Beyond the participant-researcher division: co-creating ethical relationships through care and rapport in studies of post-laryngectomy communication

– Joanna Komorowska-Mach, Konrad Zieliński, Adrianna Wojdat –

Abstract: This article presents the ethical implications for social science research emerging from our study on interpersonal communication after a laryngectomy. By tracing the evolution of our approach through specific research experiences and participant feedback, we provide empirical support for a flexible, multidimensional, and relational understanding of key ethical concepts, such as vulnerability and the researcher-participant relationship. Our approach has shifted from institutionally imposed rigid categorizations and somewhat stereotypical treatment of both the research group and the researcher-participant relationship to an emphasis on building relationships founded on mutual care and rapport. We argue that this revised perspective fosters ethical collaboration that is beneficial and secure for all parties involved, and we offer practical examples of its implementation in research practice.
Keywords: qualitative research, laryngectomy, research relationship, ethics of care, rapport, vulnerability

1. Introduction

The institutionalized research ethics in the social sciences have been the subject of widespread criticism in the last decade,[1] especially when it comes to studying so-called vulnerable populations. Paying attention to the particular sensitivities of study par-

Joanna Komorowska-Mach
Faculty of Philosophy, University of Warsaw,
Krakowskie Przedmieście 3, 00-047, Warsaw, Poland
Human Interactivity and Language Lab, Faculty of Psychology, University of Warsaw
Stawki 5/7, 19-300, Warsaw, Poland
Konrad Zieliński
Human Interactivity and Language Lab, Faculty of Psychology, University of Warsaw
Stawki 5/7, 19-300, Warsaw, Poland
Email: km.zielinski@uw.edu.pl
Adrianna Wojdat
Human Interactivity and Language Lab, Faculty of Psychology, University of Warsaw
Stawki 5/7, 19-300, Warsaw, Poland

[1] For an up-to-date overview, see Iphofen, Tolich (2018).

ticipants is necessary in order to address their needs and protect them from harm and exploitation. However, thinking about vulnerability as a permanent characteristic of specific groups reinforces thinking based on stereotypes and encourages a patronizing attitude to research participants, and it may even lead to their exclusion from entire research programs.[2]

This issue is particularly important for our research. We conduct studies with people who have had a laryngectomy – larynx removal – which affects their speaking, breathing, and swallowing. One of us (a co-author of this article) is also a person living without a larynx, which adds an additional layer to our ethical considerations. Here, we share experiences that have reshaped our thinking regarding both the ethical dimensions of research involving individuals considered vulnerable and the role of so-called insiders in such studies, but we also offer more general reflections and conclusions regarding building relationships among research participants. Our approach has evolved from rigid dichotomies, such as vulnerable/non-vulnerable or insider/outsider, to a more dynamic and relational framework based on the notions of care and responsibility.

Such an approach is not fully accepted and used in the research practice of psychology or cognitive science. We believe that describing our experiences will be helpful both for social science researchers who face similar dilemmas and ethicists interested in insights from research practice. To discuss these issues using examples from our research, we will first describe the motivations and methodology of our research project.

2. Research project on communication after larynx removal

Our research group was established in 2018 just after one of the authors of this paper, Konrad, went through a laryngectomy: the surgical removal of the larynx due to laryngeal cancer, leading to disturbed ability to produce speech, and other anatomical changes related to breathing and eating. In the following years our team, with Konrad as its leader, comprised many people with different motivations and backgrounds – students and researchers trained in psychology, anthropology, philosophy and cognitive science – who wanted to help Konrad, mainly with technology aimed at enhancing communication. Supported by engineering and medical students, the group started to develop technological ideas and products. Over time, the goals of the group expanded from solving one person's problems to looking for solutions that could serve a wider group of people.

However, the main scientific endeavor and the main research described in this article focuses on the impact of laryngectomy on the everyday life of people who have experienced it. Two anthropologists from the group initiated and designed a study aimed at learning about the practices and communicative strategies of people living without the larynx and invited for collaboration Konrad and 4 other young cognitive science researchers. At first, we focused on the communicative process, guided by the lay intuition and the literature in the domain suggesting that these people "lose their voice" (an assumption which could be harmful, as we argue elsewhere[3]). We recruited

---

[2] Levine et al. (2004); Luna (2009); Van den Hoonaard (2018).
[3] Biernacka-Gemel, Zieliński (2022).

participants for the mentioned study from laryngectomees' associations: 9 people (aged 48–77, incl. 6 women) agreed to participate and share their stories with us. Depending on the person, we met 1, 2 or 3 times for 1–3 hours in participants' homes for the inter-views. As it was often difficult to understand our research participants, we decided to conduct interviews with laryngectomees in triads (a laryngectomee, a moderator and an observer) and supplemented the sessions with videorecording, which was very useful later in the data analysis.[4]

