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Title: Organizing End of Life in Hospital Palliative Care: A Canadian Example

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Organizing End of Life in Hospital Palliative Care: A Canadian Example

Abstract:

Hospitals remain the most common location of death in a significant number of countries, and specialist palliative care is positioned as a crucial resource for improving hospital care for those nearing end of life. Little is known, however, about a substantive aspect of this work: how hospital palliative clinicians anticipate and organize a patient’s dying trajectory. In this paper I draw from a larger original ethnographic research study of palliative specialists in two Canadian hospitals. Abductive analysis resulted in framing their work as affective labour, both reflecting and re-creating a larger affective economy shaping the affective states of everyone involved in the provision and uptake of care. I articulate six analytically ideal outcomes of clinicians’ affective labour that organize end of life, including: 1) proactive co-authorship of disease trajectory; 2) mutual acknowledgement of a dying trajectory; 3) naturalizing direction and outcome of care, 4) ensuring a minimum of social disruption, 5) identification as compassionate and efficient care providers, and 6) increased specialist knowledge and interventions. In so doing, clinicians’ practices become understandable as labour to meet a diversity of – at times conflicting – individual, societal, and organizational mandates that necessarily include, but extend well beyond, the patient and her immediate social network. This is the first study to consider hospital palliative care as an affective economy, and presents a theoretically innovative and empirically grounded model to advance new ways of conceptualizing hospital palliative care. I conclude by considering how this model, and the unique insights it affords, can inform the future development of end of life care in hospital settings.

Key words: Canada; palliative care; hospitals; ethnography; dying; end of life; affective economy; affective labour

Introduction

Public discussions about end of life care often start from the premise that people do not want to spend their last days of life or die in an acute hospital setting. Yet even as rates of hospital dying decline in some countries, it remains the most common location of death in a significant number of
countries globally (Broad et al., 2013), unavoidable in many instances (Gott and Robinson, 2018), and
for some a preferred place of care, particularly as death nears (Gerrard et al., 2011; Robinson et al.,
2016). The overall importance of hospitals at the end of life is further evidenced by national cohort
studies that document 15-30 percent of hospital patients as being in the last year of life (Clark et al.,
2014; Gott et al., 2017), with an increase of admissions and progressively greater care needs for those
in the last months of life (Rosenwax et al., 2011; Bekelman et al., 2016). National-level policy
documents reflect this discordance, continuing to problematize hospitals as a suitable place for end of
life care while simultaneously acknowledging that care for dying people will remain a core remit for
the “foreseeable future” (Robinson et al., 2016). Regardless of perspectives that frame hospitals as
good or bad places for end of life, there is a common agreement about the urgent need to deliver
appropriate end of life care in these settings.

The World Health Organization describes palliative care as:

“…an approach that improves the quality of life of patients and their families facing the
problem associated with life-threatening illness, through the prevention and relief of
suffering by means of early identification and impeccable assessment and treatment of
pain and other problems, physical, psychosocial, and spiritual” (2019).

Specialist palliative care and a more generalized palliative approach are championed as ‘best
practice’ for patients facing a greater risk of near-term dying than the general hospital population
(Dalgaard et al., 2014; Gott et al., 2013). Generalist palliative care, which employs the basic precepts
of palliative care (e.g. non-specialist management of pain, symptoms, and psychosocial distress, as
well as discussion of prognosis and goals of treatment), is ideally provided by all hospital clinicians
working with critically ill patients. However, numerous barriers and challenges in providing generalist
hospital palliative care have repeatedly been identified (Dalgaard et al., 2014; Gott et al., 2012).
Specialist palliative care is provided by clinicians who have undergone training in palliative care, and
is predominantly focused on supporting critically ill and symptomatically complex patients who are
likely nearing end of life. Models of specialist hospital palliative care vary within and between
regions and countries. Specialists may function as consultants, either individually or within
interdisciplinary consult teams, acting primarily in an advisory capacity to supplement a patient’s care. Other settings have high-volume specialist units or dedicated beds, where palliative clinicians and/or specialist teams assume responsibility for patient care. Depending on resources, hospitals may combine both models. Specialists by necessity work with those defined by exceptionally high rates of near-term and in-hospital mortality, and if unavoidable, their role includes anticipating and planning a hospitalized death.

Hospital palliative care in Canada

Approximately 60% of Canadians die in hospital; similar to other Western nations leading causes of death include cancer, heart, cerebrovascular and respiratory disease (Statistics Canada, 2018). A recent national study found that of the patients who died in acute care hospitals, 44 percent were designated as palliative at some point of their admission, and 25 percent overall received primarily palliative care (CIHI, 2018). Although these numbers vary considerably depending on location, collectively they indicate the awareness and significance of palliative services in Canadian hospitals.

