# Qualitative Sociology Review

*Ethical and Methodological Dilemmas in Qualitative Research Conducted among Vulnerable Groups*

by

Małgorzata Bieńkowska, Urszula Kluczyńska & Anna Maria Kłonkowska

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# Ethical and Methodological Dilemmas in Qualitative Research Conducted among Vulnerable Groups—Guest Editors' Introduction

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This volume focuses on the ethical and methodological dilemmas associated with conducting qualitative research with groups that can be categorized as vulnerable. It is the specificity of the groups in question that unites and underpins the idea of the volume. As such, the presented articles refer to descriptions of specific studies conducted with the use of qualitative research methods among members of selected vulnerable groups. Apart from the necessary presentation of the research topics, the authors focus on the dilemmas that arise at different stages of the research process—from planning through implementation to publication of the results. These dilemmas are closely related to the chosen qualitative research methods. Hence, the featured research examples primarily serve as a background for identifying and discussing ethical dilemmas and closely related methodological problems.

"The concept of 'vulnerability' is used in research ethics to signify that those identified as vulnerable need extra protections over and above the usual protections offered to participants in research" (Rogers and Lange 2013:2141). The ethical considerations regarding vulnerable groups apply not only to research conducted within the medical and health sciences but to the social sciences as well. Although there are many ethical values, the discussion of social research ethics focuses on minimizing harm, protecting privacy, and respecting autonomy. There are codified guidelines for researchers that point to ethical behavior within social research, an example being the Polish Sociological Association's Code of Ethics, discussed in the first article of the volume. However, several qualitative methods reveal specific—for the method or studied group—entanglements and more complex ethical dilemmas, as well as related methodological problems.

In this volume, we understand the concept of vulnerable groups quite broadly, including minority groups, as well as any underprivileged populations.

> Vulnerable people are defined…as those who, due to reason of age, gender, physical or mental state, or due to social, economic, ethnic and/or cultural circumstances, find it especially difficult to fully exercise their rights before the justice system…The following may constitute causes of vulnerability: age, disability, belonging to indigenous communities or minorities, victimization, migration and internal displacement, poverty, gender, and deprivation of liberty. [*Brasilia Regulations Regarding Access to Justice for Vulnerable People* 2008:5]

The texts presented within the volume address selected vulnerable groups—parents of non-normative children, the transgender community, and palliative patients.

The introductory article reflects on research with various minority groups. The authors—Urszula Kluczyńska, Anna Maria Kłonkowska, and Małgorzata Bieńkowska—identify and analyze the most prevalent ethical and methodological dilemmas related to conducting in-depth interviews within the studied vulnerable groups.

The second article, by Maria Flis and Karol Piotrowski, relates to the Polish Sociological Association's Code of Ethics. However, the broad context of the Code of Ethics serves as a starting point for the authors' reflections on the use of metaphors in research on minority groups. The article presents the Code of Ethics and refers to its contents, at the same time pointing out the deficiencies and shortcomings in the context of the groups analyzed.

The next two articles concern research carried out among groups distinguished by gender identity. The purpose of Katarzyna Gajek's text is to reconstruct the biographical work undertaken by parents of non-normative people on otherness. Joanna Chojnicka addresses the dilemmas of using qualitative research methods to analyze social media posts within the transgender community.

The closing text of the volume, written by Weronika Kamińska, focuses on ethical and methodological dilemmas that have emerged in the process of conducting research among palliative patients. The author presents and discusses situations related to her experience with in-depth interviews conducted with hospice patients.

The volume addresses both the challenges and dilemmas of designing and conducting qualitative research within the aforementioned groups, such as reaching out to representatives of the studied populations, the research procedure, the relationship of the researcher and the study subjects, issues related to the in-group and out-group perspectives, and the social and personal responsibilities of a researcher studying vulnerable groups. These, and further related issues, are discussed in detail in the context of specific qualitative research data and methods. Therefore, the articles provide an insight into the dilemmas related to various groups of research participants and constitute a collection of guidelines for other researchers. However, our aim is not to provide unambiguous answers applicable to any research on vulnerable groups, although such might emerge. The purpose of the volume is to depict and analyze certain issues and to reflect on and search for the most beneficial solutions possible. The reflexivity of researchers who focus on vulnerable groups is an essential element in their workshop. We do not perceive questions with no clear answers as a lack of competence—we see the potential for dealing with a given difficulty, considering doubts, searching for the best way to act, and developing as researchers.

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# Researching Vulnerable Groups: Definitions, Controversies, Dilemmas, and the Researcher's Personal Entanglement

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**Abstract:** The article aims to describe vulnerable groups in the context of qualitative research in social science with special attention to ethical and methodological dilemmas. This is a theoretical study, which does not aspire to offer solutions or guidelines, but rather show elements worth taking notice of and analyzing when research is planned and carried out. We argue that in the social sciences, vulnerability is relational and crucial. However, social science researchers perceive the category of vulnerability as ambiguous and nuanced. This article shows that ascribing research participants univocally to a vulnerable group may lead not only to them being stereotyped and deprived of individuality but also to a situation where the research act itself disempowers them. We also argue that apart from issues often raised concerning the protection of participants from vulnerable groups, the researcher and their protection are also pivotal, particularly when the researcher, due to their involvement, abandons the out-group perspective or when they belong to the vulnerable group.

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> People who write are always writing about their lives, even when they disguise this through the omniscient voice of science or scholarship [Laurel Richardson 2001:34]

# The

concept of "vulnerability" is widely recognized in research ethics and is used to signify those who need extra protections over and above the usual protections offered to research participants (Rogers and Lange 2013:2141). Although ethical considerations of vulnerable groups/populations stem from research performed in medical science (Macklin 2003; Jecker 2004; Levine et al. 2004), the problem also concerns social science (Iphofen and Tolich 2018). With many ethical values in mind, the discussion on social research ethics focuses on

minimizing harm, protecting privacy, and respecting participants' autonomy (Hammersley 2018). In social sciences, researchers are bound by regulations on ethical aspects of their research, for example, in Poland, by the Code of Ethics of a Sociologist (*Kodeks Etyki Socjologa* 2012). However, several qualitative methods emphasize specific implications and the complexity of ethical dilemmas concerning the method or the studied group (Iphofen and Tolich 2018), as well as methodological difficulties when research is carried out among vulnerable groups (Van Brown 2020).

In our opinion, the starting point for any considerations of ethical and methodological issues concerning vulnerable groups should be to introduce and clarify the definition of 'vulnerable groups,' as well as to analyze any controversies that result there-

from. Moreover, apart from often raised issues regarding the protection of participants from vulnerable groups, the researcher and their protection are also pivotal, particularly, when the researcher, on account of being involved, abandons the out-group perspective or when they belong to the vulnerable group. The researcher is usually seen as a person who is not to 'spoil the research' but to retreat and show reality objectively. Such are the social expectations that underpin this view that a researcher who writes from the first-person perspective refers to or analyzes their experience, or describes their research reflections about 'themselves' out of narcissistic motives—thus, their analyses contradict science.

Bearing in mind the aforementioned observations, the paper begins by reviewing various definitions that present the specific character of vulnerable groups, difficulties in defining them, and differences in how the term is perceived by medical and social sciences. The authors go on to describe controversies in the selection of particular social groups to be considered as vulnerable and reservations related to the term, such as the relativity of the notion, the risk of stereotyping and victimization, the motivation of participants from vulnerable groups to take part in research, and also the risks and benefits thereof. Subsequent parts of the article deal with issues specifically related to qualitative research among vulnerable groups. The first is the perspective of the researcher along with a traditional division into in- and out-group perspective, but also the position 'between,' which shifts the out-group researcher closer to the in-group perspective through their cognitive and emotional involvement. Then, the first-person perspective is analyzed when research is carried out from the in-group position. The authors also present the relationship between autoethnography and

a standpoint called "mesearch." Finally, ethical and methodological dilemmas are discussed that concern qualitative research among vulnerable groups, in particular, the perspective and relationship of the researcher and the group being studied, as well as the protection of the researcher who belongs to the vulnerable group they are studying.

## Definitions, Difficulties, and Intricacies of the Term 'Vulnerability' in Medical and Social Sciences

In the context of ethical research on vulnerable groups' members, it is vital to know how researchers understand vulnerability. According to Jo Aldridge (2014:113), "for the researcher involved in designing and conducting research with vulnerable individuals and groups, dilemmas arise from the outset that first necessitate particular and careful consideration of notions of 'vulnerability,' both definitionally and conceptually."

Clinical studies show that certain groups of people are considered to be more likely than others to be mistreated or taken advantage of when participating in research studies (Levine et al. 2004:44). These groups/populations are defined as 'vulnerable,' and consequently, special guidelines were drawn to protect individuals from such groups while conducting research (Brazier and Lobjoit 1991). Along with increasing attention given to ethical aspects of research, more regard is paid to vulnerable groups, as well as to incidences of their abuse in the past (Levine et al. 2004). The Council for International Organizations of Medical Sciences (2002 as cited in Levine et al. 2004:45) mentions the category of 'vulnerable persons' being "those who are relatively (or absolutely) incapable of protecting their own interests. More formally, they may have insufficient

power, intelligence, education, resources, strength, or other needed attributes to protect their own interests." Also, Zion, Gillan, and Loff (2002 as cited in Levine et al. 2004:45) point out that some individuals who lack basic rights and liberties are particularly vulnerable to exploitation and thus, are susceptible to being abused during research.

Due to difficulties with providing a precise definition of 'vulnerability' in biomedical research, Kipnis distinguishes six types of vulnerability (2001 as cited in Levine et al. 2004:45-46): "(1) cognitive: the ability to understand information and make decisions; (2) juridic: being under the legal authority of someone such as a prison warden; (3) deferential: customary obedience to medical or other authority; (4) medical: having an illness for which there is no treatment; (5) allocational: poverty, educational deprivation; and (6) infrastructure: limits of the research setting to carry out the protocol." Later, he also added a seventh type, that is, "social vulnerability, that is, belonging to a socially undervalued group" (Levine et al. 2004:46). Although this typology is useful, it is questioned by researchers, who say that it might lead to a conclusion that everyone who fits into any of these categories is vulnerable by definition, while everyone capable of unfettered consent is undoubtedly not (Levine et al. 2004:46).

Vulnerability is also defined as related to "human suffering." Vulnerable people may suffer from:

a) the potential risk often during harm, deprivation, or disadvantage that overwhelms them and that the person does not have the capacity to confront on their own; b) the fact of having already endured such a harm; and c) the potential risk of continuing to endure it if they do not escape the position of vulnerability in which they find themselves…Vulnerability

arises as a consequence of a person's inability to overcome a risk or danger by themselves, due to a disadvantage, deprivation, or harm, whether physical, moral, social, economic, political, or family-related.… Vulnerable people display weakness, fragility, and inability to recover from unexpected problems (real or potential). [del Real Alcalá 2017:VII]

Nancy S. Jecker (2004) states that the etymology of the word 'vulnerable' cognates it with a person who can be wounded. Therefore, in a broad sense, all persons could be considered vulnerable because everyone is susceptible to being wounded in some aspects (Jecker 2004:60). In this approach, "vulnerability can be considered as an attribute inherent to human nature: individuals are constantly exposed to potential harm (whether intentional or accidental), to the risks of fluctuating circumstances (due to rearrangements in society or merely because of the changes that come with aging), or to the perspective of being dependent (as a result of innate or acquired disease or disability)" (Ippolito and Iglesias Sánchez 2015a:20).

Other researchers (see: Ippolito and Iglesias Sánchez 2015a:20) suggest that belonging to a vulnerable group cannot be defined like Fineman (2008:8) does, who observes that it is solely a universal aspect of the human condition. In the narrow sense, the term 'vulnerability' is connected with the fact that there are people who are more vulnerable than others (Jacker 2004). According to Rogers and Lange (2013), in general, there are three sources of vulnerability—inherent, situational, and pathogenic.

Inherent vulnerabilities are shared by all humans. These stem from our embodiment and our affective and social nature. They include vulnerability to injury and death, and to psychological ills like loneliness

or lack of self-respect. Situational vulnerabilities, by contrast, come into being in specific economic, social, or political contexts that vary from person to person, and may exacerbate or ameliorate inherent vulnerabilities. For example, earning an income alleviates vulnerability to hunger. Pathogenic vulnerabilities are situational vulnerabilities that occur because of adverse social phenomena. They include vulnerabilities caused by injustice, domination, and repression, and also those that occur when actions intended to alleviate vulnerability actually make it worse…All of these vulnerabilities—inherent, situational, and pathogenic—may be occurrent or dispositional. Although vulnerability is defined in terms of a potential to incur a harm or wrong, some harms and wrongs are much more likely than others. Occurrent vulnerabilities refer to very likely outcomes, such as a homeless person's vulnerability to theft or injury. Dispositional vulnerability refers to potential outcomes, such as a pregnant women's vulnerability to complications in labor, which may or may not eventuate. Dispositional vulnerabilities can become occurrent under certain conditions. [Rogers and Lange 2013:2143]

For some, vulnerability is conditioned individually, uniquely, and innately, whereas others are vulnerable due to circumstances, social environment, or as a result of structural factors or influences (Larkin 2009). Still, this differentiation appears to be problematic. For instance, sexual minorities include those who are vulnerable due to factors coming from the social environment, structural factors, or influences because

they are more likely than the general population to experience human rights violations, both from domestic authorities and individuals. They may be threatened in their bodily and moral integrity by physical and

verbal abuse; their freedom to live according to their identity and to publicly express this identity may be limited by law and public morality; their economic situation may be weakened by employment discrimination or discrimination in accessing benefits otherwise allocated to heterosexual couples. [Ducoulombier 2015:202]

On the other hand, individuals with disabilities are seen as vulnerable due to their individual backgrounds and innate features. Still, the social model of disability "focuses on determining the reasons for disabilities not connected with the individual as such, but pointing at the social barriers that limit the individual in the environment where he/she lives… and is a coherent and complementary element of the concept of individual vulnerability attributed to people who are marginalized in a given society" (Domańska 2018:25).

Levine and colleagues (2004) claim that vulnerability is both too wide and too narrow a term. On the one hand, many groups may be currently treated as sensitive, but on the other hand, the category is narrow and excludes some individuals. Thus, the term remains rather elusive and intuitive and depends on the context in which it is used (Larkin 2009:1).

Then, it is worth remembering that some individuals are susceptible to multiple vulnerabilities—not only innately or circumstantially but also potentially by research processes themselves (Aldridge 2014:113). That is why social scientists tend to focus more on whether they contribute to the research subject, becoming more vulnerable as a result of the research. Hollway and Jefferson (2000:313) claim it is crucial to ensure that the level of harm that might be predicted is no greater than that to which the participants have been exposed anyway.

## Controversies and Consequences Linked with the Term 'Vulnerable Group'

### Relativity and Dynamics

An aspect worth noting is the dynamics of being a member of a vulnerable group. One may belong to a vulnerable group at some time or in some circumstances, but not permanently, for instance, a pregnant woman in a workplace or someone for a few hours after a disaster. Thus, an individual's potential vulnerability in the research context does not depend solely on that person's belonging to a certain group but on the particular features of the research project and the environment in which it is taking place (Levine et al. 2004:47). For example, the notion that women, in general, constitute a vulnerable group is disputable. The situation depends on many factors, including the country, religion, or social class. Thus, it is impossible to univocally count women in general as a vulnerable group/population (Macklin 2003) because their potential vulnerability is not inherent in the mere fact of being female (Fines 2015:95). Similarly, researchers have discussed diversity with regard to, for example, the elderly (e.g., Levine 1982).

What is more, the researcher's perception and perspective on vulnerability—its innate or circumstantial characteristics—may change. Similarly, the research participant's self-perception may alter from other people's perceptions, especially if the participant sees themselves as resilient rather than vulnerable in a particular context (Aldridge 2014:113).

Therefore, because vulnerability is a dynamic concept and in a complex relationship to the notions of minority groups (Ippolito and Iglesias Sánchez 2015b), the term "minority groups" cannot be iden-tified with vulnerable groups. At the same time, Francesca Ippolito and Sara Iglesias Sánchez (2015b) state that minorities, such as ethnic, religious, or sexual, may be seen as vulnerable groups. However, these authors also emphasize that such terms as "vulnerability," "sensitivity," and "marginality" are often hard to distinguish from one another, and they tend to be used interchangeably as synonyms (Luxardo, Colombo, and Iglesias 2011). It is true that research carried out among vulnerable groups deals with sensitive topics that may prove to be more important than the issue of the study group itself. Therefore, such a group can be automatically counted as vulnerable when dealing with a sensitive topic.

### The Risk of Stereotyping and Victimization

While discussing controversies and problems of using and defining the term "vulnerable groups," the fear of stereotyping is a vital issue. Individuals who belong to a certain group and thus represent a feature or features that make them likely to belong to a vulnerable group may be deprived of their individuality and be perceived only through the prism of belonging to a specified group (Levine et al. 2004). Ascribing someone to a vulnerable group in clinical research (see: Brazier and Lobjoit 1991) may result in paternalism and stereotyping (Macklin 2003; Rogers and Lange 2013), but also in either excluding or over-representing them in a study (Rogers and Lange 2013).

What is more, the above issues are connected with the problem of victimization. In medical research, people who are mentally ill, poor, addicted, old, HIV/AIDS-positive, and also children are included in the vulnerable group. The term "vulnerable group" or "vulnerable population" is identified

with those who are victims, dependent, deprived, or pathology-related (Fineman 2008). According to Peggy Ducoulombier (2015:202),

> we should remember that their vulnerable status is linked to a long-term process of exclusion by which they were cast out as different. In the latter sense, vulnerability is a divisive rather than an inclusive notion. However, if one may regret the undertones of stigmatization that the 'vulnerable label' may carry, this notion, even understood in a non-universal sense, allows the recognition of the social and institutional discrimination suffered by particular groups and, as a result, may be used to impose on states specific and stricter obligations of protection.

Nevertheless, Fineman (2008:9) undertakes to deprive 'vulnerability' of negative connotations and suggests noticing its potential in referring to a universal and inevitable aspect of the human condition that must occupy the center stage of social and state responsibility. In this approach, 'vulnerability' is perceived as a conceptual tool with the potential to ensure a more robust guarantee of equality. Fineman (2008:15-16) also emphasizes that

> [w]ithin the various systems for conferring assets, individuals are often positioned differently from one another, so that some are more privileged, while others are relatively disadvantaged. Important to the consideration of privilege is the fact that these systems interact in ways that further affect these inequalities. Privileges and disadvantages accumulate across systems and can combine to create effects that are more devastating or more beneficial than the weight of each separate part. Sometimes privileges conferred within certain systems can mediate or even cancel out disadvantages conferred in others.

## Motivation to Participate in Research

In medical research, much attention is paid to the conscious consent of participants who partake in research, especially those from sensitive groups, and difficulties that are likely to occur (Brazier and Lobjoit 1991; Rogers and Lange 2013). Although the issue of conscious consent is especially taken into account in biomedical research, social science also does so. Conscious consent to partake in research is meant to safeguard participants' interests and protect them from the researcher, who might use unacceptable methods. There are procedures in medical science, and research participants sign a document. However, social science uses a kind of contract that informs participants of the aim, method, and duration of the research, as well as the potential risks and benefits for the participants. Due to the distinctive character of this discipline, it is often difficult to specify all aspects of the research and/or benefits the participant might gain from partaking in it (van den Hoonaard 2018). The aspect of "giving them a voice" can be seen as a benefit for representatives of a given group (Hollway and Jefferson 2000). Still, not every participant may consider it as significant to them. On the other hand, it cannot be assumed that participants gain nothing, but it is a highly individual issue. Nonetheless, a stereotypical assumption that by belonging to a vulnerable group, one sees oneself as deprived of the sense of agency (which is the very reason for having no such sense and aversion to participating in research) may be false. Researchers often emphasize that within various disciplines there are situations when participants are willing to share their experiences and enjoy the research (van den Hoonaard 2018). In short, the researcher's conviction that individuals taking part in a study because they belong to a vulnerable group are isolated or lonely makes them disempowered (Russell 1999).

## The Researcher's Perspective

The objective character of the out-group perspective is often raised when discussing the role of the researcher. At the same time, out-group investigators may be seen as "colonizers" imposing their interpretation of experiences that are unavailable to them. An example of a strategy developed to protect vulnerable groups from such practices would be the guidelines developed by Jacob Hale (1997), who made a list of 15 recommendations for non-transgender researchers investigating a subject. He emphasized respect toward the interlocutors and a simultaneous critical analysis. Hale stressed that while transgender people cannot be treated as experts in their experience, researchers must not behave as "colonizers" who know better and tell a better story. This reveals the problem of recognizing the respondents' subjectivity in the research process and the role of the researcher's perspective.

Additionally, in social science, vulnerability is tightly linked with the sense of security. Individuals who belong to groups that suffer from discrimination or prejudice may be afraid of being identified and might not trust the researcher. Moreover, research within a vulnerable group may be hindered by the group's inaccessibility. Thus, the question of studying 'one's own' group appears, as well as the in- and out-group perspective that entails certain dependencies and dilemmas.

The position of the researcher versus the study population is a very important factor during research on vulnerable groups, including affiliation to the group, abandoning the in-group perspective, the lack of affiliation, and the out-group position. In social science, discussions on the in- and out-group perspective are not a novelty, as there appear to be as many arguments for as against each position, often with it being possible to raise the same issues in support as against both perspectives (Serrant-Green 2002:38 as cited in Dwyer and Buckle 2009:57).

**A Space In-Between**

Sonya Dwyer and Jennifer Buckle (2009) offer an interesting view that challenges the dichotomy of insider versus outsider status, showing that such a dichotomy is an oversimplification of possible relationships between the researcher and the study group. Also, these authors stress that there is a third option—the space between. This perspective is developed as a result of great involvement (cognitive and emotional) with the social group being studied. Consequently, even if the researcher is not its member, they entirely abandon the distanced, outsider's perspective of a disinterested person: "We may be closer to the insider position or closer to the outsider position, but because our perspective is shaped by our position as a researcher (which includes having read much literature on the research topic), we cannot fully occupy one or the other of those positions" (Dwyer and Buckle 2009:61). This positioning draws attention to the special status of qualitative research,

> [t]he process of qualitative research is very different from that of quantitative research. As qualitative researchers, we are not separate from the study, with limited contact with our participants. Instead, we are firmly in all aspects of the research process and essential to it. The stories of participants are immediate and real to us; individual voices are not lost in a pool of numbers. We carry these individuals with us as we work with the transcripts. The words, representing experiences, are clear and lasting. We cannot retreat to a distant "researcher" role. Just as our personhood affects the analysis, so, too, the analysis

affects our personhood. Within this circle of impact is the space between. The intimacy of qualitative research no longer allows us to remain true outsiders to the experience under study and, because of our role as researchers, it does not qualify us as complete insiders. We now occupy the space between, with the costs and benefits this status affords. [Dwyer and Buckle 2009:61]

**Protecting the Group, Protecting the Researcher**

When research is carried out among vulnerable groups from the in-group position or even in a situation when the cognitive and personal involvement of the researcher places them in the space between, an important ethical issue appears—one not frequently dealt with—of costs and benefits. Although the ethical responsibility to protect participants from vulnerable groups is obvious, researchers are paid far less attention when they take up the in-group position, especially the first-person perspective. Thus, when talking about the protection of vulnerable groups' members, the researcher must also be protected, as they identify with the group in question and share their experience as a member of that group.

> With regard to vulnerability, Tolich argues that we should treat all people mentioned in the text as vulnerable or at risk of harm in some way, including the auto-ethnographer themselves. By taking this approach, an auto-ethnography will be focused on the aim of the narrative, as well as its likely impacts on a diverse group of participants. Tolich notes that "no story should harm others" (2010:1608), and where harm might be possible, researchers can take steps to reduce this. This will include the researcher themselves, who should view their auto-ethnographies as an 'inked tattoo': once a narrative is out there, you

can't retrieve it, so Tolich cautions auto-ethnographers to be very careful. The other issue linked to vulnerability is the issue of confidentiality, not so much external confidentiality, as good qualitative researchers will often build in quite clear confidentiality guarantees for participants in research, but internal confidentiality, which Tolich outlines as the risk of exposing confidences amongst the participants themselves. Even if a nom de plume is used, there could be significant harm caused amongst family members, because they recognize themselves and their comments. [Gibbs 2018:152]

Once the research procedure has taken notice of the researcher and their vulnerability, costs, and benefits, the relationship between the "I" of the researcher and the research subject takes a new perspective. In the analyzed in-group perspective, where the individual "I" of the researcher becomes involved in the research process, the term "re-search" overlaps with the term "me-search," a non-academic term that "links the terms 're-search/practice' and 'me'" (Edward 2018a:83) and suggests that the in-group perspective is limited while studying the first-person experience of the researcher.

## Me-Search or Mesearch. A Term Both Present and Absent in Social Science Research

The term "mesearch" is relatively new in the discussion on social science research. When looking at its etymology, it should be noted that "Me-search… means pursuing a scientific question when the answer to that question is idiosyncratically relevant for the individual researcher (as opposed to when the answer is relevant per se)" (Altenmüller, Lange, and Gollwitzer 2021).