For these interviews, we designed a scenario focusing on everyday life, communi-cation strategies, familiarity with technology, and the larynx removal process. As these were in-depth interviews, we did not rigidly adhere to the questionnaire and adjusted the questions over time. The meeting agenda also included generative techniques such as drawing a self-portrait or coloring a timeline of the process from initial symptoms and oncological diagnosis, through surgery in the hospital, until the present time. We began to build our understanding of the problem and therefore progressed from asking questions only about communication to the bodily changes themselves, and we started to ask specifically about issues that had arisen during earlier interviews. We discussed the self-image of living with a stoma (opening in the neck through which we inhale air), the uncontrolled outlet of mucus, coughing, and the social shame associated with breathing, speaking and eating in a non-normative way.

Moreover, as observers we participated in speech therapy sessions or laryngec-tomee club meetings to experience laryngectomees' real-life communication strategies. Some valuable insights were also gathered outside of the study setup during, for exam-ple, consultations with laryngectomees and doctors in hospitals.

In the process of the data analysis, the videos and observers' notes were coded by the group of anthropologists and cognitive scientists in MAXQDA software and Google Sheets. Observations and interpretations were noted and then analyzed during in-person workshops. The most important challenge was integrating the various researchers' insights; we achieved this using methods like personas, the K-J prioritizing, and affinity mapping. The whole research team had access to all data during the analysis, including the videos from interviews and field notes. The data had been anonymized afterwards when the analysis was completed. The full report has been presented at several conferences and described in several papers.[5]

Immediately after surgery, laryngectomees rely on gestures, drawing, and a quiet whisper. Then they usually learn a substitutive method of speaking: esophageal speech, tracheoesophageal speech, or electrolarynx-assisted speech.[6] Some laryngectomees have a voice prosthesis implanted. Alternative approaches to voice restoration involve bionic technologies, such as wearable devices with artificial intelligence[7] or text-to-speech with voice copies.[8] Yet the results of our interviews and observations have shown that most laryngectomees communicate multimodally, adapting their speaking methods, whisper,

---

[4] For a detailed description of the methodology see Biernacka-Gemel (2022).
[5] Ibidem, Biernacka-Gemel, Zieliński (2022).
[6] Van Sluis et al. (2018) describe these 3 ways of producing basic vibrations in detail.
[7] Fuchs et al. (2016); Ahmadi et al. (2019).
[8] Repova et al. (2021).

gestures, and other communication means to the context, interlocutors and environment. We describe our conclusions on communication elsewhere.[9]

From the methodological point of view, the project has undergone important changes. We started with individual in-depth interviews and participatory observations focused on communication and its context. Later, based on the data from the interviews and the most important conclusions, we moved on to the bodily changes that really affect social participation. Most recently, we started diary studies supported by interviews to catalog important, frequent and problematic communicative encounters. We aim to capture the needs and values of laryngectomees more precisely and pass this knowledge on to technology designers, doctors and speech therapists.

3. "Vulnerability" and "insider-outsider" concepts in our research practice

In our studies, we faced many day-to-day dilemmas and hardships that arose in real-life contexts during actual interactions between people involved in the study. In this section, we will show how these two dimensions manifested themselves and how our thinking has evolved towards more individualized, dynamic and relational categories.

3.1. People without a larynx as "vulnerable subjects"

Contemporary approaches to vulnerability are moving away from viewing vulnerability as a label assigned to specific groups towards more fine-grained, contextual and multidimensional views.[10] However, institutionally practiced science remains entrenched in a more rigid paradigm that requires predetermined assumptions regarding entire populations. For instance, research proposals submitted to ethics committees require a declaration regarding whether the studied population is vulnerable and, if so, how this will be addressed.[11] As we undertook our research in this kind of academic environment, we also initiated our research by attempting to determine to what extent and in what sense the participants of our study as a group should be considered vulnerable.

In the most narrow sense of the term, "vulnerable subjects" refers to research participants who cannot provide fully informed, voluntary, and conscious consent to participate in a study, or who may not have the capacity to safeguard their rights and well-being[12] and therefore may "experience real or potential harm and require special safeguards to ensure that their welfare and rights are protected."[13] Such a meaning of vulnerability applies to laryngectomees only to a very limited extent. We distinguished two aspects of our participants' potential problems with voluntary, explicit and informed consent. Firstly, due to difficulties in communication, consent to participate in the study or particular activities or conversations was sometimes physically expressed

---

[9] Zieliński et al. (2023).
[10] Racine, Bracken-Roche (2019).
[11] For a comprehensive discussion of ethical code principles and the operational practices of ethical committees in this regard see Surmiak (2022b).
[12] Silva (1995).
[13] Moore, Miller (1999): 1034.

