

The perspective of the nursing staff on terminal sedation in pediatric onco-hematology: A phenomenologic-hermeneutic study

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(RECEIVED May 2, 2012; ACCEPTED July 7, 2012)

ABSTRACT

Objective: The study was designed to explore the subjective perspective on end-of-life practices in three different groups of pediatric onco-hematologic nurses.

Method: In 2004–2005 each member of the nursing staff of the Pediatric Onco-Hematology Ward of the University of Padua, Italy, and the Oncology Ward and Home Assistance Module of the Giannetta Gaslini Hospital, Genoa, Italy was interviewed using a semistructured questionnaire with open questions on end-of-life procedures. The results were returned to the interviewees through group meetings. Here, we examine replies given regarding terminal sedation.

Results: With regard to the nurses from Padua, common features came together in a consolidated practice. The amount of suffering and physical pain was considered an element in determining the use of sedation: “when there is atrocious suffering.” Another aspect was “painful awareness,” the difficulty in being able to bear the fact that the child is aware that death is imminent. The nurses from Genoa stated that the procedure was adopted mainly for three reasons: to sedate the pain, to calm the hunger for air, and to control the anguish caused by the realization that death was imminent or unavoidable. It was noted that the nursing staff of the Home Assistance Unit, Genoa found themselves in a privileged position regarding this procedure both because of the strong relationship established among child, parents, and nurse, and because of being able to take shared decisions after in-depth discussion.

Significance of results: The results enlighten the critical role of the nursing staff with respect to this procedure, given the involvement with the families and their ability to understand the child’s demands and intimate expectations.

KEYWORDS: Phenomenologic-hermeneutic approach, Pediatric onco-hematology, terminal sedation, Hospital staff

INTRODUCTION

A recent review article on end-of-life care sedation for children reveals that the prevalence of terminal sedation may vary across countries according to cultural differences, legal context, and preferred place of death (Kiman et al., 2011). The development of guide-

lines on palliative care for children (Collins, 1996; Committee on Bioethics and Committee on Hospital Care of the American Academy of Pediatrics, 2000) and their adaptation to the adolescent population (Freyer, 2004) is still judged to be incomplete with respect to many issues raised by terminal sedation, in particular as the problem of assessing when and by whom a symptom is defined as “refractory” in a pediatric setting (Morita et al., 2002; Solomon et al., 2005; Geert Pousset et al., 2011; Kiman et al., 2011) and when the intervention is prompted by the urge to

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relieve non-physical symptoms such as anguish or existential suffering in the child (Berde & Wolfe, 2003; Postovsky & Ben Arush, 2004a, 2004b). In an attempt to determine to what extent healthcare providers are in agreement with one another and with published guidelines regarding a series of ethically relevant clinical issues in end-of-life situations in pediatrics, Solomon et al. (2004) collected self-report data from a sample of 781 clinicians (among whom were 53 nurses and 96 attending physicians from different onco-hematology wards) in seven pediatric hospitals in the United States. Although terminal sedation was not explicitly mentioned in the survey, in the subsample of participants from the onco-hematology wards, 21% of the physicians and 23% of the nurses declared concerns related to inadequate pain control in terminally ill children; 45% of the physicians attributed this state of affairs to the fear of hastening the child's death, and the proportion reached 68% when the nurse group was considered. In this article no hints are found that could explain this statistically significant difference in the causal attributions obtained from physicians and nurses. In an attempt to improve the quality of end-of-life assistance at Children's Hospital, a staff survey was designed in order to examine practices specific to escalating and intractable distress at end of life (Houlihan et al., 2006); in this survey 66% of the participants reported that physicians rely on the nurses to assist them with symptom management. Furthermore, 57% of the nurses referred to feeling that patients experienced delays in symptom control because physicians were not readily available; a percentage as high as 64% of the nurses declared that they wished that they could write the orders themselves rather than waiting for the physicians. Less than 20% of both nurses and physicians in this sample declared to be worried that opioids might hasten the child's death. Role clarification was set, therefore, as one of the main goals for the guidelines (the so called "End-of-Life Rapid Response Model of Care") that were developed based on the evidence emerging from the data.

