

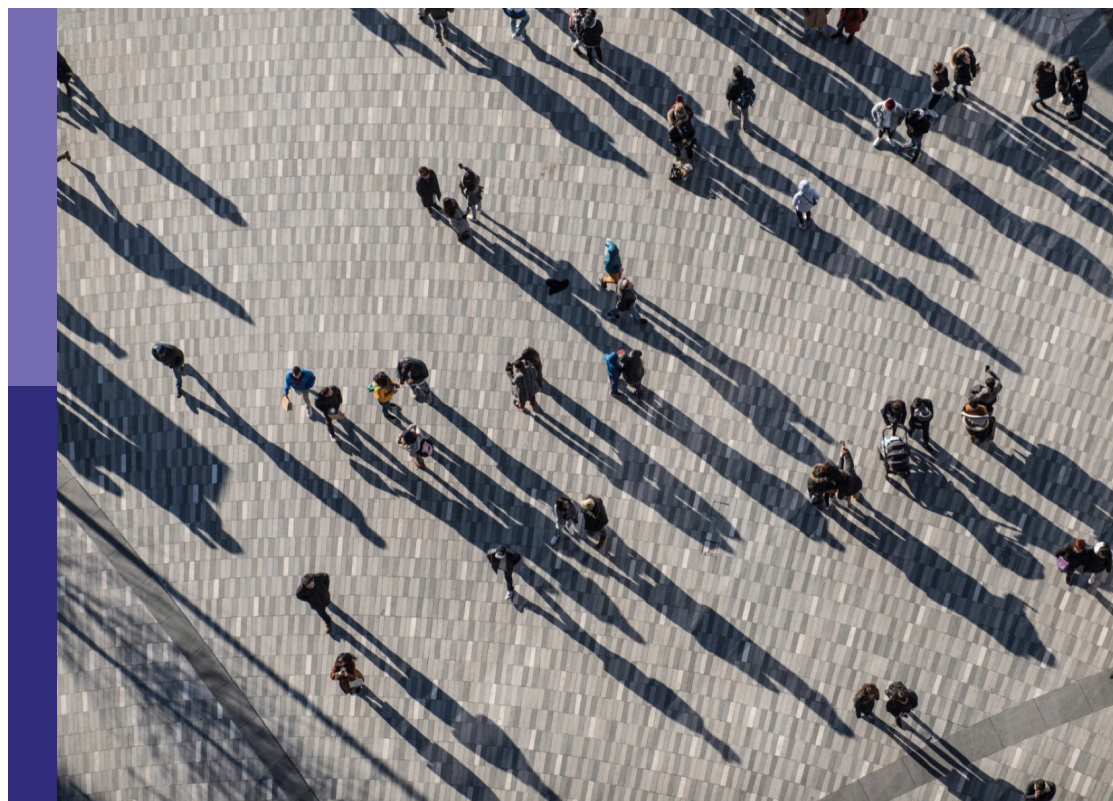
# Intersections of ageing and disability during the COVID-19 pandemic

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**Published in**

Frontiers in Sociology



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ISSN 1664-8714  
ISBN 978-2-8325-6119-5  
DOI 10.3389/978-2-8325-6119-5

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# Intersections of ageing and disability during the COVID-19 pandemic

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## Citation

Simmonds, B., Berghs, M., eds. (2025). *Intersections of ageing and disability during the COVID-19 pandemic*. Lausanne: Frontiers Media SA.  
doi: 10.3389/978-2-8325-6119-5

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RECEIVED 25 September 2024  
ACCEPTED 30 September 2024  
PUBLISHED 14 October 2024

CITATION  
Simmonds B and Berghs M (2024) Editorial:  
Intersections of ageing and disability during  
the COVID-19 pandemic.  
*Front. Sociol.* 9:1501580.  
doi: 10.3389/fsoc.2024.1501580

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# Editorial: Intersections of ageing and disability during the COVID-19 pandemic

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## KEYWORDS

ageing, disability, COVID-19, human rights, precarity, care ethics, intersectional feminism

## Editorial on the Research Topic

### Intersections of ageing and disability during the COVID-19 pandemic

The pandemic exposed the loss of human rights of older and disabled people and illustrated the critical commonalities these two groups have. As sociologists with personal and professional experience of ageing and disability, we were concerned with the proliferation of such “care-less” spaces (Rogers, 2017) and wanted to explore what could be learnt. Considering the general population’s positive trajectory in increased life expectancy, not enough has been written about experiences of ageing with, and into, disability. This Research Topic brings together a range of epistemological and methodological perspectives in five papers to understand how to situate a better future of care.

