifer Fox, PH.D, RN, School of Nursing, Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Australia

Carol Windsor, PH.D, RN, School of Nursing, Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Australia

Shirley Connell, PH.D, B HlthSc (Hons), School of Nursing, Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Australia

Patsy Yates, PH.D, RN, School of Nursing, Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Australia

c. Corresponding author

Jennifer Fox

Mailing address

Institute of Health and Biomedical Innovation
Queensland University of Technology
60 Musk Avenue
Kelvin Grove, 4059, Queensland, Australia

Email address

jennifer.fox@qut.edu.au

Telephone

d. Address for reprint requests

As above

e. Short title

The positioning of palliative care in acute care

f. Number pages

Manuscript: 29 pages

Tables: 0 pages

Figures: 0 pages

ABSTRACT AND KEYWORDS PAGE

a. Full Title

The positioning of palliative care in acute care: A multi perspective qualitative study in the context of metastatic melanoma

b. Abstract

Objective: The positioning and meaning of palliative care within the health system lacks clarity which adds a level of complexity to the process of transition to palliative care. This study explores the transition to palliative care process in the acute care context of metastatic melanoma.

Method: A theoretical framework drawing on interpretive and critical traditions informs the research. The pragmatism of symbolic interactionism and the critical theory of Habermas brought a broad orientation to the research. The integration of the theoretical framework and grounded theory methods facilitated data generation and analysis of 29 interviews with patients, family carers and health professionals.

Results: The key analytical findings depict a scope of palliative care that was uncertain for users of the system and for those working within the system. Becoming 'palliative' is not a defined event and nor is there unanimity around referral to a palliative care service. As such, ambiguity and tension contributed to difficulties in negotiating the transition to palliative care.

Significance of Results: The findings point to uncertainty around scopes of practice in the transition to palliative care. The challenge in the transition process lies in achieving greater coherency in care within an increasingly specialised health care system. The findings may not only inform those within a metastatic melanoma context but may contribute more broadly to palliative practices within the acute care setting.

KEYWORDS: Palliative, Acute, Specialisation, Melanoma, Transition

INTRODUCTION

In recent years palliative care has become an important component of the cancer trajectory with a number of studies identifying the benefits of early referral to this form of care (Bakitas, et al., 2009; Higginson & Evans, 2010; Temel et al, 2010; Zimmerman et al., 2014). Nonetheless, the transition to palliative care is often poorly negotiated and health professionals face substantial challenges in determining the appropriate time for referral (Johnson et al., 2011a; Broom, Kirby, Good, Wootton & Adams, 2012; Wentlandt et al., 2012; Ramchandran & von Roenn, 2013). Hence, while there has been significant growth of palliative care services, the extent of use of this specialty service varies considerably (Hardy, Maresco-Pennisi, Gilshenan & Yates, 2008; Johnson et al, 2008; Campbell et al., 2010; Wentlandt et al., 2012). To date there has been little in-depth exploration of factors that influence the positioning of palliative care in the acute care sector.

Although palliative care is relevant to all disease types, the development of a relationship between palliation and oncology underpins the current position of palliative care. In the 1950s, all treatments for advanced cancer were very much palliative and while treatments made it possible to prolong the lives of patients there were questions around the point at which these treatments should cease. Two opposing views evolved in the treatment of cancer, one where death was seen as a largely natural process that ended pain and suffering and the other where death was something to be resisted with medical intervention. As Rynearson (1959) wrote at the time:

Despite all the impressive ministrations science can provide, he [sic] [the patient] is still dying and is still suffering. There simply is no other treatment to apply now, for there is no treatment for death. (*p.* 85).

As new chemical treatments were developed that temporarily halted or slowed the growth of some forms of cancer, issues around ongoing treatment arose more frequently and

personal, medical and research interests became more intertwined. It was suggested that successful treatments could only come from doctors who do too much when the odds appear overwhelming rather than those who do too little (Karnofsky, 1960). Thus ongoing aggressive treatment avoided the defeatism that was perceived a major barrier to the advancement of medical knowledge (Karnofsky, 1962). This approach was associated with the appearance of a culture of experimentation and clinical trials that saw the establishment of medical oncology as a specialty in the US in 1973, the formation of the European Society of Medical Oncologists in 1975 and the establishment of the Medical Oncological Group of Australia in 1977 (Casali, 2011; Baszanger, 2012; Medical Oncology Group of Australia, 2013).

