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Going against patients' will? A qualitative study of how palliative health-care professionals handle competing considerations when children are excluded from parental illness and death

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ABSTRACT

Purpose: The Norwegian Health Personnel Act (HPA §10a) obliges health professionals to contribute to meeting minor children's need for information about their parents' illness and prognosis. Previous research has shown that many parents withhold information about illness and anticipated death from their children. This study explored main considerations for palliative health-care professionals in these situations, and how they negotiate conflicting considerations of confidentiality and child involvement.

Method: This qualitative exploratory study involved semi-structured interviews with 11 palliative health-care professionals. Hermeneutics informed the data analysis.

Results: The health professionals' main considerations were sustaining patients' hope and building trust in the professional–patient relationship. Both concerns were grounded in respect for patient autonomy. The health professionals negotiated patient autonomy and child involvement in different ways, defined in the present analysis on a continuum ranging from granting full patient autonomy to going directly against patients' will.

Conclusions: The professional–patient relationship is the primary consideration in the health care context, and decision making on the degree of children's involvement happens in a dialogical process between health professionals and patients. Close professional–patient relationships might increase the emotional impacts on health professionals, who consequently might give greater relative weight to patients' will. We propose that procedures for initiating collaboration with professionals in the child's everyday life context help health professionals involving the child without threatening trust.

1. Introduction

Communication about end-of-life issues presents complex challenges to health professionals (Parry et al., 2014). That complexity increases when patients are also parents of minor children. The Norwegian Health Personnel Act (HPA §10a) obliges health professionals to involve the children of their patients so they receive information about their parents' illness and prognosis.¹ However, the structural and organisational working conditions of palliative health-care professionals hinder rather than facilitate child involvement. Several studies in Scandinavian countries have shown that the dominant medical logic, time pressures and limited economic resources result in health professionals

prioritising patients and medical issues over the patients' relatives and psychosocial issues (Dencker et al., 2017; Karidar et al., 2016). Nurses have reported that they are unqualified or insufficiently trained to support children (Golsäter et al., 2016). In a literature review, Franklin et al. (2018) confirmed the findings of several Scandinavian studies reporting that encountering children in close proximity to death in the workplace has emotional and existential effects on health professionals, creating a need for self-distancing and -protection.

Previous studies in European contexts, including Norway, have found that many parents want support and advice from health professionals on how and when to inform their children about their own condition (Fearnley and Boland, 2017; Semple and McCance, 2010).

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¹ The law states that health personnel shall contribute to meeting minor children's needs for information about their parents' illness and prognosis. Other Scandinavian countries mandate similar obligations (Danish Health Authority, 2012; Swedish Law of Health and Medicine, 2017).

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Many parents withhold information and keep their children away from the health care system (Asbury et al., 2014; Hailey et al., 2018). In a study of nurses' interactions with the children of patients in the field of palliative oncology, Karidar et al. (2016) found that "[s]ome parents excluded their children from being involved in matters related to the illness and forthcoming death and the physical meeting with healthcare professionals, some parents included their children from the beginning to the end of the illness, and some parents included their children after the healthcare professionals had persuaded them to do so" (p. 24). The nurses found it problematic when the parents did not involve their children in what the nurses considered the right way, and Karidar et al. (2016) claimed that "the parental strategy of inclusion or exclusion of their children is the biggest challenge for nurses' compliance with the [Swedish] law and for nurses to do what they consider to be a good job" (p. 27). These findings indicate that there are frequent conflicts between meeting children's need for information and maintaining confidentiality on behalf of the patient (Clark, 2006). In this paper, we call such morally challenging situations *moral problems*, a term that Clark (2012) prefers to *dilemmas* because the former implies that evidence and reasoned solutions can and should be sought and that there may often be more than just two alternatives.

Empirical evidence on health professionals' handling of moral problems to do with confidentiality is generally scarce and fragmentary (Clark, 2006). As a cornerstone of professional ethics and the professional-client relationship, confidentiality restricts how health personnel may share information about patients' health and other personal matters. According to traditional theory, one purpose of professional confidentiality is to secure patients' right to privacy and the general population's trust in health care providers to prevent treatment withdrawal due to fears about unauthorised sharing of personal information (Bok, 1988; Kipnis, 2006). As Clark wrote, "the basic idea of privacy follows quite naturally from the core principle of autonomy in liberal rights theory" (Clark, 2006, p. 130). Beauchamp (2010) defined the principle of autonomy as respect for "an autonomous agent's right to control his or her affairs in accordance with personal values and beliefs" (p. 62). This normative principle is based on common moral experience and socioculturally influenced. In Western societies, which stress individualism, patient autonomy in information-sharing decisions is important and seemingly self-evident (Rising, 2017).

