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

Author: Dr. Marian Krawczyk**,** Lord Kelvin Adam Smith Fellow**,** School of Interdisciplinary

Studies**,** Glasgow End of Life Studies Group

Author affiliation: University of Glasgow

Declaration of interest:
No conflict of interest to declare.

Address:
Dumfries Campus

University of Glasgow

Rutherford/McCowan Building

Crichton University Campus

Dumfries DG1 4ZL

Scotland

Email:

Marian.Krawczyk@glasgow.ac.uk

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

2   **Abstract:**

3   Hospitals remain the most common location of death in a significant number of countries, and

4   specialist palliative care is positioned as a crucial resource for improving hospital care for those

5   nearing end of life. Little is known, however, about a substantive aspect of this work: how hospital

6   palliative clinicians anticipate and organize a patient's dying trajectory. In this paper I draw from a

7   larger original ethnographic research study of palliative specialists in two Canadian hospitals.

8   Abductive analysis resulted in framing their work as affective labour, both reflecting and re-creating a

9   larger affective economy shaping the affective states of everyone involved in the provision and uptake

10   of care. I articulate six analytically ideal outcomes of clinicians' affective labour that organize end of

11   life, including: 1) proactive co-authorship of disease trajectory; 2) mutual acknowledgement of a

12   dying trajectory; 3) naturalizing direction and outcome of care, 4) ensuring a minimum of social

13   disruption, 5) identification as compassionate and efficient care providers, and 6) increased specialist

14   knowledge and interventions. In so doing, clinicians' practices become understandable as labour to

15   meet a diversity of – at times conflicting – individual, societal, and organizational mandates that

16   necessarily include, but extend well beyond, the patient and her immediate social network. This is the

17   first study to consider hospital palliative care as an affective economy, and presents a theoretically

18   innovative and empirically grounded model to advance new ways of conceptualizing hospital

19   palliative care. I conclude by considering how this model, and the unique insights it affords, can

20   inform the future development of end of life care in hospital settings.

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

22   affective labour

23   **Introduction**

24   Public discussions about end of life care often start from the premise that people do not want

25   to spend their last days of life or die in an acute hospital setting. Yet even as rates of hospital dying

26   decline in some countries, it remains the most common location of death in a significant number of

27 countries globally (Broad et al., 2013), unavoidable in many instances (Gott and Robinson, 2018), and

28 for some a preferred place of care, particularly as death nears (Gerrard et al., 2011; Robinson et al.,

29 2016). The overall importance of hospitals at the end of life is further evidenced by national cohort

30 studies that document 15-30 percent of hospital patients as being in the last year of life (Clark et al.,

31 2014; Gott et al., 2017), with an increase of admissions and progressively greater care needs for those

32 in the last months of life (Rosenwax et al., 2011; Bekelman et al., 2016). National-level policy

33 documents reflect this discordance, continuing to problematize hospitals as a suitable place for end of

34 life care while simultaneously acknowledging that care for dying people will remain a core remit for

35 the "foreseeable future" (Robinson et al., 2016). Regardless of perspectives that frame hospitals as

36 good or bad *places* for end of life, there is a common agreement about the urgent need to deliver

37 appropriate end of life *care* in these settings.

38 The World Health Organization describes palliative care as:

39 "…an approach that improves the quality of life of patients and their families facing the

40 problem associated with life-threatening illness, through the prevention and relief of

41 suffering by means of early identification and impeccable assessment and treatment of

42 pain and other problems, physical, psychosocial, and spiritual" (2019).

43 Specialist palliative care and a more generalized palliative approach are championed as 'best

44 practice' for patients facing a greater risk of near-term dying than the general hospital population

45 (Dalgaard et al., 2014; Gott et al., 2013). Generalist palliative care, which employs the basic precepts

46 of palliative care (e.g. non-specialist management of pain, symptoms, and psychosocial distress, as

47 well as discussion of prognosis and goals of treatment), is ideally provided by all hospital clinicians

48 working with critically ill patients. However, numerous barriers and challenges in providing generalist

49 hospital palliative care have repeatedly been identified (Dalgaard et al., 2014; Gott et al., 2012).

50 Specialist palliative care is provided by clinicians who have undergone training in palliative care, and

51 is predominantly focused on supporting critically ill and symptomatically complex patients who are

52 likely nearing end of life. Models of specialist hospital palliative care vary within and between

53 regions and countries. Specialists may function as consultants, either individually or within

54 interdisciplinary consult teams, acting primarily in an advisory capacity to supplement a patient's

55 care. Other settings have high-volume specialist units or dedicated beds, where palliative clinicians

56 and/or specialist teams assume responsibility for patient care. Depending on resources, hospitals may

57 combine both models. Specialists by necessity work with those defined by exceptionally high rates of

58 near-term and in-hospital mortality, and if unavoidable, their role includes anticipating and planning a

59 hospitalized death.

60 *Hospital palliative care in Canada*

61 Approximately 60% of Canadians die in hospital; similar to other Western nations leading

62 causes of death include cancer, heart, cerebrovascular and respiratory disease (Statistics Canada,

63 2018). A recent national study found that of the patients who died in acute care hospitals, 44 percent

64 were designated as palliative at some point of their admission, and 25 percent overall received

65 primarily palliative care (CIHI, 2018). Although these numbers vary considerably depending on

66 location, collectively they indicate the awareness and significance of palliative services in Canadian

67 hospitals.

68 The evolution of specialist hospital palliative care in Canada evidences the changes in

69 palliative care generally within Western contexts, and comes with attendant benefits and challenges.

70 First, similar to many other countries, Canadian palliative care has significantly extended its original

71 focus on end-stage cancer patients (Government of Canada, 2018). In spite of symptom burden

72 similarities, however, many conditions do not have the same trajectories of decline, particularly

73 during acute exacerbations which bring patients to the hospital. Second, scope of practice has

74 expanded to those still seeking curative and aggressive life-extending treatments (CHPCA, 2013).

75 Reflecting the ongoing advance of treatment protocols in acute care settings, hospital palliative

76 clinicians increasingly employ complex interventions as late-stage symptom management techniques

77 to improve quality of life, even amongst the very old. These treatments can provide significant

78 benefit; they can also increase symptom burden, prognostic uncertainty and/or the need for further

79 interventions. Third, given the success of chronic disease management and the rise of multi-

80 morbidity, patients may now be living with their symptoms for years, have survived previous 'near-

81 death' hospitalizations, and/or not been told in clear language that their condition is considered

82 terminal or that they are sick enough to die (Krawczyk and Gallagher, 2016). Others may believe that

83 a cure is "just around the corner", that death is an enemy to be "fought at all costs", and/or assert the

84 "right" to pursue curative, experimental, or investigative treatment, regardless of prognosis or medical

85 futility. Patients and families may disagree about care goals. Canadian clinicians have also recently

86 begun to grapple with patients' now-legal requests for medical assistance in dying, and they continue

87 to debate the ethics and practicalities of referrals and/or administering the procedure (Gallagher,

88 2018). Fourth, location of care engenders numerous tensions. Canadian hospitals are publically

89 characterized by their curative and life-sustaining aims, and entry as a patient into these institutions

90 assumes extraordinary 'life-saving' measures will be employed to defeat death. Finally, similar to

91 elsewhere, Canadian hospital palliative clinicians need to demonstrate their relevance and alignment

92 with this acute care ethos, while also being aware of financial considerations to reduce length of stay

93 and resource use (CSPCP, 2016; May et al., 2015).

