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Experiences of palliative care nurses in the utilisation of palliative sedation in a hospice setting

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ABSTRACT

Background Palliative sedation, or bringing about a state of decreased or absent awareness (unconsciousness), is one of the therapies used in end-of-life healthcare settings in order to manage refractory symptoms such as pain, dyspnoea and distress. It is intended to relieve the burden of intolerable suffering of patients who are in the process of dying. Nurses are centrally involved in the utilisation of palliative sedation in end-of-life care; however, there is minimal research available in relation to their experiences in this regard. The dearth of research prompted this study.

Aim To explore the experiences of palliative care nurses in the utilisation of palliative sedation in end-of-life care.

Methodology A descriptive phenomenological methodology was adopted involving unstructured interviews. A purposive sample was used of 10 palliative care nurses with at least 1 year's experience of working in a hospice setting in Ireland. The data were analysed using Colaizzi's seven-stage phenomenological method.

Findings Data analysis led to the identification of four core themes: (1) information sharing, (2) timing of palliative sedation, (3) level of sedation and (4) palliative sedation as a last resort. The results indicate that the participants were generally satisfied with the processes that underpinned decisions to introduce palliative sedation. They saw it as a highly complex intervention, in part because it involved individuals with very complex conditions and symptoms.

Conclusions Palliative care patients, families and the general public in Ireland need to have greater understanding of the role of palliative sedation in the treatment of refractory symptoms at the end of life.

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INTRODUCTION

Palliative sedation is a decreased or total loss of consciousness caused by the administration and titration of sedative medications (eg, midazolam, levomepromazine, haloperidol phenobarbital and hyoscine hydrobromide) for a patient with a life-limiting condition who is imminently dying and is experiencing physical refractory symptoms (Broeckaert and Olarte, 2002; Davis and Ford, 2005; Kohara *et al*, 2005; Morita *et al*, 2005; Dickman, 2006; Cellarius, 2008; Kirk and Mahon, 2010). Several international palliative care associations, including the Irish Association for Palliative Care (IAPC, 2011), all justify the use of palliative sedation for the treatment of refractory physiological symptoms as well as, in some cases, for existential, spiritual, emotional or psychological distress (National Ethics Committee and Veterans Health Administration, 2007; Cherny and Radbruch, 2009; Kirk and Mahon, 2010). A refractory symptom within the context of palliative sedation is any symptom which cannot be adequately controlled in spite of every tolerable effort to provide relief within an acceptable time frame without consciousness being compromised (Broeckaert and Olarte, 2002).

Palliative sedation has historically been viewed as ethically controversial for a number of reasons. It is beyond the scope of this article to address the ethical concerns that palliative sedation gives rise to in great detail. However, it will provide the broad consensus among ethicists, clinicians and empirical researchers in relation to these concerns (Carr and Mohr, 2008; Cherny and Radbruch, 2009; McCarthy *et al*, 2011; Berlinger *et al*, 2013).

First, there is a concern that palliative sedation may inadvertently lead to a hastened death. Controversies about the perceived relationship between palliative sedation and an early demise arise

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because it is usually administered in the final days and hours of a person's life. The extant literature suggests, however, that while it accompanies the dying process, palliative sedation does not play a part in hastening that process: when correctly administered, titrated and monitored, it does not, or is highly unlikely to, hasten death (Carr and Mohr, 2008; Cherny and Radbruch, 2009; McCarthy *et al*, 2011; Berlinger *et al*, 2013). Even if it were granted that, on a rare occasion, the medication to relieve intractable symptoms has the foreseeable risk of hastening death, ethicists generally agree that taking such a risk is justified if the dying patient consents to it, the purpose of the sedation is to relieve suffering and the dosage is adequate and proportionate to ensure that relief (McCarthy *et al*, 2011; Berlinger *et al*, 2013).

Second, the unconscious patient is unable to maintain an oral intake of nutrition and hydration and this prompts a further decision about the provision of artificial nutrition and hydration (ANH), which itself raises ethical challenges. However, ethicists distinguish between the decision to administer palliative sedation and the decision to withhold or withdraw ANH and other life-prolonging therapies. In many cases, the patient will have ceased ANH before sedation is applied (Kahn *et al*, 2003). Where life-prolonging measures such as ANH are withheld during palliative sedation, it is viewed as acceptable to do so as long as certain criteria are met: that the patient has refused them, that they are futile, that they intensify the patient's suffering and that they are too stressful and burdensome for the patient's system to bear (Quill and Byock, 2000; Woods, 2007).