On the initiative of the Child Neuropsychiatry Department of the University of Florence, a seminar of interdisciplinary research entitled "Il pupazzo di garza" (the gauze puppet) was held in Florence from November 2002 until June 2003, dedicated to exploring experiences connected with potentially fatal diseases in children and adolescents (Papini & Tringali, 2004). Approximately 120 physicians, nurses, and bioethicists from all the centers that were members of the Italian Association for Pediatric Onco-Hematology participated in the initiative. A study on end-of-life procedures from the perspective of the medical and nursing staff was conducted

during this forum, with the aim of investigating the amount of thought given to certain ethical problems and concepts such as defining the terminal phase of life, the importance of the quality of life, and other related issues. The medical and nursing staff of the children's Onco-Hematology Wards of the Regina Margherita Hospital, Turin, Italy, and the San Gerardo Hospital, Monza, Italy, were asked to reply to a semistructured interview. Their replies showed the need for an emotive approach to a dying child (Kreitler & Krivoy, 2004) as well as strong concern for the relational aspect of the quality of life. The discussions on euthanasia, terminal sedation, and distinguishing between appropriate medical treatments and those considered "overdone" indicated that the level of awareness of ethical problems and the use of correct terminology was not adequately developed (Morita et al. [2002] reported similar observations in a review article in which pediatric settings were not included) and therefore required further study (Galletti, 2004; Dixon-Woods et al., 2005). At the end of the seminar, an inventory was drawn up of the problems that were most keenly felt and difficult to deal with. Among these, terminal sedation was considered to be particularly complex, and was chosen as the focus of the present study. The complexity lay in the fact that opinions differed and there was no shared definition regarding this procedure either when comparing the positions of the various centers of pediatric onco-hematology, or when referring to the different positions expressed by the staff working in these centers. Although similar divergences have been reported within palliative care teams working with adult patients (White et al., 2004; Bruce & Boston, 2011; Swetenham et al., 2011), the specificity of the pediatric setting, with its very peculiar relational implications among patients, parents, and staff members, and the nature of the therapeutic bond that is established with children on the one hand, and adolescents on the other, deserves, in our opinion, a dedicated investigation.

METHOD

Between October 2004 and December 2005, the medical and nursing staff of the children's Onco-Hematology Ward at the Polyclinic of the University of Padua, and the Cancer Ward and the Home Assistance Unit of the Gaslini Hospital, Genoa individually replied to a semistructured questionnaire with open answers (Montesperelli, 1998; Bichi, 2002). The interview contained six questions on the procedures, practices, and subjective experiences of assisting patients, children and adolescents, in end-of-life situations. Beginning from the methodological approach of the hermeneutic interview (Gadamer, 1960;

Vattimo, 1987), the research project developed in such a way that the staff taking part were immediately actively involved so that it became a study *with* the staff rather than *on* the staff (Spradley, 1980). Seventy-two people were interviewed in total: 47 members of hospital staff from the Ward in Padua of whom 27 nurses and 18 physicians, and 20 members of hospital staff from Genoa of whom 14 were nurses and 2 physicians.

The interviews took place in a reserved and suitable setting with no limits being imposed on the length of the interview, and where the interviewees could be sure of being listened to for as long as they wished to speak. Relating to a kind and friendly person, interested and trained to listen, formed a context that facilitated personal narration, and aided expression and working through the interviewees' emotive and cognitive experiences (Lewin, 2005; Bichi, 2007; Papini et al., 2011).

The interview was based on the following questions:

1. Do you consider it useful to reflect on the problems regarding the end of life in childhood and adolescence?
2. How are the final 24 hours of life of the child dealt with? Whose are the decision-making and operating roles? Are any special measures taken regarding the other patients in the hospital? What are the greatest difficulties that you have come up against? Are there any suggestions that you wish to make?
3. In your opinion, can inducing the suspension of the state of consciousness be counted among end-of-life procedures? If so, how and when?
4. What were your feelings when you realized that a child had died? How do you usually deal with this trauma? Is there a specific experience that you would like to talk about?
5. How are the 24 hours following the death of a child dealt with?
6. Do you have any further observations to make? Anything further to add?

