FORUM ARTICLE



Doing ageing research in pandemic times: a reflexive approach towards research ethics during the COVID-19 pandemic

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Abstract

The outbreak of COVID-19 has had a significant impact on societies and individual lives across the globe. In this paper, we address the impact of the pandemic and the protective measures on empirical social scientific ageing research through the lens of 'ethically important moments'. One of the most crucial measures for preventing the spread of the virus includes social distancing; therefore, empirical research methods based on person-to-person direct contact (as in interviews) and first-hand observation have been scaled back since 2020. For ageing research, the challenges are particularly pronounced due to the ongoing discussion regarding vulnerabilities associated with higher age and age-based discrimination. Hence, many researchers focusing on ageing are facing some difficult questions: How and under what conditions can we carry on with empirical research without putting our research participants and ourselves at risk? Firstly, we systematically identify the key dimensions and challenges that have shaped social scientific research during the lockdowns associated with the COVID-19 pandemic: fragmentation, fluidity, ambiguity and uncertainty. Then, using insights from two international research projects, we illustrate and critically reflect on the ethically important moments and practical dilemmas that have resulted from these pandemic challenges when researching with and about older adults.

Keywords: COVID-19 pandemic; ageing research; older adults; pandemic ageism; research ethics; ethically important moments

Introduction

The global public health emergency caused by the outbreak of COVID-19, and the pandemic policies and regulations aiming at 'flattening the curve', have often specifically targeted older people, as higher age was among the factors increasing the

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risk of a severe or lethal course of the disease (World Health Organization (WHO), 2020). Thus, the pandemic brought chronological age to the centre of political decisions (Fletcher, 2021) and public debates (Lichtenstein, 2021). The long-lasting efforts by scholars in ageing research to combat age-based categorisation (Ehni and Wahl, 2020), othering (Verbruggen *et al.*, 2020) and discrimination (D'cruz and Banerjee, 2020) seemed to have been countered by the prevalent pandemic ageism over the last two years (Previtali *et al.*, 2020; Barrett *et al.*, 2021).

Like many researchers in ageing studies, we found ourselves in between contradictory ethical *callings* amidst the pandemic. On the one hand, there was a *call* for 'urgent and ongoing data collection and rigorous analysis of social and economic inequalities' in this unprecedented period (British Society of Gerontology (BSG), 2020: 7). Yet, and contradictory to this call, the pandemic measures brought much of social science research based on person-to-person contact to a halt, with new ethical and methodological challenges emerging (Rutherford, 2020). We were, for various periods of time, grounded either by our universities and regional lockdowns, or because we felt that we could not responsibly continue our fieldwork, even if it would be legally possible.

On the other hand, and as Fletcher (2021: 490) argues, pandemic ageism calls for reflection on 'the ways in which we categorise persons and how we might do better'. Hence, as ageing researchers, we knew we could not homogeneously classify our research subjects as a 'risk group' and bring research to a halt altogether. Instead, we had to make a range of ethically challenging decisions. We had to decide whether to postpone planned face-to-face interviews for an unpredictable amount of time and focus, for example, on introspective approaches in the interim (Harris and Holman Jones, 2021; Humberstone, 2021). We had to decide whether to move to a remote interview mode (Self, 2021) and, if so, what technologies to use. Most importantly, we had to determine when and how to ethically restart research based on face-to-face encounters with older people again. While the moment of stopping research was quite clearly marked by the 'hammer' of strict nationwide lockdowns in the early spring of 2020 (Pueyo, 2020), the moment of re-establishment of person-to-person engagement with older people in our fieldwork was unclear, as the measures were easing and tightening gradually within the ongoing pandemic. The 'dance' phase brought in deep ethical ambiguity and moral tensions. Romania (2020: 59) has aptly labelled this state 'interactional anomie', 'a condition of uncertain knowledge of what rules of conduct regarding social distance shall be applied to interactions with non-familiar people in public spaces'. The complexity of the situation gave rise to vivid discussions amongst our international research teams on how to reply to the call for conducting research. How do we assess pandemic-related risks in our fieldwork? How do we take the vulnerabilities of older people into account and respect their refusal to be made vulnerable at the same time? How do we navigate in the new situation of a face-to-face interview in the new moral and interactional order of pandemic social encounters?

