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# Refractory suffering: The impact of team dynamics on the interdisciplinary palliative care team

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## ABSTRACT

*Objective:* This qualitative study aimed to describe the skill sets that experienced palliative care clinicians possess when managing refractory suffering.

*Method:* Thirteen tape recorded semi-structured interviews and four online questionnaires were completed by participants with at least two years clinical palliative care experience. The research team undertook cross sectional thematic analysis of the transcribed interviews.

*Results:* In the face of refractory suffering, team cohesion was identified as a key requirement to support the interdisciplinary team. However, team cohesion was found to be undermined by philosophical differences between team members, a paradigm shift concerning cure versus care and individual opinions regarding the chosen approach and levels of respect between the individual disciplines involved in the care of a person with a life limiting illness.

*Significance of results:* The findings of this study highlight the precarious nature of the interdisciplinary team when significant challenges are faced. As a result of witnessing refractory suffering the division and fracturing of teams can easily occur; often team members are completely unaware of its cause. The findings of this study contribute to the limited literature on the nature of refractory suffering from the perspective of the interdisciplinary team.

**KEYWORDS:** Refractory suffering, Palliative care, Interdisciplinary teams, End-of-life issues

## INTRODUCTION

Refractory symptoms that cause suffering are defined by Cherney and Portenoy as symptoms that cannot be controlled adequately in a tolerable time frame despite aggressive use of usual therapies, and seem unlikely to be controlled adequately by further invasive or noninvasive therapies without excessive or intolerable side effects/complications (Bruce et al. citing Cherney & Portenoy, 2006).

The suffering of patients and their families affects clinicians, who grapple personally and professionally with their own suffering in the face of another's distress. Clinicians also feel impotent and powerless when unable to relieve it. Yet this "mutual suffering" (Graham et al., 2005) is often not articulated within palliative care teams (White et al., 2004). Identification of specific skill sets required to manage a patient's refractory suffering is absent in most of the palliative and symptom management literature. While there is recognition that witnessing suffering affects the carer, identifying protective qualities remains the domain of the individual concerned. This identification requires self-reflection and insight, and often goes unrecorded or unnoticed because it is considered to be an inherent trait of the healthcare worker.

A larger project was undertaken to understand what skills and capabilities are required to assist one to manage refractory suffering, and whether they could be translated into an educational context to teach future palliative care clinicians. This article

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focuses on the unexpected finding of the impact refractory suffering places on interdisciplinary team dynamics.

The fact that the practice of palliative care involves an interdisciplinary team may also be a reason why mutual suffering often goes unrecognized. Within palliative care there is a tendency to refer patients and distressed families onto another team member for consultation, thereby providing the initial team member with temporary respite from a difficult situation. It is only when members from multiple disciplines who are involved in the care experience distress that the team begins to recognize that suffering is occurring not only within the patient and family but also within the team.

There is relatively little published literature on refractory suffering in palliative care. Within this, the major focus in the literary discourse over the past decade and a half has been the use of palliative sedation in managing both refractory symptoms and unrelieved existential distress. Clinical and ethical issues have dominated this debate, with little attention being paid to the personal and professional impact of refractory suffering on clinicians, and more broadly, on its effect on the interdisciplinary team.

## LITERATURE REVIEW

A search of the literature using key words such as "end-of-life issues," "suffering," "refractory suffering/symptoms," "palliative care," and "multidisciplinary teams" revealed very little evidence relating to the interdisciplinary team and the way different disciplines manage the phenomenon of refractory suffering within the palliative care client group. Studies discussing palliative sedation were most likely to make reference to the interdisciplinary team; however these articles usually highlighted one discipline as the point of focus, and often it was nurses who were studied. (Morita et al., 2004; White et al., 2004; Bruce et al., 2006)

Bruce et al. (2006) highlighted the importance of case conferences to help alleviate some of the emotional burden associated with caring for suffering patients at the end of life. These authors identified the nurse as having a pivotal role within the interdisciplinary team in linking the patient and family with other healthcare workers so that their needs were holistically and promptly met.

