

Reaching hard-to-reach young people: Methodological and ethical considerations in data collection

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Abstract

Researchers and service systems often struggle to reach young people who use drugs and have mental health conditions or social support needs. Our aim was to explore what kinds of methodological and ethical challenges should be considered when reaching hard-to-reach young people. During 2023 and 2024 we conducted thematic interviews focusing on near-death experiences related to overdoses, violence, and suicides, along with ethnographic fieldwork, in low-threshold services aimed at young people who use drugs in Finland. The data consisted of 41 field notes, 27 interviews with 24 young people (19–32 years), four group interviews with 17 staff members, 43 participant-produced photos, and six project documents. We conducted a thematic analysis on the methodological considerations. The results illustrate that the continuous evaluation of consent is needed when interviewing people who use drugs daily. Also, flexibility, patience, and time were essential when conducting these thematic interviews with hard-to-reach young people. Several precautions supported the interviewees and researchers' well-being during data collection. Effective preparation, including training and opportunities for peer and professional support, is recommended for future qualitative research involving young people with traumatic experiences.

Keywords

young people, substance use, ethnography, hard-to-reach, methodology

Introduction

Young people who face multiple challenges in their lives, such as drug use, homelessness, mental health disorders, or who exhibit criminal behavior, are often difficult for researchers to reach. They may have a weak connection to the service system or be estranged from the support structures that could help them. Further, they are at high risk of overdoses (Lyons et al., 2019), suicide attempts (Pompili et al., 2012), and violence (Leschied, 2011). Based on the data from a research project that included interviews with young adults aged 19 to 32 years with near-death experiences related to overdoses, severe violence, and suicide attempts, we aimed to analyze *what kinds of methodological and ethical challenges should be considered when reaching hard-to-reach young people*.

We collected data on the lived near-death experiences of hard-to-reach young people through low-threshold services for young people. The data included interviews with 24 young people (27 interviews) who had near-death experiences, 43 photos taken by the young people, and ethnographic observations (41 periods) in low-threshold services directed at young people who are homeless or use drugs.

Out of the numerous ethical and practical challenges related to hard-to-reach young people, this study focuses on three issues: first, how to obtain research consent from individuals who are using drugs or in otherwise vulnerable positions; second, what kinds of special considerations should be taken into account when gathering data on the personal experiences of sensitive issues among hard-to-reach young people; and, finally, what kinds of specific procedures are necessary for preparation, training, and after care. Challenges related to these issues often occur when conducting research on hard-to-reach groups, and this analysis will offer suggestions to solve these challenges.

Methodological and ethical challenges in studying hard-to-reach young people

Rockliffe et al. (2018) defined hard-to-reach groups as populations “that are difficult to reach or involve in research or public health programs” (p. 1). Paradoxically, parallel challenges prevent these groups from receiving help, but also make it difficult for researchers to produce information on how these services could be developed to support those most in need. Young people who use drugs daily and have other social or health disadvantages are often defined as hard-to-reach due to their weak connection with the

service system. As a result, they are a heterogeneous group that is underrepresented in society and in survey studies (Johnson, 2014).

Within the field of youth research, research methods have evolved to focus more on young people themselves, in contrast to the traditional adult-centered approach, where caregivers, teachers, authorities, and other adults act as informants on behalf of young people (Rutanen & Vehkalahti, 2019). It is important to reflect on whose voices are heard as representatives, as young people in vulnerable positions might never be reached through traditional research methods, such as surveys (Kiilakoski et al., 2018). Youth research also emphasizes the use of participatory methods that focus on different ways of communicating and building trust with young people. The photovoice method (Harley, 2015; Wang & Burris, 1997) can be used to enhance participants' agency by involving them in the knowledge-generation process through taking photographs of daily life (Bates et al., 2017). Representation of different communities can be a source of empowerment or help the underrepresented communities become visible (Sutton-Brown, 2014).

In conducting research with people who use drugs, special consideration is required toward confidentiality due to the criminalization of drugs in most countries. Ethnographers studying the illegal supply and distribution of drugs have suggested that some issues, such as future events and real names, should be avoided to preserve the confidentiality of their informants (Sandberg & Copes, 2013). The protection of confidentiality requires detailed consideration to be given to the ethical, spatial, and technical aspects of the research process. In some situations, the protection of participant confidentiality may override the need for written, formal consent. In these situations, consent can be provided as "tacit consent"; however, this does not exempt the researcher from their duty to properly inform potential participants about the research and their rights (Goldim et al., 2011).