In qualitative social research, reflecting on one's own practices plays a substantial part in the research process and its ethical evaluation. We argue that there is a lack of critical reflection on the ethical and practical aspects of empirical research in the context of a world health crisis (Kara and Khoo, 2020; Rutherford, 2020), and in this article, we aim at opening such reflection in answering the second *call*

(Fletcher, 2021). As, amongst others, Guillemin and Gillam (2004: 263) point out, qualitative research ethics encompass at least two interrelated dimensions: procedural ethics, defined, for example, by ethics committees, and 'ethics in practice', encompassing the 'ethical issues that arise in the doing of research'. Many of the ethical challenges we encountered in our fieldwork at the onset of the pandemic fall beyond the scope of procedural ethics in our institutions. Even the most detailed ethical guidelines, codes of conduct (e.g. International Sociological Association, 2001; British Sociological Association, 2017; American Sociological Association, 2018) or suggestions from ethical committees could not prepare us for the research design dilemmas and unique situations in the field (Atkinson, 2009; see also Karmakar et al., 2020; Lobe et al., 2020).

Moreover, in 2020, when we conducted our research, there were no guidelines for social pandemic research (see Dawson et al., 2020; WHO, 2020), and none of the major professional associations had commented officially on research ethics during the ongoing health crisis (Hanafi, 2020; Pleyers, 2020). In this Forum Article, we use the lens of 'ethically important moments', those 'difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research' (Guillemin and Gillam, 2004: 262), to explore the ethical and practical challenges we encountered in our fieldwork at the beginning of the pandemic. We address three questions: What is characteristic of the pandemic condition in terms of doing qualitative research? How did we adjust our research designs accordingly? What ethically important moments emerged during the fieldwork that were related to age and ageism? We use this Forum Article as a platform to make our reflection on the research process public, and use it as an initial effort in advancing the discussion about ethical aspects of ageing social research in the pandemic context and beyond. In the following section, we briefly explore four dominant features that have shaped social scientific research during and in between the lockdowns at the beginning of the COVID-19 pandemic: fragmentation, fluidity, uncertainty and ambiguity. We continue by outlining the ethically important moments we have encountered in two ongoing international research projects. We stress the relational, situated, and embodied nature of the ethicality of research conduct. In the concluding discussion, we posit a selective set of questions that, from our perspective, seem crucial for a debate on the ethicality of social research in pandemic settings.

Features influencing qualitative research at the onset of the COVID-19 pandemic

Before exploring the ethically important moments we have encountered in research with older adults, we outline briefly the conditions that undermined our conduct. We identify four main challenges generated by the nature of and the responses to the 2019 novel coronavirus pandemic in our regions: fluidity, uncertainty, ambiguity and fragmentation. These features have always been present in the research process to some extent, but the early pandemic situation made them central to research planning and conduct. By fragmentation, we mean the uneven spread of relevant information and lack of coherent guidelines regarding the social distancing and other preventive measures required in different jurisdictions and institutions.

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These 'variabilities in risk governance across national policy regimes' (Brown, 2020: 3) translate into additional challenges in co-ordinating fieldwork for national and international projects.

Not only fragmentation but also fluidity characterised the pandemic research context: local preventive measures, their interpretations and related practices in everyday life of pandemic cultures (Davy, 2020) were shifting quite rapidly as new expert information regarding the nature and spread of the virus was becoming available and became (or not) part of everyday life. Fluidity and fragmentation complicated the research process and increased overall uncertainty (Higgins *et al.*, 2020). Uncertainty also stemmed from a lack of reliable knowledge about the future development of the pandemic and from the nature and scope of preventive measures introduced by different (and possibly changing) governments (Cook, 2020; Weible *et al.*, 2020) under various timeframes (Brown and Galantino, 2020; Ward, 2020).

Anticipation plays a central role in procedural ethics, a fact extensively criticised in recent debates (Markham, 2018; Bell and Wynn, 2021). Fluidity and uncertainty of the situation render research re-planning and adjustments of research protocols especially challenging. The entanglement of fragmentation, fluidity and uncertainty leaves researchers in an ambiguous position, in which they nevertheless must make research decisions before data collection is initiated, as well as in the field. We consider ambiguity mostly in terms of new forms and definitions of risks and safety connected with interpersonal contact (Brown, 2020) and new forms of risk management that, in many aspects, contradict the use of standard social science research techniques (Rutherford, 2020). All of these factors are dynamically interconnected, and in their entanglements, they influence many parts of the research process significantly, as we highlight in the following section.