Kyba (2002) explores the medicalization of dying through access to technology and advances in science, and in particular how the tension of the cure versus care paradigm is paramount within the critical care environment. Critical care teams were studied to try to understand the ethical and moral dilemmas faced with end-of-life care in the critical care unit. Kyba concluded that all team members should have optimal input into difficult decision making, however nurses were identified as being passive participants, which contributes to ineffective communication within the interdisciplinary team.

The personal impact of refractory suffering on palliative care nurses is stated clearly within the literature (Morita et al., 2004; White et al., 2004; Beel et al., 2006). Feelings of impotence, failure, and distress along with physical symptoms such as insomnia and pain; discomfort, lack of understanding, and struggle with the situation; and a sense of carrying a burden feature strongly (White et al., 2004). One response to these feelings is the need to find ethical, meaningful, and sustainable ways of living and working with people who are suffering (Maeve, 1998).

Most nurses, physicians, and pharmacists who participated in research projects agreed with the use of sedation in managing refractory *physical symptoms* (Beel et al., 2006) . Many, however, express uncertainty and difficulty in determining appropriateness of palliative sedation for *existential distress* (Blondeau, 2005; Beel et al., 2006). Doctors' responses to palliative sedation have also included ambivalence and difficulties in clinical decision making (Morita et al., 2002).

The impact of refractory suffering on the interdisciplinary team has not been evaluated as yet. Most studies make reference to teams but none have examined the effects of adaptability or function of the team as a whole. Peer support, clinical supervision, and team meetings have been identified as being necessary for individuals who struggle within a team (Sinclair & Hamill, 2007). Clinical supervision has been shown to facilitate reflective practice and personal growth (Cutcliffe & McFeely, 2001; Teasdale et al., 2001) and often this is underutilized in the current palliative care team.

In summary, a review of the literature found very little research on the impact of refractory suffering on interdisciplinary team dynamics. The aim of our research was to explore ways of capacity-building for sustainable clinical practice for palliative care clinicians working with refractory suffering.

## METHOD

Initially, the research team conducted a scoping exercise of the national and international literature, in order to gain insights into the broad area of study. This exercise formed the basis for the development of the interview guide and the questionnaire.

Palliative care practitioners with at least 2 years of clinical experience were invited to participate either

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by interview or by filling out an online questionnaire. In order to canvas views that tapped into the multidisciplinary nature of palliative care, the sample was a purposive cross-section of disciplines usually involved in palliative care teams. Participants self-selected or were invited into the study. A total of 17 clinicians consented to participate, 13 by face-to-face interview and a further 4 by an online questionnaire. The sample comprised ten nurses from different care settings, five doctors, and two allied health clinicians, one each from social work and pastoral care.

The interviews were semi-structured and sought clinicians' experiences of refractory suffering, together with its impact on both their personal lives and their professional practice including their clinical decision-making capabilities. The interviewers were both experienced palliative care clinicians and researchers.

Questionnaires were completed anonymously and returned questionnaires were de-identified by administrative personnel before being given to the research team.

The research team analyzed the data. Each interview was subjected to preliminary data analysis by the interviewer, to identify the emerging issues. The process also highlighted which issues required further exploration. This information was added to the pro forma of subsequent interviews. When all the data had been collected, thematic analysis was conducted on the total data base independently by the four team members in order to identify the main themes. Cross-sectional analysis was performed to cluster and label core themes that were interrelated and repeated.

Ethics approval for the study was gained from the Repatriation General Hospital Ethics committee in September 2007, and from Flinders University in October 2007. The data were kept in a locked storage facility according to the National Health and Medical Research Council guidelines.

As the research teams were exploring the subjective nature of refractory suffering, the theoretical perspective of constructivism was chosen (Liamputtong, 2010).

## RESULTS

The importance of the interdisciplinary team in the management of refractory suffering was a strong theme running throughout the interviews. The most important aspects of this were: cohesion within the interdisciplinary team, philosophical alignment, paradigm shift, and interdisciplinary respect.

### Cohesion within the Interdisciplinary Team

Within palliative care, as in any area of healthcare delivery, effective team functioning is vital (Parker-Oliver et al., 2005).

