Hopeful dying? The meanings and practice of hope in palliative care family meetings

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ABSTRACT

Hope can carry considerable allure for people facing imminent mortality and for those who care for them. Yet, how hope is variously and relationally (re)produced within end-of-life care settings, remains under-researched. In this study, we aimed to better understand hope as it circulates within palliative care, drawing on video recorded family meetings and pre- and post-meeting qualitative interviews, within two hospitals in Queensland, Australia. Our findings highlight family meetings as an important site for articulations of hope and hopefulness. The results illustrate how hope is recalibrated within the transition to and through palliative care, the tensions between hope and futility, and the work of hope in discussions of goals and expectations. Through our analysis we argue that *hopefulness* within family meetings, and in palliative care more broadly, is collectively produced and opens up discourses of hope to the lived experience of terminality. Attending to the nuances of hope, including moving beyond the determinative (hope for *more* life/hope for a *quick* death), can elucidate the possibilities and problems of the collective negotiation of hope at the end of life, including how hope can be drawn on to express support and solidarity.

1. Introduction

Hope often offers considerable allure for those nearing the end of life. In contexts where biomedical treatments cannot offer the possibility of cure or significant longevity, hope retains profound meaning, shaping experiences and relationships within and between families and professionals (Wrigley, 2019). As a medical specialty, palliative care has come to occupy an important space between and amongst countervailing emphases on hope (cure) and acceptance (death) (Brown et al., 2015; Clark, 2002). Relations of hope are highly complex in this context, imbued with cultural and moral value, reflected in the many idioms that weave hope into forms of adversity or despair (e.g., 'while there's life there's hope', 'hope against hope') (see also Kylmä et al., 2009; Little and Sayers, 2004; Wrigley, 2019). In the context of terminal illness and the transition to the end of life, hope as tied to future expectations is significantly challenged (Brown et al., 2015; Brown and de Graaf, 2013).

As such, palliative and end-of-life care settings have become sites of interest for exploring how people live *with* and *mobilise* hope, and indeed, what they hope *for* (e.g., Duggleby and Wright, 2005; Eliott and Olver, 2009, 2007; Holtslander et al., 2005).

Family meetings (sometimes called family conferences) have become common in palliative care settings within and outside Australia (Forbat et al., 2018). Usually in response to the collective acknowledgement that care strategies are in constant need of re-assessment at this critical juncture (see also Broom et al., 2014; Kirby et al., 2014), family meetings represent key opportunities for information-sharing and care planning, bringing together health professionals, the patient and their family/carers, in an attempt to reach consensus (Hudson et al., 2008). Such encounters may be interpersonally and emotionally challenging (Brown and de Graaf, 2013; The et al., 2001; Thorne et al., 2006), and tensions can emerge around the vital pursuit of such things as *more time* vis-a-vis comfort and quality of life (Kenny et al., 2017; MacArtney et al.,

2015). Family meetings thus provide an important site for exploring the social dimensions of hope, and how it is assembled (or dispersed or otherwise) collectively at the end of life. Here, drawing on video recordings of family meetings, and pre- and post-meeting qualitative interviews with family members, patients and health professionals, across two Australian hospitals, we examine the relational dynamics of hope and hopefulness within hospital palliative care settings.

Rather than neatly define hope, in this article we follow Petersen and Wilkinson (2015: 116) in our aim to "elucidate the tensions, multiple interpretations, and 'in situ' experiences of hoping." We recognise the slipperiness of hope, evading consistent definition, elusive in its hypothetical 'not yet' futurity, and comprised variously of cultural presuppositions and ascriptions (Ahmed, 2004; Bloch, 1986; Brown, 2015). We thus understand hope broadly, as the intentional or unintentional, individual or collective desire for a possible outcome, anticipated, achievable or otherwise, with or without rationality or probability (see also Simpson, 2004; Wrigley, 2019). In turn hopefulness, as a disposition or attitude, can also be articulated and experienced variously – one may be *hopeful* about a particular circumstance but not display hopefulness in other aspects of life, or may be hopeful about living (and dying), yet not about other particular things (e.g., the possibility of good weather, or a favourite sports team winning their next game). Below, we position the various objects and experiences of hope at the end of life as part of a disposition of *hopefulness,* co-constructed through and by mutually supportive and relational practices and dynamics (McGeer, 2008). Hopefulness in this way includes the process and experience of *hoping for* something, and *living with* hope more broadly (Kylmä et al., 2009). In taking this position, we aim to contribute new insights around the discourses of hope (see also Good et al., 1990) within experiences of illness, treatment and care.

2. Background

2.1. Conceptualising hope in palliative care

Research in the context of advanced illness has usefully pointed to the inherent temporal ambiguities of hope, variously encapsulating anticipation, aspiration, intention, expectation and optimism (e.g. Brown and de Graaf, 2013; Duggleby and Wright, 2005; Eliott and Olver, 2009, 2007). Much of this work focuses on how hope enables individuals to cope *now*, revealing the privileging of individual resilience and perseverance, even in contexts of terminal illness (Alacovska, 2018; Cook and Cuervo, 2019; Mattingly, 2010; Petersen and Wilkinson, 2015). In these terms, hope retains a paradoxical present-future orientation, asking us to 'keep going', and requiring the *hoper* to work towards realising the object of hope (Simpson, 2004). Indeed, in recent years hope in medicine has become synonymous with anticipation and optimism: of new treatment options, technologies and possibilities (Brown, 2015; Petersen and Wilkinson, 2015). As Brown notes, "hope has become a vector for the embodiment of, and indeed, the embodied reproductivity of, promissory futures …" (2015: 120). Given this embeddedness of hope in promise and possibility, discourses of hope are perhaps most alluring within contexts of despair and desperation, or 'near-hopelessness' (see also Good et al., 1990; Novas, 2006; Petersen et al., 2014).