Ethical practice in interviews with older adults in pandemic times

This reflexive article is based on two research projects and utilises two crucial stages of the research process as examples: the (re-)planning of fieldwork and the interview situation itself. PROJECT1 was initiated in March 2020 and aimed at reconstructing reconfigurations of intergenerational provisioning during the pandemic in three European countries. PROJECT2 was an international study initiated in March 2019 that aimed at analysing the origin of gender differences in exclusion from social relations across European countries and the consequences of this exclusion for health and wellbeing in older age. The latter project was already ongoing when the pandemic broke out, whereas the former was implemented in March 2020 explicitly to research the pandemic situation. Both projects deployed mixed-methods research designs, with qualitative data collection (problem-centred, face-to-face interviews) scheduled for 2020.

Planning for the interview

In terms of *planning*, the fundamental ethical question of the research in the evolving health crisis and possibly disastrous and traumatic setting of the pandemic context had to be answered: Should we do the research at all? (O'Mathúna, 2018: 445). The answer was affirmative (as a unified response to the first ethical call). In

moving from face-to-face to remote interviews in PROJECT2, the adjustments needed to be approved by local ethical committees at the institutions involved, a process taking from several days to several months and possibly deepening the existing fragmentation of data collection across different countries. Discussions also revealed various levels of trust in local ethics bodies in different countries as their understanding of the specificities associated with social research was questioned (Gillam and Guillemin, 2018), especially in the context connecting the highly medicalised discourses of the pandemic with the medical roots of procedural ethics (Strujo et al., 2020). In their approvals, the local committees were helpful in adjusting the formalities for the remote interviews. However, none of the institutions involved in the projects made a formal comment on how to transition from a remote mode back to face-to-face interviewing. This resulted in some of the countries represented in our project conducting all interviews remotely, and some deciding to switch back into the face-to-face mode, applying various forms of protective measures. The dynamically and unevenly developing situation in the countries involved in the projects and the uncertainty about the future led us to consent to these localised strategies of conduct.

Due to the fuzzy nature of the 'dance' phase of the pandemic (Pueyo, 2020), the deliberative debates amongst the PROJECT2 teams pointed to the importance of values related to age and ageing in the ethical decision-making involved in the research process (Hammersley, 2018). The discussion from the Czech context serves as an example, in which the state pandemic measures were eased quite promptly in late spring 2020, making it possible to proceed with face-to-face interviews earlier than in partner countries. This micro-ethical moment evolved into a thorough discussion of a complex question: how to balance the protection of older people, addressed as most vulnerable to the lethal effects of COVID-19, and how to hear their voices via research involvement. For how long should protection from the risk of infection (resulting in not conducting face-to-face interviewing) outweigh the risk of social isolation (D'cruz and Banerjee, 2020) that many older people suffered during the pandemic (and include those who agreed to face-to-face interviews when the state measures let us do so despite the ongoing pandemic)? What does it mean to be ethical in such a setting, and who should handle the responsibility for such decisions?

The ethical challenges in the planning phase thus entailed anticipating the potential harm associated with data collection amongst older research participants. The level of risk would (ostensibly) be addressed in official documents, such as ethics approvals, information sheets and consent forms (Msoroka and Amundsen, 2017). At least in the initial phase, the pandemic situation brought to the fore again the distinction between the medicalised notion of age-related vulnerability (Fletcher, 2021), which undoubtedly affected our perception of older people as a vulnerable research subject (Van den Hoonaard, 2018). Age became an easy proxy for vulnerability, as the other relevant factors, such as weakened immunity, chronic disease or obesity (Williamson *et al.*, 2020; Tehrani *et al.*, 2021) on the side of potential interviewees, were much harder, or even impossible, to take into account in the research planning and sampling process. Being aware of the ethical complexity of the situation, we aimed at obtaining consent ahead of remote as well as face-to-face data collection, as advised by ethical committees. However, the

actual level of risk, often hard to determine in the social research context (Van den Hoonaard, 2018), became extremely difficult to assess beforehand in a pandemic context, in which the very bodily presence and co-breathing or touch could lead to potentially lethal contamination.

In this overall situation of uncertainty and anxiety, some gatekeepers (from nursing homes or non-profit organisations) were more reluctant to connect potential older participants with researchers. In PROJECT2, we learned how important it was to provide extensive information on protective measures to gatekeepers before the recruitment stage. The PROJECT1 team decided to rely less on stakeholder co-operation, integrating a provision through which participants interested in qualitative interviews could leave their contact details through an online survey instead. However, this can lead to shifts in the study populations (*see* below), which might be different from the sample structures produced through gatekeeper recruitment (*e.g.* Ellard-Gray *et al.*, 2015).