Both acute intoxication and the compulsive need for substance use raise ethical questions regarding agency when young people who use drugs daily are being studied. Goldim et al. (2011) referred to substance use disorders as a "static" vulnerability. In contrast, acute intoxication is considered a "dynamic" vulnerability, as a person's capability to provide research consent can change quickly. According to Pickering (2018), the academic discussion on consent while intoxicated is often rather paternalistic, because people who use intoxicants are to be protected from themselves; therefore, by protecting people, researchers simultaneously delimit the voices that are heard and those that are not. The loss of agency due to the compulsive need to use substances has been particularly discussed in the research context of heroin-assisted treatment trials (see Pickering, 2018), and views have alternated between a total lack of autonomy (Charland, 2002) and various degrees of autonomy (Foddy & Savulescu, 2006; Uusitalo & Broers, 2015). Uusitalo and Broers (2015) argued that the account of voluntariness in providing consent should be considered in actual situations, rather than assuming that people who are addicted are incapable of providing voluntary consent. Thus, agency is always situationally related to the service system and to societal, personal, and spatial relations (Ranta, 2020).

Furthermore, concerns have been raised about giving monetary compensation for participation in research studies (e.g., that offering money would lead to more extensive drug use); however, empirical studies do not support these concerns (Festinger et al., 2005). Remuneration for interviews can be seen as an incentive to encourage participation; however, it can also be viewed as compensation for the time people spend working (Pickering, 2018). Researchers working with people who use drugs have stated that the amount should be "enough to show respect for their time and expertise, but not so much

as to be coercive”; however, some have argued that money would make interviews “a transaction, rather than a conversation” (Sandberg & Copes, 2013, p. 187).

The participation in research of people who use drugs regularly is often driven by multiple motives (Pickering, 2018). For people who use drugs, their motivation has been found to vary and to include rewards both for themselves (e.g., money) and for others (e.g., drug user activism and altruism; Barratt et al., 2007; Fry & Dwyer, 2001). An Australian study (Barratt et al., 2007) showed that people who inject drugs have negative attitudes toward research for the following reasons: personal discomfort in being studied; inconvenience; and fear of negative impacts of the study results. However, positive attitudes were found to be related to the possibility of providing information, improving drug policy, and the situation of the drug user community.

Conducting research with the aim of gathering information from young people who use drugs is time-consuming or sometimes even described as “messy” (Thulien et al., 2022). It requires resources (Teitler et al., 2003), and there is uncertainty around the actual data collection. Entering the field can be more difficult when one encounters vulnerable groups (Pacheco-Vega & Parizeau, 2018) than when one encounters groups with whom the researcher shares common skills and knowledge (Chughtai & Myers, 2017). It can also be difficult to negotiate access to the field, build mutual trust, and demonstrate that the researcher has credibility and that the research topic is of special importance (Bengry-Howell & Griffin, 2012). When encountering people on issues related to illicit behavior, such as drug use or violence, the researcher must have the time to build trust, even before first contact is established (Sandberg & Copes, 2013). Additionally, researchers studying violence and drug-related topics should be prepared with strategies for unexpected events, such as someone offering drugs or exhibiting aggressive behavior (Sandberg & Copes, 2013).

Conducting ethnographic research on young people who use intoxicants or have a compulsive need for substance use can be mentally or emotionally demanding for researchers (Berger, 2021), who often have limited access to psychosocial care (Backe & Fitzpatrick, 2024). Although preparations such as training and support groups for handling trauma have been suggested in the literature (Neves & Malafaia, 2015), they may occur infrequently or are not discussed in scientific articles. Discussing traumatic experiences can also cause distress among participants (Decker et al., 2011; Disch, 2001). Debriefing and providing options to guide participants to professional care have been suggested in previous literature (McSherry, 1995); however, it is unclear how often such procedures are implemented in study protocols.

Case study: Ethnographic study of lived near-death experiences among young people

Context

The study is part of a larger project called “Out of Despair” (Out of Despair, 2022). We collected this data for the subproject “Youth as Service Users” as a case study concerning hard-to-reach young people who were using low-threshold services and who used drugs daily, as well as had additional challenges such as mental health or housing difficulties. Hereafter, this group is referred to as *hard-to-reach young people*.