Third, there is a worry that palliative sedation is a form of physician-assisted suicide (PAS) or 'slow euthanasia' (Billings and Block, 1996). However, the standard distinction between palliative sedation and euthanasia is clearly articulated and defended by ten Have and Welie (2014). They point to key differences related to the intention of the intervention, the intervention itself and its outcome. With palliative sedation, the intent is to relieve unmanageable symptoms. That intent is evidenced when the doctor selects drugs and titrates dosages to the intended effect of controlling symptoms. Were the drugs to have a life-shortening effect on the patient, and the authors argue that this does not happen, that would be considered an adverse outcome. In the case of euthanasia, however, the doctor intends the death of the patient. He/she selects drugs and dosages that are lethal by all objective measures; they are administered in order that the patient loses consciousness, stops breathing and his/her heart stops beating. Only if this outcome is achieved will the intervention be considered successful. If the patient continues to breathe, the intervention would be considered unsuccessful (ten Have and Welie, 2014).

Palliative care nurses spend most of their working hours with patients facing death. They support many patients who are in the process of dying and consequently are in a unique position to offer insight into the practice of palliative sedation. They are closely involved in the process of palliative sedation because of their role in administering and monitoring medications and their often continuous proximity to the patient. However, in spite of nurses' involvement in carrying out palliative sedation, there is a paucity of research specifically on nurses' experiences, knowledge and attitudes in relation to this therapeutic intervention (Bruce and Boston, 2011). This is particularly the case in relation to Irish nurses' experiences of palliative sedation (McIlfatrick and Murphy, 2013).

Studies have indicated that nurses consider it important that patients have given their informed consent to palliative sedation (Beel *et al*, 2006; Venke Gran and Miller, 2008; Inghelbrecht *et al*, 2011; Gielen *et al*, 2012; Patel *et al*, 2012). In Beel *et al*,' (2006) Canadian qualitative study and Venke Gran and Miller's (2008) Norwegian mixed-method study, nurse participants revealed that it was helpful and a relief that the patients themselves had verbally communicated to the nurses that they were at a stage in their illness where their situation had become unbearable. That said, the studies reviewed also indicated that the extent to which consent was secured was not always clear. For example, Morita *et al*,' (2004) quantitative Japanese study (a nationwide cross-sectional questionnaire survey involving 2607 nurses working at hospitals and palliative care units where end-of-life cancer care is provided) found that 29% of the nurse participants were unclear about patients' wishes, 17% were unclear about families' wishes and 8.1% found that the wishes of patients and families conflicted. Even though consent for palliative sedation has been shown to be an important ethical concern for nurses, it is not evident from the available studies whether the consent was obtained in the early phase of a patient's illness or at the time when their symptoms were refractory.

The timing and the appropriateness of palliative sedation has been shown to be important to nurses when starting palliative sedation. For example, it has been found that some nurses believe that palliative sedation is introduced either too soon or too late (Brinkkemper *et al*, 2011). They are also concerned that the practice should not be done on a whim, that death must be imminent and that it be used as a last resort after every treatment option has been exhausted (Gielen *et al*, 2012).

Given that nurses usually administer palliative medication, it is not surprising that their role in the decision-making process has also been found to be important to them. In Brinkkemper *et al*,' (2011) study, nurses (n=201) claimed to be in agreement with doctors in decisions to carry out palliative

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sedation in the vast majority of cases. Nevertheless, a fifth of the participants reported that they had refused to carry out palliative sedation in the preceding year. Unclear or wrong indications for palliative sedation by the general practitioner were mentioned in seven of these cases as a reason for refusal. In Arevalo *et al*,' (2013) Dutch quantitative study, nurses felt involved in the decision to use sedation in 84% of cases; however, their involvement was somewhat less in home care situations (69%).

Finally, while studies in this area are few, it would seem that nurses' views on whether or not palliative sedation therapy contributes to shortening life or hastening death can depend on the palliative care practices of the country in which they work. Zinn and Moriarty's (2012) qualitative study with five participants working in a Scottish hospice found that these nurses were satisfied that the level of medication was proportionate to the need to manage refractory symptoms. The research participants had no discomfort about administering increasing doses of medication when necessary to reduce suffering and reiterated that medication was carefully titrated until effective. They believed that palliative sedation, even if required in large doses, could relieve suffering without 'killing' the patient, and recognised that the patient was dying of their underlying disease. The findings of Rietjens *et al*,' (2007) study in the USA also confirm those of Zinn and Moriarty (2012) in that seven nurse participants stated their belief that palliative sedation did not hasten the dying process. In contrast, Inghelbrecht *et al*,' (2011) extensive study found that 77% (n=4428) of the nurses thought that palliative sedation was partly or clearly intended to hasten death and only 4% believed that it actually had no life-shortening effect. This study was undertaken in Belgium where euthanasia is legal, which may have influenced the participants' views that palliative sedation hastens death.