Pertinently here, hope and hopefulness may also ebb and flow (or function variously and multiply) across subjects as well as time (Eliott and Olver, 2009; Simpson, 2004). How hope is individually or collectively articulated is integral to conceptualising hope in palliative care. Much scholarship takes the starting point of hope as individual, innately 'within', or as affective, an emotional attitude or inner power bound up in desires, beliefs, imagination and possibilities (Eliott and Olver, 2002; Kylmä et al., 2009). Studies in palliative and end-of-life care have shown, through interviews with patients and those who care for them, how hope as a noun tends to be constructed as individualised, whereas hope as a verb (through the expression of hoping) is more of an

interpersonal construct (Eliott and Olver, 2009; Duggleby and Wright, 2005). Research has also pointed to hope as relationally co-constructed (Brown and de Graaf, 2013; Eliott and Olver, 2009; Simpson, 2004; see also Alacovska, 2018). Eliott and Olver (2009), for example, note the interpersonal obligations imposed by hope that move beyond conceptualisations of individualised hope common in medical and psychological discourses. This interpersonal co-construction of hope can increase the potential for uncertainty and abstraction even further, all the while maintaining the positive meaning-making allure of being hopeful.

Taking hope to broadly comprise dynamic experiences of *hope for something* and *living in hope* (Benzein et al., 2001), foregrounds how much hope has to offer, holding considerable value for patients, families and professionals (Eliott and Olver, 2002; Simpson, 2004; Wrigley, 2019). Indeed hope, however precarious, comes starkly into focus within palliative care, where family meetings present important interpersonal settings for the collective negotiation of orientations towards present and future (e.g., Forbat et al., 2018; Hudson et al., 2008). As such, we wanted to explore the appeal and undulations of hope to better understand the relational dynamics within family meetings (and the various subject positions) (see also Kylmä et al., 2009), including the dynamics of hopefulness *in practice* therein.

2.2. Hope and therapeutic culture

Within therapeutic culture hope is bound up in the moralities associated with illness, creating moral conditions for patients and families, reinforced by various biomedical tropes. The 'ideal' good patient/subject is one who remains positive yet realistic, who submits willingly to available (legitimised) forms of biomedical care, in the pursuit of an improved present *and* future (see also Eliott and Olver, 2007; Youll and Meekosha, 2011). Here, the burden inherent to expectations around hope is evident, including the imperative to sustain positivity no matter the circumstances or suffering (see also Alacovska, 2018). Within medicine, the professionally and institutionally sanctioned mobilisation of normative practices of hoping permit the privileging of certain ways of being-in-illness (e.g., accepting, resilient, stoic, as well as positive) (Eliott and Olver, 2007). This is evident in the elevated notion that instilling hope in patients can be therapeutically beneficial (perhaps most visible within the field of cancer care) (Brown, 2015). Indeed, hope can be mobilised in different ways to serve professional or other purposes. Zimmermann (2004, 2007) for example, has comprehensively charted the ways that the death denial thesis within clinical literature has sustained the affordance of implicit strategies for clinicians in controlling 'correct' ways to die. Patients 'in denial', or with 'unrealistic' hopes, she argues, can thus be managed through truth-telling and candour (Zimmermann, 2007; see also Perakyla, 1991), revealing what Brown (2015: 131) terms "an implicit value system structuring the management of emotions in practice and care". Yet, 'truth-telling' might also be a type of strategic hope work, as an important aspect of acceptance within experiences of 'the good death' (Eliott and Olver, 2007; Hagerty et al., 2005; McNamara, 2004; Miyaji, 1993).

The disciplinary potential that therapeutic discourses of hope might bring to end-of-life care contrast with dispositions of *hopefulness*, which may offer opportunities for greater interpersonal negotiation around hope (Brown and de Graaf, 2013; Eliott and Olver, 2007). Here we see hopefulness as an orientation towards the *doing* of hope and hoping *in relation*, regardless of likelihood or probability of the realisation of outcomes (see also Kwong, 2020). As a "complex interplay between futurity, agency and one's social context" (Cook and Cuervo, 2019: 1103), hope clearly does a lot. This includes doing the 'work' of hope (Peraklya, 1991); that is, the emotional work of feeling and expressing hope, comprising variously *being* hopeful and displaying/foregrounding hope and hopefulness to/with others. Indeed, the importance of such emotionally reflexive labour in palliative care communication has been foregrounded in recent research (Olson et al., 2020). As we argue below,

hopefulness can reflect the interpersonal imperative to balance or resolve tensions related to temporality, optimism, positivity and realism amidst (medical) futility (see also Brown et al., 2015; Eliott and Olver, 2009; Kwong, 2020).