94   One way to conceptualize these diverse considerations is to structure hospital palliative care

95 within a micro-meso-macro analytical framework. On the micro-level, the priority of hospital

96 palliative care is to improve patients' and families' quality of life and eventual death through expert

97 physical symptom management within individualized therapeutic relations of person-centred care. On

98 the meso-level, the priority of hospital palliative care is to improve quality of care through developing

99 and delivering interventions which form clinicians' day-to-day work and practice settings. On the

100 macro-level, the priority of hospital palliative care is to standardize, extend, and make cost-efficient

101 institutional care for those with advanced life-limiting illness. Ideally, clinicians are able to negotiate

102 care outcomes that meet all of these system priorities and needs of heterogeneous stakeholders, yet as

103 evidenced in the previous section, they may also face systemic complexities, challenges, and even

104 contradictions in their attempts to do so. The purpose of this paper is to identify how hospital

105 palliative clinicians anticipate and organize a patient's dying trajectory within this multitude of

106 considerations.

107

Hospital palliative care as an affective economy

109   I draw on a diversity of theoretical sources to understand clinicians' work of anticipating and

110   planning a patient's dying trajectory. First, I build on Strauss et al.'s (1982) definition of "trajectory

111   work" to characterize all the work done by palliative clinicians over the course of a patient's

112   hospitalization as well as the impact on those involved with that work and its organization. Second, I

113   am also indebted to Hochschild's (1983) concept of "emotional labour" where management of

114   emotional displays in self or others promotes 'positive' individual and group emotions that align with

115   organizational imperatives. The concept of emotional labour has been applied a range of end of life

116   care concerns, including nurses' and patients' co-construction of "symbiotic niceness" in palliative

117   care (Li, 2004), to compare similarities between family and hospice care models (e.g. James, 1992),

118   and the importance and emotional costs of end of life hospital care (Ryan and Seymour, 2013;

119   Skilbeck and Payne, 2003; Stayt, 2009). However, there is a lack of consistent definition across this

120   literature, and focusing on emotions can obscure the entanglement between the physical and cognitive

121   aspects of feeling states. I therefore prefer the term "affective labour" (Hardt, 1999) to define the

122   immaterial yet formative work of producing and modifying experience in oneself or another in service

123   of achieving a desired state of being. Third, my framework also draws on political and economic

124   considerations of affect, particularly from those who have examined the ways in which affective

125   labour both reflects and creates "economies of affect" (Ahmed, 2004; Richard and Rudnyckyj, 2009)

126   and/or "emotive institutions" (Buchbinder and Timmermans, 2014). These authors have provided

127   compelling insights into the ways in which the experiences we claim as personal are generated within

128   specific relations, contexts, and systems - economies of production.

129   Collectively, this theoretical underpinning enables me to structure an affective economy of

130   hospital palliative care as a discursive system for producing and regulating experience in order to

131   achieve specific outcomes of care. I invoke the term *affective* to highlight that the entirety of the

132   patient, including her subjective 'felt' experiences and social relations, are marked as a legitimate site

133   of clinical work. This concern for the affective totality of the patient is conjoined with the term

134   *economic* to make visible how institutions such as hospitals manage the affective resources of

135 everyone involved in the provision and uptake of care. In this paper I give particular attention to

136 clinicians' affective labour, which I define as activities that naturalize and conjoin their biomedical

137 interpretations of the patient's nascent *physical* signifiers with their cultural authority to define the

138 appropriate *emotional* orientations to these understandings. If successful, this labour produces six

139 'idealized' outcomes of care that both reflect and re-create a larger affective economy of hospital

140 palliative care. Similar to palliative care itself, the central functions of an affective economy of

141 hospital palliative care can be parsed into three system levels. On the micro-level, it generates

142 collective interpretations of the affective experiences of advancing disease and end of life which

143 simultaneously mark the curative limits of medicine and its palliative benefits. On the meso-level, it

144 re-establishes social and institutional order threatened by the temporal ambiguities and emotional

145 excess common to dying and death. On the macro-level it extends the capacity of palliative principles

146 to govern the biological process of dying for a broad range of hospital patients who are potentially

147 sick enough to die. However, while palliative clinicians' occupy a privileged position within this

148 economy, these orientations are negotiated, validated, and/or contested through the affective labour of

149 all involved parties.

150   In developing this framework, I build on 60 years of published ethnographic work identifying

151 hospital clinicians as the central group responsible for mediating the experiences of dying amidst the

152 paradox of uncertainty and hope offered by acute care interventions. This research has provided key

153 insights into the biomedical values and resource considerations (Cassell, 2005; Sudnow, 1968;

154 Zussman, 1992), communication techniques (Glaser and Strauss, 1965, 1968; Kaufman, 2005; Li,

155 2004; Perakyla, 1991), institutional routines (Chapple, 2010; Seymour, 2001; Timmermans, 2000),

156 and larger social norms (Bluebond-Lagner, 1978; Moller, 2000) which give shape to hospital dying

157 trajectories under different structural conditions. Most – either explicitly or implicitly – also address

158 ways in which clinicians shape patients' and family members' emotional states in order to achieve

159 desired outcomes. However, there is very little ethnographic research specific to hospital palliative

160 care, and no research has yet conceptualized palliative care as affective labour or as an affective

161 system for achieving desired care outcomes on multiple system levels.

162

163   This paper draws from, and is specific to, a larger doctoral research project conducted over

164 11 months in two large acute care teaching hospitals in Western Canada during 2008-2009. Both

165 hospitals are nationally recognized acute care, teaching, and research institutions. While Hospital "A"

166 has twice the number of beds of Hospital "B", both service a largely urban population and have

167 achieved significant recognition for their palliative care services. Each consult team organized

168 themselves slightly differently, but both structured their purpose as advising on pain and symptom

169 management needs in advanced life-limiting illness, including goals of care conversations and

170 discharge planning. If needed, this included facilitating transfer to their respective palliative units.

171 Both teams were comprised of rotating palliative physicians (who also worked on the unit) and

172 dedicated nurses. While physician or nurse consultants might only see a patient or family member

173 once, they were also at times intensively involved in care. Consultation was frequently an initial step

174 towards admission to the palliative unit, and both units admitted most patients from their own

175 hospitals rather than from community settings. Both palliative units consisted of 12-16 beds,

176 fluctuating dependant on staffing levels and other administrative considerations. Unit "A" utilized a

177 care model where the patient's preceding physician (GP, hospitalist, or specialist) continued primary

178 care, in conjunction with comprehensive support from the unit-based palliative care team. The

179 palliative clinicians in this unit often wound up providing the majority of patient care, and shortly

180 after my study they switched to the same care model followed by Unit "B", consisting of a rotating

181 roster of palliative physicians and an interdisciplinary team who were responsible for the care of the

182 patients once admitted to the unit.