In Ireland, as elsewhere, palliative sedation is often misunderstood by the general public and health professionals working in a non-hospice setting (Sinclair and Stephenson, 2006; van der Kallen *et al*, 2013). In a national survey of 667 members of the general public in Ireland, undertaken by McCarthy *et al* (2010), 68% of the participants had never heard of or known anything about it. As such, palliative care nurses working in Ireland have to administer palliative sedation against a background of a very low level of knowledge among patients and their families. This underlined the need to identify and describe the concerns and experiences of nurses working in palliative care in the island of Ireland.

AIM

The aim of this study was to explore the experiences of palliative care nurses in the utilisation of palliative sedation in end-of-life care.

METHODOLOGY

Study setting

The study was carried out in a designated specialist palliative care centre for a southern Irish city and county. At the time of the study, the centre comprised 24 inpatient beds and a day unit. It also provided a community-based programme and a dedicated specialist palliative care service to acute hospitals across the region.

Design

A phenomenological perspective is appropriate for exploration of little known or poorly understood phenomena (Mapp, 2008). A phenomenological qualitative methodology was therefore deployed in this study in order that palliative care nurses' experiences with the utilisation of palliative sedation could be captured and described from their perspective.

Sample

The study used a purposive sample of 10 inpatient palliative care nurses with over a year's experience of working in a hospice setting. Purposive sampling is a non-probability sampling method in which the researcher chooses participants who are likely to provide the most relevant information (Polit and Beck, 2010). The requirement of having over a year's experience was utilised in order to ensure that the nurses included had sufficient experience of palliative care and working in a palliative care setting. The sample comprised eight staff nurses and two clinical nurse managers.

Recruitment

A letter of invitation was given to all palliative care nurses with over a year's experience of working in the inpatient hospice setting. Potential participants were also provided with an information sheet explaining the aim of the research and what would be required of them if they participated. They also had the opportunity to ask questions if they needed further clarification about the study. It was stated by the researcher (ID) that participation was voluntary and participants could withdraw from the study at any stage of their involvement.

Participant anonymity and confidentiality was maintained throughout the research study. Research participants were not identifiable to anyone other than the researcher (ID) and this was achieved by assigning a number to each participant. Taped and transcribed interviews were stored securely on one computer accessible only to the researcher. Permission for the study was granted by the University College Cork Clinical Research Ethics Committee.

Data collection

Ten participants were interviewed at the hospice for 30–40 min by ID. The interviews were conducted

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over a 6-week period. They were largely unstructured following an initial question that asked participants to talk about their experiences in relation to palliative sedation. An interview guide and set of prompts were also used to support the initial question (Seidman, 1991; Holloway and Wheeler, 2002). These questions and prompts raised topics that were identified in the literature as important and were used to encourage some participants to move forward in their recounting of their experiences.

Inviting research participants to discuss end-of-life issues such as palliative sedation may cause participants to recall unpleasant or distressing memories. To prevent potential harm to them, an information sheet had been given to participants, explaining the study. It was also anticipated that if the participants became upset during the interview, the interview could be stopped and they would be offered immediate support and access to a counseling service. However, none of the participants were unduly distressed in the course of the interviews.

Data analysis

The 10 interviews were transcribed and analysed using the seven-step framework of Colaizzi (1978): (1) the transcripts were initially read (ID); (2) significant statements from the transcripts that were applicable to the research phenomenon were extracted (ID); (3) meanings were attributed to significant statements; (4) the formulated meanings were organised into clusters of themes (ID). In an attempt to stay faithful to the research participants' reports of their experiences, both researchers (ID and JMcC) read and re-read the transcripts independently and discussed and agreed on the final themes; (5) the results were combined into an exhaustive description of the researched phenomenon; (6) an exhaustive description of the phenomenon was formulated; (7) the interview transcripts along with the themes identified were returned to the participants and validated.

FINDINGS

Four core themes emerged from the data analysis: (1) information sharing; (2) the timing of palliative sedation; (3) the level of sedation and (4) palliative sedation as a last resort.