## Mesearch as "Selfie"

The term "mesearch" entered or even became widespread through popular science media, where it was presented as anti-science or scientific anti-objectiveness. The term, which is often hyphenated, is described as narcissistic, biased, non-scientific, and related to the social media culture and the reality overloaded with *selfies*. Mesearch, which is presented and popularized in popular science papers, is treated sarcastically or humorously. In short, it should be avoided. Media warn potential audiences to be suspicious of research that is not research because it is designed from the perspective of a narcissistic researcher who writes about themselves. They assume that the researcher has no theoretical background or research reflection, and they point to the "threats" coming from the researcher who writes from the first-person perspective. Also, the term is assumed to question the research methods adopted.

Then, the term "me-search" used in popular science and described in various media is frequently avoided by researchers who oppose the above-mentioned connotations and do not wish to be seen as those dealing with non-academic activities. They are also unwilling to struggle or prove the grounds of their scientific stance. Thus, the majority of researchers do not use the term, and scientific databases do not provide many records of texts where the term "mesearch" or "me-search" is used (Nash and Bradley 2011; Raw 2016; Wiklund 2016; Edward 2018b; Rios and Roth 2020; Altenmüller et al. 2021; Brown and Patterson 2021; Devendorf 2022).

However, if such mesearch does occur, the authors explain the scientific reasons behind or discuss the grounds for their stance, risks, and benefits, as well as how the research is or should be carried out. What is more, the term "mesearch" is never used without any explanation or reference to methodological doubts. It appears that what prompts the greatest opposition is the use of the first-person perspective, which is commonly thought to be the opposite of the objectivity synonymous with scientificity.

In the context of studies on vulnerable groups, mesearch is usually understood as a narcissistic presentation of one's perspective when talking about a group and an unjustified generalization of one's experience, considerations, and conclusions over the experience of the group. Thus, the researcher presents themselves like a self-advertisement and looks for fame and applause. This is how society sees it from the perspective of their contemporary culture and phenomena that take place in social media.

## Mesearch as the Synonym of Autoethnography

Mesearch/me-search is also sometimes treated by researchers as the synonym of autoethnography. Autoethnographic research has a solid position in social science. In the context of studies on vulnerable groups, a researcher who belongs to the vulnerable group they are analyzing performs autoethnographic research. One of the practical aims of autoethnography is to bring about social change by empowering marginalized groups (Bielecka-Prus 2014).

Adams, Holman-Jones, and Ellis (2015) have noted a plethora of aims for autoethnography, including the need to place personal experience in research and writing; illustrating personal mean-making; demonstrating reflexivity; offering resistance narratives; and seeking responses from audiences. There are many reasons why people choose the autoethnographic method. Commonly, it is because writers notice from

their own experiences that there is a gap in the published literature so they use their autoethnography to write that in. [Gibbs 2018:149]

During autoethnographic studies, research is based on personal experience and transcribes the personal to the cultural (see: Richardson 2001; Lofland et Al. 2006; Bielecka-Prus 2014; Kacperczyk 2014a). An autoethnographer is primarily interested in studying the cultural and contextual influences on their self-reflection (Nash and Bradley 2011:16). Autoethnography is "understood as auto-narration based on the introspection process, an act in which the narrator reflects on their own life experience, simultaneously referring it to the social context in which they have occurred" (Kacperczyk 2014b:37 [trans. UK, AMK, and MB]). As a result, very personalized tests are designed.

Truth be told, the question of who the researcher is cannot be ignored entirely because research participants should know that. According to Krzysztof Konecki (2021:26 [trans. UK, AMK, and MB]), "My self-definition is indispensable for them to place me in their own world and adjust—I wish to stress—adjust their answers to my questions. It is so not only because the research concerns a living person who I interact with but also the documents I analyze, and they adjust to my questions, too; they are 'players,' even though they are lifeless partners of the interaction in my game, which I call 'data analysis.'" Therefore, if the reflection on the researchers themselves is vital in the case of outgroup research, it is even more so when it concerns autoethnography.

In autoethnography, the emphasis is on the researcher's reflexivity. In the process of developing knowledge, where their sensitivity plays a role

(Kacperczyk 2014a:8), "autoethnography trumps other sociological methods by enlarging our understanding of reflexivity in the research process. No other sociological method has the potential to disclose the multiple reflexivities that are involved in our everyday research projects, which include not just the researcher's reflexivity but also the reflexivities of the researcher's subjects" (Ruiz-Junco and Vidal-Ortiz 2011:206). For autoethnography, the reflection on the research process is of great importance, as it is strictly connected with the personal, biographical experience of the researcher (Lofland et al. 2006). According to Carolyn Ellis, Tony Adams, and Arthur Bochner (2011:5),

> [w]hen researchers do *autoethnography*, they retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity. However, in addition to telling about experiences, autoethnographers often are required by social science publishing conventions to analyze these experiences…Autoethnographers must not only use their methodological tools and research literature to analyze experience, but also must consider ways others may experience similar epiphanies; they must use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders.

The authority of the researcher also has to be borne in mind, especially when the researcher appropriates the subject of their research and becomes the "data surgeon" (Konecki 2021:25 [trans. UK, AMK, and MB]). That is why, in qualitative research, the position of the researcher toward the phenomenon being studied is widely discussed. To reveal the situation where the relationship between the researcher and their researched subject is obvious,

the researcher has to adopt the first-person perspective (see: Nash and Bradley 2011; Konecki 2021). Although the first-person perspective is not indispensable in research, it is possible and practicable. Moreover, texts written from the first-person perspective do not exclude other perspectives,

> [a]utobiographers also can make a text artful and evocative by altering authorial points of view. Sometimes autobiographers may use first-person to tell a story, typically when they personally observed or lived through an interaction and participated in an intimate and immediate 'eyewitness account'…Sometimes autobiographers may use second-person to bring readers into a scene, to actively witness, with the author, an experience, to be a part of rather than distanced from an event…Autobiographers also may use second-person to describe moments that are felt too difficult to claim…Sometimes autobiographers may use third-person to establish the context for an interaction, report findings, and present what others do or say. [Ellis et al. 2011:5]

Still, whatever the narration, the researcher is like a prism or a filter who is not in the foreground, even if they use the first-person perspective. So, they should reflect upon research assumptions, their attitude, and the process they undergo themselves. The first-person research perspective is not about the researcher, whose role is to be a tool in the research procedure.

**Autoethnography vs. Me-Search**

What is easy to notice is the fact that researchers like to use autoethnography more than mesearch. It might be so due to the above-mentioned reservations and the fact that autoethnography is well-rooted in the methodology literature.

Mesearch seems to be a wider term than autoethnography because it refers to the first-person perspective in the context of those who stick to strict methodology and those associated with an egocentric and subjective *selfie*. So, if mesearch is to be scientific autoethnography, it has to obey certain rules. Atkinson and Delamont (2006 as cited in Gibbs 2018:150) "argue that autoethnography can become unreflective personal narratives, and that for autoethnographies to gain credibility, they must be analytic, and be connected to, and critiqued within, broader social contexts." According to Sparkes (2000:21 as cited in Gibbs 2018:148), autoethnography is focused on "highly personalized accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding." Anita Gibbs (2018:149) has reached similar conclusions that autoethnography as a scientific method

> can be distinguished from autobiography or personal narrative, by being more critical or political, and making the linkages of personal to cultural and organizational. Autobiography is selective writing about past or current experience (Roberts 2002), whereas in autoethnography, "your life is the data," in other words life events and experiences are treated as data to be collected, analyzed systematically, and critically reflected upon. Having said that, sometimes the lines are blurred and the terms are used interchangeably.

In her autoethnographic analysis, Gibbs (2018:149) points to the condition that "the ethnographic and critically reflexive study of the self, as well as of others with whom the researcher might have a close personal or familial connection. It is personal ethnography that critically connects the topic to the wider social, political, cultural, and ethical contexts and discourses of the topic." Therefore, autoethnography refers "the personal to the cultural" and—as

the name suggests—combines three elements—"auto (to do with self/personal experience); the ethno (to do with culture/insider insight), and graphy (to do with writing, documenting, or analyzing)" (Gibbs 2018:149).

## The Researcher as a Vulnerable Group Member: Dilemmas

Having described the complexity of the abovementioned issues, that is, research among vulnerable groups, the difficulty in defining the term, and the consequences of assigning (or not) research participants and the researcher to such a category, a few key aspects appear that concern ethical and methodological dilemmas worth paying attention to when planning, performing, and considering research.

These dilemmas interweave and raise doubts about the researcher's role, involvement, affiliation with the vulnerable group, the uniqueness of the research, and relationships that exist or will appear. This article does not aspire to offer solutions or guidelines but rather to show elements worth taking notice of and analyzing when research is planned and carried out.

The starting point can be the researcher's declaration about their relationship with the group being studied, both before, during, and after the completion of the research. The list of questions to pose can include the following: Does the researcher belong to the vulnerable group they study? If so, do they declare their affiliation with the group? Why do they reveal (or not) their affiliation? What are the risks and/or benefits of doing so for the researcher and/or the studied group? If the researcher does not belong to the vulnerable group in question, what is the level of their involvement (cognitive and emo-

tional) that exists or will appear in the course of the research? How does the involvement that appeared affect the relationship of the researcher toward the group being studied?

Once the researcher's position versus the vulnerable group has been defined, the motifs of the research should be looked at and verified. Again, there are questions to be asked: Why is this vulnerable group the subject of the research? What are the motives for taking up the topic, both conscious and unconscious? To what degree have they been instilled by personal factors? Do they change in the course of the research?

Another aspect is access to the chosen group. As mentioned above, some groups are easier to reach, and they tend to be overexposed, whereas others are hard to get through or even impossible, unless one is the group's member or creates a relationship of trust that involves personal involvement. Therefore, how has the researcher reached the individuals being studied persons, or how do they intend to reach them? Again, the question of the researcher's position toward the group returns—now in the context of access. Or did the researcher have to recruit research participants from the out-group position? How may the method of reaching the group affect the researcher-participant relationship and the whole research situation? Is the group frequently studied and 'exploited' due to research? If so, are the participants tired of partaking in repeated research? If not, is the situation new to the participants?

The method of reaching participants may influence the research situation. Regardless of how the group has been reached, the paramount issue is their conscious consent to take part in research. So, how can a researcher obtain it? What information may

the participant need from the researcher to see the whole situation? Does the researcher realize what consequences (risks and benefits) participants may incur as a result of taking part in the research? What is the participant's motivation to partake in the research? What are their expectations? What do they need from the researcher? How does the way the presenter introduces encourage participants to join the research (authority, member of the vulnerable group, others)? What is the researcher's stance toward the participants and how does it change in the course of the research?

Additionally, it is vital to reflect upon the sense of obligation before, after, and in the course of the research. It may be related to the participants' sense of obligation as they agree to take part in the research or who are ready to give information due to their specific relationship with the researcher. Likewise, this sense may also concern the researcher who feels obliged toward the participants to protect the given vulnerable group and influence the groups' positive perception by society. Therefore, one may wonder if the sense of obligation toward the participants affects research results, interpretation, and presentation thereof. Then, the question is whether the researcher is aware of it.

Similarly, the researcher-participant relationship may play a role. It may occur during the research and have an impact on the participants and the researcher. Again, how does this relationship affect the research results? Does the researcher represent the research group's interests consciously or unconsciously? Does it not transpire that the group's image is 'looked after' by research participants or the researcher is under the group's pressure? Finally, if the researcher belongs to the group being re-

searched, does the sense of obligation make them represent the group's interests even more so?

What is especially important is the multi-level protection of all research participants. It includes prevention from direct threats resulting from the study situation, for example, maintaining the participants' anonymity, as well as safeguarding them from emotional consequences stemming from their participation in the research. Thus, it is vital to protect the privacy of the participants and minimize their lack of comfort.

Correspondingly, the researcher is also to be protected. They should ask themselves if they are sufficiently secure and if the level of their privacy is acceptable to them. Next, when the researcher belongs to the vulnerable group being researched, they require special protection, for instance, concerning the emotions they experience and their feeling of identity with the participants.

Nonetheless, many dilemmas connected to research on vulnerable groups are independent of the researcher's relationship with the group. Some may turn out to be specific to a given situation when the researcher is highly involved or affiliated with the vulnerable group. The point is that these issues concern the researcher, their protection, and the consequences that the research situation or the results' publication may have.

However, many other problems may occur. One of them is the issue of revealing to the participants and later—due to the publication of the research results—to a wider audience the fact of being a member of the given vulnerable group. On the one hand, this problem concerns the protection of one's "I" and privacy, but on the other, it relates to the openness of

research participants. Last but not least, there is the impact of the researcher-participant relationship on the methodology and research results.

In a situation when the researcher reveals their identity as a member of the vulnerable group being researched, the group may happen to have certain expectations. For instance, the group may expect the researcher to be their spokesperson, a representative of particular participants, or someone who would make society perceive the group in some way.

What remains is the matter of the conscious or unconscious generalization of one's experiences upon the group's experiences, as well as the interpretation of the data collected from one's standpoint. This is particularly important when the research is carried out from the first-person perspective when me-search becomes the methodological *selfie*, instead of a mindful and thorough autoethnography.

## Conclusions

In biomedical research, the category of vulnerability is mainly associated with the issue of conscious consent, inequality of power, and the potential possibility of being harmed.

> Regulations and policy documents regarding the ethical conduct of research have focused on vulnerability in terms of limitations of the capacity to provide informed consent. Other interpretations of vulnerability have emphasized unequal power relationships between politically and economically disadvantaged groups and investigators or sponsors. So many groups are now considered to be vulnerable in the context of research, particularly international research, that the concept has lost force. In addition, classifying groups as vulnerable not only stereotypes them, but also may not reliably protect many individuals from harm. Certain individuals require ongoing protections of the kind already established in law and regulation, but attention must also be focused on characteristics of the research protocol and environment that present ethical challenges. [Levine et al. 2004:44]

However, in social science, the term "vulnerability" is relational (van den Hoonaard 2018). Power inequality between the medical researcher and the participant is not as strict as in social science (see: Sleat 2013). According to Will C. van den Hoonaard (2018:305), social science "should abandon the doctrine of vulnerability." He also questions the validity of the category of vulnerability and claims that every individual should be deemed vulnerable. In medical science, a quite arbitrary list was drawn of groups treated as vulnerable (see: Sieber 1992). Western ethics committees have made them "untouchable" because researchers have to obtain their special consent to undertake the research. In consequence, some groups may be excluded from research (van den Hoonaard 2018). Medical researchers concentrate on the issue of conscious consent, vulnerability to harm or abuse, whereas social science researchers pay attention to the question of whether they do not make the subject of the research more vulnerable in the course of, or as a result of, the research (Iphofen 2009).

Social science researchers perceive the category of vulnerability as a less stable concept, which is seen as ambiguous and nuanced. Ascribing research participants univocally to a vulnerable group may lead not only to them being stereotyped and deprived of individuality but also to a situation where the research act itself disempowers them (Lee and Renzetti 1990:512).

Nevertheless, the fact that research participants realize they belong to a vulnerable group may let the researcher notice the situation's complexity and reflect on their prejudices and assumptions. In this way, the researcher becomes better prepared to protect the vulnerable, to inform themselves of their prejudices and of the susceptibilities of others to harm (Jacker 2004:61).

It is generally assumed that research should be objective. However, in the case of qualitative research, this is by definition something remote, and research on vulnerable groups seems to be a manifestation of this. As Nash and Bradley (2011:82) comment:

> [q]ualitative (ethnographic) and quantitative research methodologies, along with their unique languages, are shaped by a view of the world that is objective (out there to be studied), naturalistic, measurable, testable, and in-reviewable. Narrative (phenomenological, SPN) research methodologies, along with their unique languages, are shaped by a view of the world that is subjective (in here to be expressed), constructivist (at least partly constructed by the observer), and interpretive.

Still, the researcher is always 'someone,' and even if they adopt the stance of a 'naive researcher,' they have certain assumptions. Even though the researcher meticulously follows research procedures, regardless of the research type, they always bring into play their personality, opinions, stereotypes, fears, experience, and, in short, themselves. A researcher is a person who is not able to entirely "suspend themselves" (Konecki 2021 [trans. UK, AMK, and MB]). However, they should be aware of that fact. It is not only about being biased toward certain conclusions, noticing, or overlooking some data. Pierre Bourdieu and Loïc Wacquant (2001) no-

tice that the researcher is always a person of some gender, race, or nationality and that this affects their perception of reality and position toward the group being researched. The complexity of the researcher's identity and the variety of their experience rules out a simple division into in- or out-group relationships with the research participants. As this article shows, this is particularly important for qualitative research. Therefore, when describing research dilemmas in the case of vulnerable groups, both the participants and the researcher should be taken into consideration, particularly when the researcher belongs to that group themselves.

A researcher participates and experiences the study situation just like the participants they observe or talk to. Simultaneously, they project reality, consciously or unconsciously, according to their perception and experience, no matter if they work from the in- or out-group perspective. Many a time, the researcher's cognitive and emotional involvement, which develops in the course of the research, places them in the space between. To sum up, "the researcher is always a me-searcher, someone whose personal worldviews change over time, and when they do, they result in different takes on what constitutes valid, worthwhile research. Thus, *me-search* and *research* are allies, not enemies" (Nash and Bradley 2011:XIV).

Research on vulnerable groups broadens researchers' ethical awareness, but one can assume that any research—including that on groups not perceived as vulnerable—poses ethical challenges and can indicate new areas prompting researchers to deepen their ethical skills.

Knowledge of ethics does not necessarily prepare researchers for situations they cannot foresee.

Above all, the researcher should be attentive to what is happening in the research process and open to confronting their beliefs with their subjects' perceptions of the world.

Working with vulnerable groups highlights another important issue. It often involves working with the emotions of the subjects, as well as the emotions of the researchers. As researchers, we are taught to focus on the subjects' narratives and the emotions that accompany them. However, we are not prepared for our emotions, which may be significant as well. This was pointed out by Rhonda Shaw and colleagues in an article discussing their research experiences with vulnerable groups (2020:290-293). Undoubtedly, research with vulnerable groups also engages researchers emotionally and thus can be extremely exhausting and difficult for the researchers.

This raises the question of whether researchers working with vulnerable groups should have additional support in the form of supervision. So far, such institutional support is not practiced in social sciences, even though research among vulnerable groups highlights the significance of the researchers' emotional engagement in the course of research. However, this is a broad topic for a separate article.

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## Citation

# The Conceptual Metaphor as an Ethical Kaleidoscope in Field Research

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**Abstract:** Attention to metaphor as a tool for cognition and action has already been called by the classic work by Georg Lakoff and Mark Johnson—*Metaphors We Live By* (1980). However, some four decades after this publication's first edition, the role of metaphor as a useful instrument in empirical research seems to have been forgotten. Therefore, the first step taken in the text at hand is to highlight that codes of ethics neither resolve nor befit the dynamically shifting circumstances of research conducted in the field. Ethical codes are often insufficient. Hence, an objective here will be to critically assess the broad application of such codes in general. The second step will be to turn to metaphor as a tool in developing the sociological imagination as understood by C. Wright Mills. The metaphor can also assist in finding oneself when confronted with difficult, ambiguous circumstances that may arise during fieldwork. Metaphor as a tool, as an ethical kaleidoscope coherently links the field research experience precisely with the sociological imagination.

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The objective herein is to endeavor an escape from the impasse presented by the interminable creation of codes of ethics within the social sciences—codes, however, which do not live up to the challenges and dynamics of fieldwork. It is certainly not our claim that such codes are unnecessary and superfluous in the social sciences, but it is vital that an ethical code be supplemented by a tool sufficiently adaptable and tractable to afford quick responses to the unexpected, problematic situations that arise in the course of research. An apparatus of this kind would—for scholars drifting untethered on the open, unfamiliar waters of new fieldwork—instantly provide something of a rescue pontoon.

This tool would also constitute a response to Karl Popper's call, postulated in his classic *The Logic of Scientific Discovery* (2002) released in 1959—scholars should break away from the safe havens of academic hypotheses, confronting instead the novel, perilous challenges of the world of science and learning. Facing up to those challenges could result in a more abundant harvest of knowledge. "Methodological rules are here regarded as conventions. They might be described as the rules of the game of empirical science" (Popper 2002:32). With this in mind, the rule we propose here in social sciences research is the implementation of metaphors as a kind of ethical kaleidoscope guiding the experience of the anthropologist in the field and their ethical reflection.

An identification of the metaphor with the kaleidoscope is substantiated by the Greek etymology of the latter. Indeed, the very word embodies three lexemes: that is, *kalós* (beautiful), *eîdos* (shape or form), and *skopós* (aim or look at). Metaphor understood literally as a kaleidoscope manifests as a tool that facilitates the perception of beauty in all its shapes and forms—in other words, a tool drawing us closer to the world of ideas embodied in ethical codes. These, in turn, are an expression of cultural values universally appreciated in a society, and thus, by the same token, taken under careful consideration in the course of scholarly research. This is so because of metaphor's communicative function—making use of conceptual systems that go hand in glove with daily feats of cognition inherent in our activities, thoughts, and deeds. These elements allow us to transcend the limitations of individual experiences consisting of words and images that do not necessarily correspond with one another.

When used in this context, the creative power of language also permits discernment of intrinsic ambiguities in the word "kaleidoscope." With every rotation and realignment of the pieces inside, this optical tool provides us with a different image and a different view of the same elements. Here, too, the power of metaphor allows us to recognize a diver-

sity of discourses; it aids in hearing a community's polyphony, especially the voices of subordinated groups or individuals. The kaleidoscope shifts and rearranges the rather ossified frames of reference—including the researcher's persona—that are used in perceiving the world.

Looking back at the perambulations of social scientists in the field, we come across the metaphor-as-tool among the innovations of sociology. From precursors like Émile Durkheim and on, the metaphor is universally found in the instrument set sociologists use in the research process. Moreover, it has reappeared time and time again as a cornerstone in various, new sociological paradigms, such as engaged (public) sociology or feminist sociology, in which the researcher becomes the voice of the less powerful (Denzin and Lincoln 2005).

It is impossible not to notice the power relations generally arising in any research situation between the researcher (e.g., physician, sociologist, or even the quasi-enquiring society as a whole) and the researched (e.g., the patient, interlocutor, or minority groups respectively). We argue, however, that the vector of symbolic power runs from the researched group or individual toward the researcher and not vice versa. This is particularly the case in the course of (quasi-) social research in which participants decide how much of their biography, thinking, or experiences to reveal and how that will be presented—something that swiftly brings Michel Foucault's power-knowledge concept to mind. Directing the situation is thus the person under study, whereas the researcher must seek out a procedural manual to wisely and carefully negotiate that strange land.

In this case and for our purposes, the conceptual metaphor of the guest is also of assistance. The guest appears a perfect fit within the environs of contemporary social science research in which increasingly more space has been devoted to ethical standards and the psychological comfort of the groups and individuals who are the focus of inquiry. The use of metaphor in the research context renders it possible to adapt the standardized principles included in a sociological code of ethics to a given situation.

## The Researcher's Responsibility vis-à-vis Ethical Codes

As Mirosława Marody (2021:77 [trans. MF and KP]) observes, "Responsibility is, in many ways, a peculiarity as it conjoins seemingly contradictory properties. This is already evident in its lexical definition: according to the Dictionary of the Polish Language [*Słownik* 2022], responsibility is 1) a moral or legal obligation to be accountable for one's own or someone else's actions and 2) taking upon oneself the duty to care for someone or something." Plainly clear in this definition is that the first meaning refers to responsibility understood in categories of agency appraised by the broader community. Yet the second is decidedly individualistic with positive connotations. According to Marody, the internal fissure contained within the concept of responsibility is a consequence of the historical evolution of the term's meanings and senses.

Still, in the eyes of Zygmunt Bauman, the development of morality had been effectively blocked in the formation of modernity. One reason for this was a desire to frame a universal, unequivocal, and all-encompassing code of ethics (Bauman 1993). Three decades earlier, Leszek Kołakowski had accomplished this in his *Ethics without a Moral Code* (1971) released in 1962. Bauman, however, argued that normative tendencies inevitably lead to a blunting of individual sensitivi-

ty and to obscuring the fact that there is an extraordinary complexity intrinsic to moral dilemmas (Flis 1994). Among other things, he pointed out that the driving forces of modernity were reflected in disciplinary practices aimed at shaping obedient and simultaneously captive individuals (Foucault 2006). In Bauman's opinion, it has been the postmodern condition that has compelled the Western world to undergo an axiological transformation. "The denizens of the postmodern era are, so to speak, forced to stand face-to-face with their moral autonomy, and so also with their moral responsibility" (Bauman 1995:43). Bauman discerned responsibility as a cornerstone of contemporary public life. Postmodernity's retreat away from moral codes has resulted in a shift toward the emotive sphere. In this context, Richard Rorty (2002) wrote about the ethics of sensitivity, whereas Bauman (1993) indicated a need for the development of the moral self.