The *doing* of hopefulness can also centre dynamic and collaborative forms of care and caring that foreground meaning- and value-making in patients' daily activities and social relationships to open up (rather than limit) possibilities for the future (Eliott and Olver, 2007, 2009,). Drawing on Sayer (2011: 3) we find utility in conceptualising hopefulness as a "lay normativity"; that is, an example of the normative rationales or orientations towards the world around them, that matter to people. Lay normativity is concerned with the ways that humans "flourish or suffer", and as a concept attunes us to social actors' capacities as well as their vulnerabilities. Thinking with hopefulness as a negotiated moral and interpersonal practice helps extend our analysis beyond the momentary or individual experience. This leads us to posit palliative care family meetings not as a critical or fateful *moment* (Giddens, 1991), but as a dynamic process complicated by considerations of past, present and future, held in a critical setting, within various (inter) personal, (inter)professional and moral agendas and imperatives. To address these, below we aim to explore the relational dynamics of hope within a series of family meetings, as a part of a broader qualitative study focused on transitions to and through palliative care (Broom et al., 2014; MacArtney et al., 2015, 2017).

3. Methods

We obtained university and hospital ethics approval to conduct pre- and post-meeting one-on-one interviews, and to video record family meetings within two hospital sites in metropolitan Queensland, Australia. First, we gained consent from the relevant health professionals working within each hospital setting; this included palliative care and oncology physicians, nursing staff, social workers, as well as physiotherapists, occupational therapists and medical students. Then, patients and their family members/carers were approached, explaining the study aims, and what participation required. Recruitment took place during late 2014, and all appropriate patients and families were invited to take part during the fieldwork period; we were cautious to ensure that patients were cognitively able to undertake an interview, or participate in the meeting, were not in significant pain, and were capable of providing informed consent. Recruitment was based on the existing schedule for family meetings within the two hospitals (meetings were not orchestrated for the purposes of the study). The treating physician or social worker initially explained the study to potential participants, providing an information form, and asking if the patient would be interested in taking part. The researchers then received details of those participant volunteers, so that interviews could be arranged around the meeting. Prior to each meeting, all participating members were contacted by Author C, who again explained the study, and gave participants an opportunity to ask any questions. Only when/if all meeting participants had given consent did we start the process of data collection.

We video-recorded thirteen family meetings for inpatients under the care of specialist palliative care physicians at the two hospitals. Author C sat in on each meeting, in a corner of the room with the video recorder, and did not participate in the meeting discussion. One hospital (n = 7 meetings) had a specialist palliative ward, with bed space for both private and public patients. The other (6 meetings) had a dedicated palliative care service, with bed space within an acute cancer ward. In both settings, family meetings were conducted for in-patients, including those receiving end-of-life care, those needing symptom stabilisation, and/or those recently transferred to the care of palliative care (usually from oncology). As such, some patient participants would remain as inpatients within palliative care or elsewhere in the hospital, while others might be discharged to be cared for at home, or be discharged to another care service. The patients (7 male, 6 female, aged between 52

and 82) were all living with cancer, apart from 2 who had diagnoses of motor neurone disease (MND). Meetings lasted from 20 min to 1 h, and comprised a total of 82 participants: 13 patients, 29 health professionals and 40 family members/carers (some professionals participated in multiple meetings and pre- and post-meeting interviews). Meetings had between 6 and 18 participants (mean: 9; median: 8). Author C conducted a total of 90 pre- and 75 post-meeting interviews with meeting participants (patients: 13; family members: 39; health professionals: 29), lasting between 5 and 15 min, which focused on individual expectations and feelings about the upcoming meeting (in terms of content and approach), desired outcomes and priority issues, and then reflections about the meeting (including tone, approach and coverage of pertinent issues).

3.1. Limitations

Our study is limited in various ways, including inclusion of a relatively small sample of meetings, in two hospitals in a single city. The meetings were conducted at different points of hospital admission and facilitated variously by physicians and social workers, highlighting potential variation in both the *hope profiles* of participants, and in interprofessional orientation or authority in shaping the negotiation of hope. The presence of a researcher and video-recording equipment may also have shaped or impacted the interpersonal dynamics within meetings in subtle ways. Our sample is also limited to patients and family contexts that could be categorised as not overtly distressed, as compliant (i.e., amenable to participating in research), and where the likelihood of family or lay-professional discord was relatively low.

3.2. Analysis

Rather than focusing on specific aspects or facets of lay-professional conversation, language or interactional order (as has been usefully explored by Eliott and Olver, 2007; Maynard et al., 2016), we sought to uncover the broader circulation of norms, and discourses in the taken-for-grantedness of forms of hope and hopefulness within family meetings. Our aim was to explore the relational dynamics of hope within the meetings, supported by interview accounts, including the work of hopefulness in practice. Video and audio dialogue from meetings and pre- and post-meeting interviews were professionally transcribed verbatim. Analysis began with an initial read of the meeting and interview transcripts, whereby key discursive patterns, devices and actions were identified by Authors A and C, then documented and discussed with authors B, D and E. These discursive patterns included descriptions of language and the affective and processual accomplishments of these exchanges, and were iteratively added to following analysis of the pre- and post-meeting interview data. Our approach was best described as at the meso-level, incorporating the situated use of language in context, to uncover shared or collective accomplishments, practices and meaning-making within meetings (Alvesson and Karreman, 2000; Potter and Wetherell, 1995). Finally, Authors A and C reviewed the videos again, returning to the relevant literature and theoretical guidance for the themes discovered.

