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Ways of ‘Being With’

Caring for Dying Patients at the Height of the COVID-19 Pandemic

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Abstract: Palliative care professionals often speak of the importance of forming meaningful relationships with patients and their families. Trust and rapport, usually established over extended periods of time through face-to-face interactions, and a ‘gentle honesty’ regarding end-of-life and death are key aspects of developing a sense of intimacy with people who are approaching the end of their lives. A fundamental feature of this intimacy is conveying a sense of ‘being with’ a patient. However, these ways of working were greatly challenged by the impact of COVID-19. This article explores how intimacy both was and was not established at the height of the pandemic, and it describes the extent to which shared concerns functioned as a new means to create a sense of a common experience.

Keywords: communication, COVID-19, end of life, intimacy, palliative care

The notion of care is often linked to ideas of touch, highlighting the extent to which it is conveyed through closeness and ongoing interaction (Kelly et al. 2018). As part of this, it is frequently assumed that proximity is the only way to establish this kind of intimacy, and therefore that distance and the adoption of presumably detached technological mediators obstruct and prevent a genuine ability to care (Brewster et al. 2013).[1] In this piece, we use this framing as the background to examine the relationship between intimacy and proximity in palliative care practice in England, and explore whether they always need to be as closely tied as commonly assumed.

The academic interest in intimacy has traditionally revolved around familiar and romantic relations (Berlant 1998; Törnqvist 2016). As such, the term is not often used in reference to the relationship established between a medical professional and patient; indeed, the role of a great deal of social studies of medicine has been to highlight the inequality in such relationships. However, establishing intimacy seems apt to describe a key quality of specialist palliative care which focusses on patients who are at the end of life. Central to this is building trust and rapport with patients and those close to them in order to provide a particular kind of care that constitutes a significant shift away from a standard focus on the ‘aggressive treatment’ of disease. In its place, the clinical perspective is embedded within a broader commitment to support the patient in many practical and emotional ways – what the specialists themselves proudly refer to as a ‘holistic approach’.

Over the past several years, we have been ethnographically studying hospital and community palliative care service providers in England, following their daily working practices and understanding how they see themselves professionally.[2] A common mantra in palliative care is that ‘end-of-life care is everyone’s business’ (Henry et al. 2015; Watson et al. 2019) – referring to the forecast that the care for an ageing population means all medical professionals will need to deliver palliative care – which will

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include having honest conversations about death and dying, and planning ahead as much as possible (known as Advanced Care Planning; see Borgstrom 2015). Currently, however, palliative care remains a specialism in its own right, with particular expertise in things like pain management and a uniquely broad approach to what is in a patient's best interests.

Typically, those regularly providing palliative care – the specialist teams – establish relationships with patients and their family members through repeated visits and conversations, mainly face-to-face, over an extended period of time, often right up to a patient's death. Indeed, the professionals prefer it when they see patients early on, in order to have a longer time to establish the kind of relationship that allows them to talk openly about death and dying. Dealing explicitly with mortality and the many physical and emotional burdens that accompanies it shapes how staff form a genuine sense of closeness with patients, and establish a space for shared, quiet, recognition of the situation. These relationships, however, do not include crude expressions of sympathy or pity. If 'intimacy builds worlds', as Lauren Berlant writes (1998: 282), the world palliative care practitioners work to build is one in which compassion is accompanied by a level of practical, realistic truthfulness. This version of intimacy consequently foregrounds a degree of frankness regarding end of life and death by avoiding euphemisms or false hopes; as one of the clincial nurse specialists said, they are there to provide a 'gentle honesty'.

As part of this, palliative care staff view one of their core functions as 'being with' a patient during their illness and end of life, rather than simply being part of a clinical team that intervenes on the body. As one nursing consultant said:

> I suppose the biggest [thing] for me . . . is just *being* with people, I think makes a difference. And I think even very complicated cases or things where you don't think that you're making a difference at all, is to keep going back, and give people a sense that you're curious and interested in them . . . So, that [is] an exercise in *being* . . . because you've got . . . very little to offer apart from just making time.