Codes, as Kołakowski pointed out, have been created to shift the burden of personal responsibility onto a set of rules and regulations of conduct via the introduction of set behavioral patterns. The implicit assumption upon which the codification of conduct for fieldwork was built was a belief in "the repetitive nature of moral situations and, consequently, in the possibility of the re-applicability of solutions worked out once and for all. Thanks to this, the ethical life of each person is conferred in the primed form of a series of normative schemes" (Flis 1994:63 [trans. MF and KP]). Ethical codes thus infer a cause-and-effect relationship. They point toward the existence of ready-made, remedial means to counter specific effects—the provision of a norm or commandment. The codified world of scholarly research manifests itself as one that is invariable, stable, and fossilized—a world that does not take into account the context in which studies are conducted.

Yet, here, a question arises: Is ethics possible without its code? This issue is articulated by Magdalena Środa (2020:427 [trans. MF and KP]), who writes that this would be ethics "devoid of the illusions of universalism, but with the hopes of crossing cultural and genre boundaries, cosmopolitan, and unlike deontology—emotive." This scholar underscores that we cannot press for such a solution as yet, as the humanities have not thus far developed an ethics without a core anchored in autotelic cultural values. The essence of such values is general and abstract in nature, and their endorsements lie in "truths revealed" found in religious scriptures. Those scriptures, in turn, function based on listed, internalized sanctions with the intent of navigating a human being's conscience. Hence, ethics without a code takes the shape of a utopia—and thus a mission, a project for sociological and humanistic thought in the 21st century.

Social sciences research ethics constitute a particular and distinct branch of normative ethics. The task before this category of ethics is to problematize the academic research process in terms of compliance with rules according to which the researcher should proceed. For this, among other reasons, attempts have been made to codify good ethical practices; an outcome in our field in Poland is the Code of Ethics of a Sociologist created and ratified by the Polish Sociological Association in 2012 (*Kodeks Etyki Socjologa* 2012). Nevertheless, examples of the susceptibilities and frailties in codes of ethics can be found in articles by social anthropologists who, while conducting research, have had to cope with situations generated by "the field." In his article on the methodological conundrums that anthropologists face today, Jacek Nowak (2010:124 [trans. MF and KP]) calls attention to the fact "that anthropology becomes an implement for the emancipation of

the communities studied. This gives rise not only to tensions of a cognitive and methodological nature but also to the surfacing of new ethical-moral dilemmas." With reference to James Clifford (1997:189), it could be said that present-day fieldwork is "a mixture of observation, dialogue, apprenticeship, and friendship." Researchers are increasingly employed by institutions established by ethnic groups who are the very focus of inquiry; naturally, this generates ethically problematic situations. The researcher is subject to pressure, persuasion, or even manipulation on the part of the respondents. Still relevant, too, is the problem of covert participant observation. The applicable norms and standards in this matter remain ambiguous.

Still, other problems are pointed out by Natalia Bloch (2011:210-211 [trans. MF and KP]) in her article on how the factor of power figures in fieldwork situations: "I would like to place particular emphasis on the dynamics of power relations in the field—in other words, to consider who, in all these years, has actually reigned in our mutual relations: they or I?" Delving deeper, she draws attention to the fact that: "the bottom-upness and the personal touch in the acquisition of material, as well as shared experiencing seem to be our greatest asset. They are, however, also a hazard because they call into question the credibility of the knowledge we generate…Therefore, an indispensable element of field research is an anthropological reflection upon the place an anthropologist occupies in a given community" (Bloch 2011:212-213 [trans. MF and KP]).

These examples show that, from an ethical perspective, the research condition has two dimensions. At the outset, concerning cultural universals, there is the rational-universal dimension and the emotional-agentive one (Środa 2020:428). The former re-

solves problematic situations and ethical dilemmas through formal processes. This is an expression of an initiatory act *vis-à-vis* the ethos of a sociologist whose task—at least on the declarative level—is to be particular about the maintenance of a high standard in any scholarly investigation. The latter, the emotional-agentive dimension, pertains to the actual conduct of the researcher in the field. First of all, this situation verifies the expediency of the code of ethics. Secondly, it lays bare the degree to which principles implied by the code have been internalized by the social scientist; it also reveals their skill and competence in designing a research project on the cornerstones of a rightly shaped conscience. Inasmuch as, on the rational-universal level, codes point to proper and fitting norms, on the emotional-agentive level, codes are incapable of effectively answering the question of what to do in a concrete, specific, dilemmatic situation in the field.

In his text on the fluidity of the pertinent knowledge with regard to fieldwork, Tarzycjusz Buliński (2014:100 [trans. MF and KP]) underlines the fact that

> The process paradigm presupposes a long-range epistemology. The researcher is able to come to know the way of life of the Other by confronting it head-on with his own way of life; it is his own experiences that he interprets in an intersubjective text…A metaphor reflecting this paradigm is the image of the anthropologist as a tool. The researcher's attention is focused on analyzing his own experience in relation to Others.

The process paradigm assumes that knowledge gathered in the field is subjective and comes to be only as a result of the personal encounter and engagement of the social scientist. That knowledge is motile, kinetic, and continuously transmuting. The researcher must be in possession of "thick" and

practical knowledge and experience—and this is facilitated by Lakoff and Johnson's cognitive theory of metaphor.

An interest in the cognitive function of metaphor developed based on Anglo-Saxon thinking wherein a belief in the metaphorical nature of language gained in popularity and renown by way of cognitive linguistics. Understood thusly, metaphor becomes a vital instrument serving in the conceptualization of everyday life experiences. Moreover—by coalescing reason and imagination—it ceases to be a mere matter of language—it becomes a matter of thinking and cognition (Krzeszowski 2020:9). This approach stands in contradiction to the usual understanding of metaphor as a stylistic medium or rhetorical embellishment. In their groundbreaking work, *Metaphors We Live By* (published in 1980), George Lakoff and Mark Johnson evidence the fact that the system of concepts that we customarily use in action is, in essence, metaphorical. Indeed, "metaphor is pervasive in everyday life, not just in language but in thought and action" (Lakoff and Johnson 1980:3). These scholars extensively substantiate their thesis, yet one of its most interesting features—from a sociological perspective—is the coupling of metaphor with experience. Here, experience is embedded in a latticework of concepts and processes that build cognitive frameworks or structures of a cultural nature.

Entering upon these assumptions, Lakoff and Johnson's cognitive theory of metaphor is constructive in social sciences research for several reasons. Firstly, it highlights the ubiquitousness of metaphors put to use in day-to-day life, occupying a central place in any and all processes that utilize a linguistic system. A metaphor understood in this way is not only a rhetorical figure but can be considered against the broader backdrop of language usage. Secondly, the structure of metaphors—and especially cognitive metaphors—is characterized by a systematicity, so that projections taking place within its boundaries can be described in strict, formal categories. Thirdly, the mappings and projections found within the metaphorical structure can be described in categories of pattern leading to concretization. Therefore, metaphor is a schematic structure serving as the foundation for the conceptualization of various, idiosyncratic statements. Fourthly, metaphor is typical not only for the process of constructing linguistic utterances but also comprises a constitutive component of any and all human processes—mental processes that prescribe our actions and behavior.

Likewise, metaphor is a tool for conceptual reduction in the identity debate. It facilitates communication within specific conceptual systems. It is a creative tool for language. In terms of the primal and original, physical experience of humankind, conceptual metaphor constitutes a representation of the complex aspects found in the world surrounding us. In this context, metaphor can become the subject of sociological analysis because it concerns the way we understand the world.

We are especially interested in the theory of conceptual metaphor. It stands as the cornerstone for a redefinition of the concept of "metaphor" itself, understood as a reflection of (cultural) knowledge and experience. Metaphors assist in the planning and designing of future activities. Thanks to awareness of which actions are more likely to be coherent and consistent with metaphor, its strength will be augmented. This, in turn, will allow us to reconcile experience: "This is connected with the performative function of metaphor—as a tool that allows the visualization of the (yet) nonexistent. Metaphor creates

reality by shifting the horizons of the imagination" (Burzyński 2012:17 [trans. MF and KP]).

It often happens that a single new metaphor opens up many different, closed systems. Metaphor is something of a pollinating energy. From the perspective taken by Lakoff and Johnson, this is possible because "metaphor" is perceived not as a "metaphorical expression" but as a "metaphorical concept." In other words, metaphor is not merely a matter of language but a way of comprehending the world. In fact, interest in metaphor as a tool of cognition has enjoyed a long tradition in the social sciences (Lewis 1947; Cassirer 1963). As Lakoff and Johnson have shown, metaphors accompany us in our commonplace acts of cognition—in daily activities, thoughts, and deeds.

The use of metaphor thus becomes a valuable research tool in the establishing and rooting of personal responsibility for one's conduct. Here, responsibility is understood as "the reasonable anticipation of the effects of one's actions upon others and taking action only when those effects are good (or at least not harmful) for others" (Sztompka 2021:13 [trans. MF and KP]). Thus, metaphor is a mechanism by which we realize the instrumental value of responsibility and the set of social practices that are formed around that core. Metaphor creates a culture of concern and accountability that stems from caring for the well-being of "Others."

## Metaphors as a Tool for Consistency in Research Situations

In the preamble of the Code of Ethics of a Sociologist (*Kodeks Etyki Socjologa* 2012 [trans. MF and KP]), formulated and ratified by the Polish Sociological Association, we read:

The Code of ethics of a sociologist denotes the ethical issues and principles, as well as problems and conflicts of interest that may arise in professional practice. Making sociologists more sensitive to the ethical dimension of their professional pursuits, the Code will also help them make decisions and resolve concerns in other situations. Any deviation from the principles of the Code should be the effect of a well-conceived decision by a sociologist and not a lack of knowledge.

Scrutinizing this code of ethics, it is noticeable that the principles listed therein are general statements proposing certain standards to be applied in the practice of research. Their axiological core is derived from utilitarian ethics and points toward the happiness of another human being as an autotelic value—that is, a value in and of itself. Therefore, a quest for the truth should be ensconced in another human being—in Others and their well-being.

This can be justified by the proposal Paul Ricoeur presented in his *Oneself as Another*, in which he proposes that the crux of morality should be responsibility—that is, simply a *norm*. Ethics, in turn, is the same as a teleological *intention* directed at others—an intention expressed by the slogan: "aiming at a good life lived with and for others" (Ricoeur 1992:172). Thus, morality manifests itself as a generalized, socially objectified set of individual and autonomous duties that is external with regard to the individual. In this case, whereas ethics constitutes the individual conscience, morality—following Florian Znaniecki's concept (1973:37)—determines human behavior by and as a member of society (specific duties and responsibilities are assigned to a position, not to a person). Thus, morality constitutes the sphere of an individual's external, structural determination, while ethics is the field of their inner freedom and the domain of unlimited choice.

Morality is also a realm of both incommensurate scales of values and the construction of identity. According to Ricoeur, responsibility and faithfulness appear to be the building blocks of identity and interpersonal relations—and thus create a chance for understanding.

For our purposes here, we believe that not any less important than familiarizing oneself with the research field is finding the appropriate formula or narrative by which the researcher *tells* themselves. As Michael Carrithers points out in *Why Humans Have Cultures* (1992), a person makes use of one's narrative thinking skills to understand oneself and the environs in which one must function. Therefore, reaching back to the very nascence of the research process to skillfully root oneself in the field under study and to accurately discern the hidden aporias inherent in the researcher-subject relationship—all this can serve as a universal postulate underpinning the process of research design. Narrating oneself is thus an act of creation that entails the fashioning of a certain metaphorical figure. It is, by the same token, a finding of oneself, situating oneself in the research field thanks to the conceptual function of metaphor. This entails a response to the question: "Who or what is actually this speaking 'I'—this voice that lays fingers on solely foreknown footholds in such a way that a story sounds certain and inspires trust?" (Tokarczuk 2020:151 [trans. MF and KP]). The search for the right metaphorical figure is a step toward telling oneself, as well as finding oneself in the field.

Studying culture is akin to dancing flamenco—it requires an iron discipline that is the keystone for improvisation. Without scholarly discipline, researching and learning become garrulousness; without improvisation, they become a reiteration of codified figures. Just as the essence of flamenco is the *duende*—a state difficult to describe or put in words whose prerequisite is a receptiveness to subtle shades of living as a human—so the deepest sense of research into culture is a reconstruction of the hidden mechanisms of its operation. The accomplishment of this requires plunging into as many of its levels as possible and reproducing the relations between them. Dancing flamenco is not merely the mastery of rhythmic beats, and studying human cultures is more than the correct application of rote methods. Of great necessity in both flamenco and cultural studies are bravado and intuition. The end product of the creative undertaking—again, in both flamenco and cultural studies—is difficult to separate from the dancer, from the anthropologist. The masterwork will be marked (for better or worse) by the scope of the "artist's" imagination.

And what, in fact, does this imagination entail? This question has been answered for social scientists by C. Wright Mills (2000:7), who wrote that the sociological imagination,

> For that imagination is the capacity to shift from one perspective to another—from the political to the psychological; from examination of a single family to comparative assessment of the national budgets of the world…from considerations of an oil industry to studies of contemporary poetry. It is the capacity to range from the most impersonal and remote transformations to the most intimate features of the human self—and to see the relations between the two.

The essence of the sociological imagination is, therefore, the realization of one's position in society as a fieldwork researcher and, consequently, a conscious entry into that field. This situation is possible when the researcher sets oneself up as a subject of

reflection, too—entering into an internal dialogue and striving to find a metaphorical figure suitable for the telling of oneself. The process of becoming aware of oneself and one's agency in the field carries with it a burden of responsibility not only for oneself and one's behavior but also for the relationships that will take shape between the researcher and the respondent. Inherent in the sociological imagination is a demand for accountability for one's conduct. The researcher is not absolved of responsibility via reference to preexisting codes of ethics.

Looking further, Anna Horolets describes in an article the ethical and cognitive consequences of situating the researcher in the position of a guest. This can lead to excessive influence and/or control of the respondents over the researcher. Horolets aims to propose a more pragmatic vision of ethnographic research. She draws attention to those structural determinants arising in the researcher-respondent relationship that are not the effect of ethical choices made by individuals and, therefore, cannot be addressed by ethical codes. If hospitality is a certain cultural code, then it can be identified with a conceptual metaphor that could be the basis for the redefining of the concept of metaphor understood as a reflection of cultural knowledge and experience. Horolets signals to the reader that "the fundamental ethical dilemma for the anthropologist is the necessity to combine that which is personal with that which is professional. Cultural differences and status differences magnify the difficulties for the anthropologist-guest in ethically navigating the field" (Horolets 2016:63 [trans. MF and KP]).

Problems of this sort are expunged by the theory of conceptual metaphor that we have adopted herein. Metaphor creates reality by shifting the horizons of the imagination. The new metaphor opens up closed systems of thinking that have been constrained or limited by barriers in cognition and information processing associated with the limitations of memory. It is often the case that when a single new metaphor unlocks several different, closed systems, a kind of nourishing, pollinating energy is released—that is, metaphor acts precisely as an ethical kaleidoscope for social scientists conducting fieldwork. Metaphor assuages a critical feature of ethnographic practice—a structural vulnerability when faced with refusal by respondents in the field. As Horolets notes, "The hospitality of the respondents should be seen more as metaphor rather than the definition of a situation since genuine human relationships of a researcher with respondents do occur, but are not the rule" (Horolets 2016:67 [trans. MF and KP]).

The metaphor of the researcher as a guest turns out to be tremendously accurate in the research situation especially. To speak in the language of Michel Foucault (2006), the relationship initiated between the guest and the host is one of power asymmetry. The researcher, as a guest, is a privileged individual because they have been invited into the world of the respondent, who is the host in this situation. However, the former must demonstrate high sensitivity in interactions so as not to commit a blunder; they must also be careful to avoid a door being closed (literally or figuratively) by the host. The latter, in turn—by the very act of opening the door to a visitor—allows the guest to cross a certain boundary that is (primarily) that of intimacy, that is, opening the world of feelings, emotions, secrets, or memories of the respondent-host. It is at this point that the asymmetry of power begins to change its vector as the guest begins to gain insight into areas of the subject's memories and cognitive processes that are not accessible to all. The host "gifts" their guest

a part of the host's identity. It is only here that material is provided based on which sociological ethics can be shaped (as typified in the processes by which nearly all ethical codes have been formed).

There is a reason why it can be said among sociologists that the best interviews are generally those accompanied by strong emotions (from sadness through anger to laughter, etc.). A high degree of sensitivity and imagination is needed before such moments in which the respondent opens up before the researcher—it is too easy to behave tactlessly or in such a manner as to offend the host. Środa notes (as did Derrida earlier) that the category of hospitality is of a pre-ethical nature. A state of affairs full of emotional tension cannot be restrained or otherwise held back by rigid norms that are part and parcel of ethical codes. Otherwise, a research situation would become reified, the dynamics of the interview would fade, and the interactional vitality would be extinguished. Abstract ideas—such as empathy and sensitivity—find their concrete form in the conceptual metaphor that the figure of the guest becomes—a role quite natural, quite near and dear to all because it is woven into our everyday lives.

## Concluding Remarks

In light of the considerations and deliberations above, prudent is a return to the issue of ethical codes to reflect upon their role in the designing of research, as well as in the very process of doing research itself. As we have already substantiated, the Code of Ethics of a Sociologist points to certain standards and norms that are values in and of themselves. Those intrinsic values constitute the axiological core of appropriate and correct conduct. It is worth recalling and examining one of the points

contained in this Code by the Polish Sociological Association, found under the heading of "Relations with Research Participants": "8) In relationships with respondents, sociologists should act honestly, in a manner that is impartial, responsible, and trustworthy" (*Kodeks Etyki Socjologa* 2012 [trans. MF and KP]). This code of ethics stands, therefore, as an ontology of ethical conduct by social scientists. It speaks of the duties and obligations of the researcher in the field, yet it neither speaks of the precise manner in which they should be executed nor does it detail the acts to be performed to meet the standards declared. Its nature is such to constitute a program or rather a framework within which each fieldwork researcher must find a suitable formula or procedure. The anthropologist, sociologist, or other social scientist must learn to negotiate within this *a priori* matrix for the shaping of a culture of research responsibility.

From our perspective and in our opinion, such a universal and pragmatic formula is a metaphor acting as an ethical kaleidoscope, navigating the researcher toward morally correct, professional conduct. Due to its stimulation of the imagination and conscience, metaphor can thus alleviate the moral aporias that come to the researcher's mind in the course of doing fieldwork. The mechanism of its functioning is based on the appropriate shaping of sensitivity and working with that to "stay on the lookout for marginalized people—people whom we still instinctively think of as 'they' rather than 'us'" (Rorty 1989:196). Therefore, the conceptual metaphor surfaces as a fundamental element in a culture of responsibility, including a social scientist's responsibility for the physical environment and human culture in which they conduct research and create relationships. Ultimately, metaphor can bridge the boundary between "us" and "them"; it can also contribute to more fac-

ile entry into the field for the researcher, anchoring interpersonal relations in the field in sincerity, trust, and mutual respect. Hence, we can say that codes of ethics constitute, at best, a broad framework within which room is left for the imagination and sensitiv-

ity of a sociologist. The social scientist is thus given the opportunity and space in which to design their "I in the field." The conceptual function of metaphor allows us to answer the questions: "Who am I in the field?" and "How should I proceed?"

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# Biographical Work of Parents of Children with Non-Normative Sexual Orientation and/or Gender Identity

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**Abstract:** This paper aims to reconstruct the biographical work (Corbin and Strauss) undertaken by parents of non-normative people. The initiating event of biographical work is the disclosure of a non-normative sexual orientation and/or gender identity by the child. For many parents, this is an event that causes a breakdown of previous schemes of action, a gradual loss of control, and suffering.

The empirical data consist of autobiographical narratives of parents of people with non-normative sexual orientation and/or gender identity. The study involved mothers and fathers residing throughout Poland, who were selected according to the snowball procedure. The data were collected through the narrative interview technique and compiled according to the analytical procedure proposed by Fritz Schütze, which is part of the interpretative research paradigm.

In the course of four parallel biographical processes (contextualizing, coming to terms, reconstituting identity, and recasting biography), the new experience is integrated into the biography, its consequences are understood and accepted, a coherent identity is reconstituted and a new course for one's life are charted. The analysis of the narrators' biographical work has made it possible to identify three categories that organize the course of the parents' lives and identities—stigma, normalization, and activism.

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Coming out as a person with a non-normative sexual orientation and/or gender identity is an important part of one's identity development, an affirmation of self-identification in the personal and public sphere. It requires acknowledging one's membership in the LGBTQIA community, as well as disclosing that to others (Cohen and Savin-Williams 1996). It can be described, among other things, as a model consisting of successive stages (self-awareness, self-labeling, self-disclosure, stabilization of identity, and active involvement in the community) (Coleman 1981/1982) or a process conditioned by one's subjectivity, interactions, and socio-historical context (D'Augelli 1994). Coming out becomes, for non-normative people, a career, a transformative, ongoing process (Guittar 2013). It is not a one-off event, as it is repeated over a lifetime concerning subsequent individuals (Rhoads 1994). Due to the need for recognition and affirmation of identity, the coming out process is hindered by homonegating processes present in discourses (Russell and Bohan 2006), which result in, among others, fear of rejection (Cohen and Savin-Williams 1996).

Due to the roles parents play in their children's lives, coming out to them is particularly difficult. Children delay disclosing their non-normative sexual orientation and/or gender identity for fear of hurting or disappointing their parents (Cramer and Roach 1988), weakening bonds, rejection (Hersch 1991), or violence (Savin-Williams 1989). In the first instance, they choose people who are considered open and accepting, usually friends or siblings (Rotheram-Borus and Langabeer 2001). These fears are not unfounded, as parents' first reactions to coming out are often negative (Robinson, Walters, and Skeen 1989; Savin-Williams and Ream 2003) and accompanied by strong emotions. Shock is indicated above

all, but also panic, sadness, shame, guilt, or fear for the child's safety (Ben-Ari 1995; LaSala 2000). In contrast, reactions indicative of unconditional acceptance and support are less frequent (Savin-Williams and Dubé 1998; D'Augelli 2005).

Negative attitudes and emotions of parents may result from the normative references they adopt that are characteristic of the heteronormative culture resulting homo/transphobia. The concept of heteronormativity makes it possible to analyze the categories of gender and sexuality in relation to power and oppression. Depending on the theoretical basis, it emphasizes oppression against homosexuals (Foucault 1978), oppression resulting from patriarchal gendered norms (Rich 1980), hegemonic masculinity or idealized femininity (Butler 1990), or the discrepancy between biological sex and gender performance (Rubin 1984) (Marchia and Sommer 2019). Heteronormativity frames the deemed natural differences between men and women, their respective gender roles, and socially accepted sexual identities, relationships, and behaviors. It legitimizes the claim to conform to a socially accepted norm (Habarth 2015), as well as justifies prejudice or discrimination against people with a non-normative psychosexual orientation (homophobia) or gender identity (transphobia). At the core of transphobia is an essentialist understanding of gender as a biologically determined category, assigned to the individual and immutable (Lombardi 2009). Analysis of the phenomenon of homophobia indicates that it is based on three pillars—sexual stigma (socially shared knowledge of the negative valuing of non-normative identities, non-heterosexual relationships, behaviors, or communities), heterosexism (a cultural ideology embedded in the structure of society and power relations that perpetuates sexual stigma), and sexual prejudice (people's internalized

negative attitudes toward otherness) (Herek 2004). Studies of homophobia and transphobia indicate that these attitudes correlate, among others, with right-wing authoritarianism, religious fundamentalism, and hostile sexism (Nagoshi et al. 2008).

The disclosure of a non-normative sexual orientation and/or gender identity by the child results in the parents being forced to confront their worldview, stereotypes, knowledge, and fears. It is possible to identify some factors significant to this process and analyze them in the context of the individual, the dyad (parent-child relationship), and the family (Heatherington and Lavner 2008). From an individual perspective, the parent's gender (Ben-Ari 1995; D'Augelli, Hershberger, and Pilkington 1998), race and ethnicity (Merighi and Grimes 2000), religion (Newman and Muzzonigro 1993), place of residence, and child's characteristics, for example, their status in the family or the age at which they came out (Savin-Williams and Dubé 1998), as well as previous suspicions about their non-normativity, may be relevant to the parent's reaction. From the perspective of the parent-child dyad, the quality of the relationship (Savin-Williams and Ream 2003), attachment (Holtzen, Kenny, and Mahalik 1995), and individuation (Floyd et al. 1999) become salient. Concerning the family system, family cohesion/ closeness/support (Waldner and Magruder 1999) and global family climate (Darby-Mullins and Murdock 2007) are important.

