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# Sources of vulnerability and ethical challenges in qualitative research with pediatric cancer patients

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## Abstract

Qualitative research with children and adolescents with cancer has been gaining momentum since the early 2000s. However, a focused discussion of ethical aspects of qualitative research with this patient group has been largely neglected to date. Applying a relational perspective on vulnerability, in this article we discuss ethical challenges in qualitative research with patients in pediatric oncology. These vulnerabilities and ethical complexities should be acknowledged and call for practical measures, but should not be overemphasized in a way that adds barriers to the inclusion of pediatric cancer patients in qualitative research.

## Keywords

Health and illness, pediatric cancer patients, qualitative research, research ethics, vulnerability

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## Introduction

Due to the close integration of treatment and research, children and adolescents with cancer (*pediatric cancer patients*[1]) come into contact with research comparatively early and frequently (Boles and Daniels, 2019), as many of them receive their treatment as part of a clinical trial (between one-third and 86 % of patients aged <15 years in the US; Schapira et al., 2020). In addition, they may participate in studies on supportive care or illness experience. In this respect, scholars have emphasized the need to involve patients themselves in research and to expand dominant psychological, quantitative approaches with social-scientific, qualitative methods (Boles and Daniels, 2019; Dixon-Woods et al., 2005; Woodgate, 2000a). *Qualitative research* refers to methodologies in which primarily textual data is generated through engaging with people in everyday life settings. It comprises and often combines methods such as interviews, participant observation / ethnography, focus groups, and the analysis of documents or objects. While quantitative research aims at measurement, qualitative research can be characterized as "[…] an interpretative approach to data collection and analysis that is concerned with the meanings people attach to their experiences of the social world and how people make sense of that world." (Mays and Pope, 2020: 2).

Since the early 2000s, qualitative studies have become increasingly established in research with pediatric cancer patients[2] (see the systematic reviews on different aspects of illness and treatment experience by Comas Carbonell et al., 2021; Jibb et al., 2018; Lin et al., 2020; Paterson et al., 2023; Tomlinson et al., 2016; Werthern et al., 2022; Woodgate, 2000b). While these studies have expanded the body of knowledge on illness experiences of pediatric cancer patients, a dedicated examination of *ethical* aspects of qualitative research with them has been neglected to date. Merely drawing on reflections on ethical issues of *biomedical* research with this patient group (e.g., Alahmad, 2018; Dupont et al., 2016; Unguru et al., 2010) appears to be of limited use, as these are often restricted to formalized aspects of research ethics and as qualitative research partly raises different ethical questions. Most qualitative studies on pediatric cancer patients, however, only mention obtaining ethics approval and orientation towards general ethical principles. Exemplary exceptions are: (1.) Bluebond-Langner's reflections in her pioneering work (1978: 236-255), in which she addresses aspects such as role conflicts, emotions and the ethical justifiability of her research; (2.) Boles' and Daniels' article (2019) on the ethical conduct of experiential research with pediatric cancer patients and on their preferences in this regard; (3.) Norbäck et al.'s (2023) qualitative study on ethical challenges of recruiting patients for research from the perspective of healthcare professionals.

This lack of ethical reflections is surprising, as pediatric cancer patients may be regarded as a "uniquely vulnerable patient group" (Boles and Daniels, 2019: 8), whose "[…] vulnerability is not simply a social construction" (Dixon-Woods et al., 2005: 159). In addition, the emergence of interdisciplinary *childhood studies* since the 1990s has led to an intensified focus on the ethics of research with minors (Kirk, 2007), so that there are plenty of theoretical and empirical reference points. Against this background, a dedicated exploration of ethical aspects of qualitative research with pediatric cancer patients seems expedient (Boles and Daniels, 2019; Norbäck et al., 2023). Pursuing this concern, in this article we address the question which specific vulnerabilities and ethical challenges may arise in qualitative research with this patient group.[3] First, we introduce our relational perspective on the concept of vulnerability, which aims to analyze interacting factors resulting in particular vulnerabilities, rather than assuming vulnerability as an inherent characteristic of a group of participants. Accordingly, in the second step, we identify three overarching sources of vulnerability in qualitative research with pediatric cancer patients. In the third section, we explore three ethical challenges in this type of research.[4] We conclude with a discussion.

