

Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience

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Abstract

Background: Families of patients in vegetative or minimally conscious states are often horrified by the suggestion of withdrawing a feeding tube, even when they believe that their relative would not have wanted to be maintained in their current condition. Very little is known about what it is like to witness such a death.

Aim: To understand these families' experience of their relatives' deaths.

Design: Qualitative study using in-depth narrative interviews analyzed inductively with thematic analysis.

Participants: A total of 21 people (from 12 families) whose vegetative or minimally conscious relative died following court-authorized withdrawal of artificial nutrition and hydration. All had supported treatment withdrawal.

Findings: Interviewees were usually anxious in advance about the nature of the death and had sometimes confronted resistance from, and been provided with misinformation by, healthcare staff in long-term care settings. However, they overwhelmingly described deaths as peaceful and sometimes even as a “good death.” There was (for some) a significant “burden of witness” associated with the length of time it took the person to die and/or distressing changes in their appearance. Most continued to voice ethical objections to the manner of death while considering it “the least worst” option in the circumstances.

Conclusion: Staff need to be aware of the distinctive issues around care for this patient group and their families. It is important to challenge misinformation and initiate honest discussions about feeding-tube withdrawal and end-of-life care for these patients. Families (and staff) need better support in managing the “burden of witness” associated with these deaths.

Keywords

Artificial feeding, end-of-life care, minimally conscious state, qualitative research, tube feeding, vegetative state

What is already known about the topic?

- Withdrawal of artificial nutrition and hydration can be a difficult issue for families of terminally ill or dying patients in part because cultural conceptions of food and water as “basic care” conflict with the medico-legal definition of the feeding tube as a form of technological intervention.
- Resistance to withdrawal of feeding tubes—by families and by some healthcare staff—can lead to inappropriate ongoing treatment that is not in the patient's best interests and/or not what the patient would have wanted.
- There is no research about how families of vegetative and minimally conscious patients experience their relatives' deaths following withdrawal of such treatment.

What this paper adds?

- Insights from an in-depth analysis of interviews with 21 family members who witnessed a death, following feeding-tube withdrawal, from a relative who had been sustained long term in a vegetative or minimally conscious state.

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- Interviewees generally experience deaths as peaceful and calm—in stark contrast to what they had sometimes been told to expect by healthcare professionals.
- For some, there is a significant “burden of witness” associated with the length of time it took their relative to die and/or distressing changes in appearance
- We explore how families’ accounts of these deaths are framed by socio-legal context.

Implications for practice, theory, or policy

- Professionals involved in the care of vegetative and minimally conscious patients need to initiate open, honest, and ethically engaged discussions with families about feeding-tube withdrawal and end-of-life care.
- Attempts to persuade families that feeding tubes are “medical technology” rather than “basic care” are not, by themselves, likely to be particularly helpful.
- Families (and staff) need better support in managing the “burden of witness.”

Introduction

No one knows quite how many people are being sustained with long-term disorders of consciousness after profound brain injury; however, estimates in the United Kingdom (based on numbers of patients in these conditions in nursing homes) range from 4,000 to 16,000 patients in the vegetative state, with three times as many in minimally conscious states; these are people who are completely unaware of themselves and their environment (vegetative) or virtually so (minimally conscious).¹ The majority are able to breathe on their own. Once stabilized and in the absence of acute infections, the only medical treatment keeping them alive is a feeding tube delivering artificial nutrition and hydration (sometimes also referred to as clinically assisted nutrition and hydration).

In survey research, most people report that they would not want to be sustained in either a permanent vegetative state or minimally conscious state.² In English law, clinicians can provide medical treatments for patients who are unable to consent, on the basis of their “best interests,”³ now usually interpreted by the courts as meaning that an individual should not be given life-prolonging treatment if it is clear that they would not consent to it themselves.⁴ However, despite the recommendations of the National Clinical Guidelines,⁵ the default option in England and Wales is to continue tube feeding these patients indefinitely⁶ (and this also seems to be the norm across many European countries).⁷