In some cases, it may be legitimate to share information against patients' will (Bok, 1988). For instance, HPA §23-4 makes it clear that health professionals should take action if severely ill parents are inattentive to their children's needs. If children suffer serious neglect, health professionals have a duty to report it to Child Protective Services (CPS). Deciding when it is legitimate to share information against patients' will and when it is not, is a complex, challenging task where first principles, such as the principle of confidentiality, fall short in guiding health professionals (Clark, 2006, 2012). The decision-making process is a discretionary process in which health professionals need to handle the tensions between the abstract general rules of confidentiality and the conditions and circumstances of specific situations, requiring substantial interpretive work on several levels (Clark, 2012; Loyens and Maeschalck, 2010).

Clark (2012) outlined three interrelated principles from Gadamer's hermeneutics. First, all understanding is historically conditioned and inherently biographical. Second, the act of interpreting a text, a human act or another social phenomenon follows a circular, iterative movement (Clark, 2012). Interpretation and understanding are conditioned by preconceptions; what we already know contributes to establishing a frame of meaning that makes interpretation possible (Clark, 2012). The interpreter moves between, on one hand, projecting the meaning of the whole as a frame of reference to establish the meaning of the particularities and, on the other hand, using the achieved understanding of the particularities to revise the meaning of the whole. Third, professionals' search for understanding is a *dialogic* process that has two implications worth mentioning here.

First, language carries historical, social and cultural meanings, so palliative health-care professionals' way of talking functions to ascribe rights and duties to actors in episodes, which we call discursively assigned moral positions (Harré et al., 2009). Second, in dialogue, the professional tries to understand the other's *horizon*, defined by Gadamer as "the range of vision that includes everything that can be seen from a particular vantage point" (as cited in Clark, 2012, p. 125). Trying to understand another's horizon entails attempting to grasp the "conceptual apparatus that makes the individual's world intelligible to him or her self" (Clark, 2012, p. 130). This frame of meaning is then negotiated in a process of comparing, revising, discarding and replacing other frames of meaning and, ideally, moving towards a fusion of horizons and mutual understanding (Clark, 2012).

The present study investigates how palliative health-care professionals handle the moral problem of meeting children's need for information while maintaining patient confidentiality. The study aims to provide thinking tools for health professionals and to produce knowledge about the context-specific conditions that could inform policy-making procedures. We pose the following research questions:

1. What are the main considerations for health professionals in situations when parents withhold information about illness and anticipated death from their children?
2. How do health professionals negotiate conflicting considerations in these situations?

2. Method

2.1. Design

The study was a qualitative, exploratory interview study with purposeful sampling (Patton, 2015).

2.2. Participants

We recruited health professionals who had worked in palliative care for at least two years. We included doctors and nurses of both genders from four public hospitals of different sizes and two municipal health services, all geographically dispersed throughout Norway. The first author, who conducted the interviews, visited hospitals and presented the project, inviting professionals to make contact if interested in participating. This process obtained six participants, five of them were female. We recruited the other four participants through mediators, aiming to achieve a more balanced combination of genders and professions. In addition, we included one of two pilot interviews in the final data to ensure a gender balance that represented the gender distribution within palliative care. The Data Protection Official for Research in Norway was notified of and approved the research project. All participants volunteered and provided written informed consent.

A total of 11 professionals participated in our study. At the time of the interviews, the participants had 2–17 years of experience in palliative care, and their ages ranged from mid-30s–60s. The participants comprised three doctors and eight nurses (eight women and three men). Two participants came from municipal health services and nine from specialist health services. The nine professionals from specialist health services worked in palliative wards ($n = 2$), or multidisciplinary palliative teams ($n = 7$). One of these seven worked ambulant, one in a multidisciplinary hospital team and five worked in palliative teams that operated both in hospital and ambulant.

2.3. Interviews

The first author conducted the interviews. All but one took place in the health-professionals' workplaces during working hours, while the remaining interview took place in the participant's home at the participant's request. The interviews were conducted as open-ended dialogues

that allowed the participants to talk freely about their experiences. An interview guide (Appendix 1) helped the interviewer focus the interviews towards producing data that consisted of 1) stories about the children whom the professionals encountered during their years of practice in palliative care and 2) the professionals' views on the needs and understandings of death and illness among the young children of palliative patients, as well as on the ideal ways to support such children. As a warm-up at the beginning of the interview, the interviewer asked about the participants' biographical information and, at the end, about their roles and competences. The individual interviews lasted 62–128 min and were audio-recorded. The first author transcribed the interviews verbatim, resulting in 315 pages of text. We de-identified the participants upon transcription, changing or deleting all personal names and place names.