(or partially expressed) by someone else or in the company of someone else, usually a family member. For example, the wife of one of our esophageal-speaking participants was present during his first conversation with us, and she was the first to say that he agreed to participate in the study.

Secondly, laryngectomees' ability to consent freely to participate in a study may be limited by a factor that Kipnis calls "medical vulnerability."[14] This category includes people with severe medical conditions who lack satisfactory treatment options and may incorrectly estimate the risks and benefits of enrolling in a study because of a misconception that its purpose is primarily for their benefit. For example, in our first study, discussing our parallel technological project with research participants led them to expect that working with us would give them access to new technologies to solve their problems. Over time, we became more careful in sharing such information.

However, it was notably easier to regard the participants in our study as vulnerable in the second, broader sense of the term as a group which has more general susceptibility to potential side effects, harm, or discomfort that may be induced during research. The WMA Declaration of Helsinki sees vulnerable groups as these that "may have an increased likelihood of being wronged or of incurring additional harm" and therefore "should receive specifically considered protection."[15] Such broadly understood vulnerability refers, among others, to people suffering from chronic illness,[16] "physically challenged individuals,"[17] those with "an increased relative risk or susceptibility to adverse health outcomes,"[18] and members of stigmatized or marginalized groups.[19] People without a larynx may meet any of these conditions. These are often people who have been diagnosed with cancer, have undergone invasive treatment, and deal with trauma related to amputation and a broad spectrum of its medical, psychological, and social consequences. Addressing these issues has positively impacted our study, allowing us to see different difficulties that may be characteristic of people without a larynx, but – as we claim – it narrowed our view.

Over time, we started to question the whole "subpopulation approach" to vulnerability, which assumes necessary and sufficient conditions that populations must fulfill to be considered vulnerable.[20] One of the reasons for this change was insight from Konrad, who, as a laryngectomee himself, was also initially seen by some of us as a vulnerable person, especially regarding talking about surgery, cancer, and some physiological aspects of life without a larynx. However, Konrad firmly rejected any special treatment and the label "vulnerable" itself. Knowing a lot of people in a similar condition, he also claimed they would not feel respected if they were considered in that way. His feelings and thoughts on the subject, which he shared with us during several discussions, were a first-person account of how, despite good intentions, considering someone vulnerable

---

[14] Kipnis (2001).
[15] World Medical Association (2013).
[16] Nyamathi (1998).
[17] Shivayogi (2013).
[18] Flaskerud, Winslow (1998): 69.
[19] Allen (2002).
[20] Luna (2019).

may be felt as condescending, disempowering, and implying unwanted compassion instead of partnership. Labeling one of our team members as vulnerable also made it easier to overlook the individual vulnerabilities of other research team members. Some aspects of the interviews that we conducted during our research proved to be more burdensome for those who did not have similar experiences as our participants. For example, the sight of the stoma (the opening in the neck used for breathing) or some reports of the interviewees' medical experiences were harder to bear for non-laryngectomized interviewers.

In our relationships with research participants, we could also observe various shortcomings and negative consequences of labeling the whole group as vulnerable (also raised by critics of this approach[21]). Treating laryngectomees as a group requiring special care carried the risk of patronizing and limiting the subjects' autonomy, which manifested itself, for example, in making certain decisions for research participants. It also did not account for individual differences, which over time became a significantly more important factor in assessing research-related risks.

In time, we gained more trust in our participants' ability to decide what is too hard, tiring or unpleasant for them; so, instead of assuming and imposing our own categories, we started being more open to individual and contextual feedback. We started to see vulnerability not as a permanent feature of a person or group but as something that depends on circumstances and changes over time. This led us to give up thinking about vulnerability as a group characteristic, and instead we took a more individualized, relational and contextual approach.

We were especially inspired by two-step procedure proposed by Luna, who recommends first identification of dispositionally understood layers of vulnerability, and then evaluation of their importance and possible interactions, which may have a cascade effect.[22] Although we didn't follow her protocol exactly, we adopted thinking about vulnerability through her metaphor of layers and started to multidimensionally and flexibly ascribe and evaluate our participants' vulnerability. The layers of vulnerability which we ascribed in our study included time since larynx amputation, age, sex, overall physical and intellectual ability, socioeconomic status etc. We also re-evaluated some initial assessments, taking into account feedback and additional information from our participants. For example, one of our laryngectomized interviewees proved to be much more vulnerable because of the recent death of his son-in-law than because of the larynx amputation which had taken place several years previously. Such a tailor-made approach to a given participant and interaction guided us during the most recent phases of our studies (see section 4).

Reactions to laryngectomy and its consequences vary from person to person. Each of the participants of our study is vulnerable in a unique way and for individual reasons not necessarily related to laryngectomy. A more individualized and relational view of susceptibility to harm and discomfort allowed us to look at our own personal difficulties, experiences and limitations and see our own, sometimes unexpected, vulner-

---

[21] Levine et al. (2004); Luna (2009); Racine, Bracken-Roche (2019).