183 **Methods**

184   This ethnographic study consisted of approximately 1,000 hours of fieldwork with physicians,

185 nurses, social workers and other allied health professionals specializing in palliative care. I observed a

186 range of daily clinical activities (e.g. medical rounds, individual bedside consultations, medical and

187 family meetings), educational activities (e.g. lunch and learns, conference presentations, professional

188 development seminars) and administrative tasks (e.g. bed count meetings, regional collaboration

189   meetings), and spent unstructured time in clinical (e.g. nurses' stations) and semi-public areas (e.g.

190   common rooms). Field notes were written when perceived to be unobtrusive and where possible in

191   verbatim shorthand. Reflective notes were written at regular intervals throughout the day.

192   During this time I followed 36 patients, along with eight family members, to discharge or

193   (more commonly) death, including chart reviews, and conducted at least one interview with patients

194   or their family members. Interviews focused on illness history, coping with physical symptoms,

195   emotional responses to illness, relationships with clinicians, decision-making, gaps in care and care

196   goals. Interviews averaged one hour. I also conducted 43 semi-structured interviews throughout the

197   study period with both palliative and non-palliative physicians, as well as with hospital administrators,

198   using a mix of purposeful and opportunistic sampling. Topics included defining palliative care,

199   evolution and challenges in providing care, ways of meeting those challenges, and (if relevant)

200   techniques for developing therapeutic relationships, including dealing with difficult emotions.

201   Interviews averaged 45 minutes. All interviews were digitally recorded and transcribed verbatim.

202   *Study population*

203   The senior clinical staff in Unit "A" were older and more experienced, with a lower turnover

204   rate, than their counterparts at Unit "B", and collectively had a somewhat more conventional

205   perspective in limiting aggressive treatments than Unit "B". There was a range of specialist palliative

206   experience on the units and teams, from less than a year to more than 20 years; interview participants

207   averaged close to five years of experience. Professional affiliations are detailed in Table 1.

208   Approximately 85% of consult and unit staff were female. Unless otherwise indicated I use the

209   generic term 'clinician' to encompass all those in medicine and allied health specializing in palliative

210   care, as well as the pronoun 'she', to highlight both the interdisciplinary ethos and the predominance

211   of female carers in palliative care.

212

213

214 *Table 1: Professional affiliations of interview participants*

Staff interviews	Hospital "A"	Hospital "B"
Palliative physicians	5	4
Non-palliative physicians	3	2
Palliative nurses	11	9
Allied health professionals	3	2
Administrators	2	2
Total	**24**	**19**

215

216   Table 2 summarizes the basic demographics of the patients and family members who agreed

217 to participate in the research, and who were recruited almost equally from consult teams and the units

218 at both hospitals.

219 *Table 2: Basic demographics of patient and family member participants*

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

220

221 In consultation with clinicians, reasons for not approaching patients for participation included:

222 cognitive issues, symptom burden, extreme psychosocial distress, impending discharge, imminently

223 dying, and/or not speaking English. If any of these issues were present, I asked about approaching

224 family members (except in cases of pending discharge or imminently dying). My recruitment

225 materials stated the goal of the study was to better understand how hospital clinicians communicate

226 treatment options in advanced life-threatening illness. Written consent was obtained for all study

227 participants, and I conducted several information sessions with unit and consult clinicians before the

228 start of the project. While no clinician refused to participate, I worked particularly closely with 19

229 clinicians across the two hospital sites. Non-palliative clinicians and other hospital staff provided

230 verbal consent for observing activities relevant to interactions with study participants. Posters

231 informing all hospital staff of the researcher's presence were also in place throughout the observation

232 period. Ethics approval was granted by required University and Health Authority Ethics Committees.

233   Interview transcripts, field notes, and chart data were organized and coded in NIVO 10. All names

234   have been changed.

235   *Analysis*

236   My analytic strategy was abductive and iterative (Timmermans and Tavory, 2012), employing

237   a social constructionist approach (Green and Thorogood, 2018). I tacked back and forth between

238   examining the empirical materials generated by the study to develop open codes and categories, and

239   subjecting the materials to conceptual abstraction through focused coding based on pre-existing

240   theoretical insights. Three perspectives of hospital palliative care triangulated my analytic strategy.

241   The first was based on the ideal outcomes of palliative care reflected in ongoing public conversations

242   and advocacy. The second came through reading research and literature on institutionalized end of life

243   care that positioned these practices within a theoretical spectrum ranging from enabling new

244   emancipatory subjectivities to regulating biomedical subjects. The third emerged through my

245   fieldwork, which found that processes of care were often ambiguous and uncertain, and at times

246   subject to intense negotiation by all involved parties. In constructing 'analytically' ideal outcomes I

247   draw on Max Weber's conceptual "ideal types" (Kluge, 2000) as they reflect the archetypical micro-,

248   meso-, and macro-level health system benefits of hospital palliative care, rather than to signify what

249   clinicians' necessarily understood as the desired outcome of care, or to typify what actually occurred

250   in any particular instance.

251   Throughout the study, the development of analysis and concepts were discussed and refined

252   with input from members of my dissertation committee. Study results were presented to participating

253   clinicians, during and after the study period. No clinicians disagreed with the findings. Additionally, a

254   senior palliative consultant from hospital "B" read the entirety of my dissertation manuscript. I

255   discuss further reflexive aspects of this field work elsewhere, including considerations of 'studying

256   up', boundary blurring, and the ethical challenges in research with terminally ill participants

257   (Krawczyk, 2015, 2017).

258

259   **Findings**

260   In detailing the outcomes of clinicians' affective labour to organize a hospital dying

261   trajectory, each outcome is further contextualized through reference to previous findings within

262   ethnographic research and critical inquiry about institutional end of life care.

263   *1. Co-authorship of disease trajectory: "You have to prepare for both"*

264   In hospital palliative care it is often unclear until late in in admission if the patient will survive to

265   discharge, and clinicians commonly operate within heightened conditions of uncertainty. In these

266   instances, patients and family member emotions such as hope play a powerful role in shaping

267   direction of care. As the patient's capacity to strive fluctuates, yet hope remains, clinicians attempt to

268   proactively order this ambivalent affective terrain by presenting information in ways that parallel hope

269   for a cure or life extension with hope for physical comfort, a dignified death, and emotional closure

270   (Kaufman, 2005; Perakyla, 1991). This work of 'reframing' hope interprets physical signifiers in

271   ways that orient patients and families away from the sick role, and the responsibility for getting better,

272   towards mutual acknowledgement regarding the potential for terminal decline (Parker-Oliver, 2000).