2.4. Data analysis

Data analysis consisted of three theoretically informed phases: first, reading transcripts and separating a subset of the data, second, working with analytical questions and third, returning to the complete data set to analyse discursive positioning. *Theoretically informed* refers to how theoretical inspirations and concepts opened for interpretations of data. Preliminary findings in early stages functioned as analytical cues and generated analytical questions for further analysis, inspired by Haavind's (2019) interpretive analysis.

First, both authors read the transcripts and together discussed the preliminary themes and tendencies. Data contained stories about successful and unsuccessful support and stories about health professionals not having access to the children, as well as the participants' thoughts, views and meanings. As we wanted to explore the considerations that health professionals need to handle when patients exclude their children, we needed to focus the analysis on stories of exclusion as a subset of the data. Therefore, we identified the stories in the data in which the health professionals experienced a moral problem related to child involvement. This was done manually using Microsoft Word (Microsoft Office, 2013) and was guided by the following three inclusion criteria:

1. Children were not told that their parent was going to die until the last days or hours of the parent's life.
2. One or both parents wanted to keep the impending death confidential.
3. Children either knew about the disease but not the impending death or did not know about the disease at all.

Seventeen stories met the inclusion criteria (see Table 1) and formed the subset of the data used in the second phase of the analysis.

In the second phase of the analysis, we posed the following analytical questions:

1. How did the health professionals talk about what they did when the parents did not want to inform their children about their own impending death?
2. What did the health professionals say they would do in future or hypothetical cases?
3. How did the health professionals justify their actions?
4. What did the health professionals say about their discretionary thresholds and turning points?

The first author systematically examined the stories to find answers to the questions listed above. Not all the stories were detailed enough to generate answers to all the analysis questions, but such stories still functioned to systematise the reading of the text, allowing us to constantly revise and discard our preliminary understandings instead of reproducing them (Clark, 2012). In addition, we reflected on which values and considerations (Clark, 2006) seemed to be in play within each story and across the stories in order to find patterns and

Table 1

	Children in the story	Who is ill?	Summary of story ^a
1	Boy, eight years old	Mother	Told by medical doctor: Single mother who have not accepted her prognosis. Fast progression of the disease after an operation and hence no time to prepare the boy for the imminent death.
2	Two children, approx. one and four years old	Mother	Told by nurse: The children were physically present in the hospital frequently and in longer periods, however the parents did not tell the children that mother was going to die before the day it happened.
3	Three children, the youngest twelve years old	Mother	Told by nurse: Health professionals did not encounter the children. The patient solemnly declared having a good dialogue with her children, whereas the health professionals experience that the mother do not accept her own prognosis.
4	Two girls, fourteen and sixteen years old	Mother	Told by nurse: The parents had known it in a year or more that the mother's disease was incurable, but did not tell before the disease progressed fast.
5	Four children, the youngest six years old	Mother	Told by nurse: Single mother haven't told her children about her cancer before she came to a point of no return at home. Came to the ward by ambulance. Did not want the children to see her. Died within a day and a night.
6	Four children, the youngest six years old	Mother	Told by nurse: Single mother that had told her children that she was going to make it, and live until the children had grown up. She was marginal when she came to the ward, died within 24 h.
7	Two girls, three and six years old.	Father	Told by nurse: The parents instructed the health professionals that the children should not be informed about the father's imminent death, until just a couple of days before he died.
8	Boy and girl, nine and eleven years old.	Mother	Told by nurse: Father did not want the children to know that mother was going to die.
9	Three children, six, nine and thirteen years old	Father	Told by nurse: Parents recently separated. Parents disagreed on whether to talk to the children about death or not, where the father was most restrictive.
10	Two children, eleven and fifteen years old	Father	Told by nurse: Father ill, did not tell his family about his disease (not even his wife).
11	Girl, ten years old	Father	Told by medical doctor: Daughter not present in hospital – the father did not accept the disease as palliative.
12	Boy and girl, eight and thirteen years old	Mother	Told by nurse: Disease far progressed when detected. Parents disagreed on whether to talk about death or not. The boy was kept away from the dying mother, and was not told the mother was dying.
13	Two children, three and six years old	Mother	Told by nurse: Mother was very closed off – did not even want to talk about talking with the children about the disease.
14	Three children (age span 2–7)	Mother	Told by med. doctor: Of African origin*. Mother did not want to talk about her disease. The children stayed at the hospital in long periods when no one else could look after them.
15	Five minor children	Mother	Told by medical doctor: The parents kept all the children physically away from the ill and dying mother and sent away to relatives. Member of a religious sect*.
16	Three children (age span 7-adolescent)	Mother	Told by nurse: Parents did not reject openly to telling the children about

(continued on next page)

Table 1 (continued)

Children in the story	Who is ill?	Summary of story ^a
17	One adolescent	Mother death, but postponed it again and again. Told by nurse: Mother from Russia*, did not want to talk about the seriousness in the diagnosis – rejected using the word cancer.

