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Care foundations: making care central in research with care-experienced people

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Considering a 'caring' view in the research process

The field of leaving-care research has experienced increasing diversity in its philosophies and methodological approaches within social sciences research over the past two decades, but challenges with power imbalances between researchers and participants still exist (Hunter et al, 2011a, 2011b). As care-experienced people often experience limited control over their affairs during their time in care (Sinclair et al, 2005; Unrau et al, 2008) and high levels of relational instability (Avery and Freundlich, 2009; Chambers et al, 2018), the temporary and structural nature of research relationships pose potential harms to this population. Researchers can address this risk of harm by paying attention to how the distance between 'the studied' and 'the researcher' can be closed, sharing power and balancing benefit to participants with benefit to the field. We suggest that these risk-reduction activities create 'care' in the research relationship.

The nature of distance in the research relationship depends on which approach to constructing knowledge (epistemology) the researcher adopts. In the positivist tradition, truth is absolute; there exists one truth and knowledge is generated by observing and analysing evidence (Moon and Blackman, 2014). Distance is necessary to maintain objectivity; getting too close to the research participants invites bias and clouds the ability to see the truth. In constructivist and subjectivist traditions, truth is relative and knowledge is co-constructed between the researcher and the participant. Knowledge is derived by examining either how participants create meaning around different experiences (constructivism) or how reality itself is perceived and shapes the experiences of participants (subjectivism) (Moon and Blackman, 2014). In both traditions, researchers evaluate evidence and generate claims about the lives of participants.

To avoid harms that might come from the inherent power imbalance within relationships (Cohn and Lyons, 2003), research must be free from coercion and conducted with informed consent (respect for persons); minimise harm and maximise benefits to participants and society (non-maleficence and beneficence); and treat all participants as equal, while avoiding overburdening those who are most vulnerable (justice) (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). In a traditional paradigm, research has focused heavily on non-maleficence to participants and beneficence to the field (Pieper and Thomson, 2016). Noticeably missing from this paradigm is the maximised benefit towards participants themselves within the context of the study (positive beneficence); the paradigm sees ethical standards as met, so long as society benefits and participants are relatively unharmed (Ruch, 2014; Pieper and Thomson, 2016).

In a parallel process, the academy and other social institutions evaluate and credential researchers on their ability to secure funding, publish, or affect social change using their research (Hammersley, 2003). Scientific research-funding bodies, editors of high-impact journals and policy-making bodies may privilege positivist research in both academic and practical forms of inquiry (Rogers, 2012; Levitt et al, 2017). In this sense, 'objectivity' in the research process, and the distance this requires, is valued and rewarded.

In our exploration of care, power (by virtue of objective distance) and traditional ethics (due to the lack of attention to positive beneficence) present the greatest barriers to establishing care in the research relationship. When preference is given to distance, the inherent hierarchy of the research relationship positions the researcher as the sole expert. Researchers evaluate the ability of participants to recount or make meaning of their experiences. This power represents a form of *epistemic injustice*; plainly, decisions by those with power (in this context, researchers) about who knows something by virtue of their experiences or credentials and whether they possess the ability to derive meaning or advance inquiry from their experiences (Fricker, 2007; Grasswick, 2017). The voices of participants, their needs as individuals or their stated desires for policy/practice change may be overlooked by the researcher (expert) making meaning of participants' experiences. This represents a specific type of power imbalance; participants' credibility in knowing the field based on lived experience or ability to inform inquiry is limited to what the researchers deem relevant or plausible.

Adding complexity to the matter of epistemic injustice is the case of an insider researcher – a researcher who is also part of the population they study. The ability of insider researchers to remain objective is questioned and their work may be seen as less credible (Grasswick, 2017). This extends to research viewing participants as co-equal partners in the construction of knowledge. Yet excluding research participants' voices may contradict the helping professions' declared aim of producing emancipatory research with vulnerable populations (Rogers, 2012; Ruch, 2014). If the purpose of research within the helping professions is to empower those most vulnerable, we believe a deeper investigation into the concept of care (shared power and positive beneficence) is necessary to explore our ethical conduct of research with care-experienced people.

In this chapter we discuss how 'care' (in research conduct and interactions) can be inserted into the design, conduct and dissemination of research. First, we describe how researchers can attend to the positive beneficence of research by anticipating and planning around the risks and needs of participants in leaving-care research. Second, we illustrate the value of engaging care-experienced people in the analysis, interpretation, drafting and dissemination of research data. Third, the care-experienced authors of this chapter provide reflections of their experiences as both researchers and participants. The chapter concludes with a summary of practical advice for those engaging with care-experienced people in research.