[22] Luna (2019); for alternative interesting approaches to multidimensionally understood vulnerability see Lange et al. (2013) and Racine, Bracken-Roche (2019).

abilities. For example, one participant who used transesophageal speech had problems using his voice prosthesis, leading to fatigue due to obstructed breathing. During the interview, one of us considered stopping it; however, instead, she asked the participant if he wanted to continue. When he explicitly confirmed, she respected his decision. She gave the participant the authority to determine what discomfort he would accept without pressing to continue or end the interview. She also reflected on her discomfort from a false assumption about the participant's state.

Questioning the top-down, categorical approach to vulnerability enabled us to direct more of our efforts to giving our participants broad information and agency, to being in touch with their needs and feelings, and to leaving them to make the decisions concerning how they want to participate in the study. As a result, we are much more able to tailor our attentiveness to each of the research subjects individually. In our assessment, this not only led to more ethically conducted research but also contributed to the establishment of relationships between researchers and study participants that later proved to be highly significant for the whole study.

3.2. The insider-outsider dichotomy in our study

The direct motivation for our research program was Konrad's surgery. This first-hand experience influenced the formulation of research questions and the research planning process from the outset. It also facilitated our ability to connect with participants and influenced their willingness to take part in the study. Furthermore, the research participants themselves stated that the fact that one of our team members had also undergone laryngectomy surgery held significance for them. They often referred to a shared sense of experience or even expressed their concern for Konrad's health and wellbeing.

All of these factors initially made us consider the distinction between insider and outsider researchers that is commonly used in social sciences as a useful tool for describing our team. Generally, insider researchers are part of the studied community or share its experiences or characteristics. In contrast, outsider researchers do not belong to the research group or do not feel identity-bound with it.[23] We considered various methodological issues related to the role of the insider. We discussed how to ensure the anonymity of study participants whom Konrad knows personally. We deliberated on how to distinguish conversations conducted by Konrad within the context of his research from those conducted privately. We wondered whether the fact that Konrad is a laryngectomee somehow affects potential participants' freedom of consent and the feeling that they had the right to opt out of the study.[24]

Then, however, we gradually moved away from emphasizing the insider-outsider dichotomy, which we came to understand is not particularly useful when understood literally and rigidly, and the boundaries between these two roles are not easy to draw.[25] Laryngectomees share some unique experiences, but they do not constitute a community

---

[23] Bonner, Tolhurst (2002).

[24] For description of this and other possible risks associated with the role of insider see Toy-Cronin (2018).

[25] Ibidem.

in a typical sense.[26] For some, being a laryngectomee is a crucial part of their identity. For others, it is not, partially because the need to remove the larynx usually concerns older adults, whose identity and sense of belonging are already well established. Many people without a larynx cannot or do not want to build relationships with other laryngectomees. Others became members of formal associations or informal groups, where they can exchange their experiences or spend time with other people in similar situations.

We also started to question Konrad's "insiderness." Indeed, Konrad as a laryngectomee has the opportunity to formulate the research problem better and ask participants more appropriate questions. Also, having a laryngectomee in the team motivated other laryngectomees to enroll in the study. However, it was more important for some participants whether the interviewer is young, educated, and has certain temperamental features or attitudes to life. Sometimes their primary motivation for enrolling in the study was the possibility of sharing their experience with people who have not undergone laryngectomy (e.g., to teach them about it). Others saw Konrad as an obvious outsider to their group. Some laryngectomees expressed strong normative beliefs about how a person should deal with the absence of a larynx: for example, they seemed to assume that mastering esophageal speech indicates greater diligence or motivation than the use of external devices, such as the electrolarynx used by Konrad. These beliefs even led to questioning the validity of our research and the fact that one of the researchers is a laryngectomee did not reduce this kind of distrust but even increased it. When referring to Konrad's electronic larynx, one of the esophageal-speaking persons said, "Drop this f… pipe, speak as we do!". During an interview conducted by Konrad and a second researcher, another participant's wife asked whether this second researcher could ask questions instead of Konrad, suggesting she did not accept Konrad's way of speaking. None of these people considered Konrad an insider in their community, confirming that being an insider or outsider is an ascribed but not intrinsic characteristic.[27]

Similarly to thinking in terms of the vulnerable and non-vulnerable, the insider-outsider dichotomy promotes seeing people as representatives of stereotypically understood groups, regardless of their self-identification and individual characteristics. These notions also fail to capture the complexity of the relationship between us as researchers and participants in our studies.