Theme 1: information sharing

This theme describes the sometimes ambiguous role that the study participants assumed in relation to communicating with patients and families. A central concern of the participants was their felt obligation to share relevant information with patients and families. They indicated that patient autonomy was best protected through ensuring that patients and families were informed about the effects of palliative sedation. Several participants referred to situations where they and the team took care and spent time and effort to inform and support patient involvement in decisions about their treatment. One participant, for example, reported on a case that involved a patient who had herself been a nurse:

> The patient had specifically said that she didn't want to be sleepy and I suppose again we kind of sat down with her and said how her pain wasn't under control that you know this was what she needed after a long, long, frank discussion for about two hours with her on her own, with her friends, with her and with her husband as communicators for her she did ultimately agree that she would take sedation. (Participant 6)

Many of the participants acknowledged that the dying process itself made honest communication difficult and they suggested that it was important to be sensitive and careful in terms of what is said to both patients and relatives, in the best interest of the patient. However, many participants also indicated that they were unhappy with the communication process and information sharing that they experienced with some patients and families. Several participants acknowledged that it was not always possible or appropriate to give the full facts about palliative sedation to patients who were not fully autonomous or starting to die.

However, some participants struggled with administering palliative sedation in circumstances where they felt that patients would want, but did not have, an exact understanding of its side effects, in particular that they would no longer be able to communicate with their loved ones. They justified the lack of disclosure as a means of protecting both patients and the health professionals but remained uneasy about such practice:

> You know they use terms like, 'we can give you whatever it takes to make you comfortable' but we don't say, 'but you know the downside of that now is you are going to go to sleep and you are not going to wake up again and you are not ever again going to talk to your family. This will relax you, this will help you sleep, this will make you more comfortable in the bed, this will help with your breathing, this will relax the muscles of your chest'. I think we are not very good, I know it is in the spirit of protecting everybody maybe including ourselves so we do, we get the something that makes them comfortable and they'll sleep more and they are comfortable but at a cost that really isn't explained. (Participant 2)

Participant 2 suggested that the focus on symptom relief by health professionals might sometimes obfuscate the need to listen to the voice of the patient. Referring to one case of a patient who had adamantly refused to be sedated, she felt strongly about the obligation to protect this patient's rights:

> She really wanted to live until she died and even though she was restless and would have benefited [from medication] and we explained you know that in dying that the organs are failing, that it gives a feeling

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> of restlessness and that we could help with that and she didn't really want to be because she wanted to be aware that she was still alive until she was no longer alive and that really touched me. I just admired her so much I actually felt so strongly in minding her rights. I found it nearly hard to go off duty in case if someone would give her sedation at some stage. So it's like I'm not sure how we are respecting people's autonomy when we are so focused on having them symptom free. (Participant 2)

Participants were also concerned about the level of understanding that the family had of what was happening. They acknowledged that they used metaphors such as 'relaxant', 'more restful', 'comfortable' and 'sleep more' to indicate that sedating the patient would render him/her unconscious. However, they believed that relatives without a medical background would not realise that the patient would not be able to speak or wake up towards the end of life when on palliative sedation.

Participants acknowledged that dealing with families presented particular challenges. Generally, they reported that families realise why sedation has to be given to patients when they have symptoms of distress or restlessness. However, two participants struggled with how much information to give to families about palliative sedation because they felt that if the patient's condition warranted the sedation from a clinical perspective, the family should not be given the authority to postpone it. This was especially of concern when there was conflict among members of a family who were involved in deciding on palliative sedation:

> You could be looking at one person who would say oh they want them restful and another would say they want them conscious at all costs. (Participant 5)

Participants also had suggestions as to how patients might be supported so that they could give their genuine informed consent to the treatment. One participant suggested that palliative sedation should be discussed with the patient in an appropriate manner and that the family needed to be informed that the dying process had begun for the patient, that their time was short and that to manage their dying might require sedation proportionate to the needs of the patient. Several participants also suggested that palliative sedation could be discussed much earlier in the patient's disease trajectory and they saw this as a means of promoting the patient's autonomy. The patient's level of awareness of their actual stage in their disease could be ascertained and their wishes for sedation established before things started to change.

Theme 2: timing of palliative sedation

This theme has many facets, such as time being taken from patients when they are reduced to an unconscious state from sedative medication and the timing involved in starting sedation too early or too late for patients. The concern of participants was that the patient's time is very limited, and therefore the more precious time to interact with family was considered of particular significance. A further worry was expressed by the participants that the patient was being 'robbed' or 'cheated' of something that was in very 'short supply'. On the contrary, they were also concerned to avoid inflicting unnecessary suffering by not taking appropriate and timely action. A key concern was that the final moments of someone who is dying may have a deep significance for their family:

> I suppose then in an end-of-life care situation if the sedation is gone in and the person is no longer aware of their family around them or no longer able to interact with them that would be a disadvantage, are you robbing them of some of that precious time where in the last maybe days maybe or hours or minutes of life possibly and I mean sometimes people take huge, what is the word, significance I suppose in any little interaction that somebody would have for them in those last minutes and hours of life. (Participant 1)