## A processual, relational, situational and analytical perspective on vulnerability

Since the publication of the *Belmont Report* in the US in 1979, vulnerability has become a central concept within ethics guidelines and considerations regarding the protection of research participants (Bracken-Roche et al., 2017). It refers to a social group's "[…] *identifiably increased likelihood of incurring additional or greater wrong*" (Hurst, 2008: 195; emphasis in original) as a result of their participation in research. While the concept fulfils important functions, researchers have voiced significant criticism over the years, particularly of its operationalization in formal research ethics reviews (Bracken-Roche et al., 2017; Carter, 2009; Hurst, 2008, 2015; Luna, 2019; Traianou and Hammersley, 2024). Central points of criticism concern the *reduction* of vulnerability to the question of a person's capacity to give informed consent (which ignores other sources of harm); An *extension* of the concept to all kinds of social groups (which ultimately renders it meaningless); The implication that certain groups of people are *inherently* vulnerable (which neglects the situational circumstances which make them vulnerable); And the approach of Institutional Review Boards (IRBs) to 'label' certain social groups as vulnerable (without any analytical procedure), which can be stigmatizing and contribute to their exclusion from research.

In their critique, the authors cited above and others have argued (1.) that the vulnerability of research participants should not be reduced to issues of informed consent but should be understood as a potentiality which runs through the entire research process and therefore has multiple sources; (2.) That vulnerability should be understood as a *relational* and *layered* phenomenon that arises in concrete social situations and should therefore not be misunderstood as an inherent characteristic of certain social groups; And (3.) that concrete vulnerabilities should be identified using *analytical approaches* in ethics reviews, instead of taking them for granted. These suggestions can be integrated into a processual, relational, situational, and analytical understanding of vulnerability as the result of relations and interactions both between people as well as between people and systemically and historically shaped contexts. Thus, vulnerabilities in qualitative research with pediatric cancer patients should be analyzed starting from the *social situations* in which patients and researchers enter social relationships and interact with each other.

However, this concept of vulnerability is not without pitfalls. First, its emphasis on processuality, relationality, and situatedness should not result in fragmented, merely subjective interpretations of vulnerability – concise definitions such as Hurst's (2008) should remain at the core. Second, researchers should not lose sight of systemic and historical factors shaping vulnerability when focusing on the individual context (see also ten Have's, 2016, critical remarks on situational conceptualizations of vulnerability). Third, established ethical principles and procedures (such as informed consent) should not be neglected, as this may in turn cause other dilemmas. Finally, putting this complex perspective on vulnerability into practice requires sensitivity and skill on the part of researchers.

## Sources of vulnerability in qualitative research with pediatric cancer patients

We identify three overarching characteristics of qualitative research with pediatric cancer patients that may cause vulnerabilities and ethical challenges: (1.) patients' disease- and therapy-related burdens; (2.) ethically significant features of qualitative methodology; (3.) minors' psychosocial, physical and cognitive development and power imbalances in their relationships with adults.

### *Cancer- and treatment-related burdens*

Throughout the course of their illness and treatment, pediatric cancer patients are exposed to various burdens and disruptions of their lifeworld. On a bodily level, these include primary disease symptoms (Linder et al., 2018), side effects of chemotherapy such as fatigue (Tomlinson et al., 2016) and problems with eating (Green et al., 2010), as well as unpleasant examinations, treatments, or surgical procedures. The various effects of cancer treatment on physical appearance and body image (e.g., hair loss, weight changes or amputation) can be burdensome for patients, also due to (feared) inappropriate reactions by others (Williamson et al., 2010).

Pediatric cancer patients may experience their diagnosis as shocking and frightening (Mant et al., 2019). They are exposed to ongoing uncertainty (Sisk et al., 2021) resulting from fluctuating health conditions, unforeseen illness events and the overall uncertainty of treatment success, as well as to the life-threatening nature of their illness (Comas Carbonell et al., 2021).

In addition, they may face difficulties in maintaining social contacts as a result of long-term or repeated hospital stays, making them vulnerable to social isolation (Christiansen et al., 2015). Both their social situation and their health status potentially limit the *agency* of pediatric cancer patients (Davies et al., 2018) and reduce their options for action. Increased *dependence* on parents and other caregivers may be particularly problematic for adolescents, as growing independence is important to them (Kim et al., 2018).

