

Original Article



What does it take to deliver brilliant home-based palliative care? Using positive organisational scholarship and video reflexive ethnography to explore the complexities of palliative care at home

Palliative Medicine
2019, Vol. 33(1) 91–101
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/0269216318807835
journals.sagepub.com/home/pmj

**\$**SAGE

Aileen Collier<sup>1,2,3</sup>, Michael Hodgins<sup>4</sup>, Gregory Crawford<sup>5,6</sup>, Alice Every<sup>6</sup>, Kerrie Womsley<sup>7</sup>, Catherine Jeffs<sup>6</sup>, Pat Houthuysen<sup>6</sup>, Srey Kang<sup>7</sup>, Elizabeth Thomas<sup>7</sup>, Valerie Weller<sup>7</sup>, Cindy Van<sup>7</sup>, Caroline Farrow<sup>6</sup> and Ann Dadich<sup>4</sup>

#### **Abstract**

**Background:** Despite the increasing number of people requiring palliative care at home, there is limited evidence on how home-based palliative care is best practised.

**Aim:** The aim of this participatory qualitative study is to determine the characteristics that contribute to brilliant home-based palliative care. **Design:** This study was inspired by the brilliance project – an initiative to explore how positive organisational scholarship in healthcare can be used to study brilliant health service management from the viewpoint of patients, families, and clinicians. The methodology of positive organisational scholarship in healthcare was combined with video-reflexive ethnography.

Setting/participants: Home-based specialist palliative care services across two Australian states participated in the study. Clinicians were able to take part in the study at different levels. Pending their preference, this could involve video-recording of palliative care, facilitating and/or participating in reflexive sessions to analyse and critique the recordings, identifying the characteristics that contribute to brilliant home-based palliative care, and/or sharing the findings with others.

**Results:** Brilliance in home-based palliative care is contingent on context and is conceptualised as a variety of actions, people, and processes. Care is more likely to be framed as brilliant when it is epitomised: anticipatory aptitude and action; a weave of commitment; flexible adaptability; and/or team capacity-building.

**Conclusion:** This study is important because it verifies the characteristics of brilliant home-based palliative care. Furthermore, these characteristics can be adapted for use within other services.

#### **Keywords**

Community health services, quality of healthcare, qualitative research, patient care team, palliative care

#### What is already known about the topic?

- Specialist home-based palliative care can improve symptom management and quality of life and prevent hospitalisation at the end-of-life.
- There is significant variation in how home-based palliative care is delivered, even within similar jurisdictions.
- The clinical practices and contextual factors that enable exemplary palliative care are not well understood.

#### Corresponding author:

Aileen Collier, School of Nursing, Faculty of Medicine and Health Sciences, The University of Auckland, Auckland 1142, New Zealand. Email: aileen.collier@auckland.ac.nz

<sup>&</sup>lt;sup>1</sup>School of Nursing, Faculty of Medicine and Health Sciences The University of Auckland, Auckland, New Zealand

<sup>&</sup>lt;sup>2</sup>College of Nursing and Health Sciences, Flinders University, Bedford Park, SA, Australia

<sup>&</sup>lt;sup>3</sup>School of Health Sciences, University of Tasmania, Hobart, TAS, Australia <sup>4</sup>School of Business, Western Sydney University, Parramatta, NSW,

<sup>&</sup>lt;sup>5</sup>Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, SA, Australia

<sup>&</sup>lt;sup>6</sup>Northern Adelaide Palliative Care Service, Northern Adelaide Local Health Network, SA, Australia

<sup>&</sup>lt;sup>7</sup>Community Health Nursing Services, Hoxton Park Community Health Centre South West Sydney Area Health Service, Hoxton Park, NSW, Australia

#### What this paper adds?

• The study identified some of the characteristics that enable brilliant home-based palliative care – notably: anticipatory aptitude and action; a weave of commitment among different individuals, within and beyond a palliative care service; flexible adaptability; and team capacity-building.

 Using the combined methodology of positive organisational scholarship in healthcare and video-reflexive ethnography, this study also revealed the importance of context in delivering brilliant home-based palliative care.

#### Implications for practice, theory, or policy

- The aforesaid conditions can be adapted for use within other services, particularly those committed to brilliant palliative
  care.
- Despite the contributions of this study, policies are required to guide and sustain brilliant home-based palliative care across different settings.

#### Introduction

With ageing populations and the global rise of cancer, chronic illnesses, and multi-morbidities, the need for highquality palliative care has never been greater. Correspondingly, the number of people requiring palliative care is expected to increase.1 Technologies continue to increase, as do debates about how Western health systems can remain economically sustainable. Hospital stays have become shorter, patients spend most time at home,<sup>2</sup> and outpatient care has become increasingly complex with patients and carers expected to assume what were once clinician responsibilities.3 Although many people prefer to die at home,<sup>4</sup> this preference can change<sup>5</sup> and is more complex than previously assumed.<sup>6</sup> Nevertheless, homebased palliative care services are associated with: the reduced use of other health services; improved quality of life; reduced symptom burden;<sup>7</sup> and better patient and carer satisfaction.8 Yet, there are significant disparities in service provision, even among well-resourced countries. 1,9 Furthermore, there are large variations in the configuration of home-based palliative care services worldwide, 10,11 with a combination of geographically-dispersed public, private, and not-for-profit services. The needs of many people remain unmet with inequitable access to palliative care. 12 Given these challenges, it is perhaps extraordinary when home-based palliative care is successful.