4. The proposed ethical approach to the research relationship

In general, the evolution of our ethical approach was a gradual departure from thinking about research in terms of "us" and "them." Instead, we started to look for other ways to conceptualize our approach to building ethical relationships with our study participants. Initially we focused mostly on building rapport and creating space for the participants to bring forth their values and categories, thus avoiding imposing our own categories on the studied phenomena.[28] Being open to our participants' points of view allowed us

---

[26] As Bradley (2021: 543) states, "biosocial groups do not simply exist, and must first be formed and found and their sustainability requires ongoing work and care from biosocial actors themselves."
[27] Hammersley, Atkinson (2007).
[28] De Jaegher (2021).

to recognize the contexts and dynamics of alaryngeal communication and reconsider our assumptions. As our involvement in the research and participants' experiences progressed, we felt the need to recognize their agency and started to draw from feminist approaches[29] in order to foster empowerment in the research process. Finally, we noted that the relationships we form go beyond individual ones and are established between our research group and whole families impacted by laryngectomy.

4.1. Rapport and trust-building

The first challenging aspect of the relationships in qualitative research is that the data-gathering process and data quality depend on how much the participants are open to the researcher. Researchers use various interview techniques to achieve this.[30] However, these techniques alone are usually insufficient when researching sensitive topics like the body, illness, and trauma. Building a positive relationship based on cooperation, trust and a sense of security, in literature often called rapport,[31] is necessary. Such a relationship goes beyond superficial interactions and aims to build a sense of comfort and security that will encourage people to freely share their experiences, practices, and ways of thinking. To build such a relationship, time is an essential factor.

In the first phase of our study, our focus was on the chosen interviewing methods. The number of meetings and the time between them varied from participant to participant. For logistic reasons, we met with most of them for only one interview, but some we met two or three times, sometimes even a month after the first interview. This hindered the trust-building process. Therefore, in the second phase, we met with each participant thrice for in-person interviews, while maintaining contact between meetings through a diary study lasting one week, enabling progressive building of rapport with the participants and gradually deepening trust.

With each subsequent interview, the participants spontaneously started to share more private information (e.g., about their stoma hygiene rituals). The moderators also felt more at ease in their homes, building small "traditions," like always asking for tea or remembering to take their shoes off. They also learned the communication habits of their interlocutors and got accustomed to their stomas.

Another challenge was the definition of research boundaries. We met with the participants multiple times, visited their houses, met their families, and sometimes had contact outside of the research context, so there was no clear end to the researcher's engagement with the participants. The researchers were responsible for establishing the boundaries of the relationship with each participant. We believe that while this relationship should be based on trust and positive emotions, it should not enter the realm of friendship.[32] As Corrine Glesne[33] pointed out, rapport and friendship require

---

[29] Campbell, Wasco (2000).
[30] Davies (1999); Hammersley, Atkinson (2007).
[31] Spradley (1979); Glesne (1989).
[32] For example of a research project presenting a different approach in a study with the blind, see Pietrowiak (2021). See Surmiak (2022a): 121–125 for a broader discussion of issues and approaches related to this topic.
[33] Glesne (1989).

confidence and trust, but friendship also means liking and mutual bonding. Friends do things for each other that they would not do for others, and they share what they would not otherwise share. Being aware of the potential for harm when crossing this boundary, we focused on building these relationships with purpose and intent, communicating the expected course of the study at the beginning, and clearly saying our goodbyes when the cycle ended for the participants.

Last but not least, conducting research with people who had experienced oncological illness and may still experience or expect some problems concerning their health or social functioning made us aware of the possibility of difficult emotions arising in both participants and researchers. We did not want our interviews to turn into therapy-like sessions (though some researchers observe that interviews can have therapeutic-like effects[34]). We believed that doing so would exceed the limits of participants' consent and our competencies.

Establishing and cultivating rapport between researchers and participants is multifaceted: on the one hand, it is a pivotal catalyst; on the other hand, a delicate balance must be maintained so it does not transgress into the realms of friendship or therapy.

4.2. Care and empowerment as critical values for building rapport

Inspired by the works of feminist scholars, we think that amplifying the voice of any marginalized community may contribute to a more comprehensive exploration of its experiences. This approach is built on the ethics of care, which is a framework established by feminist scholars that focuses on respecting the individuals participating in studies and providing them with the necessary support.[35] The feminist perspective in qualitative research questions the "all-knowing expert" position and challenges the underlying power differential. Scholars identifying with the feminist movements have observed how the topics and concerns of scientists reflect those of the dominant societal groups and ignore the concerns of marginalized groups.