273   *Hospital "A", May 2009, palliative care unit: Frank is a middle-aged patient on the unit who was*

274   *recently diagnosed with a rapidly advancing cancer who wants to know about treatment options.*

275   *Penny [his palliative physician] feels that the test results they are waiting for are going to indicate*

276   *that he is too sick to receive any further chemotherapy. However, when she approached the topic*

277   *previously, both Frank and his wife stated their belief that he's sick in part because he's not eating*

278   *and want to know what they can do to increase his appetite. Before entering the room Penny states,*

279   *"It's so hard to reframe why he's not eating…we need to reinforce that the reason that he's not well*

280   *enough for the chemo is because he's too sick, not because he's not eating." Once in the room she*

281   *does exactly that, informing them that the reason he is not eating is because he's not feeling well*

282   *rather than the other way around. She states that "It's not your fault, it's not your wife's fault, and*

283   *it's not our fault. You don't want to eat because the disease is so advanced and your tumour is very*

284   *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"

312 Communicating knowledge that a patient is nearing end of life can be challenging for hospital

313 clinicians, even for those specially trained in palliative care. In my research, even as palliative

314 clinicians became increasingly certain of the patient's imminent terminal decline, they often used

315 conversational techniques which relied upon but did not necessarily explicitly refer to an "open

316 awareness" (Glaser and Strauss, 1965) that the patient was dying.

317 *Hospital "B", June 2009, consult visit: Sally [the palliative consultant] was talking earlier this week*

318 *with Thomas [a patient with advanced ALS who hospital staff do not expect to survive to discharge].*

319 *Before we go into his room for a scheduled visit, Sally recounts the previous conversation where she*

320 *told him that he needs to increase his use of morphine "to ease his discomfort". He typed in the word*

321 *"terror" into his communication device, and also asked if he could pick a day and end it all. I ask*

322 *what she thinks he is anxious about, and she says she thinks it is caused by the breathing issues, but*

323 *that she believes he's at peace about dying as he's talked about having a life-limiting illness. Once*

324 *inside the room, after a brief review of his current symptom management, she tries to guide the*

325 *conversation to increasing his sedation to reduce his anxiety about being short of breath. Her*

326 *language seemed vague and non-specific, but at the same time guiding in use of terms such as "in my*

327 *experience," "in the future," "as things progress," and saying "some people prefer to be more*

328 *sedated for their symptoms." He doesn't respond to those prompts, instead focusing on the possibility*

329 *of stabilization [referencing an intervention suggested by a resident], returning home, and spending*

330 *time with his boyfriend and dogs. It was clear that this was frustrating Sally, but she was also*

331 *respectful and backed off, saying they'd "wait and see," and then changing the subject.*

332 Ideally, palliative clinicians are able to generate an interactional context where "the patient, after a

333 series of encounters that lead her to accept the inevitability of death, recognizes this inevitable

334 outcome and thus renders herself unproblematic" (May, 1992: 596). In turn, the patient is afforded the

335 opportunity to actively shape their experience of dying, thereby maximizing their comfort and dignity.

336 The resulting clinical decision-making can then be framed as reflecting the patient's (or family

337 members') preference. Yet, as Thomas's case evidences, and as others have also highlighted,

338 awareness is best envisioned as an enmeshing of multiple actors within ambivalent and shifting "webs

339 of conscious knowledge and emotional responses" (Mamo, 1999: 33; Timmermans, 1994) which may

340 require ongoing negotiation up to, or near, the point of death.

341   *3.   Naturalizing direction and outcomes of care: "It's about simplifying things"*

342   Hospital palliative clinicians are increasingly continuing and/or initiating acute interventions,

343 justified in the name of improved quality of life. Consequently may deal with, and even replicate, the

344 same conundrum experienced by other hospital specialists, where patients' lives can be extended

345 through aggressive medical intervention, yet who report poor quality of life and cannot be discharged.

346 One way that palliative clinicians attempt to expedite movement through this liminal zone is by

347 harnessing drugs and medical technologies to mimic a 'natural' dying process.

348 *Hospital "B", February 2009, weekly palliative care unit rounds: Two senior physicians are*

349 *discussing Joan, a symptomatically unstable patient who has been on the unit for almost a month, and*

350 *who has been repeatedly advocating for further aggressive interventions.*

351 *Dr. A: I think she may be dwindling now; she's losing hope [about getting strong enough for a new*

352 *treatment] and she's talking about letting things go.*

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

354 *Dr. A: Should we discontinue the IV?*

355 *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*

356 *giving her a lot of medications through it. We would have to switch them. How much is she still*

357 *vomiting?*

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

359 *Dr. B: If you say to her that we're decreasing her IV, she's going to say she'll get dehydrated, and her*

360 *urine will be dark, so it's going to be a real process to parallel decreasing the IV with her decreasing*

361 *health…It's very hard; this is really challenging…The question to ask her is where she wants this to*

362 *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

388 normative psychological frames built on a collective repository of difficult but 'common' experiences

389 at the end of life.

390 *Hospital "A", December 2008, palliative care unit: Sarah, the daughter of a newly admitted patient,*

391 *is extremely upset with news that her mother will probably not regain consciousness, and is likely*

392 *close to death. She keeps requesting aggressive therapies, openly states that she is "angry" at Rita*

393 *[the palliative physician] for "not doing enough," and is often at the nursing station strenuously*

394 *requesting consultation with other specialists as she feels her mother's breathing indicates distress.*

395 *Two days later I have a chance to talk with Rita and ask how the daughter is doing. She laughs and*

396 *says, "We had a long talk, so no more inappropriate behaviour, and she understands medically why*

397 *we are not going to [give desired invasive intervention]. She's becoming institutionalized–I swear we*

398 *do that so well." Shortly after this exchange, in an interview with Sarah, I ask about her relationship*

399 *with the clinicians. She replies that, "The people on the ward are taking care of her [mother] but they*

400 *are also taking care of me, so that's made it easier for me to settle…They just treat me like a next*

401 *door neighbour. It's kind of an informal comfortable atmosphere that they create and foster. For me*

402 *it's been a positive experience... [Before] I hadn't been able to say that I wanted my mother to go*

403 *[die], to have no more suffering and because I felt bad for having those thoughts I was getting angry*

404 *(she begins to cry)…I confessed this to Rita and she told me 'Don't feel guilty-you want her to go for*

405 *all the right reasons', which gave me permission to verbalize it, and I don't feel like anyone is judging*

406 *me for that."*

407   Palliative care is an important practice for making visible and legitimatizing forms of

408 affective distress about the end of life that previously have been ignored, pathologized, and/or seen as

409 moral weakness. Clinicians' work to resolve emotional 'disorder' is labour that names, gives meaning

410 to, and thereby validates the (at times) overwhelming complexity and weight of emotions that

411 commonly attend end of life. The use of psycho-normative framing rules, however, is a double-edged

412 sword. Those who do not conform to the emotional expectations within an 'appropriate' timeline may

413 face the stigma of emotional co-morbidity; being labelled as 'depressed', in 'denial' and/or are

414 understood to require further psychological interventions (Fischer et al., 2000). Hospital palliative

415 care can therefore be conceptualized as the affective labour to order the individual physical body *and*

416 the emotionally disordered social body at end of life (Lawton, 1998; Philpin, 2007). Through the

417 labour of interpreting and normalizing the affective states of the patient and her social network,

418 clinicians are able not only to compassionately ensure a minimum of social disruption, but also

419 efficiently organize the "sentimental order" of care settings (Glaser and Strauss, 1968).