The evolution of specialist hospital palliative care in Canada evidences the changes in palliative care generally within Western contexts, and comes with attendant benefits and challenges. First, similar to many other countries, Canadian palliative care has significantly extended its original focus on end-stage cancer patients (Government of Canada, 2018). In spite of symptom burden similarities, however, many conditions do not have the same trajectories of decline, particularly during acute exacerbations which bring patients to the hospital. Second, scope of practice has expanded to those still seeking curative and aggressive life-extending treatments (CHPCA, 2013). Reflecting the ongoing advance of treatment protocols in acute care settings, hospital palliative clinicians increasingly employ complex interventions as late-stage symptom management techniques to improve quality of life, even amongst the very old. These treatments can provide significant benefit; they can also increase symptom burden, prognostic uncertainty and/or the need for further interventions. Third, given the success of chronic disease management and the rise of multi-morbidity, patients may now be living with their symptoms for years, have survived previous ‘near-
death’ hospitalizations, and/or not been told in clear language that their condition is considered terminal or that they are sick enough to die (Krawczyk and Gallagher, 2016). Others may believe that a cure is “just around the corner”, that death is an enemy to be “fought at all costs”, and/or assert the “right” to pursue curative, experimental, or investigative treatment, regardless of prognosis or medical futility. Patients and families may disagree about care goals. Canadian clinicians have also recently begun to grapple with patients’ now-legal requests for medical assistance in dying, and they continue to debate the ethics and practicalities of referrals and/or administering the procedure (Gallagher, 2018). Fourth, location of care engenders numerous tensions. Canadian hospitals are publically characterized by their curative and life-sustaining aims, and entry as a patient into these institutions assumes extraordinary ‘life-saving’ measures will be employed to defeat death. Finally, similar to elsewhere, Canadian hospital palliative clinicians need to demonstrate their relevance and alignment with this acute care ethos, while also being aware of financial considerations to reduce length of stay and resource use (CSPCP, 2016; May et al., 2015).

One way to conceptualize these diverse considerations is to structure hospital palliative care within a micro-meso-macro analytical framework. On the micro-level, the priority of hospital palliative care is to improve patients’ and families’ quality of life and eventual death through expert physical symptom management within individualized therapeutic relations of person-centred care. On the meso-level, the priority of hospital palliative care is to improve quality of care through developing and delivering interventions which form clinicians’ day-to-day work and practice settings. On the macro-level, the priority of hospital palliative care is to standardize, extend, and make cost-efficient institutional care for those with advanced life-limiting illness. Ideally, clinicians are able to negotiate care outcomes that meet all of these system priorities and needs of heterogeneous stakeholders, yet as evidenced in the previous section, they may also face systemic complexities, challenges, and even contradictions in their attempts to do so. The purpose of this paper is to identify how hospital palliative clinicians anticipate and organize a patient’s dying trajectory within this multitude of considerations.
I draw on a diversity of theoretical sources to understand clinicians’ work of anticipating and planning a patient’s dying trajectory. First, I build on Strauss et al.’s (1982) definition of “trajectory work” to characterize all the work done by palliative clinicians over the course of a patient’s hospitalization as well as the impact on those involved with that work and its organization. Second, I am also indebted to Hochschild’s (1983) concept of “emotional labour” where management of emotional displays in self or others promotes ‘positive’ individual and group emotions that align with organizational imperatives. The concept of emotional labour has been applied a range of end of life care concerns, including nurses’ and patients’ co-construction of “symbiotic niceness” in palliative care (Li, 2004), to compare similarities between family and hospice care models (e.g. James, 1992), and the importance and emotional costs of end of life hospital care (Ryan and Seymour, 2013; Skilbeck and Payne, 2003; Stayt, 2009). However, there is a lack of consistent definition across this literature, and focusing on emotions can obscure the entanglement between the physical and cognitive aspects of feeling states. I therefore prefer the term “affective labour” (Hardt, 1999) to define the immaterial yet formative work of producing and modifying experience in oneself or another in service of achieving a desired state of being. Third, my framework also draws on political and economic considerations of affect, particularly from those who have examined the ways in which affective labour both reflects and creates “economies of affect” (Ahmed, 2004; Richard and Rudnyckyj, 2009) and/or “emotive institutions” (Buchbinder and Timmermans, 2014). These authors have provided compelling insights into the ways in which the experiences we claim as personal are generated within specific relations, contexts, and systems - economies of production.

Collectively, this theoretical underpinning enables me to structure an affective economy of hospital palliative care as a discursive system for producing and regulating experience in order to achieve specific outcomes of care. I invoke the term affective to highlight that the entirety of the patient, including her subjective ‘felt’ experiences and social relations, are marked as a legitimate site of clinical work. This concern for the affective totality of the patient is conjoined with the term economic to make visible how institutions such as hospitals manage the affective resources of
everyone involved in the provision and uptake of care. In this paper I give particular attention to 
clinicians’ affective labour, which I define as activities that naturalize and conjoin their biomedical 
interpretations of the patient’s nascent physical signifiers with their cultural authority to define the 
appropriate emotional orientations to these understandings. If successful, this labour produces six 
‘idealized’ outcomes of care that both reflect and re-create a larger affective economy of hospital 
palliative care. Similar to palliative care itself, the central functions of an affective economy of 
hospital palliative care can be parsed into three system levels. On the micro-level, it generates 
collective interpretations of the affective experiences of advancing disease and end of life which 
simultaneously mark the curative limits of medicine and its palliative benefits. On the meso-level, it 
re-establishes social and institutional order threatened by the temporal ambiguities and emotional 
excess common to dying and death. On the macro-level it extends the capacity of palliative principles 
to govern the biological process of dying for a broad range of hospital patients who are potentially 
sick enough to die. However, while palliative clinicians’ occupy a privileged position within this 
economy, these orientations are negotiated, validated, and/or contested through the affective labour of 
all involved parties.