By the 1970s and 1980s, a cure for cancer was deemed possible which gave rise to the public rhetoric of scientific progress and an imminent cure. As a result, the issue of treatment withdrawal was put aside (Holleb, 1972). Where cancer was constructed as a disease that could be controlled, death was constructed as the enemy and symbolic of failure (Baszanger, 2012). Yet, such views prompted recognition of the need for an alternative for those dying patients for whom physicians could do no more and for those dying in a highly medicalised and treatment focused environment (Clark, 2007). Palliation of impending death was left to those working within the philosophy and practice of palliative care and the issue was then the point at which definitive treatment of a patient with advanced cancer be stopped and the patient referred to hospice or palliative care (Potter, 1980). Yet oncologists such as Krakoff (1979) expressed the concern that:

In our rush to provide for the dying, we may neglect those who may not be quite ready to die...in seeking "death with dignity" we may overlook treatable disease and provide patients with the indignity of premature death.
(p. 108–109)

Ethical and moral issues were at play but so too were the boundaries and mandate of oncology (Baszanger, 2012). This issue is evident today where ongoing advances in therapies

and the redefining of cancer as a chronic disease have blurred boundaries between active treatment and terminal phases. While “to palliate” means “to make (a disease or its symptoms) less severe without removing the cause” (Oxford Dictionaries, 2013), in the world of cancer care “to palliate” means something more complex than this definition implies. When it is used in the context of palliative care it may be understood as a philosophy of care, an institution of care, or a service provided by a group of health professionals with specific knowledge and expertise.

This paper presents findings from the first author’s doctoral research that explored how the concept of transition to palliative care was constructed and negotiated in the acute care setting of metastatic melanoma. Melanoma is a form of skin cancer and is one of the most aggressive of human malignancies. In Australia, in 2012, 1,515 people died from melanoma (Australian Government, 2014). The incidence of melanoma in this country is increasing more rapidly than that of any other cancer and it is predicted that by 2020 it will be the third most commonly diagnosed cancer in Australia (Australian Institute of Health and Welfare (AIHW), 2012). When detected early and the disease is superficial melanoma has a five-year relative survival rate of 95% (AIHW, 2010); however this rate falls to below 10% for metastatic disease with the median survival being less than 12 months (Hodi et al., 2010; Thompson, Scolyer, & Kefford, 2009).

The Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand recognises that palliative care referrals are appropriate at any stage of illness and recommends that “referral for palliative care be based on the needs of the patient and family, not just the stage of disease” (Australian Cancer Network Melanoma Guidelines Revision Working Party, 2008). Despite these recommendations many cancer clinics and oncologists have not incorporated these standards into routine practice and this has implications for timely

referrals (Hui et al., 2010; Broom Kirby, Good, Wootton, & Adams, 2012; Wentlandt et al., 2012). This research applied a critical lens to the transition to palliative care process to generate insight into the relationship between the positioning and practice of palliative care in the acute care context of metastatic melanoma. The paper focuses on the lack of clarity around the meaning of palliative care and confusion around its role within the acute health care system. Other aspects of the findings of the study will be reported elsewhere.

METHOD

Study Design and Theoretical Framework

The research drew on interpretive and critical knowledge informed by the works of Mead, Blumer and Habermas. The pragmatism of symbolic interactionism (Mead, 1934; Blumer, 1969) and the critical theory of Habermas (1984, 1987) provided a broad orientation that gave focus to both the micro level of interpretation and the structural level within which the transition to palliative care was constructed and negotiated. The Mead and Blumer focus on the dynamics of interaction provided insight into the ways in which meanings were constructed. In extending this framework, Habermas' concepts of system and lifeworld were germane where the system represents technical scientific rationality and the lifeworld denotes the everyday world that humans share with others. Hence, these latter ideas extended the analysis from human action to the systemic and structural levels. The critical theoretical frame also countered any tendency for an over-reliance on the words of participants at the expense of examining the whole of which they were a part (Alvesson & Sköldbberg, 2009).

The methods were drawn from the interpretive works of Glaser and Strauss (1967) and Charmaz (2006, 2009, 2011a, 2011b). Although traditionally associated with symbolic interactionism, the methods align with the approach adopted in this research. The theoretical frame recognises the researcher's active role in shaping data and analysis and the constraints

that historical, social and situational conditions impose upon actions (Charmaz, 2011a). Grounded theory methods have also become generalised, reconstructed and contested and as Charmaz (2011b) has acknowledged, can be used in flexible ways. The flexibility of the methods allowed for multiple perspectives to be explored, alternative interpretations to be generated and the analysis of these within the context of broader structures. The result was a critical understanding rather than a simple description of the experience.

Participants

Patients and family carers were recruited through a major public hospital in Queensland, Australia and from a melanoma advocacy and support group. Health professionals were recruited through the same public hospital. The hospital has a specialist melanoma clinic and a consulting palliative care service. Ethical clearance to conduct the study was obtained from the Human Research Ethics Committees of the major public hospital and the Queensland University of Technology.

In recruiting patients it was recognised that there were unique challenges with the research as patients may have been unwell, emotionally fragile and fatigued (White & Hardy, 2010). While the researcher was cognisant of this issue patients were willing to participate. Those taking part perceived that the interviews allowed them to make a contribution to society and articulated the benefit of voicing concerns.

Patient participants had been diagnosed with metastatic melanoma and at the time of interview half of those recruited had been referred to palliative care. The total sample consisted of eight patients, eight family carers and 13 health professionals. The age distribution of patient participants was 21-30 years (n=1); 31-40 years (n=3); 51-60 years

(n=2); and 61-70 years (n=2). Six patient participants were male. The median time from diagnosis of metastatic melanoma to interview was seven months (range 1-72 months).

