Theorising the hospice gaze: A Foucauldian collaborative ethnography of a palliative day care service

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**Introduction**

Foucault’s theories have been applied to empirical work in palliative care settings to explore how busyness (Nagington et al 2013) and control of knowledge (Nagington et al 2016) become disciplinary mechanisms. However, his work on the medical gaze (Foucault 1973) remains under-utilised in palliative care. Whilst some authors have mentioned Foucault’s work on the medical gaze in relation to palliative care (Hibbert et al 2003; Pastrana 2008), it has only been utilised for detailed analysis by Bishop (2011) in his critique of policy documents and definitions. This article uses Foucault’s work as a theoretical aporia to explore the complexities of the gaze in the context of a hospice day-care. We challenge Bishop’s (2011) conceptualisation of the palliative gaze as driving simply towards efficiency, and suggest the ‘hospice gaze’ pushes in the opposite direction, producing a slow and gentle attunement of staff with patients. We also provide a detailed, ethnographic analysis of how gazing operates in terms of space and place, something that Bishop does not account for. Finally, we suggest the hospice gaze allows patients significant degrees of agency, offering ethical ways to conceptualise space, death and language practices in healthcare.

*The medical gaze*

Foucault's oeuvre contains multiple conceptualisation of how observational practices mediate power/knowledge. His later work on panoptic gazing in prisons (Foucault 1977) argues that it requires no specialist knowledge nor any specific agent; indeed, just the belief among ‘the observed’ that observation is or maybe present is enough to generate order and compliance. Via these mechanisms, governmentality emerges where power becomes diffused across the social body and is not reliant on any specific actors to wield it. People become self-disciplining. While clear parallels exist for certain elements of medical practice, such as public health (Brown and Duncan 2003), it does not fit broader characterisations of the medical gaze where Foucault argues the body and its pathologies meet the "loquacious gaze with which the doctor observes" (Foucault 1977 p xii) in order for the doctor "to see and say" (Foucault 1977 p xiii). The loquaciousness of the medical gaze requires that doctors mediate the body and its pathologies into extant patterns of knowledge, which they must operate within as part of the doctor’s professional status. Always and already inaugurated as the mediating subjects of the medical gaze through its operation, both doctor and patient become trapped as "two living individuals... in a common, but non-reciprocal situation" (Foucault 1977 p xvi). Over time this exclusive position has expanded to include nurses, midwives, and allied health professionals who, wishing to gain professional prestige and to expand their scope of practice, have incorporated medical knowledge into their training.

The medical gaze operates, we argue, in three primary ways. Firstly, it regulates and standardises environments such as hospitals into laboratory-like spaces, aiming to standardise influences on bodies so observed signs and symptoms can be attributed to underlying pathologies. This requires that the spaces between professional and patient be clearly delineated. For example, patients are placed in orderly fashions into beds where they must remain unless directed otherwise, and professionals then move around them. Changes to the environment are only ever in order to gain further knowledge about the body and the associated patient. Secondly, death is crucial to the development of the medical gaze as it, along with the corpses it produces, offers resources for professionals to gain further knowledge. It operates upon the patient-as-corpse exploring the minutest of details, documenting and disseminating findings in order to bring about more complete and perfect sets of knowledge about life and disease. Death is not therefore a failure of medical power, but an opportunity to extend it. Thirdly, all of this is captured within a cohesive and scientific discourse (one that is alien to the lay patient) which encapsulates the narrative about the patient and their body before any doctor-patient encounter occurs.

In summary, the medical gaze can be read as offering a non-reciprocal compelled inauguration. For medics, whilst they are compelled into particular ways of understanding the human body in order to be recognised as medics, the gaze offers them agency and professional power (Freidson, 1986) to (re)organise space, death and language, thereby sustaining the continued operation of the gaze. Patients however become subjugated to the medical gaze, but gain no such agency. In what follows, we argue that the hospice gaze has features that allow for wider degrees of patient autonomy and agency.

*The palliative gaze*

The only author to apply the medical gaze to palliative care is Bishop (2011) who, similar to Foucault, relies on documentary analysis not empirical data. However, reviewing his work is helpful in establishing current thoughts about “gazing” in palliative care. At first, Bishop suggests palliative care may not be amenable to the medical gaze, because the key aim of palliative care is to cover and cloak symptoms rather than to uncover them. He suggests in the early stages of palliative care’s modern development friendship, compassion and a holistic care approach were the basis of caring for dying people. The patient-professional distinctions were therefore less distinctive and more malleable, avoiding the power dynamics of the medical gaze. However, Bishop traces how the discourse of palliative care mutates over about fifty years from an egalitarian sort of friendship into a totalitarian biopolitical regime deeply invested in producing a non-reciprocal patient-professional divide. Furthermore, palliative care becomes coupled to processes for stable financial reimbursements, so capitalist structures and ideologies can produce and manage profitable systems of care orientated towards efficiency rather than friendship. This mutation began with attempts to define palliative care as the study and management of the biological, psychological, social and spiritual aspects of the dying person, to enact mastery. Next, a body of knowledge and practices was established by a specific group of people, namely physicians. Specialist training led to scientific forms of knowledge production about palliative care drawing on statistical analyses and clinical trials. Assessments were then developed to measure everything from pain to spiritual distress to open up the internal experiences of the patient, representing them as manageable objects of clinical intervention, worthy of fundable pathways of care. What emerges is a palliative gaze that no longer cloaks but instead produces a maximum visibility, serving to cyclically produce further knowledge so that further reimbursement can occur, all the time producing a wider divide between patient and professional.