Some participants acknowledged that, despite the warrant for palliative sedation, they viewed the patient's loss of consciousness and their inability to communicate with their families as causing the 'social death' of patients—they were only biologically alive:

> They are not living socially, they are not living as people they are just alive but only biologically alive, if that makes sense, so maybe you have cut their real living down by a few days, to biological living. (Participant 2)

Participants saw the challenge as a matter of getting the right balance and they found it difficult when the right balance proved problematic to find:

> I think we struggle sometimes with the call of when we give palliative sedation, sometimes we might give someone palliative sedation and then if they don't die for a longer period of time maybe five or six days then you know we struggle with it and if they die soon enough afterwards you think that is ok, you made the right call. (Participant 3)

A final concern in relation to timing expressed by participant 10 was that nurses and doctors disagree about when palliative sedation should be started and that often it is started too late. For her, the doctors are slower to act but nurses, who are constantly at the bedside, have a responsibility to administer the medication when they consider that the patient needs sedation.

Theme 3: level of sedation

This theme describes the participants' awareness of the significance of the level of sedative medication that they were responsible for administrating. They reported that when they had initially started work in palliative care they were concerned about the level of

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sedation being utilised; however, as they gained experience, they reflected that they felt more confident and comfortable in administering palliative sedation. In general, participants were satisfied that palliative sedation in a hospice setting was used appropriately and proportionally as warranted by the patient's symptoms:

> I do feel I suppose in our care setting here that we appropriately use sedation, we don't jump in with very high levels, we start at a low level of sedation usually in a syringe driver and titrate it up as appropriate. (Participant 9)

However, one participant stated that it caused her 'concern' and 'discomfort' when 'heavy sedation' was prescribed and wondered if the patient realised the consequences, that they were going to be sleeping and that their life had 'changed utterly' before it had 'ended at all' (Participant 2). Participant 3 also described how she struggled with giving palliative sedation to an alert and active patient but did acknowledge that it was warranted as the patient did have 'that awful total pain' and was very distressed.

Finally, the participants reported that the dosage of palliative sedation has to take into account the patient's previous condition such as alcoholism, depression, anxiety or dependency on medication. Some of these patients sometimes required higher levels of sedative medication and the study participants were satisfied that the levels of sedation achieved were appropriate to their individual situation.

Theme 4: sedation as a last resort

The final core theme to emerge from the interviews with participants reflects their overall concern about, but also confidence in, the decision-making process that preceded palliative sedation. Overall, the study participants reported that the decision-making process that preceded any therapeutic intervention was reflective and well considered by the multidisciplinary team involved. Several justifications were offered by participants to support the use of palliative sedation: it was used as a last resort; the patient was imminently dying and it was a means of controlling refractory physical and psychological symptoms, for example, agitation, restlessness, pain and breathlessness; it helped to make the patient comfortable and settled and eased the journey; and it maintained the dignity of the patient.

When they touched on the issue of whether or not palliative sedation contributed to shortening patients' lives, they indicated that, in their experience, it did not. Instead, they reported that for these patients, who were often suffering from terminal restlessness, death from their disease was already imminent:

> I don't think I've ever thought that it shortens people's life giving them palliative sedation…I think if they are settled then, they were dying of their disease, they needed management of their symptoms and part of that management was giving them sedation, and I just have to say when you see them having sedation I think they die more comfortably than someone that is distressed and climbing out of bed and agitated and their families are looking at them distraught. (Participant 3)

Participants viewed palliative sedation as easing symptoms that were not being alleviated by conventional palliative symptom management and positively easing patients' struggles, helping them to relax and even extending their lives:

> In my experience it doesn't actually, doesn't shorten their life somebody that you might have thought was going to die today if they become more relaxed and aren't fighting for breath and not deriving any benefit from oxygen they could last another twenty four hours because the struggle is taken off them they are not running the marathon by trying to sit up and battle the confusion. (Participant 5)

Specifically, they saw palliative sedation as a last resort to manage physical and psychological pain, which caused extreme distress but was resistant to standard treatment and the usual interventions from health and allied professionals.

Finally, a number of the participants viewed palliative sedation as an intervention that helped to maintain dignity in a patient's dying. They indicated that they felt they had an obligation to maintain the dignity of their patients and that dignity was at risk when a patient became delirious or 'lashed out' (Participant 5).