^a The professionals made explicit that the patient had immigrant- or religious minority background, the other stories do not provide such information.

similarities.

In the third phase of the analysis, we returned to the complete data and read all transcripts again to see how the professionals discursively positioned themselves in the episodes (Harré et al., 2009). We categorised positions by how much weight the participants put on patient autonomy, and we created what Patton (2015) called an analyst-constructed typology: we placed the positions on a progressive continuum ranging from full respect for patient autonomy to violations of patient autonomy. We discussed the typology with health professionals in the field of palliative care to assess its credibility (Patton, 2015).

3. Results

All participants told at least one story about parents who withheld information from their children or excluded them in other ways. See Table 1 for an overview of the stories.

3.1. Main considerations

3.1.1. Sustaining patient hope

An important consideration in the stories was patients' hope. The health professionals described hope as a valuable, healthy and life-enhancing quality and stated that challenging patients' hope could be harmful. Cecilie (Story 3, Table 1) described her dialogue with a severely ill mother as follows: "I cannot tell her [the mother] that she is not going to live until her son celebrates confirmation, as she hopes. She will break down completely." The data indicated that working to sustain patients' hope was integral to professional conduct. However, this consideration seemed to compete with children's involvement. For instance, in four stories, a patient or the healthy parent withheld information from their children due to a deep hope that a cure would emerge or that the patient would still live for a long time.

The health professionals highlighted an unclear border between hope and denial. Andreas (Story 1), a medical doctor, spoke about a mother transferred from another hospital:

She had a deep hope that everything was going to turn out well and that she would return to a better state again, but in reality, the prognosis was bad, and her expected lifetime was very short. The health professionals in [the previous] hospital said that she had not taken it in and did not accept it. She was divorced and had a child who lived with her father when she was hospitalised. It was dramatic as we could see how fast it went; it was within the night shift [...]. Nevertheless, it was clear to us that we had to do something with that boy as no one had informed him that his mother was going to die within a very short time.

Andreas used the term "hope" when taking the patient's perspective as his frame of reference. When taking the health professional's perspective as the frame of reference, he and other health professionals described such patient behaviour as not "taking in" or accepting the prognosis. Still, both doctors and nurses expressed uncertainty about how precise the doctors' estimates of remaining life were, emphasising that they repeatedly turned out to be wrong. In many cases, this

uncertainty seemed to prevent the health professionals from challenging a patient's potential denial or non-acceptance of anticipated death. The health professionals' active sustaining of patients' hope and the more passive refusal to take the patient's hope away led them to withhold information from children in some cases.

3.1.2. Building trust

The health professionals emphasised the importance of trust in multiple relationships. Story 4 from nurse Dina demonstrated that the professionals considered trust to be important in various relationships in addition to the traditional patient–professional relationship. In this story, the mother's disease suddenly progressed quickly, and the parents were in a hurry to tell their daughters about the impending death. When telling this story, Dina highlighted that she and her colleagues experienced difficulties forming trusting relationships with the daughters, who accused the health system of not doing enough to save their mother. Dina got the impression that the daughters consequently felt distrust towards the health system. She reflected that, despite this undesirable consequence, distrust in the parent–child relationship would be even worse, so she was prepared to take the blame. Dina's story involved three relationships of trust that were also discernible in other stories: the child–professional relationship, children's trust in the health system and the child–parent relationship. Dina's and several others' stories indicated that gaining trust in one relationship could compete with other considerations.

While Dina's example concerned trust in relationships involving children, the health professionals' main consideration seemed to be the patient–professional relationship. The nurses who worked in municipal health services and ambulant specialist health services told stories about patients who were mothers and who initially lacked trust in the health professionals. The nurses explained how through a wary, circumspect process, they stayed in line with the patients and got increasingly close to them. In this way, the nurses developed trusting relationships to the patients, making it possible to provide palliative care. In Story 13, municipal nurse Jenny recounted how she worked hard to establish a trusting relationship with a patient, who eventually let her into her home. Jenny stressed the following:

You had to be extra careful as it had been so difficult to get contact with the patient. I, therefore, did not dare go into topics she did not want to discuss when I noticed she would not talk about them.