*Moving towards a hospice gaze*

We find much to agree with in Foucault and Bishop’s writings. For example, palliative care has experienced a cultural shift towards medical frameworks of knowledge raising important questions for the operation of professional power in those settings. However, documentary analysis cannot fully account for how any form of gazing operates within the complex milieu of the social world, where there is always resistance to power (Foucault 1978). Therefore, our work does not aim to use the medical or palliative gaze as canonical lenses that fundamentally shape our analysis. Instead, using empirical data from our ethnography of a hospice day-care centre, we use Foucault and Bishop’s works as starting points to develop and illustrate what we call a hospice gaze, a way of structuring professional-patient interaction that differs from the medical gaze in significant ways, most notably in how it slows down care, adapts space to patients, and gives patients significantly more agency over their care.

**Methods**

Our ethnography combined observation and interviews (Denzin 1997). Between May and September 2016 we spent 43 days observing practice at a hospice day-care centre, and conducted 13 in-depth interviews with a wide range of key informants including doctors, nurses, social workers, clinical and general managers, therapists, volunteers, and maintenance staff. Ethical approval was granted by the Research Ethics Committee of the University of Manchester. Pseudonyms are used and other minor details changed to maintain confidentiality.

*Team Ethnography*

We adopted a team ethnography approach with all four of the research team spending time in the hospice day-care centre. Whilst this contrasts with the tradition of the lone ethnographer spending months or even years in a particular setting, it can give nuanced accounts of power dynamics and the multifaceted nature of specific cultures, behaviours, or organisations (May and Patillo-McCoy, 2000; Scales et al., 2011). Sometimes we would primarily spend the day sitting in the lounge, chatting with staff and patients, and observing the social interaction. On other days we would shadow specific members of staff. On most occasions there was just one researcher present, though on a few occasions two were, allowing us to perceive different perspectives on the same day. A team approach made it possible to develop and contrast insights about how space functioned to shape patient experiences in the day-care unit. These contrasts emerged both from the practical aspects of having two team members in two different places at once, but also from the range of disciplinary perspectives in the team (nursing, organisational studies, and psychology), as well as a range of ages and genders.

Team ethnography has practical problems, such as: writing and/or cleaning up fieldnotes for mutually intelligibility (Creese et al., 2008); conducting regular team meetings to reconcile perspectives (Gerstl-Pepin & Gunzenhauser, 2002); and negotiating the presence of multiple researchers in the field to minimise the disruption to care (Briggs et al., 2003), something that is a concern with all ethnographies but is enhanced with a team ethnography. However, once these issues are acknowledged and managed, the team approach offered insights that would have otherwise been difficult to glean.

*Researcher positionality*

Similar research in hospice day-care centres has previously involved researchers taking on specific roles such as volunteers, in order to give them legitimate reasons to spend large amounts of time in day-care (Lawton 2002). We decided against this approach as it would have limited our ability to shadow a wide range of staff and take advantage of impromptu opportunities. We therefore initially entered the field without pre-defined roles, spending our time sat around coffee tables with patients getting to know them and the staff. As time went on we would sometimes help out with something minor such as fetching a paper or finding patients assistance from staff.

As relationships developed, we were invited into staff-patient consultations, and attended routine meetings where patients were discussed. We were also offered snippets of experiences that the patients had such as tea and toast in the morning, or massage therapies. Therefore, by gradually engaging in the cycles of activity in day care, we became embedded in the social dynamics of the field (Lewis & Russell, 2011) and became participant-observers despite having no pre-defined role.

*Consent*

After gaining access to the site via conversations with the hospice team, consent was an ongoing and emergent process. The first step of consenting patient participants consisted of posters and information sheets placed around the day-care centre. We then spoke with participants about the research, ensuring they had read the information leaflet, answered any questions, and recorded their consent via a consent form. In most cases this was unproblematic. However, in some cases it was apparent that patients were either too unwell or generally overwhelmed with other experiences to consent to the research. Because of the open-plan nature of the day-care unit it remained possible that we would still have interactions. These patients were made aware of who we were, and we made notes about our conversations and why we did not feel it was appropriate to engage them further at that moment in time. Such record keeping was necessary as an aide-memoire of who had or had not been consented, and to liaise as a team. With these patients we avoided in-depth involvements such as accompanying them to consultations, or interviewing, until (and unless) they had formally consented. In most cases we consented patients at more appropriate times and include all data about them. Where this was not possible, data that were collected such as initial conversations were not used.

