



Researching lived experience in health care: Significance for care ethics

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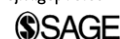
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Bernadette Dierckx de Casterlé

Catholic University of Leuven, Belgium

Sofie TL Verhaeghe

Ghent University, Belgium

Marijke C Kars

University Medical Center Utrecht, The Netherlands

Annemarie Coolbrandt

Ghent University & University Hospitals Leuven, Belgium

Marleen Stevens

Ghent University & Catholic University College St Lieven, Belgium

Maaïke Stubbe

Ghent University, Belgium

Nathalie Deweirdt

Ghent University, Belgium

Jeroen Vincke

Ghent University, Belgium

Maria Grypdonck

Ghent University, Belgium

Abstract

The aim of this article is to demonstrate the usefulness of qualitative research for studying the ethics of care, bringing to light the lived experience of health care recipients, together with the importance of methods that allow reconstruction of the processes underlying this lived experience. Lived experiences of families being approached for organ donation, parents facing the imminent death of their child and patients being treated using stem cell transplantation are used to illustrate how ethical principles are differentiated, modified or contradicted by the narrative context of persons concerned. The integration of empirical data into ethics will help caregivers in their ethical decision making and may enrich care ethics as a narrative and interpretative field.

Keywords

care ethics, empirical ethics, lived experiences, organ donation, qualitative research, stem cell transplantation

Corresponding author: Bernadette Dierckx de Casterlé, Centre of Health Services and Nursing Research, Faculty of Medicine, Catholic University of Leuven, Kapucijnenvoer 35 blok, 3000 Leuven, Belgium
Email: bernadette.dierckxdecasterle@med.kuleuven.be

Introduction

Ethicists increasingly make use of empirical research. The study of the practice of care can contribute more to clarifying ethical questions than the use of ethical theories and principles.¹

In the social sciences, in nursing, and more recently in medicine, qualitative research has acquired an important place. In the field of ethics it can be of great value. In this article, we will demonstrate the value of qualitative research about the lived experiences of patients and family members to an ethics of care in the domain of nursing and health sciences.

The ethics of care has received attention in nursing and other health sciences. In Gilligan's² early work she formulated a care ethics as an alternative to the justice orientation demonstrated in Kohlberg's work.^{3,4} It is, however, the work of Tronto⁵ that has inspired nursing ethicists to develop further an ethics of (health) care,⁴ especially in the Netherlands and Flanders.⁶⁻⁸ An ethics of care is experienced as being particularly helpful in elucidating the ethical aspects of everyday care, not only ethical dilemmas. As formulated in the wake of Tronto,⁵ it emphasizes relationships rather than autonomy.^{9,10} Interdependence and vulnerability are given a central place.⁹ Patients and nurses (or other health care providers) enter into a relationship. Responsibility comes about through nurses' connectedness to the patients and their families.⁹ Taking up responsibility requires from nurses an awareness of what patients' situation means to the patients themselves, and the clearer their understanding the better nurses can know what their responsibility entails. The quality of this relationship is a distinct feature of good care, irrespective of a contribution to health.⁷ The emphasis on relationships also implies that patients are to be seen in the context of their social relations, and not only, or primarily, as autonomous individuals.⁹ Good care implies responsiveness: caregivers are attentive to how their care is received and how it affects patients and their family members. They observe and adapt care accordingly, if possible in dialogue with patients and/or their families.

Empirical qualitative research on the lived experience of health care recipients aligns itself well with the requirement of nurses' empathic commitment towards patients and their family members. It unfolds what it means to patients and their families to have to go through the experience of ill health and/or treatments, and uncovers how these experiences are rooted in patients' lives and their existence, as is illustrated in Pascal and Endacott's study of the lived experiences of cancer patients.¹¹ The insights gained from that study assist the understanding of a number of existential and ethical challenges associated with a cancer diagnosis.