These burdens cause the serious impact that pediatric cancer can have on their identity (Posa et al., 2021), relationship to the world and self, psychosocial development and life course, and can result in long-term psychosocial and physiological consequences (Hendriks et al., 2022). As pediatric cancer affects fundamental aspects of existence in their totality, it can be understood as an *existential experience*. This multitude of *manifest* burdensome experiences as well as *latent* vulnerabilities appears as the most obvious source of ethical challenges in qualitative research with these patients.

### *Ethically significant features of qualitative research*

A discussion of ethically significant features of qualitative methodology in the context of healthcare research requires engagement with the incoherence between epistemological and ethical orientations of qualitative research on the one hand, and IRBs on the other. IRBs still primarily comply with a *biomedical* understanding of science, whose classical methodological repertoire does not include non-standardized methods (Opsal et al., 2016; Pollock, 2012). This lack of fit can lead to an attribution or overemphasis of risks of qualitative research, so that projects may be regarded as "ethically precarious" (Morrow and Richards, 1996: 102) or "'burdensome'" (Woodgate et al., 2017: 4). Although qualitative research is not inherently ethical and entails identifiable risks (Hadjistavropoulos and Smythe, 2001; Taquette and Da Borges Matta Souza, 2022), it should be recognized that these are comparatively low and that even the most obvious risk, emotional or psychological distress, rarely actually occurs (Guillemin and Gillam, 2004; Opsal et al., 2016; Pollock, 2012). Here, we highlight four features that may raise ethical questions:

(1) Qualitative research is *emergent*: its exact design evolves over the course of the research process, as researchers gain further access in their field, adapt data generation[5] methods or pursue other thematic tracks based on initial analyses. This means that researchers cannot fully inform their participants in advance about some elements of the research (Pollock, 2012). As a result, the implications and consequences associated with qualitative research may be difficult for participants to grasp. This may raise concerns about the validity of their informed consent or assent.

(2) Many qualitative methodologies such as ethnography rely on the *establishment of close* or *trustful relationships* between researchers and participants. In research on sensitive topics, as well as with minors, this can even be a prerequisite for its feasibility (Woodgate and Edwards, 2010). However, an increasing entanglement of researchers in these relationships and a concomitant tendency towards blurred roles or role ascriptions may result in further ethical dilemmas (Taquette and Da Borges Matta Souza, 2022).

(3) As many qualitative methodologies rely on an *in-depth thematization* and *narrativization of subjective experiences*, research on sensitive topics such as illness may cause psychological distress to participants. However, a profound thematization of meaningful subjective experiences in research can also serve as a *social recognition* of these experiences. While participation in qualitative research offers no prospects of health benefits, it can thus still be a positive experience for participants (Opsal et al., 2016).

(4) Finally, the *representation of participants' accounts* poses particular ethical challenges in qualitative research (Pickering and Kara, 2017). A more formal issue is that complete anonymization of qualitative data is hardly realistic, so that

> there remains a residual risk for participants to be identified. More complex, however, is the question of how qualitative researchers can *write about others* in an ethically adequate manner: How can they 'transfer' participants' self-interpretations or everyday practices into scientific knowledge and how can they represent them without harming individuals or social groups?

## *Minors' development and generational relations as sources of vulnerability*

Minor age of study participants is seen as a factor that principally increases their susceptibility to harm or injustice (Hurst, 2015). There are different explanatory approaches regarding this vulnerability. A rough distinction can be made between a more developmental-psychological explanation and one focusing on generational power relations (although these approaches can overlap). In the former, the vulnerability of minors as research participants is deduced from their ongoing psychosocial, physical and cognitive *development*, from differing linguistic, intellectual, and cognitive capacities, from their dependence on adults, but also from ascribed negative characteristics (such as incompetence or irrationality). In biomedicine and ethics reviews, the assumption of an age- or development-related *inherent* vulnerability has been dominating, and the focus has been on more formalized elements of research ethics such as informed consent, risk-benefit analyses, and confidentiality (Alderson, 2007; Carel and Györffy, 2014; Carter, 2009; Kirk, 2007; Morrow and Richards, 1996; Woodgate et al., 2017).