Barriers to withdrawal reported by families⁶ include the following: not accepting the diagnosis or its implications; believing that any life is better than none; hoping for “a miracle”; searching for a cure/waiting for future scientific breakthroughs; religious or ethical objections to “ending life”; and/or the belief that withdrawal is ethically equivalent to euthanasia. People also may not know that withdrawal of artificial nutrition and hydration can be lawful or may believe that even if the patient would

rather not have their life prolonged, it would be preferable for the patient to die of “natural causes” (such as infection).⁶ It is commonly observed that cultural conceptions of tube feeding as “basic care” come into conflict with its medico-legal definition as a form of technological intervention.⁸ The apparent requirement (in England and Wales) for a court hearing even with consensus between health professionals and family members that withdrawal of the feeding tube is in the person’s best interests has also been a significant barrier.⁹

An additional important barrier to withdrawal—the one to which this article is particularly addressed—is family members’ expectations of what a death after feeding-tube withdrawal will be like. This includes the belief that it is cruel (even “barbaric”),¹⁰ a view also represented in some bioethics literature (sometimes characterized as “the sloganism of starvation”¹¹) that describes withdrawal of artificial nutrition and hydration as, for example, characterized by “a long period of suffering that might constitute an actual crime of torture” during which the patient experiences “atrocious pain.”¹² The belief that feeding-tube withdrawal leads to a “bad death” is one reason why many patients are continued to be given treatment that is not (or may not be) in their best interests.⁶

Most empirical research on withholding/withdrawing life-sustaining interventions focuses on critical care, where ventilation is the most commonly withdrawn treatment.^{13–16} Research focusing specifically on withdrawing, withholding, or refusing nutrition and hydration^{17–20} has found that subsequent deaths are not particularly painful. But this research concerns very old, frail, and/or terminally ill patients at the end of life. By contrast, vegetative and minimally conscious patients are usually neither old nor terminally ill; they are clinically stable following sudden-onset brain injury and are not otherwise “dying.” Advice to staff about how to medically manage the deaths of these

patients—as well as how to support, and what to communicate to, families—cannot simply be transferred from feeding-tube withdrawal in other contexts.⁵

It is also important to acknowledge that the context for families in these situations may have some distinctive characteristics. Family members may face having to watch a physically robust body that they have been caring for, often for years, deteriorate as a direct result of treatment withdrawal and unrelated to other causes of decline (e.g. cancer), and most have had to initiate and pursue withdrawal of the feeding tube (including going to court), sometimes actively opposed by at least some healthcare staff. This makes the family experience very different from treatment withdrawal when the decision is initiated by clinicians (or indeed the patient) and then simply implemented after discussion with the patient and/or their family, as is the norm in other situations. The existing literature also recognizes that withdrawing or withholding nutrition and hydration from patients who are not ventilator-dependent or terminally ill can be particularly fraught.²¹

Despite highly publicized court cases regarding feeding-tube withdrawal from patients in prolonged disorders of consciousness (e.g. *Schiavo* in the United States,²² *Englaro* in Italy,²³ *Bland* in England²⁴), there is no published research exploring how families experience their relative's subsequent death. Our study fills that gap and uses empirical data to reflect upon implications for medico-legal policy and practice.

Method

The research reported here arose out of a broader in-depth narrative interview study of families in the United Kingdom with experience of a relative in a prolonged disorder of consciousness (i.e. coma, vegetative or minimally conscious state; for other publications from the same study see the literature^{6,9,10} and other publications available open access on our research website cdoc.org.uk). Our ongoing study currently includes interviews with 85 family members, but for the present analysis, we extracted from the broader study just the subset of interviews conducted with people whose relative died after court-approved withdrawal of artificial nutrition and hydration.