Furthermore, listening to the lived experiences of health care workers can help us to understand what it means to (have to) provide care in a specific situation or under particular conditions. As an example, Izumi's phenomenological study demonstrates how listening to nurses' voices can further understanding of their ethical concerns about their connectedness to patients and how to find a way of bridging the gap between abstract universal ethics and practical local ethics.¹²

In what follows we will describe the results of three of our research projects on the lived experience of patients and family members in order to show what information such studies generate and explicate how this information is relevant to an ethics of care in nursing. This article, however, does not aim to address and debate normative problems raised by the studies. The study findings will be used as 'cases' in order to demonstrate the usefulness of qualitative research on the ethics of care in nursing. First we will discuss the methodology that was developed in these (and others of our) studies to encourage understanding about the way in which the results we present are empirically grounded. Next, we will briefly describe the findings of three qualitative research projects, which will help us to explain the significance of qualitative research findings in care ethics. These studies focus respectively on decisions about organ donation, truth-telling to stem cell transplant patients, and parents' response to the imminent death of their child.

Qualitative research about the lived experience

The qualitative studies we will discuss here pertain to the domain of the study of the lived experience, in which many studies in disciplines such as nursing are situated. These research projects investigated how people (often patients or their family members) experience their life when characterized by the presence of a specific condition, such as a demanding health-related situation. We have also investigated the lived experience of professionals. Lived experience researchers study reality as it is seen and lived by the participants. They try to uncover the meaning that events and occurrences have for the participants and how they give meaning to their situation. Qualitative research into lived experience aligns itself to a phenomenological view of human existence and may employ hermeneutic approaches for the analysis. In hermeneutical interpretation, researchers read interview transcripts as texts and try to uncover the messages these texts contain. In their analysis, they try to discern the common factors in the participants' experiences and how individual differences take form.

In some of the approaches, researchers also try to uncover the processes underlying these experiences. This was the case for all of our own studies. Why is it that persons experience what they do experience? What processes lead to their experiences and how does their experience evolve over time? Qualitative research for uncovering¹³ or reconstructing¹⁴ such processes most often takes place within the grounded theory paradigm, which was created and developed by Glaser and Strauss^{13,15,16} and at present exists in numerous, not always explicitly identified, variants.¹⁷

The methodology we use in our studies is such a derivation. We try to explain behaviour, thoughts, feelings and meaning by reconstructing the situation from the perspective of the actors we study and what happens to these actors. In this reconstruction, we use data from interviews with the participants placed in their context (as we understand it, according to what the interviewees recount or suggest), sometimes also making use of participant observation or our experiential knowledge of a situation.

The qualitative research approach has two important characteristics that differentiate it from quantitative research and make particularly valuable its contribution to (decision making in) the ethics of care. Qualitative research gives an important place to subjectivity, both in the researcher and in the participants. Second, qualitative research is far less reductionist than quantitative research. It studies experiences as a whole and in the rich context in which they occur. Thus, care ethics and (many forms of) qualitative research have the common factor that they do not reduce the situation to be judged to a limited number of variables, but rather address the situation in all its richness and complexity.

This refusal to reduce the situation to a limited number of aspects (variables), however, requires much of the practitioner, the ethicist or the researcher. They must be open to the complexity of the everyday world in its specific context and engage in a dialectic interpretive process between the whole and the various parts in a hermeneutic circle in order to seek comprehension of the meaning of phenomena.¹⁸ It is obvious that the better a situation is understood in its complexity, the better the practitioner (the ethicist, the researcher) will be able to make a proper judgement. The aforementioned characteristics of qualitative research make it easier for users of research to connect with situations as lived by the participants. This connection is uniquely important for valid thinking in the care ethics field.