The process of parents coming to terms with coming out and their child's non-normative sexual orientation and/or identity is often described using a linear model of grief (Kübler-Ross 1969). As part of the therapeutic process, parents move through stages—from experiencing emotional shock through denial, anger, bargaining, and depression to accep-

tance (Robinson, Walters, and Skeen 1989; Strommen 1989; Saltzburg 2004). In the course of working through a difficult experience, parents engage in reflection on the stigma attached to otherness, search for blame, confront heterosexist perceptions and expectations of the child, and confront anxieties about the child's safety and possible loss (Bernstein 1990; Saltzburg 2004). A different perspective is provided by narrative therapy, which aims to deconstruct the dominant narrative underpinned by homophobia and heterosexism and then co-create new meanings that build an alternative story. It allows the discovery of storylines concerning sadness and loss, aloneness and marginalization, doubt, and fears of estrangement in the parents' stories (Saltzburg 2007). Interpretive work can also be associated with destigmatizing stigma, which requires challenging heteronormative conceptions of normality, conventional understandings of gender, gender roles, sexuality, and family, denial of stereotypes, and normalizing actions (Fields 2001). The concept of moral career allows us to look at the identity of parents and the actions they take, arising from the imperative to love and support the child. It reconstructs the process of change that results in heterosexual parents, functioning in traditional families, engaging in public advocacy for the LGBTQIA community, and becoming "radical normals" (Johnson and Best 2012). The basis of a parent's reconstructed identity may be the image of a proud, heterosexual activist. Before that, however, they undertake identity work that begins with the child's unexpected coming out. Mother/father becomes aware of their ignorance about non-normativity and the consequences of homophobia and, therefore, seek knowledge, support, and allies among people in a similar situation (Broad 2002). However, parents do not always achieve the degree of acceptance of the new situation that enables their coming out. Consequently, they may re-

main in the "transparent closet," creating rules of silence about their child's sexuality and/or identity because they are unable to come to terms with the consequences for themselves and their family. They may also enter the "family closet" and hide their child's non-normativity from those outside their narrow circle (Švab and Kuhar 2014). When analyzing parents' reactions to coming out, it is also worth taking into account the social, cultural, or historical contexts, which allow us to note the cultural tools and coping strategies available to parents (Martin et al. 2010).

An analysis of the literature indicates that coming out of their children, interpreted in the context of dominant narratives, is a difficult life experience for many parents, associated with unforeseen change, disorientation, disorganization, loss of control, breakdown of current schemes of action, and suffering. These characteristics make it possible to consider it a trajectory experience (Schütze 2006) that affects the course of their biography and identity. The disclosure of a non-normative sexual orientation and/or gender identity by a child requires a cognitive and emotional effort of the parent to accept the sudden change and its consequences, to adapt to the new conditions, to control the situation, and to reconstruct their biography. These activities are part of the concept of biographical work, which consists of four parallel biographical processes—contextualizing, coming to terms, reconstituting identity, and recasting biography (Corbin and Strauss 1985; 1988). Contextualizing involves integrating a new experience into one's biography, establishing the extent of change and constraints, and anticipating the potential course of the trajectory. Coming to terms is related to understanding and a specific level of acceptance of the conditions and biographical consequences of change. Reconstituting identity is about

reconstructing it into a conceptual whole, taking into account constraints on action or reorientation of values. Recasting a biography is about giving biography new directions (Corbin and Strauss 1988). The concept of biographical work, consistent with the ontological and epistemological assumptions made, will provide an interpretative framework for the empirical data.

## The Current Study

This paper aims to reconstruct the biographical work undertaken by parents of non-normative children. From a biographical perspective, identity presupposes a person's continuity in time and space, a sense of reflexive biographical permanence (Giddens 1991). The autobiographical narrative that constitutes identity can become disintegrated under the influence of new experiences (Rosner 2003), and it is then necessary to reconfigure and reinterpret them in line with different interpretative assumptions (Horsdal 2004). Reconstructed, under the influence of a new experience (e.g., a child's coming out), the personal narrative allows the biographical work of the narrator to be captured.

The data used in this paper come from thirty-two autobiographical narratives of parents of non-normative people. The research sample was selected according to the snowball procedure while taking into account the minimum and maximum contrast strategy derived from theoretical sampling (Glaser and Strauss 1967). The interviewees were initially recruited from organizations for parents of non-normative people in different parts of Poland, but it was then possible to reach narrators not affiliated with these institutions through the first informants. Due to the location of the headquarters of the parents' organizations, initially, the interviews were con-

ducted in large cities, but, over time, the research area was determined by the places of residence of subsequent narrators, which made it possible to also include the perspective of residents of small towns and villages. Twenty-seven mothers and five fathers of adolescent or adult children representing a spectrum of non-normative orientations and/or gender identities participated in the study. Parents differed in age, education, occupation, marital status, family structure, place of residence, time since coming out of their children, or involvement in activism.

The research focusing on the biographical experiences of parents of LGBTQIA people was set in an interpretative paradigm, with symbolic interactionism (Blumer 1954) as the theoretical basis. Empirical data were collected through a narrative interview technique (Schütze 2008), which consisted of three main phases—spontaneous narration, clarifying (follow-up) questions, and theoretical questions (Hermanns 1987). Meetings with the informants took place at a time and place convenient for them, and the average interview length was about 2.5 hours. With the consent of the narrators, the interviews were audio-recorded and then carefully transcribed. At the same time, the data were anonymized. All the interviewees were informed about data processing and the study procedure, and they gave their consent to take part in the study. The study was positively assessed by the bioethical commission of the University of Lodz.

The application of Fritz Schütze's integrated concept of the study of autobiographical narratives determined the further steps of the analytical procedure. The analysis of the collected empirical data included—analysis of the communicative schema, structural description of the narrative, analytic abstraction, comparative analysis, generating a theoretical model, and verification of the theoretical model (Schütze 2008). The distinction of communicative schema, the extraction of narrative units, and, based on these, process structures (biographical action schemes, institutional expectation patterns, trajectories of suffering, and biographical metamorphoses) made it possible to capture the narrators' experiences of the described biographical fragments. The comparison of biographical models indicated a link between biographical processes and the narrators' ways of dealing with their children's non-normativity. Confronted with new knowledge about their children (after coming out), they performed a cognitive and emotional reordering of their lives in the course of an autobiographical narrative. The fundamental aim of the analysis was to reconstruct the biographical work of parents of non-normative children in the context of four parallel biographical processes (contextualizing, coming to terms, reconstituting identity, and recasting biography).

## Findings

### Contextualizing

The event that triggered the biographical processes involved in the biographical work was the coming out of the child. In reconstructing the chain of events, the narrators point to this moment as a significant or even turning point for their biography. The planned or spontaneous disclosure of a non-normative sexual orientation and/or gender identity triggered different reactive behaviors from the parents. For the majority of them, coming out came as a complete surprise (only a few confirmed their previous suspicions in this regard) and, therefore, caused an intense experience with violent reactions. In some cases, the emotions were so strong

that the narrators were unable to reconstruct the event, and they spoke of a shock that took away the ability to speak and generated the question, "Why did this happen to me?" When describing their immediate behaviors after becoming aware of the child's non-normativity, they indicated, among others, outbursts of crying, interrupting the conversation, leaving the room, and comments hurtful to the child ("Why are you doing this to me?"), or hugging the child and reassuring them of the constancy of their feelings. Less emotional reactions were limited to confirming acceptance of the new fact ("I understand"). The activities undertaken at that moment were related to the strength of the emotion felt (surprise, shock) and its sign (positive or negative emotions), but also to the awareness of the importance of the response to the child ("I knew that if I didn't say anything right away, I would hurt her"). Reconstructing the moment of coming out in retrospect stimulated the narrators' reflection on their behavior at the time. Some parents admitted that their behavior was homo/transphobic ("I cried, I shouted...I know I behaved badly, but at that moment it was the end of the world for me"), and they were unable to understand their reaction, or overly optimistic:

It was a moment of enthusiasm for me...something is happening with the identity, but we'll get through it, whereas afterward it was worse, for a week, I was completely off balance.

Nor were their thoughts, emotions, and behaviors always consistent ("I knew I couldn't hurt her, reject her, but everything was screaming inside me").

Regardless of the initial reaction, the parents had to incorporate the new experience into their biography, but not everyone was ready to start this work:

I was in a serious condition. I seemingly functioned normally on a day-to-day basis, but I was overwhelmed by black despair. I don't know why. I thought my heart was going to burst. After work, I just lay there and cried.

Some people only reconnected with their child after some time ("I was not able to talk to my child in person. It was only after a week that I called her"), and others pretended that the coming out had not happened ("I thought she would still change, think things over and change her mind"). The difficult experience generated suffering, disrupted the previous order, and took away control of one's life. During the following days, weeks, or months, the narrators tried to cope with the change and its consequences.

Parents searched their memory for symptoms or situations that were indicative of their children's non-normativity but, due to lack of knowledge, had previously been misunderstood or misinterpreted by them:

My son is very handsome. He always brought home girls. I didn't want to believe him when he said they were just friends. I thought he was so successful.

They found signs in behavior, appearance, or conversations that made a different sense in a new context ("My child never walked around in dresses, didn't want clothes from the women's section, didn't play with dolls, but that didn't make me suspicious or worried").

The narrators reflected on the source of the strong, especially negative feelings that accompanied them ("I have no idea why I reacted so badly, probably out of fear. I thought at the time that he wasn't going to

have an easy life"). Based on previous experience and knowledge, they searched for the source of the child's non-normativity, often referring to prejudices rooted in their worldview. Driven by a sense of guilt, they most often found the causes in themselves:

> I have wondered many times, "Why did this happen to me? What did I do wrong?" Maybe I brought him up badly, or maybe it was because his father wasn't at home all the time.

They also spoke of unfulfilled expectations resulting from an imagined vision of their children's lives ("I was convinced she would have a normal life, fall in love, get married, have children") or a sense of loss ("I had to come to terms with the fact that I would never be a grandma").

The most common emotion described by parents was fear related to a sense of threat. They feared a lack of understanding from those closest to them or from extended family:

> I told my husband that if he had a problem accepting our child, I would move away from him immediately and file for divorce.

> My parents are very aged. They don't know anything until now, and it will stay that way. They don't need this knowledge and probably won't understand anything anyway.

They saw potential causes in conflicting values, overtly demonstrated prejudices, or generational differences. They were also accompanied by fear of imagined social ostracism, both toward the child and the family as a whole ("I thought, what will people say, they will point fingers at us now"). Particularly in smaller communities, due to the nature of their func-

tioning ("In our village, everyone knows everything about everyone else. It's not good to stand out"), the narrators feared gossip, exclusion, or hostility from neighbors, but also physical attacks or property damage ("I was afraid that if it got out, they would set our house on fire"). Similar anxiety manifested itself in the workplace, generating tension, stress, and some difficulties in relationships with co-workers:

> I know it was completely irrational, but I had the feeling that everyone already knew. I felt I had this information written on my forehead.

The fear was mainly related to the child's safety in public spaces, especially in situations where non-normativity was noticeable or could provoke aggressive reactions:

> Girls are allowed more. Their queerness is not stigmatized as much. I know it's silly, but I thought it wasn't so bad because she could be gay or trans, but I still shuddered every time she went out with a girl. I was afraid they would be attacked by the fact that they were holding hands.

Prejudice, physical and verbal attacks on non-normative people were analyzed in the context of the growing acceptance of this type of behavior in the public space, which was legitimized by the actions of right-wing politicians and representatives of the Catholic Church:

> In this country, my child will not know peace. Every day, I hear in the media, from the mouths of high-ranking politicians, that I have a pervert at home who is not a human being but an ideology.

> Well, where is the love of neighbor in the church if they can spread hatred from the pulpit?

The coming out of the child caused the narrators to reflect on their faith and religiosity ("I was very religious, but after what I found out about my child from the priest's mouth, I gave up going to church. I can pray anywhere"). Harmful stereotypes, hostility, or expressions of discrimination stopped being about a group of strangers and started being a real threat to their children:

> There were comments under the articles and, of course, all hate poured out there. I couldn't accept that they were writing such awful things about people like my daughter. I knew it wasn't true. She is a smart and good person.

Harmful beliefs disseminated in the media or by people in the immediate surroundings started to be taken personally, aroused resentment and anger:

> I started to be disturbed by the jokes of my colleagues at work about homosexual people. It hurt me when I listened to it, but I did not yet have enough courage in myself to stand up to them.

The child's disclosure of psychosexual orientation and/or gender identity generated the narrators' reflections on the concept of sex/gender (biological/cultural), as well as on romantic and sexual relationships:

> I did not want to imagine my child's relationship...A child's sexuality is difficult even in a hetero relationship...It was easier for me when someone told me that it was necessary to focus attention on feelings and not physicality. My child loved another person.

Shifting the focus from the child's sexual behavior to their relationship with another person did not always bring relief. Parents feared, among others, po-

tential loneliness or amorous disappointment and lack of understanding, acceptance, or rejection:

> Visually, she already looks very good, but she has not undergone all the operations, and even the best-performed organ reconstructions will not ensure fertility. I am afraid that she will be alone all her life and will not find a person who accepts her.

The experience of the child's coming out was difficult for the narrators, giving rise to many, often negative emotions, disrupting feelings of constancy and security, causing loss of control and powerlessness. The lack of effective schemes of action did not solve the biographical problem, which affected the relationship with the child, but in the case of the informants, did not lead to a break in the bond. The parents were fighting an internal battle, as the prejudices ingrained in their worldview conflicted with their knowledge of and love for their children. Analyzing their actions and their consequences allowed the parents to imagine scenarios of probable events:

> I knew that if I didn't act, his depression would drive him to a suicide attempt because he had already started to cut himself. I had to protect my child. I'd rather have a living son than a dead daughter.

Attempts to understand the situation revealed gaps in the narrators' knowledge of non-normative people, as well as the stereotypes and prejudices they internalized. Most were aware of the existence of a sexual minority ("I was only aware that there were lesbians and gays"), and a few had contact with representatives of the community ("I had a gay friend. He used to come to our house with his partner"), but, in general, their knowledge was limited:

I graduated from medical school, and even there, the subject was treated briefly. I knew the names and brief characteristics, but later found that my knowledge was outdated.

Consequently, they referred to familiar stereotypes, held certain beliefs about the characteristics inherent in non-normative people, and believed that behavior or dress betrayed psychosexual orientation.

Attempts to theoretically work through the experience, to understand and make sense of the situation triggered the need to seek reliable sources of information. A safe and anonymous knowledge resource was the Internet:

I started looking for information on websites. I wondered where it [homosexuality] came from and if it was my fault...I found out good and bad things. Actually, every evening, I was looking for something new. I thought I had already read everything, but I kept looking.

At the same time, some parents start to talk to their children about topics that bother them, treating them as experts:

I was stuck in such a stupor for a long time, but once my son came to me, I sat him down next to me and said, "I can't do this anymore, help me understand it all."

Children who had been coming to terms with their non-normativity for a long time provided answers, shared materials from LGBTQIA support organizations and talked about meeting specialists or other parents. Meetings with people in a similar situation were preceded by a long reflection and required a public coming out by the parent:

My daughter told me about parents' meetings. I had been gathering for several months to go there. When I entered the room, no one was there yet, so I thought I still had time to back out. As I was walking toward the door, the other lady came in, so I was already stupid to run away. I stayed, and it was a very good decision.

Talking to other parents was an important part of working through the experience. Finding similar experiences, sharing emotions, discussing difficulties, and looking for solutions provided comprehensive support and also increased the sense of agency.

**Coming to Terms**

Love for the child and alternative knowledge resources helped the parents to confront their previous way of thinking. Gradually, they reached an appropriate (for them) degree of acceptance of the biographical consequences of their children's coming out. However, this did not always mean unconditional acceptance of the changed situation. Some returned to their routines and ignored the child's non-normativity or introduced certain rules for the functioning of the family (e.g., omitting the non-normative child's partner during meetings attended by the partners of the other children) or disclosure of information:

I immediately said that she could be whoever she wanted, but that she should keep these revelations to herself...I also didn't want everyone in the neighborhood talking about us.

New experiences or actively acquired knowledge meant that the narrators' messages and behaviors also changed over time ("I wouldn't do that today, but it happened. I didn't ask my son if I could tell his

grandparents he is gay"), currently judged by them as homo/transphobic. The source of the feedback was often the children who stated that the parents' reaction was hurtful to them:

> My child tested me a bit because there were these conversations about same-sex marriages, and she asked what I thought and I said I had nothing against marriages, but, of course, I threw in total nonsense that I would probably think about adopting children. She then asked me what it takes for a child to be happy in a family...I hadn't thought like that before, some patterns I threw around without thinking...I backed off and said I was talking crap.

In relation to new knowledge resources, they were, again, confronted with their expectations of the child ("Where is it written that in exchange for the room and board, she has to provide me with grandchildren? Preferably a boy and a girl. There is no such contract"), and they also found alternative ways of realizing their life plans ("If one day she wants to have children, nothing stands in the way and there are various possibilities, for example, in vitro"). Variation in terms of family structure was associated with vocabulary ("My daughter is planning to get married abroad, and I will have a *córkowa* [a feminine term for the daughter's female spouse]").

An important issue for accepting the biographical consequences of coming out was the parents' realization of the irreversibility of the situation ("I waited for it to change. More years passed, and nothing changed, except that our relationship became worse"). Over time, coming out became an event that brought many changes, and they started to notice the positive ones as well. They also appreciated their children's courage and trust in revealing their

secret ("My child's coming out is a compliment to me that she trusted me and opened up to me"). However, some were accompanied by a sense of guilt for not being the first to find out ("It turned out that his sister had known for a year already") or only after a few years ("I am very sorry that I found out so late. I could have helped her earlier, and because I didn't know anything, she was alone with it all").

The turning point, but also a kind of resolution of the internal conflict, was the recognition that no matter what the circumstances, their child is still the same person ("Nothing has changed in my child. She is still very capable, helpful, has lots of friends, is liked, has her passions and dreams"). They concluded that non-normative sexual orientation and/or gender identity were only one of the many characteristics (although sometimes foregrounded) that characterized their child. In addition, there was a redefinition of the category of a norm concerning psychosexual orientation and/or gender identity. The narrators accepted a spectrum of diverse behaviors and attitudes while, at the same time, recognizing that queerness is not the result of a disorder or illness ("Such people were, are, and will be. It is not their choice or illness, they are simply that way").

Acceptance of biographical change was linked to the disclosure of one's identity (as a parent of a non-normative child). Sometimes these were strategically planned coming outs, other times, they occurred in response to a specific situation:

> In the beginning, I was very emotional every time I had to tell someone that my child was different. I was afraid of what they would think of me, whether they would reject him or turn away from our whole family...To this day, I have spoken about it many times, and it is much easier for me. I've also come to the con-

clusion that I don't have to explain myself to everyone, especially if it's not an important person to me. Now, I tell strangers when I want them to think about the nonsense they repeat, but I don't always have the strength to do it.

When deciding to disclose a non-normative psychosexual orientation and/or gender identity in a wider group (extended family, friends, co-workers, acquaintances, neighbors), the narrators reckoned with the possibility of breaking off the relationship ("What people say indirectly about my child is also a signal for me whether I should continue to maintain contact with them"). Sometimes, they were positively surprised by the reaction ("The grandfather just said he would have a granddaughter from now on"), but there were situations where further contact was hurtful to the child or them and required a strong reaction:

> It is difficult to hide the changes that are taking place in my child. My mother-in-law is a great believer, and at every opportunity, I hear what a bad mother I am for supporting this madness, and my child gets a text message from her saying that divine punishment will befall her for all this. There is no point in further contact as nothing will change in this matter.

The lack of tolerance for hostile and discriminatory behavior toward non-normative people was also linked to a reflection on one's religiosity and membership of religious groups. Many parents talked about giving up their participation in religious practices, while others planned to officially withdraw from the church community ("I started the apostasy procedure. I don't want to be in a church that hates my child"). In exploring the issue of non-normativity, narrators made contact with parents with similar experiences, non-normative people, or their

allies. Meetings through parents' support groups or LGBTQIA advocacy organizations enabled new social relationships to be built ("My child's coming out opened the door to the world of diversity for me. I gained a lot of acquaintances and friends").

**Reconstituting Identity and Recasting Biography**

The coming out of a child changes the self-identification of the parent, as well as their perception and evaluation by others—concerning becoming the parent of a non-normative person. A sense of continuity is provided by the realization of the parental role and its constitutive elements, such as love for the child, providing care and protection, or comprehensive support ("I love you more than life, and after what you said [after coming out], I can only love you even more"). This also becomes a priority for many narrators and the axis of the activities undertaken, especially in situations where the child has symptoms of depression or self-mutilation. Caring for the child's well-being requires overcoming one's fears and numerous parental coming outs, initially in the private sphere, and later also in the public sphere. Counteracting stereotypes and prejudices, reacting to discrimination, taking advocacy action (e.g., on the school premises), or engaging in gender reconciliation procedures are new directions that focus the narrators' activities:

> I stopped caring what people thought of me because my child's life was at stake. I explain what the situation is, but I don't care if I offend the teacher if she doesn't understand that by addressing my child with a deadname, she is hurting him.

Some parents focus their actions only on their children, others become active on behalf of the whole non-normative community, joining alliance organi-

zations and building an identity as a parent-activist. Not every parent, currently reconciled to their child's non-normativity, was ready to admit their previous homo/transphobic reactions. Detailed analysis of the narrative structure made it possible to identify fading out of awareness that ensured the coherence of the parent's reconstructed identity (e.g., the coming out experience could not be presented as traumatic because it did not fit into the self-presentation of a supportive, accepting person).

Biographical work and the normalization of the family situation (e.g., the end of the transition procedure) mean that the non-normativity of the child is no longer a primary experience for many people. Parents return to routines ("We live our daily lives normally, and not everything revolves around our child's sexual orientation. Besides, we have a second child who requires our attention"), they function satisfactorily on a private and professional level, they also experience their children's successes and failures in the educational sphere ("I am very proud of her because she got into a prestigious university abroad"), professional sphere ("My daughter had to change her job because she was discriminated against in the previous one"), or private sphere ("I am very happy because I am going to be a grandma").

Summarizing their narratives, the parents point out the changes in their lives after their child's coming out, noting some limitations, but also new opportunities. Depending on the course of the biographical work, they focus more strongly on one or the other. The stigma attached to the child is difficult to accept, and a significant change for parents is a greater fear for the child's safety and future. They stress that prejudice and discrimination will cause their child to eventually decide to leave the country, which will

be very difficult for them. Those who, for various reasons, have not chosen to disclose their child's psychosexual orientation and/or gender identity are burdened by secrecy, self-control during the talks, or forced lies. The personal coming out of narrators, especially at the beginning, is a strong emotional experience and, as a result, some parents have severed ties with people once important to them. The uncertainty, the responsibility for irreversible decisions (e.g., mastectomy), and the internal struggle against ingrained stereotypes and prejudices are difficult.

Contact with non-normativity also triggered several positively valorized changes. The narrators highlighted changes in their worldview, greater sensitivity and attentiveness to manifestations of any discrimination, and the courage to stand up for themselves and confront hurtful points of view. They question their previous fears ("I will become a grandmother thanks to in vitro," "My daughters are planning to get married abroad"), and they value new acquaintances and involvement in parents' organization activities. It is also important to be able to help children who do not have the support of their loved ones and to share experiences with parents who are starting their biographical work.

## Conclusion

In the course of the autobiographical narrative interviews, parents of children with non-normative sexual orientation and/or gender identity created a narrative about their experiences. The narrative became a form of organizing one's biography, provided with a kind of order and gave it direction. Maintaining a coherent narrative of life required, among others, rooting in the past, integrating new experiences with earlier ones and making sense of

them, resolving emerging contradictions, and indicating the relationship of the current situation to the planned future. In the course of reconstructing events, reflection on them also occurred, leading to a reinterpretation of the situation. Composing a coherent autobiographical story was also indicative of maintaining the integrity of identity and its continuity over time.

The analysis of the autobiographical narrative made it possible to reconstruct the process of biographical work undertaken by the parents. They verbalized the course of their inner work and their way of thinking about reality and themselves. The narrative required them to identify significant fragments of their lives embedded in a specific context (social, cultural, political, and historical) and to indicate their involvement in significant events. In reconstructing the course of events, the narrators indicated that in addition to their activity (including cognitive and emotional), the actions of interacting partners (e.g., the child or other parents from advocacy and support organizations for LGBTQIA people) were equally important in constructing a coherent biography. By reliving specific situations, they could grasp their strategies of action, ways of interpreting reality, or understanding the significance of particular episodes for the course of life. As a result, there was a tying together of experiences into a coherent and unfolding life story over time, which also included the narrators' self-presentation.

The interpretative frame of the socially dominant narrative (heteronormativity) meant that the disclosure of a non-normative sexual orientation and/or gender identity was considered by the parents as an experience that triggered trajectory potential. Concerning the child's coming out, there was a revision of their biography—some elements of the biography were altered and others providing continuity were maintained. The biographical work proceeded through four biographical processes—contextualizing, coming to terms, reconstituting identity, and recasting biography, which were easy to distinguish only on an analytical level. There was also some difficulty in comparing and presenting the biographical workflow of different narrators. However, the narratives reveal three categories in which the narrators' biographies and self-representations are embedded—stigma, normalization, and activism. These categories may characterize particular fragments of life and changes in biography and identity, or one of them becomes the dominant line for the course of life and self-identification.