Ethics

Research ethics committees at the Universities of York and Cardiff initially approved the study, which subsequently received the National Health Service (NHS) approval from Berkshire Research Ethics Committee (REC reference number: 12/SC/0495). Participants signed printed consent forms, which offered varying degrees of confidentiality, ranging from permission to use their first names and display (specified) video clips of their interviews on an online

resource through to complete confidentiality. Where interviewees consented to have film publicly displayed, it is possible to see a summary of the patient's story and hear/see quotes used in this article in the context of other parts of the interviewee's account—see [healthtalk resource: \[www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/peoples-profiles/confirmed-permanent-vegetative-diagnosis\]\(http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/peoples-profiles/confirmed-permanent-vegetative-diagnosis\)](http://healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/peoples-profiles/confirmed-permanent-vegetative-diagnosis). Links to specific segments from particular interviews have been provided where available. For those who wanted maximum confidentiality, great efforts have been taken to avoid jig-saw identification (i.e. enabling identification of a particular interviewee by cross-referencing information provided in an article with information in a published court judgment or media report). This is a particularly acute issue because (a) the population pool is small (i.e. only around 100 families have been involved in such cases) and (b) certain clinical/legal details are already in the public domain (e.g. in published court judgments). Pseudonyms are used throughout, except where interviewees requested that at least their real first names be used (further information about our anonymizing strategies has been published elsewhere^{25,26}). Quotations from our interviews are identified (where this is consistent with our confidentiality agreements) with a name/pseudonym and a tag (F1, F2, F3, etc.) indicating from which of the families the participant originated.

Design

This was a qualitative study. Semi-structured narrative interviews (average length about 2 h) were conducted by one or the other of the two authors with the aim of eliciting participants' stories of what had happened from the date of the brain injury to the current day. Information about treatment withdrawal (how they first became aware it was possible, their views about what it might be like, and their experience of the process) was often volunteered without the need for specific questioning. Where questions were required, we asked, for example, "When you first heard about the possibility of withdrawing artificial nutrition and hydration, what was your reaction to that?" "Did clinicians explain what would happen before they withdrew the treatment?" "What was it like after they withdrew treatment?" and "How was her death?" We also used probes (e.g. "can you say a bit more about that?" and "How did you feel about that?") to elicit more in-depth consideration. The subset of interviews used for the analysis reported here were recorded (audio, and sometimes video too) between 2013 and 2017 and constitute around 50 h of data. Some participants volunteered for successive interviews at different points in time (e.g. a year or more before treatment withdrawal, once the court application had been initiated but before its completion, and after their relative had died).

Recruitment

Recruitment was initially via snowball sampling: the authors are sisters and have a sister who was in a disorder of consciousness, a fact that informed and supported recruitment. We subsequently recruited via referrals from clinicians and lawyers working in this area and via Internet contacts. Everyone who volunteered and met our inclusion criteria was interviewed (more than once if they so requested). Because of the nature of our recruitment methods, it is difficult to know how many people were informed about our research and decided against participation.

Participants/setting

This article draws on interviews with 21 members of 12 families, whose vegetative or minimally conscious relative died after court-authorized cessation of artificial nutrition and hydration. They represent around 10% of all families in England and Wales with experience of court-approved withdrawal of artificial nutrition and hydration from a relative in a vegetative or minimally conscious state. These criteria exclude two participants (from different families) who had experienced temporary withdrawal of artificial nutrition and hydration from their relative without an application having been made to the court (in both cases treatment was recommenced after about 10 days; one patient died of infection more than a year later and the other is still alive). All interviews were conducted away from the NHS premises (generally in people's homes). Some interviewees spoke with us one-to-one; others opted to meet us in pairs.

Data analysis

All interviews were transcribed in full and analyzed using thematic analysis.²⁷ We looked for patterns in the way that interviewees described their experience of the death of their relative and also looked for differences between different members of the same family and across diverse families. Our analysis is conducted from a largely inductive and realist approach, but we interrogate and complicate this analytic perspective when we discuss the “strengths and limitations” of the study.

Findings

We begin by describing the characteristics of our sample participants. We then report the three key themes that emerged from our analysis. As we will show, our interviewees were fearful in advance but describe their relatives' deaths as less bad than they had feared—some even spoke of a “good” death. However, there was a clear “burden of witness” for about half of them and most retained in-principle ethical objections to the manner of death. In quoting

from the interviews, we usually identify the speaker using a pseudonym; this is followed by F1, F2, F3, and so on to indicate which of the 12 families the speaker is from.

Characteristics of our sample

Each of the patients had been the subject of at least one court hearing concerning feeding-tube withdrawal, and all 12 families had supported—and in most cases actively lobbied for—withdrawal, which they believed to be in accordance with the wishes of the brain-injured person such that their death would be a much-wanted “release.” These characteristics are typical of the 100 or so cases that have thus far reached the courts in England and Wales.

