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OPEN ACCESS

‘I think it’s wrong, but it helps’ – a focused ethnography of benzodiazepine practices in specialist palliative care

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ABSTRACT
Benzodiazepines are a class of drug extensively used in palliative care. Their use has predominantly been studied within a biomedical framework. Our study instead focused on the sociocultural aspects of benzodiazepine practices. We aimed to explore clinicians, patients and family members’ values, beliefs, knowledge and feelings regarding use of benzodiazepines, including in-situ clinical decision-making processes, affects and actions. Social theory understandings of affect, the body and of suffering provided the theoretical lens through which data were analysed. Analysis generated the following themes: (1) A special specialty; (2) The suffering body and the moral imperative to ‘settle; (3) The liminal body – living and dying; and (4) Organizational realities. Use of benzodiazepines were largely governed by social and moral norms, cultural expectations and organizational realities as part of affective assemblages of care.

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Background

Palliative care and prescribing practices

Palliative care is an approach that ‘improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness, by preventing and relieving suffering through the early identification, correct assessment and treatment of pain and other problems’ (World Health Organisation, 2023). Medicines are often used to attempt to address this suffering globally. In Australia, the median number of palliative care-related prescriptions per person increased from 1.8 to 2.9 between 2016–2017 and 2022–2023 (AIHW, 2024). Many of these medicines are prescribed ‘off-label’; that is, for indications, dosage and route of administration not

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listed in the product information (Hagemann et al., 2019). Up to 70% of off-label medication use in palliative care has no or minimal supporting evidence (Remi et al., 2021).

Internationally, benzodiazepines are extensively used in specialist palliative care as one means of addressing suffering (Clark & Currow, 2015). Several benzodiazepines (midazolam, lorazepam, diazepam) are listed on the International Association for Hospice and Palliative Care (IAHPC) List of Essential Medicines for Palliative Care (International Association of Hospice and Palliative Care, 2007). For instance, more than half of patients in a UK hospice received benzodiazepines and for diverse symptoms, including anxiety, agitation, pain, breathlessness, insomnia and delirium (Henderson et al., 2006). This usage continues, despite several Cochrane reviews reporting no evidence that benzodiazepines are effective for many of these indications (Beller et al., 2015; Li et al., 2020; Simon et al., 2016). Further, benzodiazepines are associated with a range of side effects: impaired cognitive function including impaired memory, dizziness, drowsiness, and falls (Li et al., 2020). In non-palliative care settings, benzodiazepine protocols underscore the need for short courses, low doses, and avoidance of 'anticipatory' prescribing (a common practice in palliative care) (Brandt et al., 2024).

Benzodiazepines practices in palliative care have primarily been studied within a biomedical framework; that is, one that privileges rational technical knowledge rather than contingent and/or experiential knowledge (Pope, 2003). The biomedical model is a functional and necessary component of care in response to physical symptoms such as pain (Kearney, 2000; Lewis, 2007; Wade & Halligan, 2004). Nevertheless, there is a body of literature that questions modern medicine's biomedical approach in relation to palliative and end of life care (Lewis, 2007). As a relatively new specialty, palliative medicine has, to some extent, sought to legitimize itself by embracing a rational analytical, logical, evidenced-based practice approach aligned with dominant paradigms (Kearney, 2000). Dying has become increasingly medicalized, requiring clinical skills and expertise (Broom, 2015; Kaufman, 2005). At the same time, the palliative care movement continues to promote a holistic and social response to death and dying (Kellehear, 2022).

Sociological scholarship views prescribing as a symbolic and social act embedded in a 'complex matrix of social and institutional values' (Ceuterick et al., 2023, p. 2). Sociological studies of prescribing in other settings have highlighted that social norms, organizational culture and relationships can play a significant role in prescribing practices. For example, antibiotic prescribing is often governed by emotive and relational pressures to act, professional hierarchies and 'bureaucratic routinisation' rather than best practice (Broom et al., 2014). Localized norms and peer practices tend to determine antibiotic prescribing rather than clinical guidelines and/or epidemiological concerns (Broom et al., 2016). There is a dearth of literature exploring sociocultural aspects of prescribing practices in palliative care, including benzodiazepine practices.