Simmonds’ article, “*From bare life and necropolitics to a feminist care ethic: ageism in the COVID-19 pandemic and future directions*,” illuminates how necropolitical decision-making was based on age as a proxy measure for health and was used to determine who received treatment. She explains “exceptional” practices that took place to ration care for older people, particularly in the first wave of the pandemic, using triaging tools in some cases regardless of availability or chances of survival. These practices contravened human rights and challenged equality legislation, yet they are not discrete incidences; rather, they can be seen as part of a continuum which, due to neoliberalization and austerity measures in the United Kingdom, often reduce older people’s treatment in the health and social care system to “bare life” conditions outside of legal protection. Simmonds argues that care ethics need to shift from employing universalistic impartial ethical frameworks, like utilitarianism, to guide decisions about care in a detached manner using standardized protocols toward relational, therapeutic, and reciprocal approaches, which integrate the care ethic characteristics of attentiveness, responsibility, competence, and responsiveness within caring networks.

Berghs et al.’s empirical research entitled “*The indignities of shielding during the COVID-19 pandemic for people with sickle cell disorders: an interpretative phenomenological analysis*” discusses the intersecting discriminations of being in a minority ethnic group, ageing, and having a chronic health condition. These intersecting structures of inequality are discussed in relation to the emotional impact they had on this population of people with sickle cell. Specifically, they refer to the fear of being “triaged” and there not being anyone to advocate for them if admitted to hospital and the ableism alongside racism, which has contributed to their condition being placed lower down the “hierarchy of illnesses.” This

article also contributes to theorising the concept of time, as how this group experienced time both sped up and slowed down during the lockdowns, and the chronicity of sickle cell did not correlate with a specific temporality, even if some described pandemic time being dissimilar to their everyday lives. Interestingly, findings also point to an inverse relationship between age and disability; when people aged, they moved from acute to less disabling chronic illness. Finally, a major theoretical contribution of this article was related to the conceptualisation of the “ethics of crisis.”

The theme of temporality was also present in [McFarland et al.’s](#) work, “*Greying arts access: crafting creative online programming to promote older adults’ artistic engagement in and beyond pandemic time.*” This participatory designed research based in Canada contributes perspectives on some of the unintended consequences of the pandemic, which enhanced access to the arts for people growing older with, or into, disability via online technologies whilst also highlighting the need for technological advancement to be designed *with* not just *for* older and disabled groups. Their innovative findings point to a shift from “pandemic time,” when virtual spaces, adapted for wider society, improved the inclusivity of older and disabled people. Their findings also point to ways in which digitalisation can both include older people in cultural artistic engagement whilst simultaneously excluding those with less digital literacy. This segues nicely into [König and Seifert’s](#) article, “*Internet usage, frequency and intensity in old age during the COVID-19 pandemic—a case study for Switzerland.*” [König and Seifert](#) analyzed large-scale survey data reporting on internet usage in later life and found that, although a growing proportion of older adults use the internet, the picture is complex. Gender differences continue to exist (women use it less) but the gap is decreasing, and class-based indicators (such as education and employment) have shaped usage. Further, interestingly they did not find that COVID-19 had any significant influence on digital adoption for older age groups despite its perceived importance in ensuring social bonds during pandemic-related restrictions on movement. Therefore, their findings point to a focus on including older people and making technology accessible.