The interviews, with the interviewees' consent, were recorded on tape and their entire contents were then transcribed in preparation for the second phase in which the data were collectively processed (Altheide & Johnson, 1994). The contents were analyzed and then sorted into phenomenological categories (Husserl, 1931) each with a different "theme" characterized by the replies to the open answers (Altheide & Johnson, 1994; Bichi, 2007). A space was set aside for

accounts of specific experiences and observations. Following the hermeneutic approach (Elliot et al., 1999), the material was gathered and organized according to the above mentioned methods and then re-presented to the interviewees collectively in order to validate the interpretation of the researchers and in order to refine the development of the implications contained in the texts. These feedback meetings were also crucial in creating a common space that could act as a structured container of the emotional events (Bion, 1962; Carli & Paniccia, 2003; Correale, 2006) regarding both the shared and individual problems that had emerged during the interviews.

Our research revealed the particularly difficult and trying nature of the work of the nursing staff regarding terminal sedation (Papini, 2009; for a similar focus of research involving nurses in adult palliative care settings see Morita et al., 2004; Beel et al., 2006; Bruce & Boston, 2011). Consequently, the present study aimed to specifically examine the nurses' responses, with particular reference to the third question on the questionnaire, namely, "In your opinion, can inducing the suspension of the state of consciousness be counted among end-of-life procedures? If so, how and when?" In posing this question to the staff, researchers deliberately decided to employ an "open" definition ("the suspension of the state of consciousness" instead of "terminal sedation" or "palliative sedation") in order to avoid implicit biases that could influence the way in which the participants would delimit and describe the procedure.

RESULTS

When analyzing the contents, some particular themes emerged from the mass of replies. We will present the results relating to emergent themes separately: first, those of the group of nurses from Padua, followed by the group of nurses from Genoa, and last but not least, the results of the interviews with the nurses of the Home Assistance Unit for Child Cancer Care, Genoa.

The Nurses from the Onco-Hematology Ward, Padua

When to Sedate: "When There is Atrocious Suffering"

We noted some common aspects in the descriptions given by the nurses from Padua of their wide and complex experience, which converged in the use of a consolidated practice. The aspect of suffering and physical pain was considered by the nurses the determining factor when deciding to sedate. As one of

them declared, “when the suffering is atrocious” (Nurse 1).

The interviews also demonstrated that when faced with the realization of being unable to contain the suffering, the preparation for mourning began. The suffering reached its peak in the manifestation of hunger for air, which was a terrifying experience because of the degree of anguish suffered by the child and those trying to assist. A nurse described it thus: “the use of the suspension of the state of consciousness is necessary because we see the pain, and the dyspnea, the hunger for air, are terrible” (Nurse 13).

When to Sedate: Avoiding the Awareness of the Imminent Death in Children and Adolescents

The interviews also underlined the distressing realization by nurses and parents of the difficulty of being able to tolerate a child being aware that death is imminent. One nurse said “inducing the suspension/suspending the state of consciousness could be considered a possibility when the patient is aware (that he is about to die), when he’s old enough to understand and this realization causes him problems. . . It helps to limit his anxiety, his fear of death” (Nurse 7). Nevertheless, the need to know is sometimes clearly shown by adolescents. As one nurse reports: “with teenagers who want to keep a grip on their lives and decide for themselves to the very end, it’s much more traumatic, sometimes we’ve had to sedate kids who didn’t want us to, they wanted to know the truth right up to the last moment, and when they were getting worked up because of this need our answer was to sedate them” (Nurse 9). Another nurse added “. . . in situations where we have a teenager who is fighting with all his force to be conscious until the very end, well, in that case, I really don’t understand its use and I think we should talk about it a little differently from the way we do at the moment because at the moment it’s taken for granted that he must be terrorized at the prospect of death and so we immediately have to make him unconscious but instead we should . . . talk to him, have the possibility to listen to him, to accompany him and accompanying him means really being there for him, staying near to him without necessarily having to make him unconscious” (Nurse 24). Another nurse’s experience supported what has just been related: “he made me close the door with me inside and then he asked me, looking into my eyes, ‘am I dying?’ And I wanted the earth to swallow me up, you can’t tell lies to someone who asks you that kind of question and who puts his trust in you, but neither can you let down a parent who has told you that ‘he mustn’t find out’” (Nurse 16).