4. Results

The family meetings typically occurred as part of a patient's initial admission into palliative care, on the basis of their worsening condition, or a re-admission to hospital. Pre-meeting interviews revealed that meetings, regardless of their timing, were approached by health professionals as an opportunity for sharing information, care goals and wishes, and ensuring consensus on care planning. Each meeting began with introductions, usually led by a palliative care consultant/physician at one hospital, and a social worker at the other, who outlined the meeting's purpose, often flagging a particular agenda or priority such as ongoing place of care or treatment options.

4.1. Recalibrating hope

It was within pre-meeting interviews, and early within meetings, that we first observed collective emphasis on comfort and reassurance via *recalibrating* the (various) meanings or conditions of hope. Such attempts, part of what Olson et al. (2020) term the 'reflexive emotional work' of health professionals in palliative care, formed conversational and affective anchors throughout the meetings. Pre-meeting interviews were punctuated by descriptions of patient and family uncertainty; we heard accounts of shock, fear, grief and trepidation describing the transition to palliative care:

Husband: I think you live the journey not what to expect when you're struggling with cancer … So you just get in that mode of "well, this is the next thing" and maybe this is the next thing, I don't know. (pre-meeting) [Family Meeting #8, FM8]

Another participant:

Husband: I know ..[the oncologist] has to be harsh and hard but when she came and told [patient] that there's no more treatment, bang, like that. It hit [patient] really badly and ..[the oncologist] sort of said, "Well, that's it." … (pre-meeting) [FM10]

Rather than casting an individual physician as insensitive or blunt, the excerpts above can be read as revealing of the challenges inherent to shifting goals of care. Indeed, the need to resolve tensions and fears related to the transition to palliative care (and the move 'beyond' oncology) was clear, particularly as palliative care sat outside of a curative-hope approach to care (MacArtney et al., 2015). We saw frequent attempts in pre-meeting interviews to foreground support and information-giving as expressions of (palliative) care and comfort, reorienting treatment and care – and hope – *within* the constraints of poor prognosis. This clarification work was viewed as most challenging in circumstances where health professionals anticipated the need to 'break bad news':

Social worker: Look, I think this is probably going to be quite an emotional, complex meeting. […] it's quite difficult because I think they think there's going to be a cure and we're concerned because my understanding is prognosis is quite poor. (pre-meeting) [FM10]

What developed in the meetings themselves were professionals' attempts to recalibrate, gently repositioning what hope might mean vis-à-vis medical futility (see also Broom et al., 2013, 2014, MacArtney et al., 2015, 2017). While *positive reappraisal* on the part of patients has been previously noted as a means to 'transform' the meaning of hope, and life (Duggleby and Wright, 2005), the meetings became *collective* opportunities to clarify associations or assumptions linking palliative care to withdrawal of treatment, giving up, abandonment, uncertainty or imminent death.

An important strategy emerged to convey comfort and empathy (see also Forbat et al., 2018; Ragan et al., 2008) in the use of comparisons: complimenting or praising the patient in relation to equivalent cases or norms. Foregrounding resilience and strength offered a means of recalibrating perceptions of how well the patient was doing (or had done) despite worsening health, with patients described as 'amazing', 'courageous', 'stoic', and 'trying their very best':

Trainee Physician: For the sake of family I would also point out that [patient]'s done very well with her diagnosis to date … It's a very aggressive type of cancer and quite often we see that our patients, unfortunately, don't survive very long. So I would illustrate at the outset that [patient] has done very well with the course that she's taken. [FM13]

And in another meeting (a different trainee physician):

Trainee Physician: [Patient]'s battled this cancer for a long time and he's been very stoic and courageous throughout it. [He]'s had many different lines of chemotherapy. He's had this cancer, as you say, probably for seven years and really probably done a lot better than average already, which is great … [FM11]

Poor test results or deterioration could be moderated with more positive language around stoicism and fortitude. Such language also seemed to implicitly establish a norm of positivity, perhaps functioning to create and reinforce patients (and families) as *compliant*. Thus, regardless of the intent of treatment or outcome, what emerged was a framework of hope based on reassuring (compliant) patients. This also resonates with Krawczyk's (2019) work on clinicians' affective labour in palliative care, including proactive co-authorship which ideally eventually leads to mutual acknowledgement of dying trajectories.

This collaborative recalibration of hopes centred around information-as-reassurance; several participants spoke of experiences of greater clarity, or feeling 'better' (or as one participant said, 'a lot happier now') given more information and understanding of care planning, which emerged as an important aspect of feeling cared for (Clayton et al., 2005). This was especially the case for those families whose transition were characterised by moves towards more holistic models of care and comfort, away from a narrower fixation on cure (usually associated with chemotherapeutic or other options with curative intent):

Husband: I think we've focused so much on chemo but then it hit us badly … and it failed again and it really did hit us badly and then when [oncologist] turned up in the ward and says, "I'm sorry, I'm not going to put a team together anymore," that's when it really turned. [FM10]

Indeed, we heard several accounts of moments of realisation related to treatment options and the imperative to recalibrate focus. Such realisations frequently included articulations of the unfolding realities of illness and care, constitutive of flourishing or suffering, to which we turn our attention below.