A theme of resistance is exemplified by [Alnamnakani’s](#) article entitled “*A narrative case study of an older disabled Muslim woman during the COVID-19 pandemic in the UK.*” This gives an in-depth account of a disabled older Muslim woman’s experience of discrimination during the pandemic. This powerful piece skilfully illustrates the indirect impact that COVID restrictions had on

experiences of disablism, racism, and sexism related to public transport. This article makes an important theoretical contribution which is the assertion of agency over structure. Although Zora refused to be labeled as a victim, instead calling herself “brave” for acting against her abuser and addressing the collective safety of women, the incident still had a lasting effect on her willingness to use public transport alone. This article illustrates how political decisions in shaping social spaces that place women in vulnerable positions (particularly women who are older, minority ethnic, and/or disabled) need consideration.

This Research Topic illustrates how easily “care-ethics” can be suspended, allowing for “care-less” spaces (and times) to proliferate ([Rogers, 2017](#)). Demonstrating that vulnerability is fluid and existential, for instance, the pandemic revealed how political decision-making produced precarious groups who were then failed in terms of care ([Simmonds, 2021](#)). These articles offer in-depth original epistemological and methodological insights, evidencing the need for an “anti-ableist and anti-ageist ethics of care” to ensure the maintenance of human rights and dignity in society.

## Author contributions

BS: Writing – original draft, Writing – review & editing. MB: Writing – review & editing.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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RECEIVED 28 July 2023

ACCEPTED 12 October 2023

PUBLISHED 26 October 2023

## CITATION

König R and Seifert A (2023) Internet usage, frequency and intensity in old age during the COVID-19 pandemic—a case study for Switzerland.  
*Front. Sociol.* 8:1268613.  
doi: 10.3389/fsoc.2023.1268613

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# Internet usage, frequency and intensity in old age during the COVID-19 pandemic—a case study for Switzerland

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**Introduction:** This study examines the digital divide among older adults in Switzerland within the rapidly evolving digital environment. It investigates changes in internet usage among this population, focusing on the proportion of users, frequency, and the intensity of their internet usage during the COVID-19 pandemic.

**Methods:** Drawing on Swiss data from the Survey of Health, Aging, and Retirement (SHARE), conducted in 2021, the study analyzes a sample of 1,205 older adults.

**Results:** The findings indicate a growing proportion of internet users over time. It also highlights that gender differences persist but are decreasing. Notably, around 9% of individuals in this study had never used the internet, while recent users exhibited high activity levels, spending an average of approximately two and a half hours online daily. The study identified age, education, employment, living arrangements, and attitudes toward technology as influential factors shaping internet usage among older adults. Importantly, the COVID-19 pandemic did not have a significant impact on internet adoption among this demographic.

**Discussion:** These findings shed light on the complex dynamics that shape internet usage among older adults and underscore the need to promote digital inclusion and engagement within this population.

## KEYWORDS

COVID-19, healthy aging, ICT, internet usage, pandemic, SHARE, Switzerland

## 1. Introduction

In recent years, we have witnessed the digitalization of numerous everyday activities due to high levels of technological innovation and the rapid diffusion of information and communication technology (ICT; [Lechman, 2017](#)). Unfortunately, certain segments of the population, especially older adults, lack access to or proficiency in using this new technology ([Seifert and Cotten, 2021](#)). As a result, older adults may be at higher risk of feeling excluded from our digital society ([Seifert and Rössel, 2019](#)). Given the rapid evolution and widespread use of technology, individuals today are faced with an ever-changing technological landscape that requires continuous upgrading of devices and software as well as the acquisition of new technology skills ([Seifert and Charness, 2022](#)). Therefore, access to current digital technologies, such as smartphones, tablets, smartwatches, smart home devices, and the internet is increasingly becoming indicative of a person's ability to function effectively in our current day-to-day environment. For instance, in Switzerland, bills were recently transitioned to QR code bills which can now be scanned with an online reader like a smartphone. However, without these

technological devices, internet access, and technical skills, it is no longer possible without high effort to pay bills directly to the bank using a payment slip. Although this is a minor example, it illustrates that the exclusion of older people from using technology could also result in their exclusion from society (Seifert et al., 2021). Digital ability and access accumulate over time through individuals' exposure to digital technologies in institutional, employment, social, and family settings, which provide opportunities for both formal and informal learning (Cotten, 2021). Older adults, in particular, often lack these opportunities. Therefore, they struggle to adopt these modern technologies (Seifert and Cotten, 2021).