Matter of Conflicts: Contradictory Wishes in the Parental Couple

Sometimes sedation is a source of conflict for the parents themselves. One of the greatest difficulties that the nurses have to deal with is that of the contradictory orders of the parents: “The mother or father asks for it because they don’t want to suffer. But I’ve seen some parents who wanted it, who agreed to it, because they didn’t want the child to be aware, they wanted him to take some drugs that would mean he was out of it. But then they wanted him back so that they could still talk to him or still communicate with him at the moment of death” (Nurse 15). It is a dramatic situation for the families. On one hand they want to avoid their children’s suffering but on the other they cannot stand to be separated from them. The suspension of the state of consciousness eliminates the pain but at the same time it eliminates any possibility of interaction between parent and child. It acts as a preliminary of mourning.

Voicing Doubts

As one nurse explained, “it’s important for a child not to wake up in pain even though it’s sometimes difficult for parents to accept because they would like to always see their child awake – it’s really difficult for the parents, it’s something that can be compared to death” (Nurse 18). In this context another nurse voiced her doubts concerning sedation, which she felt deprived the child of the possibility both of living, of consciously processing the moment of passage, of death, and of a last exchange with his parents. “My doubts are based on the fact of the meaning of death, of this passage. And besides, it takes away the possibility of any relationship between parents and child, however painful that may be. . . I have no solution, not even a suggestion to give, it’s just one big question mark” (Nurse 3).

Other accounts show how, at the end, the medical and nursing staff chose to follow the parents’ wishes. “. . . It’s a matter of respecting the parents’ choice, because there are parents who may not want to see their child suffer, while others may choose not to sedate him so that they can talk to him and he’s still active. So it depends on what the parents want, on the path that they’ve decided, even if their decisions can change, vary from hour to hour. At the last moment they can even change a decision that they took three weeks before” (Nurse 21).

Respecting the Child’s Wish

However, it has to be remembered that the most important actor in this drama is the child. Sometimes it may be the patients who, worn down by the pain,

will turn to those who are taking care of them and beg them to put an end to the suffering. On this subject one of the nurses said, “in my opinion, sedation is definitely to be considered one of the end-of-life procedures when you can see the child’s suffering. . . and he asks you: ‘help me, I can’t stand it any more!’ because I’ve seen so many. . .” (Nurse 20). The choice of the right moment to sedate the patient is a very difficult and delicate one. “Personally, I’m against sedating a child who is still vital, who may be in pain but is still able to interact, to communicate,” one nurse said emphatically (Nurse 17).

Concerns About Hastening the Child’s Death

Moreover, sedation may shorten the patient’s life but this, in the opinion of some, is of no great importance when contrasted with the amount of pain suffered. As one nurse pointed out, “I don’t feel it really changes anything if you live five minutes more or less, nothing changes” (Nurse 5). Conversely, other nurses found the choice of sedation an extremely difficult one to make, as once made, there is no turning back, and therefore it is difficult to distinguish between it and the practice of euthanasia. The following statement exemplifies this point of view: “it’s not simple to decide to use a treatment on him (the child) which in any case becomes euthanasia; these aren’t easy drugs to use, as well as having specific pharmacological knowledge you need to have the conscience to say I’m going to put you on this drug” (Nurse 9).

The Nurses from the Onco-Hematology Ward, Genoa

The replies given by the nursing staff from Genoa were characterized by a marked tendency to offer short and concise answers, which lacked any explicit emotive processing of the topic under discussion. All the nurses declared themselves in favor of the procedure, which was adopted principally for three reasons: to sedate the pain, to calm the hunger for air, and to control the anguish caused by the knowledge that death was imminent and unavoidable.