To improve access to palliative care, policies in several nations – including the United Kingdom, Australia, and New Zealand<sup>13</sup> – endorse home-based palliative care, irrespective of diagnosis. These policies also support capacity-building among non-specialist clinicians to provide palliative care. Yet, how this is to be achieved and evaluated remains unclear.<sup>14</sup> Furthermore, these policies are part of a 'measure and manage'<sup>15</sup> approach to understand and improve palliative care by evaluating performance or 'impact' against a metric. However, given the complex interactions between patients, carers, and clinicians, causal relationships cannot always be established. When

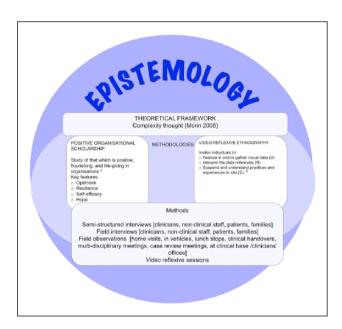
studies and meta-syntheses have attempted to evaluate the primary outcomes of specialist home-based palliative care services, investigators have found it difficult to ascribe the outcomes to one component of the service. This is largely due to significant variation in what was provided, how it was provided, when it was provided, as well as who and what were involved.11 Furthermore, common measures to evaluate home-based palliative care do not necessarily capture the concepts that are meaningful to patients or carers, such as a sense of security.16 In other words, although there is evidence to support home-based palliative care, there is limited evidence on how it works best for those involved. 10,17 Along with the growing recognition that the 'measure and manage' approach is limited, 18 there is a growing movement in the field of patient safety to better understand what goes right in healthcare. Given the complexities of home-based palliative care along with these recent developments in patient safety, the time is ripe to better understand, not only how evidence-based palliative care unfolds within the community but also the circumstances in which it goes right, or is brilliant. The aim of this study is to determine the characteristics that contribute to 'pockets of excellence' in home-based palliative care. Instead of awarding attention to poor care, errors, and oversights, brilliance redirects scholarship to the characteristics ascribed by the Brilliance Group (Table 1).20-22

# Theoretical framework

Theoretically, this study draws from complex thought described by Morin.<sup>23</sup> Complex thought is, 'systemic, connective, and contextualising; it aims to distinguish and associate elements of a system, rather than reducing or disjoining'.<sup>24</sup> Furthermore, it takes a participatory approach to create knowledge relevant to the communities it serves (Figure 1).

#### Table 1. Brilliance Criteria.<sup>22</sup>

- (1) Has quality and safety and well-being of both patients and staff/practitioners at its core.
- (2) Accounts for value for money and rich versus poor brilliance (i.e. the difference between millions being used for an intervention compared to much smaller amounts).
- (3) Explains how it delights consumers (something for both patients/consumers and staff/practitioners/consumers) that creates new meanings and understandings of service.
- (4) Accounts for context what is it in the eye/mind/perception of the beholder and how it is created to support brilliance.
- (5) Explains the relational dimensions of what shapes or co-creates the brilliance.
- (6) Examines the ethics of the situation or process so that brilliance is not about a compromised or undesirable outcome.
- (7) Accounts for how brilliance is framed as an entity either as a thing, person, practice or process, or all of these; and what these choices entail.
- (8) Accounts for the evidence garnered to make a claim for brilliance, or tells, shows, or describes how the notion of evidence is used.
- (9) Is reflective in accounting for how the vignette deals with the left- and right-brain and the either/or-ing of framing brilliance.
- (10) Explains the type of phenomenon brilliance entails a journey, an event, or a snapshot in time and what this means for our understanding of brilliance.
- (11) Considers accountability mechanisms for brilliance.



**Figure 1.** Relationship between epistemology, theoretical framework, methodology, and methods.

## **Methods**

To 'make visible' the complex elements of home-based palliative care, focus on that which is positive, and engage service providers, this research combined two methodologies – positive organisational scholarship in healthcare (POSH) and video-reflexive ethnography (VRE). POSH is 'the study of that which is positive, flourishing, and life-giving in [healthcare] organisations'.<sup>25</sup> Challenging the tendency to concentrate on all that is negative, it seeks to study triumphs and achievements because of their inherent allure.<sup>22,26</sup> It does not ignore negative organisational aspects;<sup>27,28</sup> but rather, it represents 'an alteration in focus'<sup>26</sup> – a deliberate attempt to redress the preoccupation with the negative.

VRE acknowledges methodology and method as both describing and creating social realities. It can be transformative and interpretive, simultaneously acting as a methodology and an intervention.<sup>29</sup> In keeping with its philosophy of 'nothing about us without us', VRE seeks not to privilege one kind of knowledge over another and to dissolve the power imbalances between academics and participants. VRE invites participants to: feature in and/or gather visual data (V) in collaboration with researchers; interpret the data reflexively (R); and suspend and understand practices and experiences, in situ (E). VRE involves the negotiated filming of practice and/ or participant accounts of practices, supplemented by reflexive viewing to co-analyse footage.30 Here, reflexivity is distinct from reflection. While reflection is individual and focussed, reflexivity is collaborative, socially distributed, open-ended in purpose, and immediate in effect.31 Reflexivity is concerned with perturbing, reviewing, and reimagining practice.32 Thus, VRE encourages the co-construction of new meanings by challenging assumptions – be they the researchers', managers', clinicians', patients', or carers'.33,34 It requires researchers to embark on a journey with participants in directions that are uncertain to capture what are often contested perspectives and produce footage that might have different meanings to different people at different times and in different settings.33

A.D. is an experienced health service management researcher with expertise in POSH and mental health. M.H. is a research assistant with experience in qualitative research. Together they led field research in New South Wales (NSW), Australia. A.C., a palliative care nurse researcher experienced in VRE, led field research in South Australia (SA). The authors applied a multilayered reflexivity approach to reflexivity, as described by Nicholls.<sup>35</sup>

Table 2. Fieldwork.