'Being with', then, is often not established through what is actually said or done – but precisely through *not* saying something or entering the conversation with an agenda, and *not* doing something. Through regular, ongoing interactions, palliative care professionals progressively convey that they are genuinely interested in the patient – and that they themselves also have something 'at stake'. The overall value of proximity is one that therefore not only enables regular, ongoing communication, but also affords a partial blurring of boundaries and establishes a sense of shared experience.

But of course, these ways of working were greatly challenged by the impact of COVID-19 during the height of the pandemic over the spring of 2020. Not only did the workload grow exponentially as the rates of people dying increased, but the strict restrictions on face-to-face encounters, and often the curtailed timescale between first contact and death, meant that staff could not adopt their usual strategies to provide support. Before the pandemic's true impact became evident, we discussed with our collaborators first about how they were preparing for, and then how they adapted to, the unfolding challenges. What follows is a description of the changes palliative care practice underwent during the initial weeks and months of the pandemic, and how this impacted relationships with patients and their family members – and among staff members themselves. We then turn to what this may tell us more generally about intimacy in palliative and end-of-life care.

Intimacy under Threat

Across the NHS (National Health Service), some of the earliest responses within palliative teams consisted of a new concern with just how to provide the care that was clearly going to be necessary. For those COVID-19 patients who were extremely ill, it was frequently unclear whether they were going to survive or not, and when it was clear that they were not, death often occurred within days if not hours. Those already receiving mechanical ventilation were frequently unconscious by the time palliative care workers were contacted. And for palliative care staff in the community, there were also issues of how to access their non-COVID caseload, especially since many of these patients were discharged in order to free up capacity.

As public health measures to contain the spread of COVID-19 came into effect, finding regular opportunities for proximity with patients and those close to them was no longer achievable. Staff who were not based in hospitals worked from home as much as possible, particularly if they were themselves deemed to be at an increased risk, leaving only a 'core team' in the office. Those working in hospital had to drastically reduce all face-to-face interactions. Because COVID-19 patients were often so ill that they were not able to talk, and relatives were not allowed inside the hospital, staff had very little opportunity to gain any sense of the patient as a person, or what their wishes might be.

The requirement to wear Personal Protective Equipment (PPE) posed an additional obstacle to establishing any sense of intimacy – not only for staff, but also for relatives. It was not just that gloves, gowns and masks were uncomfortable and cumbersome, but that they introduced the sense of an alien barrier. When patients were close to death and a few family members were allowed into the hospital for one last time, even they were required to wear full PPE. Loved ones became hesitant about how close they could approach the dying person, while the staff were acutely aware that many patients had often not affectionately touched anyone for days, sometimes for weeks. One consultant described how 'regulating intimacy' became one of her key tasks when dealing with visitors – not in the sense of curtailing it, but desperately trying to find ways to establish it. Modest acts of intimacy, such as the touching of somebody's arm, that normally would go unnoticed now became very obvious in their absence.

Meanwhile, as need for their services kept growing, other health-care professionals suddenly had to take on end-of-life care tasks that previously had been outside of their remit, leading many to feel out of their depth and anxious. The palliative care specialists abruptly had to switch their focus from dealing directly with patients to supporting these colleagues by providing education sessions and handouts, going to their meetings, accompanying the debriefing rounds, and maintaining ongoing communication. Looking after the dying had finally and suddenly become 'everyone's business'. But it meant the specialists had to, at least partially, give up forging their own close relationships with patients in order to teach and support others to integrate intimacy within their encounters with patients and families.