The main objective for the data collection was to conduct thematic interviews with hard-to-reach young people regarding their near-death experiences related to overdoses, severe violence, and suicide attempts. We used ethnographic observation to provide

additional information and help recruit interviewees while the researchers were present and familiarizing themselves with the young people. The interviewees were given the additional assignment to take photos of subjects that gave them “hope.” The idea was derived from the photovoice method (Wang & Burris, 1997).

The researchers involved in the planning phase and in the data collection had conducted ethnographic studies involving vulnerable individuals (Kaskela et al., 2021; Kaskela & Tourunen, 2017; Mäkilä et al., 2022; Pitkänen et al., 2022). Ethical approval was obtained from the Ethics Committee of Youth and Childhood Studies in June 2023. Permits for the study were also obtained from three NGOs and two city administrations in Finland to conduct interviews and observations later in 2023. Recorded consent was obtained from the participants.

Data

The data consisted of 41 field notes, 27 interviews with 24 young people (19–32 years old), four group interviews with staff members, 43 photos¹ taken by young people, and six project documents. The analyzed project documents included the study protocol, research plan, interview schedule, ethics board statement, privacy policy, data management plan, and information brochure for the interviewee.

The data were gathered between November 17, 2023, and July 9, 2024. Field notes (total of 21,516 words) were written on 41 observations that lasted from 20 minutes to 6 hours (mean: 2 hours 44 minutes). Young people were informed about the study by researchers and staff members, as well as through leaflets left on the sites’ tables and walls. Before final recruitment to the study and the interview, a researcher provided information about the study verbally and an informative brochure. We also provided an opportunity for young people to take photos of things that gave them hope and “things that help them to cope through challenging times” with a disposable camera. The interviews were conducted in a quiet space at the sites where the participants were recruited and lasted an average of 40 minutes. The interviewees were offered a €5 gift card as a courtesy for their participation. The interviews were recorded, transcribed verbatim, and pseudonymized by removing any information that might potentially identify the participants.

The criteria for inclusion were being aged under 30 years² old and having had a near-death experience (as outlined in the project description). Most but not all of the young people were using drugs daily. Many of the interviewees also faced challenges, such as severe mental health issues, engagement in criminal activity, homelessness, and low incomes.

The interviews were conducted on five sites in two cities in Finland. Two sites were the main sites for ethnographic observation; however, both encountered unexpected problems with the facilities just as the observation periods were supposed to begin. While waiting for the main sites to be available for observations, we recruited interviewees through three other low-threshold services (outreach work, housing services, and youth services).

The first main site was a shelter for homeless young people under 30 years of age who use intoxicants. They aim to provide a safe environment and the opportunity to wash, eat, rest, and service coordination for a variety of problems in their lives. The second main

1 10 of these photos were excluded from the study after the development of the films, as they contained photos of recognizable persons. Identifiable photos were to be handled with extreme caution before exclusion.

2 Two people over 30 years old were interviewed, as they had fresh memories of the near-death events from when they were under 30 years old.

premise was a day center for young people under 30 that offers a safe space to hang out, play games, watch TV, and cook. There was also an opportunity to discuss subjects around substance use or other issues, and to receive service management from staff. Both sites offered food. It was not necessary to be sober or to reveal one's name to enter these centers.

Analysis

The data were analyzed from the perspective of methodological challenges and solutions. The analytical approach involved content analysis of the data. ATLAS.ti version 24 (ATLAS.ti Scientific Software Development GmbH, 2024) was used. The data were read and coded into smaller entities better suited for deeper analysis; some codes (e.g., "interview situation" and "recruitment") were determined before the analysis; however, a few codes (e.g., "informants and gatekeepers") were added because we realized there was extensive data on that subject. Altogether, the data were structured into six codes (Researcher's own role, Recruitment, Conditions in the sites, Interview situation, Considering the protocol, and Informants and gatekeepers), which were read several times, resulting in notes that eventually evolved into a preliminary text used in the present article. After coding the findings and considering them within the context of previous literature on the topic, the results were organized under three headings (Consent in the context of vulnerable populations; Collecting data from hard-to-reach young people; and Preparations, training, and after care), as the most important contributions could be structured under these headings.

Results

Consent in the context of vulnerable populations

There were several issues related to consent in the study of hard-to-reach young people's near-death experiences. In this section, we will focus on three important consent issues addressed in our data collection that could benefit future research with vulnerable populations. These issues were anonymity versus written consent, consent and intoxication, and communication of consent.