## 2. The digital divide in internet use

Even though older adults are increasingly adopting digital technology nowadays, they often exhibit slower adoption rates for the latest technology (Perrin and Atske, 2021). The term “digital divide” refers to the perceived gap between those who have access to the latest information technologies and those who do not, and it is applicable on a global scale. The internet serves as a prime example of modern digital technology and is thus well-suited for illustrating the digital divide. Castells (2003) defines the digital divide as the unequal access to the internet and argues that internet access is a necessary prerequisite for addressing inequalities in a society where dominant functions and social groups are increasingly organized around online platforms.

Although internet use through various devices such as computers, smartphones, and smart televisions has become widespread since the late 1990s, there is still a digital divide based on age and cohort groups regarding individual internet use (Hunsaker and Hargittai, 2018). Younger individuals are currently more inclined to embrace the internet, while adults who did not grow up using these technologies tend to use the internet less frequently. For instance, in the United States in 2021, despite the numerous benefits of the internet and the overall increase in internet usage among the general population, approximately 25% of adults aged 65 and above were not connected to online communities (Faverio, 2022). A representative survey conducted across European Union countries revealed that only 53% of individuals aged 50 years and older used the internet (König and Seifert, 2020). In Switzerland, a survey conducted in 2019 among people aged 65 and older indicated that only 74% of the respondents used the internet (Seifert, 2022). These figures are roughly comparable to internet usage among older individuals in the United States.

From these findings, the question of which older adults use the internet and which do not arises. Aside from sociodemographic characteristics (e.g., age, generation, gender, education, and income) and personal factors (e.g., health, attitudes toward technology, and ICT-related anxiety), environmental circumstances, including the availability of ICT infrastructure, also contribute to the differences in technology usage between the younger and older populations (Hunsaker and Hargittai, 2018; König et al., 2018; König and Seifert, 2020). The significance of sociodemographic and socioeconomic determinants is also emphasized in international literature. For instance, studies such as Scheerder et al. (2017) illustrate how internet use varies among different age groups and individuals with diverse educational backgrounds and financial resources. A recent study by König and Seifert (2020) focused on older adults in Europe (people

aged 50 and older) and examined changes over time to their internet usage, including transitioning online and offline, as well as the predictors of such changes at the micro, meso, and macro levels. Respondents who had not used the internet in the 7 days before the baseline but had used it in the 7 days before the follow-up interview were classified as “becoming online,” whereas the opposite behavior defined was classified as becoming offline. Overall, a major finding was the low but not negligible percentage of older adults who no longer use the internet. These changes were influenced by shifts in personal resources (such as financial resources), health-related issues (such as health limitations), and social circumstances (such as a loss of social support). Consequently, older adults can experience both gains and losses in technical competency and usage as they age.

## 3. Besides basic access: frequency and intensity of internet use

The change in the digital divide over time and among older adults makes it clear that older people can learn new technologies and that the status of being an offline is not unchangeable. However, it also means that former online users can become offline due to factors such as increasing health problems or a lack of support from their social environment. Therefore, the dichotomy of “user/non-user” often argued by the classic technology acceptance model (TAM; Davis, 1989; Venkatesh and Davis, 2000) should not be seen as a static condition. Instead, it should be seen as a dynamic process in which older people can experience gains and losses. Accordingly, internet access is only the first level of ensuring online participation. Once this level is achieved and the internet is accessible, older adults still tend to use the internet less and have fewer related technical abilities (Hargittai et al., 2019). This phenomenon, known as the second level of the digital divide (Scheerder et al., 2017), indicates that besides access to the internet, it is important to consider what older adults actually do with the internet and how frequently and intensely they use it. Research shows that, compared to younger adults, older adults use the internet less frequently and with lower intensity (Seifert and Rössel, 2019). According to the second level of the digital divide approach, the actual use of the internet is defined in terms of frequency, duration of internet use, and/or the type of activity performed online (van Deursen and Andrade, 2018). In our study, we focused on the frequency and duration (intensity) of internet use among older adults.