Finding New Ways to Make Contact

Given that trust was previously 'built up by seeing somebody talking [to your loved one], and being in that environment [with them]', as one of the doctors put it, abiding to the physical-distancing guidelines meant that staff had to find ways that did not rely on physical proximity or the non-verbal cues and silences that were often so important. So as the more usual practices to create a sense of intimacy became unavailable, staff worked hard to establish new ways, despite the need to maintain physical distance. In many instances, digital technology provided a novel means to establish and maintain relationships. Although palliative care staff working in the community were already used to having routine telephone check-ins with patients, the use of technology – such as video conferencing – quickly became 'the new norm' to speak to patients and their families. Many of the organisational hesitations and technical 'obstacles' were suddenly de-prioritised, as the urgency to address COVID-19 provided a new rationale for swift decisions and changes to the services, which at the time of writing were still ongoing.

In both settings, this reliance on technology-mediated communication meant that staff frequently found that they were establishing close relationships with relatives rather than with patients, who were often physically unable to speak for themselves. In the community, family carers served as their 'eyes and ears', giving reports about any changes and how the patient was. In the hospital, family members were absent from the wards during the initial period of the pandemic – as one consultant acknowledged: 'I don't think anybody consciously thought this, but basically it was like, "I haven't spoken to any relatives because there isn't anybody here"'. So once using tablets and mobile phones became the norm, many doctors took to calling families regularly, aware that the uncertainties about the disease were often exacerbated by the inability of patients, families and staff to meet face-to-face. One intensive care consultant described the clinical staff's realisation of the importance of this contact with relatives as one of the few gains of the pandemic. He explained that the increased communication with family members instilled a strong sense not only of their trust in the medics, but, reciprocally, the staff being more open to families about what care could be offered and what the limitations were.

The use of established and new technology demonstrated how intimacy could sometimes be established across physical distance. Perhaps without intending to, its limitations were compensated for by making more frequent contact and being open about all the uncertainties that accompanied the extraordinary nature of the situation. Nevertheless, this kind of intimacy had limits. As one consultant made clear, it was always 'very difficult telling someone their loved one is dying if you've not seen them in person or [even if you had] to not do this in person'. And sometimes the new mode of proximity was undesired: when family could not visit a patient in hospital, staff found themselves unexpectedly thrown into very private family moments as they held the phones or tablets for patients to enable families to say their goodbyes.

So whilst communication technologies could be used to 'keep in touch', it was not always experienced as ideal in the intimate contexts of end of life.

Intimacy Revisited

Intimacy is often tied to a sense of spatial proximity. But in many instances during the pandemic, palliative care staff and patients' families managed to establish it despite distance, often with the aid of communication technologies. As part of this effort, the classic professional–patient or professional–relative asymmetry was sometimes noticeably dissolved; video calls could feel stripped of the usual markers of status and expertise, which often encouraged relatives to speak more freely. And yet, it could only partially replace the sense of intimacy or proximity that would have made it easier to have some of these conversations and for family members to show affection for their loved one.

One feature that did prove significant – that was not part of the staff's normal practice – was a greater sense of things being shared, and a communal understanding built upon the common experience of the situation as it unfolded. This not only emerged within teams, and when supporting other professionals, but also in their relationships with patients and relatives. During the height of the pandemic, the staff had to wrestle with lots of uncertainties – they were anxious about contracting the virus, and worried they might inadvertently pass it on to colleagues, patients or loved ones at home. It is not that this sense of COVID-19 as a collective experience ever provided direct comfort to those who were at the end of life, but it certainly blurred the usual categorical distinction defining who should be cared for. The collective sense of vulnerability established a new ground on which to foster a sense of intimacy, even across distance. In this way, the commitment to 'being with' was established not through the usual methods that relied on regular proximity, but instead on shared feelings of loss, uncertainty and not being in control.

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Notes

1. For an empirically informed counter-argument to this claim, see Pols (2012); and Pols and Moser (2009).
2. Erica Borgstrom (2014) conducted her doctoral research on choice in end-of-life care in the United Kingdom. She has researched end-of-life care since 2010. In 2018, Simon Cohn, Erica Borgstrom and Annelieke Driessen commenced the ESRC-funded Forms of Care project on 'active non-interventions' in UK palliative care (ES/P002781/1). See https://www.lshtm.ac.uk/research/centres-projects-groups/forms-of-care and @Formsofcare on Twitter for more information.

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