DISCUSSION

Participants in this Irish study shared similar concerns with those expressed by palliative care nurses in the research undertaken in other jurisdictions. The first theme, information sharing, demonstrated their concern to respect patient autonomy, inform patients in a timely and sensitive manner and, where appropriate, ensure that patients' families were included and updated about the decision-making process. In this, the participants in this study clearly signalled their awareness of the obligation to gain informed consent, and they shared the concern demonstrated by 60% of the 415 palliative care nurses in Gielen *et al*,' (2012) study of Flemish palliative care nurses' attitudes to palliative sedation, who believed that the permission of the patient should be required before administering deep continuous sedation. Similarly, the European Association of Palliative Care (EAPC) advises that the aims, benefits and risks of the proposed sedation should be discussed with the patient (Cherny and Radbruch, 2009).

Dean and Beard (2015) acknowledged the challenge of introducing to patients the concept of sedation and the reality of distress that can occur with dying. The

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participants in the current study also struggled with the question of whether it was always appropriate to give the full facts about palliative sedation (ie, that it would lead to unconsciousness and the inability to communicate) to a dying patient and their families, especially in situations where the patient could not exercise their autonomy because of drug-induced or disease-induced cognitive impairment. The participants were of the opinion that they had to be sensitive and careful in their judgement of when the time was right to be honest with patients or family members. They felt that they could still be honest in telling half of the truth and not telling patients or family members everything. When the participants used words like 'restful', 'relaxant', 'comfortable' and 'sleep more', they usually felt they had to use these metaphors as it was too late to be giving the full facts about sedation when a patient is confused, agitated and starting to die. Such findings are similar to those of Erichsen *et al*,' (2010) Swedish phenomenological study of honesty in palliative care, which involved 16 nurses caring for children and adults in palliative home-based care.

It has been argued that health professionals as truth tellers search for ways to communicate with dying people honestly, sensitively and compassionately, and that the use of metaphor as a figurative language allows a truth to be shared without the harsh glare of reality (Hutchings, 1998). However, many of the participants also indicated their discomfort with an overly paternalistic approach to both symptom management and truth-telling and they were anxious to find ways to ensure that patients and families were adequately informed, for example, to give the true facts about palliative sedation earlier in the patient's disease trajectory. However, evidence is lacking on the effect that advanced discussions on sedation have on the well-being of patients (Dean and Beard, 2015).

The participants also indicated that family members lacked insight about their role in the decision-making process in relation to palliative sedation and that this could lead to confusion and conflict. While they did not directly refer to current policy documents from the EAPC (Cherny and Radbruch, 2009) and the Irish Association for Palliative Care (2011) they seemed well informed about the responsibilities of family and the multidisciplinary team in this regard, that is, that the family's role is to articulate what the patient would have wanted and how their reasoning led to this conclusion, and that it is the medical team who takes responsibility for the decision (Cherny and Radbruch, 2009; IAPC 2011).

Study participants were also consistent with the views of palliative nurses in other studies in terms of their concern about the timing of palliative sedation. In Brinkkemper *et al*,' (2011) Dutch study, a nationwide survey of 201 nurses on palliative sedation of patients at home, 18.5% of the nurse participants believed that palliative sedation was not started at the correct moment. This finding is similar to the results of this study where the nurse participants felt that sedation was being started too early or too late for patients. Participants also struggled with prolonged dying, where dying lasted more than a few days after patients were started on palliative sedation. This is a similar finding to that found in Rys *et al*,' (2013) Belgian qualitative study that explored the views of 10 doctors, 24 nurses and 14 care assistants in relation to justifying continuous sedation until death in nursing homes.

The level of sedation was the third theme identified by the participants in this study. According to Broeckaert and Olarte (2002), when sedating palliative care patients, there should be a clear match between the dosages of medication given and the dosages needed for symptom control. In short, there is a need for the individual titration of medication. In Zinn and Moriatry's (2012) Scottish study exploring the experiences, perceptions and knowledge of five hospice nurses with regard to palliative sedation, participants had no difficulties administering increasing doses of medications when necessary to provide a peaceful death. The findings in this study indicate that participants became more confident with time in using higher doses of palliative sedation as warranted by the patient's end-of-life condition (eg, severe breathlessness, refractory pain, terminal restlessness) and/or the patient's previous life experience (eg, alcoholism, depression, anxiety, dependency on medication). In the Irish High Court Case of Fleming v Ireland & Ors [2013], an expert witness in palliative care (Professor Tony O'Brien) stated that the practice with regard to medication dosage levels should be that 'the level of sedative medication is carefully titrated to ease the patient's distress but is not administered in such doses whereby the clear intention is to shorten a person's life'. The finding from this study confirms the High Court witness's comments that palliative sedation is started at a low level and is increased as appropriate to the patient's need.