Considering care during research design

How can we implement 'care' as an empathic, caring researcher-researched relationship at the early stages of study design? 'Care' can have different facets as different actors and actions are involved in the planning stage of a research project with care-experienced young people: choosing the research topic, designing and testing the research tools, establishing relationships with care-experienced people and gatekeepers, and ensuring potential participants can make informed decisions about participation. Apart from the common ethical principles, of voluntariness or confidentiality, and methodical considerations, in this section, we consider the relationship between the different actors in leaving-care research and how to establish a caring, trustful foundation in the early stage of the research.

Leaving-care research aims to understand and improve the lives of young people in the transition from care to adulthood. Participants need to be protected from harm such as re-traumatisation, by using, for instance, a trauma-informed research approach (Epp et al, 2022). This applies for researchers as well. A leaving-care researcher may be confronted with sensitive information. Care in the choice of topic addresses the researchers' abilities to keep participants safe while dealing with such topics themselves in terms of self-care and maintaining emotional boundaries. Emotional boundaries are essential considering the risk of secondary trauma for researchers exposed to traumatic reports (Whitt-Woosley and Sprang, 2018; van der Merwe and Hunt, 2019). The challenge is maintaining professional boundaries to protect oneself from secondary trauma while simultaneously being empathic. This balance is important for addressing participants' potential emotional reactions adequately. As many leaving-care researchers have training in social work practice or related professions, their clinical training in how to deal with traumatic content, emotional distress and mental health issues may also be helpful in the role of a researcher (Mendes et al, 2014). A caring professional relationship means that researchers are prepared to deal with this content adequately, for instance, by undertaking extra training to deal with emotional distress occurring during the research process.

As in participatory research, care-experienced young people may get involved in the early research design. If this is not possible, for example, due to limited financial and time resources (Kelly et al, 2020), it is important to consult a small group of care-experienced young people for reviewing the research tools before starting the data collection. The early feedback from care-experienced young people helps to clarify language and emotional reactions. The integration of their ideas and wishes implies a respectful and participatory attitude, which harmonises the roles of researchers and the researched. Consulting people with care experience in advance to develop a common language can increase engagement with gatekeepers and potential participants. For example, among the first steps in designing a leaving-care research project researchers are strongly advised to consult care-experienced people at the beginning of the process to discuss the preferred, inclusive terminology which is suitable for the group they want to address, like 'care-leaver', 'care-experienced people' or 'young people leaving care'.

Furthermore, gatekeepers can be protective of the young people they work with. They may raise concerns about the potential triggering effects and overall safety of children and young people participating in research. It is, therefore, essential to address any concerns raised by gatekeepers and to have a safety plan in place to ensure research participants can receive the support they need if they become distressed as a result of participating in the research process.

The following example is presented by the second author to demonstrate how she addressed safety concerns by gatekeepers whom she approached to collaborate in her PhD research project about suicidal ideation among care-experienced people. I (Göbbels-Koch) will write in the first person about my experiences. For this study, I conducted an online survey and semi-structured interviews with care-experienced adults in England and Germany between July 2020 to June 2021 (see Göbbels-Koch, 2022). As a preparation, I reviewed the literature on triggering, so-called iatrogenic effects of questions about suicidal ideation and suicide risk screening tools in research (DeCou and Schumann, 2018). Current evidence does not suggest that questions about suicidal experiences would be harmful (Bajaj et al, 2008). Moreover, participation in research on sensitive topics can also offer beneficial effects (see Mendes et al, 2014).

Several gatekeepers raised concerns about triggering effects of questions related to this sensitive topic. Having reviewed the literature on those feared effects, I was able to address these concerns with evidence-informed background knowledge and confirm that research on such sensitive topics is safe to conduct while still having safety measures in place, such as having supportive contacts available and a protocol on how to intervene if a participant shows distress or discloses being at imminent risk. In this context, additional training on interventions for addressing emotional reactions or distress, such as disclosure of the acute risk of suicide or traumatic content, can benefit both participants and the researcher's confidence in safely conducting research. Furthermore, a beneficial impact of well-prepared research with a 'caring' principle was confirmed by participants themselves. At the end of the interviews conducted for this study (see Göbbels-Koch, 2022), some of the care-experienced participants reflected on how they felt after talking about their experiences of suicidal ideation:

> 'Yeah, good. Actually, I feel better now 'cause I do like getting stuff off my chest. It has the opposite effect of what you think it would. I actually feel much better now.' (Male, 19 years old)
>
> 'But actually this is been (-) a lot more pleasant than I sup(-) pleasant […] would not work, it's been (-) it's been nicer than I thought it would be talking about this stuff actually.' (Female, 30 years old)

These quotes contrast the concerns raised by a few gatekeepers previously. The feedback of previous participants could be discussed with future gatekeepers during the research process. Therefore, being aware of possible concerns may help to have a constructive conversation with gatekeepers to assure them about the safety of participation and that the researcher cares for everyone involved. Being able to address concerns about participants' wellbeing is about creating trusting relationships with gatekeepers.

At the same time, gatekeepers also play an essential supportive role after a young person has participated in a study. They can provide additional support and extended debriefing after participating in a study for which researchers may have only limited resources. Hence, establishing collaborative relationships with gatekeepers is essential in the study design for leaving-care research.

Forming caring relationships in a research project may profit from multiple contacts with (potential) participants. Longer relationships help build rapport to make the young person feel more comfortable, confident and possibly more communicative during the interview (Keller et al, 2016). A meeting or call in advance may be useful when planning to conduct one-to-one interviews with care-experienced young people. Such an introduction provides participants with further information about the research and the opportunity to ask questions before agreeing to participate. Inviting potential participants to ask the researcher questions gives them an empowering opportunity that further balances the roles between the researcher and the researched and builds rapport (Karnieli-Miller et al, 2009).

Furthermore, the researcher and the potential participant can get an idea of how the participant feels about talking about the topic. If investigating a sensitive topic, this would be an opportunity to discuss together a safety net in case of distress (see Keller et al, 2016). This approach would contribute to a caring and trustful relationship where the steps to build rapport start ahead of the first interview.

'Care' in research with care-experienced people can be implemented from an early stage of the study design and provides multiple advantages for the research process. Starting off the research with a 'caring' principle can be reached by engaging with gatekeepers, care-experienced advisors and potential participants during the conceptualisation and design of the study.

Considering care during analysis and dissemination

Youth engagement has been described as the meaningful and sustainable involvement of young people in decisions that affect them (Smith et al, 2009; Checkoway, 2011). This can and should include their engagement in research that affects young people, to ensure they are not just subjects of research, but active participants in knowledge generation and mobilisation. Hawke et al (2020) believe such engagement is a moral imperative and note the particular value of engaging youth as full partners from design to dissemination.

Engaging vulnerable individuals in research projects that relate to their lived experiences and needs increases the quality of the research, as well as its relevance to the target population (Hawke et al, 2020). Effectively engaging vulnerable youth in the research process offers both the youth and the researcher the opportunity to learn from the other's experience and expertise, as they work towards a common goal (Powers and Tiffany, 2006). However, there is a dearth of training and learning opportunities about youth engagement across academic settings, which can result in a failure to engage young people in authentic ways and exclude them from key stages of the research (Hawke et al, 2020).

Ensuring the sustained meaningful engagement of care-experienced young people throughout the research process can be challenging. In addition to many researchers lacking experience in effective youth engagement strategies (Hawke et al, 2018), care-experienced youth often have histories of trauma, have experienced unhealthy relationships with adults and can be struggling with personal and systemic issues that make committing to a lengthy project difficult. Meanwhile, researchers who do engage young people often focus solely on getting their input into the design and data collection for their study and pay little attention to keeping young people engaged post-data collection. For example, a review of 399 studies that considered engaging youth in research found that participants were most likely to be involved in identifying the needs, priorities and goals of research, and in designing or conducting the research; and were least likely to be involved in data analysis, interpretation and dissemination of findings (Jacquez et al, 2013).

The pressure on researchers to publish is often cited as a reason why the time and effort required to successfully sustain youth engagement is too difficult to achieve (Tsang et al, 2020). There is often an assumption that youth are not interested in data analysis or have not yet developed the cognitive skills to understand empirical concepts (Jacquez et al, 2013). However, an evaluation of a project to engage care-experienced youth in research clearly contradicts these assumptions and as one participant noted: 'There were many skills around data analysis and problem solving that I learned. I think the problem-solving skills will be very useful in other situations' (Peled, 2021: 8).