4.2. Tensions between futurity and futility

A key theme within meetings related to discussions of plans and wishes (and probabilities) for a positive and long/er future, against the ever-present spectre of mortality. This futurity-futility tension dominated conversation in several meetings, variably inflected by discussions about symptoms, pain, treatment options, place of care, and patient and family coping. Hope and despair required constant reconciliation, including in the imperative to *keep going* (pursuing further treatment, or trialling being cared for at home, for example) as well as through *acceptance* (as acknowledging death, or concessions around mobility or care needs, for example). Brown et al. (2015) have similarly articulated this ambivalence of hope amid vulnerability and uncertainty. Here, hope and despair coexisted in tension through *possibility*, notably through discussion of the continuation of treatments, attached to the (often implicit) implication of terminality:

Trainee Physician: … [proposed treatment] it's unlikely to completely take it away … The theory is it will shrink the tumour. [FM9]

We also observed, perhaps unsurprisingly, examples of hope despite a lack of options:

Husband: They have said there's not much chance of treatment but there's always hope. (pre-interview) [FM13]

Highlighting how feeling informed was associated with feeling cared for, and in turn how such (prognostic) information was bound up with hope and hopefulness as something of value, another participant

commented:

> Husband: I mean miracles still happen. You know what I mean? This [information] is good. I'm welcoming it because we haven't had it [information] up until now but it's still just a guideline for me because if I start giving up hope … [trails off and conversation moves on] [FM8]

Hopes for a miracle were articulated in accounts of not giving up, 'stubbornness' and not wanting to 'let go'. In this way, hope for miracle-as-cure or miracle-as-recovery were not a-priori expectations. Rather, they reflected an acknowledgement of prognosis and 'hopelessness', and offered a way of making sense or sensitising dissent or dissatisfaction. That is, positioning 'giving up' or 'losing hope', through the lens of lay normativity, as *bad*, regardless of logics of realism or pragmatism related to advanced disease (see also Sayer, 2011). Moreover, they were revealing of the inter-relational importance of hope, made evident here through implicit requests (directed at health professionals) for support and solidarity:

> Patient: Do you want to say something?
>
> Daughter: All I want to say is I am stubborn … I won't let go easily <crying>.
>
> Physician: No one has and you haven't all along but unfortunately there's nothing any of us can do now to stop this taking its course. [FM10]

As a form of perseverance and holding on, hope (in this case, perhaps as 'hoping against hope') was a means through which some positivity could be injected into an otherwise hopeless future; but also, critically this expression of hope signalled what (and who) was valued by patients and carers. Moreover, it exposed the 'hope work' done by professionals to demonstrate care and support via maintaining, dismantling or curtailing expectations (Perakyla, 1991). In some meetings, though, participants were more despondent, with for example little to 'look forward to':

> Wife: We just don't get to do anything. [Patient] doesn't get to do anything very pleasant anymore, nothing to look forward to …. [FM2]

Our analysis also found unexpected dynamics in making sense of palliative care. The in-patient specialist palliative unit was the hoped for place of care for the patient below, who understood his referral as equating to imminent decline and death. During the meeting he was surprised to learn that he was perhaps not as close to death as he had imagined, and found a future away from the in-patient unit unsettling:

> Patient: I was still under the impression that I'd be able to hopefully move in here [specialist palliative care unit] and spend my last days here.
>
> Social worker: We're funded by the government for acute palliative care, so people are coming here for symptom management or end-of-life care but unfortunately we can't keep people indefinitely … We'd love to keep everyone but we can't. [FM7].

This excerpt, along with corresponding pre- and post-meeting interviews, revealed a more pragmatic approach to terminal illness and a rigid adherence to 'time left'; the patient's daughter joked:

> Daughter: You should see dad's funeral arrangements. Dad's such a high achiever that if you said, "Look, you're going to last five more weeks," in four weeks and six days he'd have his best suit on and be lying on the bed with his arms crossed. <laughter> (post-meeting interview) [FM7]

The sense of precarity around the patient's condition was ever-present across the meetings. Families and patients had invariably already endured acute highs and lows, and the medical stabilisation of the patient occurred in tandem with the need for stability and caution in future expectations. This is exemplified in the exchange below; the patient, a woman in her seventies with MND, was admitted to hospital following a critical deterioration in her condition. Her family had been extremely worried and told to prepare for her imminent death; as her daughter said, "we've been on this emotional rollercoaster where we thought she was going to die". Once admitted, however, her condition improved, a cause for celebration and renewed optimism. The family meeting thus became a setting for new tensions, where relief and hope needed to be tempered; death (and suffering) had been averted, for now, but the future (beyond days) remained uncertain:

> Trainee Physician: It's difficult to know what will happen from here. So we're trying not to be too optimistic about the future, but at the same time maybe not as pessimistic about the future as it was at [previous hospital]. It's a difficult course to tread and you're still in this period of wait-and-see …
>
> Daughter: Which we're grateful that the goalposts have changed obviously.
>
> Patient: What was that I'm sorry?
>
> Trainee Physician: We were just saying that your time with us is obviously not measured in days anymore.
>
> Patient: Oh, no. No.
>
> Trainee Physician: Which doesn't disappoint anyone but maybe does raise some issues for where will you be looked after down the track. It does raise some other issues if you, say, have months to years potentially. Who's to know what will happen. It's just a very uncertain disease at this point. [FM4]