In developing this framework, I build on 60 years of published ethnographic work identifying 
hospital clinicians as the central group responsible for mediating the experiences of dying amidst the 
paradox of uncertainty and hope offered by acute care interventions. This research has provided key 
insights into the biomedical values and resource considerations (Cassell, 2005; Sudnow, 1968; 
Zussman, 1992), communication techniques (Glaser and Strauss, 1965, 1968; Kaufman, 2005; Li, 
2004; Perakyla, 1991), institutional routines (Chapple, 2010; Seymour, 2001; Timmermans, 2000), 
and larger social norms (Bluebond-Lagner, 1978; Moller, 2000) which give shape to hospital dying 
trajectories under different structural conditions. Most – either explicitly or implicitly – also address 
ways in which clinicians shape patients’ and family members’ emotional states in order to achieve 
desired outcomes. However, there is very little ethnographic research specific to hospital palliative 
care, and no research has yet conceptualized palliative care as affective labour or as an affective 
system for achieving desired care outcomes on multiple system levels.
This paper draws from, and is specific to, a larger doctoral research project conducted over 11 months in two large acute care teaching hospitals in Western Canada during 2008-2009. Both hospitals are nationally recognized acute care, teaching, and research institutions. While Hospital “A” has twice the number of beds of Hospital “B”, both service a largely urban population and have achieved significant recognition for their palliative care services. Each consult team organized themselves slightly differently, but both structured their purpose as advising on pain and symptom management needs in advanced life-limiting illness, including goals of care conversations and discharge planning. If needed, this included facilitating transfer to their respective palliative units. Both teams were comprised of rotating palliative physicians (who also worked on the unit) and dedicated nurses. While physician or nurse consultants might only see a patient or family member once, they were also at times intensively involved in care. Consultation was frequently an initial step towards admission to the palliative unit, and both units admitted most patients from their own hospitals rather than from community settings. Both palliative units consisted of 12-16 beds, fluctuating dependant on staffing levels and other administrative considerations. Unit “A” utilized a care model where the patient’s preceding physician (GP, hospitalist, or specialist) continued primary care, in conjunction with comprehensive support from the unit-based palliative care team. The palliative clinicians in this unit often wound up providing the majority of patient care, and shortly after my study they switched to the same care model followed by Unit “B”, consisting of a rotating roster of palliative physicians and an interdisciplinary team who were responsible for the care of the patients once admitted to the unit.

Methods

This ethnographic study consisted of approximately 1,000 hours of fieldwork with physicians, nurses, social workers and other allied health professionals specializing in palliative care. I observed a range of daily clinical activities (e.g. medical rounds, individual bedside consultations, medical and family meetings), educational activities (e.g. lunch and learns, conference presentations, professional development seminars) and administrative tasks (e.g. bed count meetings, regional collaboration
meetings), and spent unstructured time in clinical (e.g. nurses’ stations) and semi-public areas (e.g. common rooms). Field notes were written when perceived to be unobtrusive and where possible in verbatim shorthand. Reflective notes were written at regular intervals throughout the day.

During this time I followed 36 patients, along with eight family members, to discharge or (more commonly) death, including chart reviews, and conducted at least one interview with patients or their family members. Interviews focused on illness history, coping with physical symptoms, emotional responses to illness, relationships with clinicians, decision-making, gaps in care and care goals. Interviews averaged one hour. I also conducted 43 semi-structured interviews throughout the study period with both palliative and non-palliative physicians, as well as with hospital administrators, using a mix of purposeful and opportunistic sampling. Topics included defining palliative care, evolution and challenges in providing care, ways of meeting those challenges, and (if relevant) techniques for developing therapeutic relationships, including dealing with difficult emotions. Interviews averaged 45 minutes. All interviews were digitally recorded and transcribed verbatim.

Study population

The senior clinical staff in Unit “A” were older and more experienced, with a lower turnover rate, than their counterparts at Unit “B”, and collectively had a somewhat more conventional perspective in limiting aggressive treatments than Unit “B”. There was a range of specialist palliative experience on the units and teams, from less than a year to more than 20 years; interview participants averaged close to five years of experience. Professional affiliations are detailed in Table 1. Approximately 85% of consult and unit staff were female. Unless otherwise indicated I use the generic term ‘clinician’ to encompass all those in medicine and allied health specializing in palliative care, as well as the pronoun ‘she’, to highlight both the interdisciplinary ethos and the predominance of female carers in palliative care.
Table 1: Professional affiliations of interview participants

<table>
<thead>
<tr>
<th>Staff interviews</th>
<th>Hospital “A”</th>
<th>Hospital “B”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative physicians</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Non-palliative physicians</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Palliative nurses</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Allied health professionals</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Administrators</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>19</td>
</tr>
</tbody>
</table>

Table 2 summarizes the basic demographics of the patients and family members who agreed to participate in the research, and who were recruited almost equally from consult teams and the units at both hospitals.

Table 2: Basic demographics of patient and family member participants

<table>
<thead>
<tr>
<th>Gender</th>
<th>Patient participants (n=28)</th>
<th>Family members (n=8)</th>
<th>Patients of family members (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>20 male/8 female</td>
<td>2 male/6 female</td>
<td>3 male/5 female</td>
</tr>
<tr>
<td>Average age</td>
<td>61 years/54 years</td>
<td>76 years</td>
<td>76 years</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td>23 cancer 2 COPD 2 End Stage Heart Failure 1 Amyotrophic Lateral Sclerosis (ALS)</td>
<td>n/a</td>
<td>6 cancer 1 Parkinson’s 1 Late stage dementia</td>
</tr>
<tr>
<td>Number of admissions (during study period)</td>
<td>1 admission (n=21) 2 admissions (n=4) &gt;2 admissions (n=3)</td>
<td>n/a</td>
<td>1 admission (n=7) 2 admissions (n=1)</td>
</tr>
<tr>
<td>Average total number of hospital days (during study period)</td>
<td>23 days</td>
<td>n/a</td>
<td>26 days</td>
</tr>
</tbody>
</table>