Finally, nurses in this study indicated that, in their experience, palliative sedation did not contribute to hastening the patient's death. This contrasts starkly with the findings of Inghelbrecht *et al*,' (2011) two-phased Belgian study, involving nurses from hospitals, home care and nursing homes (n=4478), in which 77% of the nurses thought that palliative sedation was partly or clearly intended to hasten death. However, the broader extant literature suggests that, while it accompanies the dying process, palliative sedation does not play a part in hastening that process: when correctly administered, titrated and monitored, it does not, or is highly unlikely, to hasten death (Carr and Mohr, 2008; Cherny and Radbruch, 2009; McCarthy *et al*, 2011; Berlinger *et al*, 2013).

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LIMITATIONS OF THE STUDY

The small sample size and the single setting utilised in this study do not allow for generalisability of the findings. However, the advantage of this sampling method resulted in a large amount of rich data being obtained from palliative care nurses in a hospice setting. Qualitative research allows research participants to raise topics and issues which the researcher might not have included in a structured quantitative research design and this adds quality to the data collected in qualitative research (Carr, 1994). Finally, the inclusion criteria of having over a year's experience in palliative care may have limited the range of concerns that palliative care nurses have with palliative sedation.

RECOMMENDATIONS

- There needs to be a greater awareness among palliative care patient populations about palliative sedation. Education on palliative sedation is needed for patients' families and the wider public. Specifically, they need to be informed about its use and its consequences in relation to patient consciousness and capacity for communication.
- Discussions about palliative care sedation need to take place much earlier in their disease trajectory so that patients views and preferences in relation to it can be invited and documented.
- There is need for improved communication within the multidisciplinary team and between the team and patient's families around treatment decision-making and family involvement and support.

CONCLUSION

Palliative care patients, where appropriate, families and the general public in Ireland need to have a greater understanding of the role of palliative sedation in the treatment of refractory symptoms and of its use as a last resort at the end of life, when a patient has reached an actively dying phase. Palliative sedation does not hasten death when used appropriately and proportionally. Respect for patient autonomy through patient involvement in decisions about palliative sedation is a key concern of the palliative care nurses.

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REFERENCES

Arevalo J, Rietjens J, Swart S, Perez R, van der Heide A (2013) Day-to-day care in palliative sedation: survey of nurses' experiences with decision-making and performance. *International Journal of Nursing Studies* 50, 613–621

Beel A, Hawranik P, Mcclement S, Daeninek P (2006) Palliative sedation: nurses' perceptions. *International Journal of Palliative Nursing* 12, 510–518

Berlinger N, Jennings B, Wolf S (2013) *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*. New York: Oxford University Press. pp. 5–6

Billings J, Block S (1996) Slow euthanasia. *Journal of Palliative Care* 12, 21–30

Brinkkemper T, Klinkenberg M, Deliens L, Eliel M, Rietjens J, Zuurmond W, Perez R (2011) Palliative sedation at home in the Netherlands: a nationwide survey among nurses. *Journal of Advanced Nursing* 67, 1719–1728

Broeckaert B, Olarte J (2002) Sedation in palliative care: facts and concepts. In: Have H, Clark D, eds. *The Ethics of Palliative Care European Perspectives*. Buckingham: Open University Press. pp. 166–180

Bruce A, Boston P (2011) Relieving existential suffering through palliative sedation: discussion of an uneasy practice. *Journal of Advanced Nursing* 67, 2732–2740

Carr L (1994) The strengths and weakness of quantitative and qualitative research: what method for nursing? *Journal of Advanced Nursing* 20, 716–721

Carr M, Mohr G (2008) Palliative sedation as part of a continuum of palliative care. *Journal of Palliative Medicine* 11, 76–81

Cellarius V (2008) Terminal sedation and the "imminence condition". *Journal of Medical Ethics* 34, 69–72

Cherny N, Radbruch L The Board of the European Association for Palliative Care (2009) European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. *Palliative Medicine* 23, 581–593

Colaizzi P (1978) Psychological research as the phenomenologist views it. In: Vaille R, King M, eds. *Existential Phenomenological Alternatives for Psychology*. New York: Oxford Press. pp. 48–72

Davis M, Ford P (2005) Palliative sedation definition, practice, outcomes, and ethics. *Journal of Palliative Medicine* 8, 699–701

Dean A, Beard B (2015) Is sedation at the end of life compatible with the principles of palliative care? *End of Life Journal* 5, e000001

Dickman A (2006) Symptom control in care of the dying. In: Ellershaw J, Wilkinson S, eds. *Care of the Dying: A Pathway to Excellence*. Oxford University Press, King's Lynn. pp. 42–61