Palliative care, suffering and the 'good death'

The contemporary idea of a 'good death' is central to palliative care philosophy. Characteristics of a 'good death' identified in the literature are various and include: pain and symptom control (Vig et al., 2002), attention to spiritual beliefs, and a sense of 'completion,' including meaningful time with family and friends (Steinhauser et al., 2000). However, several authors have questioned whether a 'good death' is possible (Masson, 2002; Scarre, 2012; Walters, 2004). Scarre (2012, p. 1085) has argued that for a death to be good, an individual must have an awareness of the existential significance of the event at the same time as having an 'absence of mental anguish'. These, suggest Scarre, are mutually exclusive, thus even the best death is unable to be 'good'. Sociological critiques have taken this further, arguing the 'good death' is a form of social control (Hart et al., 1998; McNamara et al., 1994). The relationships between the contested concept of the good death and the potential goals of benzodiazepine use in palliative care make benzodiazepine practices an important focus of sociological study.

Theoretical framework

Affect theory

In this current study, we adopted notions of the body from social theory as the theoretical lens for this paper; in particular, drawing our inspiration and critique from affect theory, whereby Spinoza's affectio is the capacity of one body (human or otherwise) to affect or be affected by another (Seigworth, 2011). Inherent in this paradigm is a move beyond individual subjectivity towards group subjectivity. Here, the individual is always already constituted from pre-personal or transpersonal intensities that emerge when bodies affect and are affected by one another (Massumi, 2002). This paradigm enabled us to depart from a view of the person as a dissectible material body; that is, a reduced, singular, or medical-technical view of the body, seen in terms of a fixed enclosed unit, or set of physiological processes. Rather, the body defined by what Mol (2002) calls the 'body multiple' is always becoming, as well as inter-related with its surroundings, meaning that it is never fixed, always in flux, open and with transformative potential to affect and be affected (Fox, 2002). Applied to the argument of this paper, this means that a body can mean different things at the same time. Here, individual actions are inseparable from associations of networks that 'spatially and temporarily link one actor with another' (Duff, 2014).

The aims of this focused ethnographic study were to explore specialist palliative care clinicians' (nurses, doctors, allied health professionals), patients and family members values, beliefs, knowledge and feelings regarding the use of benzodiazepines and in-situ decision-making processes and actions concerning benzodiazepine practices. Social theory notions of affect, the body and of suffering provided the theoretical lens through which we analysed our data.

Methods

Given our qualitative study was concerned with how benzodiazepine practices unfolded in situ and over time, we used focused ethnographic methods (Wall, 2015), an approach underutilized in palliative care research (Walshe et al., 2011). A focused ethnographic approach seeks to study a specific issue in a particular context and by researchers who have 'insider' knowledge of the cultural group (Wall, 2015). This approach was particularly suited to yield in-depth data concerning the culture and context of benzodiazepine practices in a specialist palliative care unit and within a limited timeframe (Figure 1).

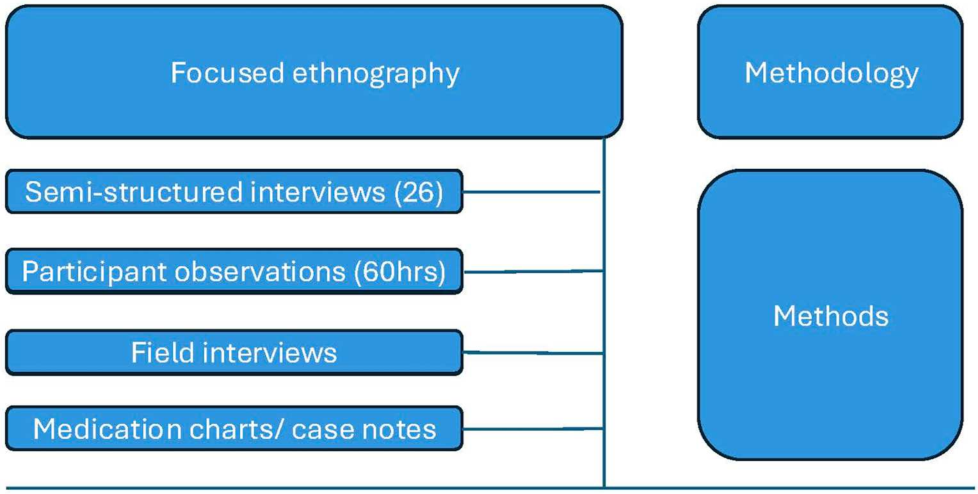

Figure 1. Study methodology and methods.