In the latter approach, the vulnerability of minors as research participants is rather deduced from their position in the generational order. This perspective has been dominant in *childhood studies*. Scholars from this field have increasingly considered vulnerability in its ambiguity and discursive constructedness, conceptualized it as a relational and situational phenomenon, and drawn attention to the social positioning of minors by adults and associated power imbalances (e.g., Andresen, 2014; Carter, 2009; Christensen, 2000; Frankenberg et al., 2000). In this context, authors have criticized that the categorization of minors as an inherently vulnerable population can be stigmatizing and contribute to their exclusion from research (Carel and Györffy, 2014; Hurst, 2015) – which may particularly affect minors in *factually* more vulnerable life situations (Carter, 2009). In addition, the assumption that the ethics of research with minors is fundamentally different from the ethics of research with adults has been critically discussed (Alderson and Goodey, 1996; Punch, 2002).

In our view, both these aspects should be acknowledged. Neither should developmental factors and the dependence of minors on adults be completely negated, nor should they be understood as the sole determinants of vulnerability in research with minors. A relational perspective, as outlined above, opens up the view that even if one recognizes the potential significance of minors' psychosocial and cognitive development for research ethics, the *manifestation of vulnerabilities* still depends on situated interaction and how researchers deal with these peculiarities in their practice – that is, in their (asymmetrical) generational relationships with minors (see Schweiger and Graf's, 2017, perspective on minors' vulnerability that integrates developmental and situational assumptions).

The following ethical challenges have been repeatedly emphasized in literature on qualitative (health) research with minors (Alderson and Goodey, 1996; Alderson and Morrow, 2020; Carter, 2009; Duncan et al., 2009; Harcourt and Sargeant, 2011; Helseth and Slettebø, 2004; Huang et al., 2016; Hurst, 2015; Kirk, 2007; Kousholt and Juhl, 2023; Morrow and Richards, 1996; Punch, 2002; Wright, 2015):

Especially in regulatory ethics, minors are viewed as vulnerable with regard to *informed consent* or *assent*, as it is considered unclear to what extent they are capable of understanding implications of research participation, weighing up advantages and disadvantages and making self-determined decisions. In this respect, they may be exposed to the harm of making decisions without adequate preconditions and thus potentially against their actual will. Contrary to these assumptions, some authors have argued that minors' competences to consent are more dependent on social context and personal experiences (Alderson, 2007; Ashcroft et al., 2003) and have proposed more interaction-oriented understandings of informed consent (e.g., Kousholt and Juhl, 2023).

The capacity to give informed consent can be seen as a case of an overarching ethical issue, namely the unclear capacity of minors to *act self-determined* in relationships with adult researchers and to *exercise their rights as participants*. This includes asking questions about the study, refusing or discontinuing participation, refusing to address certain topics in interviews, or requesting practical or methodological changes. This vulnerability stems from both generational power relations and personal experience. At the same time, powerlessness and the 'incapacity' to act in a self-determined way may be attributions and expectations from adults which impose a victim role on minors that does not do justice to their capacities. In this perspective, scholars have pointed out the fluctuation and negotiation of power in research relationships (e.g., Davidson, 2017).

*Building trust* can be particularly important in research with minors, who may feel uncomfortable with anonymous or distant research relationships (Woodgate and Edwards, 2010). At the same time, establishing trustful relationships with young participants may be demanding insofar as it takes place less through demonstrating a certain professional status but rather through spending time together and participating in familiar activities (Coyne et al., 2009).

A peculiarity of research with minors is the *special role of parents* and of *the family as a social system.* This begins with the legally justified dependence of researchers on contact with parents for purposes of study information and consent and extends to the concern not to isolate the perspectives of minors from those of their parents or families. The special role of parents and family may have ethical implications insofar as it increases the *complexity of the social fabric* in which researchers operate, in which they become entangled, in which they must justify their actions and in which they may be exposed to divergent demands from different parties.