420   *5. Efficient and compassionate: "We are relentless in a non-intrusive way"*

421   Hospital palliative care is framed as being able to achieve desirable care outcomes not only in

422 relation to the patient and her social network, but also in relation to other hospital clinicians, the

423 hospital itself, and broader health care systems. One key way that clinicians can evidence the

424 institutional and system-wide benefits of hospital palliative care is through demonstrating their ability

425 to expedite symptomatically challenging and/or potentially long-stay patients to home or hospice

426 discharge. At the same time, patients and families may, for various reasons, wish to remain in an acute

427 care setting as death approaches. Clinicians can then be faced with the challenge of providing

428 compassionate individualized care in tandem with efficient transitions. In the interview excerpt below,

429 a senior social worker from Hospital "A" identifies how she attempts to proactively negotiate these, at

430 times divergent, priorities.

431   *"If you can respond to their concerns [about discharge] families often become very reasonable.*

432 *Most families are advocating and need to know we're doing everything we can. That we're not going*

433 *to abandon her, or any patient…I spend hours challenging families [about appropriateness of a*

434 *hospice admission] with no response, so instead it's just better to say that you'll come back in a*

435 *couple of days. And when you go back, at that point the patient is often ahead of you, thinking about*

436 *hospice. That's why it is so huge if we are able to be pro-active in conversations and then there are no*

437 *crisis or egos…We are doing it in a compassionate way. But we're also quite efficient and try to be on*

438 *top of the current information about the patient, so we are relentless in a non-intrusive way. So you*

439 *make future meetings where you're working on the patient but also the family as well. Usually one of*

440 *the two of them [patient or family] is already thinking that way, and we have to explore the conflict*

441 *between the two positions, and try to come up with transition options so they feel safe".*

442   While the dual identification of compassionate and efficient can cause relational tensions, both

443   components are integral to clinicians' professional identity, as is evidenced in other studies (Li, 2004;

444   James 1992). The affective labour required to be simultaneously compassionate and efficient, then,

445   not only maintains local social order and is generative of professional identity, but they can also be

446   read as attempts to advance larger organizational care priorities, including the expansion of palliative

447   care (Floriani and Schramm, 2012).

448   *6.   Increased specialist intervention and new forms of knowledge: "It's like solving a puzzle"*

449   Advocates of palliative care have laid claim to an ambitious territorial scope. In hospital settings

450   this is evidenced through the promotion of two developmental pathways. The first is to increase the

451   reach of specialist practices, encompassing new drugs and medical technologies, as well as applying

452   these to new patient populations. This shift is evidenced in the perspective of a clinical nurse

453   specialist from Hospital "B".

454   *Gina: [Palliative care] is developing; it's becoming more of a specialty. It's a more specialized area*

455   *in medicine; it's evolving and maturing and growing and has more confidence. It's becoming more*

456   *technical so it's not just withdrawing things and giving opioids and letting people die; it's more going*

457   *after things and investigating and trying different approaches sometimes…I really enjoy that part of*

458   *it; it's like solving a puzzle.*

459   Scholars interested in end of life have shown how new knowledge, expertise, and practices may

460   occur even in adverse circumstances where the patient does not have a 'good' death. Instead of these

461   deaths destabilizing the need for medical intervention, problematic deaths signify the need of further

462   expertise, where the hope is that increased interventions will improve future deaths (Perakyla, 1991;

463   Timmermans, 2005). Yet integration of palliative care across acute settings can also paradoxically

464   function to re-establish its reputation as a speciality specific to the very end of life, as reflected in the

465   following conversation in Hospital "A".

466   *Consultant 1: It's the ones where the family wants to keep the person alive to the last nanosecond*

467   *possible on all kinds of life support and the patient is suffering, and we get called in to solve it.*

468   *Consultant 2: Or when you go to a unit late in the evening to do the new consult and the file is 5*

469   *inches thick and the person has been in and out of the ICU and nobody is really talking about*

470   *anything because they've been on this trajectory of active, active interventions and suddenly they call*

471   *palliative care and we're supposed to make sense of it all.*

472   *Consultant 1: [Sarcastically impersonating a non-palliative clinician] Can you please tell the patient*

473   *that they're dying? [Reverting back to normal voice] Uh, no (laughs).*

474   This leads to the second developmental pathway: diffusing specialist knowledge throughout

475   health systems as a whole, rather than relying on specialist expertise. One particularly clear example

476   of this is the growing interest in palliative 'assessment' tools, many of which have been developed by

477   palliative specialists in the hospital setting, to assist non-palliative clinicians identify patients who

478   would benefit from generalist palliative care (Maas et al., 2013). In generating new forms of specialist

479   knowledge for managing both current *and* future dying bodies, palliative clinicians have had both

480   significant success and challenges in expanding knowledge and expertise across diverse populations

481   of hospitalized patients.

482   **Discussion**

483   *An affective economy of hospital palliative care*

484   Using data from two hospitals in Western Canada, my analysis identified six ideal care

485   outcomes that both reflect and structure hospital palliative clinicians' attempts to organize a dying

486   trajectory. The first outcome is to generate mutual agreement of where current physical symptoms

487   locate a patient within the general arc of a potential dying trajectory. If this is accomplished, clinicians

488   can employ a script that proactively locates anticipated further decline within a double biomedical

489   narrative; beyond the ability of medicine to cure but within its ability to palliate. This produces the

490   conditions for the second ideal outcome: implicit acknowledgment, if and when necessary, that end of

491   life is approaching. Acknowledgement also offers patients and families an opportunity to shape the

492   dying process. Third, this affective work naturalizes direction and outcomes of care practices which

493   facilitate transitions along the institutional care pathway amidst the prognostic uncertainties that

494   increasingly mark hospitalized dying. This leads to the fourth outcome, where social dislocations

495   threatened by the dying process are sutured to a collective experience through framing individual

496   patient and family member experiences as part of the 'common' experiences of dying, thereby

497   preserving the long-term stability of organizations and relationships. In turn, this enables the fifth

498   outcome, where by achieving the previous outcomes, clinicians are able to identify as simultaneously

499   compassionate *and* efficient. This promotes the sixth outcome: ensuring the need for increased

500   specialist intervention, as well as expansion of generalist palliative approaches, to all advanced life-

501   limiting conditions. When successful in achieving all six outcomes, clinicians are able to proactively

502   facilitate co-authored understandings that on the micro-level generate affective experiences of end of

503   life which mark the curative limits of medicine *and* its palliative benefits, re-establish social and

504   institutional order threatened by temporal ambiguities and emotional excess on the meso-level, and on

505   the macro-level extend the capacity of palliative expertise and principles to order the biological

506   processes of dying across hospital settings. I conceptualize all of these as components of an affective

507   economy of hospital palliative care, visualized in Figure 1. Overall, my analysis offers a theoretically

508   informed, empirically grounded model of the multiple entanglement between experiences of the

509   individual body, concerns that structure the social body, and the larger body politic (Scheper-Hughes

510   and Lock, 1987) in hospital palliative care.