Autonomy and social benefit in decisions about organ donation

Organ donation is a very relevant and important topic. For several otherwise lethal or incapacitating diseases, transplantation is the only or the preferred treatment. Because of the limited availability of organs, there is strong pressure to 'harvest' as many organs as possible. In some countries using an opting-out system, everyone who has not registered an objection against donorship can legally be considered a donor. The idea is that in such a system objection by family members can be avoided. Another argument put forward is that in this

way the autonomy of deceased persons is optimally respected.¹⁹ It is their decision that is carried out, without their family members having the opportunity to obstruct the execution of the 'will' of the deceased. A further argument is that it becomes possible to harvest organs without having to burden family members with a question (whether or not they are prepared to donate their relative's organs) that is out of place. Thus, opinion shows, an opting-out system is advantageous for all parties. Our research, however, makes clear that the suffering of seriously distressed family members may be greatly increased by such an approach.

In two qualitative studies that used a phenomenologically inspired grounded theory variant, as described above, we interviewed family members who had been approached for potential organ donation.^{20,21} A total of 25 family members were asked about their experience of being approached to consent to donation, and about the influence the (refusal of) donation had on their experience of the events surrounding the death of their loved one and on the grieving process. Our aim was not to find out how numbers of donations could be increased but to improve care for family members who were approached for donation. We made this clear early in our contact with the (potential) respondents.

The findings showed that all respondents considered the request to donate organs to be a legitimate request. It came for them at an unfortunate time, but they considered it reasonable that it was made, even under the current circumstances. They understood the societal relevance of the request, which gave it its legitimacy. Although their loved one had to die, almost all understood and agreed that the doctors were trying to save the lives of others. It was especially important that the physicians had done their utmost to save the life of their loved one and that they had experienced consideration from the caregivers with regard to their own needs. In these circumstances, the request was not seen as unnatural. When we asked a respondent whether she felt that the question was out of place she said, 'No, it did not feel that way at all. It flowed naturally out of the care that we had received.'²²

That the respondents understood the relevance of the request and considered it appropriate did not, however, mean that they were ready to consent. Some who refused felt, at that time, unable to contribute to others' happiness. The shock they were experiencing had shaken their world-view to such an extent that they were not able to think about a properly ordered world. A mother who was approached for the donation of organs from her daughter, who was victim of a car accident, said: 'When I went home I thought, where are all these people going? My daughter is dead. The world should stand still.' In this mood it was impossible for her to consent. She refused and later still believed that she could not have done otherwise. She is at peace with the decision, even though she understands the consequences for others.²²

Most of all, the request to donate organs confronts persons to whom the question is addressed with the fact that the death of their relative is inevitable and irrevocable. Although, rationally, they know that their loved one has ceased to live, because that has been explained to them, they do not yet consider him or her as dead. They see their loved one breathing and having a normal appearance. They cannot imagine him or her being dead. Moreover, the reality of the death is something they cannot accept. Many of the respondents cannot refrain from having, at moments, the very unrealistic hope that it is not true, that it will prove to be an error, a nightmare from which they will wake and know that it was a dream. They have these flashes of hope, which they know are unrealistic but cannot prevent from arising. The request for organ donation confronts family members with the irrevocability of the death. It makes the uncertain certain. The request forces them to see that they have to give (the body of) their beloved one over to death. It does this to an extent that is more final than the information doctors have given them about the patient's condition. Once the organs are taken, they can no longer think that the expectation of death could be a mistake. Thus, consenting to organ donation means surrendering to death. Family members can be helped or forced to make this necessary step. If they are not able to do so, even after being told that organ donation is being considered, they are not able to consent.