In order to bypass the risks stemming from face-to-face settings, both projects at least partially planned for remote interviewing, either online or via phone (cf. Dodds and Hess, 2020). Especially in ageing research, however, this decision entailed a range of problems. Not all older adults have access to an electronic device with stable internet, telephone connection, or the respective communication software, and many do not feel entirely competent or comfortable using such systems (Van Boekel et al., 2017; König et al., 2018; Seifert et al., 2020). Hence, the online design was likely to result in a different sample if compared to a face-to-face context, and the scope of the differences is difficult to identify (Davies et al., 2020). Further, data security arose as an ethically important issue and was the subject of procedural ethical assessments (Markham, 2018). In co-operation with ethical committees, we adjusted the informed consent for online interviewing. However, the actual risk of the research event was negotiated with our participants. Even though researchers had access to secure online platforms and planned to use them, some participants preferred to use systems they were accustomed to, like Zoom or Skype, actively adjusting the research situation according to their needs and re-framing what was set in advance as a risk. Dilemmas of this kind slipped from the scope of procedural ethics. This (originally unplanned) ad hoc co-production also became central to the interview situation itself.

Doing the interview

With regard to the *interview situation itself*, a variety of ethically important moments had arisen. The pandemic strengthens the connection between the private lifestyles of both the interviewer and the interviewee. The disguised behaviour of the virus made even the asymptomatic or infectious but not yet ill people potential suspects in transmission, causing the medicalisation of social relationships (Romania, 2020). Meeting other people in usual settings, such as in public transportation, turned the interview into a dicey situation even before it actually started, simply increasing the risk of transmission by asking people to leave their (not necessarily safe) homes (Durnová and Mohammadi, 2021). Moreover, the pandemic measures brought new rules into the established social order of personal interaction and imbued even its very basic details, such as a handshake, with a new morality.

The procedural ethics were set by legal measures currently in force (such as mandatory mask-wearing in public or closed spaces, disinfection, physical distancing, etc.).² These measures not only varied geographically, but they were also quite fluid in terms of time and perplexing, with many controversies on what is actually effective (e.g. Cheng, 2020); and most importantly, they translated the behaviour in daily encounters in which many people might not be sure about what is appropriate in a particular situation or even actively oppose the new pandemic etiquette in diverse ways (Hanratty et al., 2021).

In some cases, research participants, informed about safety rules through information sheets and briefed during phone conversations arranging the face-to-face interviews, refused to wear a mask once the interview started. Such refusals would, in turn, put the interviewer at potential risk (Sikic Micanovic *et al.*, 2020). The line between respect for the interviewee's autonomy and self-protection for the researcher remained ambiguous, not least because of the widespread view on masks as constituting the protection of others (Cheng *et al.*, 2020; Zimmerman, 2020), and was addressed on an individual basis, according to the researcher's reading of a particular situation (Markham, 2018).

The portrayal of older adults in the public discourse regarding COVID-19 contributed to this reluctance: especially in the early months of the pandemic, older adults had been depicted as a homogeneous, at-risk group in need of protection (BSG, 2020), whereas younger adults had been viewed as more or less safe from severe consequences (Ayalon et al., 2021). Even though this view has since been contested by scientific research, it has still impacted the ways older and younger adults perceive themselves and others - in the interview situation, we often represented ourselves and were perceived as young and fit by our participants (Tarrant, 2014). The ethicality of the interview situation thus emerged as relational, embodied and contextual. Despite being defined as chronologically 'old enough' (to participate in the research) by the researchers and as 'older' in the situation of the interview with visually younger interviewers, many participants did not identify as 'old', distancing themselves from the category of an age-related 'risk group'. Asked if he perceived himself as at-risk, a 72-year-old study participant replied strictly: 'No. NO. Not at all. Well yes, if you take my age, because I am older than 65, but other than that - no'. Another research participant, aged 68, would not believe in any correlation between risk and age and hence refused to wear a mask during the interview situation, saying: 'Is this because I am at risk? Oh my God, guys, seriously? In December, I was still the old grandma; nobody cared about me. And now the government wants to save my life, whatever it takes. What a paradox.' When suggesting safety measures, we had created a scenario in which older research participants would immediately assume that these measures were designed primarily to protect them and not necessarily the researcher. As previous research on ageism and stereotype threat shows (Weiss and Lang, 2012), older adults might refuse to identify as 'old'; they prefer to adhere to their personal definition of age over the societal and chronological one (Baars, 2010). This scenario occurs especially when they associate old age with frailty, dependence and deficiency, to prevent damaging one's own identity - strong notions of the 'othering' of old age (Higgs and Gilleard, 2014; Van Dyk, 2016) were expressed while negotiating the level of risk in the interview context.