The research context

The site was a specialist palliative care unit, situated in a large healthcare organization in metropolitan Australia. The field researcher (Author 1), a palliative care nurse and experienced ethnographer, had no prior direct contact with staff in the unit, except for the research nurses who helped facilitate site access. The site health organization granted ethical and governance approval for the study 09/05/2016 HREC reference number LNR/16/SVH/116. In addition, the researcher took a situated approach to the ethics, whereby ethical decisions were made in the context of particular situations as well as regulatory ethics processes (Clark, 2012).

Data collection

Author 1 collected data pertaining to the prescribing and administration of benzodiazepines in July and August 2016. These data included semi-structured interviews with unit staff, field observations of interactions, and accompanying field-interviews (impromptu interactions with clinicians, patients, and family members to clarify an action or decision between the researcher and participants in the field), and entries in medical case notes and electronic prescribing records. Author 1 attended the unit for ten days over a five-week period and at sporadic times throughout Mondays to Fridays, for approximately 6–8 h on any given day, and at different times of the day including early morning and evenings. Observations included shadowing of consenting clinicians, patients and family members during medical ward rounds, multidisciplinary meetings, nurse and medical handover meetings, and medication rounds. The field researcher hand wrote and voice-recorded unstructured field-notes of observations.

Participants

We used purposive and convenience sampling to recruit three participant groups: clinicians (doctors, nurses, allied health staff), patients, and family members. Clinicians

($n = 40$) were emailed the written study information accompanied with an invitation to participate in a semi-structured interview lasting approximately one hour, prior to the fieldwork phase. These interviews foreshadowed the focus of observations and field-interviews, in keeping with the purposeful approach of focused ethnography (Higginbottom et al., 2013). Semi-structured interviews were audio-recorded with consent and transcribed verbatim. Clinicians identified patients and/or family members who may be interested in participating and requested permission to forward their details to Author 1. The researcher subsequently invited these patients and/or family members to participate. In addition, a study poster was placed in staff, patient and family areas and on the wall in public and staff areas around the unit.

Data analysis

Data analysis proceeded concurrently with data collection. Author 1, as the field researcher, expanded on field-notes at the end of each day to identify meanings and relationships between data sets. Roper and Shapira's ethnographic framework guided data analysis (Roper & Shapira, 2000). Author 1 led the analysis, systematically and individually analysing each data type to produce descriptive labels and subsequently comparing and contrasting these labels across all data sources. Following initial coding, all data types were regarded as inseparable from and informing the others. Analysis involved sorting for patterns, identification of outliers or negative cases, memo-ing (including reflective remarks), and generalizing with constructs and theories. We then as a team and individually reflexively questioned our own practices, values and feelings about the use of benzodiazepines, asking what we may have overlooked and/or taken for granted. Author 1 led these discussions in several meetings (in person and virtually) with Authors 2 and 3. As part of an iterative analysis process, Author 1 sought disconfirming information and alternative analytical viewpoints from Authors 2 and 3 in the form of written critical review and critique of descriptive labels.

Findings

We recruited (22) clinicians (over half of all invited) who included nurses (13), doctors, (6) and allied health staff (3). The clinician sample size was ultimately determined by their availability, busy clinical schedules, willingness to participate and the frequency and duration of the researcher's time in the field. Participants were assigned pseudonyms. Four patients consented to participate in a semi-structured interview. No family members consented to participate in a formal semi-structured interview; however impromptu field interactions between the researcher and family members, as well as patients and between staff, patients and families, informed the analysis. Fieldwork generated a total of 60 h of participant observation, including these field interactions. Analysis generated the following themes: (1) A special specialty; (2) The suffering body and the moral imperative to 'settle; (3) The liminal body – living and dying; and (4) Organizational realities.

A special specialty

Clinicians, for the most part, contrasted the speciality of palliative care with other hospital medical specialties. A logic and ethos of 'comfort', as opposed to curative and/or rehabilitative treatment goals, provided the reasoning behind a 'different' approach:

> I think anxiety, dealing with distress is quite different in palliative care, sort of distress across the spectrum of emotions is quite, is a different focus in palliative care, takes on a different complexion in palliative care than elsewhere in the hospital. (Nurse)

The nurse above conveys how articulations of anxiety and distress in a palliative care context are imbued with meanings unique to this setting. Thus, for many clinician participants, responding to anxiety and distress was underpinned by cultural mores and values concerning the relief of ‘suffering’ and the ‘good death’. This logic of comfort often provided a justification for how benzodiazepines were used. For instance, the nurse quoted below articulates the rationale for trying midazolam for other symptoms rather than sedation:

> I thought midazolam would have been just for sedation but recently having used that, the midazolam did help with their breathing as well. It relaxes their breathing, but the intention wasn’t to sedate, but to help with the breathing. (Nurse)

Further, the ‘logic of comfort’ meant that the norms and guidelines associated with the use of benzodiazepines in specialist palliative care were considered different to those for other patient populations and/or in other settings:

> You know, it [use of benzodiazepines] is interesting. It is not the same rules for across the road [acute hospital]. (Nurse)

The nurse quoted above deems ‘the rules’ of using benzodiazepines as not applicable to them. Different rules associated with value-laden routinized practices reflected the locally understood unique moral requirements of providing specialist palliative care in that setting.

Some clinicians, like the nurse quoted below, drew from their experiences in non-palliative care settings. The following quote highlights how they were able to map the normative practices of one specialty (older people) to palliative care, and thereby question benzodiazepine practices:

> And then there is also the age factor where they are quite elderly and if you give them benzos and they fall over, and it is really a very fine line between using benzos and not using the benzos. (Nurse)

The quote above shows how the ‘special specialty’ can be contested and is not necessarily ‘fixed’. The special moral qualities championed as part of the palliative care assemblage affect the care of bodies, but bodies can still affect how this care is understood and performed. Further, this quote, as well as those of others, highlighted the tensions associated with implicit goals of care and/or treatment. That is, the moral imperative of resolving suffering at the end of life with benzodiazepines for symptom management has potential, in turn, to produce and re-produce suffering.

The suffering body and the moral imperative to ‘settle

The social imaginary of the ‘good death’ was a powerful affective force underpinning the use of benzodiazepines. Clinicians tended to regard suffering to be antithetical to peace and comfort and therefore necessary to quell for a death to be ‘good’. The term clinicians used most frequently to articulate this desired peace and comfort was ‘settled’. Here, the word settled usually meant the converse of being ‘unsettled’ and/or ‘agitated’. Being 'unsettled' or agitated was typically described as someone who was bedbound but moving around in bed, trying to get out of bed, pulling at bed clothes or other material objects, or moaning and or grimacing, and/or who was considered at risk of hurting themselves or others. These behaviours often prompted the prescription and/or administration of a benzodiazepine, as the quote below highlights:

> Someone who is generally crawling out of bed or not safe to be left alone. Sometimes they can be pacing. We have had patients who are, not here but other places, I have seen, terminal restlessness but in the sense that they are pacing around and just not settled. That is when we would give benzodiazepines and try to settle them down. (Nurse)

The quote above shows how a nurse is prompted to administer a benzodiazepine when a person is deemed to be in the last days and hours of life and unsafe and unsettled. The dying body through the clinical gaze, is made peaceful by the benzodiazepine. Here, however, the nurse's actions, are inseparable from affectus and the palliative care assemblage including family members, clinicians, enculturated practices, and their associated clinical technical tools, as well as normative expectations of the good death. Reflecting on their reasons for administering benzodiazepines, the doctor below questions whether doing so primarily for the benefit of family members has the potential to cause harm to a patient:

> So, it is easier to see the patients, or the family as well, to see the patients calm and sedated rather than trying to climb out of their beds. I mean I recognise we are saying we are trying to help the patients but in reality, it might be that we are harming the patients. (Doctor)

Here, decision-making rather than an individual clinically objective endeavour was imbued with emotions subsumed, produced and reproduced through circulating relationality between and among bodies.

Within the milieu of *affective flows* nurses (in particular) expressed how difficult it was to witness a person's suffering:

> I can't be watching someone when I know I can do something. And there are drugs that are available. Then no, I can't deprive my patient of something (medication) that would make them comfortable. (Nurse)

This quote shows how suffering was sometimes reduced to an ameliorable problem that can be fixed by medication. For this nurse and other participants, to not administer a benzodiazepine in circumstances in which they considered a person to be suffering was often deemed an immoral act of denying a person relief of that suffering. There was a presupposed moral and social expectation for the use of these medications, given their availability and assumed potency.