In this and similar stories, the nurses were reluctant to approach children or to talk about them with the patients after having worked hard to gain the patients' trust.

3.2. Patient autonomy versus child involvement: five positions

The identification of the two main considerations related to patient autonomy further made us aware that across the 17 stories, the participants negotiated and talked about patient autonomy in different ways. We established a continuum of five positions ranging from full respect of patient autonomy to violations of patient autonomy. These positions overlapped and were not mutually exclusive. The health professionals adopted several positions within the same interview and sometimes even within the same story.

3.2.1. "It is not my business"

On one end of the continuum, the health professionals did not take any steps to involve the children or to convince the parents that their children needed to be involved. The health professionals' stories gave sparse descriptions of such situations, indicating that they did not place themselves as responsible in these episodes, and so did not ascribe to themselves the duty to make the parents disclose their diagnoses or prognoses to the children. The health professionals explicitly stated that they could not do anything as "it is not my business," "I was not the

closest one to the family” or they did not encounter the children. The professionals also used children’s young age as a justification for doing nothing.

3.2.2. “Stay in line”

The health professionals frequently described how they followed or stayed in line with the patients during the progression of their illness. Rather than jeopardising patients’ hope or trust in the patient–professional relationship by raising the topic of children’s involvement, the health professionals seemed to let the right moments “appear” by themselves. After introducing the topic, the health professionals gave patients the time to process the information. Building trust and empathy with patients, the health professionals did not dispute the patients and parents’ views, even when the health professionals favoured greater child involvement. Fanny stated the following: “I am afraid of saying that the parents are wrong. They know their own child.” When illness suddenly progressed quickly or the disease’s time span was short for other reasons, some parents died before information about their anticipated death reached their children.

3.2.3. “Presenting a realistic picture”

This position challenged patient autonomy more than the previous positions as the health professionals disputed patients’ views by presenting their own perspectives. The health professionals most commonly did so by talking about what they generally did or would do in hypothetical cases. Some health professionals referred to research on the potential risks of not involving the children and cited this knowledge as an authority to challenge patients’ views.

3.2.4. “Make the opportunity”

This position involved an element of disguise that challenged patient autonomy. In front of patients, the health professionals respected their views while actively creating opportunities to involve the children to a greater extent than their parents wished. In Story 1, Andreas asked a mother to allow her son to come to the hospital and intended to convince her to allow the son to see her once he arrived. However, she died while the son was present in hospital but before Andreas could convince her that the son should see her. In several stories, the health professionals sought opportunities to be temporarily alone with the children and ask them leading questions about their parents’ illness and prognosis despite explicit parental instructions not to introduce the topic of death. In these cases, the patients most likely thought that the health professionals respected their autonomy.

3.2.5. “It is the child’s right”

The fifth and final position favoured children’s involvement over patient autonomy. This position was represented by only one story that came from nurse Elisabeth (Story 5), who worked in a palliative ward. When a single mother arrived at the ward, Elisabeth soon became aware that the patient had not told her children anything about her disease. When in the ward, the mother refused to allow her children to come see her. Elisabeth confronted her, saying, “They will see you. You are going to die, and it is the children’s right to see you before you die.” Going directly against the mother’s will not to meet with her children, Elisabeth physically brought them to her, one by one. A special condition in this story was that the time constraints demanded an immediate decision and did not allow the health professional enough time to convince the patient to consent to the children’s involvement.

4. Discussion

In this study, we have explored health professionals’ ways of handling the moral problem of dying patients excluding their minor children from their illness and impending death. A main finding is the strength and impact of the health professionals’ respect for patient autonomy, defined as patients’ right to control situations in accordance

with their own personal values and beliefs (Beauchamp, 2010) and concretised in the professionals’ work to sustain patients’ hope and build trust. The themes of hope and trust are not new to the field and have been thoroughly discussed in the clinical and palliative literature as fundamental considerations in health professionals’ practice (see, e.g., Parry et al., 2014). However, our study points to an extra dimension when the patients are also parents of minor children. Although the health professionals often equated patients’ hope with denial, the main pattern seemed to be that patients controlled situations in accordance with their perceptions of reality. The health professionals prioritised establishing trust rather than working to involve the children if there was any danger that the professional–patient relationship might be challenged.