The biography embedded in the category of stigma refers to heteronormativity as a basis for understanding reality, which, in effect, results in the parents' prejudice against people with non-normative sexual orientation and/or gender identity. They verbalize their beliefs and judgments in relation to an unspecified group. The emotional bond with the child means that they do not overtly dislike the child, but their actions are often hurtful, and the child's difference is difficult to accept. Parents ignore the child's coming out, as well as the biographical problem associated with it, and return to routines. Non-normative sexual orientation and/or gender identity becomes a taboo subject, is not discussed at home, and is not revealed outside the immediate family (cf. "family closet," "transparent closet"). Attempts to understand the situation are mainly related to identifying causes and apportioning blame. The new experience evokes negative emotions, a sense of loss, and grief, but the parents are not prepared to work through their difficult experiences, which has several consequences for the course of their lives. By ignoring the fact of coming out, parents fail to integrate the new experience into

their biography, to give it meaning and relevance to their story. Their efforts are focused on recovering their lost identity and sense of continuity, but they avoid reconstructing it to take account of the change, resulting in internal tension and lack of coherence.

A biography built on the category of normalization requires parents to challenge heteronormative conceptions of normality, health, or illness and adopt alternative references. For example, the understanding of gender, sexuality, and the definition of family changes. It is important to detach norms from the natural order and point to the process of their social legitimization and cultural embeddedness. The acceptance of non-normativity is linked to the recognition of the legitimacy of diverse patterns of functioning in society. The narrators' self-presentations are based on the image of a "normal" person who lives according to established rules, fulfills assigned roles, and discharges duties toward the family or society. The parents indicate, among others, their heterosexual orientation, functioning in professional life and conventional family arrangements, as well as the love and care they give to their loved ones. When talking about the child, they emphasized their social adaptation and positively valorized attributes, for example, that the child is a good, valuable person, successful, has a job, passions and dreams, lives in a stable relationship, and is raising a child of their own. In this context, non-normative sexual orientation and/or gender identity, which belong to the private sphere, appear as one of many attributes. Normalization triggers parents to reflect on the sources of gender stereotypes, social pressures to conform to socially accepted (as good and natural) role models, and practices of exclusion of Others. These reflections are the subject of conversations with the interactants, but the narrators do not need to take action in the public space.

A biography organized around the category of activism requires prior normalization. Parental acknowledgment of diversity in sexual orientation and/or gender identity results in a growing disagreement with socially reproduced stereotypes and hostile attitudes toward non-normative people, especially toward their children. Opposition to manifestations of discrimination is generalized to other socially marginalized groups. Discord and frustration give rise to the need to oppose and counteract unequal treatment, which indirectly serves to protect one's child. The narrators alone, or with other parents, participate in events that bring the voice of non-normative allies into the discourse. This requires the courage to publicly come out and express or argue one's case, to overcome the fear of negative evaluation, and to find the strength to stand up to others. The narrators make the public aware of the presence of LGBTQIA people in society, their functioning within family arrangements, their rights, and society's refusal to respect them. They emphasize that their advocacy stems from the imperative to love and protect the child inherent in the role of parent. On this basis, they build an identity as accepting and committed parents by becoming "radical normals." Some narrators become members of alliance organizations, within which they fulfill their needs, but also co-create a support network and provide a reference group for subsequent parents.

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## Citation

# Transitioning (on the) Internet: Shifting Challenges and Contradictions of Ethics of Studying Online Gender Transition Narratives

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**Abstract:** The use of social media in qualitative research has become extremely popular. YouTube, in particular, has attracted attention from scholars working on (self-)representation of minority groups, including the transgender community (e.g., Dame 2013; Horak 2014). Most academic disciplines, however, have been slow in responding to the increasingly challenging nature of social media in terms of their ethics and methodologies. For example, there is a common misconception that any publicly available YouTube videos can be freely used for research. Many studies openly reference the YouTube channels they discuss (Wotanis and McMillan 2014) or anonymize data, but do not seek informed consent from creators (Raun 2020). What is more, researchers rarely reflect on how their work could impact the communities under study or the way creators use social media (Leonelli et al. 2021). At the same time, researchers wishing to protect vulnerable communities may find themselves falling short of FAIR (findable, accessible, interoperable, and re-usable) research principles required by funders. In this contribution, I discuss these and other challenges using, as a case study, my project, which investigates gender transition narratives on Polish social media. I wish to show that there is no one-fits-all approach to the ethics of social media studies—as the very nature of social media is in constant flux—and call for attentiveness and reflexivity as an inextricable component of qualitative social media research methodology.

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The use of social media in qualitative social research is definitely here to stay. A plethora of data easy to access, collect, and process offers a whole new world of possibilities that would have been considered science fiction only twenty years ago.

As Facebook, Twitter, Instagram, YouTube, and other social media sites, platforms, and applications are weaving themselves into the fabric of many people's lives (Tagg et al. 2016; Williams, Burnap, and Sloan 2017a), it is becoming increasingly important and relevant for social studies to shine a light on online behaviors and practices. At the same time, there is (still) a difference between offline and online realities, and we should take care not to expect the results of such studies to apply to, and contribute to, our understanding of, social life in general (also because of the existence of a digital divide—the over-representation of Western/global North perspectives on the internet). This is the approach taken in my project, as well as by most authors whose works are discussed in this article—we make it clear that we study *online* discourses, behaviors, and communities, and we find it worthwhile because we believe that there is something qualitatively new and different about digital technologies and the things they make possible.

Social media, however, can also be used to "mine" or "grab" large quantities of information on people's opinions, attitudes, offline behaviors, and so on. This applies especially to Twitter, which is commonly used to gather data *en masse*, to study, for example, political movements, terrorism, responses to climate change (boyd and Crawford 2012), or the impact of air pollution on health and wellbeing (Leonelli et al. 2021). While this understanding of "using social media in research" pertains to quantitative studies and will thus not be considered here, it is important to emphasize that most publications on ethics in social media research—some of them exclusively—focus on mining online data rather than studying the online environment in its own right, qualitatively. There is a good reason for it—the practice of mining online data for research is definitely associated with considerable problems, risks, and challenges, not only related to ethics. "Critical questions for big data" include the issues of defining knowledge and its limits, claims to objectivity, accuracy, and representativeness, or the value of information devoid of context (boyd and Crawford 2012).

The question of ethics is, of course, also a central one. This is exemplified by such scandals as the 2006 Facebook friendship study, in which students' data, pulled without consent, could be de-anonymized (boyd and Crawford 2012:671-672) or the collection of thousands of transgender YouTubers' videos used to train facial recognition software (Vincent 2017). Practices such as those described by Williams and co-authors, whereby "papers were being published in reputable journals with tweets quoted verbatim, with unacceptable and ineffective methods of anonymization, and without informed consent from users" (Williams et al. 2017b), are becoming more and more objectionable, concerning both qualitative and quantitative research.

Ethical issues are compounded by the fact that large amounts of social media data are, of course, not only mined by researchers but also by businesses for commercial purposes. What is more, some social media platforms—most notably Twitter—have monetized access to their users' data, adding a financial dimension to the equation.

While the literature on the challenges of using social media data is constantly growing, and the effort to come up with solutions is tangible, there is no consensus regarding what an approach to social media research that would be both ethically and methodologically sound could look like. As a result, even within one institution, legal stipulations and ethical requirements are sometimes incongruent, and ethical and methodological principles sometimes contradict each other, as the present article intends to show. By the way, the abovementioned prioritization of the quantitative perspective and the fact that the difference between qualitative and quantitative approaches is often not spelled out may be adding to the confusion.

With this article, I would like to refocus the debate on the ethics of social media research in two contrasting directions. First, I would like to zoom in on vulnerable communities, especially from the perspective of a researcher who does not belong to the community in question. The other direction is to zoom out to include broader methodological issues since focusing on ethics only could conceal important conflicts between ethical and methodological research principles. What is more, by focusing exclusively on qualitative research, I hope to address this gap in the literature.

The arguments in this article are based on my experience doing research on gender and sexuality discourses on Polish social media. As my current project involves online gender transition narratives, the transgender community will be given particular attention. To provide more context, the discussion in this article will be grounded in a review of the available literature on the use of social media by women and the LGBTQ+ community, with a special focus on the transgender community, published in the

last twenty years and methodologically similar to my research. Table 1 appended to this article summarizes the relevant information on these publications.

The increasing recognition of ethics is not, of course, limited to social media studies. For example, for a discussion on ethics in qualitative migration research, see Justyna Bell, Agnieszka Trąbka, and Paula Pustulka (2020).

## Zooming In on Vulnerable Communities

### Defining a Vulnerable Community

Social media appear to be "inherently democratizing, enabling anyone with access to participate, liberated from traditional biases associated with gender, age, race, social class, (dis)ability, and physical attractiveness" (Herring et al. 2004:1). Facebook and Twitter can accommodate Donald Trump, the British royal family, the Black Lives Matter movement, and dissident groups in undemocratic states. Importantly, the present section is concerned with social media users considered vulnerable. Different ethical issues will pertain to police officers and police violence victims' Twitter accounts (Schneider 2018). This may bring more confusion into an already complex situation involving legal and ethical principles that may contradict each other.

Legal stipulations apply to all social media studies. But considering legal frameworks is complicated due to the lack of clarity about which country's laws should apply to specific projects. Should it be the country where the project is based (in my case, the UK), where the social media platform in question is based (US, in most cases), or where the social media users whose accounts are studied are based? In the

UK, researchers are advised to rely on *public task/interest* as the legal basis to process publicly available data for research purposes (UKRI n.d.). This position is supported by several research funders and regulatory bodies, including the Medical Research Council (MRC) and Health Research Authority (HRA). What is more, if the social media data are anonymized, it is no longer subject to the General Data Protection Regulation (GDPR), and can therefore be used lawfully for research purposes.

My current project focuses on YouTube videos, which are subject to US legal provisions, such as the USA Patriot Act. YouTube's terms and conditions also need to be consulted. The section on *fair use* allows re-using YouTube material for "commentary, criticism, research, teaching,"[1] and similar purposes.

Since the social media users in my project are Polish, live in Poland, and upload their videos from Poland, the Polish interpretation of *fair dealing* should also be consulted. Poland has implemented the Illustration for teaching or scientific research (Art. 5.3(a) InfoSoc) exception in Article 27 and Article 100 of the Copyright and Related Rights Act.[2] None of these resources, however, mention vulnerable research participants, whether individual or collective.

Many ethical guidelines I have consulted emphasize that these legal frameworks were not developed with social media in mind and that *legal* does not automatically mean *ethical*. My university's guidelines, for example, recommend considering:

- whether the information is truly public, that is, is it available to anyone on the internet or is it password-protected or shared in a group with gated access,

- whether the information used for research purposes is sensitive, that is, can it increase the risk of harm or distress to anyone,

- whether the information is truly anonymous, that is, can direct quotations lead to the identification of an individual.[3]

In a guide developed specifically for social media research ethics, Leanne Townsend and Claire Wallace (n.d.) include, among others, the following questions. They cover the same issues as the recommendations above, with one additional question concerned with *vulnerability*:

- Can the social media user reasonably expect to be observed by strangers?

- Are the research participants vulnerable?

- Is the subject matter sensitive?

- Will the social media user be anonymized in published outputs?

Finally, we have found a source that singles out vulnerable participants as in need of a special approach. But what is meant by *vulnerable* exactly? My university's guidelines define vulnerable adults as experiencing or being "at risk of abuse or neglect," having "needs for care and support," and being "un-

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[1] See: https://support.google.com/youtube/answer/9783148?hl=en#zippy=%2Cthe-purpose-and-character-of-the-use-including-whether-such-use-is-of-commercial-nature-or-is-for-nonprofit-educational-purposes. Retrieved November 23, 2023.

[2] See: https://copyrightexceptions.eu/#info53a. Retrieved November 23, 2023.

[3] School Research Ethics Committee (SREC) recommendations, personal communication.

able to protect himself or herself against the abuse or neglect or the risk of it." Examples include people "with learning disabilities, mental health problems, older people and disabled people."[4] Under this definition, the LGBTQ+ community as a whole would not be classified as vulnerable, although particular individuals under the umbrella might be. What is more, according to UK law, sex life and sexual orientation are special category data, but gender identity is not. On the other hand, gender reassignment is a protected characteristic, according to the Equality Act 2010.[5] Confusion remains.

Different people will have different opinions on this, but, for me, a community is vulnerable if it is marginalized or at risk of discrimination in social life, both online and offline. Such a community may engage in practices that are not widely known and consider social media a safe space to talk about them (Mitra and Gajjala 2008; Miller 2017). The increased visibility that comes with research may threaten this.

The LGBTQ+ community in Poland is, unfortunately, a case in point. Currently, Poland is officially the worst country in the EU for the LGBTQ+ community to live in—at 13%, it has scored the lowest in the 2022 Rainbow Europe ranking.[6] To contextualize this result, Europe's overall score is 38%, and EU overall score is 48%. While the situation of LGBTQ+ people has never been good, it has worsened considerably since the community became a target of

a hate campaign embarked on by some politicians and representatives of the Catholic Church. In March 2019, local governments across south-eastern Poland started passing declarations in condemnation of what they called "LGBT ideology," which became known as declarations of LGBT-free zones (Janiszewski 2021). In July of the same year, Catholic archbishop Jędraszewski called LGBTQ+ people "the rainbow plague" (*tęczowa zaraza*), in parallel to the "red plague" (i.e., Communism). The LGBTQ+ community had probably never been so visible before, even if many politicians who voted for the declarations (and probably many ordinary Polish citizens) were not able to explain the acronym when asked to do so by journalists. As a result, the public acceptance of LGBTQ+ rights and gender equality, which had been growing steadily for years before, fell again in 2019 (Świder and Winiewski 2021:9). This shows the possibility of a negative impact of increased visibility.

The Polish transgender community may be considered an example of a group that uses the internet (especially YouTube) as a safe space and whose practices are relatively unknown in wider society. In many ways, transmen in Poland can benefit from a general lack of knowledge about trans issues. For example, their chest scars (the effect of mastectomy) do not automatically "out" them in public spaces such as swimming pools—many people are not aware of where they come from and assume they are an effect of an accident. Another example is visiting public restrooms, which many trans YouTubers on English-speaking channels report to be a serious problem. Transwomen especially sometimes experience feeling unwelcome in women's restrooms, where they are perceived as a threat, and uncomfortable about going to men's restrooms, for the obvious and valid reason that they are not men.

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[4] Cardiff University's Safeguarding Children and Adults at Risk: Guidance Note 1. Full Definitions and Relevant Legislation are available at: https://www.cardiff.ac.uk/public-information/policies-and-procedures/safeguarding. Retrieved November 23, 2023.

[5] See: https://www.legislation.gov.uk/ukpga/2010/15/contents. Retrieved November 23, 2023.

[6] See: Rainbow Map Europe 2022 (https://www.rainbow-europe.org/). Retrieved November 23, 2023.

In contrast, one of the Polish trans YouTubers once admitted (in 2018) that visiting public restrooms is not an issue for him simply because the low visibility of the transgender community means that few people in the country can actually recognize (and be offended by) a transgender person entering a public restroom.

On the other hand, the latest report on the situation of LGBTQ+ people in Poland mentions that 57% of the study's trans respondents avoid going to public restrooms despite needing to (Mulak 2021:324). This could be a result of the fact that the visibility of the trans community in Poland has increased due to the hate campaign against LGBTQ+ people described above, and, in particular, after the arrest of the non-binary activist Margot Szutowicz in August 2020 (Hume 2020).

The discussion above shows how dynamic the situation of the LGBTQ+ people in Poland is. Thus, they should be considered vulnerable not only because increasing their visibility can have adverse consequences but also because their socio-political context is so unstable and its future difficult to predict. A social media research study violating (even if unwittingly) an individual's privacy can be extremely distressing and even dangerous if personal data are breached or if sharing sensitive information leads to stigmatization. But, if that individual belongs to a vulnerable community, the whole group may be worse off as a result.

Most publications on my review list do not refer to women[7] or members of the LGBTQ+ community as

vulnerable. One exception is Alexander Dhoest and Łukasz Szulc (2016), who studied the use of social media by gay men with migration backgrounds in Belgium. With "**such a vulnerable group**, for whom confidentiality is so important, gaining and respecting trust were key issues throughout the research process" (Dhoest and Szulc 2016:4 [emphasis added]). It is not clear, however, whether they use the term *vulnerable* based on any legal definition or their judgment.

Others, even if they do use the term *vulnerability*, do not necessarily connect it to a need for a special approach to ethics.[8] Let us have a look at two examples of studies on trans vlogs. In the first one, Avery Dame (2013:48 quoting Valentine 2007:217 [emphasis added]) recognizes "the risk of using discourse as a form of violence against **vulnerable populations**" while still providing online identifiers (OIs) of vloggers under study without making it clear if informed consent was obtained or not (see the following subsections). In a similar vein, in a study that does not mention ethics at all and does provide links to videos through which research participants

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[7] Three studies on women on social media (Marwick 2013; Wotanis and McMillan 2014; Spallaccia 2020) are included in the review because they are particularly good at pointing out that bullying, discrimination, and stigmatization do not cease online. The internet is not a utopian democratic space it was once

thought to be (Turner 2006). For example, Wotanis and McMillan (2014:914) write that "'sexist and often abusive comments' are a part of YouTube culture"; Marwick (2013 citing Herring 2004) agrees that the online environment is "hostile to women" and that cyberbullying targets women, sexual minorities, and people of color disproportionately. What is even more worrying, cyberbullying can affect offline lives in significant ways: "[Cyber gender harassment] discourages [women] from writing and earning a living online. It interferes with their professional lives. It raises their vulnerability to offline sexual violence. It brands them as incompetent workers and inferior sexual objects. The harassment causes considerable emotional distress. Some women have committed suicide" (Citron 2009:375 as cited in Wotanis and McMillan 2014:915). While the same can probably be said about the LGBTQ+ community—that it is not immune from bullying and discrimination online—the internet has usually been presented by researchers as a safe space, at least against the "offline" background—it offers "a relatively safe way to explore their sexuality in a homophobic national or cultural context" (Dhoest and Szulc 2016:7).

[8] The exceptions here are King (2017), Miller (2017), and Raun (2020).

can be easily identified, Laura Horak (2014:582 [emphasis added]) explains that "these videos have broken open the mainstream media's stranglehold on trans representation and provided many otherwise **vulnerable subjects** the opportunity to shape themselves and their world".

The use of the word *otherwise* here is puzzling. Does it mean that a trans person ceases to be vulnerable when they start posting videos online? Does the decision to start posting YouTube content make you a public person, an activist? Is it what Tobias Raun (2020:34-35) has in mind when he writes that

> you agree that millions of people are allowed to watch and discuss your vlog, including researchers. When you sign up for a YouTube account, you agree to be "solely responsible for your own Content and the consequences of submitting and publishing your Content on the Service"?

As we will see in the following subsections, these authors clearly do not think that transgender, or more generally LGBTQ+, populations are not at risk in the "real world." The problem is, rather, that the internet is considered to be a safe space for them (see footnote 8) and also, possibly, that social media content is considered in the light of general legal and ethical guidelines, which, as we have seen, are not perfect, age very quickly, and do not consult and reflect the voices and needs of marginalized groups.

**Contextualizing the Community**

In all my publications concerned with gender and sexuality discourses and the LGBTQ+ community, I always include a section on the socio-political situation of the group in the given country (Poland and/or other Central-Eastern European states). Sometimes,

I feel uncomfortable doing this because I anticipate accusations of typecasting the LGBTQ+ community as poor, passive victims of "uncivilized" post-socialist states with their unenlightened, bigoted populations. This may reinforce the stereotypical division between the modern, progressive, sexually liberated West and the conservative, traditional, and sexually repressed East (Kulpa and Mizielińska 2016; Wiedlack et al. 2020). I still do it, though, because I realize that not all readers are familiar with this part of the world, so the information helps them contextualize my study better, but also simply draws their attention to a struggle they may not be aware of.

This is, thus, something I am sensitive to, and I discover with surprise that not all authors do it. Some write about social media practices of gay, lesbian, or transgender people without mentioning their marginalized status in society at all. Maybe it is because they believe that online practices are de-localized and de-territorialized to the extent that belonging to or residing in a particular nation-state does not matter anymore (Enguix and Ardévol 2012)? Maybe they have gone through reflections similar to mine and do not want to typecast the group as helpless minority victims of a bigoted, homophobic, and transphobic majority? Or maybe they assume everyone knows that the community is discriminated against, or can Google it if they do not?

The problem with this is that LGBTQ+ internet studies have a clear bias toward the US or the English-speaking world. Łukasz Szulc (2014) has noticed that US-based studies usually have general titles, such as "Computer Cross-Dressing," "Lesbians Who Are Married to Men," or "Gay Men's Use of Online Pictures in Fat-Affirming Groups," which suggest a universal/universalizing perspective. At the same time, studies based in other places, for ex-

ample, Poland, Malaysia, or Japan (i.e., Szulc's "Domesticating the Nation Online: Banal Nationalism on LGBTQ Websites in Poland and Turkey" [2016]), tend to include the place name in the title, implying that they talk about particular and local rather than general and universal issues.

Among the publications included in my literature review, only two mention a specific nation-state in the title— Brian King's "Querying Heteronormativity among Transnational Pasifika Teenagers in New Zealand: An Oceanic Approach to Language and Masculinity" (2017) and Rahul Mitra and Radhika Gajjala's "Queer Blogging in Indian Digital Diasporas: A Dialogic Encounter" (2008). Interestingly, these two also devote the most space to discussing the socio-political contexts of their case studies. King informs us about Pasifika peoples and masculinities in New Zealand, while Mitra and Gajjala embed their study in a postcolonial, racist, homophobic, hetero-normative context and familiarize us with the history of the Indian gay movement from a diasporic rather than—or in addition to—a national perspective. Admittedly, Tobias Raun (2020) also provides an extensive discussion of the socio-political situation of the trans community, but his contribution is a Ph.D. thesis with a completely different affordance of space.

All the other publications have general titles that do not point to any specific location (e.g., "'I'm Your Hero? Like Me?': The Role of 'Expert' in the Trans Male Vlog" [Dame 2013] or "Archiving the Wonders of Testosterone via YouTube" [Raun 2015]). Out of these:

- some locate their studies in places that would be considered the "West," for example, the US (Alexander 2002; Raun 2020), the UK (Jenzen

2017), Belgium (Dhoest and Szulc 2016), or Germany, among others (Heinz 2012);

- others do not mention the location at all, but it is clear that they are concerned with social media in the English language (e.g., Sundén 2002; Miller 2017; Miller 2019; Martino, Omercajic, and Cumming-Potvin 2021). English is, thus, construed as the unmarked, universal language of social media that does not require an explanation, while other languages are presumably marked and need to be explicitly named and explained.

While some of these publications with general titles provide a bit of context, this tends to be very cursory and unspecific, listing nominalizations (*homophobia*, *transphobia*, *prejudice*, *risk of violence*, physical and psychological *abuse*, and *discrimination* [Miller 2017:3], *bullying* [Jenzen 2017:1627], and *stigmatization* [O'Neill 2014]) or using academic terms such as *marginalized* and *subaltern* (Martino, Omercajic, and Cumming-Potvin 2021:4), for example: "transpeople continue to be disproportionately affected by *discrimination*, *violence*, *suicide* and other forms of *self-harm*, *unemployment*, *underemployment*, *substance abuse*, *HIV status*, *and access to medical services*" (Heinz 2012:339 [emphasis added]); "mainstream representations of trans people are often *distancing* and *objectifying*, treating trans people as freaks or curiosities" (Horak 2014:575 [emphasis added]).

For another example, Tobias Raun (2015:703 [emphasis added]) writes that "body-altering procedures are laid out for visual consumption and inspiration, which potentially challenges the *pathologization* and *stigmatization* of trans." The use of nominalizations (in italics) suggests that these phenomena are generally known and do not require any explanation, but

someone not familiar with the transgender community at all may struggle to understand how and why it is pathologized and stigmatized. In turn, Jordan Miller (2019:816) writes that "Trans people who do not adhere to transnormativity are often negatively impacted in the form of social estrangement, religious condemnation, violent hate crimes and street harassment, police violence, loss of familial and community support, and institutionalized discrimination in healthcare facilities, prisons, housing, and the workplace," as if suggesting that trans people who do adhere to transnormativity do not experience these things.

Many studies on the LGBTQ+, and especially transgender, groups on social media tell the story of empowerment, celebration of identity, and community-building, which is why they may be reluctant to cast the "real-world" situations of these groups in a negative light. I believe, however, that without contextualization, these studies fail to paint the full picture and may even lack social relevance, offering an exercise in social media analysis and not much more. To quote Łukasz Szulc (2014:292) again:

> To ignore the context of one's research means to follow utopian imaginations of the Internet as a deterritorialized cyberspace, which only obscures rather than explains the social role of the Internet. To take the context of one's research for granted means failing to address one's non-U.S. colleagues, who may be unfamiliar with the context, as well as working against the commitment to internationalize media studies.