511
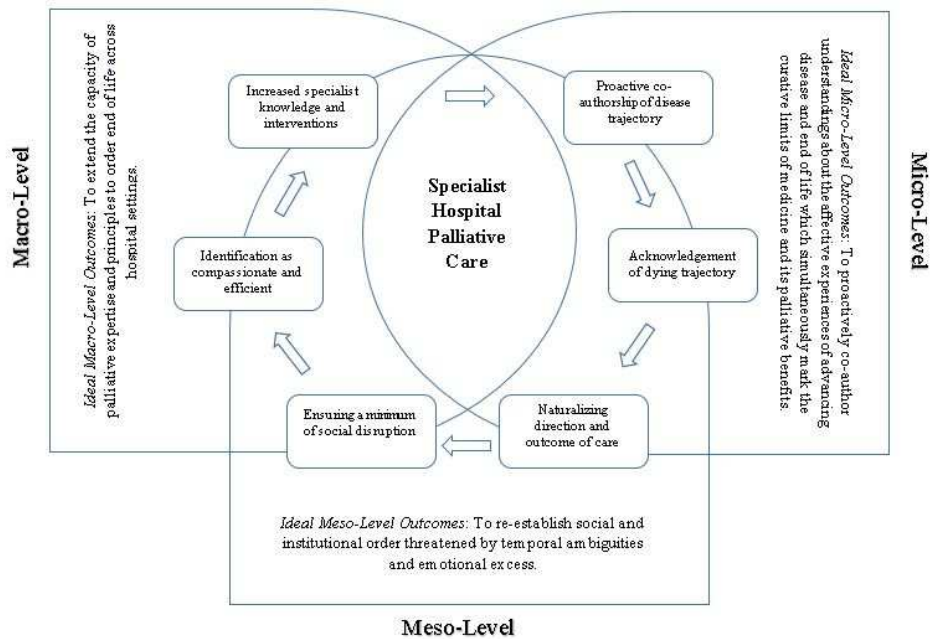
Figure 1: Components of an affective economy of hospital palliative care

513

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

528 continue to structure clinicians' everyday work, even as they prioritize acute physical symptom

529 management for purposes of stabilization and discharge. Second, this model articulates how

530 infrastructures of hospital palliative care are comprised of multiple – and at times divergent –

531 priorities and interests. In so doing, an affective economy framing makes clear that ambiguity,

532 negotiation, and even conflict are constitutive components of hospital palliative care, rather than

533 reflecting a failure of practice or uptake of principles. Third, it highlights that the 'immaterial' aspects

534 of clinicians' work determines not only their clinical decision-making to successfully organize a dying

535 trajectory, but also their ability to the meet the heterogeneous system priorities and individual

536 perspectives detailed here. Finally, an affective economy of hospital palliative care evidences how

537 practice tensions emerge partly as a result of the successes in mainstreaming palliative care.

538   Some may argue that clinician's affective labour skills are no longer necessary as hospital

539 palliative care is now primarily specialist acute physical symptom management in service of

540 stabilizing patients for discharge to another institutional or community setting. Yet as evidenced

541 elsewhere (Bruera et al., 2015; CIHI, 2018), many patients receiving hospital palliative care do not

542 survive to discharge. Further, while clinical expertise in symptom management is a fundament of

543 palliative care, affective relations are the mechanism and context within which conversations and

544 decisions about clinical care take place (Canning et al., 2007; Sampson et al., 2014) and are

545 repeatedly identified by patients and families as a key signifier of quality end of life hospital care

546 (Masel et al., 2016; Virdun et al., 2015). Others may rightly point out that many hospital patients only

547 receive palliative care once they are in the last days of life and/or are no longer fully lucid; so far

548 advanced in their biological decline that a dying trajectory no long needs ordering, only terminal

549 physical symptom management. However, my findings indicate that even in these instances,

550 interactions with family members and/or requests for palliative services evidence demand for specific

551 forms of expertise to organize the ends of life for *others* involved in the provision and uptake of care.

552 Finally, it is also important to note that while only a subset of hospital patients receive palliative care

553 or care informed by a palliative approach, it is an authorized ideal of what care services should be

554 provided, and the standard to which other hospital end of life care is held.

555   This study is specific to a single geographic region in Western Canada, and field work was

556   conducted a decade ago. However, research included two differently sized hospitals with different

557   models of care, and the author engaged in member checking regarding analytical results. While future

558   research is required to determine its relevance to other hospital settings and regions, study findings

559   have been contextualized within current considerations reflected in palliative care literature

560   internationally.

561   **Conclusion**

562   This paper presented a theoretically innovative and empirically grounded model of hospital

563   palliative clinicians' work to anticipate and organize patients' dying trajectories. I articulated how this

564   work was given shape through affective labour, enabling clinicians to naturalize and conjoin their

565   biomedical interpretations of the patient's nascent physical signifiers with their cultural authority to

566   define the appropriate emotional orientations to these understandings. The key finding is that this

567   labour is crucial not only to organize appropriate care for those who are nearing end of life, but also to

568   organize a heterogeneous range of priorities shaping clinicians' daily work, professional identities,

569   and the expansion of palliative care. Collectively, my analysis and corresponding model enable

570   substantively new insight into to how clinicians attempt to meet social and organizational mandates

571   that necessary include, but extend well beyond, the individual patient and her immediate social

572   network. To the best of the author's knowledge, it is the first study to use the concepts of affective

573   labour and affective economies to understand how clinicians negotiate and "simplify" the

574   complexities that constitute the everyday work of hospital palliative care.

575

576

577

578

579

580 **References**

581 Ahmed, S. (2004). Affective economies. Social Text, 22(2), 117-139.

582 https://muse.jhu.edu/article/55780 (accessed 31 July, 2019).

583 Bekelman, J.E. et al. (2016). Comparison of site of death, health care utilization, and hospital

584 expenditures for patients dying with cancer in 7 developed countries. Jama, 315(3), 272-283.

585 10.1001/jama.2015.18603

586 Bluebond-Langner, M. (1978). The private worlds of dying children. Princeton University Press.

587 Broad, J. B. et al. (2013). Where do people die? An international comparison of the percentage of

588 deaths occurring in hospital and residential aged care settings in 45 populations, using published and

589 available statistics. International journal of public health, 58(2), 257-267.

590 https://doi.org/10.1007/s00038-012-0394-5

591 Bruera, S. et al. (2015). Frequency and factors associated with unexpected death in an acute palliative

592 care unit: expect the unexpected. Journal of pain and symptom management, 49(5), 822-827.

593 https://doi.org/10.1016/j.jpainsymman.2014.10.011

594 CHPCA: Canadian Hospice Palliative Care Association. A Model to Guide Hospice Palliative Care:

595 Based on National Principles and Norms of Practice. http://www.chpca.net/media/319547/norms-of-

596 practice-eng-web.pdf (accessed 31 July, 2019).