The theme “Sustaining patients’ hope” illustrates the importance of parents coming to terms with their own disease if their children are to be involved and informed about illness and prognosis. This point accords with the findings by Hailey et al. (2018), showing that the parents who have incurable advanced cancer but do not share prognostic information with their children commonly do not consider their own death to be either imminent or likely. Logically, as long as patients themselves do not think of their illness as incurable or life threatening, it makes no sense to tell their children that it is.

Interestingly, mothers were overrepresented in our sample of 17 stories. We do not know if the gender distribution in our data represents a tendency in the patient population; quantitative studies with larger samples are needed to investigate that. However, the findings from previous research suggest that the sick parent’s gender affects children’s adjustment to parental cancer (Tavares et al., 2018). Even in Scandinavian countries with high gender equality, mothers often have the primary responsibility to communicate with children about emotionally challenging topics. If the mother is in denial, there might be no one to replace her in talking to her children about illness and death. Confronting patients and telling them that their hope amounts to denial might facilitate children’s access to the health care context and prognostic information. However, such truth-telling requires many considerations (Rising, 2017). Health professionals might think that patients will break down if confronted with their prognosis and consequently withdraw from treatment, leading to negative consequences for both the parents and the children (Kipnis, 2006).

The main pattern in the stories is that health professionals follow patients’ will, practicing strict confidentiality. This is in line with findings from a study on the Norwegian health and welfare sector, which found that health personnel want or practice nearly absolute confidentiality. Health professionals in particular seemed to put special restrictions on themselves regarding information sharing (Stang et al., 2013). Stang et al.’s study further indicate that health personnel and other welfare workers do not have sufficient knowledge about the legal regulations in HPA §23–4 that trump confidentiality. Still, we found three positions that directly or indirectly challenged patients’ view: “Presenting a realistic picture,” “Make the opportunity” and “It is the child’s right.” The conventional precept of confidentiality as absolute (see, e.g., Kipnis, 2006) implies that these positions involve “breaching” confidentiality and are thus unethical. However, according to Clark (2006), a strict view on confidentiality falls short in complex clinical situations. Consequently, he proposed to discard confidentiality “as a first-order principle of professional ethics” (Clark, 2006, p. 121) and suggested, instead, paying attention to the following three classes of rights that confidentiality purports to serve (see Fig. 1): 1) the patient’s right to privacy, 2) the patient’s right to safety and 3) the well-being, welfare and interests of all individuals other than the patient (the public good). In practice, these classes of rights often conflict, creating a three-cornered contest.

Applying Clark’s (2006) triangle to the study results shows that privacy trumps the public good, indicating a bias towards securing patients’ rights over children’s rights. This bias can be understood in light of the professional–patient relationship.

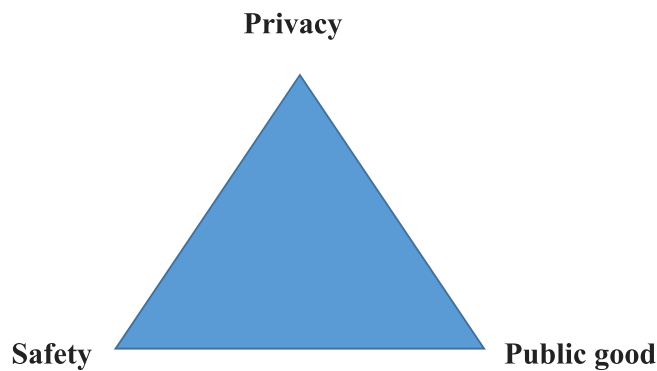


Fig. 1. Confidentiality as a three-cornered contest. Model adapted from Clark (2006).

4.1. Primacy of the professional–patient relationship

Previous studies have shown that time pressures and limited resources hinder health professionals from involving children and that the dominant medical logic contributes to this situation (Karidar et al., 2016). On the one hand, the medical logic in the palliative oncological field prioritises medical issues and treats psychosocial issues as secondary considerations. Thus, health professionals are trained to prioritise patients and the treatment of medical conditions. On the other hand, the dominant medical logic is a *discourse* that provides arguments that health professionals draw on to discursively position themselves (Harré et al., 2009). This discourse may provide shared and personal rationalisations in the working environment, both of which legitimise not involving children, making it easier for health professionals to deal with emotional stress.

Previous research has shown that such emotionally and existentially challenging encounters may create a need for protection and distance among health professionals (Franklin et al., 2018). Golsäter et al. (2016) studied how nurses perceive their roles when caring for the children of seriously ill patients and found that some nurses are convinced that the children are not their responsibility. These findings align with the “It is not my business” position (see Section 3.2.1), whereby health professionals adopt arguments as to why the patients’ children are not their responsibility. Instead of viewing these utterances as individual nurses’ and doctors’ established perceptions or static beliefs about their roles, we suggest that these claims should be read as discursive positioning having as effect to create emotional distance and decrease distress (Franklin et al., 2018; Harré et al., 2009).