“Frequency” of internet use is often measured by the number of times individuals spent online within a year, and a distinction is commonly made between daily use, several times a week, several times a month, and less frequently (Seifert, 2022). Friemel (2016) observed an exponential decline in the frequency of internet use among Swiss older adults after the age of 70, indicating a decreasing trend in internet use within this age group. Therefore, there is a significant difference between older adults who use the internet only once a month and those who use it on a daily basis. In addition to frequency of use, the intensity of internet use is often assessed in media research in general (Nie and Erbring, 2002) by measuring the amount of time spent online per day (i.e., how intensively does the person use the Internet on a normal day). The results of this study revealed that older adults exhibit a diverse range of activities on the internet. For instance, a study conducted in the Netherlands (van Boekel et al., 2017) demonstrated that among individuals aged 65 years



and older, the oldest respondents (within a mean age 74 years) spent the least amount of time on the internet. These individuals, referred to as “minimizers,” reported the lowest frequencies of engagement in most internet activities and primarily utilized the internet for traditional purposes like email. On the other end of the spectrum were the “maximizers,” who were relatively younger (within a mean age below 70 years), spent the most time on the internet, and participated in a wide range of online activities. Therefore, it is crucial for research on the digital divide to encompass not only the basic categories of “use” and “non-use” but also the frequency and intensity of internet use as well as factors that predict differences in frequency and intensity.

## 4. The impact of the COVID-19 pandemic on internet use among older adults

The COVID-19 pandemic had a comprehensive and diverse impact on our everyday lives, and internet use played an especially important role in enabling older individuals to communicate, work, and receive healthcare during the pandemic (Seifert et al., 2021). However, the aforementioned digital divide was also evident during the pandemic (Robinson et al., 2020). With social distancing mandates in place in many areas of the world, social interactions were often minimized. One way in which many individuals with digital resources were able to overcome these social distancing mandates was through the use of ICT to maintain contact with their social connections. Although older adults are increasingly bridging the digital divide, a significant portion of them do not use the internet and therefore were not able to benefit from social connections, such as video calls and online meetings, via the internet.

Although internet use can assist older adults in maintaining social interaction, those who do not use the internet or only utilize its basic functions (such as those who only use email, referred to as “minimizers”) may experience social isolation due to their lack of skills and access to digital technology. The challenge of acquiring new technology skills, such as internet use, is particularly significant for older adults, some of whom had to adapt and learn these skills during the pandemic (McClain et al., 2021). Current research indicates that there was only a slight increase in internet usage among residents of long-term care facilities in Austria. This unexpected lack of a “digital push” during the pandemic highlights the existing gaps in research regarding the internet usage patterns of older adults, especially considering the ongoing impact of the pandemic.

## 5. Research questions

As the literature has indicated, numerous studies emphasize the digital usage or non-usage of the internet, particularly among older individuals, and provide explanatory factors for these patterns. However, there has been limited consideration of the COVID-19 pandemic’s context, and a comprehensive differentiation between predictors of Internet use, frequency, and intensity is absent. The present study seeks to address this research gap by utilizing data from Switzerland.

In line with the current state of research, we focused on three research questions:

- (1) How did the proportion of older internet users change between 2011 and 2021 as well as in the light of the COVID-19 pandemic?
- (2) How frequently and intensely are older adults using the internet during the first year of the pandemic?
- (3) What are the predictors for internet use, frequency, and intensity at the micro, meso, and macro levels?