The possibility of consent, or what it takes to consent, is also influenced by the construction that the family member makes of the person in death. 'They can have everything [all her organs] of Claudia's', says her

husband, who in the interview clearly shows how dear she was to him.²¹ For him, Claudia is not in her dead body and the donation does not violate her or the image he has of her. On the other hand, family members may feel very reluctant to consent when the patient does not have external wounds caused by an accident. 'He was so beautifully whole', a mother said about her son who died in an accident. She wanted to preserve this integrity, but consented anyway because of the seriousness of the consequences for others. It cost her, however, great effort and it felt like a great sacrifice to do so.²¹

Once family members have accepted that death is the only possible outcome, they can think about the request and deliberate it. They see their role in the donation procedure as a logical continuation of the role they had to play in the period after the accident. They have been staying at the side of their loved one, trying to make sure that those things are done that need to be done for him or her. They are their relative's advocate (see also Verhaeghe²³⁻²⁵). Not asking about donation would strongly violate this role. In our study, no person felt that they should not have been asked, even though some experienced it as a very difficult decision to make in someone else's place. As with treatment decisions, most of the respondents tried to make the decision they thought the patient would have made. Even without the topic ever having been discussed among them, some family members knew what they had to do. 'It was entirely in the line of the way he lived', said parents of a son who died in an accident and donated not only organs but also his bones.²⁰

Donation can play a role in the grief process. It may be a consolation that the death is not entirely meaningless. When the patients concerned are those who 'lived for others', donation can be seen as an expression of who these persons really were. Some find a degree consolation in the knowledge that part of their relative 'still lives on'. For others, that their organs are still continuing to live is a burden rather than a consolation: what if his liver is given to a drunk? Teenage children who were involved by their mother in the decision about donation of her husband's organs consented to donation, but excluded his heart.²¹

Family members have a great need to have a clear picture of what happened and what has been done with and to their loved ones from the moment they entered the hospital, right up to their arrival at the mortuary.²³ If they do not have such clear detail, they cannot forget and this greatly hampers their grieving process.²³ Not knowing whether organs have been harvested, or not being allowed to be part of this important event, would seriously increase their burden, make their grieving much more difficult and perhaps cause them life-long damage.

By describing and explaining the viewpoint of family members, our studies allowed a more contextualized ethical discussion about the value of an opting-out system in decisions about organ donation. They illustrate the importance to close family members of the events surrounding organ donation and demonstrate why it cannot be conceived as an issue involving only the deceased person and the potential recipients. It makes clear that, from family members' perspective, it is unjustifiable for them to be by-passed in the decision-making process on the grounds that the deceased person has given legal consent by not opting out. Being faced with a very sad and devastating event that overturns their lives dramatically, they would be forced to relinquish this final vestige of control. Our study also makes clear why, from the perspective of family members, it is inhumane to think about 'harvesting' organs. It conveys a message of ownership that is, as our data show, entirely at odds with their perception of the situation and with the role they have played until then. In donating the organs of their loved one, something all respondents do in accordance with the supposed will of the deceased, the family members act as ethical subjects. They know that their consent is a gift of life. At the same time the study makes clear that there needs to be room for refusal by the family, even if the patient has declared consent to donation. Indeed, patients cannot foresee what the effect of their donation would be on those they love. It is not respecting the autonomy of persons when one acts according to their expressed intentions, but when, by doing so, this creates consequences they would never have wanted or accepted. It is clear that family members are violated if organs are 'harvested' against their will when they are unable to consent or they are not asked.

Should doctors refrain from making promises they cannot keep? The case of stem cell transplant patients

In two studies we addressed the lived experience of patients being treated with stem cell transplantation and the way in which nurses help these patients to endure the worst part of the therapy.^{26,27}

Stem cell transplantation is the treatment of choice in many patients with leukaemia. The promise is great: if patients survive the treatment there is a real chance of cure. The dangers, however, are also great. Even if the disease responds to the treatment, the likelihood that patients may succumb to its complications is substantial. Undergoing a stem cell transplant thus brings with it a huge amount of uncertainty. Hope and despair can be very close together under these circumstances. Moreover, the therapy is very demanding. After a stem cell transplant has been carried out, the patient goes through a phase that is tremendously taxing. While the uncertainty is at its height, the patient is completely devoid of physical strength.

In our studies we investigated how patients manage to get through this very harsh period and what nurses do to sustain them at this time. We used both interviews with patients and nurses and participant observation. Twenty-two patients and 18 nurses took part in these studies.