Providing opportunities for care-experienced youth to engage in the post-data-collection process offers them the chance to gain skills in areas such as public speaking, leadership, teamwork, time management, planning and facilitating workshops and creating dissemination materials (McCreary Centre Society's Youth Research Academy, 2016). For example, an evaluation of a project that engaged young people with mental health challenges in data analysis, interpretation and dissemination (Peled et al, 2017) found that all 27 participants stayed engaged until the conclusion of the project and all reported that the experience was meaningful to them. The majority also reported improvements in their research skills, emotional wellbeing and connectedness to other young people and their community.

Similarly, a large-scale survey of homeless youth that included young people in all stages of the research process (Smith et al, 2020) found that the youth not only gained skills in survey design, data collection, creating dissemination materials, workshop facilitation and public speaking, but also noted that the experience improved their employment opportunities, increased their self-confidence, helped them find their career path and made them feel they were making a difference in the lives of other homeless youth. After disseminating the findings, one of the youth researchers stated: 'Sharing what we found felt good and it let people know not all homeless youth use drugs or alcohol, and that the number who do is dropping' (Smith et al, 2015: 13).

Engaging care-experienced young people post-data collection can be challenging. It is important to ensure researchers strike an appropriate balance between honouring youth's abilities and commitment, while also not overwhelming or tokenising their input. There is a need to ensure sufficient time and resources are in place to support the engagement process, nurture relationships between members of the research team, work through challenges and celebrate successes. However, participants in such projects (for example, Peled, 2021: 11) recognise the value of these opportunities: '[T]he information I learned has informed my career choice … I've also realised that I bring value to the table.' Another stated: 'I felt that I was able to participate in a meaningful activity and that I was listened to. The research projects exceeded my expectations' (Peled, 2021).

An example of meaningfully engaging care-experienced youth throughout the research process comes from McCreary Centre Society's Youth Research Academy (YRA) which is based in Vancouver, Canada and was co-developed by author four [AS].[1] The YRA is designed to engage care-experienced youth in community-based research. Trained and supported by experienced community researchers, youth members of the YRA conduct academically rigorous, community-based research projects that address issues of concern to youth in and from care and the agencies that serve them.

Members of the YRA learn to create an analysis plan, conduct data analysis, write reports and disseminate findings. For example, under the guidance of a senior community-based researcher they learn basic SPSS skills (statistical software), including how to set up a data file, run frequencies and crosstabulations, perform data transformation skills such as recodes, and save and interpret the output. Throughout the process, they reflect on their findings and interpret the data (for example, McCreary Centre Society's Youth Research Academy, 2022). As one YRA participant noted: 'Youth in care need a voice and sometimes it's hard for us to speak up and I really think getting us involved and to share research helps. It gives us a voice and helps us to tell a story without making us have to expose our own story' (male youth) (Peled, 2021: 22).

Evaluation results show that the YRA model has not only offered authentic youth-led research to statutory and community agencies but has also offered impactful learning opportunities for youth with care experience (Smith et al, 2019). For example, one youth who analysed data about vaping reflected:

> 'I learned some new SPSS analysis skills and learned about the various associations between vaping and other aspects of youth health. I learned about opinions that other youth have on vaping, how different things that can happen in your life can affect if you vape or not, and that I had some big misconceptions about vaping' (non-binary youth). (Smith et al, 2019: 35)

YRA members' engagement in the development and delivery of dissemination materials has also been shown to increase their sense of ownership, satisfaction and enjoyment in the process, as well as their sense of optimism and chance to network (Smith et al, 2019; McCreary Centre Society's Youth Research Academy, 2020). As one female youth researcher noted in Peled (2021: 10): 'Before joining the YRA, I had no idea that there was a community of youth from care, and only by going out doing presentations and workshops and things did I find all the other opportunities available to us, and MANY other great connections.'

Learnings from the YRA model show that significant change can occur when young people with care experience are supported and trained to fully engage in the entire research process. For example, having reviewed dissemination materials created by the YRA from a research project about how to better support youth who use substances, the British Columbia Representative for Children and Youth called on the government to create a number of youth-specific supports (Charlesworth, 2018).