Concluding discussion

According to Fletcher, a chronologic epistemology is foundational to gerontology. In his article on ageism during the COVID-19 pandemic, he suggests: '[C]hronological quarantine should be a powerful reminder to all ageing researchers that we cannot always develop methodologies sophisticated enough to fully respect the reality of aged heterogeneity, but we should nevertheless always be trying to advance in that direction' (Fletcher, 2021: 485). This Forum Article represents such an effort. The early period of the pandemic served not only as an opportunity for epistemological reflection but also as a magnifying glass for the existing tensions between the premises of procedural ethics and 'ethics in practice' with regard to qualitative research (Guillemin and Gillam, 2004). The call for urgent research (BSG, 2020) should be accompanied by a discussion on how to conduct social research ethically in pandemic times. To open such a discussion, we have explored the adjustment of the research process in two international projects and made part of the ethical reflection of our research practice public. It is itself a product of pandemic times, inevitably subject to the fluidity, ambiguity or flexibility of the situation. Therefore, it serves not as a comprehensive review of pandemic research ethicality, but merely as a theoretically informed and empirically grounded commentary. We have focused on the characteristics of the pandemic condition in terms of doing qualitative research with older adults and explored ethically important moments (Guillemin and Gillam, 2004) as they emerged in the re-planning of our fieldwork under the relative novelty of the early pandemic conditions and while conducting the interviews. As Hughes et al. (2021) point out, social research is inevitably 'messy'; there are many unplanned outcomes of various interactions in the field irrespective of an ongoing pandemic. However, we argue that the fragmentation of pandemic measures (e.g. geographically, temporally), the flexibility and fluidity of pandemic-related knowledge and subsequent recommendations and rules, and the uncertainty of pandemic conditions and their framings have caused specific challenges for the ethicality of conducting social research. These challenges have not yet been addressed in professional ethical guidelines, which are clearly not tailored towards addressing an unprecedented health crisis.

Our reflection of the ethicality of pandemic research has highlighted the centrality of micro-ethics in the pandemic setting. Procedural ethics in research involves anticipation (especially of risk and potential harm) and supposes a certain level of predictability of the situation in the field. The unpredictable and rapidly evolving pandemic condition, due to its aforementioned characteristics, together with missing formal guidelines for pandemic social research, has made the planning necessary for procedural ethicality exacting. Micro-ethics have become central to ethical assessment and decision-making in the research process. We have therefore presented the pandemic ethicality as situated, relational, negotiated and embodied. In these micro-ethical events, the individualised responsibility of the researchers conducting the interviews was essential to the ethicality of the research process, as were the deliberative and reflexive team discussions. We view this text as a part of the process too.

We have also encountered our own epistemic ageism (Fletcher, 2021), represented, for example, by chronological sampling, intertwined with pandemic ageism,

leading our participants to feelings of being made vulnerable. Many of them actively objected (Latour, 2000) to the 'othering' of homogenising cultural framings of older people as an 'at-risk' category endorsed by our own practices in the field. The pandemic has highlighted the question of reflexivity in social research. Therefore, we can only hope that in response more researchers will be interested in applying reflexive approaches in ageing research in pandemic times and 'beyond'.

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Ethical standards. Approval was granted by Masaryk University, Universität Wien and Goethe-Universität.

Notes

- 1 In addition, there was a third ethical *call*, of course regarding intensified care for our communities, our significant others and ourselves in the work-from-home situation (Corbera *et al.*, 2020).
- 2 For both the interviewer and the interviewee, wearing masks during an hours-long interview became not only uncomfortable, but also problematic. For participants with hearing difficulties, masks covering the mouth of the interview partner created additional issues with hearing and, therefore, understanding each other. Both parties must speak more loudly and clearly, which was exhausting for people who easily suffer from shortness of breath. When conducting interviews in the private homes of participants, they were responsibile for ventilation or disinfection, what linked their participation with additional efforts, and took control of the 'risk management' from the researchers.

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