Most of the patients had been in a vegetative or minimally conscious state for 4 or 5 years by the time the court application was heard: the shortest period was just less than a year and the longest was 8 years. Most were between 20 and 50 years old when moved to palliative care—the oldest was in her 60s. Clinicians acting as expert witnesses had diagnosed eight of these patients as “vegetative” and two as “minimally conscious”: in the remaining two cases, there was no definitive diagnosis but insofar as the patient did not conform with the then-current requirements for the diagnosis of “permanent vegetative state,” he or she was very close to doing so. These differential diagnoses made no difference to interviewees' experiences of their relative's deaths, so we do not identify individual patient diagnoses in reporting our findings.

All but three patients died after 2010. Three died much earlier (in the 1990s)—two of these at our interviewees' homes rather than in hospice/hospital or care home as in all other cases—and we have identified the relevance of this for our analysis where appropriate.

Themes

Three themes were identified in the analysis. They arose (and are presented here) as temporally related elements of the narrative our interviewees presented first about their feelings in advance of withdrawal, then about the dying process after withdrawal, followed by their reflections about their own experience in witnessing the dying process.

Feelings in advance of withdrawing the feeding tube. Our interviewees had usually arrived at the view that it was right to withdraw artificial nutrition and hydration only after considerable time. They were prepared to support withdrawal, in spite of their continuing ethical concerns, only because they had come to believe that continuing to sustain their relative in their current (and likely future) state was a greater evil. They had also often witnessed attempts to allow the patient to die via repeated infections when antibiotics were deliberately withheld—and felt that to continue this, while not pursuing withdrawal of the

feeding tube had become morally untenable. Withdrawing the feeding tube was viewed as the “least worst” option under the circumstances.

Most interviewees reported being “apprehensive” (Lindsey, F8) or anxious in advance, for example, with “nightmares ... about being all shriveled and like a skeleton” (Olivia, F1; www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/david-and-olivia). Such fears were sometimes reinforced by reactions from staff involved in the patient’s long-term care, for example, one interviewee reports that a senior staff member at her son’s care home told the family that the patient would die an “excruciatingly painful” death if the feeding tube were removed: she was very grateful when a healthcare professional with experience of such deaths provided better information (Helen, F7; www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/helen). Likewise, Nina (F11) describes hostility from staff in her mother’s nursing home after she raised the issue of withdrawing the feeding tube. The contrast when (after a court hearing) she moved her mother to a hospice was striking: “moving into a hospice was a tremendous experience because [the staff] were so unconditionally supportive. That’s a mind blowing experience.” She found the hospice staff “respectful,” “reassuring,” “non-judgmental,” and “responsive” and the environment was “very safe and very gentle” (<https://vimeo.com/241429026>).

Families praised staff who provided excellent support—helping the family to feel informed and calm from the very first discussion of treatment withdrawal right through to the patient’s death. Olivia (F1) felt very supported by the fact that the care home staff “stood by us” and felt able and willing to care for her relative until she died rather than moving her to another facility:

They wanted her to stay and to pass [die] there ... that gave us a lot of comfort. [...] They weren’t saying, “What are you bloody doing? You can’t do that.” You know, it was the right time and it was the right thing to do [...] They wanted to be with her to the end and to look after her to the end. (Olivia, F1; www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/david-and-olivia)

Olivia’s experience was unusual insofar, as this was the only example we found of a patient being supported to die in their long-term care home setting. In all other cases, the patient either moved from the care home to die at home cared for by parents (F3, F12) or, more commonly, was moved to a hospice. When a move to a hospice was the plan, hospice staff came to visit the patient and family in advance. Interviewees reported that this provided a strong sense that “intensive care” would continue to be provided after unwanted treatment

was withdrawn. For Jonathan (F5), who initially felt that letting his sister die from “starvation” was “medieval, macabre [...] barbaric” (and compared it to abandoning unwanted babies on hillsides), meeting with the hospice staff “put my fears at rest” (<http://cdoc.org.uk/wp-content/uploads/2014/04/Information-helps-reduce-fears-F5-M.mov>). His mother was equally reassured—commenting on the skillful communication from the hospice staff and their concern for both her and her grandchildren (the patient’s children):