The study's focus on benzodiazepines meant that their use was often the focus of informal interactions between the field researcher and clinicians. The nurse below had a low threshold for administering the medication lorazepam to a patient in the late evening:

> Well, the loraz [lorazepam] was a saviour last night … It's 11:00pm and Chrystal [patient] starts shouting "Nurse". "Can you get me my pants, I'm going home, I feel like a prisoner in here, I'm leaving now". "Chrystal, it's 11:00 o'clock at night and that just isn't going to happen right now". I just knew that she was going to arc up and there was going to be no strategising with her. "Chrystal", I said, "You are getting yourself a bit wound up,

> aren't you? I think you are getting yourself a bit wound up. Shall I get you something to calm you down?" "Yes", she said. So, lorazepam and boom, that was her asleep for the whole night. (Nurse)

As the account above shows and in other participant's accounts, the normative expectation of a night shift on the ward was that patients would be 'settled' in the way that we have described. Chrystal, a long-term patient had, to some extent, become a threat to the unit's social mores of a quiet and peaceful ambience. Here, the benzodiazepine is given rescue status as saviour and a solution in response to Chrystal's shouting out.

The liminal body – living and dying

On the one hand, some participants emphasized how the palliative care philosophy of 'living well' underpinned benzodiazepine practices. On the other hand, and aware of the focus of the study, some clinicians were keen to emphasize that the use of benzodiazepines was not a ritualized practice:

> I don't want you to think that you come in and we are just going to drug you out immediately. It is not like that at all. The reality is, really you want people to have, to be available for as much life as they can be, you know what I mean, there is still joy, happiness and sadness and all those things that are good and regular for people to feel. I don't want to take that away from them altogether. (Nurse)

The quote by the nurse above shows how they viewed themselves as being at risk of impacting meaningful embodied experiences of patients in the interests of 'care' while desiring to not do this 'altogether'. The palliative care assemblage maintained a desire to affect and enhance living that could be in tension with its responsibility to provide 'care'.

How a person became socially constructed could, to some extent, justify decision-making, determining if and when they received benzodiazepines. For instance, clinicians often explicitly or implicitly classified patients as living or dying using the terms 'terminal' or 'terminal phase' in their everyday clinical language. This classification could subsequently determine how and in which circumstances benzodiazepines were used. For example, Pam was an inpatient for many weeks. Her categorization as being in the 'terminal phase' had remained unchanged for the duration of fieldwork:

> Pam is in bed and the room is dimly lit. She startles as I approach her. Nurse Anna follows me into the room. "Yes, she's been like this for most of the day, [referring to Pam's further startle at a noise outside the room] she's been sleeping most of the day." Nurse Anna tells me, "I've checked, she hasn't had much extra meds today. But Diane (names other RN) told me she says she said she feels as if she's falling." [I note that every time I have passed Pam's room this afternoon, she was turned on her side, the room was dark, and she looked asleep]. (Researcher fieldnote)

The quote above shows how these threshold determinations, often constructed into categories and/or phases, were clinicians' social formulations and drivers for expectations, clinical care and associated responsibilities and duty to detect and avoid suffering. The uncertain determination that someone might be dying meant that a variety of different expectations became prominent and mandated. For instance, despite being classified in the 'terminal' phase of illness, clinicians explained that for some patients this phase was ambiguous and subjective:

> I realise you can still be terminal, still be in terminal restlessness and still walking around. So it is quite difficult to figure out who exactly is terminal and usually, sometimes it is more straightforward because they are in bed all the time and not getting out. (Nurse)

Here, the nurse expressed the difficulty of knowing if a patient was in the final days of life, or not. For this nurse, a person spending most of the time in bed was a strong signal that someone was in the 'terminal phase'.

Sometimes patients themselves conveyed feelings of being in a kind of liminal body between living and dying. For the patient below this experience was because of sedating medications:

> They (the drugs) contribute to that in a lot of ways you know, well for me anyway. It's those drugs, whatever raft I'm taking. Particularly one of them knocks you sideways. When I wake up, I have this feeling of nothing and I mean nothing, nothing, nothing, nothing, shut your eyes and anything, nothing. (Patient)

Despite not being able to differentiate any specific medication for the way they felt, this patient put their mental state down to 'those drugs'. This patient's experience of nothingness, however, seemed to involve unnecessary loss where a technologically (pharmaceutical) induced absence created distance and discontinuity. Thus, the power of the body to act (affecting) was diminished for this person.