In the hospital where the studies took place, the nurses proved to be very capable of supporting the patients. The patients, who were interviewed while still in the hospital or shortly after their discharge, really appreciated what the nurses did for them. From their accounts, it seemed that the nurses carried them through a 'deep valley', taking over from them for as long as necessary. The observations confirmed this. They requested very little from the patients, were always available, acted immediately when there were difficulties and gave the patients hope that their problems could be overcome. Nurses and doctors collaborated closely to obtain the results for which everybody was hoping.

However, the nurses thought that the doctors were 'too optimistic' when talking to the patients during this difficult period of their treatment. They gave them more hope than the nurses thought was warranted. The doctors assured the patients that they would pull through, even when serious complications made a positive outcome unlikely. The patients leaned on their doctors. That they were in the hands of competent physicians who would do everything they could to save them was of great importance to them. It gave them the strength to tolerate what needed to be withstood in order to realize their chance to be cured. Our analysis showed that the patients were able to keep on enduring and pulling through by 'writing a positive story'. They told themselves that they were sure they would make it. They did not deny the dangers of the treatment that had been explained to them, but once they had made the choice they considered only one outcome. They gathered or interpreted information in such a way that it seemed to increase their chances of a positive outcome. 'The doctor has said 50%', a patient said in his interview, 'and I said, "You can add 20% for my courage. So that makes 70".' It was this 70 that was usually on his mind.²⁶ The competence of doctors and nurses helped them to maintain a positive story. If things went wrong, they were trusted to put it right.

The nurses believed that the doctors supported the patients' positive stories too strongly, almost without reservation. In contrast to their behaviour during the patients' decision-making process (when they had to decide whether or not to take the treatment), in this phase of physical and psychological depletion the doctors were noted to discuss only the positive aspects. The patients reported that the doctors had assured them that 'they were going to make it'.

From our interviews it is clear that this optimistic attitude on the part of the doctors had an undeniable influence on the ability of patients to bear the consequences of the choice they had made; that is, to go through the ordeal of the treatment in order to gain a cure, the only possible cure for their illness. Our studies did not provide an answer to the question of whether doctors should be more realistic, more 'honest' with their patients. They showed that patients need their doctors' optimism, that this is very functional for them, that it helps them to get through the experience and prevents them from giving up at a moment when continuing the treatment is still meaningful because a positive outcome is (still) possible. At the same time, the doctors'

behaviour is not 'honest' in any normal sense of the word and the nurses felt uneasy about this. The doctors were not telling the truth to the patients, even though they were not directly lying: they pretended to believe that everything would be all right while knowing they had nothing but their own hope to support such a statement. By laying bare the function that optimism fulfils for patients, our studies allowed a much more contextualized and differentiated discussion of the ethical question of whether or not doctors should refrain from making promises they cannot keep, as the nurses thought they should.

Parents' response to the imminent death of their child: needs that cannot be disentangled

Another of our studies dealt with the lived experience of parents facing the imminent death of their child.^{28,29} The child is suffering from cancer, and the parents have been told that there is no treatment for this disease. The parents in our study cared for their children at home. The study aimed to bring to light their (unmet) needs regarding health care. We interviewed 44 parents of 23 children during this period of caring, when they knew that they would have to let them go. Some were also interviewed after the death of their child.

Although no cure was possible and the parents knew their child was going to die, numerous decisions had to be made. Sometimes therapy could be given to prolong life (a little) or to diminish symptoms; parents found experimental treatments on the internet that could be tried on their child; decisions needed to be made about feeding. (Should they insist their child eat even after he or she indicated no longer liking even favourite dishes or just give up on eating, feeling that this would bring the moment of death closer?) Even when a child had a pump to self-administer pain medication, the parents needed to decide how to advise the child: to make liberal use of it, or to be careful not to administer such large doses that the child would go to sleep and communication with the parents would become impossible. Decisions also pertained to daily life, sometimes seeming rather mundane issues, such as whether the child could best continue to go to school or whether to put a bed in the living room, knowing that the child would never again sleep in his or her own bedroom.