They came to see [my daughter] in the care home and were very gentle with her and respectful. Then they sat with me and the children in another room and talked us through the whole process. They answered all our questions very honestly and in as much, or as little, detail as we wanted. They were superb. It makes such a difference knowing where she is going and how she will be cared for—and I think it really helped the children. (Sylvia, F5)

Death was peaceful, calm, a release. Most interviewees said that the dying process was peaceful, and many contrasted this with what they had been led to expect. “They make it sound so awful [...] but it’s not like that at all. [...] It was very peaceful” said one (Lindsey, F8); “Her life just ebbed away,” said another, adding:

And we had been told all sorts of horror stories of what probably would happen. [...] And I think it was—they just got the drugs right I think. [...], [she] never flinched, never twitched, never moved, never—yeah. It was just a very peaceful end. (Diana, F12)

Once the palliative care process started, some interviewees felt that the patient looked more “relaxed” and even “more himself.” A father had the feeling his son had finally “come back to us,” and a daughter felt more connected with her mother: some linked this to the removal of tubes, a shift to a more homely environment or being able to spend time with the patient knowing there was an end in sight. Interviewees sometimes compared this favorably with other periods (e.g. with infections):

The way he died, which was obviously through multiple organ failure because he wasn’t being fed, with his pain managed (and the last few days it was managed heavily) was far more peaceful and dignified for him and for those who loved him than watching him retch and heave and cough and be suctioned and run a high temperature, perspiring all over his bed sheets ... There was no comparison. (Jane)

The moment of (or hours around) death was reported to be calm. One interviewee said, “He just lay there and he just made a couple of shrugs and then he just passed away gently” (Kevin, F3). Another described the day of her daughter’s death:

There was no sign of distress or anything. The only difference was her breathing was more shallow, and sort of panting. And then she died half an hour later. No one could say this was a bad death. It was so peaceful. (Alison, F2)

Another interviewee described how, when her son finally died, it was reassuring to see him “without the stress and the tension and the fear that was tightening the muscles in his face. For the first time in years he looked as if he was peacefully asleep” (www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/helen).

Families were grateful for excellent care and proactive palliative management: “they are absolutely tuned in to looking after people on an end-of-life process ... and they do it superbly” (Helen, F7); “She only had to twitch her hand and they were on her with more drugs” (Sylvia, F5). One interviewee said she believed medication had not only sedated but had also hastened her son’s death—something she described as “merciful” and “an act of kindness”—in part because she had been worried about the effect on her other children of a prolonged dying and of them having to witness any signs of physiological agitation.

Only one person we spoke to, Cathy (F3), reported that the patient displayed any signs of physiological agitation. This was a home death, where there seems to have been very little palliative support (and this case occurred in the 1990s prior to the National Clinical Guidelines on end-of-life care for these patients).⁵ One factor contributing to her distress was her brother “making noises”—to which her mother (interviewed separately) also refers, saying that “in retrospect, if I had my time again, I’d still bring him home, but I would ask that he be more heavily sedated from the start.”

Most interviewees not only described the patient as “peaceful” following withdrawal of the feeding tube but also said they felt “at peace” during this time. One talked of the bedside vigil as a special family time—we “just sat with her. We were just letting her go” (David, F1) and the death itself was experienced as a “release”—not just from the dying process but from the months or years of the patient (and their family) being suspended (as we found families describing in our earlier analysis)²⁸ “in limbo”—“between life and death.” One interviewee commented “we were sad of course, but just relieved that he is finally at peace” (Hannah, F4). Indeed, a mother who brought her daughter home to die, said that the dying, death, and funeral were positive experiences after the preceding traumatic years during which her daughter had been actively treated:

I’ve got very fond memories of it strangely enough. I know that’s quite weird to say, but it wasn’t a horrible experience at all. It was a very calming, peaceful experience, the whole thing: from [my daughter] coming back home [to die] to her funeral. [...] [And] I have much more peace of

mind walking away from the grave knowing that she’s safe than I ever had walking away from the hospital knowing that she was vulnerable. (Diana, F12; <https://vimeo.com/241436698>)

The burden of witness. Despite these relatively positive descriptions of the patients’ deaths, many interviewees felt that the dying process had been hard to witness. All interviewees talked about the length of time it took their relative to die (most between 9 and 14 days after withdrawal), and some had been disturbed by changes in the patient’s physical appearance.