However, from the perspective of another patient who experienced severe breathlessness, the benzodiazepine lorazepam took on a different meaning:

> And each time they (nurses) give it (lorazepam) to me and I look for it. And any time I'm anxious they tell me I can have it, anytime and it's a Godsend, it really is, because I'm normally a very placid person, very calm but my chest the way it is and the breathing, I panic. (Patient)

For this patient, the benzodiazepine was regarded as critical to the relief of their anxiety and breathlessness. This shows how the patient construed the practice of making this benzodiazepine available 'any time', in the ways that it was, as a 'Godsend'.

Organizational realities and the affective body

The practices of and decisions about prescribing and administering benzodiazepines were rarely made in isolation. Rather, practices unfolded in complex relational scenarios whereby multiple actors and the institution formulated (and complicated) the use of benzodiazepines. Clinicians frequently spoke of having to make compromises when faced with multiple competing matters of patient safety:

> And if you have got two or three in a ward of 40 trying to get out of bed and climbing out of bed and having falls, you can't be watching, you can't be standing by 40 patients' beds. Even two or three because there are only two or three of you (nurses) anyway. So I think the reality is actually very difficult to manage delirious patients without the use of any medications. (Nurse)

The quote above shows how, as well as the moral imperative to settle, benzodiazepines became a mechanism of chemical restraint driven by what this nurse regarded as having to juggle competing safety risks in the context of limited staffing and the reality of organizational structures. The nurse felt they had little choice when juggling multiple competing risks but to administer benzodiazepines. Further, this nurse, aware that medication is not the preferred treatment for someone with delirium, conveys how they made clinical compromises in responding to risks, especially on a night shift with minimal staffing levels.

In the following quote, a doctor in specialist training conveyed how their decisions about prescribing benzodiazepines were made in the context of the medical hierarchy, as well as family and nurse expectations:

> And sometimes if there is unfinished business as well from the patient's side, if they are a little bit more awake but they tend to be quite agitated or unsettled. I just have to make a compromise as well and then just take things slowly. It is just a lot of explanation to the nurses, to the family as well. And of course I have the guidance of my consultant. (Doctor)

For this doctor, going against the social norm of prescribing a benzodiazepine to sedate a patient who was agitated, meant they were required not only to reconcile the patients need to address unfinished business with the competing family and nursing expectations of sedation, but to do so in way that was consistent with where they were situated within the medical hierarchy. This resulted in what they saw as a compromise of slowly titrating the benzodiazepine dose upwards. Nurses too expressed how benzodiazepine administration decisions likewise required accounting for numerous factors, as this dialogue with the researcher shows:

> Nurse: I gave her loraz [lorazepam] because her family are still there with her.
> Researcher: Would you mind talking me through your actions and decision-making?
> Nurse: Well about one hour ago she was agitated and calling out.
> Researcher: So, why did you decide to give her lorazepam rather than midazolam?
> Nurse: Well, it's like a stepping-stone. I go for lorazepam first, if the lorazepam doesn't work then the midaz [midazolam]. If I give her midaz, then that would knock her out and her family is still there and give her midaz and she might be awake all night.
> Researcher: I wonder if you would mind talking me through your decision making a bit more?
> Nurse: Well. She [patient] looked really frightened and you know sometimes midazolam can give you that feeling of 'dropping'. She (the patient) told me earlier that she was dying and that she didn't want to die. You can tell she is very frightened by her face and you know sometimes midazolam can make you feel like you are completely out of control. That dropping feeling and I gave her lorazepam earlier and her son didn't think it had helped and you know it helps some people and not others, so I never gave it to her. (Researcher field-notes)

As they became increasingly familiar with the purpose of the study, clinicians would often foreground the use of benzodiazepines in their conversations with the field researcher (Author 1). The research focus on benzodiazepine use often meant participants questioned the right and wrong of their own and palliative care practices, as the field researcher, becoming a part of the assemblage, implicitly disrupted affective patterns. For instance, a doctor reflected on the use of the benzodiazepine midazolam when a person is dying:

> Doctor: I don't know how we probably are in a way become dependent on midazolam as well, to be honest, as a part of our management of terminal agitation. Which is probably I think is wrong but it helps.
> Researcher: What makes you say it is wrong?