Healthy teams respect and embrace difference, recognizing that variety within a team is necessary for growth and development, and ultimately for its success (Mealiea & Baltazar, 2005).

Accepting that difference within a team is healthy, cohesion of the team mind-set regarding the goal and plans of management were identified by participants as important when faced with the patient and family's refractory suffering. The importance of presenting a united front — all speaking with the same voice — was recognized as critical in ensuring consistency of messages, and to build a trusting rapport with patients and families. An allied health staff member articulated this by saying "having one mind about this, having consensus [within the team]."

A united front was undermined when support from colleagues was felt to be lacking within the team. One doctor (Doctor 4) identified an increase in the feeling of helplessness when she perceived that she had been let down by her team. This disappointment led to the doctor feeling angry when nurses neglected to read communication regarding strategies for difficult patient management within the medical record. However, the anger was buffered by recognition that all team members have their place in the circle of care and complement the bigger whole. As Doctor 4 said "we need a range of different professions; don't try to be all things."

Nursing frustration was identified regarding the absence of significant clinical leaders from the workplace when refractory suffering was being experienced within the inpatient unit. One nurse (Nurse 5) identified a feeling of vulnerability and the need to link the medical consultant in by phone to ensure messages to the family were consistent and that they were appearing as a united front.

Similarly to the doctors and nurses in this project, the allied health professionals identified the need for cohesion of decision making within the team. The sense of responsibility around difficult decision making was lessened when reflecting the views and directions of the health team as a whole "Not all my responsibility when I work in a team" (Allied Health 1). This shared sense of responsibility was particularly relevant to the issue of relocating patients from a specialist inpatient unit to residential care facilities.

Differences were found between the inpatient nurses and community nurses interviewed. Inpatient nurses identified the importance of each other

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when managing refractory suffering within the inpatient unit whereas the community nurses identified the autonomy of their role predisposing them to greater levels of anxiety in managing refractory suffering.

For example, the inpatient nurses said:

being connected to a team [is important] (Nurse 2)

As nurses we are very good at caring for each other and are able to discuss our thoughts and feelings together (Nurse 7).

We are a team on this ward and that really helps in dealing with these situations (Nurse 8).

Inpatient nurses did, however, feel that having consistent staff without the need for agency nurses and relievers improved team function enormously. There was also consistency emerging regarding clinical team meetings and the importance of informal debriefing that often resulted from inter disciplinary teams evaluating the care required by complex individual patients. Some nurses identified the learning that emerged from these frank discussions, especially "hearing others acknowledge limits" (Nurse 2). This degree of honest sharing was felt to support understanding and cohesion within the interdisciplinary team and therefore to support the team's ability to effectively manage refractory suffering.

Community nurses identified a sense of overwhelming responsibility, as their work was largely autonomous, so the sense of being part of a team was lessened. This degree of autonomy made the community nurses feel vulnerable, and whereas they did identify the importance of colleagues in sharing the burden, they also felt afraid to initiate clinical conversations about difficult cases, as they did not want to be judged by these same colleagues. Of greatest importance from the community nurses perspective were the weekly clinical team meetings in which they could discuss challenging situations, including refractory suffering, and gain advice from their colleagues.

Access to more heads (Nurse 3).

I find the weekly team meetings very valuable for discussing challenging patients (Nurse 1).

Many of these nurses recognized that patients benefited from the specialist interdisciplinary team environment. In the face of refractory suffering, Nurse 1 stated that she pushed for an admission to the inpatient palliative care unit in order to access the team and its skills.

I advocate for hospice admission when patient really suffering to open patient up to the whole interdisciplinary team. (Nurse 1)

Team cohesion in the face of refractory suffering requires other elements to be in place in order to experience a united front. This study identified the importance of philosophies aligning. The greatest difficulty experienced is where goals of care among healthcare providers, patients, and families do not match up.

### Philosophical Alignment

Within the palliative environment, many participants saw that in order to manage refractory suffering, a philosophical alignment between patient and family goals and healthcare goals was necessary.