**Fieldsite**

The hospice is based in England, UK and is part of a multi-site organisation providing out-patient, community, and day-care services, as well as training in palliative care. It is an independent charity that receives NHS funding for approximately a third of its running costs, the other two thirds coming from trading activity and donations. Care is provided for free to all patients who met entry criteria.

The urban site we were based at is set within well-established wrap-around gardens and woodland containing a diverse fauna and flora maintained largely by volunteer gardeners. These verdant surroundings left the hospice with a quiet atmosphere which all the research team noted invited a sense of relaxation and peace upon entering. When we spoke to patients they similarly expressed that the hospice was a calming environment, with some noting that anxieties about attending day-care quickly dissipated. This relaxed, calm feeling was also mediated by the staff and volunteers who greeted patients with smiles and sometimes hugs, offering them tea and toast on arrival.

The site was divided into an in-patient unit and day-care unit that had separate entrances but were linked via a short corridor. They shared facilities such as the kitchen, staff changing rooms and library. Our research was based entirely in the day-care unit which housed several of the non-clinical staff offices. Conversations between patients and non-clinical staff were relatively common, covering topics such as the weather or sporting fixtures. These conversations would always take place in the main day-care lounge which was where patients spent the majority of their time. The lounge was encircled by a single corridor, the other side of which housed staff offices, private consultation rooms, and toilet facilities.

To be eligible for day-care, patients needed to be refer\red by a professional (which could include staff from other departments of the hospice) highlighting what their needs were. Typical reasons for referral were for pain and symptom management, and psychological support. General prognosis and potential time left to live were not eligibility criteria.

Most staff were directly employed exclusively by the hospice, but some were contracted to local hospitals or primary care trusts and did sessional work at the hospice. Within day-care the usual staffing level was three registered nurses plus one team leader who was also a registered nurse, one nursing assistant, an art therapist, and two or three volunteers. There was also often a student nurse. These staff worked almost exclusively within the day-care centre. All other staff (such as physiotherapists) generally worked across all areas of the hospice to greater or lesser extents.

The hospice day-care centre received patients between approximately 10 am and 3pm three times per week, It was mostly on these days that we conducted our fieldwork. On the other two days staff provided support on a one-to-one appointment based system. On any given day up to fifteen patients could be in the day-care centre, though it was frequently fewer. Any given patient could attend for up to 12 weeks, after which time they were due to be discharged.

**Slow consent**

As noted, consent was usually straight forward. However, one example with a patient called Jonathan required a slow and collaborative process between staff, patient and researcher. This demonstrates how the hospice gaze shapes the nurse-patient dyad differently to the medical or palliative gazes.

Jonathan had a long-term degenerative disorder and had been attending day-care on a monthly basis for several years. His cognitive abilities remained fully intact but his physical abilities were severely limited to the point that he was unable to speak and had only minimal movement in his face and limbs. However, over the time he had attended day-care he had established ways of communicating with staff via a rudimentary form of sign-language. When CM and MN met him for the first time they both felt an unease and anxiety about whether we could gain consent. We expressed this concern to Carol (one of the nursing staff) who went to sit down with Jonathan and MN. Yet Jonathan was not approached with the seriousness one may be familiar with when a nurse approaches a patient to undertake tasks such as taking their blood pressure. Instead there was a jovial way to how he was approached, Carol smiled as she walked over then crouched down close to the ground so that she was below Jonathan’s eye level, taking his hand and stroking it. After a minute or so Carol introduced MN asking him to explain the study, throughout this process maintaining eye contact and a gentle hold on Jonathan’s hand. All of this allowed her to assess if he was responding with a yes or a no and translate his answers to MN. It felt intimate and slow and, by the end, whilst a paper copy of the consent form could not be filled out by Jonathan, everyone felt confident he had understood and consented to being part of the research study. Carol posed questions and statements to him in a way that didn’t assume agreement would be forthcoming and that invited a possible decline or 'no' response. Afterwards Carol explored any other needs Jonathan may have had. Asking if he was comfortable, if he needed the toilet, and generally remaining present with Jonathan in the same way she had when she was facilitating the conversation: sat down, holding his hand, feeling for the small gestures, watching for emotion in his face. All of this was done to gradually piece together and translate these signs into a narrative that slowly and patiently crafted understanding. Rather than the drive for efficient assessment processes suggested by the palliative gaze, this is akin to what Bachmann (2011) describes as a ‘sit on the step and talking’ type of nursing care, where aims and outcomes of nursing care slowly weave and wander in an anti-teleological manner. The resting of a nurse’s gaze on a patient could be argued to induce a certain coercion, making it harder for patients to freely consent. However, this needs to be set against research which suggests that when nurses move rapidly from one patient to another it insidiously effects ability to consent. For example, Griffiths (2010) notes district nurses use phrases such as "moving swiftly on" to deflect palliative care patients who raise complex issues. Equally, Nagington et al (2013, 2016) highlight that neoliberal drives for efficiency result in patients who self-discipline in order to not bother the nurses who they perceive as constantly too busy. This results in patients failing to fully understand, and by extension consent to their care. To be clear, even our analysis of a slowness in the hospice gaze does not fully mitigate the power relations that are a fundamental feature of being in relation to others. Escape from power and its potentials to subjugate are never possible; this is an inevitable outcome of living as a subject that is inaugurated by power (Butler 1997). However, more ethical approaches to the mediation of power in healthcare relations are possible (Nagington 2016). We argue that the slowness of the hospice gaze mitigates the more insidious and highly unethical effects of neoliberalism, and that, rather than insidiously coercing patients, the hospice gaze appears to regulate the bodies of the nurses (rather than patients), slowing staff down. This allowed for what Darling (2010) describes as an ethics of embodiment, attuning professional to patient through gazing. This attunement results in greater opportunities to understand patients’ preferences and desires, by drawing out and helping them exercise their agency. This produced not only a valid form of consent to our study, but also improved the wider care that Jonathan received.