In consultation with clinicians, reasons for not approaching patients for participation included: cognitive issues, symptom burden, extreme psychosocial distress, impending discharge, imminently, dying, and/or not speaking English. If any of these issues were present, I asked about approaching family members (except in cases of pending discharge or imminently dying). My recruitment materials stated the goal of the study was to better understand how hospital clinicians communicate treatment options in advanced life-threatening illness. Written consent was obtained for all study participants, and I conducted several information sessions with unit and consult clinicians before the start of the project. While no clinician refused to participate, I worked particularly closely with 19 clinicians across the two hospital sites. Non-palliative clinicians and other hospital staff provided verbal consent for observing activities relevant to interactions with study participants. Posters informing all hospital staff of the researcher’s presence were also in place throughout the observation period. Ethics approval was granted by required University and Health Authority Ethics Committees.
Interview transcripts, field notes, and chart data were organized and coded in NIVO 10. All names have been changed.

Analysis

My analytic strategy was abductive and iterative (Timmermans and Tavory, 2012), employing a social constructionist approach (Green and Thorogood, 2018). I tacked back and forth between examining the empirical materials generated by the study to develop open codes and categories, and subjecting the materials to conceptual abstraction through focused coding based on pre-existing theoretical insights. Three perspectives of hospital palliative care triangulated my analytic strategy. The first was based on the ideal outcomes of palliative care reflected in ongoing public conversations and advocacy. The second came through reading research and literature on institutionalized end of life care that positioned these practices within a theoretical spectrum ranging from enabling new emancipatory subjectivities to regulating biomedical subjects. The third emerged through my fieldwork, which found that processes of care were often ambiguous and uncertain, and at times subject to intense negotiation by all involved parties. In constructing ‘analytically’ ideal outcomes I draw on Max Weber's conceptual “ideal types” (Kluge, 2000) as they reflect the archetypical micro-, meso-, and macro-level health system benefits of hospital palliative care, rather than to signify what clinicians’ necessarily understood as the desired outcome of care, or to typify what actually occurred in any particular instance.

Throughout the study, the development of analysis and concepts were discussed and refined with input from members of my dissertation committee. Study results were presented to participating clinicians, during and after the study period. No clinicians disagreed with the findings. Additionally, a senior palliative consultant from hospital “B” read the entirety of my dissertation manuscript. I discuss further reflexive aspects of this fieldwork elsewhere, including considerations of ‘studying up’, boundary blurring, and the ethical challenges in research with terminally ill participants (Krawczyk, 2015, 2017).
Findings

In detailing the outcomes of clinicians’ affective labour to organize a hospital dying trajectory, each outcome is further contextualized through reference to previous findings within ethnographic research and critical inquiry about institutional end of life care.

1. Co-authorship of disease trajectory: “You have to prepare for both”

In hospital palliative care it is often unclear until late in admission if the patient will survive to discharge, and clinicians commonly operate within heightened conditions of uncertainty. In these instances, patients and family member emotions such as hope play a powerful role in shaping direction of care. As the patient’s capacity to strive fluctuates, yet hope remains, clinicians attempt to proactively order this ambivalent affective terrain by presenting information in ways that parallel hope for a cure or life extension with hope for physical comfort, a dignified death, and emotional closure (Kaufman, 2005; Perakyla, 1991). This work of ‘reframing’ hope interprets physical signifiers in ways that orient patients and families away from the sick role, and the responsibility for getting better, towards mutual acknowledgement regarding the potential for terminal decline (Parker-Oliver, 2000).

Hospital “A”, May 2009, palliative care unit: Frank is a middle-aged patient on the unit who was recently diagnosed with a rapidly advancing cancer who wants to know about treatment options. Penny [his palliative physician] feels that the test results they are waiting for are going to indicate that he is too sick to receive any further chemotherapy. However, when she approached the topic previously, both Frank and his wife stated their belief that he’s sick in part because he’s not eating and want to know what they can do to increase his appetite. Before entering the room Penny states, “It’s so hard to reframe why he’s not eating…we need to reinforce that the reason that he’s not well enough for the chemo is because he’s too sick, not because he’s not eating.” Once in the room she does exactly that, informing them that the reason he is not eating is because he’s not feeling well rather than the other way around. She states that “It’s not your fault, it’s not your wife’s fault, and it’s not our fault. You don’t want to eat because the disease is so advanced and your tumour is very large and that’s why you don’t want to eat.” She then turns to the wife and says, “You need to switch
it around, in that he’s not eating because he’s not well. Yes?” The wife nods her head in agreement but doesn’t make eye contact. Penny continues, “You have to prepare for both; that you might not get well enough for chemotherapy or you may get well enough to go for it. Regardless of what happens, we will take care of you and make sure your pain is well controlled. Right now you’re not strong enough for the chemotherapy, and that’s not your fault, it’s the cancer’s fault. The cancer has grown and advanced, and you might get weaker.” She continues to discuss how they will manage his pain no matter what happens, after which there are a few moments of mutual silence before she stands up and says that she will return for further discussion once the test results are back.

Hope work privileges the clinician’s perspective of the emergent - but not yet solidified - physical state of the patient, in combination with her authority to define the ‘appropriate’ emotional orientation to these understandings. The subsequent bifurcation of hope ideally prepares patient and family members for potential entry into the “unscheduled status passage” (Glaser and Strauss, 1965b) of dying. Their acceptance of this entry will be exhibited, when and if needed, by a ‘common sense’ understanding that continuing aggressive treatments are futile and not in the best interest of the patient’s quality of life, and as such, co-produce the future social conditions for biological death.