Another concern that Szulc hints at here is that if many of the US-based studies do not problematize the socio-political situations of their LGBTQ+ populations, while the ones located somewhere else do, it suggests that the "West" represents the universal, objective point of reference, while the "Rest" is particular, local, subjective, partial, and unable to make universalizing claims. It also reinforces the stereotype that the "West" is a place where equality has already been achieved that "others" lag and should look up to (consider Mizielińska and Kulpa 2013). As a side note, I made the title of this article appear "universal" exactly for this reason. I believe we can all learn from each other's stories—not only the "East" from the "West," but also the other way round (see also the subsection on Positionality).

**Informed Consent, Anonymization, Direct References**

Having discussed the questions of vulnerability and contextualization of the studied group, let us return to the issue of social media research ethics. As mentioned in the introductory section, it is becoming less and less acceptable to use social media data in research without taking ethics into account. More and more researchers are finding it problematic to rely on the assumption that if the data are public, they may be freely used for research purposes (Williams et al. 2017a; 2017b). This assumption has probably lingered on since the times of "Web 1.0," when the internet was populated with pseudonyms and avatars rather than real names and profile photos prevalent on social media platforms of "Web 2.0." When I started researching gender and sexuality discourses on the internet back in 2015, focusing on the "departing" (Kopytoff 2011) medium of blogs, most of the gay, lesbian, and transsexual authors I followed blogged anonymously. Possibly as a consequence of that, ethical clearance for that study was unproblematic. Two parallel developments—one in the LGBTQ+ world, the other in the online world—have been underway since then.

With regard to the former, discourse has continued to shift away from the binary opposition between heterosexuality and homosexuality to a diversity of orientations and identities with straight, gay, and lesbian as just three out of a plethora of equally valid options. We have also moved away from talking about transsexuality as a diagnosis toward the transgender umbrella of identities and gender dysphoria as the diagnosis (BBC 2019). Concerning the latter, almost all anonymous blogs I used to follow have been taken down, and the discussion on gender and sexuality has moved to Facebook, Twitter, Instagram, YouTube, and TikTok, with creators showing their faces and some of their names becoming brands. While some still use pseudonyms, the fact that these pseudonyms can be connected to their faces and offline identities means that their anonymizing function has become obsolete.

As my research has followed the online content creators in this shift, obtaining ethical clearance for studying this content has also become less straightforward. A combination of the legal principle of public task/fair dealing and anonymization of personal data may not be enough in qualitative social media research, where content may need to be quoted verbatim. Informed consent is, thus, something that needs to be considered, especially with regard to YouTube, which involves visual images of individuals.

Still, only four publications in my literature review mention obtaining informed consent; all of them use data anonymization (or pseudonymization) at the same time, for example:

> At the start, we obtained informed consent and ascertained anonymity; after the initial analysis of the interviews, the participants received a general report

including their quotes, to which they could comment. All were satisfied with the way their data were treated and the degree of anonymity. In this article, their names are replaced by other names which are commonly used in their country of origin. [Dhoest and Szulc 2016:4]

All four have been published relatively recently (after 2016). What is more, out of these, three (Dhoest and Szulc 2016; Jenzen 2017; King 2017) are based on interviews or ethnographic work with LGBTQ+ producers and/or consumers of social media, rather than the analysis of social media content itself. Here, the ethical approach might have been conditioned by methodology—obtaining informed consent before conducting interviews/ethnographic work is a matter of course. The only publication I could find that relies on informed consent to study trans users' social media is Jordan Miller's (2019:817-818)—but note that this study combines an analysis of YouTube content with, again, interviews:

> Prior to each interview, I e-mailed participants the consent form, as well as a crisis-resource list in the unlikely occurrence of a negative interview experience…Five of six participants consented to the usage of any images or audio from the interviews or their public YouTube content in any presentations and publications deriving from this study. All six consented to any content of their YouTube channel and interview data being included in written form.

Informed consent is also mentioned by Tobias Raun (2020:42 [emphasis added]), but for a different reason—to explain why it has not been obtained for his study on transmen on YouTube:

> I consulted different ethical guidelines…and most of them agree that it is consistent with ethical re-

sponsibility…**not to pursue informed consent** if the material "is open and available for everyone, that everyone with an Internet connection can access, and that does not require any form of membership or registration" (Sveningsson Elm 2009:75). I also consulted the review board in Denmark, the Danish Data Protection Agency, and according to their guidelines **I did not have to obtain informed consent**, but I needed to anonymize the vloggers when publishing my material.

Note that all the sources that Raun mentions above were published before 2010, which means that they might not have been written with the social media we have today in mind.

Two further publications (Sundén 2002[9] and Martino et al. 2021) assigned pseudonyms to research participants. The most common approach, though, is to provide direct references—weblinks to the blogs/videos under study and/or OIs of social media creators without making any reference to ethics.[10] For instance, Laura Horak (2014) mentions OIs of the "most popular trans YouTubers," and a list of videos used is attached after the bibliography. Granted, providing links to online content seems to have ceased around 2015, but this may have less to do with ethics than with the instability of web addresses that can be easily changed or removed. Using OIs, in contrast, can be ascertained across the entire timespan considered—2002-2021—and thus does not "belong to the past" even though,

as mentioned before, online identifiers should be considered personal data and handled with much more consideration. Publications providing verbatim quotes of *textual* social media content should be included in this group because by copy-pasting the content into an internet browser it is possible to identify the site and thus the individual poster. Transcribed quotes of YouTube audio content do not have this function; but YouTube videos can be found if verbatim quotes of titles, descriptions, or comments to the video are included.

Why is this a problem? To illustrate, in her aptly titled book *It's a Man's World (Wide Web)*, Beatrice Spallaccia (2020) looks at examples of hate speech targeting women online. She analyzes in detail case studies of several women in the US, Italy, and Australia who have been the target of trolling, cyberbullying, and harassment, including sexual violence and death threats, providing profuse examples—and she uses real names of the affected women. She does not explain at all whether these women were informed and/or asked for consent; we only know that one of them was additionally interviewed. Spallaccia does not include any description of her approach to ethics, and she only uses the word to refer to online behavior and gaming journalism. It is clear that her intention is to expose and condemn misogynistic cyberbullying, trolling, and hate speech practices; but is using the victims' real names the ethical way of going about it?

According to a popular argument, if social media users want to protect their privacy, they go for "gated access areas of websites or websites requiring memberships since such sites are created to offer a safe, private communication space" (Heinz 2012:328). Contrary to that, the work of Matthew Williams and colleagues (2017b) emphasizes that

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[9] Sundén (2002) studied interaction in MUDs (Multi-User Dungeons). Names of characters in the article are changed, but no information concerning ethics or informed consent is provided. It should probably be assumed that the study was conducted clandestinely.

[10] To be fair, this does not automatically mean no ethical clearance was sought or informed consent was obtained. It should be common practice to provide information on ethics in publications to avoid any confusion or misunderstandings.

users' conceptions of what is public and private is blurred in online communications…The disinhibiting effect of computer-mediated communication means Internet users, while acknowledging the environment as a (semi-)public space, often use it to engage in what could be considered private talk…Online information is often intended only for a specific (imagined) public made up of peers, a support network or specific community, not necessarily the Internet public at large, and certainly not for publics beyond the Internet.

Highly emotional and intimate details of the lives of women in Spallaccia's (2020) study will be accessible in university libraries for decades after we forget all about Twitter and move on to the next thing. These cyberbullying stories may appear dominant and central now, but the affected women have the right to forget them, move on, and wish to be remembered for something completely different. Many of the reviewed studies, especially those focusing on the use of social media by the LGBTQ+ community, position bloggers and vloggers as experts, heroes, activists, role models, as if it were their obligation and responsibility to represent the community and educate everyone else: "Transgender youth may be particularly in need of media depictions and mediated role models" (Miller 2017:3). While such portrayals are undoubtedly valid, they appear to be imposed on the social media creators, to be outside their control. Do they all really want to be the face of a movement?

This is especially relevant in the case of transgender YouTubers. Many of them address their videos specifically to the transgender community. Research using their images and OIs can inadvertently "out" them as trans to their employers, colleagues, teachers, landlords, et cetera, possibly contrary to their wishes of being out as trans online but "stealth"

offline. For many LGBTQ+ people, this distinction between being out online and passing as straight/cis offline is a life-saving necessity (Dhoest and Szulc 2016; Miller 2017; Raun 2020).

**Positionality**

Ever since I started doing qualitative research on gender and sexuality discourses on social media, including blogs and YouTube, I have been inspired by how people build their gendered and sexual selves out of (multi-)linguistic resources available to them in often creative, innovative, and completely surprising ways. Having studied homophobic and transphobic discourses of Polish mainstream media (Chojnicka 2015a), I felt that the narratives I found on what I then considered "alternative" media could help raise awareness of how language contributes to social inequalities and how it facilitates change at the same time. For example, by applying Critical Discourse Analysis to study LGBTQ+ blogs, I developed a typology of strategies challenging mainstream cis/hetero-normative discursive frames (Chojnicka 2015b).

Ever since I started doing this work, I have also been constantly doubting and second-guessing myself. Does the community indeed perceive my work as beneficial—or is my research completely invisible or, even worse, perceived as extractivist? As a Polish researcher who received postdoctoral funding in Germany and the UK, do I have the right to speak about the struggles of a community I left behind? As a cis person, should I study gender transition narratives in the first place, and can I avoid speaking over transgender people if I do? Is it morally acceptable to build my academic career in this field, or am I taking space away from more vulnerable and less privileged researchers?

Joanna Chojnicka

These and similar questions are concerned with our positionality as researchers in relation to our subjects or research participants: "the call for self-reflection and understanding positionality has increased in its frequency. To think through positionality, a critical ethnographer must understand how privilege, power, and biases shape ethnographic fieldwork and representations, as well as the structures of domination and oppression that engulf the subjects we work with (Madison 2005)" (Henson 2020:325). Some authors of the publications in my literature review take up these questions, acknowledging "the researcher's disruptive possibility" and suggesting "self-conscious and reflexive inquiry" (Dame 2013:48). Brian King (2017:445) situates his ethnicity in the transnational New Zealand-Oceanic context and invites researchers, after Milani (2014), to position themselves "at the margins" to "enable reflection concerning our contributions to knowledge."

Very interesting is Rahul Mitra and Radhika Gajjala's (2008) method of interspersing their performative blogging with their analysis of "third-party" blogs, blurring the lines between subject and object of study. By doing this, they show that researchers are not god-like omniscient minds endowed with a "gaze from nowhere" (Haraway 1988) but embodied and situated human beings who can be studied like everyone else. Considering one's own positionality is especially pertinent to research on transgender communities online, whereby defining one's own (relationship to) gender identity is a common practice (e.g., Dame 2013; Raun 2020; Martino et al. 2021). Outside social media research, an insightful perspective on the positionality of migrant researchers studying migrant communities they are part of is provided by Paula Pustulka, Justyna Struzik, and Magdalena Ślusarczyk (2015) and Justyna Bell and colleagues (2020).

Tobias Raun (2020) devotes by far the most space to issues of the researcher's positionality, which is perhaps expected in the context of a Ph.D. thesis with a completely different space allowance in comparison to a journal article. He describes how, by creating a YouTube channel "Trans Researcher," he positioned himself as an "insider" because he "felt it essential to make explicit [his] researcher persona to the community, but also to have a personal and/or political stake in the community agenda in order to maintain both personal and research credibility" (Raun 2020:45-46).

Raun has also, like me, experienced people challenging his legitimacy to research the trans community. Being trans himself, he is sometimes perceived as "too personally involved and too politically invested" and so not "objective" and "critical" enough (Raun 2020:46). As a cis person, I have been deemed unable to really understand the experience of being trans and thus unable to do research about it (admittedly by fellow researchers and not by members of the trans community, who usually welcome academic interest in their issues, particularly in Poland).

This insider versus outsider debate is never trivial, especially in the case of relatively disadvantaged communities, whereby the "outsider" researcher hails from a more privileged social group, introducing the dimension of power into the picture. But, it must be kept in mind that producing knowledge from a marginalized perspective does not automatically make it critical of the dominant perspective (hence, female agents of patriarchy! [*agentki patriarchatu*] as labeled by Polish feminists), just as hailing from a dominant social group does not mean one cannot be critical of it (Jørgensen 2010:327). Tying the situatedness of knowledge to the researcher's identity may be reductive and, frankly, evokes the es-

sentialism that gender, trans, and queer studies are supposed to oppose. Thus, I agree with Marianne Jørgensen (2010:327; cf. Harding's standpoint theory 1998; 2006) that "we need continuously to critically examine the legitimacy of the knowledge we produce, whether from a marginalised position or not, in asking ourselves, and in debating with others, how our position affects the knowledge we produce, and how we through active positioning can develop the perspectives that best suit our critical purposes." Researchers need to be aware of and careful about their research questions fixing particular social phenomena as problems in need of explanation. After all, we do not see academic papers about the linguistic practices of straight people or constructing cisness on YouTube, just as we do not ask straight people when they realized they were straight or how their families reacted to it. The fact that this appears nonsensical to us implies that being straight and cis is so default, normal, and obvious that it raises no questions and requires no explanation, while being LGBTQ+ deviates from this norm, is problematic, and needs to be understood, investigated, and explained. This connects to the point made earlier about contextualizing our research subjects, with the East or the global South cast as deviating from the norm and in need of explanation while the West/global North represents the place where the "gaze from nowhere" actually comes from.

It is in this context that I appreciate Bryce Henson's (2020:325) formulation—"overdeveloped world"—which suggests that it is the West/global North that should be perceived as deviant rather than the places that we are used to calling "underdeveloped." To be really critical is to question normalcy.

My cis perspective on trans studies can complement the knowledge generated by trans scholars. I believe

that each researcher, from their unique vantage point, reveals a little patch in the great mosaic called trans studies, and only by looking at all these patches together can we arrive at a full picture of the field. It is still vital, however, that we all remain critical of our assumptions, ideologies, and blind spots and open to (even if critical) feedback from others.

## Zooming Out on Methodology

It should be clear by now that in my approach to studying social media outputs of vulnerable communities, I prioritize ethical over all other types of considerations. In this second section, I would like to discuss the methodological repercussions of such an approach by focusing on FAIR research principles and methods of disseminating data.

### FAIR Research Principles

FAIR stands for findability, accessibility, interoperability, and reusability. More and more researchers, scientists, and policymakers agree that data "used for research purposes, including those extracted from social media, should be…easily *Findable*; *Accessible* to as many as possible, in ways that are user-friendly and machine-readable; *Interoperable* to foster links with other data; and *Reusable*, i.e., easy to repurpose" (Leonelli et al. 2021:1). Accordingly, research institutions and funding bodies are increasingly requiring the application of FAIR data principles in the projects they host and/or fund.

While the development of the FAIR research principles was a huge step forward in making data more open and accessible, the FAIR framework might not be appropriate for all research disciplines and projects. For example, Sabina Leonelli and colleagues (2021:2) point out that in health-related social media

research, it "is not enough to guarantee that data collection, processing, and use are fair to those affected by these processes."They argue for making data "fair as well as FAIR," which requires "the implementation of processes of accountability, integrity, and justice as integral to the whole research process" (Leonelli et al. 2021:11). What is more, as discussed at length in the previous section, it is a misconception that the public nature of social media means that data extracted from social media can be used for research without any restrictions.

Acting according to FAIR principles, in the case of my research, would mean sharing links to, and/or content of, social media contributions of Polish transgender individuals. This would directly contradict the requirement to anonymize data discussed in the previous section. Even if social media content were anonymized and then shared, original posts could be easily found by copy-pasting a fragment of text into any internet browser (a fragment of a blog post, or a title, description, or comment in the case of YouTube videos). This forces me to actively contradict the requirements of my grant funder.

A way out of this dilemma could be to obtain informed consent from creators specifically to share their data (rather than just using them for one's research). The problem with this is that social media users unfamiliar with how academia works may not be fully aware of what this entails, even if they think and tell the researcher that they do (e.g., Tagg et al. [2016] talk about situations where research participants trust "the researcher to do no harm in ways which…often lead to their having to make decisions that extend or contradict the consent granted by participants"). It is also not clear what happens if they want to withdraw informed consent after their content has already been placed in a data re-

pository. Is there a way to guarantee that it has not been downloaded and shared further by another researcher?

To be fair, while I rely on informed consent in my current project, I also recognize potential problems that come with it. First of all, anonymization, if done really well, may protect research participants' personal data better than the informed consent route, for the simple reason that the procedure requires collecting names, surnames, contact information, and signatures and creates the need to provide a secure environment for this information. In other words, informed consent actually creates the need to collect and handle personal data in projects that would otherwise not handle them. Obtaining informed consent may also be problematic for transgender persons who have not legally changed their names yet. Is a document signed with their preferred name valid? If not, and the "deadname" must be used, this will figure in project documentation for a long period, depending on the institutional requirements for storing project data.

On the other hand, if I do not give other researchers any chance to verify my primary data, can my work be considered valid? Presumably, the goal of FAIR is not only to make research data more accessible to a wider cohort but also to make knowledge generated by academics more reliable. Granted, frameworks like FAIR seem to have been developed for, and are more suited to, "hard" sciences and quantitative studies. Creating large, expensive datasets and then using them for a study or two does seem like a waste of taxpayers' money. However, such a scenario can hardly be extended to a qualitative study in language and/or discourse-oriented studies, where material is often collected with very specific research questions and methodologies in mind.

In-depth qualitative projects in the humanities and social sciences are also highly individualized, relying on the researcher's interpretation of the material rather than constituting an attempt to find out an "objective truth" about it, and are rarely repeated or verified by others.

Unwittingly or not, hard sciences are believed to be the "science proper," and provide models for data frameworks that are supposed to apply to all academic disciplines. Arts, humanities, and social studies often struggle to be recognized as "scientific" and are endowed with less prestige and bargaining power. Academics arguing against the FAIR principles may be judged as lazy (too lazy to devise a data management plan) in the best case and as suspicious (if they do not want to share data, maybe they do something dubious with them?) in the worst case. They may, thus, feel bullied to comply against their conviction that ethics should take precedence over data openness.

**Notes on Data Dissemination**

An important concern in working with social media data is the question of whether the data can truly be anonymized. Anonymization normally involves removing any data that can lead to a person being identified, for example, names, OIs, references to places of residence, schools, workplaces, employers' names, groups, or organizations the person is a member of, among others. However, with textual social media such as blogs, Facebook posts, or Tweets, the matter is more complicated. If a quote is disseminated verbatim, that is, word for word, its original online location can be easily found using a search engine such as Google. Copy-pasting a continuous sequence of words from the quote may lead the reader to the website where it was taken

from. While certain privacy settings on blogging platforms, Facebook, and (to a lesser extent) Twitter can prevent this from happening, most blogs and public Facebook posts are discoverable by search engines. This means that no direct quotes can ever be disseminated if the priority is to keep the sources anonymous—which, of course, is in blatant opposition to the FAIR principles. Basically, it makes the piece of research unverifiable.

Quoting utterances from YouTube videos is less problematic in this sense, as they do not exist as text in the online space and are thus not discoverable. One still needs to be careful, though, when quoting video titles, descriptions, and comments from viewers, as this information can also lead to the YouTube page and thus the video in question.

Because I study Polish social media and disseminate my findings in English, in my previous work on gender transition narratives (Chojnicka 2020), I have resorted to using my English translations of the Polish posts only (without revealing the original) to avoid this problem. While this practice may be acceptable in the case of discourse analysis, it may be insufficient in more linguistically oriented studies, where the exact form in which the original utterance was made is of vital importance. Also, what if I want to write an article in Polish for the Polish audience? Using English translations as examples becomes unviable. The same applies, of course, to all research where the language of the material under study is the same as the language of dissemination of results.

Instead of thinking about this issue in terms of an obstacle, however, it is possible to use it as a challenge to come up with creative and innovative ways of representing research findings. For example, with regard to Twitter data,

> [i]n cases where consent is not provided to direct quote without anonymisation, Markham (2012) advocates a bricolage-style reconfiguration of original data that represents the intended meaning of interactions. This can include creating composite accounts and posts by selecting representative elements from the data and composing a new original that is not traceable back to an identifiable individual or interaction. Such a reconstruction is accomplished via close attention to context, to avoid the loss or change of meaning…While this may be suitable for general thematic analysis, it may not satisfy the needs of more fine-grained approaches, such as those undertaken by interactionist scholars. [Williams et al. 2017a:1162]

In my work, which focuses on gender transition narratives that are to a large extent multilingual (which range from Polish gender and sexuality-related terms that are borrowings or calques from English to engaging in code-switching/translanguaging), I am to develop innovative dissemination strategies that reflect these multilingual and translanguaging practices. This will allow me to protect my sources while remaining as faithful to them as possible, at the same time hopefully giving the target audience a better idea of what such texts are like and also engaging in the deconstruction of "proper academic writing" in English as the language of global knowledge production (as mentioned before). It is a challenge I am working on (and through) at present.

## Conclusions

I realize that this article probably raises more questions than it provides answers. My goal was not to offer ready-made solutions to the issues mentioned but to encourage researchers to think and reflect on the ethics of qualitative social media studies and how they interact and possibly interfere with established methodologies.

While it may be legal to study and reproduce publicly available data, it is not necessarily ethical. Anonymization of data is an absolute minimum, increasingly expected by ethics committees, and I would not be surprised if legal frameworks were moved in that direction in the near future. Asking social media creators for informed consent to use their content for research is a matter of human decency. This may not be possible in the case of large quantitative case studies, but they have the advantage of being able to present data in aggregated form, while in qualitative research, it is more common to quote social media content verbatim.

It should also be emphasized that, in some cases, informed consent may not be enough. Once social media content is used for research and disseminated, its creator has even less control over what happens to it and who can access it. It is, thus, the researcher's responsibility to anticipate the possibility of misuse of research findings and find a way to mitigate that risk even after obtaining informed consent. The more vulnerable or sensitive the research participants/subjects are, the more care and thought must go into this.

Probably most social media creators do not post with researchers in mind and that is perfectly reasonable. We are frequently reminded of how nothing really disappears online, how you cannot really remove anything from the internet once it has been uploaded (e.g., Ot 2022). This usually brings up a sense of dread in us, but is research not very similar? People post thousands of statements, photos, videos, and other content online throughout their lives. Sometimes they post happy, sometimes they

post sad, disappointed, outraged, depressed. While they grow, mature, and change, their older posts stay the same. It is quite random which of these posts, if any, will ever be "immortalized" in a research paper and taken to represent them in some way, even if they no longer are the people they were when they posted them.

All this holds true for any social media user, but even more so for a member of a vulnerable community. Additionally to all the other difficulties defining a vulnerable community discussed in this article, whether or not someone should be considered vulnerable can also change. A YouTuber who posted for years as a man suddenly comes out as trans and starts posting as a woman. Should we treat her posts before and after coming out differently? If she had permitted us to study her posts before coming out, would this permission still apply? It should always be the researcher's responsibility to think about all these issues and try to anticipate possible problems before they occur. In five, ten, or twenty years, we will probably have developed a completely different ethics of social media research—but our papers from today will remain the same forever.

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## Citation

# Appendix

| TABLE 1 | vulnerability mentioned? | location mentioned? | situation problematized? | direct quotes/ links/ OIs given? | pseudonymiza- tion/anonymiza- tion? | informed consent mentioned? |
|---|---|---|---|---|---|---|
| Alexander 2002 | no | US | no; discusses online queer politics but no connection to the 'real world' | yes | no | no |
| Sundén 2002 | no | no | no | yes | yes | no |
| Mitra & Gajjala 2008 | no | South Asian/ Indian diasporas | postcolonial/racist/homophobic/ hetero-normative context; history of Indian gay movement | yes | no | no |
| Heinz 2012 | no | Germany, US, Canada, Austria | yes, but globally (unspecific) | yes | no, but gated access excluded | no |
| Dame 2013 | yes | US, Canada | no | yes | unknown* | no |
| Marwick 2013 | | | | yes | no | no |
| Horak 2014 | yes | no | no, only concerning mainstream representations of trans people | yes | no | no |
| O'Neill 2014 | no | no | mentions previous works on bullying and stigmatization of trans youth in the UK | OIs of 'celebrity' YouTubers | no | no |
| Wotanis & McMillan 2014 | | | | yes | no | no |
| Raun 2015 | no | no | no | yes | no | no |
| Dhoest & Szulc 2016 | yes | Belgium | yes | does not apply | yes | yes |
| Jenzen 2017 | no | UK | yes, but in very general terms | no | yes (FG) / no (YT) | yes |
| King 2017 | yes | New Zealand | yes, very extensive | does not apply | yes | yes |
| Miller 2017 | yes | no | very general (transphobia) | yes | no | no |
| Miller 2019 | no | no | only in terms of transnormativity | yes (YT only) | yes | yes |
| Raun 2020 | yes | US | yes | yes (YT only) | yes | yes, but not obtained |
| Spallaccia 2020 | | | | yes | no | no |
| Martino et al. 2021 | no | no | no | yes (YT only) | yes | no |

* Uses "subjects' names," but it is unclear whether they are real OIs or pseudonyms.