The above excerpts highlight hope-in-futurity as a prominent consideration within palliative care experiences, frequently made visible through questions about 'time left'. Such concerns may also reflect attempts to demarcate the *limits* of futurity and establish forms of certainty:

> Son: Of course the difficult question is, are you able to say how long?
>
> Daughter: For someone like mum, what's your experience of how long is she going to have?
>
> Physician: Look, it's always hard to tell you the exact amount of time. I think the best guide is how people change over a period of time. [FM6]

Requests for information varied across the meetings; within each family we observed a range of accounts of anticipating terminality (see also Kenny et al., 2017) through ways of broaching 'how much time' a patient might have. These requests frequently involved the collective uptake of caveats related to the limits of medical knowledge and expertise to avoid commitment to 'deadlines', for example:

> Patient: I don't want to know at this stage, I know I'm a wimp, I don't want to know how long I've got.
>
> Trainee Physician: That's completely fine. Often we're very inaccurate with that at the best of times anyway. We've got averages in our heads but they often don't apply.
>
> Patient: It could be less, it could be longer.
>
> Trainee Physician: Absolutely. We don't need to talk about numbers at all. That's fine. [FM11]

In another meeting:

Son: What I've been wondering about is time courses and things like that and what to expect and that sort of thing. What sort of recovery is it going to be? Is this the beginning of the downhill slope or is there a plateau … before things go downhill?

Physician: Are you happy for me to answer that [Patient]? I think that's important.

Patient: Yeah, as long as it's not a deadline.

Physician: No one could give you a deadline. Nobody knows.

Patient: That's good.

Physician: We have to be realistic and we have to expect … to get worse over a number of weeks to months. … The reason we don't like being too specific about this is because we're always wrong.

Patient: Yep <laughter>.

Physician: But we're wrong to a certain extent. We get ballparks right, just because we've seen this before. [FM10]

It is arguably in the uncertainty of the future that hope resides, and this aspect of hope is implicitly accessed (and collectively cultivated) in relation to this uncertain future in these accounts. Indeed the collective discourse around the limitations of medical knowledge and the accuracy of prognostications was clear across the meetings and interviews:

Wife: Well it's a bit of trial and error. Let's hope it works for a while. How much longer has [Patient] got? The doctors can't even tell. (post meeting) [FM7]

Invoking the limitations of medical knowledge gestured toward kindness, affording possibility – for more time, for quality of life, perhaps even for improvement. Here, though, coercive tensions were also revealed in discourses of responsibility and (a lack of) control (see also MacArtney et al., 2015; McNamara, 2004). Talk of the limits of medical knowledge was a frequent example of the collective performance of uncertainty (albeit with a backstage of 'knowing'). Emphasising uncertainty enabled hope to be mobilised; in turn, emphasising hope could cultivate uncertainty, precariously elevating *hopeful* dispositions within the family meeting (and beyond). This also offered a strategy for deferring the closing down of future options, orienting hope as embedded in the 'not yet' (see also Ahmed, 2004; Bloch, 1986; Simpson, 2004), to which we turn our focus below.

4.3. Short-term goals, deferrals, and the work of hopefulness in context

The interplay between cultivating or curtailing hopes and fore-grounding incremental, modest, or immediate plans, goals or expectations was frequently observed within the meetings. Orienting the future incrementally – 'one step at a time' – functioned to maintain hope (and postpone distress) through a focus on 'wait and see'. Throughout the meetings we observed patients, families and health professionals defer taboo conversations or difficult realities (around deterioration, dying and death), positioning such topics as important, but 'not for now':

Nurse: … all we can do is pretty much look one step at a time, one week at a time with the first thing getting the pain under control sufficiently so that you can get out of the hospital is step number one and then obviously we would just monitor the situation as an outpatient and hope we can keep the disease under control. But I believe it's clearly going to be an ongoing problem. That's what we all have to accept … [FM12]

In another meeting:

Patient: No timelines, just medical summaries.

Social worker: Okay.

Patient: We're not ready for timelines yet. […]

[later in the meeting]

Physician: I know you don't want to think about it, but hoping for the best and planning for the worst scenario, another thing to talk about is where would be the best place for you to be cared for …

Patient: Well it depends on how well I keep. [FM10]

As illustrated in the above examples, meetings could be opportunities for clarification and reassurance (and associated recalibration), and occasions for deferral or partial avoidance of certain topics, revealing the various attempts of participants (professionals *and* patients and families) to avoid distress (see also Brown and de Graaf, 2013; The et al., 2001 on 'collusion'). The above excerpt (FM10) reveals patient and family participation (or initiation) in exchanges that re-oriented talk of future preparedness as for another (later) time, in this case, contingent on discourses of wellness and resilience. Various tropes were, unsurprisingly, drawn on by professionals to signpost future preparedness, such as 'hoping for the best, planning for the worst'. This phrasing is a notable means for recalibrating hope in palliative language to combine or balance the present with the uncertain future (Back et al., 2003; Clark, 2002). Hope-via-deferral also served to comfort worried patients or families:

Trainee Physician: There's some options for the future but we can cross those bridges later. [FM4]

Here, and across the meetings, future time retained an abstract quality, within the hopeful realm of 'not yet'. Discussion of what might happen 'down the line' was rarely temporally specific; indeed, uncertainty related to longevity emerged as a key aspect of hopefulness. Hopefulness could be maintained by discursively veiling bad news (often through deferral), as shown in the excerpt below. Indicating her belief that time away from treatment would unnecessarily advance the progress of her mother's cancer, a daughter asks when her mother can return to a clinical trial following a poor response to trial drugs. The trainee physician responds, deferring a final decision to the lead trial physician (not present at the meeting). While the daughter seems to acknowledge the futility within the trainee physician's explanation, her brother (the patient's son) does not respond to these cues in the same way:

Daughter: How long will the actual treatment be stopped? How long does she have to wait before she can go back onto the treatment?