Given the prognostic uncertainties and ongoing interventions that commonly mark hospitalized dying, however, determining its physical attributes and temporal characteristics can be difficult for palliative clinicians to accomplish. Further, some critically ill patients and their families may wish to remain in the ambiguous space provided by prognostic uncertainty (Krawczyk and Gallagher, 2016; Timmermans, 1994). Hope work both validates ambiguity and attempts to collapse it. For patients experiencing potentially irreversible decline, clinicians’ referencing the uncertainty of the disease process constructs a liminal status - not (yet) dying, but marked with the framing rules that acknowledge its imminent possibility. Further, in constructing the disease as having agency outside of medical mastery, hope work both marks the curative limits of medicine and its palliative benefits (Perakyla, 1991). As the above vignette indicates however, mutual agreement of disease trajectory is ambivalent, actively negotiated, and can be marked by competing claims to narrative authority.

2. Awareness and acknowledgement of dying trajectory: “As things progress”
Communicating knowledge that a patient is nearing end of life can be challenging for hospital clinicians, even for those specially trained in palliative care. In my research, even as palliative clinicians became increasingly certain of the patient’s imminent terminal decline, they often used conversational techniques which relied upon but did not necessarily explicitly refer to an “open awareness” (Glaser and Strauss, 1965) that the patient was dying.

Hospital “B”, June 2009, consult visit: Sally [the palliative consultant] was talking earlier this week with Thomas [a patient with advanced ALS who hospital staff do not expect to survive to discharge]. Before we go into his room for a scheduled visit, Sally recounts the previous conversation where she told him that he needs to increase his use of morphine “to ease his discomfort”. He typed in the word “terror” into his communication device, and also asked if he could pick a day and end it all. I ask what she thinks he is anxious about, and she says she thinks it is caused by the breathing issues, but that she believes he’s at peace about dying as he’s talked about having a life-limiting illness. Once inside the room, after a brief review of his current symptom management, she tries to guide the conversation to increasing his sedation to reduce his anxiety about being short of breath. Her language seemed vague and non-specific, but at the same time guiding in use of terms such as “in my experience,” “in the future,” “as things progress,” and saying “some people prefer to be more sedated for their symptoms.” He doesn’t respond to those prompts, instead focusing on the possibility of stabilization [referencing an intervention suggested by a resident], returning home, and spending time with his boyfriend and dogs. It was clear that this was frustrating Sally, but she was also respectful and backed off, saying they’d “wait and see,” and then changing the subject.

Ideally, palliative clinicians are able to generate an interactional context where “the patient, after a series of encounters that lead her to accept the inevitability of death, recognizes this inevitable outcome and thus renders herself unproblematic” (May, 1992: 596). In turn, the patient is afforded the opportunity to actively shape their experience of dying, thereby maximizing their comfort and dignity. The resulting clinical decision-making can then be framed as reflecting the patient’s (or family members’) preference. Yet, as Thomas’s case evidences, and as others have also highlighted, awareness is best envisioned as an enmeshing of multiple actors within ambivalent and shifting “webs
of conscious knowledge and emotional responses” (Mamo, 1999: 33; Timmermans, 1994) which may
require ongoing negotiation up to, or near, the point of death.

3. Naturalizing direction and outcomes of care: “It’s about simplifying things”

Hospital palliative clinicians are increasingly continuing and/or initiating acute interventions,
justified in the name of improved quality of life. Consequently may deal with, and even replicate, the
same conundrum experienced by other hospital specialists, where patients’ lives can be extended
through aggressive medical intervention, yet who report poor quality of life and cannot be discharged.

One way that palliative clinicians attempt to expedite movement through this liminal zone is by
harnessing drugs and medical technologies to mimic a ‘natural’ dying process.

Hospital “B”, February 2009, weekly palliative care unit rounds: Two senior physicians are
discussing Joan, a symptomatically unstable patient who has been on the unit for almost a month, and
who has been repeatedly advocating for further aggressive interventions.

Dr. A: I think she may be dwindling now; she’s losing hope [about getting strong enough for a new
treatment] and she’s talking about letting things go.

Dr. B: Well she still has her [tube] feeds, and her IV is going at a rip-roaring speed.

Dr. A: Should we discontinue the IV?

Dr. B: Well, we’ll talk to her about it and taper it down. If we reduce the IV the problem is that we’re
giving her a lot of medications through it. We would have to switch them. How much is she still
vomiting?

Dr. A: It’s decreased quite a bit, but she’s having shortness of breath.

Dr. B: If you say to her that we’re decreasing her IV, she’s going to say she’ll get dehydrated, and her
urine will be dark, so it’s going to be a real process to parallel decreasing the IV with her decreasing
health…It’s very hard; this is really challenging…The question to ask her is where she wants this to
go? Does she feel she wants to preserve her current quality of life or take control over her IV and
meds? It’s going to be a slow process of dropping the meds. Let’s start by saying ‘you’re not nauseous anymore, so let’s drop that medication’.

Dr. A: I’ll talk to her today and see how she deals with it.

Dr. B: OK, we have a plan…it’s about simplifying things, to make it easier and more comfortable to her.