Of the eight family carers interviewed, seven were patients' spouses and one was a patient's daughter. Patients and carers were interviewed separately. Health professional participants comprised consultants, registrars, nurses and allied health professionals. Of these, eight were from cancer services (hereafter referred to as non-palliative care health professionals) and five were from palliative care services (hereafter referred to as palliative care health professionals).

Data Collection

Data were generated through semi-structured interviews. On average patient interviews were of 64 minutes duration (range 31-88 minutes), while carer interviews averaged 68 minutes (range 37-108 minutes). Interviews with health professionals averaged 50 minutes (range 35-70 minutes). Interviews were audio recorded and transcribed verbatim. Interview questions were broadly posed, for example: *Tell me of your experience with metastatic melanoma*. The initial interviews were largely unstructured to allow for full exploration of the study phenomenon.

Data Analysis

Following the completion of each interview, noteworthy events and initial analytical thoughts and reflections were memoed. The disaggregation and analysis of data was accomplished through initial and focused coding. The constant comparative method was also used to shift the analysis from the empirical to the theoretical level (Glaser, 1978; Charmaz, 2006). During this phase a critical lens was applied to explore implicit meanings and actions and to thus identify directions to pursue. The first author questioned tacit assumptions,

explicated actions and meanings, compared data with data, and identified gaps in the data (Charmaz, 2006). In addition, the first author's supervisors reviewed the data in order to discuss potential concepts and processes that informed subsequent data collection and analysis. This latter process was not for validation purposes but rather to extend the analytical conversation, encourage further reflexivity, and promote deeper analysis.

FINDINGS

A significant insight of the phenomenon studied was the way in which palliative care was constructed and positioned in the acute care setting. A starting theoretical premise was that the construction of meaning is negotiated through an ongoing interpretive process that occurs during interactions and over a period of time (Blumer, 1969). As such it was necessary to first interpret the meanings ascribed to palliative care. This included exploring what it meant to be referred to palliative care. Thus the construction and positioning of palliative care reflected the histories, cultures and experiences of participants rather than an objective truth that sat apart from participants.

Constructing palliative care

Managing physical symptoms

The meaning assigned to palliative care by patient participants was more often focused on physical care with little or no reference to the psychosocial and spiritual dimensions. This contrasts with the generally accepted association between palliative and holistic care. More specifically, the expertise of the palliative care team in the acute sector was conceived of in terms of technical strategies for symptom relief. Patient and family carers equated palliative care with treatment such as medication for pain:

Pain relief has probably been the main thing that they have done for me, that I think is a main part of palliative care...pain management. Patient H05

I think palliative care; my interpretation is controlling pain, not really doing medical procedures, but making you as comfortable as possible to the end I guess. Patient G05

Thus, in the hierarchy of care, medical intervention appeared more prominent than the psychological, social or spiritual components as described by another participant:

Palliative care has so far been more concerned, and I don't know, maybe this is their sole role, but they seem to be more concerned about John's (husband pseudonym) symptoms and ensuring that he has medications to alleviate that. No one has really spoken to us about any other support services. Carer H04

A palliative care nurse posed palliative practice as philosophically concerned with care beyond management of physical symptoms:

In palliative care you learn that quality of life is more important or we're more about quality of life than quantity, whereas I think a lot of people who go into nursing and medicine have that view of 'life at any cost'. I know that's what was instilled in me when I was training as a nurse, that any kind of life is better than death and it's a completely different shift in consciousness and awareness when you start doing palliative care. It's just a different approach I guess. Palliative care health professional 06

Yet an oncologist was reluctant to refer to palliative care in the absence of symptoms:

When they come to us for the most part it is palliative; palliative chemotherapy because people with stage four melanoma are not curative... There are a lot of patients who actually don't want to hear palliative care and no matter what some of my palliative care colleagues think, there are patients who do not want to see them and it's very hard to force someone to meet someone they don't want to see and especially if they've got no symptoms. Non-palliative care health professional 12

The approach depicted above underlines the ambiguity and tension in the construction of palliative care. Where some described a role that included the emotional and physical aspects of care, for others, palliative care was predominately about physical concerns.

Managing end of life

The role of palliative care was recognised by patients, carers and health professionals as confined to the management of end-of-life issues. It was about what could be done when there were no options. It was overtly associated with end-of-life care. Patients and family carers sustained this view as a family carer noted:

I guess my understanding of palliative care was that they were mostly about end-of-life care and that they were more about providing medications to alleviate symptoms... and that it was more the very end of life type thing.
Carer H04

Another patient expressed similarly:

Palliative means there is no formal medical treatment that is available to you. So you are just really living with the disease. It is a matter of ameliorating all the things, the consequences of it, in a sense, making life bearable... You are at the last stage of your journey, the really last stage of your journey. Patient G06

The palliative care health professional participants reinforced the view that this form of care signified the end as indicated in the following:

I think people... feel like they're being given a choice between life and death really. It's not good death versus bad death; life equals pursuing treatments and saying yes to whatever is offered and dying is accepting palliative care.
Palliative care health professional 09

Oncologists and those in the treating team also made reference to a reluctance to refer because of an association with end-of-life care:

It's hard because people have this mentality [that] palliative care means it's the end of life... so when you actually start talking to a patient about their treatments and say, "we're going to get you to see palliative care", all of a sudden they've got the message, well I'm going to die. Non-palliative care health professional 03

Even where an oncologist acknowledged the benefits of palliative care there was an implicit assumption that such care was end-of-life:

There's always an initial concern about the word palliative care meaning that the patient is on their way out and I try to always defuse that and say, well, look no I'm not sending you on a road to your grave. I'm sending you

to see someone who can help you and improve your quality of life during the terminal stages of your disease. Non-palliative care health professional 01

Health professionals may recognise the benefits of palliative care but reinforce the belief that such care means nearing the end. This positions palliative care in the later stages of the disease trajectory where treatment is no longer impacting on disease progression.

Referral to palliative care

A palliative care referral was associated with a number of antecedents. These included the preparedness of patient and family, the readiness of health professional to refer and the ability of the health system to respond.

Patient and family preparedness

Palliative care was often associated with more serious disease progression:

We were set up with a palliative care team, pretty much straight away, so I guess that was part of, I guess knowing early on, that something was going to happen. I am guessing they don't do that type of thing unless it is that serious. Patient H03

There was an acknowledgement of the benefits of an earlier referral to palliative care and yet also apprehension or fear around the implications of such a referral as noted by one carer:

You don't want to be needing them when you are on death's door, so how early is too early to meet palliative care. So it's a hard thing to try and balance, you don't want to scare people, but you don't want them to find out too late either. Carer G03

As such, although the benefits of palliative care may be recognised by patients, carers and health professionals, in some instances the referral is delayed until the patient and family are deemed 'ready' for referral.

Health professional readiness to refer

Palliative care is a referral dependent specialty and oncologists are therefore the gatekeepers in the transition process. Oncologists tend to refer late and often at a time of crisis as indicated by a health professional:

I think sometimes there is a little bit of reluctance on the part of the oncologist to refer to palliative care because they still see the patient in active treatment even though they may be deteriorating and not managing well with the treatment and because of that will not refer them until crisis time. Non-palliative care health professional 08

A further complexity in the referral process is the perception of oncologists that they have the expert knowledge required to manage the needs of patients:

There would be a lot of oncologists that won't refer on to palliative care, they will just hold onto patients... They see themselves as physicians and that they can manage all of the patient's needs even though they're probably overworked, have too many patients on treatment... and probably can't really attend to those patient's specific needs. Non-palliative care health professional 08

Referral between specialisations thus was also an issue for health professionals:

There are political issues involved in referring patients from one professional to another. I personally don't have a problem with it but there are some other colleagues... who do have problems with that issue. Non-palliative care health professional 01

The interrelationship of specialized knowledge and the physical location of specialties was a significant factor in the transition to palliative care process.

Health system's ability to respond

The organisation of a physical separation of oncology and palliative care services impacted the way in which palliative care was able to respond as evident in the following excerpt:

So oncology is on the ground floor and second floor, it's all together. Then the palliative care office is on the fifth floor tucked away from everybody and everything. I mean that in itself speaks volumes to me of the perception that palliative care owns that little office upstairs on the fifth floor away

from everybody. It is nowhere near the oncology services ... it would make a lot of sense to have palliative care working side by side with oncology, within the oncology department. Palliative care health professional 09

The physical separation of palliative care from oncology, although unsatisfactory from a palliative care service perspective, might be appropriate for an oncology unit with a focus on clinical trials as implied in the following:

The nature of melanoma patients I've seen in the last couple of years is that they are on these trials... so the oncologist is the main person in charge. I'm not saying that they don't give a referral to palliative care but I think, not all oncologists but some, really dig their heels in and don't refer as early as they could. Non-palliative care health professional 04

Comprehensive coordination and planning to address physical, emotional and spiritual aspects of care takes time. As noted in the following excerpts time constraints were an issue for oncologists:

I (oncologist) guess a lot of palliative care is actually having the time to sit down with the patients and I certainly don't have that time to sit down with patients and I know the medical oncologists don't. Non-palliative care health professional 08

Dr P (oncologist) has said to Dr N (palliative care consultant) "we haven't got time to talk about decisions, we just make them". They (oncologists) have not got time. They've got so many people coming through those clinics. Palliative care health professional 11

While referral to a palliative care physician may be a more effective use of an organisation's workforce the timing of a referral in this research remained an issue. Where oncologists were gatekeepers of referrals, conflicts of interest arose because of the complex professional, cultural and social issues noted above.