*Source: Self-elaboration.*

# "Am I Going to Die?" Considering the Preparation for Research on an Example of Hospice Patients

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**Keywords:**
Hospice; Patient;
Dying; Research;
Ethical Issues

**Abstract:** This article concerns the situations experienced by the researcher in one of the sensitive research groups—hospice patients. The article is based on the author's experiences in three studies in Poland—94 in-depth interviews and observations in inpatient and home care hospices. Through the seven presented categories the author faced during the interviews, she analyzes the dilemmas of conducting qualitative research from a practical perspective. During studies, we learn about our preferences, sometimes defining ourselves on one of the sides—becoming a quantitative or qualitative researcher, thus deciding further scientific paths. Conducting qualitative research requires specific activities, including knowledge of the literature, selection of the proper method, and analysis of the research group (Silverman 2012). These principles turn out to be only the beginning of the process in which we intuitively, through trial and error, pave the way to deal with demanding situations, previously inexperienced emotions, coordination, and technical and ethical problems. Some studies require special preparation, particularly considering the specificity of certain research groups, such as hospice patients, who will face the dying process soon.

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## Throw into the Deep End or Just Research as Usual?

At the end of one of the interviews at the inpatient hospice about the social construct of femininity, a patient in her 50s (cancer with metastases) asked me if I could recommend what dress she could wear for her godson's wedding, which was to take place in two months. She spoke a lot about that upcoming event with great excitement. She wanted to look beautiful to hide the physical effects of the cancer (especially the ostomy pouch, which occupied a large part of the patient's abdominal surface). I advised her, and we talked about various details of the outfit and how much the patient waited for the family to see how beautiful she looked despite cancer. The patient died in a week.

Learning the methods of conducting qualitative research (without diminishing the knowledge contained in methodological manuals) is really just the tip of the iceberg of what a researcher who wants to interview vulnerable groups, including hospice patients, will face. Most of the knowledge on how to conduct research is obtained by the researcher through experience, observations, and conversations with the hospice's interdisciplinary team, families, and relatives of patients. It is not without significance that the researcher experiences their feelings and reflects on what has happened and what this situation can give, and, unfortunately, we will not read this in methodological manuals or guides on how to conduct qualitative research.

The article describes research experiences in a group of hospice patients, but it is also an invitation to discuss research with other sensitive groups. Hospice patients seem to belong to one of the most sensitive research groups, as they will soon face death, and perhaps they can already feel it is breath-ing behind their backs. This makes it a challenge in the context of research preparation (methodological and ethical) to talk with dying patients. It requires ethical preparation from the researcher, including taking into account the sometimes rapidly changing well-being of the patient due to pain or difficult memories appearing in the mind, the ability to listen carefully, and paying attention and caring for the researcher's well-being and feelings. The article aims to show and analyze real situations that the researcher has met during almost ten years of interviews and meetings with hospice patients, as well as to answer the questions on how to help researchers prepare before the fieldwork and what the researcher should expect or avoid.

## Hospice Care—Its Impact on Patients' Everyday Life and Conducting Research

The concept of hospice care arose in the 20th century in London, creating universal principles still respected and developed worldwide (Osterweis and Champagne 1979; Magno 1990). They may vary between countries in the forms or methods of providing medical and non-medical hospice services, but the core of the idea has remained unchanged. Differences in forms of care usually result from the culture and prevailing medical system in which the dying patients are found (Doorenbos and Myers Schim 2004; Fosler et al. 2015). Hospice care belongs to the broader concept of palliative care and is its last part (Billings 1998; Hui et al. 2013). It is started when not only the undertaken anti-cancer therapies are ineffective for the patient but also the patient's condition (wasting of the organism or progressive effects of the disease) is defined as impending death, most likely within the next six months of the patient's life (Buss and Lichodziejska-Niemierko 2008; Yenurajalingam and Bruera 2016). Hospice care is focused on providing patients with, above all, multi-level

comfort—holistic care (Rickerson et al. 2005; Torpy, Burke, and Golub 2012). The patient's support, according to the guidelines of the National Health Fund in Poland, includes the control of pain symptoms, support in hygienic and care activities, as well as help to meet non-medical needs of patients (religious, spiritual, emotional, social, and psychological aspects). The comprehensive help provided in this way is intended to support the patient in a new and difficult life situation.

In Poland, hospice care is provided in one of the two main forms of care—inpatient and home care (Ersek and Carpenter 2013). Inpatient care is the placement of the patient in a hospice facility. In that way, patients are under the care of staff at all times. Inpatient care is usually primarily dedicated to patients whose physical condition requires constant monitoring and help. As part of this type of care, the patient can call for help at any time by pressing a 'button,' and then a person will appear within a noticeably brief time. This often gives patients comfort and a sense of safety. On the other hand, it deprives patients of privacy—they are constantly with 'others,' which is also compounded by the fact that hospices in Poland have rooms for several people. Because of this, patients often compromise when they need to watch a different movie than their companions or want to turn off the lights when other patients would rather read a book. It is even difficult when other patients who stay in the same room are visited by relatives, as this can generate discomfort, sadness, or frustration if other patients are not visited often.

The specificity of the place also affects interviews with patients. To be able to come to the facility, the researcher always called the hospice employee who previously agreed to cooperate in starting the process. However, it often happened that when the researcher arrived on the spot, the patient's family was visiting. To not interfere in the meeting, the researcher started another interview with a different patient and returned later or conducted the interview at another suitable date. On one occasion, a patient was so excited about the upcoming interview at the agreed time that when the family unexpectedly visited the patient, the patient was angry at the family because, at that moment, she was focused on the interview, which put the researcher in an awkward situation. If there were more patients in the room at the time of the researcher's arrival, then, with the consent of the staff, the patient was offered a conversation in a gazebo, meeting room, or chapel (which was often a meeting place for the patient with a relative to have a private place to talk). Occasionally, there were patients in the infirmary who were unconscious or with a significant loss of awareness of place and time. At that time, the hospice team, including a psychologist, told the researcher that she could conduct an interview in the patient's room, and sometimes patients also liked staying in the room. During the interview, however, it happened several times that the other patient started talking to herself, calling out, and seeming to be talking to someone. The interviewed patient said that she got used to it, while the researcher had to make an effort to concentrate on the interview and not feel that the other patient needed help (the subject was also discussed with the interdisciplinary team).

In one hospice, the nurse took the researcher to the patient's room, who agreed to the interview. The researcher stayed with the patient in the room and started to talk about standard procedures related to data protection and archiving of research material. At one point, the patient looked at the researcher, exhaled, and froze. The researcher tried to ask the

patient a question, but seeing that he stopped moving and breathing, she ran to the nurse. It turned out that the patient just decided to play a trick, finding a good moment for it, and when the nurse came, he started talking and joking with both. The interview was successful—the patient told the researcher about how he was dealing with the impending death and about his relationship with his wife. This interview, however, was much more important, as a clever joke turned out to start the researcher's reflections on what would happen if the patient died during the interview or if he died living alone in a home care during the interview. Although such a situation has not happened for so many years, it does not mean it could not have happened, which still raises big ethical dilemmas and fear.

Home care is dedicated to patients whose condition allows for independent functioning to a considerable extent or who can rely on family caregivers. At this point, the hospice staff visits the patients twice a week to prepare a proper dose of medications, take medical measurements (e.g., blood pressure or sugar level), as well as to make sure whether patients need any help, including non-medical support (Terrill et al. 2018). In Poland, in hospice home care, if necessary, the patient can also be visited by a psychologist cooperating with the hospice and a priest. The hospice provides medical support and helps with the rental of medical equipment if needed. However, patients' free time during the day is determined by their sources (e.g., housing and financial conditions and support of relatives) (Abramson 2016; Carr 2016). However, if patients' socio-economic status (SES) is low—with a limited budget that allows them to meet only basic needs—and they also live alone, the quality of life during home care may be unsatisfactory for the patients (Carr and Luth 2019; Clouston and Link 2021; French et al. 2021). The is-

sue of security is also important here. In the case of home care, the patients can call the hospice staff in an emergency, but they do not have the comfort that someone will appear at that very second (as in inpatient hospice). Thus, the risk of home accidents is much greater, especially if the patient lives alone (Oliver et al. 2013; Smucker et al. 2014). Another issue is the feeling of loneliness—if the patient's relatives live far away or, due to their private situation, they cannot visit the patient often, this generates a sense of fear and loneliness, which may even intensify thoughts about death. Often, only visits by the hospice staff several times a week are not enough for the patient to reduce the feeling of loneliness.

Interviewing patients in home care looks slightly different. A crucial factor in conducting research is the safety aspect—for both the patient and the researcher. When patients invite a researcher to their home, they show great trust in both the staff and the researcher. Not knowing the researcher can cause discomfort, especially as some of the effects of the disease may make the patient appear weaker and more vulnerable in relation to the researcher. While conducting interviews in Poland, the researcher did not receive any preparation from the hospice about the risk of violence and the prevention of dangerous situations, which would result in protection for all groups (including personnel who agreed to the researcher's contact with the patient). It relied solely on mutual trust between all groups, which initially caused uncertainty, especially when the patient lived in an unsafe neighborhood, or the meeting was held on the outskirts. It often happened that the patient's family stayed in the other room. Sometimes patients in home care, to feel more comfortable, asked if the family could stay with them during the interview. At that time, the researcher assumed that the feeling of comfort in this situation was a prior-

ity, and if the presence of a loved one did not affect the patient's statements and the patient felt good to answer questions in front of a relative, then the researcher would respond to the patient's request. It was less safe when the patient lived alone. This triggered a first fear in the researcher that taking morphine would cause effects on the patient, who could behave differently or might potentially need medical help.

## Conducting Research and Its Ethical Dilemmas

These considerations are based on the researcher's experiences of conducting interviews in home care and inpatient hospices. For the analysis of the discussed phenomena, projects carried out in hospice care by the researcher were taken into account, which concerned conversations about patients' everyday lives, life experiences, identity constructs, or psychosocial needs of patients during hospice care. In this article, the author discusses collected experiences and events that significantly influenced the conducted research. It is therefore a collection of the researcher's reflections from the perspective of practical research among hospice patients. It should be noted that all interviews were conducted only by the researcher. So far, 94 interviews carried out in hospices in Poland in 2013 have been conducted with hospice patients of various ages (from 26 to 98 years) and with different SES. All interviews were conducted with the consent of the hospice management. The study involved patients whose disease state allowed them to talk freely and who agreed to the researcher's visit. During the interviews, patients could stop the conversation or pause at any time—about which they were informed before the interview, along with information on the purpose of the study and the form of data storage.

Despite the differences in age or the place of conducting the study, many situations during the researcher's contact with patients were similar and may be grouped into seven categories: *Building trust*; *Gestures and hugs during the interview*; *The appearance of the patient*; *The physical effects of the disease*; *Fainting, asking for help*; *Coordination of research with a sensitive group*; *Seeking reassurance and truth about the situation*; *Re-contact with the patient, commitment, and showing feelings*.

### Building Trust

What information the researcher obtains during the interviews is often determined by the extent to which they will gain the patient's trust (Jemielniak 2012). Building trust with the interviewer as a guideline may seem at first glance to be disingenuous in building a relationship (as it is necessary to achieve the intended goal). However, it is an important guideline if the researcher takes it seriously, as it determines what can be learned during the interview (Barbour and Schostak 2005; Dempsey et al. 2016). Building trust must, however, take place through the sincere intentions of the researcher because the patients can 'sense' the researcher's intentions and whether they care about getting to know the reflections and situation of the patient or if it is related only to the study conducted. It happens that during the interviews, the patients tell the researcher that they have never told anyone about certain emotions, and the researcher is the first person to hear about it. The researcher's assurance of the anonymity of the interview and the removal of information details that could cause someone to recognize the patients make them more open to sharing even the most sensitive and private life situations. Sometimes, a patient, feeling the researcher's sincere intentions, asks the researcher to use a specific quote from the

patient's statement in a future article, which gives the patient a feeling that what they say is important and will be noted and remembered. It is sometimes salient for the patient and can bring relief in a situation of imminent death—*Because this is a story worth telling everyone.*

A principal issue in building trust during the interview was the encouragement that the patient may also raise topics that, in their opinion, are important and which the researcher may not include in the questions. It gave the feeling that the patient could also feel involved in the interview and not only answer the researcher's questions. After the opportunity to tell the researcher everything important to the patient, they can also feel that what was said was gripping and important for the researcher. It sometimes happened that the patients, even after the interview, asked for a moment of conversation with the researcher to say something else, or during the next visit, they gave the researcher notes about life in the hospice, thus feeling that they were fulfilling a 'quest' for the researcher to get to know even more pieces of the reality of life in a hospice: *This is homework for you. These are the notes that I took daily when communicating with staff and other patients.*

Such gestures show how much trust building is salient not only for the researcher but also helps patients—they begin to feel that they can be guided in the context of reality, through which the patients had the impression that it deprived them of self-determination. It also manifests the important role of feeling to be heard.

### Gestures and Hugs During the Interview

Hospices are places where, apart from medical support, emotional, psychological, and spiritual help is also important. As a result, in hospices, there are often different relationships between staff and patients, much closer than in hospitals or other medical facilities. Patients can always count on words of support or hug people with whom they have contact. Both in the US and Poland, it has been seen that touching the shoulder or hugging are essential elements in contact with a hospice patient. It very often happened that during the interview, the patient needed to touch the researcher's arm or hug her at the end of the interview. On the one hand, the patients were used to this expression of emotions, and, on the other hand, these situations proved that during the interview, the patient felt that the researcher was an important person at that moment. This feeling was also intensified by the fact that the patient often shared with the researcher important personal thoughts, and the hug was a 'thank you' for the meeting, emphasizing the importance of the interview for both of them. However, it was seen that the expression of emotions was much greater for female patients. Female patients were more likely to hug the researcher, whereas male patients were much more reserved about expressing their feelings, reducing them to gestures such as grabbing the arm. Not sharing this kind of gesture by the researcher could cause a feeling of incomprehension by the patient or even a feeling of rejection, thus affecting the patient's well-being. Perhaps the female gender identity played an important role in referring to the researcher in this way—if the researcher had been a man, maybe the patients were not so willing to hug, and the relationship between the researcher and the patient would have been different. This is undoubtedly a topic that needs to be explored further in further research.

Knowledge of the rules of the culture of the place can significantly affect the creation of trust and rela-

tionship with the patient and can also help avoid potential misunderstandings or unpleasant situations. When entering the research field, it is worth asking people who introduce us (e.g., nurses or psychologists about their contact with patients and what the researcher can expect), which will help in preparing for interviews.

**The Appearance of the Patient, the Physical Effects of the Disease**

Hospice patients sometimes have visible physical effects that their disease has left on them. Before starting research on a specific research group, the researchers must ask themselves whether they are afraid of views related to body deformities, lack of a limb, or visible wounds. Lack of reflection on this situation before starting the study can cause unpleasantness for both the researcher and the patient. One of the patients told the researcher that once, during bath time, a volunteer helped with these activities. Looking at the patient's wound, the volunteer vomited. From that moment on, the patient was afraid of further contact with volunteers, even during other situations (apart from hygiene procedures), such as spending time together in the garden or watching a movie. The patient said that this situation made her wonder if it also disgusted other people, and for some time, she began to isolate herself from people in the hospice.

Patients who are aware of changes in their appearance tend to be sensitive to how they are perceived by the environment. One of the patients had an extensive tumor covering a large part of the face, which meant that during the day, the patient had to hide defects in the skin (no cheek and lack of parts of the nose and mouth) under a dressing. The patient said he knew perfectly well when someone was disgusted with his appearance, dodged to sit next to him, or did not want to look at him. The observation of the patient that the researcher was unconcerned about his physical defects was a relief for the patient and made him freely express his emotions or talk about how he coped with the physical effects of cancer and impending death. Interestingly, seeing that their condition did not make a negative impression on the researcher, the patients often directly communicated to the researcher their surprise, telling about the unpleasantness they experienced from other people in the context of their physical appearance. Concerning the patient's sense of social isolation, it was especially important for the patient to find someone who treated him as if he looked like before the disease as if his visual appearance did not matter.

It also often happens that patients treat the researcher as a specialist and a person with whom they would like to share literally everything in the context of the disease. There were many times when the patient showed the researcher a stoma pouch, an unhealed wound after an amputated limb, or fresh cavities after surgery on the patient's head. Patients showed their wounds to express more clearly what they must face and how much physical ailments determine their quality of life. There were also situations in which the patient checked the current content of the catheter bag in front of the researcher or the level of the exudate from his wound on the abdomen. It also happened that the patient spat out various secretions into the bag or container. These situations happened without prior information from the patient, so the researcher could not be prepared. The researcher was often treated by patients as part of the hospice team—who, with the patient's consent, referred the researcher to a meeting at the patient's home or in an inpatient hospice. Therefore,

accustomed to the fact that their situation did not require any embarrassment in contact with the hospice staff, they did the same with the researcher, treating her as part of the hospice team. Moreover, perhaps they even felt obliged to show the researcher the whole situation of their illness and ailments as an essential part of their everyday lives (they assumed it was an important part of the study).

In this context, the information from the staff about the patient's specific physical condition was helpful for the researcher to prepare her so she could 'get used to' what she might expect before the visit. During long-term cooperation with the hospice staff, it sometimes happened that the staff asked the researcher whether she would like to talk to a specific patient if the nurse or psychologist thought that the patient's condition could somehow adversely affect the researcher.

**Fainting, Asking for Help**

During the study, the researcher should constantly be aware of the nature of the research group and the consequences that the patient's condition may have. Patients in hospice care are often in a condition that can change rapidly or involve sudden alarming situations. Even when the staff stated that the patient's condition was adequate for communication with the researcher and the patient has agreed to meet the researcher, there are situations when the patient may faint during the interview. Then, the question arises as to how the researcher should react. Without medical education or voluntary training, it is difficult to have the reflex to help a patient when it unexpectedly happens. The researcher usually does not know how to help, what the help should look like, and what help the researcher can provide (or whether they should help). It is also important where the sit-

uation takes place. In a facility, the researcher has the comfort that, in case of an unexpected situation, she can count on the staff's help—she can call someone at any time, who will be able to react quickly. During the interview, the patient lost balance several times while walking or standing up. Each time, the patient was grasped, or the patient leaned on the researcher's arm, which prevented a fall. If there was a situation where the patient fell, it could be difficult for both of them and cause remorse in the researcher and fear that something could have been done differently. There were also times when the patient dropped a cannula, part of the drip mechanism, or other medical equipment during the interview. At such moments, the researcher was asked by the patient if she could put the mechanism back in. Fortunately, due to the researcher's parents' profession, she knew that she had no right to help the patient in such situations because the wrong application of the equipment could cause the patient's death. However, it is unimaginable if the researcher did not have basic knowledge about helping the patient and wanted to interfere with medical equipment even with a sincere willingness to help. Another quite specific ethical situation during interviews in inpatient care was that in the case of bedridden patients, with whom it was impossible to have an interview in the living room, patio, or chapel, there were other patients in the same room. Although they were at such a distance that allowed them to talk freely with the researcher (sometimes patients were additionally separated by a screen), in the case of the confused and problematic patients, they made communication with the researcher difficult. For example, there have been occasions when another patient lying on the bed started screaming frightfully. It was often an inconvenient situation. Initially, the researcher asked the patient whom she interviewed what action was usually taken. When the patient said that

this was normal behavior of the patient and the nurses asked him not to call in such a situation, the interview was continued. However, it happened that the situation was sudden, and the confused patient showed pain or anxiety in a way that required the researcher to call a nurse to administer proper medications to the patient. Such situations cause fear and confusion—what was normal for the staff and did not require any intervention from the researcher often was a patient's cry for help, and the information about ignoring the patient's screams and continuing the interview was awkward and gave the researcher a feeling that she must do something or help this person. On the other hand, it also required concentration to continue the interview with the patient during the screams of another patient and to focus on the interviewed patient then so that they did not feel that what they were saying was ignored. Often, to ease the event, but also to not leave the situation without discussion, the researcher asked the patient about their comfort in the room, relations with other patients, or what every day in the room looks like. At that time, patients often talked about their relationship with other patients, sometimes saying that they took the role of a mediator or caregiver for the patient in their contact with the staff, or they said that sometimes the patient begins to communicate with them. Directing the conversation in this way blurs the first awkwardness in the researcher and patient about the other patient and causes further focus on the interview.

**Coordination of Research with a Sensitive Group**

Conducting research with a vulnerable group must include undertaking a specific research concept—including a material collection plan. Usually, when the researcher determines the next research steps, they have to define a timeframe for conducting the re-

search. The researcher also wants to have an impact on figuring out the coordination of the interviews, as it also affects the reconciliation of project activities with other scientific or personal life of the researcher. The specificity of research with hospice patients can cause the researcher to not predict when the interviews will be finished, which requires setting up a time reserve for this purpose. What is more, the researcher cannot predict whether, by arranging several interviews on a given day, she will conduct any. The ethical aspect is significantly bound to issues concerning finding contact with the patient. For example, the researcher was going for interviews at an inpatient hospice several dozen kilometers away from her place of residence. She was informed that three patients had initially agreed to contact and that it would be best to come to the facility within a few hours. In the facility, however, it turned out that one of the patients experienced intense pain, the other fell asleep, and the third felt bad at that moment. It should be remembered that during the research with patients in a hospice, respect for the patient and their situation (illness or imminent death) is the most important. Apart from asking about the possibility of conducting the interview, the researcher has never encouraged the patient to the interview, ensuring that the interview would be nice or short, as it would violate the ethics of conducting interviews. Such situations occur most often in inpatient care. Getting used to the fact that the joy of the information about the interviews can turn into disorientation and sadness when, after arrival, there was no way to do any, helped to understand the differences in hospice care. Inpatient hospice is usually for patients who, for several reasons, cannot stay at home. In this context, they often have deteriorating health conditions requiring 24/7 monitoring by staff. Thus, by definition, the facility includes patients with more severe, rapidly changing health conditions. Realiz-

ing this resulted in a lack of focus on conducting a certain number of interviews during the stay in the hospice. However, there were also situations where, after the researcher arrived at the hospice, another patient, hearing that it was possible to talk to the researcher, reacted with interest, asking for details and consented to the interview.

The researcher can intuitively get the impression that in inpatient care, due to a large number of patients in one place, this part of the interviews can be conducted much faster than interviews in home care. Still, it was influenced by so many factors (a large number of patients in very poor condition, time of the day of the interviews [evening interviews usually did not take place, but only those conducted in the morning], season, or the upcoming holidays) that this was not the rule. There were places where the researcher conducted five or six interviews at one visit, but usually these were smaller numbers. It should also be noted that the topics and experiences of patients may be significantly burdensome for the researcher, which, with many interviews, could be even more aggravated. This could affect both the quality of the interviews and the well-being of the researcher after leaving the hospice. Contrary to inpatient patients, in-home care pre-arranged interviews were not conducted in only a few cases—they were usually postponed to another day at the patient's request. As mentioned before, home care patients often did not need round-the-clock care and were also in a condition that allowed them to continue their daily activities or duties from the time before the disease. Due to this, when scheduling an interview in home care, they were usually carried out the first time without interruption. Perhaps it was also influenced by the fact that by inviting the researcher, the patients had a sense of responsibility or obligation for the meeting to take place.

The researcher's mobility and allowing herself to appear as soon as possible were of immense importance in planning interviews with patients under the care of the hospice. As mentioned previously, it was seen that at certain times of the day or seasons of the year, the interviews were almost non-existent because the patients were more occupied with visiting their family and daily duties, or they felt tired. Regardless of the researcher's will, if she had not been able to show up quickly, the interview would not have happened. Two issues arise in this context. If the researchers want to conduct interviews in hospices, they must be in constant contact with the designated staff member. Refusing to visit a patient several times who initially agreed to meet with the researcher would undermine the trust of the staff member and the researcher could expose the patient to sadness, who, after being informed about the possibility of an interview, could impatiently await the researcher's presence. There is an opportunity to set up availability, but the researcher would not have a guarantee that someone would agree to the interview at that time. The help from the hospice staff is a huge favor and should not be abused.

Healthcare research was significantly influenced by the COVID-19 pandemic. At that time, hospices changed their rules about visiting patients by their relatives or contacting volunteers, which has always been an immense value of hospice care. Relatives were only able to bring things to patients, which were then quarantined. Relatives contacted patients only by phone or video calls. Sometimes it happened that relatives could see the patient through the window glass in the patient's room. Even in the situation of the patient's active dying, the family could not be with them in these last moments. The pandemic also inhibited the possibility of conducting scientific research in direct contact with the patient or visiting

medical facilities. This resulted in the inhibition of new scientific research, as well as the interruption of existing ones. Initially, the researcher offered the hospices the possibility of conducting interviews in the same way as family meetings—via a video chat, but, due to the inconvenient situation, stress, constant fear, and added duties of the staff, cooperation was refused until the number of COVID-19 infections was reduced and restrictions lifted. Even when the statistics of new cases decreased and the isolation ended, the return to research was slow, and maximum precautions were needed each time when contacting patients—protective masks, temperature check, keeping distance, or conducting an interview outside the facility, in the open air. Some hospices, even for a long time, despite the possibility of visiting relatives and restarting volunteering, were not favorable to scientific research due to the safety of patients.