Trainee Physician: That's a good question. We have to run that by – [Physician's name]'s your consultant?

Daughter: So there's no guarantee that she's going to go back onto that treatment at this stage? Is that correct?

Trainee Physician: That's correct. So sometimes in these trials when people have disease it gets worse, it gets larger on the scan. That's shown to be called progressional and therefore it's said that it's grown on the drug so therefore there's no real point in continuing with that drug. […]

[a little later in the meeting]

Son: So then back on the same [trial treatment] after that?

Social worker: Hopefully.

Daughter: Hopefully. [FM8]

Whether intended to maintain hope or to comply with hierarchies of medical decision-making, the trainee physician's deferral reveals how hope-as-possibility can be collectively retained through not closing down potential options (Simpson, 2004). Although the maintenance of hope by health professionals has been called a 'collusion of

misunderstanding' (Brown and de Graaf, 2013; Miller, 2000), potentially masking clinical 'truths' (c.f. Miyaji, 1993), the hopefulness collectively cultivated in the above exchange can also be viewed as an expression of being *cared for* (MacArtney et al., 2020; Eliott and Olver, 2009; Youll and Meekosha, 2011). The social worker and the daughter do not challenge the son's 'incorrect' response, instead affirming the values behind his response, respectfully managing the hope of another. This provides an example in practice of hopefulness as relational and ongoing, foregrounding comfort through feeling cared for by someone, rather than being comforted by the idea of 'having' hope (see also Simpson (2004), citing Lynch (1965), on the importance of hope as shared ideas and comfort with/from others).

Across the meetings, emphasising short-term goals and deferring discussion about longer-term outlook exposed multiple 'legitimate' hopes and goals (Duggleby et al., 2010). These were underpinned by the imperative to persevere, allowing (and enforcing) people to 'keep going':

> Husband: … I won't bring it [dying] up because that's like for me to go, "Well hang on, I'm giving up now," which I'm not going to. I've said this to [Patient] all the way through, I said, "The longer you can stay alive the more chance you've got of something coming up that will be able to make a difference …" Patient's husband (post meeting) [FM8]

Hope-as-perseverance brings into focus the action component of hoping (Zigon, 2009; see also Brown and de Graaf, 2013); a mechanism for coping with the adversity of today's treatment, transforming tomorrow's fear into optimism for a longer and better life. In this sense deferral facilitated a hopeful waiting game, making room for optimism via 'glimmers' of possibility (however unlikely) (see also Olsson et al., 2011; Ragan et al., 2008). Within these discourses of perseverance, vulnerability also surfaced (Simpson, 2004), where hope as 'not giving up' exposed feelings of helplessness and perhaps hopelessness:

> Social worker: … it's important taking one day at a time and having that quality time at home with mum as well ….
>
> Daughter: … if anybody gets any ideas of trying to talk me into giving up they can give that up, that idea, right here and now.
>
> Social worker: Gotcha. So you're saying you're not giving up and that's where you want to be?
>
> Physician: We're not giving up either.
>
> Social worker: We're not giving up either.
>
> Physician: We will never give up supporting [Patient]. [FM10]

Above we see nuanced discursive work on the part of the physician, reorienting a temporal framing of 'giving up' to instead focus on ongoing support. But deferring the 'long-term' could also conceal or suppress participants' views, as emerged in pre- and post-meeting interviews. For some, deferring discussions of deterioration, for example, was motivated by pragmatic aspect of ongoing treatment and care:

> Nurse: I still think there's a lot of area not covered with regards to deterioration of the patient and how she will cope then but I don't think it was appropriate to talk about that today… You can't be talking about ongoing treatment and then in the same conversation talk about end-of-life issues, which they will have but that's going to be further down the line. (post-meeting) [FM8].

Here, short- and long-term goals were mutually exclusive within the project of perseverance; deteriorating health could be broached later (deferred until deemed necessary or perhaps unavoidable), but was incongruent with discussion of ongoing treatment, for now. The interviews also revealed important divergences, oriented around the desire to address the absent-presence of imminent mortality or 'down

the track' issues whilst being careful to maintain the hope of others:

> Niece: Meetings are confronting, being in hospital is confronting, his condition is confronting. It's like what do you say and sometimes there's things that I feel like I want to talk to the doctor about which I don't know necessarily that I want to bring up in front of my uncle, like more further down the track questions which are overwhelming and I don't want to necessarily say them in that situation. (post-meeting) [FM3]

Thus, while an emphasis on short-term goals could reassure, so too could it conceal or discount 'negative' emotions or the expression of fear, anxiety and grief (Broom et al., 2009; Youll and Meekosha, 2011). It is here the potential is revealed for hope to concurrently comfort and coerce, reflective of individual desire (for life), of the desire to manage or maintain the hope of others, and as a practice of governing (dying and deaths).