Setting	Model of care	Data sources	Participants	No.	Fieldwork	Data
NSW: community health centre in outer metropolitan area, covering one of four geographical catchments of a larger area service	Consultancy model where a small team specialist palliative care nurses (n = 3) are supported by offsite palliative medicine consultants; to support co-located generalist community health nurses who coordinate the care of patients; and collaborate with external general practitioners and not-for-profit organisations	Weekly case reviews; team discussions; delivery of home-based palliative care; conversations between clinicians, with patients, and/ or with carers; interviews with clinicians, patients, and carers regarding their perceptions of, and experiences with palliative care, particularly that which is brilliant; and the documentation of	<ul> <li>Co-researchers</li> <li>Consenting clinicians (who did not co-research)</li> <li>Consenting patients</li> <li>Consenting carers</li> <li>Reflexive sessions</li> <li>Facilitators across all sessions</li> <li>Participants across all sessions</li> </ul>	4 18 30 16 4 14	August 2015– May 2017	Video (54.93 h*) Audio (23.91 h)
SA: hospital-based multidisciplinary specialist service covering an outer metropolitan area	Consultancy model where two co-located multidisciplinary teams are comprised of specialist palliative care nurses (n = 10), onsite palliative medicine consultants, a registrar or advanced trainee, and a social worker; collaborate with external occupational therapists, physiotherapists, volunteers, generalist nurses employed by a private organisation, and general practitioners	clinical notes Daily clinical huddles; delivery of home- based palliative care; conversations between clinicians, with patients, and/ or with carers; interviews with clinicians, patients, and carers regarding their perceptions of, and experiences with palliative care, particularly that which is brilliant; and the documentation of clinical notes	<ul> <li>Co-researchers</li> <li>Consenting clinicians (who did not co-research)</li> <li>Consenting patients</li> <li>Consenting carers</li> <li>Reflexive sessions</li> <li>Facilitators across all sessions</li> <li>Participants across all sessions.</li> </ul>	4 31 7 6 3 12 60	November 2015–December 2017	Video (504 h*) Audio (132 h)

<sup>\*</sup>The large difference in digital recordings between sites is accounted for by the significant difference in the size of the two specialist teams.

# Settings and participants

Following clearance from the relevant human research ethics committees, clinicians from two home-based palliative care services in the two aforesaid Australian states — were invited by A.D. and A.C. to participate in a study as co-researchers. The co-researchers were able to engage in the study at different levels in accordance with their wishes (Table 2). In addition to institutional ethics, the researchers collectively applied a situated ethics approach. That is, decisions about what and when to film and with whom were made 'in the context of time and place as well as who is involved, rather than according to a set of prescriptive rigid rules or regulations to be adhered to or wholly adopted'. As such, even if a participant provided formal consent, an ethically conservative approach was used to

film and subsequently view the footage.<sup>32</sup> For example, participants were recontacted to seek their permission to show footage for specific audiences and occasions.

## Data analysis

POSH-VRE expands conventional scholarship by encouraging academics to collaborate with and learn from non-academics to make sense of complex contexts, like home-based palliative care. For these reasons, data analysis evolved through four levels to optimise congruence between: the methodology of POSH-VRE; its participatory, interpretive, and transformative tenets; and the methods used to operationalise these tenets (Table 3 and Figure 2).

Table 3. Data analysis.

Level of analysis	Analytical method	Contributors		
1	Guided by Braun and Clark's <sup>37</sup> approach to thematic analysis, video-recordings, audio-recordings, and field-notes were analysed to construct key themes that epitomised brilliant home-based palliative care	<ul> <li>Academic researchers: A.C., A.D., M.H., and G.C.</li> <li>Clinical co-researchers: K.W., C.J., P.H., S.K., E.T., V.W., and C.V.</li> </ul>		
2	Short video-clips of approximately 2–4 min were created to depict the themes constructed during the preceding level, in a way that did not sever the exemplar from its context	<ul> <li>Academic researchers: A.C., A.D., M.H., and G.C.</li> <li>Clinical co-researchers: K.W., C.J., P.H., S.K., E.T., V.W., and C.V.</li> </ul>		
3	Group reflexive sessions ( $n = 6$ ) were facilitated and video-recorded across the two sites to analyse and critique the video-clips constructed during the preceding level. Clinicians were invited to describe: what they observed; how they felt while viewing the footage; whether and why the exemplar epitomised brilliant palliative care; and the factors that influenced these exemplars	<ul> <li>Academic researchers</li> <li>Clinical co-researchers</li> <li>Clinical participants</li> </ul>		
4	Guided by Braun and Clark's <sup>37</sup> approach to thematic analysis, video-recordings of the reflexive sessions were analysed to determine the characteristics that contribute to brilliant home-based palliative care, which were compared and contrasted across the two sites	<ul> <li>Academic researchers: A.C., A.D., M.H., and G.C.</li> <li>Clinical co-researchers: K.W., C.J., P.H., S.K., E.T., V.W., and C.V.</li> </ul>		



**Figure 2.** Reflexive sessions across the two sites.

## **Findings**

Our overarching finding was that Brilliance in home-based palliative care is contingent on context and is conceptualised as a variety of actions, people, and processes and is sometimes contested. Care is more likely to be framed as brilliant when it has the characteristics we report below as

the following key themes: 'anticipatory aptitude and action'; 'a weave of commitment'; 'flexible adaptability' and 'building team capacities by making brilliance visible'.