However, the health professionals who work in isolation might not have the same possibility to create emotional distance by saying, “It is not my business.” A literature review by Franklin et al. (2018) indicated that professionals’ opportunities to deal with stressful emotions depend on whether they work in isolation or have support from a team. In our data, the position “Stay in line,” characterised by trust and empathy for the patients, is more frequently expressed by municipal and ambulant nurses working in isolation in patients’ homes than by health professionals working with multidisciplinary teams. On one hand, emotional commitment and trusting relationships might contribute to securing patients’ rights to safety and privacy by helping health professionals understand others’ horizons—namely, to interpret and understand patients’ beliefs, values and needs (Clark, 2012; Loyens and Maesschalck, 2010). On the other hand, the fusion of horizons and mutual understanding might also increase the severity and possible impact of stressful emotions in situations with conflicting considerations as well as increase the risk of not taking the child’s perspective into account. Empathically tuning into the perspectives of children about to experience parental death is emotionally challenging (Sommer et al., 2013). When these encounters also involve challenging patients’ values and beliefs, professionals often lack the parents’ support in this

challenging task. Consequently, close professional–patient relationships might impede health professionals’ opportunities to act on behalf of the children whose parents do not want to involve them.

4.2. Going against patients’ will

Positions challenging patients’ will were associated with situations involving very limited expected lifetime. In an exception, the “Presenting a realistic picture” position was based on general statements about what health professionals have done or would do. The type of confrontation characterising this position centres on what is best for children according to general advice. This position can be aligned with a more paternalistic orientation whereby health professionals “own” the knowledge and know what is best, in line with Karidar et al.’s (2016) findings. The nurses in Karidar et al.’s (2016) study implicitly believed from the outset that they knew what was best for the children regardless of their parents’ point of view and philosophy of life.

Although the “Presenting a realistic picture” position initially seems to help secure children’s rights, it also risks implicitly conveying to parents that they are wrong about their children’s needs. This may create misunderstandings and conflicts in the dialogue with parents (Hogstad and Jansen, 2020). Believing at the outset to know what is best according to general advice may also impede health professionals’ discretionary interpretation of children’s specific needs in concrete circumstances (Loyens and Maesschalck, 2010). In several stories involving families with cultural and religious minority backgrounds, the health professionals implicitly and explicitly expressed that they did not understand these families’ decisions regarding end-of-life issues. When health professionals do not understand the patients’ horizons, they risk being ignorant of situation-specific conditions important to discretionary judgement. General advice and research framed in Western individualist conceptual apparatuses might not always be intelligible to children and families from cultural and religious minority backgrounds with other conceptual apparatuses. These children might need to receive information and support in ways other than those generally prescribed by professionals within Western sociocultural contexts.

Health professionals going against patients’ will to exclude the children and intervening to support the children’s rights might threaten not only the professional–patient relationship but also relationships within families. If health professionals provide children with information essential to the parent–child relationship, such as news about death, this communication might violate trust, which risks harming the parent–child relationship. Instead of direct interventions by health professionals, especially young children should be involved via the relationships established in their everyday lives (e.g. healthy parents, grandparents and teachers) that have the prerequisites to take the young child’s perspective (Sommer et al., 2013).

4.3. Methodological considerations

According to the hermeneutical inquiry framework applied in the present study, ‘there is no such thing as a pure description; every communicative act involves interpretation’ (Patton, 2015, p. 137). Consequently, the stories told in the interviews must be considered as representing the participants’ perspectives rather than what *really* happened (Haavind, 2019; Patton, 2015). Readers might have noticed that Stories 5 and 6 in Table 1 appear similar, and we have reason to believe that both stories originate from the same episode. The fact that the stories differ – for instance, regarding how much information the mother had shared with her children – illustrates that the two nurses experienced, interpreted and communicated the same episode differently. We want to argue that pointing to this subjective dimension in the data does not take away the strength of our study in contributing to knowledge and informing practice. Discretionary processes are interpretative, and professional practice is shaped by professionals’ lived experiences rather than objective criteria and theoretical conclusions

explicitly worked out from first principles (Clark, 2012). Exploring individual health professionals' subjective and situation-specific knowledge may contribute to *practice validity* – that is, knowledge useful for the professional practices to do with handling moral problems (Clark, 2012).

