Ethical challenges conducting research in environments for incarcerated children and adolescents

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Objective

The objective of this paper is to describe and discuss ethical challenges, and ethical stance, when conducting research with children and adolescents in compulsory institutional care. The challenges addressed have their origin in a research project, with an interdisciplinary research team, focusing on incarcerated adolescents' experience of the physical environment.

Introduction

In Sweden, The Swedish National Board of Institutional Care (SiS) provides compulsory institutional care of children and adolescents (youth). An overarching goal for the care provided by SiS is to promote a life without substance abuse, criminal activity, and violent or anti-social behaviour. The two-folded aim i.e., to (re)habilitate and to incarcerate, puts special demands on the physical environment, and adds to the experience of care and incarceration for youth in these "total institutions" (1, 2). The total institution, according to Goffman, is defined as a closed world in relation to a wider society, and includes a forced compulsory formalization of everyday life. To conduct research in this type of institutional settings is challenging from several points of view; the power structures embedded through incarceration, disciplinary distribution of space, a vulnerable group being research with, many times traumatized and struggling to handle mental health problems.

Young people's rehabilitation and reintegration take place in a socio-spatial context where the interaction between physical and spatial conditions with social interrelation must be taken in consideration. This means that the socio-spatial context can either enhance or limit these social interrelations in terms of design and spatial layout. This also counts for staff's ability to use their competence and commitment to give care and establish supportive relations. To the best of our knowledge, the field of research regarding young people in compulsory care is scarce. Young people in compulsory care are identified with complex behaviour, psychosocial problems, and anti-social behaviour which causes great difficulties in everyday activities. From time to time, threats and violent behaviour, which may also be seen as resistance to loss of power, may cause a need for coercive measures, which causes distress for all involved. Violent and anti-social behaviour can as well be explained by a variety of complex factors, e.g. neuro-psychiatric diagnosis, learning disabilities, and stress, as well as untrained staff and a poor physical environment that lacks necessary features to support staff and youth.

As researchers doing fieldwork at the SiS homes, we have met youth who have witnessed of their experiences of harm and discomfort caused by the physical environment. We have also been told disturbing stories about maltreatment from staff. Within the research group we have been uncomfortable in how to handle the troubling information, as well as what we have witnessed and experienced ourselves in regards to incidents, but also how to handle a number of environments

unworthy for youth that need care. We realised that we needed an action plan to handle what we experienced. As all researchers that do research with vulnerable groups, we are given life stories that rarely are positive. As any human being we bring these stories with us at the end of the day, and we are affected. This is another dimension we felt we needed to handle.

Rationale

General assessment and ethical considerations

This paper discusses ethical challenges in relation to research focusing on the physical environment's role for incarcerated youth, bringing on questions to ethical issues related to, in our case, qualitative methods during fieldwork including e.g., open-ended interviews and observations.

Ethical standards e.g., principle of research ethics: Respect for autonomy; Beneficence; Non-maleficence and Justice (3) are reflected upon. Further, the child rights perspective, especially through the Convention of the Rights of the Child is used to discuss and analyse ethical challenges in the field (4).

Research including children and adolescents should be guided by the aim to do good, not cause harm, and to empower the participants (5). In this specific context, the aim to do good means to raise awareness and expand the knowledge base to what prerequisites may be needed to promote care and rehabilitation for youth. Moreover, such research has an explicit child rights perspective. According to the Convention on the Rights of the Child (4), care environments aimed at rehabilitating vulnerable children must "promote the child's health, self-respect and dignity" (Article 39). This also, evidently, applies to youth who have committed crimes (Article 40). The best interest of the child, as a principle should lead, and the child protection aspect should be emphasized (4). This means not only to take in consideration the physical environment, but also to empower and support youth' voices to become heard, i.e., conducting research for and with these children and adolescents.

Youth under compulsory institutional care constitute a vulnerable group. To capture lived experience of incarcerated youth, research needs to be conducted in place. To understand, experience, and feel the physical environment through the youth's perspective, implicates a need to experience their everyday lived place and space together with the youth, that is to do research *with*, not on them (5).