# Anticipatory aptitude and action

Brilliant care was characterised by what we refer to as 'anticipatory aptitude and action,' that is, when clinicians were able to evaluate individualised needs and address them proactively and in a responsive and timely manner in collaboration with patients and families. Furthermore, along with treating recipients of care as another person and getting to know what mattered to them, this approach required clinicians to connect and engage empathically with people and in a style and manner that was individually calibrated to that person:

All of it's been brilliant ... [The new palliative care nurse] has only just started, but I can tell what he's like already ... I'm aware of who has got it ... [He's got] empathy. [The clinicians] ... have to be able to see [patients] ... as their own person, but understand where each individual is coming from and I can pick that up with them ... [I can detect that on the] first visit ... [I consider] do they need me to do the talking or are they able to stimulate me to do the talking ... [and can they] pick up when I'm covering up [issues and concerns]? ... [He] was able to do that. (Patient, SA)

Clinicians, likewise, considered getting to know the person as fundamental to enacting 'anticipatory aptitude and action'. This also meant being attuned to the needs

and preferences of patients and informal carers through the development of relationships that were reciprocal as this doctor describes,

It's a very special thing to be in that moment when patients allow you to care for them in their most vulnerable time in their lives. I think it's very special ... despite the suffering ... you see them as people ... with medicine, what happens is we see them as diseases and that's when we lose out on the experience of what medicine is ... you treat people, not the disease. So, if you look at it that way, I think you'll never go wrong, even as a curative person ... the opportunity ... to care for a person in their most vulnerable time; not everyone gets that ... It's not easy but it's beautiful, to a certain degree. (Clinician, NSW)

'Anticipatory aptitude and action' was brought to light in reflexive sessions. In the following section, we draw data from one particular reflexive session to show how this was captured and subsequently made visible and critiqued by the team.

A short montage of footage of a senior nurse on a visit with patient Nadia and her husband George (pseudonyms) were shown to the team. The footage included a home visit by a senior nurse outside in Nadia's garden (Figure 3). Nadia walks around the garden describing how it evolved. The montage also includes Nadia being interviewed by A.C. concerning what she considered Brilliant palliative care:

## Quote 1 [Nadia's interview]

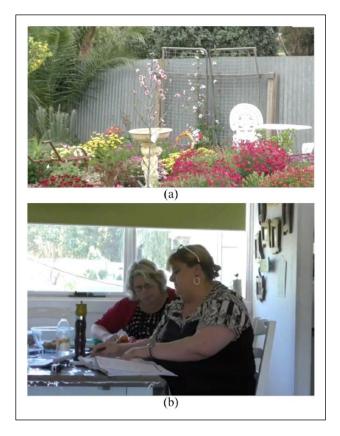
I think just like you guys (researcher), just being down to earth and being warm and welcoming and I do feel quite happy with how I am being treated and the responses, what's the word, not fast but just the, yes, just responsive you know and knowing that they are coming on the day that I need them, yes that's really important, yes and pain management and not just a cup of tea and a bit of fruit loaf (winks and smiles).

In response to watching herself, the nurse relays that following Nadia around the garden serves multiple purposes:

#### Quote 2 [Senior nurse in response to watching herself]

It's about the therapeutic relationship we have ... we needed to engage with [the patient] ... to get her to listen to us ... [And] to be able to do that, it's about being interested in what she is interested in. And she loves her garden; that's her space, that's where she finds peace and calmness ... it's really important to her ... Really, her roaming around the garden is about assessing her pain and her mobility. (Clinician, SA)

For this nurse, home-based palliative care management strategies are only possible by taking the time to meet with Nadia on her terms and by recognising what



**Figure 3.** Making home-based palliative care visible. (a) Nadia's garden and (b) clinician's discuss Nadia's medication.

matters most to her. In other words, brilliant palliative care requires recognition of patients and their family members agency. In addition, the nurse describes how she utilises the time in the garden to assess Nadia's function and symptoms.

Watching this footage together in group reflexive sessions provided the multidisciplinary specialist team with a shared space to 'step back' and review their contribution to Nadia's care over time and in its entirety. A senior consultant in the team comments,

## Quote 3 [senior consultant in response to footage]

The other thing that garden scene tells me ... what did you do between that visit and the first visit so that she could climb around in her garden? [The clinician] is [also] ... reinforcing the sense of, 'You are a whole person'; that's what that says to me and ... that helps you [to] manage the pain and the anxiety and all the other things and for that time, she [Nadia] thinks, 'This [clinician] ... understood me and valued me as a friend.' (Clinician, SA)

For this clinician, effective symptom management for Nadia is only possible in the context of viewing her as person and valuing her by engaging in what Nadia, through the lens of the doctor, regards as friendship.