4.4. Implications for practice

Reflective practice may help professionals become more engaged with ethical problems (Clark, 2012). Our discussions with the health professionals in the field of palliative care already revealed the usefulness of our analyst-constructed typology of the five positions because the typology allowed the professionals to reflect on their own ways of handling the moral problem between meeting children's need for information and maintaining confidentiality on behalf of the patient. The typology could thus be used for educational purposes.

Nonetheless, reflective practice does not in itself change the main considerations and contextual conditions that health professionals have to take into account and that limit their opportunities to take steps to involve children. The primacy of the professional–patient relationship seems to *inherently* challenge the involvement of children because it comes into conflict with the considerations tied to health professionals' prioritised tasks. Together with the fact that going against the patient's will to involve the children may also threaten the relationships within families, it may prove difficult to evade the conditions of the palliative context by, for instance, providing more training or education to professionals (Dencker et al., 2017).

We recommend that policy makers formulate procedures for health professionals working with children as next of kin that oblige health professionals to always establish interprofessional collaboration with the children's kindergarten or school when a patient that is a parent of a minor child is diagnosed with a life-limiting illness. Based on our findings, such a procedure may function as a discursive resource for health professionals, providing a convincing reason to ask for patients' permission as the procedures apply to all patients. Hence, it could help the professional to position themselves as “staying in line” with the patient while taking concrete steps towards child involvement without necessarily endangering the trust in the professional–patient relationship.

In cases when the patient still does not consent to involve the child, health professionals can seek assistance from CPS, which may access people with whom the children have established relationships and discursively position such persons with the legal and moral responsibility to involve the children (Harré et al., 2009). Professionals must report to CPS any suspicions that children are suffering serious harm or neglect. Knowing what constitutes possible harm is a difficult task, and professionals may overestimate or underestimate the probable risk of children's suffering – for instance, due to preconceptions such as sociocultural conceptions about children's needs (Hogstad and Jansen, 2020). In addition, when patients keep children away from the health care system, health professionals do not even have the opportunity to consider possible harm to the children. In these cases, professionals could consult CPS anonymously, and CPS could, situated closer to the children's everyday life perspective, assess the probable consequences of the parents withholding information.

5. Conclusions

The present study supports the findings from previous research about the contextual conditions that limit palliative health-care professionals' opportunities to involve children as relatives. Our study contributes to this established knowledge by deeply investigating the health professionals' ways of handling the moral problem that occurs when parents withhold information about their illness and impending death from their minor children. Our findings point to how the primacy of the professional–patient relationship in the health care context and the

importance given to patient autonomy in the present sociocultural context result in health professionals giving greater weight to patients' will than to children's right to – and need for – information about their parent's illness and prognosis. We propose that procedures for initiating collaboration with the professionals from the children's everyday-life context may help health professionals to involve the children without threatening the trust in various interpersonal relationships.

CRediT authorship contribution statement

Ingrid Johnsen Hogstad: Conceptualization, Methodology, Investigation, Writing - original draft, Writing - review & editing. **Kjartan Leer-Salvesen:** Writing - original draft, Writing - review & editing.

Declaration of competing interest

None declared.

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Appendix 1. Interview guide

Make the participant aware not to identify persons in the stories told. There are no right or wrong answers, I am interested in what you have to tell, your thoughts and opinions. We conduct the interview as a dialogue. I might take notes during the interview for my own recollection on questions to follow up on.

1. *Introduction.* Tell me about yourself: **education, occupation, position**, your tasks and about **how long** did you work within palliative care?
2. Own experiences.
 - a. Tell me about **your experiences** with the minor children of your patients. Successful support? No access or unsuccessful support? (Why? What could have been done otherwise?)
 - b. Do you have stories about children with **special needs** (f.ex. disabilities, language challenges, minority background)? (What needs did they have? What adaptations did you do?)
3. Reflections upon the youngest children
 - a. What do **kindergarten-aged children** (1–6) understand about: Severe illness? Death?
 - b. How would you **present to a kindergarten-aged child** that mother or father is going to die?
 - c. What is the **best way of taking care of- and supporting** kindergarten-aged children when mother or father is dying?
 - i. What are their **needs**?
 - ii. What is **important**? What is not so important?
 - iii. **Who** should provide support?
 - iv. What does supporting the child demand?
4. Professional role, competence and knowledge
 - a. What is **your role in relation to patients' minor children**? What is expected from you? What is demanded from you?
 - b. What is important for you **to feel prepared** to take care of and support the children of your patients?
5. *Thank you for your help!* How did you experience being interviewed? As expected? What did you expect? Did the information you received in advance suffice your information needs?

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