Interactions between the youth, staff and the physical environment have been studied in the research project, as well as the youth's experience of their immediate surroundings. The qualitative data collection during fieldwork in the research project uses visual methods which have proven to be suitable when conducting research with children (6). Visual methods can reduce the imbalance in power between the researcher and the participant (7, 8), images can also facilitate talk about such abstract phenomena as the physical care environment and its details. Visual methods have further been found useful in relation to ethics and security restrictions in the study of prisons (9) and psychiatric hospitals (10). The visual methods we have used are Photovoice and "Sketch and Talk" Photovoice invites participants to take images of what matters to them, in this case in relation to the physical environment, giving them ownership of the creation and interpretation of the image. The images taken are then followed up by open-ended interviews (11). This process is a means to empower and give voice to vulnerable groups when brought to decision makers and brings important democratic and critical issues in play (12, 13). "Sketch and Talk" is an ethnographic design research method for data collection. It consists of open-ended interviews with simultaneous sketching and note-taking by hand by the researcher. Mainly in the environment where the youth resides. The visual documentation focuses on phenomena of the physical environment that is essential to the participant. Moreover, the sketching is an open transparent visible process, thus giving the participant full insight to the collected data (9). Observations have also been used to

collect data, setting the researcher in a position between youth and staff, sometimes an odd experience challenging loyalty and trust.

Methods

The research project has ethical approval from the regional ethical committee (14) and the data collection is preceded by the young people's consent together with the aim of a dignified, respectful and reflective approach to not do harm. However, still there is a risk of ethical dilemmas during the data collection process for the researchers when witnessing incidents, offensive behaviour, or passed on stories of abuse and maltreatment, given in the interviews with the youth. However, it is important to stress the fact that the researchers have not asked for this type of information, the focus has solely been on the experience of the physical environment. Nevertheless, this information has become evident in stories related to the physical and socio-spatial environment. It may be in some situations obvious that confidentiality might need to be broken and measures taken immediately, while in other cases it may be that the child or adolescents would not benefit from such actions. This implies that a traditional and compulsory ethical approval to conduct these studies is not a sufficient in itself for guiding the research team. Rather, an ethical codex to guide in situations such above, was needed to guide and support the research team. Researchers in Sweden are not covered by the legislation (18) to immediately report suspicion when they see that a child may be mistreated. For development of the ethical codex, ethical standards and theories were used to critically analyse ethical challenges in the field, through cross disciplinary discussions. Ethical standards e.g., principle of research ethics: Respect for autonomy; Beneficence; Non-maleficence and Justice (3) were reflected upon in relation to specific challenges experienced during data collection. Further, the child rights perspective, especially through the Convention of the Rights of the Child were used to discuss and analyse ethical challenges in the field (4).

Experiences, implications and ethical challenges

The social and physical environment of the special residential youth homes, differentiate in several ways from other care environments such as primary care clinics, hospitals and community social services. First, the youth are there involuntary, i.e. they are cared for under permit of law. Second, a majority of the children and adolescents are underage, the youngest being 12 years old or sometimes younger, and the oldest twenty-one. Third, the youth often suffer from psychosocial and cognitive problems and/or substance abuse, lack stable family situation and relations. Fourth, the Swedish National Board of Institutional Care (SiS), unlike other care facilities has far-reaching powers, e.g., to separate a child or adolescent from the rest of the group, use physical force, and to search the youths' mail and individual belongings, to mention a few examples (15, 16, 17).

From a research perspective, the above stated circumstances, in relation to the specific social and physical environment, are important to study, but also what constitutes the ethical challenges. First, the "involuntary aspect", creates an inevitable power imbalance and tension between the staff and the youth, as well as between the researchers and the adolescents. While "we" (staff, researchers) can pack our things and leave by the end of the day, "they" (youth) remain in the institution. These opposite "degrees of freedom" (ability to leave/forced to stay) creates an entrance to the research situation (for example the interview situation), characterized by a power imbalance. Second, the respondents (i.e. the youth) are young children and adolescents, whom we as researchers and adults encounter in a situation where they are far from their parents/guardians and friends. In addition, this research need to be conducted *in place* together with the participants, often in their rooms. With this comes a great responsibility and need for responsiveness to the specific terms of temporal reality for the youth, they need "hang around time" before getting down to the possible interview situation, and their plans can instantly be changed, moreover, time is needed to build trust.