In addition, viewing footage in this way enabled the team to critique their wider role in caring not only for Nadia but also how they accomplish brilliant care for other people. Another senior nurse in the group, who critiques what is brilliant care articulates how such care is experienced differently by different people and at different times. Thus, brilliance extended beyond a 'standard' approach to communication by being able to identify and calibrate how best to connect with any one person and their family:

Quote 4 [senior nurse in response to footage]

The other thing I think about, is the skill ... [of the nurse. Her] *modus operandi* was one of informality and ... it fitted for this woman ... but for some people, that would not fit ... so I think the skill is ... fitting with individuals. (Clinician, SA)

This capacity of clinicians to evaluate the most appropriate communication 'fit' was also described by recipients of care as the following quote by a caregiver conveys:

They (clinicians) must be very good at assessing people too, for instance, you stop and think – my Graham (husband) [pseudonym] is a hard-backed Scot, temper, the lot. Then there's me. Then you get my daughter, she finds it very hard to stay in control and she's like me she doesn't like to cry in public – then if Karen (granddaughter) [pseudonym] was here, she's all logic. So you look at somebody and you'd have to be able to know that person is a feeling person, so then you do a feeling conversation, whereas when you get to someone like my granddaughter Karen, you have to say such and such will happen, you have to, not be uncaring, but you give her the facts, because she's good at organising and arranging. (Patient and informal caregiver interview, SA)

# A weave of commitment

Brilliant home-based palliative care involved a weave of commitment among and between palliative care clinicians and additional (non-palliative care) practitioners. According to reflexive session participants, brilliant care required clinicians to establish relationships with, and mediate between different services to optimise the overall care of patients and carers. When closely connected and well-orchestrated, these disparate services, and the staff members therein, represented a common care goal — and they assumed a shared responsibility for achieving this goal. In practice, this typically required the clinicians to offer a metaphorical 'open' line to the patients and carers they worked with, making themselves available and accessible:

Daughter: I think [it's] the way that they communicate ... keeping tabs on how dad is going ... [And] visits to [the]

home; keeping mum up to date with dad's progress ... I've been called as well ... all it takes is a simple phone call and then we're on the right track, having an open line of communication and knowing exactly what's been going on and that's the brilliance that I've found ... we are all on the same page. Even though it's been a learning curve ... it just took me a few days to join those dots ...

Wife: It's like a big family ... [And we] all communicate together – not just, 'Oh you deal with that; oh who cares' ... they're all connected ... you don't need anybody else because they're all there. (Carer interview, SA)

The clinicians also regarded the links between different services as significant. The weave of commitment meant that upon learning of a need, clinicians would harness their alliances, which spanned the public, private, and not-for-profit sectors, including general practices, pharmacies, and paramedic services. For example, the specialist team in SA considered their alliance with the ambulance service a critical component of homebased palliative care:

One of the great teams [is] ... the [extended care paramedics] ... they're just brilliant. For the last couple of years, I think we have relied on them quite heavily after hours ... [They're] one of the main reasons why we have been able to keep ... [patients] at home. (Clinician, SA)

The doctor in this quote describes the extended care paramedics as brilliant because they were able to action their recommendations by addressing the immediate needs of patients and families out of regular working hours and in the absence of other clinicians.

## Flexible adaptability

Through observing themselves and their own practices, clinicians at both sites conveyed the importance of taking a flexible approach to assessment and care in the homes rather than focusing on a written list or 'script':

You can't go by guidelines ... it's got to fit right with you and it's got to fit right with the patients ... I say to the students, 'One of the things is leaning forward and perhaps patting them on the shoulder or the knee'. [But] I don't think you can create a formula for a clinician to follow ... it will fail every time, if you're following a script. The only way to be doing it properly is [by] doing something that feels natural ... [and by] letting the patient in some ways, lead the agenda, even though you've got that expertise ... you need to be flexible ... to go where the patient needs to go and then bring it back when you say, 'Look, also we need to do this, this, and this.' (Clinician, NSW)

The building of relationships to enable 'anticipatory aptitude and action' and 'flexibly adapting' in the ways we

have described required clinicians to shut out other demands. This often required clinicians to exercise agency to establish and sustain this approach, even if this required them to take risks, at times, flouting organisational conventions and protocols:

Clinician 1: There's some really important data that

we need to collect, but because we are attached to a hospital, we live under

that system ...

Clinician 2: It's hospitalised, it's not personalised ...

Clinician 3: But we gotta do it ... 'cause some hobnob's gotta find it when we are being

accredited.

Clinician 1: We're supposed to go through all this

information with the ... [patients]. But ... if you're building a rapport with someone, there is ... trust happening. [Flicking pages] ... we have to ask them all this – 'Have you got a machete in the house? Have you got drugs in the house? Are your steps slippery?' My problem is, you're supposed to ask them this before you've established a

rapport with them. (Clinicians, SA)

The nurses in the quote above convey the tension between building relationships with patients and families and meeting the administrative and regulatory requirements of the organisation, some of which they deem to be privileged towards the acute hospital setting rather than home-based care.