This observation has led to the development of alternative perspectives on producing knowledge and conducting research. Feminist scholars have taken note of the bias in research from the stage of study design, through gathering data, to the analysis.[36] We followed this perspective by reflecting on our research design and execution. As Burgess-Proctor emphasizes, the starting point of inquiry in the feminist research approach is care for the participants. Following Puig de la Bellasca,[37] we define care not only as an emotional state but also a tangible, vital action and an ethico-political commitment. In our research, the perspective of Noddings is also relevant as she emphasizes that while care is one's personal responsibility in concrete situations, it is also relational as both the carer and the cared-for play important roles that contribute to the relationship.[38]

The perspective of care as relational can be applied not only to the relationship between researchers and participants but also to the study design in terms of formulat-

---

[34] Birch, Miller (2000).
[35] Burgess-Proctor (2015): 126–127.
[36] Campbell, Wasco (2000).
[37] Puig de la Bellasca (2011): 90.
[38] Noddings (2013): 47, 66.

ing research questions and choosing methods of answering them.[39] Starting from this perspective and reflecting on previous stages of research, we decided to test the new interview guides and diary study forms on ourselves in the latest research round. Both the interview moderator and diary study supervisor took the participants' role first. We iteratively modified the interview scenarios and tested three different versions of the diary study. We focused on our experience of the process because we wanted to avoid re-traumatizing the participants while still leaving room for them to open up if they so desired. Based on this personal experience, we decided, for example, to reduce the number of interviews, de-emphasize questions about the body, and place less emphasis on questions about emotions in the diary study.

Another inspiration we drew from the approach of feminist scholars was providing representation, i.e., giving participants a voice in our academic writing.[40, 41] Our motivations were similar: we wanted to provide space for the laryngectomees to talk long and uninterrupted about their everyday communication experiences in order to empower them. Following Deborah Cameron and colleagues, we understand empowerment as a contextual relationship between researcher and participant in which the participant takes an active role in the process.[42]

To foster empowerment, we constructed the interview scenarios to let the participants decide how much they want to share and when. Especially in the last phase of research, which consists of three interviews, participants could take their time between sessions and decide whether they want to continue their involvement and how. Moreover, the interviews created a situation in which the laryngectomees could share their stories in their own words and be listened to attentively. Last but not least, most of the moderators came from a non-expert position regarding laryngectomy, as opposed to doctors and speech therapists who typically talk to laryngectomees about their health and communication. This put the participants in the expert position.

4.3. Individual-individual or unit-unit relationships

We have so far discussed all the aspects of research relationship ethics in the context of the one-to-one relationship between researcher and participant. However, during the research process, we started to see some other relationships within the scope of our responsibility. Conducting research at family homes sometimes made it impossible to establish only one individual relationship. During interviews with research participants, their family members (usually spouses) were also often present: sometimes only observing, sometimes participating. Family members' larynx removal profoundly affects their relatives, who sometimes want to share their part of the story.

Our presence in a participant's home often altered the rhythm of the whole family's day. Also, some participants required assistance filling out the forms for the online diary study, which led to the engagement not only of our participants' spouses but sometimes also children and grandchildren.

---

[39] Pols (2015): 88.
[40] Burgess-Proctor (2015): 127–128.
[41] On the importance of eliciting stories about pain, see also: Frank (2004).
[42] Cameron et al. (1993).

On the researchers' side, more than one individual was also involved. As mentioned before, our research team consisted of many people with different motivations and backgrounds, and it fluidly changed during the project. Currently, two people are actively conducting research, but several other team members consult on the research design, data analysis, and ethical dilemmas. Participants are informed about this,[43] but during the interview they can forget that, in reality, they are sharing their story with the whole group of researchers.

These considerations made us question whether we are researching individual laryngectomees or their close social environment. Similarly, we as a team see ourselves as a dynamically changing, multidisciplinary research unit rather than a set of separate individuals. In reaching this conclusion, we decided to apply the results of our ethical considerations to the broader unit-unit relationship.

In the most recent research phase, we met with the participants and their spouses for an introductory meeting (conducted in person, on a video call, or by phone) before starting the research. During this meeting, we introduced ourselves as a group, presented the research procedure, and explained in detail what participants could expect and how we would handle their data. During this meeting, laryngectomees and accompanying persons could then ask questions, and they together gave informed consent to participate in the research.

5. Conclusions

Our experiences in research on laryngectomees' interpersonal communication as well as exploring and sharing our thoughts within our diverse team of researchers radically changed our perspective on research ethics in practice. We have transitioned from a top-down, institutionally regulated, rigid approach to a bottom-up, individualized view that emphasizes empowerment and is based on nurturing individual relationships among individuals engaged in the study. We have learned that giving more subjectivity to research participants is not just an ethically better choice but it also produces measurable benefits because it allows us to discover phenomena that would not be discovered otherwise.

We want to promote taking ownership of the ethical decisions together and individually with participants by carefully and respectfully building relationships. We take inspiration from various applications of ethnographic methods, such as the gradual trust-building traditionally associated with long-term field research and ethics of care, and participant empowerment frameworks originating from feminist studies. We also acknowledge that the research relationship widens beyond just the researcher and participant and involves participants' families and whole research teams.