597 CSPCP: Canadian Society of Palliative Care Physicians. (2016). How to improve palliative care in

598 Canada. http://www.cspcp.ca/wp-content/uploads/2016/11/Full-Report-How-to-Improve-Palliative-

599 Care-in-Canada-FINAL-Nov-2016.pdf (accessed 31 July, 2019).

600 CIHI: Canadian Institute for Health Information. (2018). Access to Palliative Care in Canada.

601 https://www.cihi.ca/en/access-data-and-reports/access-to-palliative-care-in-canada (accessed 31 July,

602 2019).

603   Canning, D., Rosenberg, J., Yates, P. (2007). Therapeutic relationships in specialist palliative care

604   nursing practice. International Journal of Palliative Nursing, 13(5), 222-229.

605   https://doi.org/10.12968/ijpn.2007.13.5.23492

606   Cassell, J. (2005). Life and death in intensive care. Temple University Press.

607   Chapple, H. S. (2016). No place for dying: Hospitals and the ideology of rescue. Routledge.

608   Clark, D., et al. (2014). Imminence of death among hospital inpatients: prevalent cohort study.

609   Palliative medicine, 28(6), 474-479. https://doi.org/10.1177/0269216314526443

610   Dalgaard, K. M., Bergenholtz, H., Nielsen, M. E., Timm, H. (2014). Early integration of palliative

611   care in hospitals: a systematic review on methods, barriers, and outcome. Palliative & supportive care,

612   12(6), 495-513. https://doi.org/10.1017/S1478951513001338

613   Floriani, C. A., Schramm, F. R. (2012). Routinization and medicalization of palliative care: Losses,

614   gains and challenges. Palliative & supportive care, 10(4), 295-303.

615   https://doi.org/10.1017/S147895151100103

616   Fischer, G., Tulsky, J., Arnold, R. (2000). In R. Protenoy, E. Bruera (Eds.), Communicating poor

617   prognosis: Topics in palliative care, Vol. 4 (pp. 75-93). Oxford: Oxford University Press.

618   Gallagher, R. (2018). New category of opioid-related death. Canadian Family Physician, 64(2), 95-96.

619   Gerrard, R., et al. (2011). Achieving the preferred place of care for hospitalized patients at the end of

620   life. Palliative medicine, 25(4), 333-336. https://doi.org/10.1177/0269216310387459

621   Glaser, B. G., Strauss, A. L. (1965). Awareness of dying. Routledge.

622   Glaser, B. G., Strauss, A. L. (1965b). Temporal aspects of dying as a non-scheduled status passage.

623   American Journal of Sociology, 71(1), 48-59.

624   Glaser, B., Strauss, A. (1968). Time for dying. Chicago: Aldine Publishing Company.

625   Gott, M., Robinson, J. (2018). Are we getting it wrong? Perspectives on the future of palliative care in

626   hospitals. Palliative Medicine. 10.1177/0269216318809539

627   Gott, M., et al. (2017). Likelihood of death among hospital inpatients in New Zealand: prevalent

628   cohort study. BMJ open, *7*(12), e016880. http://dx.doi.org/10.1136/bmjopen-2017-016880

629   Gott, M., et al. (2013). Palliative care need and management in the acute hospital setting: a census of

630   one New Zealand Hospital. BMC palliative care, 12(1), 15.

631   Government of Canada. (2018). Palliative Care. https://www.canada.ca/en/health-

632   canada/services/palliative-care.html (accessed July 31, 2019).

633   Green, J., Thorogood, N. (2018). Qualitative methods for health research. Sage.

634   Hardt, M. (1999). Affective Labor. boundary *2*, 26(2): 89-100.

635   Hochschild, A. (1983). The managed heart: commercialization of human feeling. Berkeley: University

636   of California Press.

637   James, N. (1992). Care = organization + physical labour + emotional labour. Sociology of Health and

638   Illness. 14(4): 488-509.

639   Kaufman, S. (2005). And a time to die: How American hospitals shape the end of life. Chicago:

640   Chicago University Press.

641   Krawczyk, M. (2015). Negotiated practices: understanding hospital palliative care as an affective

642   economy (Doctoral dissertation). http://summit.sfu.ca/item/15570 (accessed 31 July, 2019).

643   Krawczyk, M. (2017). Approaching death: Informed consent and research relationships at the end of

644   life. Medicine, Anthropology and Theory. http://www.medanthrotheory.org/read/7096/approaching-

645   death (accessed 31 July, 2019).

646   Krawczyk, M. & Gallagher, R. (2016). Communicating prognostic uncertainty in potential end-of-life

647   contexts: experiences of family members. BMC palliative care, 15(1), 59.

648   Kluge, S. (2000). Empirically grounded construction of types and typologies in qualitative social

649   research. In Forum Qualitative Sozialforschung/Forum: Qualitative Social Research (Vol. 1, No. 1).

650   http://dx.doi.org/10.17169/fqs-1.1.1124

651 Kristjanson, L. J., Aoun, S. (2004). Palliative care for families: remembering the hidden patients. The

652 Canadian Journal of Psychiatry, 49(6), 359-365. https://doi.org/10.1177/070674370404900604

653 Lawton, J. (1998). Contemporary hospice care: The sequestration of the unbounded body and 'dirty

654 dying'. Sociology of Health and Illness, 20(2), 121–43.

655 Li, S. (2004). 'Symbiotic niceness': Constructing a therapeutic relationship in psychosocial palliative

656 care. Social Science & Medicine, 58(12), 2571-2583. https://doi.org/10.1016/j.socscimed.2003.09.006

657 Mamo, L. (1999). Death and dying: Confluences of emotion and awareness. Sociology of Health &

658 Illness, 21(1), 13-26. 10.1111/1467-9566.t01-1-00140

659 Maas, E. A. T., Murray, S. A., Engels, Y., Campbell, C. (2013). What tools are available to identify

660 patients with palliative care needs in primary care: a systematic literature review and survey of

661 European practice. BMJ supportive & palliative care, 3(4), 444-451.

662 http://dx.doi.org/10.1136/bmjspcare-2013-000527

663 Masel, E. K., et al. (2016). What makes a good palliative care physician? A qualitative study about the

664 patient's expectations and needs when being admitted to a palliative care unit. PloS one, 11(7),

665 e0158830. https://doi.org/10.1371/journal.pone.0158830

666 May, C. (1992). Individual care? power and subjectivity in therapeutic relationships. Sociology, 26,

667 589-602.

668 May, P., et al. (2015). Prospective cohort study of hospital palliative care teams for inpatients with

669 advanced cancer: earlier consultation is associated with larger cost-saving effect. Journal of Clinical

670 Oncology, 33(25), 2745. 10.1200/JCO.2014.60.2334

671 Moller, D. W. (2000). On death without dignity: The human impact of technological dying.

672 Routledge.

673 Parker-Oliver, D. (2000). The social construction of the "dying role" and the hospice drama.

674 OMEGA-Journal of Death and Dying, 40(4), 493-512. https://doi.org/10.2190/YT9D-12Y2-54LY-

675 TCMN

676   Perakyla, A. (1991). Hope work in the care of seriously ill patients. Qualitative Health Research, *1*(4),

677   407-433.