# Building team capacities by making brilliance visible

By foregrounding brilliance, and as a result of the study processes along with the regular presence of academic researchers in their workplace, clinicians at both sites indicated how their relationships with fellow team members evolved during the study. These relationships were manifest through a greater understanding of and appreciation for each other's roles, regardless of discipline. The reflexive sessions encouraged team members to see themselves and each other with greater clarity:

I want to do more joint visits ... because I never have someone to debrief with ... [because] I think, 'Shit, have I even done close to the right thing?' Because I've got no clue about diseases and what's happening — I'm a specialist palliative care [allied health professional] ... I'm not a doctor and I'm not a nurse ... I just need someone to come with me ... for my skillsets ... reflection [and] ... good client care. (Clinician, SA)

Largely working alone, the clinicians did not have regular opportunities to observe, and learn from fellow team

members, when conducting home visits. The reflexive sessions thus offered an opportunity to respectfully peer into each other's working day and recognise the importance of joint visits and peer reflection of a shared experience.

Clinicians at both sites noted that the study had positively impacted relationships within the specialist palliative care teams; as well as the relationships between the specialist and generalist teams:

Traditionally, it has always been palliative care versus community health nurses and sometimes it comes from the staff themselves. I think [the study] has cemented our relationship that we are a team, and ... by their reflection on being videoed [the generalist nurses have] ... been able to see the brilliant work they've done and it's validated that they are doing good work, and it's cemented us as a team. (Clinician, NSW)

By viewing themselves with specialist clinicians, the generalist clinicians legitimised and validated the palliative care component of their role. This reaffirmed the complementary roles of the generalist and specialist clinicians, thereby bolstering teamwork.

During the reflexive sessions, the clinicians recounted their refined understandings of the interface between generalist and specialist clinicians, and their role at this nexus:

I think that makes a difference to the team, when you've got [a] ... very holistic ... view of the clients ... it's not just about, 'Oh, he needs that medication'. It's about ... organis[ing] ... a social worker and a physio because of his mobility. (Clinician, NSW)

By viewing each other's footage, generalist nurses felt affirmed in their palliative care role, and specialist nurses felt generalists had moved beyond a task focus to better recognise patients and families broader needs:

Looking at yourself on video ... there's little things you don't even realise you do and you say to yourself, 'I'm not going to do that next time'. Or by looking at other nurses' videos you say, 'You know what, I really like how they did that and I'm going to do the same.' (Clinician, NSW)

According to some clinicians, the footage also provided a meaningful way to communicate the complexity of home-based palliative care to those they felt did not understand or value the complexity of what they did — in particular, those responsible for policy development and service budgets as well as specialist clinical teams and nurses in the hospital setting. Co-researchers at both sites harnessed footage to demonstrate their role and articulate palliative care to other clinical teams and to senior management.

Clinician 1: I'd like to show [the senior executives] ...

who might not understand ... I'd like to see some senior people see it, you know the financial officer and [those] ... within

the division ...

Clinician 2: I think we are carrying the torch to fight

the fight ... to have that time with patients and to do things well. (Reflexive

session, SA)

Findings thus far described were made tangible by bringing them to light 'on screen'. In turn clinicians at both sites came to view themselves and their fellow clinicians through the lens of the camera:

I had this brilliant moment today; I wish I had the camera with me. (Clinician, SA)

Now, when I visit patients, I have this kind of eagle-eye view from above, a bird's eye view. I take a wide-angle lens from above. (Clinician, SA)

Here, in this quote, a 'brilliant moment' is one in which the nurse considers an interaction with a patient to have gone particularly well from their own perspective. By imagining the presence of the camera, the clinicians viewed what they, and others did, and how they did it. This eagle-eye view was demonstrated beyond the data collection phase of this study.

#### Discussion

The need for high-quality palliative care for people at home has never been greater, particularly given the constrained public health budgets of many Western nations. This study demonstrates that brilliant home-based palliative care can mean different things to people at different times. Nevertheless, brilliance in this context is most likely to occur when clinicians enact anticipatory aptitude and action, adapt flexibly in response to individuals and their social context, operate in a weave of commitment, and build team-capacity by recognising and revealing brilliance.

These findings reflect a meta-synthesis of the critical components of home-based palliative care from the perspective of patients and carers. These were found to include: security – that is, on-call availability and home visits; competence – effective symptom control, and skilful communication. This study suggests that these critical components of home-based palliative care are contingent on the four aforesaid characteristics. The findings support those of a recent investigation of 11 specialist home-based palliative care services in Canada, whereby intra-team communication and team-building were viewed as more important than: clinical tools; standardised processes; specialised

expertise; timeliness; physical symptom; psychosocial support; spiritual management; education; peace and fulfilment; as well as patient advocacy. The findings also align with those in other fields. For example, in the field of patient safety, relationships between health professional groups have been shown to contribute to, or inhibit patient safety. A realist review suggested that relationships between home-care and healthcare staff partly determine the effectiveness of interventions for patients. Thus, organisational well-being and collective efforts to deliver safe care are likely to require professional networks that are nurtured.