We wanted to ensure as much anonymity as possible because the interviews addressed very personal and sensitive issues, but this meant we had to make compromises on the documentation of consent. This created tension between two research ethical principles: participants' right to privacy (Finnish National Board on Research Integrity, 2019) and their "right to be forgotten" (General Data Protection Regulation 2016/679, Article 17). Different approaches were considered, but we decided not to collect written consent because it would have compromised participants' anonymity, especially given that the centers operated anonymously and that this might affect their regular routines. However, an exception was made for the four participants who took part in the photo-elicitation interview and signed permission to publish photographs under an artist name. While unique pseudonyms or identifiers might have been an option, there is a risk that they would be lost or forgotten, given the young people's challenging life situations (e.g., homelessness, substance use). Instead, consent without identifying information was collected via a voice recording after the interviewees were informed of their rights and the way the data would be used. In this context, withdrawing from the study was no longer possible after the transcripts were pseudonymized and the voice recordings deleted. Contrary to the experiences of researchers in the study by Sandberg and Copes (2013), we did not encounter reluctance from the ethical committee or organizations in approving the study without obtaining written consent from the interviewed young people.

We sometimes found it very difficult to determine whether a person was capable of providing their consent, as their level of intoxication and mental state varied considerably over time, and their capability sometimes changed rapidly (Goldim et al., 2011). This finding was parallel to that of Bell and Salmon (2011), who discovered that the ability to give consent among people who actively used drugs is not “either/or,” as their lives contained periods of impairment and periods when they considered themselves capable of giving consent. As Aldridge and Charles (2008) suggested, instead of excluding intoxicated people, we tried to ensure that participants understood the information given and that only those who were most obviously intoxicated and who could not understand why they were giving consent were excluded. In the end, it was the researcher’s responsibility to evaluate whether “the functioning of the young person was not too much impaired” and that the conduct of the interview was appropriate from an ethical standpoint:

Early in the interview, I began to suspect that part of what the interviewee was telling was delusional. [Sentences removed to ensure anonymity of the interviewee]. I tried to get information but avoided conversation on this subject and time period. I also wondered if the interviewee was suitable [to be interviewed], but I came to the conclusion that it was very likely that they understood what they were consenting to, and everything outside this event was mainly reliable information. (Excerpt from the fieldnotes, TK).

There were two things that helped us to evaluate whether young people were capable of giving consent. First, as we were conducting ethnographic observation, we often had time to get to know potential interviewees before asking them to participate, and naturally, we spoke with them while presenting the research. Second, we had also agreed with the staff beforehand that we could discuss any uncertainties we might have regarding the conditions for providing informed consent with them. Further, if there was any doubt, the interviewee and a staff member could immediately discuss the consent after the interview.

It is typical for a research participant to misunderstand what they are consenting to, especially if they belong to vulnerable populations (Sherlock & Brownie, 2014), and it was therefore very important to ensure that the young people in our study knew what they were consenting to. Various modes of communication are encouraged in the consent process (Cohn & Larson, 2007), and we had multiple options (written and verbal) to communicate what was done and how the information was used. Before the interviews began, we had discussions with staff working with the young people on the sites. As they found the original information brochure too long and difficult to read, we simplified it to short bullet points (see Heerman et al., 2015). We kept the original information brochure on hand for any young person who wanted more information, and verbally communicated the information to participants. Most participants preferred the shortened version and did not want to read the original.

Collecting data from hard-to-reach young people

Some challenges encountered in our study were specific to data collection among this group of hard-to-reach young people. There were issues related to the participants’ drug use, becoming part of the space, building trust, and finding a suitable moment for interviews. After all, the ethnographic data collection process is generally full of unforeseen events (Green et al., 2017).

During the fieldwork, we encountered drug use and drug paraphernalia. We also witnessed different states of intoxication, which can be distressing for researchers and

may require mental preparation (see section “Preparations, Training, and Aftercare”). The staff and young people communicated in a rather unconventional, humorous, but not disrespectful way, which made serious situations slightly easier to approach. The use of humor has been connected to positive outcomes in relation to traumatic stress (Craun & Bourke, 2014). However, these surroundings were challenging for a researcher to blend in:

I stayed for a long time in the staff room but then dared to come and sit by the table. I felt that I was somehow in the way. There was no contact with people. A couple of times, I tried to ask something from the young people (e.g., about the fire alarm or [name of the city]), but no one responded. Was my voice too low so that no one could hear? Yes, some noticed. A new person asked who I was, and I told them that I conducted research. (Excerpt from the fieldnotes, AH).