Palliative clinicians are responsible for delineating interventions and treatment plans ‘appropriate’ to where the patient is along their individual disease trajectory, to the acute care setting, and to the patient’s (or designates’) wishes, even within conditions of uncertainty. Establishing a treatment plan also functions as an attempt to collapse this uncertainty, temporally and physically anchoring the patient within (or outside of) a dying trajectory. As the above conversation indicates, clinicians’ ability to “simplify” care in these instances may depend on the complex affective work of ‘aligning’ specific clinical titration techniques to the individual’s nascent physical signs, thereby providing the foundation of a mutually agreed dying trajectory. Unlike medical aid in dying, the goal of alignment work is part and parcel of hospital clinicians’ everyday work with the critically ill (Chapple, 2010; Timmermans, 2000; Seymour, 2001), evidencing the increasing closeness between hospital palliative care and other forms of acute care. Similar to other hospital contexts, palliative clinicians’ alignment work is done in service of naturalizing a move towards death within an institutional space that can radically extend quantity, if not always quality, of life, and helps to ensure that clinicians’ decisions “have no perceived causative link to death” (Seymour, 2000:1241).

4. Ensuring a minimum of social disruption: “They are also taking care of me”

Palliative care structures the patient’s closest social ties as part of the “unit of care” and even the “hidden patient” (Kristjanson and Aoun, 2004), where family and friends are not only involved in care planning, but are themselves potential beneficiaries of palliative care. Consequently, the patient is only one nodal point in clinicians’ work to organize a patient’s dying process. In hospital palliative care, clinicians’ interpret individual experiences within this “unit of care” by rendering them through
normative psychological frames built on a collective repository of difficult but ‘common’ experiences at the end of life.

Hospital “A”, December 2008, palliative care unit: Sarah, the daughter of a newly admitted patient, is extremely upset with news that her mother will probably not regain consciousness, and is likely close to death. She keeps requesting aggressive therapies, openly states that she is “angry” at Rita [the palliative physician] for “not doing enough,” and is often at the nursing station strenuously requesting consultation with other specialists as she feels her mother’s breathing indicates distress.

Two days later I have a chance to talk with Rita and ask how the daughter is doing. She laughs and says, “We had a long talk, so no more inappropriate behaviour, and she understands medically why we are not going to [give desired invasive intervention]. She’s becoming institutionalized—I swear we do that so well.” Shortly after this exchange, in an interview with Sarah, I ask about her relationship with the clinicians. She replies that, “The people on the ward are taking care of her [mother] but they are also taking care of me, so that’s made it easier for me to settle...They just treat me like a next door neighbour. It’s kind of an informal comfortable atmosphere that they create and foster. For me it’s been a positive experience... [Before] I hadn’t been able to say that I wanted my mother to go [die], to have no more suffering and because I felt bad for having those thoughts I was getting angry (she begins to cry)...I confessed this to Rita and she told me ‘Don’t feel guilty-you want her to go for all the right reasons’, which gave me permission to verbalize it, and I don’t feel like anyone is judging me for that.”

Palliative care is an important practice for making visible and legitimatizing forms of affective distress about the end of life that previously have been ignored, pathologized, and/or seen as moral weakness. Clinicians’ work to resolve emotional ‘disorder’ is labour that names, gives meaning to, and thereby validates the (at times) overwhelming complexity and weight of emotions that commonly attend end of life. The use of psycho-normative framing rules, however, is a double-edged sword. Those who do not conform to the emotional expectations within an ‘appropriate’ timeline may face the stigma of emotional co-morbidity; being labelled as ‘depressed’, in ‘denial’ and/or are understood to require further psychological interventions (Fischer et al., 2000). Hospital palliative
care can therefore be conceptualized as the affective labour to order the individual physical body and
the emotionally disordered social body at end of life (Lawton, 1998; Philpin, 2007). Through the
labour of interpreting and normalizing the affective states of the patient and her social network,
clinicians are able not only to compassionately ensure a minimum of social disruption, but also
efficiently organize the “sentimental order” of care settings (Glaser and Strauss, 1968).

5. Efficient and compassionate: “We are relentless in a non-intrusive way”

Hospital palliative care is framed as being able to achieve desirable care outcomes not only in
relation to the patient and her social network, but also in relation to other hospital clinicians, the
hospital itself, and broader health care systems. One key way that clinicians can evidence the
institutional and system-wide benefits of hospital palliative care is through demonstrating their ability
to expedite symptomatically challenging and/or potentially long-stay patients to home or hospice
discharge. At the same time, patients and families may, for various reasons, wish to remain in an acute
care setting as death approaches. Clinicians can then be faced with the challenge of providing
compassionate individualized care in tandem with efficient transitions. In the interview excerpt below,
a senior social worker from Hospital “A” identifies how she attempts to proactively negotiate these, at
times divergent, priorities.

“If you can respond to their concerns [about discharge] families often become very reasonable.
Most families are advocating and need to know we’re doing everything we can. That we’re not going
to abandon her, or any patient… I spend hours challenging families [about appropriateness of a
hospice admission] with no response, so instead it’s just better to say that you’ll come back in a
couple of days. And when you go back, at that point the patient is often ahead of you, thinking about
hospice. That’s why it is so huge if we are able to be pro-active in conversations and then there are no
crisis or egos… We are doing it in a compassionate way. But we’re also quite efficient and try to be on
top of the current information about the patient, so we are relentless in a non-intrusive way. So you
make future meetings where you’re working on the patient but also the family as well. Usually one of
the two of them [patient or family] is already thinking that way, and we have to explore the conflict
between the two positions, and try to come up with transition options so they feel safe”.

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While the dual identification of compassionate and efficient can cause relational tensions, both components are integral to clinicians’ professional identity, as is evidenced in other studies (Li, 2004; James 1992). The affective labour required to be simultaneously compassionate and efficient, then, not only maintains local social order and is generative of professional identity, but they can also be read as attempts to advance larger organizational care priorities, including the expansion of palliative care (Floriani and Schramm, 2012).