When to Sedate: When Pain Overcomes Everything Else

When discussing the theme of pain control, one nurse declared, “I think the moment is right when it’s no longer possible for me to keep the pain under control in a dignified way” (Nurse 1). The use of the adjective “dignified” in this statement explicitly underlined a distancing from the problem, while implicitly showing that the failure of the treatment was to be considered in some way “undignified”. Sometimes the

intensity of the pain was measured by the total lack of interaction, “when the moments of consciousness are only moments of pain, and there is no longer any type of communication” (Nurse 1).

As terminal sedation gives respite from a situation of unbearable suffering for the child, but also for those looking after the child, it can even be considered as a liberation. “We look forward to it as something which puts an end to our joint suffering,” said one nurse (Nurse 5). In truth, the suffering of the parents and probably also that of the nurses does not come to an end when the child is sedated, but it certainly takes on a different quality. It would be useful to understand who exactly the generic term “joint” refers to in the above statement. In the interviews with the group of nurses from Genoa, the theme of the distressing realization was once again present. The realization that the end was near was feared especially in the case of adolescent patients because, as one nurse pointed out, “a one-year-old kid doesn’t understand but an eighteen-year-old kid does” (Nurse 4). This statement exemplified the paradox of the case of the 18-year-old “*kid*” who had come of age and was in possession of full civil rights. The adolescent was presented here as a subject aware of his situation in exactly the same way as an adult; however, it was still difficult to imagine leaving him under the whole weight and responsibility of this awareness.

If a Child Starts to “Ask Questions. . .”

Likewise, another nurse discussing “when” to sedate declared “from the moment when there is great suffering and from when the child, the boy, realizes that he’s reached the end, that there’s nothing more to be done, and that what’s being done is because there’s nothing more to be done in any case, well then, it would be better for him to be unconscious” (Nurse 14). According to another nurse, one of the reasons that make parents request sedation is when the patient begins to ask certain “questions,” “even though it’s not easy for a parent to sedate and let his child lose consciousness, however, it’s sometimes they themselves, who ask for it, at the moment when the child begins to ask questions. . .” (Nurse 18). At the moment when the children begin to *ask questions*, they are asking for a space, a mental space, where they can manifest and emotionally contain the fear and anguish that the thought of death brings them. Not all carers, whether they be the parents or professionals, are able to provide this mental space.

The Decision is Made by Physicians

Hardly any comments were made by the Genoa staff on the theme of moral responsibility connected with

making the decision of whether to sedate, taken by the physicians, and the practice of sedation itself, undertaken normally by the nurses. Only one nurse stated, "I can act as a go-between and describe what the child is feeling but then the decision isn't up to me" (Nurse 5). None of the staff made any mention of perceiving (or not perceiving) any kind of degree of contiguity between the practice of suspending the state of consciousness and euthanasia.

The Nurses from the Home Assistance Unit, Genoa

When to Sedate: Sedation as the Last Step

The replies of the members of the Home Assistance Unit were distinguished by being more articulate and expressing a wider view of the problems regarding sedation and the steps leading up to it. Among the reasons for its use, the hunger for air was considered to be the most important. "It's not so much the pain as the difficulty in breathing rather than the other situations that (the patient) can feel" said one nurse (Nurse 8). Moreover, the procedure of sedation was considered the last step on the scale of pain therapy, and not necessarily one that had to be taken. The theme of the distressing realization was however, still present "...it's the first thing that you notice, that he's scared and terrorized because he's becoming aware of what's happening to him!" (Nurse 9).

The Relevance of Cooperative Decision Making

When compared with the experiences related by the other interviewees, this group seemed to put the needs of the child in first place more than the others had. This could be seen by the way in practice, a decision was never made once and for all by the team, but was rather one of the possibilities to be considered as they went along. The choice of the therapy to follow came out of a collective process of decision making, evidenced here by the use of the second person plural. "We hospital staff have decided, have proposed that before sedating a kid we should evaluate the situation, talk to each other, try to see, get more opinions on whether it's right to sedate or not" (Nurse 8). Regarding this point, the following contribution, relating to a specific experience, is related in full.