Positioning palliative care

The lack of clarity around the meaning of palliative care and the differing interpretations of the scope of this care was evident in an absence of consensus among professional groups

on the positioning of palliative care in the acute care setting. A treating clinician pointed to the complexity of referral to palliative care:

So I think referral to palliative care is based on not just the patient or their tumour characteristics, but on their treating physician and where they're being treated. It's a pretty complex number of issues that need to come together for that referral to take place. Non-palliative care health professional 08

The treating team struggled with referral to the service even though palliative care was considered an important phase in the disease trajectory. This was evident in the words of a treating clinician:

Once it reaches the phase of palliative care any other role I have is supportive and typically when I have my own patients that reach that point it's not unusual for me to keep seeing the patients as almost a social visit. It's as if I cut ties with them the patient sees "well that's it. That's the end of it all". Non-palliative care health professional 13

This in turn highlights the complexity around the positioning of palliative care as a medical specialty. Health professionals, including treating clinicians, may provide a palliative approach to care with referral to a specialist palliative care service dependent upon the judgment of individual clinicians. As such, not only do boundaries exist between palliative medicine and other medical specialties, but also between palliative medicine and a palliative approach to care.

DISCUSSION

The positioning of palliative care was a salient concept in the research findings. Becoming 'palliative' is not a defined event and nor is there certainty around referral to a palliative care service and yet it is a referral dependent specialty (Tieman et al., 2009). Furthermore, research concludes that much of the care offered to dying patients in acute care settings is routine and technological care, rather than individualised and contextual (Pincombe, Brown & McCutcheon, 2003; Parish et al., 2006; Willard & Luker, 2006;

Johnson, Paul, Girgis, Adams & Currow, 2011b). This is reinforced by Breitbart (2006) who asked palliative care clinicians what they saw as their goals. As Breitbart (2006) wrote:

The response was immediate, simple, clear, and emphatic. Overwhelmingly the palliative care clinicians saw their main goal and obligation as assuring that the patients under their care die receiving adequate pain and symptom control. Nothing more, nothing less. (p. 2)

When Breitbart (2006) posed questions to the clinicians about existential concerns and helping patients achieve a sense of life completion and acceptance of death the response was, “That’s not our job!” (p. 2). This was the work of the clergy. In some sense this response reflects the broad domain of palliative care. It also points to the limitations imposed by specialisation and the technical medical agenda within the acute care setting. Against this background, palliative care has largely been constructed as technical expertise in symptom management that in turn is equated with quality of life in end-of-life care.

Indeed, in this situation and using Habermas’s (1984) terminology, the technical scientific rationality of the system dominates while the patient’s lifeworld is of lesser concern. The lifeworld signifies the knowledge and way of life of patients and is based on communication, agreement and consensus (Habermas, 1984). Palliative care arose from the hospice movement that was situated in the lifeworld and was established in response to what was considered neglect for care of the dying. The philosophy of hospice care and subsequently palliative care includes the goals of enhancing quality of life, optimising function, helping with decision-making and providing opportunities for personal growth (Ferrell & Grant, 2014).

The above goals do not readily translate into the acute care setting. This setting rests on a body of expert medical knowledge that has been shaped by science and technology and strongly influenced by a system where an instrumental focus on successful treatment and an orientation towards the control of biological process dominates (Barry et al., 2001). Thus, the

difficulty in positioning palliative care reflects the tension between the institutionalisation of palliative care in the acute setting and the development of palliative care from its origins situated outside mainstream medicine.

Furthermore, there is decisional and clinical ambiguity because there is no predefined point in the course of a life limiting illness that marks the transition from curative to palliative care. A patient's clinical situation and psychological readiness, a health professional's knowledge, understanding, attitudes and preparedness and a system's ability to respond all form part of the complex construction of palliative care. The result is levels of uncertainty and differing and contradictory perspectives that characterise the transition to palliative care.

On a daily basis oncologists interact with patients who may benefit from a referral to palliative care and indeed there is the opportunity for earlier referral. As such, oncologists play a significant role in shaping the meaning of palliative care. Yet, despite a tendency for oncologists to agree that early referral to palliative care is desirable, studies consistently show that patients are referred late (Johnson et al., 2008; Wentlandt, et al., 2012; Hannon & Zimmermann, 2013).

Most patients are referred within 30 to 60 days prior to death and with many in the last days of life (Wentlandt et al., 2012). Furthermore, oncologists are reluctant to relinquish any aspect of care even where treatment is described as palliative. This may, in part, be a result of the curative culture of the hospital environment and the deeply embedded mission of physicians to heal patients (Horowitz et al., 2014). A generalised discomfort with death and dying and a concern by physicians that frank discussions of prognosis could reduce patient hope may also influence a late referral (Howie & Peppercorn, 2013).

Ideological, clinical, professional and practical issues thus perpetuate the dichotomy between guidelines supporting early palliative care referral and the reality of clinical practice (Hannon & Zimmerman, 2013). While referral to palliative care can offer patients the opportunity to define their goals and expectations for ongoing care this may also mean confronting the limitations of medical treatment and the reality that life is finite (Wright et al., 2008). The perception of palliative care as end-of-life care constructs cancer care as dichotomous; that is cure versus care. Health professionals may perceive discussion of end-of-life issues or referral to palliative care as an admission of failure to cure (Yabroff, Mandelblatt & Ingham, 2004).

As noted earlier, palliative care evolved out of the hospice movement. This development saw palliative care positioned on the periphery of mainstream health care. Proponents of palliative care sought to address this marginalisation with the recognition of palliative care as a medical specialty. The result has been an increasingly porous boundary between the two areas and at the same time greater ambiguity and uncertainty (Arber, 2007; Meghani, 2004).