6. Increased specialist intervention and new forms of knowledge: “It’s like solving a puzzle”

Advocates of palliative care have laid claim to an ambitious territorial scope. In hospital settings this is evidenced through the promotion of two developmental pathways. The first is to increase the reach of specialist practices, encompassing new drugs and medical technologies, as well as applying these to new patient populations. This shift is evidenced in the perspective of a clinical nurse specialist from Hospital “B”.

Gina: [Palliative care] is developing; it’s becoming more of a specialty. It’s a more specialized area in medicine; it’s evolving and maturing and growing and has more confidence. It’s becoming more technical so it’s not just withdrawing things and giving opioids and letting people die; it’s more going after things and investigating and trying different approaches sometimes…I really enjoy that part of it; it’s like solving a puzzle.

Scholars interested in end of life have shown how new knowledge, expertise, and practices may occur even in adverse circumstances where the patient does not have a ‘good’ death. Instead of these deaths destabilizing the need for medical intervention, problematic deaths signify the need of further expertise, where the hope is that increased interventions will improve future deaths (Perakyla, 1991; Timmermans, 2005). Yet integration of palliative care across acute settings can also paradoxically function to re-establish its reputation as a speciality specific to the very end of life, as reflected in the following conversation in Hospital “A”.

Consultant 1: It’s the ones where the family wants to keep the person alive to the last nanosecond possible on all kinds of life support and the patient is suffering, and we get called in to solve it.
Consultant 2: Or when you go to a unit late in the evening to do the new consult and the file is 5 inches thick and the person has been in and out of the ICU and nobody is really talking about anything because they've been on this trajectory of active, active interventions and suddenly they call palliative care and we're supposed to make sense of it all.

Consultant 1: [Sarcastically impersonating a non-palliative clinician] Can you please tell the patient that they're dying? [Reverting back to normal voice] Uh, no (laughs).

This leads to the second developmental pathway: diffusing specialist knowledge throughout health systems as a whole, rather than relying on specialist expertise. One particularly clear example of this is the growing interest in palliative ‘assessment’ tools, many of which have been developed by palliative specialists in the hospital setting, to assist non-palliative clinicians identify patients who would benefit from generalist palliative care (Maas et al., 2013). In generating new forms of specialist knowledge for managing both current and future dying bodies, palliative clinicians have had both significant success and challenges in expanding knowledge and expertise across diverse populations of hospitalized patients.

Discussion

An affective economy of hospital palliative care

Using data from two hospitals in Western Canada, my analysis identified six ideal care outcomes that both reflect and structure hospital palliative clinicians’ attempts to organize a dying trajectory. The first outcome is to generate mutual agreement of where current physical symptoms locate a patient within the general arc of a potential dying trajectory. If this is accomplished, clinicians can employ a script that proactively locates anticipated further decline within a double biomedical narrative; beyond the ability of medicine to cure but within its ability to palliate. This produces the conditions for the second ideal outcome: implicit acknowledgment, if and when necessary, that end of life is approaching. Acknowledgement also offers patients and families an opportunity to shape the dying process. Third, this affective work naturalizes direction and outcomes of care practices which facilitate transitions along the institutional care pathway amidst the prognostic uncertainties that
increasingly mark hospitalized dying. This leads to the fourth outcome, where social dislocations
threatened by the dying process are sutured to a collective experience through framing individual
patient and family member experiences as part of the ‘common’ experiences of dying, thereby
preserving the long-term stability of organizations and relationships. In turn, this enables the fifth
outcome, where by achieving the previous outcomes, clinicians are able to identify as simultaneously
compassionate and efficient. This promotes the sixth outcome: ensuring the need for increased
specialist intervention, as well as expansion of generalist palliative approaches, to all advanced life-
limiting conditions. When successful in achieving all six outcomes, clinicians are able to proactively
facilitate co-authored understandings that on the micro-level generate affective experiences of end of
life which mark the curative limits of medicine and its palliative benefits, re-establish social and
institutional order threatened by temporal ambiguities and emotional excess on the meso-level, and on
the macro-level extend the capacity of palliative expertise and principles to order the biological
processes of dying across hospital settings. I conceptualize all of these as components of an affective
economy of hospital palliative care, visualized in Figure 1. Overall, my analysis offers a theoretically
informed, empirically grounded model of the multiple entanglement between experiences of the
individual body, concerns that structure the social body, and the larger body politic (Schep-Hughes
An affective economy of hospital palliative care is constituted through the affective labour of everyone involved in the provision and uptake of this specialist form of care. Given palliative clinicians’ privileged location within this economy, and the predominance of their work with patients facing near-term and in-hospital mortality, I have focused on their affective labour to anticipate and plan a dying trajectory. My findings illustrated how this work conjoins palliative clinicians’ biomedical interpretations of the patient’s nascent physical signifiers with their cultural authority to define the appropriate emotional orientations to these understandings. Findings also evidenced, however, that the success of this work was profoundly shaped by multiple - and at times conflicting – interests and priorities, including competing illness narratives, sustained prognostic uncertainty, the acute care context, and the care goals of other hospital clinicians.

Relevance to policy and practice

While in-depth ethnographic studies are not traditionally designed for transferability, my analysis provides a model, and empirical insights, which may benefit future development of palliative care policies and services elsewhere. First, it evidences how the organization of dying trajectories...
continue to structure clinicians’ everyday work, even as they prioritize acute physical symptom management for purposes of stabilization and discharge. Second, this model articulates how infrastructures of hospital palliative care are comprised of multiple – and at times divergent – priorities and interests. In so doing, an affective economy framing makes clear that ambiguity, negotiation, and even conflict are constitutive components of hospital palliative care, rather than reflecting a failure of practice or uptake of principles. Third, it highlights that the ‘immaterial’ aspects of clinicians’ work determines not only their clinical decision-making to successfully organize a dying trajectory, but also their ability to meet the heterogeneous system priorities and individual perspectives detailed here. Finally, an affective economy of hospital palliative care evidences how practice tensions emerge partly as a result of the successes in mainstreaming palliative care.