Although some interviewees reported very little change in how their relative looked (Olivia, for example, who had feared that her mother-in-law would “shrivel” reported that in practice “she looked just the same, nothing changed”), others described quite dramatic physical alterations—indexing images of starvation. One reported that although the patient was “well cared for” she became “drawn and sunken eyed” which was “harrowing” to see (Steve, F6). Another described a “well managed” death but was distressed by changes in her daughter’s appearance toward the end:

For the last three days she looked dead, gaunt, hollow cheeked ... her face was skeletal and [...] her eyes didn’t close completely. [...] It wasn’t her body anymore, never mind *her* not being there anymore.

This interviewee could not bear people to see her daughter like this and felt she should protect her daughter’s teenage children from remembering their mother this way:

That’s why I had a closed casket, I didn’t want anyone seeing her like that, [...] and I told the children not to come at the end. But she wasn’t in pain, it was peaceful. (Sylvia, F5)

After years of being hypervigilant and careful tending to their relative’s body, it could be dreadful to see it deteriorate—especially, since families often felt implicated in this. It was also distressing for some families that the method of allowing death destroyed any chance of organ donation:

First they ignored his wishes by keeping him alive all these years, now they ignore his wishes to donate his organs by the manner of his death—so no good, no good at all, can come out of all this and he can’t even leave that legacy. (John)

In addition, interviewees often found the slow death that follows withdrawal of a feeding tube painfully prolonged—and it could become harder and harder to witness as the days passed. A husband and wife recalling the death of their son commented that they would have preferred a swifter death by lethal injection.

- Peter: When they removed the tube—he were [...] 9 days [dying] [...] I would have preferred a needle.
- Annette: Quicker and not see him suffer. Well, I don't think *he* was suffering. I think it's *you* that feels for him, don't you, knowing that they are going to die anyway.
- Peter: [...] It was just deterioration, weren't it.
- Annette: I just wish it had been quicker. (F9; <http://cdoc.org.uk/wp-content/uploads/2017/11/Death-F9-Parents.m4a>)

It was particularly hard on relatives if the dying process took longer than expected—or pushed family members beyond their endurance. Cathy explains: “we’d been told it’d take seven to ten days ... I felt I could just about cope with the seven to ten days thing, but like not a second more.” In the event, it took her brother 13 days to die:

I still feel very guilty about the fact that I couldn't—I didn't, I didn't last out the withdrawal process. [Tearful] And I think halfway through day eleven or something, I just couldn't. I just, I just couldn't do anymore. [Crying] I had to go back to London. And I still feel really bad about that. (Cathy, F3; www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/cathy)

This interviewee stands out in being still deeply distressed by the death, 16 years later. Although she fully supported removal of the feeding tube, she expresses deep ambivalence: “I simultaneously had the absolute and complete conviction that it was the right thing to do, and just a horror of doing it.” She also says that while she thought her brother had gone, and wanted him to be free, she had given great care to his body and remained attached to it, even as “a thing” and she “didn't want to starve it to death” and she is still troubled by the manner of his death—although more by “the idea” of it rather than by what she saw:

... it was a fairly peaceful process. There was nothing inherently unpleasant about it, other than the *idea* of it ... It's just the idea that I found so difficult. My mother didn't find it awful. [...] She was really glad to nurse him; she felt like she was fulfilling a final duty to him. But I just found it agonising. (Cathy, F3; www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/cathy)

Cathy is not alone in finding “the idea of it” (withdrawal of tube feeding) inherently deeply disturbing. Even those interviewees who reported witnessing what appeared to be a calm and peaceful death often expressed their views (shared with many in the larger study who did not support withdrawal even as a last resort) that the legal distinction between “allowing” and “causing” death was hard to

maintain in relation to withdrawing artificial nutrition and hydration from these patients and that—if action *were* to be taken which inevitably led to death—then a lethal injection would be a kinder and more dignified option.