When entering the field, we felt we were “outsiders” (Bengry-Howell & Griffin, 2012). Young people were sometimes testing us (Sandberg & Copes, 2013) by asking questions about ourselves and even asking if we would come and do drugs with them. The language used concerning drugs was not always familiar, and we had to ask about some synonyms or acronyms. We positioned ourselves in the fieldwork process and, for example, reflected on whether we should appear like ourselves or try to dress similarly to the young people. According to Wilkinson (2016), appearance is an important signifier of the researcher’s personality and affects the fieldwork process.

Researchers also had to be aware that their role was new for the young people, who seemed unsure of our position in relation to other social positions (young people, staff, and other professionals) or even uncomfortable with our presence (Barratt et al., 2007). At one site, there was only one large room with a kitchen and a hangout area, where the young people also slept. Because we did not want to bother the young people while they were resting, the observation had to be adapted to their resting times. Sometimes, we felt that our presence might impair professional work on the sites (e.g., personal conversations); however, we learned to recognize these situations and withdraw. We did not want to disturb the work on the sites; therefore, we did not immediately present ourselves to everyone entering, but waited for a suitable moment instead. We found that being present in the space—cooking, playing board games, and interacting with young people—helped us become part of it.

A couple of young people almost fell asleep at the table. I felt more relieved and dared to talk with some young people. They were cooking bacon and mushrooms. I helped make coffee, and in these short moments, you can get into a conversation [with young people]. (Excerpt from the fieldnotes, AH).

By spending time together (Sandberg & Copes, 2013), building mutual trust (Bengry-Howell & Griffin, 2012), doing things together, and showing the young people who we were, we were able to build trust. This led us to feel more comfortable, helped us observe “what actually goes on” (Hammersley, 2018), and enabled us to arrange interviews more independently. Characteristics such as our own past, knowledge, age, and reputation of our background organizations affected how we were received.

Interviewer: And [Outreach employee, who both interviewee and interviewer knew] knows me. If you feel like it, you can definitely ask and make sure that I am a trusted person.

Interviewee: Yes, I can see that. Otherwise, I would not have talked about these issues. I am good at reading people, even if I am young; I have experienced a lot. I would not have told you these things if I had not trusted you.

There should be enough flexibility and time for conducting interviews on young people's terms, and researchers should find the "right time" (Urry et al., 2015) for the interview. The young people often verbally communicated the belief that the subject was important and that they might show some interest in being interviewed; however, they often had something else to do or something in their lives that made them anxious. Many appointments were canceled, or the young person did not appear at the agreed-upon time. This led us to mostly abandon the original recruitment protocol of approaching a young person, presenting our study protocol, and scheduling an appointment. Instead, we created a more flexible protocol that enabled us to conduct "pop-up interviews" immediately after a young person had consented to participate.

The photovoice method was designed to empower and give agency to interviewees by encouraging them to picture hope in challenging life situations. However, what started as an empowering photovoice method (Wang & Burris, 1997) to deepen understanding of precarious life situations to generate sites of social change ended up more as a photo-elicitation tool for interviews (Harper, 2002). The use of photovoice proved challenging because it also contradicted the causal or spontaneous nature of the interviews. Of the six cameras handed out, only four camera films were developed. However, in the interviews where photos were used, the photos proved to be powerful and provided an avenue for the interviewee to express themselves through metaphors (Kantrowitz-Gordon & Vandermause, 2016).

Certain times seemed better than others for recruitment; factors such as the time of day (lunch, medication dispensing) and the time of the month (payment of social benefits) were mentioned as possible explanations. Most interviewees truly wanted to share their experiences in solidarity with helping other young people in similar situations (Fry & Dwyer, 2001). Some participants were surprised by the voucher given at the end of the interview. However, the voucher appeared to occasionally influence the interviewees' intentions to participate in the study (Bockgård et al., 2024). At least seven of the 24 interviewees either asked for the voucher or had a very short interview, as they did not want to share information.

The potential interviewee had to hurry, however, they promised to participate (afterward, I began to wonder if it was because of the gift card). (Excerpt from the fieldnotes, AH).

Preparations, training, and aftercare

As described in the previous sections, conducting research on sensitive topics among vulnerable populations can be challenging both for researchers and interviewees. Conducting it in an ethically sustainable manner requires planning and follow-up to take care of the researchers and participants' well-being. The protection methods used in our data collection included gaining prior knowledge of the surroundings, professional training in interviewing people who have experienced traumatic events, support for researchers throughout the study, and the provision of aftercare for interviewees.