All this highlights the need for awareness and reflectivity when conducting research. Some ethical challenges might not be accounted for when a narrow view of research relationships is maintained or when the participant is seen as vulnerable or passive. Research participation is often considered in a specific formal way, but it can actually be reciprocal if participants are given more space to contribute to defining it during relationship building.

---

[43] Before each session the participants are informed how the recordings are stored and for how long, as well as who has access to them. The data was anonymized before any publication.

Although there is no one-size-fits-all approach, we believe that the key to ethical research is to focus not only on big plans prepared with ethical bodies' approval in mind but also on small observations and decisions made during interactions with all people engaged in a study. This ensures the empowerment of all participants, ensures that their boundaries are respected, and allows for greater mutual openness. We believe that this also translates into the credibility, representativeness, and depth of the results obtained in such studies.

Conflict of interest: The authors declare that there is no conflict of interest to disclose.

References

Ahmadi F., Kobayashi K., Toda T. (2019), "Development of a Real-Time Bionic Voice Generation System Based on Statistical Excitation Prediction," [in:] *Assets '19. The 21st International ACM SIGACCESS Conference on Computers and Accessibility*, J.P. Bigham (red.), Association for Computing Machinery, New York: 655–657.

Allen D. (2002), "Research Involving Vulnerable Young People: A Discussion of Ethical and Methodological Concerns," *Drugs: Education, Prevention and Policy* 9 (3): 275–283.

Biernacka-Gemel A. (2022), Życie po laryngektomii. *Etnografia w szczelinach ciała*, unpublished master thesis, University of Warsaw, Warsaw.

Biernacka-Gemel A., Zieliński K. (2022), „Ciało – obce, sprawcze, kreatywne. O doświadczeniu Laryngektomii," *Etnografia Polska* 66 (1–2): 47–71.

Birch M., Miller T. (2000), "Inviting Intimacy: The Interview as Therapeutic Opportunity," *International Journal of Social Research Methodology* 3 (3): 189–202.

Bonner A., Tolhurst G. (2002), "Insider-Outsider Perspectives of Participant Observation," *Nurse Researcher* 9 (4): 7–19.

Bracken-Roche D., Bell E., Macdonald M.E., Racine E. (2017), "The Concept of 'Vulnerability' in Research Ethics: An In-Depth Analysis of Policies and Guidelines," *Health Research Policy and Systems* 15 (1): 8.

Bradley B. (2021), "From Biosociality to Biosolidarity: The Looping Effects of Finding and Forming Social Networks for Body-Focused Repetitive Behaviours," *Anthropology & Medicine* 28 (4): 543–557.

Burgess-Proctor A. (2015), "Methodological and Ethical Issues in Feminist Research with Abused Women: Reflections on Participants' Vulnerability and Empowerment," *Women's Studies International Forum* 48: 124–134.

Cameron D., Frazer E., Harvey P., Rampton B., Richardson K. (1993), "Ethics, Advocacy and Empowerment: Issues of Method in Researching Language," *Language and Communication* 13 (2): 81–94.

Campbell R., Wasco S.M. (2000), "Feminist Approaches to Social Science: Epistemological and Methodological Tenets," *American Journal of Community Psychology* 28 (6): 773–791.

Ceachir O., Hainarosie R., Zainea V. (2014), "Total Laryngectomy – Past, Present, Future," *Maedica* 9 (2): 210–216.

Davies C.A. (1999), *Reflexive Ethnography: A Guide to Researching Selves and Others*, Routledge, London.

De Jaegher H. (2021), "Loving and Knowing: Reflections for an Engaged Epistemology," *Phenomenology and the Cognitive Sciences* 20: 847–870.

Flaskerud J.H., Winslow B.J. (1998), "Conceptualising Vulnerable Populations in Health-Related Research," *Nursing Research* 47 (2): 69–78.

Frank A.W. (2004), "Asking the Right Question about Pain: Narrative and Phronesis," *Literature and Medicine* 23 (2): 209–225.

Fuchs A.K., Hagmuller M., Kubin G. (2016), "The New Bionic Electro-Larynx Speech System," *IEEE Journal of Selected Topics in Signal Processing* 10 (5): 952–961.

Glesne C. (1989), "Rapport and Friendship in Ethnographic Research," *International Journal of Qualitative Studies in Education* 2 (1): 45–54.

Gordon B.G. (2020), "Vulnerability in Research: Basic Ethical Concepts and General Approach to Review," *Ochsner Journal* 20 (1): 34–38.

Hammersley M., Atkinson P. (2007), *Ethnography, Principles in Practice*, Routledge, London.

Iphofen R., Tolich M. (eds.) (2018), *The SAGE Handbook of Qualitative Research Ethics*, SAGE, London.