Erichsen E, Danielsson E, Friedrichsen M (2010) A phenomenological study of nurses' understanding of honesty in palliative care. *Nursing Ethics* 17, 39–50

Fleming v Ireland & Ors [2013] IEHC 2

Gielen J, van den Branden S, van Lersel T, Broeckaert B (2012) Flemish palliative-care nurses' attitudes to palliative sedation: a quantitative study. *Nursing Ethics* 19, 692–704

Holloway I, Wheeler S (2002) *Qualitative Research in Nursing*. 2nd edn. Oxford: Blackwell Science

Hutchings D (1998) Communicating with metaphor: a dance with many veils. *American Journal of Hospice and Palliative Medicine* 15, 282–284

Inghelbrecht E, Bilsen J, Mortier F, Deliens L (2011) Continuous deep sedation until death in Belgium: a survey among nurses. *Journal of Pain and Symptom Management* 41, 870–879

Irish Association for Palliative Care (IAPC) (2011) *Palliative Sedation: Discussion Paper*. Dublin: IAPC

Kahn M, Lazarus C, Owens D (2003) Allowing patients to die: practical, ethical, and religious concerns. *Journal of Clinical Oncology* 21, 3000–3002

Kirk T, Mahon M (2010) National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients. *Journal of Pain and Symptom Management* 39, 914–923

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Kohara H, Ueoka H, Takeyama H, Murakami T, Morita T (2005) Sedation for terminally ill patients with cancer with uncontrollable physical distress. *Journal of Palliative Medicine* 8, 20–25

Mapp T (2008) Understanding phenomenology: the lived experience. *British Journal of Midwifery* 16, 308–311

Mccarthy J, Donnelly M, Dooley D, Campbell L, Smith D (2011) *End-of-Life Care: Ethics and Law.* Cork: Cork University Press

Mccarthy J, Weafer J, Loughrey M (2010) Irish views on death and dying: a national survey. *Journal of Medical Ethics* 36, 454–458

Mcilfatrick S, Murphy T (2013) Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer reviewed publications. *BMC Palliative Care* 12, 33

Morita T, Chinone Y, Ikenaga M, *et al*. (2005) Ethical validity of palliative sedation therapy: a multicenter, prospective, observational study conducted on specialized palliative care units in Japan. *Journal of Pain and Symptom Management* 30, 308–319

Morita T, Miyashita M, Kimura R, Adachi I, Shima Y (2004) Emotional burden of nurses in palliative sedation therapy. *Palliative Medicine* 18, 550–557

National Ethics Committee, Veterans Health Administration (2007) The ethics of palliative sedation as a therapy of last resort. *American Journal of Hospice and Palliative Care* 23, 483–491

Patel B, Gorawara-bhat R, Levine S, Shega J (2012) Nurses' attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals. *Journal of Palliative Medicine* 15, 432–437

Polit D, Beck C (2010) *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 7th edn. Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins

Quill T, Byock I (2000) Responding to intractable terminal suffering: the role of terminal sedation and voluntary refusal of food and fluids. *Annals of Internal Medicine* 132, 408–414

Rietjens J, Hauser J, van der Heide A, Emanuel L (2007) Having a difficult time leaving: experiences and attitudes of nurses with palliative sedation. *Palliative Medicine* 21, 643–649

Rys S, Deschepper R, Deliens L, Mortier F, Bilsen J (2013) Justifying continuous sedation until death: a focus group study in nursing homes in Flanders, Belgium. *Geriatric Nursing* 34, 105–111

Seidman I (1991) *Interviewing as Qualitative Research: a Guide for Researchers in Education and the Social Sciences*. New York: Teachers Guide Press

Sinclair T, Stephenson R (2006) Palliative sedation: assessment, management, and ethics. *Hospital Physician* 42, 33–38

ten Have H, Welie J (2014) Palliative sedation versus euthanasia: an ethical assessment. *Journal of Pain and Symptom Management* 47, 123–136

van der Kallen H, Rajjmakers N, Rietjens J, van der Male A, Bueving H, van Delden J, van der Heide A (2013) Opinions of the Dutch public on palliative sedation: a mixed-methods approach. *British Journal of General Practice* 63, e676–e682

Venke Gran S, Miller J (2008) Norwegian nurses' thoughts and feelings regarding the ethics of palliative sedation. *International Journal of Palliative Nursing* 14, 532–538

Woods S (2007) *Death's Dominion. Ethics at the End of Life*. Berkshire: McGraw-Hill

Zinn C, Moriarty D (2012) Nurses' perceptions of palliative sedation in a Scottish hospice. *Journal of Hospice & Palliative Nursing* 14, 358–364

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