When planning the data collection, it was helpful for us to gain as much understanding as possible of the study group and the surrounding environment. We discussed with an experienced researcher who had conducted similar observations and interviews to overcome the pitfalls unique to this study group. We also had numerous conversations with staff on the sites about the study protocol and recruitment practices, and visited the sites where data collection took place. As is typical for ethnographic studies (Chaudhuri, 2017), especially at the beginning of the observation and on the secondary sites, the role of the staff as “gatekeepers” or “guides” (Striepe & Cunningham, 2022) was often crucial in the recruitment process. However, the downside to this was that it was sometimes unclear to us why some young people were invited to be interviewed and others were not (e.g., Heath et al., 2007).

A couple of people came to the lobby, and [staff members] tried to approach with an information leaflet, but without success. They did not get any connection to a young person who was staring at his phone. Another young person took candy from the table, but [staff members] did not even ask if the person wanted to be interviewed. (Excerpt from the fieldnotes, AH).

Within the framework of the larger project, we formed a group of qualitative researchers who were going to conduct interviews with young people who had near-death experiences for support, training, and sharing. This group organized custom trauma training at the beginning of data collection. A crisis work professional was hired to conduct the one-day training. Similar training has been suggested for researchers studying trauma (Van Der Merwe & Hunt, 2019). Our training was divided into two parts: 1. Preparing and encountering, and 2. Debriefing. The first theme discussed what should be taken into account in an interview situation (space, time, the researcher’s appearance, grief, and cultural differences). It offered practical advice on breathing techniques, calming down, compassion fatigue, secondary traumatization, and mental imagery training. One important fact we learned was that it is not possible to ensure that certain questions or gestures in interviews will not hurt someone; however, it is possible to minimize risks while preparing. The second part focused on understanding and identifying the need for debriefing, as well as the techniques to support it.

Since the themes related to near-death experiences were not familiar or easy for us to handle, protocols were created to support the researchers’ well-being during the data collection phase. Even with the trauma training, there were situations in the interviews (and during observations) that made us feel shaken or in despair, such as descriptions of near-death experiences and hopeless life situations:

Interviewee: I have been a victim of sexual violence. It is something that happens repeatedly, because if you run in the drug scene, violence is present constantly. And women’s role in the drug scene, as Mercedes Bentso [Finnish female hip-hop artist] says it well, it is not like a dog, but it is not like a man either. That is well put. [interviewee continues to talk about specific offenses in detail].

A protocol was introduced to help researchers handle traumatic or challenging issues quickly. After the event, there was a rule granting them permission to contact the other researcher when discussing their observations or situations related to interviews. This

protocol was used during data collection, for example, in situations where an interviewee's detailed descriptions of suicides troubled the researcher, or the researcher sought a second opinion on a decision related to informed consent.

For less acute situations, we had scheduled meetings during the data collection in the larger group (five researchers) of qualitative researchers in the project. In these meetings, similar issues that were not considered acute were discussed together. We also shared tips such as bringing tissues, snacks, and juice to the interview. Five meetings for professional guidance from occupational health psychologists were arranged during the data collection process. In each session, we either discussed cases that were causing psychological burden for one or several researchers or more general issues related to data collection based on the researchers' needs.

The interview topics were sometimes stressful for the interviewees. In some cases we felt we were digging too deep or that we had touched on a topic the interviewee could not handle. These situations evoked tears, or the researcher sensed that the topic was psychologically too heavy. These feelings were highly subjective and could have provided useful information; however, we tried to direct the interview to other subjects (such as hope) and to determine whether there was a need to end the interview.

The interviewee began to get tired after twenty minutes; the questions may also have rubbed salt into the fresh wounds of a desperate situation. (Excerpt from the fieldnotes, AH.)

As a precaution, the interviews were always conducted at sites where professionals who knew these young people were present. We had discussed with the staff about the possibility of directing interviewees to them if they felt uneasy and wanted to talk with someone. Often, the interviewees stayed at the sites and spoke with the staff, even when there did not seem to be any problems. We encountered only a few such situations, which were connected to assumed symptoms of psychosis during the interview. The final question in the interview guide was a check-up about how the interviewee felt. However, the interviews sometimes ended abruptly when the interviewee wanted to leave, so it was not possible to ask about their feelings.

The interview lasted for a while, and they³ wanted to end it before the last questions. Although I felt that I had a connection with the interviewee, they were very timid about talking about personal things. (Excerpt from the fieldnotes, AH).