**Resistance**

As noted above, patients were meant to attend for 12 weeks. This was a relatively recent change in practice driven in part by the need to claim a structured and fundable programme of work. However, staff frequently circumvented this (with full knowledge of management) with re-referrals and extensions. In the case of Jonathan this resulted in him attending once a month for several years. To be clear, this had little to no effect on waiting times. There were some capacity issues with the hospice transporting patients to and from day-care but, in general, if patients were able to find their own transport there was almost always capacity to receive them.

This did not mean that patients controlled the length of their stay. It did mean, however, that discharge practices contrasted to other areas of medical practice where it is common for the medical gaze to tightly regulate entry and exit through knowledge gathered from blood tests and other observations (Heartfield, 2005). The hospice gaze, whilst still exerting power, did so differently. Nurses and other staff would observe patients and weave together narratives that symbolised discharge, for example, they would often encourage patients to create a piece of artwork to signify their period of time in which day-care was coming to an end. Discharge was therefore constructed (with considerable flexibility) through meaningful collaboration with the patient that didn’t alienate them through an application of a medicalised discursive framework or a rigid 12 week management criteria. This, coupled with referrals to other hospice services upon discharge, or soliciting re-referrals to day-care, meant in practice that almost all patients were actively involved in constructing their discharge or onward care.

In summary, we suggest that in response to the rigid power structures becoming increasingly pervasive in health and social care services, the hospice gaze allows for acts of resistance and patient agency to emerge. It does this by engaging in a more reciprocal approach to aspects of care such as discharge which are more usually clinically mandated rather than negotiated.

**Spaces of day-care**

There were often moments for the research team where we felt overwhelmed by the complex difficulties that patients were discussing with staff (even reading back each other’s fieldnotes could prompt strong emotional responses). When observing these emotive moments we would be placed as unobtrusively as possible. We would often sit in a corner writing notes, but sometimes even writing notes felt like it would break the silence that staff were crafting to give patients time to think and feel. Hence sometimes we just sat, and wrote up our observations retrospectively. This was generally less of an issue in the day-care lounge which, whilst remaining a calm space, lacked the emotional intensity of silent pauses accompanying the overwhelming emotions in the private spaces of day-care. The private versus public spaces demonstrated how the hospice gaze functioned in a number of different ways to shape the actions of the practitioner through spatial arrangements.

*The day-care lounge*

The day-care lounge was the primary space patients spent their time. In the mornings, patients arrived from their respective transport (volunteer drivers, hospice minibus, or their own transport) to be greeted by nursing staff and volunteers. This often involved staff smiling, joking, and hugging the patients. The feeling that this conjures is more akin to entering someone’s home rather than a healthcare environment. This welcome then seemed to transform into a more diffused and constant sense of being present. CM’s fieldnotes from shadowing Carol (the nursing assistant) offers a particularly clear example of how this operated from the moment patients entered the lounge:

“Stan, who had had a hospital visit that morning before coming in here, arrived shortly after [1030]. The nurses had been talking that morning about how bad he had been looking, and I [CM] noticed that he did look thinner, his clothes seemed to be hanging off him a bit more. He came into the room without any walking aid and chose a seat in the circle to sit down in. Carol went up to him, ‘Good morning!’ smiled and rubbed his shoulder in a friendly way. Michelle [the art therapist] beckoned over to Carol from the other side of the circle of chairs, mouthing the words ‘where’s a cushion?’, mimed plumping up a cushion at the back of [another patients] chair. Carol went to the back of the room to fetch one.”

What emerges is a way of staff and patients relating to each other that is not just present at specific moments (such as when consenting) but instead a constant gaze that monitors all patients at all times. Carol explicitly stated that “I need to be everywhere, I need to see what's going on”. Carol’s claim to “be everywhere” to “see what’s going on” clearly evokes the possibility of a panoptic gaze (as mentioned in our introduction) operating in the day-care lounge. Yet patients were not becoming docile and self-disciplining. Instead, the hospice gaze could be observed to be attuning the space of the day-care lounge to the patients, so that issues such as physical comfort were always monitored and attempts made to constantly meet them.