It once happened to me that a mother asked me to sedate her kid, she said, "that's enough, I want him sedated!" But what was the reason for sedating him? Why? He wasn't in pain, he was a kid who was dying peacefully, serenely, in other words he wasn't showing any agitation, he wasn't showing signs of feeling uncomfortable. Why she wanted to sedate him was because of all the relatives,

all of the family group, who were going round and round and would finally calm down because then he'd been sedated. But we said it wasn't necessary to sedate the kid, it was the situation round him that needed to be changed, we didn't sedate him as they'd asked because there was no need for it (Nurse 8).

Therefore, the request for sedation was listened to and considered but not necessarily approved.

DISCUSSION

Taking as our frame of reference the replies of the nurses from Padua, we established the following three points:

1. Who contributed to making the decision whether to suspend the state of consciousness
2. The situations in which implementation of this procedure was indicated
3. The impact on the nurses of the actual terminal sedation.

Regarding the first point, we observed the great sense of responsibility felt by the nursing staff of all three structures for a procedure that essentially was decided upon by the physician. The nursing staff underlined in their interviews their responsibility in the decision made, although the actual decision-making powers belonged only to the members of the medical profession (for a different perspective see Houlahan et al., 2006). The report by the nurse, as stated also by Houlahan et al. (2006), who is the person caring daily for the child, may implicitly aid the physician regarding the possibility of adopting terminal sedation.

In the present study, however, the nurses did not say that they suffered from excessive emotional burden because of their participation in palliative sedation therapy as compared, for example, with what was referred to in the vast survey by Morita et al. (2004), in which 30% of the 2607 nurses from a palliative care setting for adult patients, who took part in the study, declared that they were thinking of leaving their current work situation because of sedation-related emotional burden, although only 15% of them overtly admitted to experiencing emotional distress. Another constant feature was the weight given to the parents' opinion regarding implementation or delaying of the procedure, which underlined their conflict between the desire not to break off all relations with their child and the desire that the child should not suffer excessively. As a result, the parents' opinion could oscillate or the two parents might not share the same opinion.

The second point showed the nurses to be in agreement that excessive pain and the hunger for air were indisputable indications of the need to sedate, in line with current guidelines on palliative care for children (Committee on Bioethics and Committee on Hospital Care of the American Academy of Pediatrics, 2000) and adolescents (Freyer, 2004). However, they were much less in agreement in doing so to avoid the realization that death was imminent (See Bruce & Boston, 2011, for a discussion about relieving the existential suffering of adult patients through palliative sedation; difference in attitude of physicians and nurses toward the practice of sedation in order to relieve severe fatigue and anxiety in adult terminal patients is also reported by Swart et al., 2010). Whereas the nurses from the children's cancer ward in Genoa considered the procedure indicated when death was unavoidable, the nurses from the Home Assistance Unit, Genoa did not.

The third point concerned the strong and distressing emotions transmitted through these interviews, mainly by the nurses from Padua. However, all the nursing staff talked about the very delicate situation that occurred when the relationship established between nurse and patient, a minor, could involve the latter in a decision that took no heed of the physician or even the parents' opinion. This was especially the case with adolescents. Many nurses believed that adolescents should be given the last word when deciding whether to sedate or not. In fact this view is gaining larger consensus in the scientific community (Freyer, 2004), although some authors (such as Postovsky & Ben Arush, 2004a,b) fail even to mention this issue in their suggestions for caring for children dying of cancer.

The staff of the Home Assistance Unit, Genoa should be considered to hold a privileged position, both because of the deep relationship established among patient, parents, and staff in the home context, and also because they were able to take part in joint decisions made after intense discussion. Both factors were found to protect nurses against emotional distress in the study by Morita et al. (2004). It was therefore possible for them to avoid sedating a child who was dying peacefully, without pain or hunger for air. Instead, they were able to mediate with the people who had made the request for their own personal reasons: because they could not bear to see a conscious child die.

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