> Doctor: Well, I don't know whether we are just doing it for the sake of sedating them or not. Um, or have we, sometimes I question it that, have I, have we done the right thing just by sedating them with the midazolam. Or is it the right call. You sometimes question that. (Doctor)

As this doctor's quote highlights, decisions were complex. Moreover, prescribing practices often unfolded in the context of power relationships between nurses and the medical team and according to medical hierarchies. A doctor conveyed how their decisions were made in the context of nurses' requests and patients and families' views when a person was approaching the end of life:

> Doctor: And sometimes the nurses would push me. Just give the patient some midazolam because he needs it, he needs it. And of course it is easy for me to prescribe this. It is in the system.
> Researcher: So when you say you sometimes feel pushed, is that typical?
> Doctor: It is not most of the time that I am pressured because I have to make my clinical call or clinical judgement about the patient. But sometimes like, especially if you are caught in a scenario, in a situation that the family had been really hesitant to give it to the patient because they have the fear that it would cause the patient to further deteriorate or make the patient more sleepy. I do understand that the nurses are thinking about the pain because they have been seeing the patient much more often than me. Especially if it is an overnight event that could have happened. It is just when I come back the following day, they would say, let's pump it [midazolam] up, give it to the patient.

The quote above shows how doctors sometimes took on a brokering role between nurses and family members. Further, a nurse reflected on how a senior nurse escalated a request to a senior doctor to have their desire met:

> Look if (names nurse) doesn't get what they want from the reg (medical registrar), he will just call the consultant. He'll tell them that and then that puts them [the consultant] in an awkward position and they give him what they want, and that's not right either, you know. (Nurse)

These quotes above show how clinical decisions were imbued in the complexities of clinical relationships and associated power structures, including the power of clinicians to define and subjugate, the power of patients and family members to disturb clinical notions of the good death, and the power of organizations in mandating clinical staff to take responsibility for resourcing within clinical decision-making.

Discussion

Our findings show how prescribing and administration of benzodiazepines in an inpatient palliative care setting went beyond individually reasoned clinical technical decisions. Returning to the lens of Spinoza, our findings highlight benzodiazepine practices as entanglements of affectio (the state of an affected body) and affectus (the passage of one state to another) (Cross, 2021). Here, decision-making was actively lived and felt as part of a flow of circulating 'affect' between bodies (of all kinds), the social and other entities including palliative care, as both place and philosophy, and the wider institution (Fox, 2015).

Our findings show that participants in our research tended to privilege their responses in relation to treatment of delirium and the use of benzodiazepines at the very end of life. In the current study practices were, for the most part, driven by normative imaginaries of the 'good death', whereby a person is expected to take on certain characteristics. The material body associated with the 'good death' script in our study was one that was bed-bound, moving minimally, asleep and 'at peace'. In this context, benzodiazepine practice guidelines were regarded as having little relevance.

The use of benzodiazepines persisted within a kind of causative circularity whereby the imaginary of the 'good death' was, at least to some extent, produced and reproduced by using benzodiazepines to sedate. That is, habituated use of benzodiazepines for sedation of patients further reinforced this normative imaginary. This moral duty to achieve a 'good death tended to legitimise benzodiazepine use. Here, suffering was frequently reduced to a clinical technical problem of individuals to be fixed, rather than a complex existential human and social phenomenon. In a societal context, 'the drumbeat for control' is a constant in contemporary Western societies, as part of what Fowers et al. (2017) refer to as the modern project to reduce suffering through technology.

We posit that normative benzodiazepine affective practices, are, at least in part, shaped by the quest to control suffering at all costs. Further, the palliative care clinical literature tends to locate suffering in the individual. By foregrounding affect and focusing on the materiality of the body and relationality we have shown how benzodiazepine practices arise as entanglements of relational and interpersonal interactions. That is, our data show that benzodiazepine practices are produced and reproduced through circulating affective flows between and among bodies. Clinicians often feel helpless in the face of suffering and are more comfortable responding to suffering of a physical nature (Rattner, 2022). Here our findings resonate with the work of Dragojlovic and Broom (2018) who argue that suffering is 'embodied, intersubjective and affective'. That is, clinicians themselves struggle with the 'limits of human life and their professional projects' and are active participants in the co-production of suffering (Dragojlovic & Broom, 2018, p. 24). Our data highlight how clinicians sometimes felt compelled to use benzodiazepines *in* suffering *with* others.