In addressing the complexities around the positioning of palliative care there is a distinction between a palliative approach to be provided by all health professionals and palliative care that includes specialist palliative care providers. As Hibbert et al. (2003) note, the difficulty is in identifying where regular care ends and palliative care begins and this concept underscores the separateness of palliative care from everyday medical practice. Where a 'generalist' role is actively promoted positioning the expertise of palliative medicine and palliative care becomes problematic (Hibbert et al., 2003). The issue then is whether palliative care should be a part of the role of a medical specialist or integral to the roles of all health professionals.

Modern medicine has evolved to a point where scientific expertise and the instrumental technical system dominate to the extent that the communicative practices that are essential in everyday life are often absent from the medical encounter. Habermas (1987, p. 395) suggests that social conflicts “arise along the seams between system and lifeworld”. It is within this space that palliative care tenuously sits and boundaries are drawn between the technical system and the communicative practices of the lifeworld. Indeed, the colonisation of the lifeworld has seen palliative care move from everyday life to a position where it is administered through healthcare institutions and the lens of expert medical science.

CONCLUSION

Palliative care is a modern specialty that seeks to be defined in terms of the healthcare continuum. Although palliative care is perceived as a specialty and part of a multi-disciplinary approach at the early stage of care of a patient with terminal illness, the difficulty lies in negotiating the transition to palliative care. Diverse philosophical views of health care and a hierarchy of knowledge underpinned by specialisation generate tensions and the expected seamless continuum of care through the disease trajectory does not exist.

There is no definitive position for palliative care in a metastatic melanoma disease trajectory. The different perspectives of patients, carers and health professional groups add complexity to the transition to palliative care. The implication for patients and families is an experience of uncertainty and confusion in negotiating the health system. The challenge in the transition process lies in achieving greater coherency in care within an increasingly specialised health care system.

A strength of the study is that it drew on the experiences of a diverse group of stakeholders to generate insight into the complexity of the process of transition to palliative care. Although the setting of a single site for recruitment made the study feasible in terms of resources and time, this may be considered a limitation of the study. However, the purpose of the study was not to generalise but rather to generate insight into the practices and understandings around the construction and positioning of palliative care. Thus while the findings from this research may not be an exact fit with other sites, it is likely that there will be understandings and theoretical insights that resonate across other healthcare settings and other cancer-site-specific cohorts. Research within other settings would extend the understanding developed here.

ACKNOWLEDGMENTS

We are grateful to the patient and carer participants who gave generously of their time under circumstances of severe illness and uncertain futures. Additionally, the willingness and trust of the health professionals who shared their experiences of caring for patients and families with metastatic melanoma was greatly appreciated. An Australian Postgraduate Award Scholarship supported the study. The study was part of the doctorate research of the main author who would like to especially thank her PhD thesis supervisors, Patsy Yates, Carol Windsor and Shirley Connell.

REFERENCES

Alvesson, M., & Sköldberg, K. (2009). *Reflexive methodology: New vistas for qualitative research*. London, UK: Sage

Arber, A. (2007). “Pain talk” in hospice and palliative care team meetings: An ethnography. *International Journal of Nursing Studies*, *44*, 916–926. doi:10.1016/j.ijnurstu.2006.04.002

Australian Cancer Network Melanoma Guidelines Revision Working Party. (2008). *Clinical practice guidelines for the management of melanoma in Australia and New Zealand*. Cancer Council Australia and Australian Cancer Network, Sydney, Australia and New Zealand Guidelines Group, Wellington, New Zealand. Retrieved from http://www.nhmrc.gov.au/_files_nhmrc/file/publications/synopses/cp111.pdf

Australian Government. (2014). *Causes of death, Australia, 2012*. Canberra, ACT: Retrieved from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3303.02012?OpenDocument>

Australian Institute of Health and Welfare. (2010). *Cancer incidence projections: Australia, 2011 to 2020*. Cancer Series no. 66. Cat. No. CAN 62. Canberra, ACT: AIHW. Retrieved from <http://www.aihw.gov.au/publication-detail/?id=10737421461>

Australian Institute of Health and Welfare. (2012). *Australia’s health 2012. Australia’s Health no 13. Cat no. AUS 156*. . Canberra, ACT: AIHW. Retrieved from <http://www.aihw.gov.au/publication-detail/?id=10737422172>

Bakitas, M., Byock, I. R., Ahles, T. A., Lyons, K. D., Hegel, M. T., Balan, S., . . . Tosteson, T. D. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II randomized controlled trial. *Journal of the American Medical Association*, *302*, 741–749. doi:10.1001/jama.2009.1198

Barry, C. A., Stevenson, F. A., Britten, N., Barber, N., & Bradley, C. P. (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine*, *53*, 487–505.

doi:10.1016/S0277-9536(00)00351-8

Baszanger, I. (2012). One more chemo or one too many? Defining the limits of treatment and innovation in medical oncology. *Social Science and Medicine*, *75*, 864–872.

doi:10.1016/j.socscimed.2012.03.023

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Englewood Cliffs, NJ, USA: Prentice Hall.