Our study revealed that the degree to which the parents were able to face the impending loss of their child was the factor that most influenced their decision making. When they could not face the loss, they were unable to 'let the child go' and tempted to take all possible measures to postpone the moment when the loss would be definitive. When it was too difficult for parents to face the loss, decisions were sometimes made that did not seem to be in their child's best interest. The parents' and the children's interest proved to be very intertwined and often very difficult or impossible to disentangle, not least for the parents. Of course, children in that phase of their illness need parents who can go on caring for them with all the love they can give and all the strength it requires. In that sense, parents' and children's interests coincide, but when decisions are to be made about treatment, the congruence often disappears. The father of three-year-old Leonie allowed his daughter to have a radiation treatment that required her to be isolated for four days. During these four days she could have contact with her parents only by camera. He said, 'Suppose that she's with us two months longer because of the therapy, what's four days out of two months?' Whether the treatment would yield the months he used in legitimizing the treatment was unclear, and he showed full awareness of the fact that at best it could only yield a postponement of death. Nevertheless, he considered it evident that the decision to let her have the treatment was the right one.

Our study not only made clear that autonomy cannot be considered when looking at the child in isolation from the parents.⁹ It also clarified how the needs of parents and their children are intertwined and what it demands from parents to recognize this entanglement and to try to undo it in order to make the best possible decision for their child. We saw parents who were able to do so, but only after they had been through a process that made them capable of facing the impending loss and thus recognizing not only in thought but also in deed that they had to let their child go.

Our study also throws light on the question, but without solving it, of to what extent parents can or should be accorded decision-making power pertaining to the continuation of treatment, and about measures that, as a

secondary consequence, would shorten the life of their child. It also demonstrated the types of support parents need in order to fulfil their parenting role under these extremely taxing circumstances, when this role seems to disappear by letting go but the fulfilment of that role requires just that.

The value of qualitative research for care ethics

Each of the studies discussed here has helped us to understand a situation as lived by the participants. The studies made clear how the parents gave meaning to their situation, and how that meaning explained their thoughts, behaviour and emotions. It gave voice to their needs and allowed us to understand what really mattered to them. It brought their suffering to light as well as how even sometimes very well-intended care could contribute to it. It allowed us to see these persons in the context of their relationships and their life history. The knowledge that these studies provided can help caregivers to better understand patients and their family members, and to decide what constitutes good care in specific circumstances.

Many decisions in health care indeed need a normative ethical interpretation. Questions of autonomy and social benefit, of truth-telling and hope, go beyond the clinical–technical discourse and require an ethical judgement by which all parties can enter into the dialogue.⁸ The quest for what is best for a patient cannot focus solely on the patient's wishes as an isolated individual. Patients (and their families) are to be seen in the context of their social relations.⁹ Wishes and viewpoints expressed by those concerned therefore need to be gradually constructed and then interpreted.⁸ To answer ethical questions in patient care, it is important not only to hear but also to understand the stories of both patients and others involved. This requires great skill on the part of all those involved in ethical decision making. By describing and trying to understand different perspectives, the understanding of a particular situation will be enriched with more detailed and contextualized information about the underlying value patterns. These stories indeed unfold what it means to patients or their family to go through the experience of illness, therapy or end-of-life decision making. They explain how these experiences are connected to patients' or families' existence. In this way, lived experience studies outline the narrative context in which patient care has to take shape and will help caregivers to take on their responsibility in the practice of care.¹

The studies concerning families' responses to organ donation or to the imminent death of their child illustrate the importance and meaning of the role of family members in these particular situations and of the support they (can) receive from professionals. The findings bring to light the deeper meaning of family members' consent to organ donation and thereby the significance of their involvement in this decision-making process. The study of the lived experience of parents facing the imminent death of their child increases our understanding of the way parents make decisions in this context, and hence of the consequences of increasing or limiting their role in the decision making.