The main sub-themes that emerged within the category of philosophical alignment were first, the culture concerning treatment goals, and second, the clinicians' personal philosophy.

### Culture Concerning Treatment Goals: Cure versus Care

One participant recognized that currently there existed two distinct cultures operating within inpatient palliative care units: the old culture that featured the syringe driver containing analgesics, antiemetics, and sedatives to manage all symptoms, and the newer culture where greater importance is placed on individual symptom assessment.

One nurse found that the differing philosophical perspectives held by the team members could cause friction within the team.

The hardest thing is a couple of different mindsets working in the one area- which causes friction (Nurse 5).

Conflict between members of the team was one effect of refractory suffering, however, one doctor identified that conflict could arise between a patient and his or her carer when patient choice was not in keeping with clinician expectations

Individuals may want to do it their way... not everybody is there to be rescued (Doctor 3).

These quotes highlight the struggle experienced by everyone concerned when treatment goals are not clearly articulated or when team members approach management from individual and fragmented perspectives.

Treatment goals were affected when patients and/or families did not make the adjustment from cure to

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care. Often the treating teams were all philosophically aligned regarding what care needed to be provided as the prospect of cure diminished, however the patient and/or family, having accepted palliative care's involvement, were not always ready to accept that all measures should be directed towards comfort and away from cure. For example

> . . .that's what I, what a lot of us find difficult, is that when somebody is still focusing on cure when they are skin and bone, and they are obviously deteriorating (Nurse 1).

As a result of a patient insisting on the continuation of a curative approach in spite of an advanced degenerative neurological condition, deep rifts occurred within the team

> His presence in the unit divided the nursing team and the refractory suffering he experienced was shared by all regardless of whether they were looking after him or not (Nurse 10).

This patient's suffering filtered throughout the unit and a crisis resulted.

> In short I had a nursing team in crisis (Nurse 10).

This crisis was sparked by two conflicting philosophies, determination of the patient for the team to focus on cure, and individual personal philosophies that were often at odds with those of fellow team members

### Personal Philosophy

One outcome of unrelieved suffering was the realization that counter-transference was at work within the clinical encounter. Counter-transference is the clinician's response to behaviors of the patient. Counter-transference reactions may include the therapist angrily rejecting the patient or conversely, coming to believe that only they understand the patient and unfairly criticizing colleagues for their failures (Bloch & Singh, 2001). For example, one participant reported that a patient only allowed certain staff to care for him and rejected others. The basis upon which he chose these nurses was unclear. The chosen nurses were awarded the status of 'special-ness' and those whom he refused to have care for him experienced "rejection and loss of confidence" (Nurse 10).

> To see pleasure arise from someone making themselves indispensable to a patient causes me concern as they are not thinking of that patient when they ring in sick and leave them to the care of someone not familiar in their particular care needs. I am left asking whose needs are being met here (Nurse 10).

Doctor 3 also spoke of learning to recognize one's own projections and reactions within clinical encounters, especially highly emotive ones involving distress and suffering. The issue of counter-transference was raised, as well as the need for clinicians to recognize it and its significance within the therapeutic relationship.

> . . .what you are trying to guard against is reacting inappropriately because you are responding to stuff that's inside you as opposed to inside the patient (Doctor 3).

This clinician's own personal philosophy was a strong influence on how she approached suffering of the dying patient. In addition, Nurse 1 made the point that team members did not discuss individual philosophies with colleagues, and that given the boundaries, that these healthcare professionals crossed "the very deep and personal space of the patient" and that failure to recognize one's own philosophical position could cause unnecessary suffering for the clinician. Doctor 3 alluded to the distress that resulted when a personal philosophical perspective collided with that of the patient.

> I figure an individual's got an opportunity to change their mind about whether they want intervention, whether they don't want intervention because it's one of those tough calls. And I think sometimes we're not prepared to be as flexible as we should be (Doctor 3).

In summary, clinicians need to recognize both the cultural and personal philosophies and beliefs at play in order to control the anxiety and disharmony that may result from managing refractory suffering.

> Learn to control one's own anxiety and not escalate that of patients. The rescuer can't panic, but may have to let go (briefly) so as not to drown themselves (Doctor 3).