Ensuring the sustained meaningful engagement of care-experienced young people throughout the research process can be challenging. However, their lived experience, voice and meaningful participation in the co-production of research is invaluable in enhancing the quality of the topic being researched. Additionally, ensuring dissemination materials accurately capture the challenges, supports and emerging issues of care-experienced young people, which adult researchers without care experience would likely have missed. Such engagement in the research process moves the emphasis beyond the ethical standpoint of doing no harm to a focus on authentic reciprocity.

Reflections on the advantages and challenges of insider researcher: considerations for others

Charmaz (2014) states that the researcher's standpoint shapes how we see participants' stories and may stand in juxtaposition to theirs. We may unconsciously select aspects of their lives or episodes within their stories to illustrate our own and by so doing we can support their voices or distort their realities as we know them. The idea of the researcher position arguably becomes complex when you find yourself researching a community or setting you have direct involvement or connection with. Being an 'insider' can have both advantages and challenges. The two authors of this chapter who have care experience discuss how the role of the researcher in creating caring relationships can become tricky when one is care-experienced. We also report how we mitigated issues related to, for example, power in previous research projects that related to our positions in research. We highlight how we, as insider researchers, are experts of our own experience and how research participants also are experts of their own experience. This allows us to craft a caring means of sharing power, including the power to construct knowledge.

As described earlier, there are many ways in which we can care for those participating in the research from the beginning of the research process to the end. However, during the research process we can deploy several methods to ensure caring, respectful rapport is built. For example, in research

I (Farragher) carried out, I found various ways to ensure care for both my participants and for myself as a care-experienced researcher. The aim of the research was to understand ideas and experiences of 'family' for those with care experience. I never found myself to be fully objective and understood that I had my own preconceptions and bias about family, family relationships and the care system in Ireland, given I spent several years in care. I held assumptions about truth and knowledge that are derived from a variety of social contexts. In line with my constructivist grounded theory research design (Charmaz, 2014), I understood the necessity of acknowledging and examining personal assumptions and values, to not excessively hinder or influence the findings of the study. In conjunction with a postmodern perspective, I also reflected on and was committed to adopt collaborative and participant-centred approaches to the research methodology.

One of the ways I acknowledged my position was through the process of reflecting on my position. I wrote memos and reflective notes (much like a diary) from the early stages of the research process. The recording of the researchers' decisions, emotions and insights along with field notes, memo-writing and personal notes are processes described by Greene (2014) and Probst and Berenson (2014) as exercises in reflexivity. While the meaning of reflexivity can differ depending on the context, reflexivity in qualitative research tends to be understood as an awareness of the influence of the researcher on the research and, simultaneously, how the research process affects the researcher (Greene, 2014; Probst and Berenson, 2014). As Probst and Berenson note (2014: 814), reflexivity is both a 'state of mind and a set of actions' which informs the research experience as it is taking place. Engaging in this allowed me to develop a daily writing habit, take time to stop and notice, and crucially, to reflect on what I had already read, ensuring I did not impose meaning on the data.

Additionally, according to Plesner (2011: 471), the issue of power imbalances 'has been an issue for anthropologists concerned with how to elicit stories from otherwise marginalized groups, feminists concerned with giving voice to silenced groups of women and action researchers concerned with making sure research takes into account the needs and wants of the researched'. Reading Plesner's (2011) and Nader's (1974) ideas about a researcher position made me reflect on my position during the research and how I might be viewed by participants given my insider status. The constructivist grounded theory research design that was used helped me give primacy to the data generated in the interviews and enhanced my awareness of possible bias. I emphasised key principles of respect, informed consent, beneficence, non-maleficence and integrity. I also endeavoured to help participants feel authentically cared for, by giving them a list of contact details for support services should they be upset and wish to speak with someone following an interview.

Another way in which the questions of power imbalance, ethics and control (particularly related to my own care experience and insider status) were handled was through practical steps. Before the participants met with me, they had an opportunity to read that I too had an experience of the care system and so insider status was disclosed. When I met with the participants for the interviews, and fully informed consent was given verbally and in writing, I again disclosed that I had care experience and that the current study was something I had a great interest in. Building this rapport, allowing participants to choose the time and place of interview and viewing the interviews as an occasion for both my and the participants' meaning-making, made me realise that the study was not to be carried out simply from a bottom-up or top-down approach, but with a meeting in the middle approach whereby I understood the participants were experts by experience and a co-producer of knowledge.