Adaptation of space also extended to the where and when staff and patients were expected to be at any given time. For example, staff commonly arrived in the day-care lounge looking for a patient to have a consultation with, only to find them deep in conversation with another patient or crafting something at the art table. In cases such these, staff would sometimes dismiss themselves and rearrange their workload to do something else for a while. On other occasions, staff would sit down, join in the conversation or activity, and then invite the patient to come away with them at a moment that did not disrupt the flow of whatever was currently happening. One patient, Diana, found this particularly beneficial. She had a blockage in her bronchus which made it difficult for her to breathe. She remarked that “everything had to be slow” because of how her body now interacted with the world. This was particularly frustrating as she had previously been an active entrepreneur running multiple companies in the UK and abroad. To be unable to move through the world and carry out her plans in a speedy and efficient manner made her “peeved off”. To be within a slow environment offered a shared rhythmical approach to the processes of care which is achieved by the hospice gaze attuning staff to be in rhythm with patients. Similarly, when discussing the practices of the professionals in the day-care, another patient, Gary, noted that “they have the time to spend with you [and unlike a] typical relationship with a doctor or a nurse” they offered something more akin to “a friendship, more equal”. Furthermore, he suggested that the “stress does not leak out” of the people working at the hospice. Gary specifically contrasted his experiences of cleaners in the hospital who are always different each day and do not have time to chat due to time and motion regimes. This suggests that patients are aware of the workings of both the medical and palliative gazes, and can recognise something different is occurring. Additionally, as Lillenkroken et al (2017) notes busyness can pollute the care environment and subsequently transfer onto the patients, yet what becomes clear with Gary’s comment is that polluting the environment with busyness can come from anyone. This further supports the need to carefully think about the geography of care and where busyness occurs, but without revealing it to the recipients of care; and, how the operation of the hospice gaze may alter in different spaces.

*Corridors and offices*

Our team ethnography approach meant on a few occasions two of the research team were present on the same day. One such day MN and DH offered two very different perspectives on the pace of work and how nursing staff carefully negotiated and regulated the hospice spaces to avoid a sense of busyness impinging on patient care. DH spent the day almost exclusively in the day room, whilst MN shadowed one of the nurses, Paula, who spent most of her time in the corridors and offices of day-care. The day started off, as ever, with the handover where concerns were shared about patients and plans are made for any specific care needs. They were structured by medical categories such as the diagnosis of the patient, what assessments had been done, their social and psychological situations, the plan of care and what had been implemented thus far, an evaluation of whether the care was working and, at times, prognosis. This way of working closely mirrors the extremely well-established Roper, Logan and Tierney (2000) model of nursing care where the needs of patients are mapped onto precise and pre-determined domains. This model has itself been critiqued as a form of social regulation (Hyde et al., 2006). Therefore elements of the medical gaze remain within the hospice setting where knowledge is extracted about patients, then placed into specific discursive frameworks in order to make sense of them, and at least some power over care is exerted. However, this rigid framework was commonly interrupted with comments that had nothing to do with the proforma or these models of care with expressions of affection that interrupted this extant structure such as, “I really like him, he’s a character… [and] a sweetie”. Such comments could be considered examples of the micro-resistances theorised by Thomas and Davies (2005), appearing to lay a different discursive ground for relations between patient and nurse, one tending more towards friendship, rather than the palliative gaze’s drive towards profit and efficiency. It was after the handover that DH and MN’s days radically departed, nuancing the understanding of how the hospice gaze functions within different spaces.

For DH the early part of the day had been either in the day room chatting with patients over tea and toast, or spent in the garden talking with patients. One of the patients James, had experience of commissioning public services, but he didn’t strongly identify with the other patients at least in part because he was still in employment. As such he often sat quietly in the garden or in the corner, observing other patients rather than partaking in group activities. Reflecting on his observations he said that he couldn’t quite understand “what the patient outcomes are”. To him, everyone was just sat around in circles chatting with one another, it appeared inefficient. One can, therefore, read this as a patient being able to identify that neoliberalism and the palliative gaze were not operating. For DH, the day proceeded along these so called outcomeless and inefficient lines: chatting with people about their life histories, their day-to-day hobbies, and how day-care had a slow pace. DH concluded in his notes that the day had been “sedate”. The only time that he got a sense of there being anything different occurring was when he went into the corridor to go and get his notebook from the nurses office. Here, he met MN who “looked worried”.

Since going their separate ways MN spent the major part of the day with Paula, one of the nurses. He had not spent any of the day sat around talking with patients in the lounge. On the contrary he spent it watching the intensive work that Paula had been undertaking to assist a patient who was acutely unwell and whose family had been calling the hospice for assistance. Yet, the busyness that Paula had been engaging in was not one that involved rushing around ensuring specific processes were efficiently achieved to produce predictable and measurable outcomes. For example, in surgical nursing it would be common for patients to arrive and have a standard set of pre-surgical tests performed, all with a sense of busyness that comes from efficiency-driven forms of care that conform to production line logics (Fox 1999). By contrast, at the start of Paula’s day, there were no specific outcomes to achieve with this patient, but there was still great deal of work to do liaising with the patient, family and other professionals to co-construct a plan of care. Furthermore, as the following extract from CM’s fieldnotes demonstrates, hospice nurses were often faced with unexpected and urgent situations, when patients arrived into the day-care lounge:

“One woman, a taller lady, short dark hair, glasses, came in and said she had a terrible pain in her chest. She hugged Paula, and said hello to me. I said ‘hi’, introduced myself, explained I was doing research here on gentleness. She replied, 'You've come to the right place. These people should get paid 2000 pounds a week, they're marvellous', hugged Paula again. Then, aside to Paula, 'I've got a really bad pain, I don't know if I had a heart attack last night'. Paula took her arm, led her out of the day room, then went to find a doctor. Her face changed expression when she was in the corridor: she stopped smiling, [and] look[ed] more serious.”