### Paradigm Shift

Participants from all disciplines recognized that the predominant focus was on physical symptom management within the current palliative medicine paradigm.

Historically, modern palliative care was set up in opposition to conventional medicine, whose focus

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was on cure and who saw dying as a failure of good medical care (Dush, 1993). Recognizing that providing dignified care requires a holistic approach with an understanding of the psychosocial elements of the person, palliative care set about meeting this need. It did this by focusing on the psychological, social, spiritual, and emotional, as well as the physical world of the patient. In recent years, palliative medicine has emerged as a medical specialty and consequently there has been a shift back toward a framework of exploration of symptoms, and investigations to improve the experience and comfort of the patient. Hence for many palliative care clinicians, there has been a shift in focus.

Participants strongly identified the difficulties inherent in the change of paradigm from one focus of care to another. A recurring theme emerging from this research was that of palliative care being "physically symptom driven" (Doctor 1), with its primary focus being symptom relief.

> The dominant focus in teams is medical even if the person's needs aren't (Doctor 4).

This focus was sharpened when psychosocial care was seen as being inadequate and where doctors felt either insufficiently skilled or under-resourced to provide supportive care.

> I've failed in lots of discussions and made lots of mistakes. I take longer with some of these difficult things (Doctor 4).

All clinicians highlighted the importance and value of a psychosocial specialist within the team in order to provide additional emotional support; "a limited [psychological] resource service doesn't provide enough emotional support" (Doctor 1).

Findings from this study demonstrated that psychosocial care is now seen as an area requiring specialist expertise. Clinicians articulated this expertise in two ways: first, through the availability of a specialist team member such as a psychologist/psychiatrist, and second, through training and skill development not provided in undergraduate or postgraduate education.

Nurses echoed this need for specialist expertise. One nurse spoke of the importance for her of having

> access to. . .someone who is more skilled than me (and) does have more time than me, because that's what she does [all the time]. (Nurse1).

Ultimately there was recognition that having a psychosocial specialist in the team was very useful for learning to stay with and not abandon the patient. Several clinicians (Doctor 1 and Doctor 2) lacked confidence in their psychosocial skills. Doctor 2 commented that while she had made a conscious decision not to study the psychosocial component of end-of-life care, access to study leave would enable skill development in this area. "I would love to read and learn more on refractory suffering as well as the psychiatric aspects" (Doctor 2).

Nurses also identified the tendency for physical symptoms to dominate the clinical encounter; however, there was recognition from community nurses that the domain of psychological skills sat comfortably within the nurses' role and not outside it.

> I feel my role is much more psychological support. . .when somebody does have physical symptoms, they are the first things the doctors tend to address. (Nurse 1)

Interestingly, one allied health practitioner felt that privileging the physical component of care was not solely the domain of doctors. She had recognized this to be present from some of the inpatient nurses with comments such as

> How do we treat people we don't think need to be here? (Allied Health 1).

In summary, this study recognizes the dominance that physical symptom management receives in the current palliative care climate, and that for many members of the interdisciplinary team this can be perceived as a shift in operating framework.

### Interdisciplinary Respect

Some of the participants identified that respect among the disciplines was needed in order to effectively manage refractory suffering. The role of the allied health worker within a specialist inpatient unit was particularly challenging, as reflected by this comment:

> Recognition that more treatment may prolong life which results in nursing home placement and that this is a situation to be avoided. . .Nurses can make you feel awful about placing a patient (Allied Health 1).

This clinician felt trapped in an uncomfortable place

> caught between anger of the family and anger of the nurse (Allied Health 1).

In this study, there was also recognition that tension did occur when a community patient entered a

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specialist inpatient setting, and the patient and or family sought out the community nurse to talk to instead of the inpatient staff (Nurse 5).

One medical consultant (Doctor 4) grappled with the feeling that to be approachable and gentle impaired the ability to be taken seriously by team colleagues. This ultimately increased her experience of frustration and ultimately reduced the level of respect her role deserved.