In contrast to Farragher, I (Horn) conducted a qualitative study in which I did not immediately disclose my care-experienced status to the participants; rather, I let this disclosure unfold organically as the research interviews progressed by echoing how their experiences matched (or did not match) my own care experience. I made this decision to encourage the participants to engage in rich description of their own experiences of seeking support during their time at university and to decentre my voice in the research relationship. In my view, participants who knew from the outset about my care experience might try to use our shared experiences to develop a shorthand in explaining their experiences, which could lead to miscommunication as care in the United States can be meaningfully different between jurisdictions. This would in turn lead to an issue when centring the voices of participants by not being able to accurately capture the nuance of their experiences in publications. Despite this practice of strategic disclosure, I also recognised, as an analyst of the data, my care experience allowed some insight into how some of the narrative fit together, particularly with regards to settings and how stigma was experienced in other places. While both Farragher and I made different choices about where in the process we would disclose our experiences, we both saw the value of sharing our insider status with participants as we believe sharing who we are as researchers is important in reducing the power imbalance traditionally held between researchers and participants. The value of being an insider researcher was supported by one of the participants in my study of care-leaving college graduates (Horn, 2020): '"[T]he research I'm doing as a doc student, that sort of insider perspective, that deep empathy from having that lived experience, has been so key in not only getting me through the programme, but maintaining my role in this profession long term" (Sarah).'

Despite using strategic disclosure to ensure the participants' voices stayed central to the work, I also recognised that some in the academy might view my ability to give accurate analysis of the data with great scepticism because of my care experience. Prior to engaging in research, it had been intimated to me that I should make sure I didn't allow my own experiences of care to bleed into my work. During the process of data analysis, I consulted two data auditors and shared draft findings. One of the two data auditors was a care-experienced researcher and the other a subject matter expert. The auditors reviewed three transcripts of interviews and looked at case summaries for each participant. They then reviewed the common themes I reported and determined if the data supported my findings. By adding this level of rigour to the study, I was able to ensure that my voice was placed secondary in the analysis to that of the participants.

The two of us who are care-experienced (Farragher and Horn) have had to undertake these extra steps in the research process to address issues of *participatory injustice*, a form of epistemic injustice in which members of a studied group are denied credibility to contribute to inquiry on issues important to their lives (Grasswick, 2017). Despite being as qualified by virtue of training and education in conducting research as non-care-experienced researchers, we have both been subject to critique about our ability to separate our own perspectives on the topic from those of our participants (in qualitative research) or examined data (in quantitative research). We have both received pushback from colleagues about our approach to integrating care into our research practices. Critiques such as these contribute to the larger issue of epistemic injustice and power imbalance by establishing different criteria for engaging in rigorous research for those with insider perspectives than those without. This type of practice is also reflected in the experiences of our outsider researcher colleagues who have found ways to involve care-experienced young people in their work.

How caring approaches can address and ensure meaningful participant involvement

Our experiences carrying out our own research projects have shown that developing trusting and caring relationships with care-experienced people in research design, collection, analysis and dissemination can take time and resources. Researchers need to consider their position, ethical considerations and how they can co-construct knowledge with participants in a way that is respectful, caring and empowering. Attending to these issues is necessary to practice anti-oppressive research practices (Rogers, 2012). However, we acknowledge this may not be practical or feasible for all researchers, given the constraints some institutions place on the research process, variations in access to research funding between high- and low-resourced countries, and the amount of person-labour these practices require. Our position on the importance of care in research stems from a practical barrier in the research process: participant recruitment and engagement.

When care is not present in the research process, potential participants may distrust the researcher's motivation and commitment to empowerment. They may feel frustrated by the different sense of urgency or focus researchers might place on the challenges care-experienced young people are facing. During a pre-conference convening of researchers of transition-aged youth I (Horn) attended, one panellist during a presentation by care-experienced young adults explained: "We are tired of hearing from researchers what is wrong with us. We already know what's wrong. We want researchers to help us figure out how to fix the problems."

This diverging focus between care-experienced young people wanting more information on how to fix the system and researchers continuing to produce surveillance studies highlighting the challenges care-leavers face, combined with a lack of trust in the researcher or research process to accurately depict their experiences, can lead to care-experienced young people avoiding engaging with researchers. This phenomenon is described as *epistemic trust injustice*, or the practice of a studied group viewing well-meaning, well-intentioned researchers with distrust and withholding their participation in research (Grasswick, 2017). To address this issue with care-experienced young people, researchers can begin by yielding the title of 'expert' and deconstructing the hierarchy to which this title contributes. This requires researchers to be fully committed to the process of engaging care-experienced young people, learning their language, using terms they use and, most importantly, learning what issues are most pressing from care-experienced young people's perspectives. In this way, researchers can leverage their positions to reduce the power gap between academics and participants and produce empowering research (Rogers, 2012).