Breitbart, W. (2006). The goals of palliative care: Beyond symptom control. *Palliative & Supportive Care*, *4*, 1–2. doi:10.1017/S1478951506060019

Broom, A., Kirby, E., Good, P., Wootton, J., & Adams, J. (2012). Specialists' experiences and perspectives on the timing of referral to palliative care: A qualitative study. *Journal of Palliative Medicine*, *15*, 1248–1253. doi:10.1089/jpm.2012.0264

Campbell, K. H., Sachs, G. A., Hemmerich, J. A., Smith, S. G., Stankus, N., & Dale, W. (2010). Physician referral decisions for older chronic kidney disease patients: A pilot study of geriatricians, internists and nephrologists. *Journal of the American Geriatrics Society*, *58*, 392–395. doi:10.1111/j.1532-5415.2009.02694.x

Casali, P. G. (2011). Medical oncology: The long awaited prize of recognition. *Annals of Oncology*, (2011). doi:10.1093/annonc/mdr314

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative*

analysis. London, England: Sage.

Charmaz, K. (2009). Shifting the grounds: Constructivist grounded theory methods. In J. M. Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz & A. E. Clarke (Eds.), *Developing grounded theory: The second generation* (pp. 127–193). Walnut Creek, CA, USA: Left Coast Press.

Charmaz, K. (2011a). A constructivist grounded theory analysis of losing and regaining a valued self. In F. J. Wertz, K. Charmaz, L. M. McMullen, J. Ruthellen, R. Anderson & E. McSpadden (Eds.), *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry* (pp. 165–204). New York, NY, USA: Guilford Press.

Charmaz, K. (2011b). Grounded theory methods in social justice research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The sage handbook of qualitative research* (4th ed., pp. 359–380). Thousand Oaks, CA, USA: Sage.

Clark, D. (2007). From margins to centre: A review of the history of palliative care in cancer. *Lancet Oncology*, 8, 430–438. doi:10.1016/s1470-2045(07)70138-9

Ferrell, B., & Grant, M. (2014). The future of palliative care. *Seminars in oncology nursing*, 30, 296–297. doi:10.1016/j.soncn.2014.08.012

Glaser, B. G. (1978). *Theoretical sensitivity*. San Francisco, USA: University of California.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY, USA: Sociology Press.

Habermas, J. (1984). *The theory of communicative action: Volume 1. Reason and the*

rationalization of society (T. McCarthy, Trans.). Boston, MA, USA: Beacon Press.

Habermas, J. (1987). *The theory of communicative action. Volume 2: Lifeworld and system: A critique of functionalist reason* (T. McCarthy, Trans.). Boston, MA, USA: Beacon Press.

Hannon, B., & Zimmermann, C. (2013). Early palliative care: Moving from ‘why’ to ‘how’. *Oncology*, 27(1), 36. Retrieved from <http://www.karger.com/Journal/Home/223857>

Hardy, J., Maresco-Pennisi, D., Gilshenan, K., & Yates, P. (2008). Barriers to the best care of the dying in Queensland, Australia. *Journal of Palliative Medicine*, 11, 1325–1329.
doi:10.1089/jpm.2008.0170

Hibbert, D., Hanratty, B., May, C., Mair, F., Litva, A., & Capewell, S. (2003). Negotiating palliative care expertise in the medical world. *Social Science & Medicine*, 57, 277–288.
doi:10.1016/S0277-9536(02)00346-5

Higginson, I. J., & Evans, C. J. (2010). What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer Journal*, 16, 423–435.
doi:10.1097/PPO.0b013e3181f684e5

Hodi, F. S., O’Day, S. J., McDermott, D. F., Weber, R. W., Sosman, J. A., Haanen, J. B., . . .
Urba, W. J. (2010). Improved survival with Ipilimumab in patients with metastatic melanoma. *New England Journal of Medicine*, 363, 711–723. doi:10.1056/NEJMoa1003466

Holleb, A. I. (1972). The cancer patient—Too often alone. *CA: A Cancer Journal for Clinicians*, 22, 129. doi:10.3322/canjclin.22.2.129

Horowitz, R., Gramling, R., & Quill, T. E. (2014). Palliative care education in US medical schools. *Medical Education*, 48, 59–66. doi:10.1111/medu.12292

Howie, L., & Peppercorn, J.M. (2013). Early palliative care in cancer treatment: Rationale, evidence and clinical implications. *Therapeutic Advances in Medical Oncology*, 5(6), 318-323. doi: 10.1177/1758834013500375

Hui, D., Elsayem, A., De la Cruz, M., Berger, A., Zhukovsky, D. S., Palla, S., . . . Bruera, E. (2010). Availability and integration of palliative care at US cancer centers. *Journal of the American Medical Association*, 303, 1054–1061. doi:10.1001/jama.2010.258

Johnson, C. E., Girgis, A., Paul, C. L., & Currow, D. C. (2008). Cancer specialists' palliative care referral practices and perceptions: Results of a national survey. *Palliative Medicine*, 22, 51–57. doi:10.1177/0269216307085181