**Seeking Reassurance and Truth about the Situation**

During the research, some patients were not fully aware of how serious their health condition was. Sometimes, they consciously dismissed the disturbing signs about the possible bad ending of the neoplastic disease. Even though the patients knew what the study was about and what the researcher was going to be asking, they sometimes seemed to be deliberately ignoring the fact that their death was imminent or that it could happen at any time. Some of them, as mentioned in the introduction to this article, talked about their plans for the next months, giving them importance and waiting for these events. During the interviews, the following principle was followed—not to cause strong (especially negative) emotions in the patients and not to reveal information to the patients that may adversely affect

their condition and well-being. Therefore, if the patients were convinced that they would return home soon and were occupied with what they would do then, the researcher did not move them out of this state. Initially, the researcher struggled with the sense of meaning in the research and doubts whether to research a group of hospice patients. However, the understanding that in this way patients try to take part in the present reality, or they begin to define the world in their own way, the researcher realized that this is their way of dealing with reality, regardless of how patients understand it and how do they want to understand it (what thoughts and information they admit to each other). The most morally painful for the researcher, however, was when the patients tried to involve the researcher in conversation about their plans—when they asked the researcher for advice on clothes, decorations, or opinions about the painting they wanted to buy and hang after coming back to their home from hospice. The awareness that the patient's plans would not come true, which the researcher had to hide, was very painful. Especially when, during later visits to the facility, it turned out that the room where the researcher talked to the patient a few days ago had another resident (the previous patient died). An example of this is a woman in her thirties who told the researcher that she wanted to gain strength in the hospice to help her parents organize the Holy Communion of her 9-year-old daughter in May. The sight of another patient in the room where the patient was lying before will always be painful.

Sometimes, even though the patients are aware of the impending death and talk freely about it with the researcher, the feeling of empathy for the information they hear can cause many emotions in the researcher. One of the patients told the researcher that before the interview, he had been in a shop

to buy his youngest grandson a bicycle and teach him how to ride a bike. The patient was aware that he had little time left, but expressed the hope that, at least, he could give his grandson this bicycle as a gift. Then he said that he was not afraid of death but of how his son and daughter-in-law would be able to explain to the patient's grandson that his grandfather was dead.

During the research, there was a group of patients who had not been informed by their relatives that they were in a hospice and that they had already completed cancer treatment. It often happened that the researcher was informed about this fact before the meeting with the patient. The patient's family would then notify the researcher in the corridor of the facility or at home, asking the researcher to not use the word "hospice." Putting the researcher in such a situation caused an ethical dilemma about the rightness of starting the interview—abandoning the patient who waited for an interview could constitute a greater ethical issue. Reflecting on such situations, however, it was noticed that these patients are also an important part of hospice care, regardless of whether they were informed that they were under the care of a hospice or would receive such information somehow from their family. Even though the researcher was allowed to ask the prepared questions, she felt stressed each time to not accidentally reveal to the patients that they were under the care of a hospice. During one of the visits to an inpatient hospice, the researcher was introduced to the patient by a hospice psychologist. At the beginning of the interview, the patient asked the psychologist directly: *Am I going to die? Because here you must wait for death, right?* As it turned out during the interview, the patient recently discovered that she was under the care of a hospice, and perhaps through that question, she wanted to be assured about her sus-

picions about the truth of her condition. The patient received real comfort from the psychologist and, at the same time, information that her condition may bring death, but it may be a closer or very distant event. Another patient, ninety years old, talked about her life, mentioning her grandchildren and great-grandchildren during a conversation with the researcher, then looked at the researcher and said with tears in her eyes that she did not want to die, thus shedding a few tears. In such situations, the researcher tried not to continue the topic but to leave the patient a decision at what point they wanted to stop talking about unpleasant emotions, so they did not feel ignored when opening up to the researcher. It was a solution tested by the researcher several times, and she received many thanks from patients who were surprised that, for the first time, someone wanted to hear them. At that time, patients often called the interview a kind of catharsis—cleansing of all thoughts and fears, which, due to their condition, they had in themselves and which, for assorted reasons, they did not want to expose during conversations with their relatives or hospice staff.

**Re-Contact with the Patient, Commitment, and Showing Feelings**

A big dilemma was the risk of engaging in contact with the patient through the patient's life history. A psychologist from one of the hospices was also consulted on this matter. She did not see any contraindications for contact with the patient after the interview if the patient expressed such a willingness, although, as the psychologist noted, it should be considered whether such contact would be burdensome for the researcher. It was, therefore, concluded that it would be best for both sides to re-contact at the facility only with a warm welcome. As a result, neither the patients would feel uncomfortable know-

ing that they were talking to the researcher about private stories and reflections, nor the researcher, considering her role (professional approach to being a researcher) but also her protection against the patient's death. Engaging in relationships with patients during interviews to receive information about their death would be a difficult experience for the researcher. In this context, it was also avoided when talking to the staff to not accidentally find out that the patient was dead. It was different in the case of interviews at the patient's home, where the researcher visited the patient only once, which made it possible to avoid uncomfortable or sad situations.

Another doubt during the interviews was the issue of showing/not showing emotions by the researcher. This raises questions of: 1) patient protection; 2) research professionalism; and 3) the researcher's expression as an individual feeling emotions back. Not showing emotions (or not overexposing emotions), the researcher would protect the patients so they would feel comfortable during the interview. This protection is also intended to prevent patients from generating many emotions that could cause them distress and incite the risk of leaving the patient alone with these reflections after the interview. Expressing the researcher's emotions or shedding a tear could cause the patients to be confused. On the other hand, it could cause a sense of guilt in the patients that they exposed the researcher to negative emotions, or the patients might realize that what they were telling was even more sad than they might think, which would escalate their malaise about health condition and imminent death.

Not showing emotions can be perceived as professionalism and preparation by the researcher. Self-control may allow the researcher to fully concentrate on the situation of the interview and the patient, whose reflections are very important to the researcher. On the other hand, the conscious blocking of emotions can pose a threat—suppressed emotions can cause frustration, but also a sense of guilt. They can affect the well-being of the researcher. In this context, in conducting qualitative research with a sensitive group, it becomes necessary to prepare the researcher to work on emotions, especially those with which the researcher deals during the interview with the patient and which they feel (or may feel). In conducting research with hospice patients, many different emotions can appear during one interview—from joy to crying and fear. These emotions often also have a feedback effect on the researcher who, experiencing them with a certain intensity, without being in the patient's situation, has to deal with them.

## Summary and Invitation to the Discussion

As shown above, when researching with a group of patients under the care of a hospice, the researcher must not only have workshop skills allowing for independent work on the research. The established principles of research methods turn out to be highly insufficient. When working with a sensitive group, it comes to light that the researcher's soft skills, knowledge of the environment, and preparation for the specific situations of the selected research group are equally important. Moreover, these skills can sometimes be deciding factors in whether the study will continue. The examples presented above show that the response to certain situations must be learned, and sometimes it is also necessary to 'get used to' the environment the researcher enters. If the researcher had prior knowledge of what to expect, they would know how to influence the comfort of both the patients and their own during the

interview. Then, many worries or stresses that arise during and after contact with the patient could be avoided. The discussed experiences appeared over the years of research work in the group of hospice patients. When the researcher was convinced that nothing more could surprise her during this type of project, something appeared that forced the researcher to stop and wonder why it happened, why the researcher felt such emotions at that moment, and what could help in such a situation. It should be emphasized that this is not a complete list of experienced situations—there were more. However, it is a description of the most common or difficult events that the researcher had to deal with. The selected examples aimed to show what situations, in the researcher's opinion, can help students and researchers who intend to start this type of research.

Hospice staff often see the researcher as a professional. A person who can handle any information they receive during her stay at the hospice. By this, staff can 'sense' if the researcher is 'their' person, if they can speak the language of the industry, and if the researcher understands the 'codes' used by the staff. The interdisciplinary team usually assumes that since a researcher deals with the research about hospice patients, they have basic knowledge not only in their discipline but also of patient care. Communicating with the jargon characteristic of hospice staff can help not only to better understand the reality of their work and place but also ease setting up relationships.

The presented situations raise questions about the validity of researching a sensitive group of hospice patients. Some authors analyzed from the methodological or ethical perspective the rightness of investigating hospice patients. Among the doubts, respect for the situation of approaching death was analyzed (Raudonis 1992). Clarification of moral issues was also important, including the use of patients to obtain research material and who is to decide whether a patient can participate in an interview (Addington-Hall 2022). As Sandra Pereira and Pablo Hernández-Marrero (2019) note, "excluding vulnerable patients from participating in relevant research could suggest that society is failing in its obligation to improve high-quality, evidence-based healthcare due to misguided paternalism." However, it should be remembered that in studies with palliative and hospice patients, time and changing disease status play an important role (Wilkie 1997). Being guided by the patient's welfare or simply 'using' the patient's situation may be questioned. Ashley Wohleber, Daniel McKitrick, and Shawn Davis (2012) noted that it is also questionable that research on hospice patients may take up their time, which they do not have much left. On the other hand, the omission of hospice patients for moral reasons and whether it is appropriate to meet the patient for an interview during impending death leads to the omission of an important voice of people who also struggle with other experiences such as difficulties in obtaining support and quality care, a sense of social exclusion, and misunderstanding caused by not raising topics related to death and dying in the social arena. Therefore, the solution to the dilemmas considered, including the issue of researching a group of patients in hospices, may come down to the need to start a conscious discussion among researchers on how to prepare for this type of research to be able to resolve as many dilemmas and ethical doubts as possible and to question the sense of conducting such research in general. Examining the effects of conducting research with palliative patients, Marjolene Gysels, Cathy Shipman, and Irene Higginson (2008) noted that respondents stated the interviews were therapeutic for them and their fam-

ily members. The possibility of telling a life story also plays an important role (Sivell et al. 2019). However, this position of patients may change due to the well-being and medical condition of the patient (Sivell et al. 2019).

The second thing is that when research is carried out with a sensitive group, their ethics are primarily related to the interviewee. However, there is no ethical care for the researcher. In studies involving sensitive research groups, care should be taken not only for the comfort of the subject but also for the researcher. The latter is often forgotten as it is the researcher who wants to conduct interviews as part of the project. The researcher is expected to adjust. This approach affects the quality of the study, resulting in discouragement, fear, and trauma. The researcher is someone who will probably meet the patient only one time. From an ethical perspective, it is better, and also because of the probable imminent death of the patient. However, each patient's situation is different. Sometimes the researcher learns things that the patient has only told them, not the family or the hospice team. Several aspects are important here: (1) the individual predisposition of the researcher to conduct this type of research. If the researcher is a young person, inexperienced in conducting research, or not having previously dealt with hospice patients, such research may prove problematic for the researcher or even cause trauma. Then, the researcher should consult someone about whether they are ready to start research now and what situations they may face. (2) It would be worthwhile for the researcher to be offered the support of someone, for example, at the university, who specializes in research on a sensitive group and who could provide the researcher with (ethical or personal) support and mentoring during the research. There are many situations during research that we are unable to predict. It may happen that, despite preparation, the story of one of the patients speaks to the researcher so much that they will not be able to distance themselves again. It can happen regardless of the research experience and at any stage of the research or the scientific path. It is important to have someone who can help process the situation, define it, and find its meaning, which could help the researcher move on. In working through these emotions, regular supervision conducted by professionals may be a crucial help, which would guide the researcher in understanding these experiences. (3) Research with a sensitive group may, to some extent, affect the personal life of the researcher. The more difficult the study, the more it can absorb our thoughts at work and in our free time. This constant commitment can cause a scientific burnout.

These situations may cause researchers to hesitate or not research on a sensitive group, or study it largely intuitively, based on their trial and error method. Researchers are also often ashamed to talk about dilemmas, deep reflections, or stories that they collect and believe it is not proper and that they will be unprofessional in front of their colleagues. They are afraid of being criticized and exposed to their feelings and thoughts. It would be important to implement in institutes thematic meetings related to ethics in research on specific examples of research with vulnerable groups. Communicating to students and researchers what problems the project leader is dealing with could become an invitation to discussion and an opportunity to analyze the solution to the problem. In addition, it could also become the beginning of openness in admitting that such problems exist, which, at first glance, is often taboo in the academic world. Private doubts and embarrassing events occurring during the study are not discussed, and mention-

ing them is made only in secret as the researcher can share such information only with a few trusted people. It gives the constant feeling that the researcher should always behave like a professional and that it is not proper to talk about problems other than logistic or substantive. The researcher's experiences that affect them directly as a human seem to be out of place here, escalating the feeling that these experiences happen only to them, and they must deal with them. It would be recommend-ed to create materials or a textbook based on real experiences, which could help both the researcher and the research group—to counteract uncomfortable situations and negative emotions. There is no preparation, ready-made training, manuals, or checklists that could help researchers to implement and work through potential problems that may be met during the study, and that will help in some sense considering what the researchers will see and what they will experience.

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## Citation

# Book Review
# Bjørgo, Tore, ed. 2005. *Root Causes of Terrorism: Myths, Reality and Ways Forward*. Abingdon, Oxon: Routledge

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Legend has it that prevention is better than cure. A physician ought to find out the root of a disease to uproot its causes and stop its recurrence to save human beings. Discovering the underlying factors is a must to recuperate completely from any adverse condition that hinders the normal course of events. Likewise, searching for the underpinning causes can only help eradicate the problem of terrorism—the use of violence against civilians to pursue political goals in general—to some extent. The once buzzword—terrorism—has become such an ordinary phenomenon that almost everyone in the world knows about it. Moreover, almost every human being is either an active or a passive victim of terrorism. That turns terrorism into a pandemic that was endemic when the word was first coined during the French Revolution to describe the Reign of Terror. Taking almost twenty thousand lives every year, this pandemic—terrorism—has become deadlier than most of the threats to the human race. Against that backdrop, there is a crying need for addressing its causes and adopting viable resolutions. However, that exigency was felt by a panel of experts in 2003 when thirty scholars gathered together in a symposium and amalgamated their ideas about what causes terrorism and how to curb its causes. The aim was to share the aggregated information at the Fighting Terrorism for Humanity conference. However, this amalgamation resulted in the formation of the

book—*Root Causes of Terrorism: Myths, Reality and Ways Forward*—edited by Tore Bjørgo and published by Routledge in 2005. Employing a mixed-method strategy, the book aims to examine all the subtleties regarding the spurs that give rise to the issue of terrorism. Circumstances that contribute to its perpetuation have also been identified by examining empirical data gathered on various forms of terrorist acts. However, in most chapters, the data were collected using qualitative ethnography and interviews. The writers show that social interactionism works as a driving force behind someone's motivation to become a terrorist. Societal conditions and circumstances propel terrorist motives by affecting people negatively.

Every disease requires a distinct diagnosis technique and a unique way of preventing it. Different types of terrorist acts, likewise, require distinct strategies for their prevention. The book, however, unearths variations among terrorist acts ranging from political terrorism to left-wing, right-wing, nationalist-separatist, and religious extremist terrorism and suggests feasible solutions. Besides, spatial and temporal differences among terrorist acts have been shown in furtherance of the insights into strategies adequate for the resolution of these terrorist acts. Moreover, the methods of undertaking different terrorist acts have been outlined to comprehend terrorism at large. Fostering reasonable policies to combat terrorism, the book enlightens academic experts and policymakers, as well as students from both undergraduate and graduate levels about matters regarding terrorism and provides a scope for further research in this field. Providing biblical insights into terrorism, this book has been working as a guideline since its composition for understanding and combating terrorism and other insurgencies.

Juxtaposing two dichotomous groups of scholars—one who disagrees with and the other who gives assent to the idea of finding the root causes of terrorism—Tore Bjørgo introduces us to the contents of the book in the first chapter. The subsequent chapters outline the ins and outs of terrorism—an ambiguous concept whose complex picture has been drawn in the introductory chapter. The book frames all the phenomena—either strongly or weakly—related to the causes and the resolutions of terrorism in its chapters. The voyage begins with facing ripples—phenomena that provide an easy understanding of terrorism and takes to the tidal—waves—critical issues regarding terrorism in the subsequent chapters. That sort of organization of the book does not make its reading a humdrum endeavor since complexities do not preoccupy the readers and it engrosses the readers as they keep going. Among the twenty chapters of the book, chapters two to sixteen deal with numerous types of terrorism and their root causes and suggest the ways forward. Whereas chapters seventeen to nineteen focus immensely on the strategies for preventing terrorism in the first place. In chapter two—"Exploring Roots of Terrorism"—Dipak K. Gupta delineates the motivations behind someone's joining terrorism. Whereas in chapter three—"Impoverished Terrorists"—Jitka Maleckova solely focuses on the economic aspects of terrorists' profiles. Chapter four, titled "The Social and Psychological Characteristics of Terrorism and Terrorists," frames the psychosocial underpinnings of terrorism and shows that the popular belief of terrorists, in general, being psychologically damaged is a misconception. The chapter is supplemented by the next—"The Socio-Cultural Underpinnings of Terrorist Psychology"—where Jerrold M. Post searches for unusual psychopathology in terrorists and delineates different types of terrorism. The focus moves from the types of terrorism to one of the

most nefarious ways of accomplishing terrorist acts in chapter six—"Social, Organizational, and Psychological Factors in Suicide Terrorism." Ariel Merari depicts why terrorists are involved in suicides and opposes the notion of religious fanaticism. Chapter seven—"Palestinian Resistance and Suicide Bombing"—complements its preceding chapter by portraying the motives behind the Palestinians' increased involvement in self-sacrifice. In chapter eight—"The Roots of Terrorism in the Middle East"—it has been argued that a multi-dimensional methodology must be adopted to understand the causes of terrorism in the Middle East. Chapter nine portrays how state oppression and pluralistic competition have resulted in the formation of National Separationists in a totalitarian state. The book continues further and, in chapter ten, looks for the root causes of terrorism by switching focus from the Gulf and the Middle East to an Asian terrorist group—the LTTE—in the chapter labeled "Root Causes of Terrorism." The next chapter concentrates on right-wing terrorism and provides a structural model for understanding the reasons behind the far-right ideology. The direction of the book turns toward Latin American and European social-revolutionary terrorism in chapter twelve, which explains that individuals' dire personal life leads them toward terrorism. Chapter thirteen sketches the differences between organized crime and terrorism and outlines that though these two sometimes get intermingled, they differ based on their ideologies. Chapter fourteen—"Patterns of State Failure"—depicts why and how states fail to control their subjects. Together with that, the chapter exhibits different degrees of state failure. On the contrary, chapter fifteen provides an insight into the way states perpetuate terrorism. The next chapter points out the underlying causes of state terrorism and looks for the reasons that engender these causes by stating different forms of state terrorism. How-

ever, a framework for resolving terrorism has been provided in chapter seventeen. Joshua Sinai states that a new counter-terrorism measure that focuses on grievances is required if existing measures fail to succeed. Another approach—multi-pronged—of preventing terrorism has been described in chapter eighteen. Illustrating a typology of terrorism, Alex P. Schmid outlines the eight categories from the toolbox of measures developed by the UNODC to prevent and suppress terrorism. Before Tore Bjørgo makes concluding remarks in chapter twenty, Andrew Silke describes the role state countermeasures play behind terrorism and suggests solutions to that issue. The writer argues that harsher counter-terrorism measures spawn more terrorism. He suggested that understanding the psyche of the terrorists provides a clear understanding of what to do.

The book is a mine of intelligible data on terrorism. Tore Bjørgo cut to the chase in the first chapter without making the issue of terrorism more dubious. As he notes, terror has been used by both the states and the rebels for their accomplishment. Besides, diverse terrorist groups use terrorist means in different manners to attain unique goals. Definitions of terrorism, as shown, are subjective. Hence, the definitions involve varied variables that depict distinct causes of terrorism. The causes of terrorism have been grouped among structural, facilitator, motivational, and triggering causes. Structural causes are inherent in the societal apparatus and are prompted by the facilitator causes that make terrorist acts an easy endeavor. Ideologues and demagogues use motivational factors to entice people who are deprived of their needs. They are triggered by provocative circumstances. The second chapter depicts that people who are on their beam ends engage in collective actions for their group and self-prosperity using rationality that results in both personal and group

benefits by dint of associated costs. That cause is not exclusive since every person who goes through that condition does not engage in terrorism. Hence, an expanded behavioral model that lists greed, ideology, and fear as motivation can be employed to explain the motives behind terrorism to some degree. The third chapter denies stereotyping the uneducated poor as terrorists or prospective terrorists. Listing empirical data, it has been shown that poverty has a weak connection with terrorism. Poor countries with less civil liberty do not produce terrorists. Whereas a certain degree of income accompanied by less civil liberty creates dissidents who are, certainly, suppressed by state or international politics. The fourth chapter expels the popular belief that terrorists are psychologically disturbed individuals. However, in reality, they are not. Terrorism is a political movement that utilizes media to disseminate its ideological position. In chapter five, the writer borrowed and modified Schmid's typology of terrorism from chapter eighteen to explain the sociocultural factors behind terrorist psychology. The generational pathways to terrorism provided in that chapter show that the national separatists are loyal to their disloyal parents. Whereas social revolutionaries are disloyal to their loyal parents. People go through a psychological process before engaging in terrorist acts. From the interviews with members of terrorist groups, the writer found that both ideological and personal factors such as self-fulfillment, honor, and feelings of independence and subservience motivated them to join terrorist organizations. Searching for more causes of terrorism, chapter eight outlines the causes of terrorism in the Middle East. Quoting Noam Chomsky, it has been said that terrorism has been studied by adopting the propagandistic approach that uses the interest of the powerful regime in defining and combating terrorism. It has been noted that inequality, oppression, and injustice re-

sult in terrorism. The visible difference between economic resources and employment opportunities motivates people to adopt terrorist acts. Psychological defects and non-lineage in the family also work as facilitators of terrorism. These causes prove that there is no singular reason behind terrorism. Hence, a multidimensional cause-effect methodology has been proposed. That methodology incorporates socioeconomic factors, literacy rate, democracy, and extremism as the variables that trigger terrorism, while American policy and Israeli occupation work as catalysts.

The book presents the function of ideology, poverty, psychology, religion, et cetera in a simplistic manner that shows their superficial connection with terrorism. A subtle and discerning search for the causes and their correlation could provide even greater insights into the sources of terrorism. Besides, some chapters used empirical data to prove or disprove a phenomenon. However, these empirical data are limited in number. If there were enough data and case studies, the relationship between different variables and terrorism could be made certain. Moreover, while ignoring state-induced terrorism, this book over-represents non-state actors as terrorists. Although some chapters summarized state-sponsored terrorism, that is insufficient for representing states as terrorists. In addition, aspects of modern-day terrorism, such as bioterrorism and cyberterrorism, have not been discussed.

However, the book stands out from other contemporary books on terrorism and security studies because of its multidisciplinary approach to explaining terrorism's triggering causes and humanitarian preventive methods. Contemporary writers, such as Mahmoud Masaeli and Rico Sneller (2017), analyzed

theoterrorism in their book and concluded that religious terrorism is a mere act of subjective interest rather than religious dogma and needs lenient handling strategies. Noam Chomsky (2015) notes in his book, by giving examples, that states employ the propagandist approach to define terrorism and that world powers engage in terrorism in the name of retaliation. While speaking about counter-terrorism, Claire Hamilton's (2019) book outlines three countries' counter-terrorism strategies and that counter-terrorism measures are hegemonic and curtail the citizens' freedom, while Luiz Moniz Bandeira's (2019) book shows how rancor between two world powers, the US and Russia, and their thrive to crown as the most powerful nation have made them influence geopolitical matters worldwide. Another contemporary book by Stefan Goertz and Alexander Streitparth (2019) outlines terrorist recruitment strategies by mentioning the use of subjective religious tenets. Moreover, the book mentions that terrorists use technology more and exercise new strategies as the West advances technologically. All these contemporary books' commentaries about terrorism have been crafted aptly by Tore Bjørgo in his book *Root Causes of Terrorism: Myths, Reality and Ways Forward*. The book does not speak only about a particular aspect of terrorism, which most contemporary books do. Tore Bjørgo's book provides a holistic idea about terrorism, and that makes it a classic in terrorism discourse. Moreover, it is worthwhile for readers because they can delve into the book and gather ample knowledge about terrorism, which they can hardly get after reading several contemporary books.

The contents of the book, as already mentioned, provide biblical information on terrorism. They have precisely depicted the issues about which the readers might be at the sea. The book can help readers get a foothold in the area of terrorism. The formation of the book makes it more perceptible. The current price of the book, as offered by the publisher online, is around £32 for paperback and e-book, and the price seems adequate compared to its voluminous information. The availability of the book, even after almost twenty years, proves its worth as well. Scholars, students, practitioners, and policymakers who are interested in comprehending issues related to terrorism must read the book to expand their understanding.

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