Some may argue that clinician’s affective labour skills are no longer necessary as hospital palliative care is now primarily specialist acute physical symptom management in service of stabilizing patients for discharge to another institutional or community setting. Yet as evidenced elsewhere (Bruera et al., 2015; CIHI, 2018), many patients receiving hospital palliative care do not survive to discharge. Further, while clinical expertise in symptom management is a fundament of palliative care, affective relations are the mechanism and context within which conversations and decisions about clinical care take place (Canning et al., 2007; Sampson et al., 2014) and are repeatedly identified by patients and families as a key signifier of quality end of life hospital care (Masel et al., 2016; Virdun et al., 2015). Others may rightly point out that many hospital patients only receive palliative care once they are in the last days of life and/or are no longer fully lucid; so far advanced in their biological decline that a dying trajectory no long needs ordering, only terminal physical symptom management. However, my findings indicate that even in these instances, interactions with family members and/or requests for palliative services evidence demand for specific forms of expertise to organize the ends of life for others involved in the provision and uptake of care. Finally, it is also important to note that while only a subset of hospital patients receive palliative care or care informed by a palliative approach, it is an authorized ideal of what care services should be provided, and the standard to which other hospital end of life care is held.
This study is specific to a single geographic region in Western Canada, and field work was conducted a decade ago. However, research included two differently sized hospitals with different models of care, and the author engaged in member checking regarding analytical results. While future research is required to determine its relevance to other hospital settings and regions, study findings have been contextualized within current considerations reflected in palliative care literature internationally.

**Conclusion**

This paper presented a theoretically innovative and empirically grounded model of hospital palliative clinicians’ work to anticipate and organize patients’ dying trajectories. I articulated how this work was given shape through affective labour, enabling clinicians to naturalize and conjoin their biomedical interpretations of the patient’s nascent physical signifiers with their cultural authority to define the appropriate emotional orientations to these understandings. The key finding is that this labour is crucial not only to organize appropriate care for those who are nearing end of life, but also to organize a heterogeneous range of priorities shaping clinicians’ daily work, professional identities, and the expansion of palliative care. Collectively, my analysis and corresponding model enable substantively new insight into how clinicians attempt to meet social and organizational mandates that necessary include, but extend well beyond, the individual patient and her immediate social network. To the best of the author’s knowledge, it is the first study to use the concepts of affective labour and affective economies to understand how clinicians negotiate and “simplify” the complexities that constitute the everyday work of hospital palliative care.
References


Virdun, C., Luckett, T., Davidson, P. M., Phillips, J. (2015). Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. Palliative medicine, 29(9), 774-796. https://doi.org/10.1177/0269216315583032


Table 1: Professional affiliations of interview participants

<table>
<thead>
<tr>
<th>Staff interviews</th>
<th>Hospital “A”</th>
<th>Hospital “B”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative physicians</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Non-palliative physicians</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Palliative nurses</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Allied health professionals</td>
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<td>2</td>
</tr>
<tr>
<td>Administrators</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>24</strong></td>
<td><strong>19</strong></td>
</tr>
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</table>

Table 2: Basic demographics of patient and family member participants

<table>
<thead>
<tr>
<th></th>
<th>Patient participants (n=28)</th>
<th>Family members (n=8)</th>
<th>Patients of family members (n=8)</th>
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</thead>
<tbody>
<tr>
<td>Gender</td>
<td>20 male/8 female</td>
<td>2 male/6 female</td>
<td>5 male/3 female</td>
</tr>
<tr>
<td>Average age</td>
<td>61 years/54 years</td>
<td>/76 years</td>
<td>/76 years</td>
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<tr>
<td>Primary diagnosis</td>
<td>23 cancer</td>
<td>/n/a</td>
<td>6 cancer</td>
</tr>
<tr>
<td></td>
<td>2 COPD</td>
<td>/n/a</td>
<td>1 Parkinson’s</td>
</tr>
<tr>
<td></td>
<td>2 End Stage Heart Failure</td>
<td>/n/a</td>
<td>1 Late stage dementia</td>
</tr>
<tr>
<td></td>
<td>1 Amyotrophic Lateral Sclerosis (ALS)</td>
<td>/n/a</td>
<td></td>
</tr>
<tr>
<td>Number of admissions (during study period)</td>
<td>1 admission (n=21)</td>
<td>/n/a</td>
<td>1 admission (n=7)</td>
</tr>
<tr>
<td></td>
<td>2 admissions (n=4)</td>
<td>/n/a</td>
<td>2 admissions (n=1)</td>
</tr>
<tr>
<td></td>
<td>&gt;2 admissions (n=3)</td>
<td>/n/a</td>
<td></td>
</tr>
<tr>
<td>Average total number of hospital days (during study period)</td>
<td>23 days</td>
<td>/n/a</td>
<td>26 days</td>
</tr>
</tbody>
</table>
Figure 1: Components of an effective economy of hospital palliative care
• Hospital palliative care is shaped by diverse health system priorities
• Clinicians use affective labour to meet patient, family member, and system needs
• Hospital palliative care can be understood and modeled as an “affective economy”
• Negotiation and ambivalence are constitutive features of hospital palliative care