The *handling of confidentiality* in research with minors also has special features due to their dependency and the unavoidable involvement of other adults. If researchers witness child endangerment, they have a clear obligation to inform other adults. However, they may also encounter situations in which their obligations are more ambiguous, such as when minors disclose less clearly defined experiences of harm, or when researchers are confronted with demands from parents to share with them what their child has told in interviews. This can lead to loyalty conflicts.

Two further ethical challenges arise from the fact that usually, adult researchers control most parts of the research process. The first concerns the chosen *methods of data generation and analysis*. While all social research should align its methods with the field studied, with its research interest and its participants, in our own research we have gained the impression that, compared to adults, minors are potentially more sensitive to the choice of data generation methods and may already experience an inadequate choice of methods as a ‘violation’ (e.g., of their trust in the researcher). The second aspect resulting from the unequal distribution of control over the research process concerns the *inadequate handling of accounts* of minor participants by adult researchers, especially in the phases of interpretation and representation. This includes distorting, devaluing, disregarding or attacking perspectives of minors, which in itself constitutes a violation of ethical research and, once published, can have concrete negative consequences for minors, who may have limited resources to counteract inappropriate use of their data. On the other hand, adult practices and claims of representing minors’ ‘voices’ must be challenged, as they presuppose verbality and notions of authenticity, disregarding the *silences* within, and the *relational emergence* of minors’ accounts (Carnevale, 2020; Spyrou, 2016).

## Vulnerabilities and ethical challenges in qualitative research with pediatric cancer patients

Drawing on the identified sources of vulnerability, we now discuss three ethical challenges in qualitative research with pediatric cancer patients.

### *Agreeing to participate in qualitative research in an existentially unsettled life situation*

At the beginning of their treatment, pediatric cancer patients must process study information simultaneously with a disruption of their lives (Boles and Daniels, 2019). During this phase, they experience various burdens and have many demands on their time. These factors can make it more difficult for them to understand scientific studies and make decisions about participation. This raises questions about the ‘validity’ of their agreement to participate in research. Researchers should be aware that (younger) children may agree to participate because they mistakenly assume that this has an influence on their treatment or because they feel that they ‘owe’ something to the treatment team. The latter refers to the dependence of minors on adults, a factor of vulnerability which can be increased in pediatric cancer patients (Norbäck et al., 2023). It can therefore be even more difficult for these patients to make self-determined decisions that potentially run counter to the expectations of involved adults.

A relational perspective, however, opens up the view that the vulnerability of pediatric cancer patients with regard to their agreement to research participation is also the responsibility of the researchers and depends on how adequately they inform their potential participants about the study (Alderson, 2007). In addition, a *processual understanding of* *consent* (Klykken, 2022), which recognizes the need to revisit this agreement repeatedly over the course of participation, mitigates the vulnerability mentioned here anyway, because it is no longer tied to a single situation in which resources for adequate decision-making were potentially impaired. Furthermore, it should be considered that pediatric cancer patients *become experienced* with their illness and treatment (Pyke-Grimm et al., 2020), that they develop *self-advocacy skills* through day-to-day decision-making (Pyke-Grimm et al., 2022), and that this may in turn increase their awareness of their own preferences as well as their competence to make well-considered decisions regarding research participation.

### The psychological burden of communicating about cancer

An obvious vulnerability of pediatric cancer patients as participants in qualitative research is the potential psychological burden of communicating about their life-threatening illness and associated unpleasant experiences. As Huang et al. (2016: 349) note: “Recollection of events when children experienced pain and fear might result in discomfort and anxiety.” This risk appears to be increased in qualitative methods due to the limited possibility (and desirability) to plan interviews in minute detail, so that sensitive topics may arise unexpectedly, and due to the concern to explore meaningful experiences *in depth* (Hadjistavropoulos and Smythe, 2001; Taquette and Da Borges Matta Souza, 2022).

Researchers should take these risks seriously and implement practical measures to detect and respond early to psychological distress in their participants. However, apart from the fact that burdens associated with participating in qualitative health research rarely exceed burdens to which patients are exposed in their everyday lives and that the risk of causing harm is comparatively low, empirical findings pointing in a different direction should also be considered. While (vulnerable) participants may experience the depth that qualitative methods seek to explore as ‘stirring’, they report positive experiences more frequently than negative ones. This applies to research with minors in general (Crane and Broome, 2017) as well as to research with ‘vulnerable groups’ or on sensitive topics (Alexander et al., 2018; Opsal et al., 2016). To date, however, there are hardly any insights on how pediatric cancer patients experience participation in experiential research.