Despite these difficulties, people from all disciplines talked of the value in engaging in interdisciplinary team case presentations. Those from each discipline acknowledged a need for a safe environment where limitations in care could be fully discussed free from judgment.

This finding recognizes the importance of the interdisciplinary team, but multiple disciplines make up this team, and each discipline has specific skill sets of value that require recognition and respect.

## DISCUSSION

In this research, an unexpected finding was the identification of the challenges the interdisciplinary team face in the presence of refractory suffering. This finding prompted a return to the palliative care literature to understand its prevalence. Although healthy and successful palliative and healthcare teams have been reported on in the literature (see Mickan & Rodger, 2005; Parker-Oliver et al., 2005; Junger et al., 2007), there has been very little written about the impact of unrelieved suffering, in either the patient or the family, on interdisciplinary teams.

This study adds to the current literature on the topic of refractory suffering particularly in relation to the role of the interdisciplinary team. The paucity of studies exploring the "whole team approach" was surprising, given the philosophy that underpins palliative care, which, "uses a team approach to address the needs of patients and their caregivers" (Therapeutic Guidelines, 2005, p.2).

In terms of the impact of refractory suffering on the clinical team, what the study findings highlight was the precarious nature of the interdisciplinary team when significant challenges are faced. Division and fracturing of teams can result, and often team members are completely unaware of the causative factor. Although the team members who participated in this study could articulate their role and function within the specialist interdisciplinary team, it was hard to ignore the feelings of helplessness from some of the study participants concerning refractory suffering within their patient population. When patients are suffering, team members seek one another out for support and advice. However, where care expectations are not met, there is evidence of disappointment in the entire team. The area of conflict between nursing and medical staff as a result of refractory suffering has been identified by Beel et al. (2006) in relation to palliative sedation, but otherwise has gone largely unreported.

Philosophical non- alignment was an area that was identified as a gap between care providers. Reluctance to talk openly about philosophical differences has been identified through this study as an unseen, unrecognized root cause of team suffering. Given that palliative care crosses boundaries into the very private world of dying people, a shared philosophy concerning treatment goals is critical if both patient and team suffering are to be minimized in the setting of refractory suffering (Bruce et al., 2006).

Ultimately, when clinicians were faced with a situation of refractory suffering, they retreated to their primary area of expertise. If, however, this area of expertise did not resolve the suffering, then other team members made judgements about level of competence, leading to diminished sense of team cohesion with individual team members feeling a lack of respect and support (Kyba, 2002).

### Recommendation for Further Research

An area worthy of further study in the setting of refractory suffering is what happens when "compassion fatigue" (as opposed to staff burnout) sets in. Clinicians struggling with managing people they perceive as not requiring specialist palliative care may be code for staff exhaustion or staff protection. Staff is required to make significant investments in patients and families who are facing death and sustainable practice may be reliant upon philosophical alignment of palliative care services. A clear statement about what a service offers and where services are offered, e.g., hospice, acute hospital, or residential care facility, will enable philosophies to be aligned more accurately, thereby decreasing confusion.

The literature has looked at the impact of unrelieved suffering on nurses but not the whole palliative care team, so although findings of the study regarding individual team members identified similar impacts to those reported by White et al. (2004), findings about the whole interdisciplinary team experience are new.

The changing palliative care paradigm to one of a major focus on physical symptoms, as palliative care has embraced palliative medicine over the last three decades, has been identified by Dush (1993) and Abel (1986). They argue that high technology healthcare has influenced the physical care priority of the

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palliative care team. Certainly it is a prevalent theme within this study. Of particular interest is the facility with a consultant psychiatrist on staff. Clinicians from this service identified a greater lack of confidence in their individual abilities to conduct a psychosocial assessment. This might be because having defined expertise within a team raises awareness from other staff members of the specific skill sets required, and therefore they refer to the specialist and lose practice and skills.

Palliative care demands a "total person" approach, and this study supports the belief that people are complex individuals and that single disciplines cannot meet all needs. Although there are challenges emerging for the interdisciplinary team, it is evident from this study that palliative care relies on this model to meet the care needs of patients, particularly those experiencing refractory suffering.

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