Researchers must understand the unique circumstances each young person may be experiencing and be attuned to challenges that youth may experience in getting and staying involved in research. These challenges could include lack of access to transportation, lack of food, fear of tokenism, stigma, fear of no change or follow up, previous negative experiences participating in research and fear of sharing their story as it makes the care experience too real. Thus, if we wish to ensure those with care experiences participate and keep participating so that their voices are heard, then we as researchers must do all we can at every stage to ensure young people are cared for within the research process. Attending to these challenges creates conditions where anti-oppressive and caring research can be conducted.

Drawing on our experience, we have generated a practical checklist for researchers to consider when approaching and researching the area of care-leaving (see Table 8.1). While we are mindful that not every step can be

Table 8.1: Checklist for care-leaving researchers

1. What is your position in the research? What are participants' views on your role? How might you be perceived by the participants?
2. What power imbalance and challenges to participation may arise (for example, timing of interview, place, funding)?
3. What steps could you take to establish a more trustful and harmonised relationship with participants?
4. What kind of language or terms do participants use to describe their identities and experiences?
5. How can the participants be supported best, during the research process and in follow-up? Do you have a safety plan in place for if a participant becomes distressed? What are the options of support from collaborating gatekeepers?
6. How can you address concerns (for example, trauma-informed safety) that gatekeepers or prospective participants may raise about getting involved in your research project?
7. What steps can you take to meaningfully engage young people throughout the whole research process, including analysis and dissemination?
8. What is your plan to address the barriers young people may experience to staying meaningfully involved in a research project?
9. How will you support youth who wish to be involved in dissemination activities to ensure this is a safe and positive experience for them?
10. Have you elicited feedback on your research tools from care-experienced young people and implemented their recommendations?
11. Have you made your research findings accessible to care-experienced populations, including your participants?
12. Do you have a mechanism for practising accountability to the care-experienced community to ensure your findings accurately reflect their experiences?
13. Are there other organisations and/or resources you can access that will help support you as a researcher and/or your participants during the research process? In what ways may they be of help?
14. What can you do to ensure your own self-care during the research process?

carried out by all researchers, we suggest that regardless of budget, timeframe or scale of the research project all the questions are worthy of consideration.

Conclusion

Care in research concerns two important aspects of the practice of research: power and knowledge. While there has traditionally been a power imbalance within the relationship between the researcher and the researched, many studies have highlighted how children and young people can feel 'powerless' because they have been subjected to the care system. Children and young people in care have consistently reported feeling unheard and invisible, as though their voices do not matter, and feeling a lack of power over decisions in their lives.

In this chapter, we have provided a rationale as to why attending to issues such as power is not just important for those participating in research but can also lead to a caring research process. We have described the importance of why those with care experiences should have their voices heard. Meaningfully engaging care-experienced young people in all aspects of the research process benefits these youth (for example, skills development, improved education and employment prospects, and increased connections) and their peers whose voices get amplified by having their experiences included from design to dissemination. Such engagement also benefits the researcher, who can learn much from young people whose involvement in research often comes from a motivation to contribute to positive change within the care system and to ensure other young people do not go through the same challenges that they have.

As a mix of authors with a range of different experiences from different parts of the world, we believe that integrating care can be done in many little ways. In this chapter, we have provided examples of how we have implemented a caring approach to studies from design to dissemination and our learnings from this. We also reflect on the dual role of care-leaver and care-leaving researcher, with implications for a caring community of care-leaving scholars. While positions in research can be complex, we have outlined several ways ethical and power issues can be anticipated and addressed in research studies. Drawing on our learnings, we concluded with a checklist particularly aimed at early career researchers (regardless of whether they are an insider or outsider researcher or on a continuum) to consider how they can enable opportunities for care, empowerment, reflexivity and participation to be built into the research process, from beginning to end. This may ensure a 'care process' is adhered to for those participating in research. Finally, while we are mindful that not all the ideas proposed in this chapter can be implemented by every researcher in every study, we encourage all researchers to intentionally move towards a more caring and inclusive research process, by increasing the number of caring measures they build into their research programme.

Note

[1] https://www.mcs.bc.ca/youth_research_academy

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