The studies on the lived experience of patients being treated with a stem cell transplant elucidate the crucial importance of hope and optimism in the care process. The findings demonstrate how patients interpret the information from the viewpoint of their own frame of reference and clarify the role that positive messages play in helping them to negotiate such a stressful experience.

Listening to the lived experience of patients, family members and health care worker helps us to better understand vulnerability and interdependence as cornerstones in ethical practice. Moreover, the findings underline the importance of nurses' attentiveness to how care is received and what care does to patients and their family members.

For ethicists or those engaged in ethical deliberation, the studies increase understanding of the interpersonal aspects of ethics in complex situations and show that ethical decision making about real-life issues cannot be reduced to abstract theories of ethics and principles. The qualitative findings may be used to clarify the essential understandable meaning of good and bad as actually lived in the experience of patients and their family members.³⁰ The qualitative method provides a specific understanding of caregiving in a complex

environment that we mostly take for granted and which therefore often remains hidden.¹⁸ The qualitative studies discussed above show how the (theoretical) ethical arguments or principles are differentiated, modified or contradicted by the lived experience of the persons concerned. The studies about organ donation and parents' response to the imminent death of their child both offer a more nuanced and contextualized view of the principle of autonomy. Respecting patients' autonomy in bioethics means that they are the most important decision makers. According to the research findings relating to organ donation, respecting the autonomy of persons who have (or have not) opted out, implies more than acting according to their expressed intentions; the consequences of this decision for significant others also needs to be taken into account. A better contextual understanding of parents facing the imminent death of their child makes clear that autonomy cannot be respected by looking at the child in isolation from the parents because of the intertwinement of the needs of parents and their children. The studies about the lived experience of patients treated by stem cell transplantation contribute to thoughtful reflection on the concepts of truth-telling and hope in care. From a conventional ethical perspective, caregivers are expected to be honest and to tell the truth to patients. Having insight into the meaning of hope for these patients may help health professionals to acquire a more adequate understanding of the concept of truth-telling in these caregiving situations.

However, interpretative qualitative methods are demanding because they require going beyond the existing available interpretation of values, principles and norms.¹⁷ Understanding can never be complete. The other always escapes us to some extent³¹ and interpretations retain a certain degree of uncertainty.⁷ Outcomes of qualitative studies such as the ones discussed here do not allow us to make predictions in other cases or determine what actions we should take. Indeed, because each person assigns meaning to the events in their own world, the lived experience can never be predicted.⁷ The knowledge provided by the studies, however, can serve as an important heuristic tool that can help health care professionals to decipher what they see and hear, and, if there is no opportunity to gather much information, to make well-informed guesses about what is most likely the case and hence what is the most appropriate approach.³² Thus, this knowledge can contribute considerably to the adequacy of ethical decisions attuned to a specific situation.

Conclusions

Our contention and experience is that qualitative research on the lived experience, in which experience and meaning are not only described but explained, greatly contribute to both ethical discussion and ethical decision making. The first takes place on a global, generalized level; the second at the particular.

The ethics of care must take account of the social context when making ethical decisions. The clearer the understanding of the situation as lived by those involved, the better health care workers can decide what constitutes good care in specific circumstances. Empirical research about patients' and family members' experiences can avoid ethical decisions being based on erroneous beliefs that a decision maker may have about what is the case, and so contribute to thoughtful ethical reflection on ethical activities and decisions in daily care. Ethics has to examine critically and explain the experiences uncovered in empirical studies in order to understand what they can tell us. The integration of empirical data (and their interpretations) into ethics will promote dialogue between researchers and ethicists and could enrich care ethics as a narrative and interpretative field.

Conflict of interest statement

The authors declare that there is no conflict of interest.

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