678   Philpin, S. (2007). Managing ambiguity and danger in an intensive therapy unit: Ritual practices and

679   sequestration. Nursing Inquiry, 14(1), 51-59. https://doi.org/10.1111/j.1440-1800.2007.00354.x

680   Richard, A., Rudnyckyj, D. (2009). Economies of affect. Journal of the Royal Anthropological

681   Institute, 15(1), 57–77. https://doi.org/10.1111/j.1467-9655.2008.01530.x

682   Robinson, J., Gott, M., Gardiner, C., Ingleton, C. (2016). The 'problematisation' of palliative care in

683   hospital: an exploratory review of international palliative care policy in five countries. BMC palliative

684   care, 15(1), 64.

685   Rosenwax, L. K., et al. (2011). Hospital and emergency department use in the last year of life: a

686   baseline for future modifications to end-of-life care. Medical Journal of Australia, 194(11), 570-573. .

687   https://doi.org/10.5694/j.1326-5377.2011.tb03106.x

688   Sampson, C., et al. (2014). The practice of palliative care from the perspective of patients and carers.

689   BMJ Supportive & Palliative Care. http://dx.doi.org/10.1136/bmjspcare-2013-000551

690   Stayt, L. C. (2009). Death, empathy and self preservation: the emotional labour of caring for families

691   of the critically ill in adult intensive care. Journal of clinical nursing, 18(9), 1267-1275.

692   https://doi.org/10.1111/j.1365-2702.2008.02712.x

693   Statistics Canada. (2018). Death and causes of death, 2017. https://www150.statcan.gc.ca/n1/daily-

694   quotidien/181129/dq181129g-eng.htm (accessed 31 July, 2019)

695   Scheper-Hughes, N., Lock, M. M. (1987). The mindful body: A prolegomenon to future work in

696   medical anthropology. Medical anthropology quarterly, 1(1), 6-41.

697   Seymour, J. E. (2000). Negotiating natural death in intensive care. Social Science & Medicine, 51(8),

698   1241-1252. https://doi.org/10.1016/S0277-9536(00)00042-3

699   Seymour, J. (2001). Critical Moments—Death and Dying in Intensive Care. Buckingham, Open

700   University Press.

701   Skilbeck, J., Payne, S. (2003). Emotional support and the role of clinical nurse specialists in palliative

702   care. Journal of advanced nursing, 43(5), 521-530. https://doi.org/10.1046/j.1365-2648.2003.02749.x

703   Strauss, A., Fagerhaugh, S., Suczek, B., Wiener, C. (1982). Sentimental work in the technologized

704   hospital. Sociology of Health & Illness, 4(3), 254-278.

705   Sudnow, D. (1967). Passing On. The Social Organization of Dying. Englewood Cliffs, NJ: Prentice-

706   Hall.

707   Timmermans, S. (1994). Dying of awareness: The theory of awareness contexts revisited. Sociology

708   of Health & Illness, 16(3), 322–339. https://doi.org/10.1111/1467-9566.ep11348751

709   Timmermans, S. (2000). Sudden Death and the Myth of CPR. Chicago: Temple University Press.

710   Timmermans, S., Tavory, I. (2012). Theory construction in qualitative research: From grounded

711   theory to abductive analysis. Sociological Theory, 30(3), 167-186.

712   https://doi.org/10.1177/0735275112457914

713   Timmermans, S., Buchbinder, M. (2012). Saving babies?: the consequences of newborn genetic

714   screening. Chicago: University of Chicago Press.

715   Virdun, C., Luckett, T., Davidson, P. M., Phillips, J. (2015). Dying in the hospital setting: A

716   systematic review of quantitative studies identifying the elements of end-of-life care that patients and

717   their families rank as being most important. Palliative medicine, 29(9), 774-796.

718   https://doi.org/10.1177/0269216315583032

719   World Health Organization. (2019). Definition of Palliative Care.

720   https://www.who.int/cancer/palliative/definition/en/ (accessed 31 July, 2019).

721   Zussman, R. (1992). Intensive care: Medical ethics and the medical profession. Chicago: University

722   of Chicago Press.

*Table 1: Professional affiliations of interview participants*

Staff interviews	Hospital "A"	Hospital "B"
Palliative physicians	5	4
Non-palliative physicians	3	2
Palliative nurses	11	9
Allied health professionals	3	2
Administrators	2	2
Total	**24**	**19**

Table 2: Basic demographics of patient and family member participants

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

Figure 1: Components of an affective economy of hospital palliative care
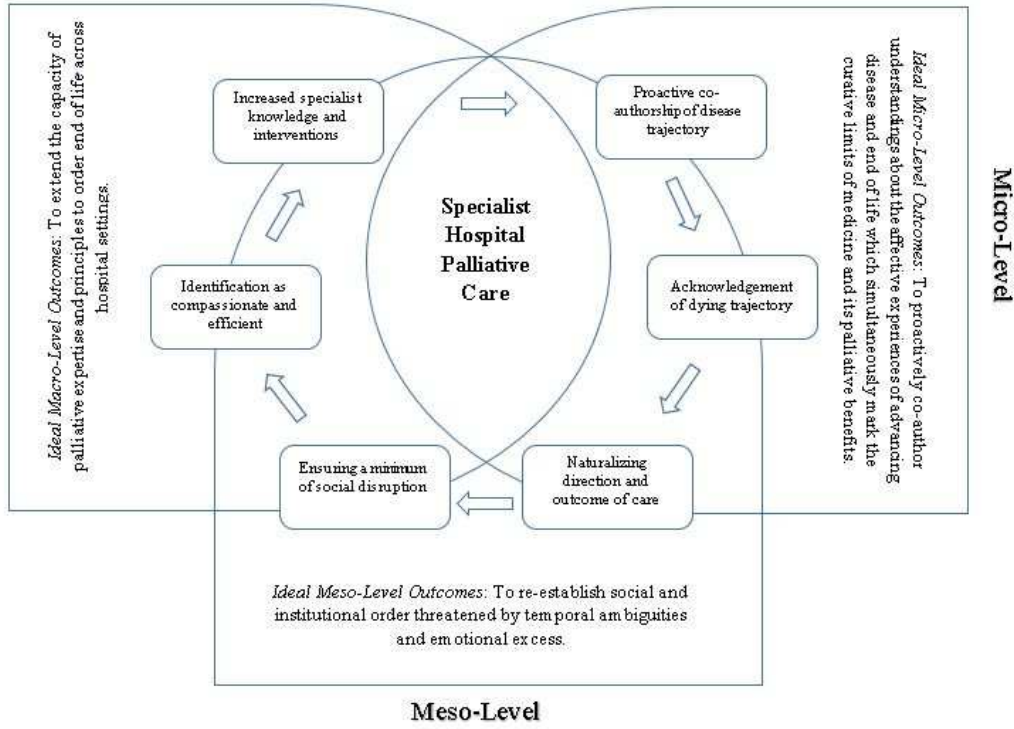
- Hospital palliative care is shaped by diverse health system priorities
- Clinicians use affective labour to meet patient, family member, and system needs
- Hospital palliative care can be understood and modeled as an "affective economy"
- Negotiation and ambivalence are constitutive features of hospital palliative care