Interprofessional teams that care for people with high-level needs and operate in complex situations need to adapt to rapidly changing environments. The findings from this study suggest that home-based palliative care teams do this by engaging with systems and processes to make them work. Rather than make isolated clinical decisions based on cognition, the two interstate palliative care teams – irrespective of jurisdictional differences – engaged in adaptive practices, even if that meant flouting organisational conventions to get what they needed for the patients and carers they worked with, as detailed elsewhere.<sup>42</sup>

The practices revealed in this study were promulgated via POSH-VRE. Encouraging clinicians to view their own work encouraged understandings of each other's roles, until now, taken for granted. Furthermore, the clinicians came to appreciate each other and their contributions to the team in new and tangible ways. For instance, some identified an increased capacity to critique their own practices and those of their team. Finally, some clinicians were better able to convey the complexities of what they did to other clinical specialties, managers, and senior executives. Together with academic researchers, homebased palliative care clinicians demonstrated what Nicolescu<sup>43</sup> referred to as transdisciplinarity. They worked together to create new and integrative knowledge to address complex issues and problems 'through the practice of one's profession and discipline in concert with others, instead of alone'.44

## Limitations

There are no claims that the research team's fluid understanding of brilliant home-based palliative care fully reflects that of all stakeholders. As such, acknowledging, wrestling with, and appreciating the situated nature of brilliance might require diverse processes in different contexts. A focus on brilliance might have privileged findings towards those practices that were deemed to be so. Although the study deliberately examined brilliance, it did not negate the clinicians' ability to systematically scrutinise their own and others' practices. A further limitation was the omission of patients

and carers from the reflexive sessions. Nevertheless, patients and carers were provided opportunities to view footage and were involved in decisions about who should view footage in which they were depicted. Furthermore, due to institutional ethics processes, it was beyond the scope of this study to include external clinicians – such as general practitioners – who were not employed at the two services. It is also noteworthy that, despite the differences and models of care across the sites, negotiated data analysis reveals synergistic findings of what brilliance means in the context of home-based palliative care.

## Conclusion

The findings from this study have implications for clinicians and managers. They suggest that efforts are required to build expansive relationships and grow team intelligence in ways that align with (rather than contradict) conventional forms of clinical evidence in palliative care. This might involve organisational initiatives that encourage and support clinicians and their teams to engage in projects that span the domains of research and quality improvement; regularly reflect on what they do and how they do it; consider the varied ways they demonstrate meaningful impact, not only those captured by metrics; widen their experiences to build interprofessional empathy through, for instance, secondments to varied roles or shadowing colleagues; and/or extending their networks to individuals and organisations that represent diverse interests across the academic, public, private, and not-forprofit sectors.45-48

## **Acknowledgements**

The authors would like to thank all the reviewers of this manuscript. The authors also wish to thank Dr Jennifer Wiltshire, Professor Meera Agar and Ms Janeane Harlum for their support of this research as well as all patients, families and clinicians at the study sites.

## **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## **Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was funded by the Agency for Clinical Innovation and Western Sydney University (NSW), and Flinders University and the Modbury Hospital Foundation (SA).

# ORCID iD

Aileen Collier https://orcid.org/0000-0002-4930-3470

#### References

- World Palliative Care Alliance. Global atlas of palliative care at the end of life. London: World Health Organization, 2014.
- Jordhoy MS, Fayers P, Saltnes T, et al. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet* 2000; 356(9233): 888–893.
- Jenerette CM and Mayer DK. Patient-provider communication: the rise of patient engagement. Semin Oncol Nurs 2016; 32(2): 134–143.
- Higginson IJ and Sen-Gupta GJ. Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. J Palliat Med 2000; 3(3): 287–300.
- Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care 2013; 12: 7.
- Hoare S, Morris ZS, Kelly MP, et al. Do patients want to die at home? A systematic review of the UK literature, focused on missing preferences for place of death. *PLoS One* 2015; 10(11): e0142723.
- Gomes B, Calanzani N and Higginson IJ. Benefits and costs of home palliative care compared with usual care for patients with advanced illness and their family caregivers. JAMA 2014; 311(10): 1060–1061.
- Brumley R, Enguidanos S, Jamison P, et al. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *J Am Geriatr Soc* 2007; 55(7): 993–1000.
- Addington-Hall J, Gerard K, Brien S, et al. Variations in out of hours end of life care provision across primary care organisations in England and Scotland: final report. London: NIHR (National Institute for Health Research), Service Delivery and Organization Programme, 2011.
- Seow H, Bainbridge D, Brouwers M, et al. Common care practices among effective community-based specialist palliative care teams: a qualitative study. BMJ Support Palliat Care. Epub ahead of print 19 April 2017. DOI: 10.1136/ bmjspcare-2016-001221.
- Luckett T, Davidson P, Lam L, et al. Do community specialist
  palliative care services that provide home nursing increase
  rates of home death for people with life-limiting illnesses?
  A systematic review and meta-analysis of comparative
  studies. J Pain Symptom Manage 2013; 45(2): 279–297.
- Dixon J, King D, Matosevic T, et al. Equity in the provision of palliative care in the UK: review of evidence. *Report no*. 2894, April 2015. London: London School of Economics and Political Science, Personal Social Services Research Unit.
- Department of Health. Supporting Australians to live well at the end of life: the national palliative care strategy 2010.
   Canberra, ACT, Australia: Commonwealth of Australia, 2010
- 14. Oishi A and Murtagh FEM. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals. *Palliat Med* 2014; 28(9): 1081–1098.
- Runciman W, Hunt TD, Hannaford NA, et al. CareTrack: assessing the appropriateness of health care delivery in Australia. Med J Aust 2012; 197: 100.

 Saramento VP, Gysels M, Higginson IJ, et al. Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers. BMJ Support Palliat Care 2017.