The corridor served as a boundary between the soft, slow and usually jovial day-care lounge, where the hospice gaze operated in a more diffuse manner, to a more intense operation accompanied with a greater sense of purpose and action. The corridor gave time and space for this transition to happen and prevented busyness polluting the day-care lounge environment. The hospice gaze therefore differed from the medical gaze, in that its operation adapted in relation to the space, rather than adapting the space to itself. This appeared second nature to the staff. Echoing what Nagington et al (2013) noted about busyness in relation to palliative care in community settings, Paula noted on a separate occasion to CM “if you look busy, people don’t ask you things. So, you need to pretend that you’re not busy, even if you’re frantic, so that people will approach you and you can talk to them, and find out what they need, what’s worrying them”. Staff in day-care therefore engaged in a high degree of emotional regulation to avoid bringing any worries in from outside (whether that be institution or personal). For example, Carol was clear that “whatever goes on with your home life or whatever worries you, I still have a smile on my face. I might have all the worries of the world on my shoulders but I never come into work and offload about my personal life [onto patients]”. Whilst this type of emotional regulation has at times been documented as being a highly stressful activity to maintain (Boyle, 2005; Mann & Cowburn, 2005; Zammuner & Galli, 2005), it was common practice amongst the staff to offer peer support in the form of daily debriefing sessions at the end of the day, thus ameliorating the labour of such work. Day-care (specifically its busyness and staff’s emotional states) was therefore heavily regulated through the geography of day-care spaces, as well as clearly delimited times, and formed a key part of how the hospice gaze was operated in a reflexive manner. Yet this did not occur with the same aims as the medical gaze which restricts in order to regulate. Instead, the consistency and regulation of the lounge environment as a calm and slow place prevented patients seeing busyness, and gaining an understanding about staff’s worries and stresses. Therefore, patients continued to be able to express their needs and access help without self-disciplining as Nagington et al (2013) notes can occur when busyness predominates.

*Side-rooms*

In side-rooms a different aspect of the hospice gaze emerged which relied on keen attentiveness to the patients’ changing and sometimes only partially articulated needs. Side-rooms provided quiet and private places for staff to engage with patients and relatives in “one-to-one” sessions. They were furnished with large comfortable chairs, carpets, a small table, a box of tissues, and art-work. One side-room was more medical looking with cupboards and wipe down surfaces. It also contained a large comfortable chair and a stereo system. This room was usually used when patients were receiving intravenous transfusions, though it was sometimes use for the one-to-one sessions. There were also rooms that contained massage chairs and tables for patients to receive complementary therapies. Stereo systems were in these rooms to play relaxing music.

One-to-one sessions could last far longer than what patients were previously used to within other healthcare settings. For example, DH observed Daniel, one of the hospice doctors in consultations with Joan. She had experienced a fall during the past week and the nurses had requested he see her:

“Daniel is sitting opposite Joan, who is in a wheel chair. Daniel is relaxed in his chair, with his arms on his lap, he doesn’t move much when he speaks. He also speaks with a soft voice, and is not rushed when speaking [he has an] attentive gaze, and smiles at beginning but then more serious or neutral expression on face…. Daniel makes some enquiries about the fall, when doing this he is nodding in response to Joan’s replies… After each question he gives Joan time to reply… it does not feel rushed. Joan then scratches her eye, and has an expression of frustration then sadness, and complains about how it still itches. Daniel comments on this and how it maybe from her recent shingles infection. Then asks “do you think it is possible for me to check your blood pressure?” To which Joan agrees (but Daniel does not check blood pressure immediately).”

The consultation took almost an hour. The lack of rush was accomplished through several means. Firstly, it was achieved through the manner in which Daniel held his body, facial expressions, and the pace and tone of his voice. He also slowly carried out the tasks of medical assessment with no urgency or rush. After the consultation DH asked for Joan’s reflections. She said that she had “been feeling very anxious about the fall [but] was very reassured [and] didn’t feel rushed with the doctor… he had taken his time.”