Methodological and ethical challenges in the research process

This section presents an overview of the methodological and ethical challenges that arose during the research process. This provides an opportunity to examine the results in relation to consent, data collection, and planning, training, and after care. This is presented in Table 1.

3 The singular "they" was used as a generic third-person singular pronoun to avoid making assumptions about gender (American Psychological Association, section 4.18).

Table 1. Methodological and ethical considerations in conducting qualitative research with hard-to-reach young people

	Consent	Data collection	Planning, training, and after care
Researcher's own role	Continuously assess functionality.	Become part of the space by being present. Find your own position and blend in.	Participate in training, receive support, and offer after care.
Recruitment	Inform people in several different ways. Use clear and understandable language.	Build trust through interaction and participatory methods. Find the "right time."	Communicate with staff members beforehand.
Conditions on the sites	Get to know the potential interviewees.	Prepare yourself for the participant's drug use, and intoxication. Ensure that the routine activities continue without disruption.	Familiarize yourself with the research sites and target group in advance.
Interview situation	Continue to evaluate consent and assess the level of intoxication.	Determine the role of any financial incentive.	Prepare yourself to address trauma.
Considering the protocol	Think about how to ensure anonymity and consent.	Allow sufficient time. Show flexibility and patience.	Ensure you are adequately prepared. Plan ahead, secure training, and establish a support network.
Informants and gatekeepers	Determine whether on-site staff could be consulted to assist in evaluating consent.	Ask about interviewees' intentions to participate.	Offer the possibility of aftercare for the interviewees if needed.

Discussion

This research was based on data on hard-to-reach young people who have experienced near-death experiences. The data was analyzed from the perspective of what kind of methodological and ethical challenges should be considered when reaching hard-to-reach young people with drug use and multiple challenges. Taken together, our findings demonstrate that working with hard-to-reach young people and sensitive issues poses challenges, but more importantly, the findings provide different approaches to overcome these challenges, as revealed in the analysis.

The study showed that in the context of young people who use drugs daily, the process of giving consent should be planned carefully so that it considers the group's special characteristics. When research is conducted in anonymous services, the requirement for written consent can contradict the service principles and be perceived as potentially harmful to people in vulnerable positions. From a scientific perspective, there is tension between "scientific positivism," the need to document consent, and "ethics of care," the need to protect people's privacy (see Neves & Malafaia, 2015). Bengry-Howell and Griffin (2012) have argued that, instead of traditional informed consent, consent should be seen as a more reciprocal, informal, and flexible process, formed case by case, depending on the setting and participants. If the gathering of written consent is deemed potentially harmful

(e.g., sensitive topics or people using anonymous services), verbal consent collected via voice recording, as done in this study, is one way to overcome this challenge.

Furthermore, the evaluation of participants' ability to give consent for interviews should be considered an ongoing process, from before the interview through to after it. The study showed that recognizing a person's dynamic vulnerability was not easy (Goldim et al., 2011) due to acute mental health issues or intoxication, as the ability to provide consent was situational and could change rapidly. There is no easy way to determine a person's current ability to provide consent, and the researcher's evaluation process was a balancing act between not being methodologically groomed (Bengry-Howell & Griffin, 2012) and not being too paternalistic (Pickering, 2018). However, different preparations helped in the process. First, it was important to provide multiple ways for participants to communicate their consent. Second, the researchers could consult staff members on the sites if they doubted the participant's ability to provide consent. Finally, a longer ethnographic observation period often enabled researchers to evaluate participants' ability to consent before and after the interviews.

Another issue related to consent was the use of a reward for participation. In the study of vulnerable low-income groups, such as those in this study, even small rewards can cause static vulnerability (Goldim et al., 2011). In contrast to Anglo-American discussions on participation as work (e.g., Pickering, 2018; Slomka et al., 2008), in Finland only rewards "insignificant in value" (e.g., "packages of coffee" or "candy") can be given to participants without them being subject to tax (Tax Administration, 2019), and the process of "hiring" interviewees by rewarding them with higher fees would complicate data collection and would require participants to hand over personal tax documents (loss of anonymity), thereby possibly resulting in an unexpected cut in social benefits (a negative consequence for the participant). Even though the vouchers were low in value, there were moments when we were not sure whether the young person was participating voluntarily or to obtain a gift card. However, it would not have been plausible to deny participation on the grounds that the researcher doubted the participant's motives.