Adaptability by the researchers in terms of taking a break or ending the interview whenever the youth need or wish is a must. This, also, refers to the third aspect, concerning the youth's psychosocial and cognitive problems and/or substance abuse withdrawal. This aspect has two sides; first, the youth may have a "bad day", feeling sad or have received a troubling message; they may also have difficulties to understand the research information due to ADHD or autism with consequences as restlessness, difficulty to focus or communicate. Thirdly, due to the above-mentioned psychosocial and cognitive difficulties, there could be a risk of externalizing behavior, threat and violence. These two sides, put demands on the researcher. On the one hand, to be sensitive and responsive to the youth's needs and feelings, on the other hand, to take into consideration the researchers' own security. This sets certain difficulties to personal integrity, as well as to risk for the researcher to either be subject to provocations, or risk to be accused for improper behavior. The fourth and last aspect, concerning the caregivers' far-reaching powers to intervene, could lead to that the researchers may witness situations of misconduct where staff exceed their possession of power. This leaving the researchers in a difficult ethical situation.The decision to take action direct, or to await and document the results from the research, constitute a careful valuing that needs to take place in every single situation. Direct action may benefit the child or adolescent in a specific situation of for example being cared for in an unworthy physical environment. Accordingly, the intention with our research being to raise knowledge and to contribute to improvement in the institutional physical environment, could potentially be challenged by direct action, through denied further access to the research field. Which in turn would lead to lack of knowledge and hence lack of potential improvements.

When doing fieldwork, how do we maintain our security but not communicate distrust? So far there have been a few incidents, though not severe. But we need to remember that we are the intruders, and violate private space. We also need to remember that it is possible that we might do harm unintentionally, or stir up feelings in the group of youth, leading to turbulence. We have also experienced situations where youth have been corrected by staff regarding youth's behavior directed towards us. Where does that place us in relation to the youth, and their trust in us? Staff and leaders will also be provoked when/if we come with serious critique pointing out their failure to how the physical environment has been neglected. The ethical dilemma here is not so much communicating what we see, but if the research project gains by bringing up troubling issues with the physical environment now, or in our papers and final report.

Navigating in partly new territory, we needed to be open for re-evaluation of how we conduct our methods, and emphasize respect and ethical stance in our approach to the youth we met. This shows in guiding principles of "hang around-time" spent at the institutions and the wards, to create relationships and gain trust, and wait for the youth to come to us. A necessary but gentle and sensitive process characterized by respect and dignity for the youth. The second guiding principle connected to data collection, regarding the researchers' safety and data reliability has developed to that two researchers always are present in interview and observational situations, and to be cautious to our composition of gender. The necessity to balance the teamwork in this intimate situation, with the respect for the respondent's integrity was discussed in the research group, resulting in practical guidelines aiming for power equalizing while maintaining security. This led to rethink how to approach the youth at the actual interview situation, e.g. the two researchers now sit on the floor, while the young person usually sits on the bed or on the floor. It is not only the difference in height that mitigates the imbalance in power, the researchers always ask if it is ok to sit on the floor, or enter the room, i.e., the respondent can place the researcher in the distance or place that is desired, or chose another place for the interview.

With the bundle of ethical dilemmas and experiences mentioned the research group stated a step-by-step action plan. The action plan constitutes several steps, from open and continuous discussion of ethical dilemmas within the research group, to consulting colleagues and professionals and if needed, breaking the secrecy for the benefit of the child. In the case researchers note serious abuse or severe incidents during ongoing data collection, the ethical codex states a five-step plan: 1, discussion within the research group. 2, information to the head of the unit or the head of the institution. 3, if deemed necessary, the research and development manager at SiS is contacted. 4, in cases were the situation so requires, report to the Health and Social Care Inspectorate (IVO), 5, debriefing. If any of the researchers are subjected to offensive behavior or violence during data collection, the procedure is similar as to what was just described.

Besides the guiding principles, the ethical codex also states that the research group should establish a contact network with children's rights organizations. This partly in order to be able to convey to the youth what support they can get when needed and partly to exchange advice and experiences with regard to noted misconduct.

Conclusion

Research in the context of compulsory institutional care of youth requires constant ethical awareness and sensitivity, as well as precautions to handle unforeseen ethical dilemmas, hence the need of the ethical codex. Irrespective of the research being qualitative and implicate close interaction between researchers and vulnerable groups, or quantitative with access to highly sensitive large-scale data material, there is a necessity for the researchers to be power sensitive, self-reflective and to practice high ethical standards. As researchers, we need to remember that we are the intruders, and violate private space, though doing research on the physical environment can possibly be less provocative than other areas of research, nevertheless, we need to create awareness also to our specific field of research.

We hope that the ethical challenges discussed in this paper can aid other researchers in the field of creating knowledge in similar settings.

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