Empirical findings on the preferences of this patient group regarding clinical communication should also be considered. Although the preferred extent and forms of disease-related communication and involvement in medical decision-making vary individually and are influenced, for example, by the patient’s age and gender, pediatric cancer patients seem to prefer honest, transparent communication that is tailored to their needs and leaves room for hope (Jalmsell et al., 2016; Lin et al., 2020). Researchers should therefore discuss communication preferences with participants and give them control over topics discussed in interviews (Boles and Daniels, 2019).

However, the vulnerability mentioned here can also be thought of in a different way: Pediatric cancer patients can namely be vulnerable to *communication taboos* imposed by adults. In this case, the ‘violation’ that patients are exposed to consists of restrictions on discussing aspects of their illness experience, which can also pose a psychological burden. Adults may taboo communication due to assumptions that minors do not yet understand the mechanisms and scope of their illness and treatment, that they are not yet able to communicate about sensitive topics and burdensome experiences, or that they should be protected from doing so. In contrast, even early qualitative studies (e.g., Bluebond-Langner, 1978) have shown that pediatric cancer patients are capable of understanding and communicating about their situation, and subsequent research has underscored this.

## *Pediatric oncology as a challenging setting for relationship building and data generation*

A third ethical challenge of qualitative research with pediatric cancer patients is the conditions that pediatric oncology as a clinical setting provides for relationship building, establishing trust and generating data (Bishop, 2014; Coyne et al., 2009). As mentioned above, disease and treatment trajectories of these patients are characterized by high degrees of uncertainty (Sisk et al., 2021). In addition to the fundamental uncertainty about treatment success and prognosis, there are unplanned events such as spontaneous hospital admissions due to deteriorating health conditions, postponements of therapy phases and inpatient stays, but also patients' fluctuating psychoemotional states. The resulting limited plannability of contact can make it difficult to build trustful relationships with participants and to establish one's role as a researcher – especially if one is not part of the treatment team. While the emergent nature of qualitative research may cause irritations in biomedical ethics reviews, it becomes obvious here that it can in fact be particularly suitable for research in settings characterized by uncertainty, as data generation must often be designed and conducted spontaneously and flexibly anyway. Another aspect that shapes relationship building is the importance of the family, especially of parents, in the care of patients. By assuming a mediating role between their child and the researcher, they can contribute to the ethical quality of the research. On the other hand, their involvement can cause ethical dilemmas if they restrict their child's autonomy to participate or make claims that violate confidentiality.

The research setting poses challenges not only for relationship building in general, but also for data generation. For example, the methodological scope of research with pediatric cancer patients appears to be more limited, as it may be difficult or impossible for some patients to participate in certain methods (e.g., focus groups or methods that require mobility) due to their health status. This results in additional vulnerability, as these challenges may tempt researchers to limit their methodological repertoire *in advance*, even though creative approaches may be especially appropriate for this patient group. The 'violation' to which pediatric cancer patients are exposed here is that they may be denied appropriate opportunities to express their perspectives (on "cascades" of vulnerability resulting from previous vulnerabilities or responses to them, see Luna, 2019).

Finally, limitations in ensuring confidentiality must be acknowledged, as the presence of third parties (parents, other patients, healthcare professionals) may be unavoidable when generating data in the clinical setting (Coyne et al., 2009). Researchers may also face dilemmas if patients disclose negative experiences with the treatment team on which they themselves rely as researchers.