A soft and slow approach was standard in hospice consultations. It was also common practice to observe the nurses just sat in the consultations with doctors, gazing at the patients. This could, at first glance, be seen as inefficient and going against the much-argued case that nurses are autonomous practitioners and not doctor’s servants (Witz, 2004). However, the following extract from CM’s fieldnotes suggests that something more subtle was occurring:

“Patrick [the doctor] asked how she was, and Trisha [the patient] started talking about the pain she was in, about how badit was. Her face suddenly crumpled and she began to cry. She looked down at the floor and was sobbing. Mary [day-care manager, nurse] moved from her seat and went to sit on the seat next to Trisha, with her hand on her back. The doctor’s voice didn’t change as he continued to ask her questions about the pain, when and where she felt it, what it felt like. He nodded his head as she answered - every now and again would shake his head instead of nodding - to recognise that he had heard what she was saying; [he] didn’t interrupt when she was speaking. She talked about how the pain is worse at night when she couldn’t find ways to distract herself and it seemed like she was the only person in the world, and she felt very alone. At a point when she had finished talking, and when Patrick wasn’t saying anything more, Mary asked, ‘Are you fed up?’ Trisha raised her gaze from the floor, and said ‘yeah’. Mary’s gaze was on Trisha’s face, checking how she was doing.”

This demonstrates how the hospice gaze extends to the emotional and psychological wellbeing of the patient; watching closely for signs of distress, and offering physical comfort (a hand on a patients back) or poignant questions to help the patient express their emotional state. Whilst on this occasion the hospice gaze is being enacted by the nurse, there were other examples where doctors or social workers operated with the same constant, present gazing. This contrasts with Bishop’s arguments that the palliative gaze aims for efficient assessment processes, because for the hospice gaze slowness predominates in consultations, enacting a sense of compassion and attunement to patients’ emotions, helping them to be articulated.

**Death**

Death was one of the most emotionally complex topics addressed in day-care. It was approached in several ways, such as: helping patients make plans for how they would like to be cared for in the last few days of life; monthly memorial services held in the day-care lounge which relatives and staff from across the hospice services would attend; yearly memorial services at a local church; and finally memory boxes. These different elements allowed for planning, memorialisation and mourning to take place around death. The processes around memory boxes were particularly revealing in terms of how they illuminated aspects of the hospice gaze as being labour intensive and slow, adopting a quite different approach from the power/knowledge dynamics that are so central to the Foucauldian clinical gaze.

Michelle, the art therapist, and the nurses were most intimately involved in helping patients create memory boxes. These usually took the form of wooden boxes decorated by the patients, filled with letters and other materials which helped patients’ loved ones remember and mourn them in a way which felt affirming for the patient. The hospice gaze would frequently adapt these processes to the patient. For example, Michelle was working with a patient called Joanne who had significant disabilities due to her cancer diagnosis and wasn’t able to write any letters. She had for several weeks insisted that she had “loads of stuff at home” to go into the box, yet nothing had yet gone in. Michelle had noted this but, rather than seeing it as a process that must be completed, read it as a sign that Joanne was not fully coming to terms with “her situation”, i.e. a cancer diagnosis that appeared to be deteriorating quite visibly. She therefore made a gentle attempt to customise the box by encouraging Joanne to make a CD rather than write a letter, a suggestion which Joanne embraced, along with a suggestion to incorporate yellow roses, her favourite flower, into the design. When reflecting on this Michelle was clear that she had “got somewhere” today and helped Joanne “engage with [her] situation”. The hospice gaze in this situation worked to enable carers to learn about the patient, and then use this knowledge to offer the patient the power to individualise the processes at hand in accordance with their abilities and preferences. As such the hospice gaze stands in stark contrast to the strategies described in classical ethnographies of death and dying by authors such as Glaser and Strauss (1967). In this study, medical practitioners deliberately obfuscated and reduced patient’s knowledge about death, thus reducing patient’s power over death. This was justified by constructing death as a biological inevitability rather than a social process which could be narrated and engaged in in meaningful ways. The hospice gaze operated in the opposite direction. Far from constructing it as an unknowable biomedical inevitability, it instead (re)constructed death in keeping with patient’s own knowledge about themselves. Death was not used to perfect the power of the medical gaze. Rather, death was the context that stimulated the hospice gaze to attune staff to patients’ knowledge about themselves, offering patients enhanced degrees of agency and dignity.

**Towards the hospice gaze**

As discussed earlier, Foucault (1977) argues the medical gaze produces a non-reciprocal way of understanding and relating to the human body and its pathologies between healthcare professionals and their patients. Furthermore, Bishop (2011) suggests the palliative gaze aims to create systems of assessment and care which are cost and time efficient, along with a specialist discursive apparatus inaccessible to the patients subjected to it. We wish to argue for a further development of these theories; the hospice gaze. We suggest that the hospice gaze, through its diffuse but at times intensive gazing, produces significant elements of agency for patients, as well as resisting the ever-growing mechanisms and ideologies around ‘efficiency’ in healthcare sectors. In the hospice there was no product or outcome of care which proceeded the patient entering day-care. As such, the outcomes of day-care were not predefined and, whilst staff may have known why patients were referred to day-care (such as pain management), it was commonplace to see staff and patients co-produce additional outcomes such as helping patients plan where they wished to be cared for at the end of their life, producing memory boxes, or learning how to manage fatigue. These emerged between patient and professional during their stay, and did not take the form of what Fox (1999) has referred to as the Fordist production line of healthcare where “the sick person [enters] as the raw material and the healthy person [leaves] as the product” (p1308). In such cases, the “product” of care is already established before the patient enters in the shape of specific surgical treatments like appendectomies that have clear and specific financial reimbursements, governed by processes largely outside of the control of the patient. The hospice gaze did not take this approach. Rather, it operated in a co-operative way to shape services to the patient.