Suffering and the professional response to that suffering is an affective assemblage shaped and understood through individual patients, their family members, clinicians and institutional policies and practices. Here affectio and affectus are inseparable in shaping the actions of actors as part of the affective assemblage. As Cross contends, 'Spinoza himself doesn't dwell or insist upon the distinction between affectio and affectus or even always employ the terms consistently'(Cross, 2021, p. 193). This lens, applied to benzodiazepine practices, has allowed us to move beyond cartesian mind-body or emotion/reason dichotomies. We have shown how the use of benzodiazepines unfolds as part of the sociopolitical and cultural milieu in which suffering is expressed, whereby the extensive use of benzodiazepines is produced and reproduced as part of the histories, ideologies and practices of palliative care (Broom, 2017). We argue then that, paradoxically, the moral imperative to relieve what we refer to as 'clinical technical suffering' as part of the 'good death' script, may potentially produce and reproduce suffering by diminishing the capacity of the body to affect and be affected.

Benzodiazepines as a technological intervention for a variety of different types or aspects of suffering were themselves given agency as part of the assemblage. The use of benzodiazepines meant that control over suffering and uncertainty became (theoretically) possible.

Our findings resonate with previous work investigating palliative sedation that showed how terminal restlessness, confusion or delirium were socially contested definitions rather than medical categories (Seymour et al., 2007). This is despite emerging clinical studies in delirium and palliative care (Agar et al., 2017; Hosie et al., 2020). Thus, how clinicians understand and construct these imprecise terms determines whether sedation is construed as contraindicated or necessary (Seymour et al., 2007). Further, we argue that a significant driver of the extensive use of benzodiazepines in palliative care is the prevailing discourse of the palliative care assemblage described by Rattner (2019, p. 360, 362) as 'disciplining dying', a discourse 'directing palliative care clinicians to do certain things a certain way' in response to the kind of suffering 'that leaks out of attempts to box it and is messy, chaotic and deeply sad'.

Manifest in our findings is the view that suffering of any nature can and should be relieved and that it is the ethical duty and obligation of palliative care teams to do so. Here, the body was reduced to that of the palliating gaze described by Bishop who drew from Foucault. Bishop (2011) suggested the palliating gaze is one in which the patient is under constant surveillance and that assessment extends the gaze 'into the crevices of the patient's psych, his social life and his religious life' (Bishop, 2011, p. 283).

Our findings also resonate with those of a seminal hospice ethnography whereby benzodiazepine use unfolded in a conflicting environment in which clinicians strive to uphold the hospice ideal of the good death, yet at the same time were hindered in doing so by the increasing organizational pressures and routinization of care (McNamara et al., 1994). Nurses and doctors sometimes questioned the extensive use of benzodiazepines, a finding consistent with Kamell and Smith (2016) whereby 39% of physicians who responded to a survey thought that benzodiazepines were overused within their own palliative care unit.

Moreover, our data highlight how the liminality between living and dying meant that when a person was constructed primarily as a dying body rather than a living person, extensive use of benzodiazepines was legitimized. This brings to light a contradiction between the palliative care philosophy of helping people live until they die and the normative positioning of people as dying bodies. Further, how patients' biographies and personalities came to be viewed and articulated as part of a collective narrative were often used to justify prescribing decisions and practices. Our findings also resonate with the work of Randall and Downie (1999), highlighting the common focus on the will of others over the patient as death approached. Here our findings highlight that the use of benzodiazepines was rarely, if ever, discussed with patients themselves. There was often an assumption the person could no longer self-define 'good death' combined with the presumption that what constituted 'good' is determined by an external (often 'expert', as in 'specialist') judge of the experience.

Limitations

The study took place at one in-patient site with its associated organizational culture. The study of practices in other settings, such as caring for the dying at home, might yield different findings. Further, adopting a different theoretical perspective may have led to alternative findings heretofore not considered. A further limitation is that no family members consented to participate in a semi-structured interview. Nonetheless, their perspectives were gathered in field-work interactions and informed analysis. These data were collected in 2016, and practice may have changed since that time. Nevertheless, recent studies have shown that the use of benzodiazepines by palliative care clinicians remains high (Hosie et al., 2021) and thus our findings revealing the heretofore not studied complexities of benzodiazepine practices in specialist palliative care remain highly relevant.

Conclusion

In sum, benzodiazepine prescribing and administration decisions in a specialist palliative care unit were largely shaped by social and moral norms and expectations, as well as organizational realities. More nuanced understandings of what a 'good death' entails, along with extending the role and expectations of specialist palliative care to include care of older people with frailty or dementia, makes benzodiazepines use – including the medical extreme of sedated dying as a clinical goal and expression of good care, increasingly problematic. Good deaths have many appearances, and benzodiazepines may only have a role in some of these. More sophisticated and nuanced approaches, and new affective practices and patterns, are needed to interrupt the palliative care assemblage.

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