We conceive these aspects not only as *practical* challenges, but as *ethically* significant, as they concern the question of how to responsively shape relationships with research participants. Methodology has an ethical dimension, insofar as it opens up the scope in which participants can appropriately contribute their perspectives. In this perspective, we draw on an understanding of ethics that Guillemin and Gillam (2004) have termed “ethics in practice” and, drawing on Paul A. Komesaroff, “microethics”, and that Rossman and Rallis (2010) have adopted as “everyday ethics”. In this understanding, research ethics is neither exhausted by adherence to formal criteria in ethics reviews nor does it only become relevant in ‘big’ dilemmas. Rather, it should be regarded as a *situated* social practice (Kousholt and Juhl, 2023) which unfolds in the relationships between researchers and participants. This understanding continues to be influential in discussions of qualitative research ethics (Pollock, 2012; Taquette and Da Borges Matta Souza, 2022; Woodgate et al., 2017) and may be even more relevant in ethnography, where researchers and participants share their everyday lives to some degree. From our own experience, even seemingly ‘banal’ situations such as entering a patient’s room without knowing whether it is the right moment to approach them can be understood as “ethically important moments” (Guillemin and Gillam, 2004). A relational perspective on challenges to relationship building posed by the research context calls attention to the importance of communicating openly with pediatric cancer patients about their participation and trying to give them as much control over it as they wish (Boles and Daniels, 2019).

## Discussion

Qualitative research with pediatric cancer patients can produce particular vulnerabilities and ethical challenges. These should be understood as *relational* phenomena that arise in concrete social situations. Thus, qualitative research with these patients can be ethically more complex and challenging than research in settings in which fewer sources of vulnerability can be identified. At the same time, it shares some issues with research with other ‘vulnerable’ groups of participants (e.g., minors with other chronic conditions), so that it should neither be considered as a singular case in ethical terms, nor as completely congruent with qualitative research in other settings (Punch, 2002, has presented this argument in reference to the relation between research with adults and research with minors). The same applies to its relation to biomedical research: both forms of research may raise unique ethical complexities as well as some that they share.

What consequences does this diagnosis have for the practice of qualitative research with pediatric cancer patients? First, the identified vulnerabilities and ethical challenges require suitable practical measures. Although these are not the focus of our article (see Boles and Daniels, 2019), we would like to point out three relevant measures that are based on our own experience:

*Processual consent*, that is, repeated communication about the agreement to participate (Klykken, 2022), is a way to better capture the validity of this agreement, as it is no longer tied to a single situation. In research with pediatric cancer patients, this can be especially relevant, as fluctuating health and emotional states can affect both patients’ decision-making capacity and their actual willingness to participate. Thus, consent processes should be designed in a manner that is responsive to the participants' capacities and life situations.

*Participatory research* can mitigate power imbalances between pediatric cancer patients and adult researchers insofar as it aims to give participants as much control over their participation as possible and as they desire. In this way, it can counteract the risk of patients experiencing research as a burden and facilitate the building of trustful relationships. Nevertheless, participatory research is not *automatically* 'better' or more adequate, neither in ethical nor in epistemological terms. It is a complex approach whose implications have been challenged (Davidson, 2017; Gallacher and Gallagher, 2008; Horgan, 2017) and whose quality still depends on its implementation in practice, which faces particular challenges in hospital settings (Bishop, 2014). Thus, researchers should engage in an honest dialogue with patients regarding the desired and realistic degree of participation – and acknowledge their demand for guidance.

*Collaboration with healthcare professionals and parents* is essential not only because they act as gatekeepers for pediatric cancer patients, but also because researchers – especially if they are not part of the treatment team – require knowledge about the patient's psychosocial and health status, course of treatment, and life situation in order to responsively align their research practice with these aspects (Coyne et al., 2009). This collaboration can thus contribute to the ethical quality of research.

However, these measures may also contribute to the ethical conduct of qualitative research with other groups of participants or in other settings. This brings us to a final argument: while it is essential to tailor ethical practice to the respective research setting and its *relational* vulnerabilities, the alleged ethical 'exceptionality' of research in which more vulnerabilities and ethical challenges can be identified should not be overemphasized. Such an overemphasis of (participant) vulnerability can, first, lead both researchers and IRBs to overlook the agency of participants considered 'vulnerable'. However, *agency* and *vulnerability* are not mutually exclusive opposites but can exist simultaneously (Andresen, 2014). Second, this failure to recognize agency can result in additional barriers – for example, when IRBs present inadequate obstacles to research in settings characterized by vulnerability or when researchers themselves shy away from conducting such projects (Traianou and Hammersley, 2024).