- 17. Wye L, Lasseter G, Percival J, et al. What works in 'real life' to facilitate home deaths and fewer hospital admissions for those at the end of life? Results from a realist evaluation of new palliative care services in two English counties. BMC Palliat Care 2014; 13(37): 1–11.
- Braithwaite J, Wears RL and Hollnagel E. Resilient health care: turning patient safety on its head. *Int J Qual Health* Care 2015; 27(5): 418–420.
- Dixon-Woods M, Minion JT, McKee L, et al. Culture and behaviour in the English national health service: Overview of lessons from a large multimethod study. *BMJ Qual Saf* 2014; 23: 106–115.
- Dadich A, Fulop L, Smyth A, et al. A POSH way to enhance health service management: inquiry and engagement intertwined. In: *Proceedings of the 2014 ACSPRI social science methodology conference*, Sydney, NSW, Australia, 7– 10 December 2014. http://conference.acspri.org.au/index. php/conf/conference2014
- Fulop L, Fitzgerald JA, Campbell S, et al. (eds). The brilliance project in healthcare: an exploratory study. In:
   Proceedings of the Australian and New Zealand academy of management conference, Wellington, New Zealand, 7–9 December.
- 22. Dadich A, Fulop L, Ditton M, et al. Finding brilliance using positive organizational scholarship in healthcare. *J Health Organ Manag* 2015; 29(6): 750–777.
- 23. Morin E. *On complexity*. Cresskrill, NJ: Hampton Press, 2008.
- 24. Carroll K. 2009 Unpredictable predictables: complexity theory and the construction of order in intensive care.

  Doctorate Dissertation, University Technology Sydney, Sydney, NSW, Australia.
- Cameron KS and Caza A. Contributions to the discipline of positive organizational scholarship. Am Behav Sci 2004; 47(6): 731–739.
- Cameron KS and Spreitzer G (eds). Oxford handbook of positive organizational scholarship. New York: Oxford University Press, 2012.
- 27. Ryff CD and Singer B. Ironies of the human condition: well-being and health on the way to mortality. In: Aspinwall LG and Straudinger UM (eds), A psychology of human strengths. Washington, DC: APA, 2003, pp. 271–287.
- 28. Oliver C. Critical appreciative inquiry as intervention in organisational discourse. In: Peck E (ed.) *Organisational development in healthcare: approaches, innovations, achievements*. Oxford: Radcliffe Publishing, 2005, pp. 205–218.
- 29. Mertens DM. *Transformative research and evaluation*. New York: The Guildford Press, 2009.
- 30. ledema R, Mesman J and Carroll K. *Visualising health care practice improvement: innovation from within*. London: Radcliffe Publishing, 2013.
- 31. ledema R. Creating safety by strengthening clinicians' capacity for reflexivity. *Brit Med J Qual Saf* 2011; 20: S83–S86.

- 32. ledema R, Carroll K, Collier A, et al. Video reflexive ethnography in health research and healthcare improvement: Theory and application. 1st ed. Abingdon: CRC Press; Taylor & Francis Group, 2018.
- Collier A and Wyer M. Researching reflexively with patients and families: two studies using video-reflexive ethnography to collaborate with patients and families in patient safety research. Qual Health Res 2016; 26(7): 979–993.
- 34. Iedema R, Hor S-Y, Wyer M, et al. An innovative approach to strengthening health professionals' infection control and limiting hospital-acquired infection: video-reflexive ethnography. BMJ Innov 2015; 1: 157–162.
- Nicholls R. Research and indigenous participation: critical reflexive methods. Int J Soc Res Method 2009; 12(2): 117–126.
- Clark A. Visual ethics in a contemporary landscape. In:Pink S (ed.) Advances in visual methodology. London: SAGE, 2012, pp. 17–36.
- Braun V and Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3(2): 77–101.
- Leonard M, Graham S and Bonacum D. The human factor: the critical importance of effective teamwork and communication in providing safe care. Qual Saf Health Care 2004; 13: i85-i90.
- 39. Manojlovich M, Kerr M, Davies B, et al. Achieving a climate for patient safety by focusing on relationships. *Int J Qual Health Care* 2014; 26(6): 579–584.
- 40. Goodman C, Dening T, Gordon AL, et al. Effective health care for older people living and dying in care homes: a realist review. *BMC Health Serv Res* 2016; 16: 269.
- 41. Cunningham FG, Ranmuthugala G, Plumb J, et al. Health professional networks as a vector for improving healthcare quality and safety: a systematic review. *BMJ Qual Saf* 2011; 21(3): 239–249.
- 42. Dadich A, Collier A, Hodgins M, et al. Using positive organizational scholarship in healthcare and video reflexive ethnography to examine positive deviance to new public management in healthcare. Qual Health Res 2018; 28(8): 1203–1216.
- 43. Nicoleescu B. *Manifesto of transdiscplinarity*. Albany, NY: State University of New York Press, 2002.
- 44. McGregor SLT. Transdiciplinary knowledge creation. In: Gibbs P (ed.) *Transdisciplinary professional learning and practice*. Basel: Springer, 2015, pp. 9–24.
- 45. Alvesson M and Sveningsson S. Changing organizational culture: cultural change work in progress. 2nd ed. Abingdon: Routledge, 2016.
- 46. Elsbach KD. Organizational perception management. New York: Routledge, 2013.
- Greenhalgh T and Fahy N. Research impact in the community-based health sciences: an analysis of 162 case studies from the 2014 UK research excellence framework. BMC Med 2015; 13: 232.
- 48. Schein EH. *Organizational culture and leadership.* 4th ed. Hoboken, NJ: Jossey-Bass, 2010.