Johnson, C., Girgis, A., Paul, C., Currow, D., Adams J. & Aranda, S. (2011a). Australian palliative care providers' perceptions and experiences of the barriers and facilitators to palliative care provision. *Support Care Cancer*, 19, 343–351. doi:10.1007/s00520-010-0822-0

Johnson, C., Paul, C., Girgis, A., Adams, J., & Currow, D. (2011b). Australian general practitioners' and oncology specialists' perceptions of barriers and facilitators of access to specialist palliative care services. *Journal of Palliative Medicine*, 14, 429–435. doi:10.1089/jpm.2010.0259

Karnofsky, D. (1960). Why prolong the life of a patient with advanced cancer? *CA: A Cancer Journal for Clinicians*, 10, 9–11. doi:10.3322/canjclin.10.1.9

Karnofsky, D. (1962). Rationale for aggressive or extraordinary means of treatment of advanced cancer. *CA: A Cancer Journal for Clinicians*, 12, 166–170. doi:10.3322/canjclin.12.5.166

Krakoff, I. H. (1979). The case for active treatment in patients with advanced cancer: Not everyone needs a hospice. *CA: A Cancer Journal for Clinicians*, 29, 108–111.

doi:10.3322/canjclin.29.2.108

Mead, G. H. (1934). *Mind, self and society: From the standpoint of a social behaviourist*. Chicago, MA, USA: Chicago University Press.

Medical Oncological Group of Australia. (2013). *History of MOGA*. [Webpage]. Retrieved from <http://www.moga.org.au/about-moga/history-moga>

Meghani, S. (2004). A concept analysis of palliative care in the United States. *Journal of Advanced Nursing*, 46, 152–161. doi:10.1111/j.1365-2648.2003.02975.x

Oxford Dictionaries. (2013). <http://www.oxforddictionaries.com/definition/english/>

Parish, K., Glaetzer, K., Grbich, C., Hammond, L., Hegarty, M., & McHugh, A. (2006). Dying for attention: palliative care in the acute setting. *Australian Journal of Advanced Nursing*, 24(2), 21. Retrieved from <http://www.ajan.com.au/>

Pincombe, J., Brown, M., & McCutcheon, H. (2003). No time for dying: A study of the care of dying patients in two acute care Australian hospitals. *Journal of Palliative Care*, 19, 77–86. Retrieved from <http://criugm.qc.ca/journalofpalliativecare/?lang=en>

Potter, J. F. (1980). A challenge for the hospice movement. *New England Journal of Medicine*, 302, 53–55. doi:10.1056/NEJM198001033020111

Ramchandran, K., & Von Roenn, J. H. (2013). Palliative care always. *Oncology*, 27, 13–16. Retrieved from <http://www.karger.com/Journal/Home/223857>

Rynearson, E. H. (1959). You are standing at the bedside of a patient dying of untreatable cancer. *CA: A Cancer Journal for Clinicians*, 9, 85–87. doi:10.3322/canjclin.9.3.85

Temel, J. S., Greer, J. A., Muzikansky, A, Gallagher, E. R., Admane, S, Jackson, V. A., . . .

Lynch, T. J. (2010). Early palliative care for patients with metastatic non–small-cell lung cancer. *New England Journal of Medicine*, 363, 733–742. doi:10.1056/NEJMoa1000678

Thompson, J. F., Scolyer, R. A., & Kefford, R. F. (2009). Cutaneous melanoma in the era of molecular profiling. *The Lancet*, 374, 362–365. doi:10.1016/S0140-6736(09)61397-0

Tieman, J. J., Sladek, R. M., & Currow, D. C. (2009). Multiple sources: Mapping the literature of palliative care. *Palliative Medicine*, 23, 425–431.

doi:10.1177/0269216309102727

Wentlandt, K., Krzyzanowska, M. K., Swami, N., Rodin, G. M., Le, L. W., & Zimmermann, C. (2012). Referral practices of oncologists to specialized palliative care. *Journal of Clinical Oncology*, 30, 4380–4386. doi:10.1200/jco.2012.44.0248

White, C. D., & Hardy, J. R. (2010). What do palliative care patients and their relatives think about research in palliative care? - A systematic review. *Supportive Care in Cancer*, 18, 905–911. doi:10.1007/s00520-009-0724-1

Willard, C., & Luker, K. (2006). Challenges to end of life care in the acute hospital setting. *Palliative Medicine*, 20, 611–615. doi:10.1177/0269216306071064

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., . . . Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association*,

300, 1665–1673. doi:10.1001/jama.300.14.1665

Yabroff, K. R., Mandelblatt, J. S., & Ingham, J. (2004). The quality of medical care at the end-of-life in the USA: Existing barriers and examples of process and outcome measures.

Palliative Medicine, 18, 202–216. doi:10.1191/0269216304pm880oa

Zimmermann, C., Swami, N., Krzyzanowska, M., Hannon, B., Leighl, N., Oza, A., . . . Lo, C.

(2014). Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *The Lancet*, 383, 1721–1730. doi:10.1016/S0140-6736(13)62416-2