This brings us to another type of vulnerability of pediatric cancer patients regarding their participation in qualitative research: the *vulnerability to inadequate exclusion from research*. This exclusion represents a potential 'violation' insofar as it denies them the opportunity to act upon social structures that affect them (Pollock, 2012). In this respect, pediatric cancer patients – like other groups of people in vulnerable life situations – are potentially exposed to *epistemic injustice,* which consists of denying certain groups of people the capacity and the opportunity to act as 'knowers' (Carel and Györffy, 2014; drawing on Miranda Fricker). In contrast, while recognizing their vulnerability, the potential of pediatric cancer patients to exercise agency, both in terms of interpreting and coping with their illness *and* as participants in qualitative research, should be acknowledged.

## Conclusion

The purpose of this paper was to address the gap that exists regarding the ethical aspects of qualitative research with children and adolescents with cancer. Proceeding from a relational perspective which understands vulnerability not as an inherent characteristic but as the result of both social relationships as well as relations between people and situational circumstances, we have identified three sources of vulnerability for this type of research: patients' disease- and therapy-related burdens; ethically significant features of qualitative research; and the psychosocial and cognitive development of minors and power relations between them and adults. We then discussed three ethical complexities in which these sources of vulnerability come into effect: the problem of agreeing to participate in research in an unsettled life situation, psychological burdens arising from communication in the context of a life-threatening illness, and challenges for relationship building and data generation when conducting research in pediatric oncology. One limitation of our contribution is that some ethical challenges (e.g., those emerging when research relationships end) as well as some broader ethical discourses (e.g., on the way adults *use* minors as research participants; Spyrou, 2024) had to be excluded.

On this basis, the ethically challenging nature of qualitative research with pediatric cancer patients has become obvious, which is why we have referred to three practical approaches that can mitigate identified vulnerabilities (processual consent, participatory research, collaboration with health professionals and parents). However, recognizing vulnerabilities and ethical challenges in qualitative research with pediatric cancer patients should not result in the construction of this research as an 'exceptional case' and fundamentally precarious undertaking, as this can favor the exclusion of these patients from research.

While our contribution has drawn on the *theoretical foundation* of the question of pediatric cancer patients' vulnerabilities – entailing the limitation that we have not included patients' accounts –, further empirical research on their actual experiences and needs as research participants (Boles and Daniels, 2019), on the perspectives and experiences of involved healthcare professionals (Norbäck et al., 2023) and parents, and a stronger culture of publishing "ethically important moments" (Guillemin and Gillam, 2004) that researchers experience when working with pediatric cancer patients is required. This could help to break down fixed notions of vulnerabilities of this patient group and show that the substantial ethical work is not exhausted in the procedural ethics of institutionalized ethics reviews, but that it unfolds *situationally* in the research encounters with these patients.

### Declaration of conflicting interests

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## Notes

1. The World Health Organization (2021) defines childhood cancer as cancers affecting patients aged 0-19 years. We use the term pediatric cancer (patients), as it is not linked to a specific phase of life, but to the respective branch of medicine. Therefore, the term seems more suitable to include adolescents treated in pediatric oncology. However, it should be borne in mind that pediatric cancer patients represent a highly heterogeneous group due to their age spectrum, different types of cancer and individual courses of disease. Where it is necessary to group young people of different ages, we usually refer to them as *minors*. When we refer to *parents,* other legal guardians are also included.
2. This is due to increased survival rates (which, however, are unevenly distributed globally; World Health Organization, 2021), as well as due to changes in scientific conceptions of minors stimulated by *childhood studies* and the shift from research *on* minors to research *with* them (Dixon-Woods et al., 2005).
3. Our considerations are based on two empirical research projects which are being conducted at the Department of Pediatric Hematology, Oncology, and Hemostaseology at the Center for Pediatric and Adolescent Medicine at the University Medical Center of the Johannes Gutenberg University in Mainz, Germany.
4. We understand *ethical challenges* as aspects of or situations within research in which researchers are confronted with the vulnerability of their participants, in which they may have to make difficult decisions with uncertain consequences, and in which 'universal' ethical principles must be weighed against each other.
5. Drawing on Spyrou's (2024) recent critique of "extractivism" in childhood studies, we choose the term data *generation* over *collection* to abandon the notion of data as something pre-existing, merely to be gathered by the researcher.

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