Further to this, whilst we did see the medical gaze operating to extract knowledge about patients in standardised ways (such as in patient handovers), this did not translate knowledge about patients into a subjugating, inaccessible, and unintelligible discursive framework. Rather, what Darling (2010) describes as an ethics of embodiment could be observed that attuned practitioners’ minds and bodies to those of the patients, where we saw staff slowly reading patients’ words and bodily enactments. In doing so they tentatively grasped towards a translation that helped patients construct meaningful narratives in relation to their experiences of severe and life limiting diseases and death. In other words, the hospice gaze does not aim to engage a loquacious discursive apparatus that linguistically excludes patients from knowledge and power, nor does it attempt to produce efficiency. Instead, the hospice gaze is gently laconic, aiming to engage in what Davidsen and Reventlow (2010) describe as the timeless rhythm of psychoanalytic encounters, where one remains in the present moment in order to become attuned to patients in a non-regulatory manner.

The hospice gaze is also reflexive. Staff self-regulate their bodies and speech dependent upon the patients and the different spaces within day-care, as well as specific times of day. At times, this resulted in staff resisting the prevailing discourses of efficiency, and instead engaging in the “slow ethics” (Gallagher, 2012) of care practices. This stands in contrast to the palliative or medical gaze, where patients become docile subjects of medical power/knowledge discursive apparatuses in order to become the efficient subject of the type of production line healthcare identified by Fox (1999).

With regards to death, the hospice gaze engages it in a radically different way from the medical gaze. Instead of using it as an opportunity to further perfect knowledge and power, the hospice gaze would slowly adapt processes so as to offer patients the power to narrate death in ways that felt secure and meaningful for themselves. As with other aspects of the hospice gaze this required a slow approach which rejected efficient and standardised processes, but which simultaneously still constituted skilled and labour intensive professional work.

Finally, the hospice gaze also gives an affirming recognition to a form of labour that Cohen (2011) has described as the "gaps" in the labouring of professionals such as nurses. In her writings on ‘body work’, which she defines as "involv[ing] the manipulation or touch of another's body" (p 1919), Cohen suggests anything that does not include tactile interaction becomes a "gap" in the productive labour capacity of staff. These gaps offer the potential for efficiency savings either through increasing patients or reducing staff to fill/contract them. Whilst so called "gaps" may exist in the efficient application of labour to tasks that involve the tactile application of the labouring body of the professional to the patient, in the hospice day-care centre these gaps were already filled with the hospice gaze. Whether it was Carol’s constant gazing around the day-care room adapting the space to the patients’ bodies, or Mary's intense gazing that helped her pose a poignant question, the hospice gaze functioned to support these moments of labour. In fact, we wish to suggest that, in this setting calls for efficiencies that focus on increasing time spent on body and emotional labour would intrinsically reduce time for the hospice gaze to function.

**Conclusion**

Our paper offers a new interpretation of the medical and palliative gazes. We argue that, rather than being loquacious and efficiency driven, the hospice gaze is a cooperative and gently laconic way of seeing, listening and knowing. It sits in the gaps of more identifiable forms of care and resists patients’ bodies and minds being conformed to so called “efficient” practices. It does this by engaging in slow practices of care with the desire to attune the spaces and processes of care with patients’ bodies and minds, and intensively observes patients in order to grasp towards meaningful translations that help them narrate their experiences. The hospice gaze is also reflexive, and those who engage in its mode of seeing, listening and knowing adapt as much to their patients as their patients to do them. All of this helps patients and their loved ones narrate severe illness and death in ways that give them a sense of power over something which can feel profoundly disempowering. In summary. the hospice gaze offers significantly more agency to patients, and results in a more ethical operation of power by professionals.

Our work also provides an important empirical counterbalance to the theoretically and historically driven analyses of gazing in medical and hospice settings put forward by Foucault (1973) and Bishop (2011), respectively. We have demonstrated that whilst concerns about agency and efficiency are pressing in palliative care, when such matters are examined in the complex milieu of the social world, coherent and largely successful ways of resisting unethical practices emerge. In addition to this, as noted above closer attention could be paid to the productive labour of "gaps", and how they may in fact be vital in the production of ethical and high-quality care.

Finally, we note non-NHS hospices have for decades been criticised for providing a Rolls-Royce level of care, providing (as our hospice did) high levels of resources to a small and select patient group (Brown and Walter 2014). This contrasts with NHS palliative care services that are far less well resources and often conducted within environments that are designed for acute and critical care situations such as ICU, dialysis, or specialist cancer units. We therefore think that whilst our construction of the “hospice gaze” may well find resonance across non-NHS UK hospice settings, further research is needed to examine how gazing operates within other settings where palliative care is frequently conducted. The contrasts and learning which emerge from such work could help facilitate the design of higher quality palliative care services.

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**Keywords:** slow care, palliative care, hospice, Foucault, medical gaze

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