Kipnis K. (2001), "Vulnerability in Research Subjects: A Bioethical Taxonomy," URL = https://aapcho.org/wp/wp-content/uploads/2012/02/Kipnis-VulnerabilityinResearchSubjects.pdf [Accessed 4.03.2020].

Lange M.M., Rogers W.A., Dodds S. (2013), "Vulnerability in Research Ethics: a Way Forward," *Bioethics* 27 (6): 333–340.

Levine C., Faden R., Grady Ch., Hammerschmidt D., Eckenwiler L., Sugarman J. (2004), "The Limitations Of 'Vulnerability' As A Protection For Human Research Participants," *The American Journal of Bioethics* 4 (3): 44–49.

Luna F. (2009), "Elucidating the Concept of Vulnerability: Layers not Labels," *International Journal of Feminist Approaches to Bioethics* 2 (1): 121–139.

Luna F. (2019), "Identifying and Evaluating Layers of Vulnerability – A Way Forward," *Developing World Bioethics* 19 (2): 86–95.

Moore L.W., Miller M. (1999), "Initiating Research with Doubly Vulnerable Populations," *Journal of Advanced Nursing* 30 (5): 1034–1040.

Noddings N. (2013), *Caring. A Relational Approach to Ethics and Moral Education*, University of California Press, Berkeley, Los Angeles, London.

Nyamathi A. (1998), "Vulnerable Populations: A Continuing Nursing Focus," *Nursing Research* 47 (2): 65–66.

Pietrowiak K. (2021), „Relacja, zobowiązanie, współpraca. Założenia i wyzwania badań etnograficznych wśród osób niewidomych," *Etnografia. Praktyki, teorie, doświadczenia* 7 (7): 99–110.

Pols J. (2015), "Towards an Empirical Ethics in Care: Relations With Technologies in Health Care," *Medicine, Health Care and Philosophy* 18 (1): 81–90.

Puig de la Bellacasa M. (2011), "Matters of Care in Technoscience: Assembling Neglected Things," *Social Studies of Science* 41 (1): 85–106.

Racine E., Bracken-Roche D. (2019), "Enriching the Concept of Vulnerability in Research Ethics: An Integrative and Functional Account," *Bioethics* 33 (1): 19–34.

Repova B., Zabrodsky M., Plzak J., Kalfert D., Matousek J., Betka J. (2021), "Text-to-Speech Synthesis as an Alternative Communication Means after Total Laryngectomy," *Biomedical Papers* 165 (2): 192–197.

Shivayogi P. (2013), "Vulnerable Population and Methods for Their Safeguard," *Perspectives in Clinical Research* 4 (1): 53–57.

Silva M.C. (1995), *Ethical Guidelines in the Conduct, Dissemination, and Implementation of Nursing Research*, American Nurses Publishing, Washington.

Spradley J.P. (1979), *The Ethnographic Interview*, Holt, Rinehart & Winston, New York.

Surmiak A. (2022a), *Etyka badań jakościowych w praktyce. Analiza doświadczeń badaczy z osobami podatnymi na zranienie*, Wydawnictwo Naukowe Scholar, Warszawa.

Surmiak A. (2022b), „Etyka naukowych badań społecznych. Pomiędzy kodyfikacją i instytucjonalizacją a praktyką badawczą," *Diametros* 19 (74): 36–50.

Toy-Cronin B. (2018), "Ethical Issues in Insider-Outsider Research," [in:] *The SAGE Handbook of Qualitative Research Ethics*, R. Iphofen, M. Tolich (eds.), SAGE, London: 455–468.

Van den Hoonaard W.C. (2018), "The Vulnerability of Vulnerability: Why Social Science Researchers Should Abandon The Doctrine of Vulnerability," [in:] *The SAGE Handbook of Qualitative Research Ethics*, R. Iphofen, M. Tolich (eds.), SAGE, London: 305–321.

Van Sluis K.E., Van der Molen L., Van Son R.J.J.H., Hilgers F.J.M., Bhairosing P.A., Van den Brekel M.W.M. (2018), "Objective and Subjective Voice Outcomes after Total Laryngectomy: A Systematic Review," *European Archives of Oto-Rhino-Laryngology* 275 (1): 11–26.

Walker S., Read S. (2011), "Accessing Vulnerable Research Populations: An Experience with Gatekeepers of Ethical Approval," *International Journal of Palliative Nursing* 17 (1): 14–18.

World Medical Association (2013), "World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects," *Journal of the American Medical Association* 310 (20): 2191–2194.

Zieliński K., Biernacka-Gemel A., Wojdat A., Komorowska-Mach J., Rączaszek-Leonardi J. (2023), "Researching Communication in Context: Engaged Epistemology and Ethnographic Fieldwork Transforms Understanding of Interactions after Laryngectomy," *Proceedings of the Annual Meeting of the Cognitive Science Society* 45: 229–236.