In the data collection process, flexibility in response to challenges that arose during the data collection was a key feature that enabled us to study hard-to-reach groups of young people with acute drug use. Ethical or practical challenges occur unexpectedly, and often a decision, either to act or not, must be made on the spot using one's "personal, reflexive, context-specific ethical decision-making process" (Deuchar, 2015, p. 59). Even when the goal is to conduct interviews, data collection strategies should evolve to meet the needs of hard-to-reach groups. In this study, this meant, for example, that researchers had to adapt to the rules (e.g., anonymity) and routines (e.g., sleeping times) of low-threshold services and learn to build trust with people by talking and doing things together. As this study shows, ethnographic fieldwork can greatly support recruitment for interviews, and this should be considered when designing data collection for similar groups, as it improves the understanding of the interviewees' life situations and provides insight into how to approach them.

As a participatory method, photo-elicitation can create an open and creative way to discuss psychologically burdensome topics and to picture experiences without verbal expression. Although we found the method somewhat challenging with hard-to-reach subjects, the use of photos in interviews allowed us the possibility to broaden verbal-only interviews and deepen our understanding of the participants' lives (Bates et al., 2017).

Another main challenge in relation to data collection was time. Since the interviews had to occur on the young people's terms, it could take some time to find a suitable

time for the interview with these hard-to-reach groups. Compared to research interviews in general, it takes much longer for researchers to earn the trust of hard-to-reach young people. Trust-building requires that researchers first find their own position in the field, which can be a complex process (Chamberlain & Hodgetts, 2018). Initially, the researcher balances between being an insider and an outsider (Deuchar, 2015). Researchers should be ready to change their pre-planned interview protocol to meet the needs of hard-to-reach young people. The “right time” framework, suggested by Urry et al. (2015) for interviews with young people in vulnerable situations, offers a good approach for this.

Flexibility does not mean being unprepared; in contrast, various preparations, such as discussing with people who know the field beforehand, preparing to handle traumatic issues, and creating models to ensure well-being of researchers and interviewees, all increase flexibility during the data collection. Although ethnography “is learned mainly by doing,” ethnographers working with hard-to-reach populations have determined that some sort of training is useful (Sandberg & Copes, 2013, p. 181). Based on the experiences from our study, training in discussing traumatic issues and the opportunity for debriefing with someone (peer support and professional guidance) should be added to the research protocols for vulnerable, hard-to-reach populations to protect both researchers and interviewees. Researchers should readily be able to secure an opportunity to talk with another researcher about concerning issues, in addition to scheduled meetings and professional guidance from occupational health psychologists. The data collection process also showed that researchers should be prepared for questions that can feel challenging, and to decide beforehand what to reveal about themselves and what not to (Sandberg & Copes, 2013).

The researcher should remain reflective regarding sensitivity when studying hard-to-reach groups and their traumatic issues. Although interviews about sensitive and traumatic topics do not usually seem to cause distress for participants (Decker et al., 2011), it is important to take precautions before entering the field. Based on this research, it is beneficial to organize training on trauma-related issues for the researchers and to ensure that interviewees can speak with the trained staff on the sites after the interview, if needed.

Conclusion

To conclude, this study illustrated how consent should be considered in relation to anonymity, intoxication, and modes of communication when studying hard-to-reach groups. Ethnographic observation is a good way to get to know potential interviewees, build trust, and, in the end, identify suitable moments to conduct interviews. When conducting qualitative research on sensitive topics and among vulnerable groups, the well-being of researchers and interviewees should be considered when designing research protocols.

The findings are useful in preparation for data collection, in training researchers to engage with populations who are normally unheard (e.g., in political decision-making and in studies addressing the general population), and they provide new insights into ethical issues related to studies of young people who use drugs. There are no simple instructions for ethically conducting qualitative research with any hard-to-reach population, as researchers must often balance two or more conflicting ethical principles. There is therefore a need for flexibility, patience, and sufficient time, as the realities in the field will not match the original research plan, and solutions to difficult and unexpected

situations must often be made on the spot during observations and interviews. Effective preparation, planning, and training can provide tools to be reflective in the right way in these moments. We highly recommend that professional supervision and peer support are considered when designing study protocols addressing vulnerable populations or sensitive issues. This should already be done in the early stages of the research process to secure sufficient funding in the budget. These practices are standard with most occupational groups working with similar groups and issues (e.g., Dunsmuir & Leadbetter, 2010; Laming, 2009), but are sometimes overlooked in research.

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