5. Conclusion

Hope is palpable as a social relation in palliative care, offering insights into the nuances of its cultural importance and the workings of hope more broadly. It is paradoxical that hope plays such a vital part in the choreography of (modern) dying; and the family meeting provides a unique lens through which to view how hope comes to matter in different ways to different people. Our analysis above extends conceptualisations of hope in palliative care by considering the practical workings of hope and hopefulness using both interview data and observational data from meetings themselves, including analysis of multiple speakers within this naturalistic setting. While previous work has explored how hope is used in talk through interviews with those nearing the end of life and those who care for them (Duggleby and Wright, 2005; Eliott and Olver, 2009), our findings demonstrate how hope is collectively cultivated and expressed; moreover, our study highlights how the *process* of hopefulness plays out in real-time palliative care encounters.

In their qualitative study of dying cancer patients' talk about hope, Eliott and Olver (2009: 629) suggest that hope necessitates "familial involvement and support in activities that shape and reflect patients' hopes". Our analysis unpacks *how* hope is collectively produced between patient, family and health professionals, and how hope is variously and relationally drawn on in expressions of support and solidarity. We saw the foregrounding of resilience, for example, in the affective labour of professionals, as a means to recalibrate hope and express care and support for (often anxious) patients and families. These opportunities to collectively foster comfort and build empathy highlighted how hope could be mobilised in the reorientation of expectations and goals of/for care. Hope also emerged within various careful negotiations related to future treatments and the possibilities/implications therein. Such discussions revealed the importance of shared or united values, most obviously in the clear consensus that 'giving up' or 'losing hope' was *bad*, even/especially in the context of advanced disease. The emphasis on short-term goals similarly reflected various stakeholders' expressions of sensitivity to patient (and family members) values. In this way the production of hopefulness within meetings was central to reaffirming solidarity with/between patients and families in terms of next steps, as well as in avoiding taboo conversations (including around deterioration and dying). This hope-as-deferral also made room for optimism, via shared (and sharing) vulnerability and uncertainty; discussions in meetings around the limits of medical knowledge ('we don't know', 'we're always wrong'), for example, was striking, sustaining hope and helping to foreground patient and family priorities and preferences through expressions of uncertainty.

As we demonstrate through the data presented above, *expressions* of hopefulness in relation made room for feeling supported and cared for, for cultivating comfort via alleviating (or emphasising) uncertainty, and

for feeling like family and professionals were engaged and not giving up. Indeed, within most of the meetings, the collective 'doing' of hopefulness came to matter in and of itself. Transforming hope into hopefulness in this way, regardless of how it is subjectively understood by any one actor (as object, as process, as realistic, as future orientation and so on), is central to the demonstrative aspects of care and solidarity inherent to family meetings (see also Wrigley, 2019). While an attitude or disposition of hopefulness has been recognised across therapeutic contexts as a "salient quality of a 'survivor' attitude" (Miller, 1985: 23; see also Petersen and Wilkinson, 2015), our findings underline hopefulness as likewise valued in the context of terminal prognosis. Instead of necessitating associations with likelihood or probability (for cure, for recovery, for longevity) *per se*, hopefulness in palliative care, we argue, retains potential as an important aspect of person-/patienthood, concurrently signifying what is valued, wished for and idealised (Brown and de Graaf, 2013; Eliott and Olver, 2009; Sayer, 2011). Conceptualising hopefulness as a lay normativity avails a focus in on what matters to people in "trying to work out what kind of life is a good one, or what flourishing consists of" or, indeed, what suffering consists of (Sayer, 2011: 256). In turn, as a disposition towards living (and dying) – building on what Eliott and Olver (2009) call 'life-affirming' – hopefulness, we argue, may reveal the various ways of qualitatively knowing and tacitly 'doing' dying (c.f. Wahlberg, 2018). Moreover, this allows for what Back (2015) calls a *hopeful sociology*; in the context of this study, where family meetings offer 'islands of hope' (quality time at home, making the patient comfortable, offering more options down the track, feeling cared for and looked after) within 'the sea of despair' (deterioration, increasing care needs, imminent mortality).

Yet, the limitations and coercive potential of hopefulness in practice must be noted. While we observed hopefulness-in-situ (Petersen and Wilkinson, 2015), we also want to resist positioning this hopefulness as a category of resilience or a marker of success. The emphasis within meetings and interviews on certain 'hopeful' pursuits as expressions of care (e.g., a focus on increasingly small or modest goals over talk about long term longevity) also points to the enduring presence of forms of 'good' patienthood within therapeutic culture. Like Alacovska (2018), we see the problems inherent to discourses of hope in subjecting people (in this case patients and families) to "assuming unconditional acceptance of and adaptability to conditions of precarity though the banalization or routinization of hardship" (Alacovska, 2018: 1133). Analysing hopefulness within medicine, we argue, can sensitise us to experiences of suffering or vulnerability, allowing for interpretations that can move beyond privileging a resilient subject capable of accommodating ever-increasing uncertainty or fear (see also Simpson, 2004). Particularly given the importance of *consensus work* ('getting everyone on the same page') within palliative care family meetings, we argue that attending to hopefulness offers potential for recognising what matters to patients and families in and beyond treatment and care, nearing the end of life.

Credit author statement

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