Discussion

This is the first empirical study of family accounts of deaths following withdrawal of artificial nutrition and hydration from patients in vegetative and minimally conscious states. Our analysis finds that these are surprisingly “good” deaths. In particular, they were described as peaceful and calm for the patient, and the death was believed to be “appropriate,” “in accord with [the patient's] wishes” and death led to “a sense of closure.”²⁹

All the same, these deaths can also carry a heavy “burden of witness” for families associated with the prolonged dying process and, for some, appearance of “starvation,” in a context where families have had to advocate for stopping treatment after many years of the patient being sustained in this way. They may feel responsible for (even if proud of) the decision but still burdened by it; and the manner of these deaths also remain very problematic to families on principle.

The medical literature sometimes suggests that if only families could be persuaded to accept the medical definition of tube feeding as an “artificial” or “clinical” technological intervention, they would be more willing to accede to its withdrawal,¹³ but it was not a revised understanding of the meaning of tube feeding that led these families to support withdrawal but rather the conviction that continuing to maintain their relative was morally untenable and that withdrawal was the only (lawful) way out.

Strengths and limitations

The small number of interviewees (and families) represented here may not be typical of all family experiences of withdrawal of tube feeding from patients in vegetative and minimally conscious patients. Even though we have interviewed a substantial proportion of the overall population of families in England and Wales who have been through this experience, it is possible that there has been a selection bias (e.g. those most traumatized by their relative's death may be least willing to be interviewed). We also need to acknowledge gaps in our research which does not include interviews with family members who witnessed such deaths while not believing that feeding-tube withdrawal was the right thing to do.

Our analytic perspective has involved treating our interview data as providing “transparent” (realist) accounts of interviewees' experiences in relation to the death of their relatives. An alternative reading might focus on the “motivated” nature of interview accounts. Our interviewees' reports of “calm” deaths are viewed through their clear commitment to the idea that death is a “release”

for their relative. Their descriptions may thus be selective, motivated in part by a need to justify the fact that they supported—indeed advocated for—withdrawal from their relative. All the same, it is also instructive to note that other interviewees whose relatives died after they assented to the withholding of *other* kinds of treatment (e.g. withholding treatment for gangrene) provided far more harrowing accounts.⁶

In a published account of Terri Schiavo's death, her brother—who opposed withdrawal—claims that “one of the most pathetic lies out there is that killing someone by denying them food and water is a ‘peaceful’ and ‘painless’ experience.” Writing for LifeNews (a “pro-life” news agency), he juxtaposes his own description of Terri Schiavo's “thirteen day agonizing death” with that of her husband, who supported withdrawal and whose attorney said, days before her death: “She looked beautiful ... I've never seen such a look of peace and beauty upon her.”³⁰ Neither description is ethically, emotionally, and ideologically neutral: both support the opposing positions the speakers have taken in relation to feeding-tube withdrawal.

Recommendations

Our research findings point to the need for professionals involved in the care of patients in prolonged disorders of consciousness, throughout their care trajectory, to be honest and open in discussion of these issues and for palliative care professionals involved in delivering end-of-life care to understand some of the challenges specific to this particular patient group and their families. Families are likely to imagine bad deaths after feeding-tube withdrawal—and may have been exposed to criticism and misinformation.

Clinical teams need to consider how best to counter misinformation and to provide compassionate and respectful support for families, including offering psychological help and effective case management³¹. They need to be in a position to share high-quality information about the withdrawal process and ensure the delivery of appropriate palliative care (detailed guidance for which is included in the National Guidelines).⁵

Preparation of family members for what the dying process may be like could emphasize a degree of unpredictability—including some uncertainty about how long it will take and any possible noises or movements from the patient and how to understand them. Information about how other families have arrived at a decision to support withdrawal and how they experienced their relative's death should also be provided (e.g. via the online healthtalk.org resource) and this could include the information that other families have felt “proud” to have stood up for their relative by advocating for withdrawal of treatment that their relative would not have wanted—that it is a “brave” and “courageous” action.

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