## 6. Data and methods

### 6.1. Data

To address our research questions, this study utilized data from the Survey of Health, Aging, and Retirement (SHARE), which provides standardized information on individuals aged 50 years and older in various European countries. Our main sample consisted of the Swiss subsample from the second COVID-19 survey, conducted between June and August 2021. Specifically, our main variables of interest were derived from the additional drop-off questionnaire, which was administered exclusively to the Swiss sample shortly after the field phase using written questionnaires (for further details, see Börsch-Supan, 2022e). Depending on respondents’ reported internet use in the regular second COVID-19 survey, two different versions of the questionnaire were sent. While most questions were similar in both versions, respondents who indicated internet usage for activities such as emailing, information search, online purchases, or any other purpose at least once since the outbreak of the COVID-19 pandemic received a questionnaire Version A. This version included questions on individual internet usage, usage behavior, and technology experience. On the other hand, respondents who did not report recent internet use received questionnaire Version B, which was designed to gather information on their reasons, concerns, and motivations for not using the internet. In total, out of 1,751 participants from the second COVID-19 survey, 1,566 completed the additional Swiss drop-off questionnaire, resulting in a response rate of 89 percent.

While the Swiss drop-off questionnaire in 2021 includes a range of ICT-related questions, the SHARE generally asks about recent internet use in the later stages of participants’ life based on a single item starting from Wave 4 (2010/12). Although the wording of this question varies to some extent across subsequent waves, comparing them still provides initial insights into general internet use and its variations over time. Therefore, we also incorporated data from the Swiss sample of Waves 4, 5, 6, and 8 (for details, see Börsch-Supan, 2022a,b,c,d) to examine internet use trends over a 10-year period.

### 6.2. Dependent variables

Since the study focused on internet usage, frequency, and intensity, we considered different dependent variables. The first question regarding internet use was introduced in the fourth SHARE wave as follows: “Do you regularly use the World Wide Web, or the internet, for sending and receiving e-mail or for any other purpose, such as making purchases, searching for information, or making travel reservations?” From Wave 5 to Wave 8, the time limit for regular internet use was specified by asking “During the past 7 days, have you used the internet, for e-mailing, searching for information, making

purchases, or for any other purpose at least once?” While internet use was not included in the first COVID-19 survey conducted in 2020, the second survey in 2021 included the following question: “Since the outbreak of Corona, have you used the internet, for e-mailing, searching for information, making purchases, or for any other purpose at least once?” All questions contain two answer options, “yes” and “no.”

In addition to capturing this so-called recent internet use, the additional drop-off questionnaire conducted in 2021 for the Swiss subsample covers a wide range of other internet-related items. First, we assessed whether respondents had ever used the internet independently, with response options of “yes” or “no,” based on the question: “Have you ever used the internet without help?” Second, to compare general internet use over time and across different SHARE waves, we examined recent internet use based on the question “In the last 6 months, how often have you used the internet yourself on average?” Respondents could choose from six options: “daily,” “several times a week,” “several times a month,” “less often,” “never,” and “do not know.” We excluded the “do not know” responses and categorized respondents who reported daily usage or usage several times a week as “recent” internet users. Conversely, those who reported less frequent usage (several times a month, less often, or never) were classified as “non-recent” internet users. Third, we used this information with the initial coding to capture internet frequencies on a five-point scale in reverse coding from “never” to “daily.” Respondents defined as internet users in the second COVID-19 survey who answered Version A of the drop-off questionnaire were asked more questions about their daily internet usage. Therefore, we included internet intensity by using two different answers to a question. The question was, “On days when you use the internet, on average, how many hours and minutes do you spend on the internet on those days?” Respondents provided estimates for their private and professional internet use separately. Based on both answers, we calculated the overall intensity and recorded the total and private usage times in minutes. Therefore, we define intensity in terms of the duration of general internet use and did not specifically focus on different internet uses (e.g., e-commerce, social networking). We aim to incorporate intensity as a variable by considering the duration of general internet use in our analyses, as this approach is rarely used as an explanatory variable for older individuals (Hunsaker and Hargittai, 2018). As most of the surveyed individuals were already retired (78%), we analyzed professional internet use separately.

### 6.3. Independent variables

To analyze the patterns of different types of internet use in the later stages of life, we examined basic sociodemographic and economic variables. These include age (measured as a continuous variable in years), gender (differentiating between “men” and “women”), educational level, occupational status, and financial situation. Education was assessed based on the respondents’ level of education according to the International Standard Classification of Education (ISCED). It was categorized into three levels: “low” (ISCED 0–2 indicating (pre)primary and lower secondary education), “medium” (ISCED 3–4 indicating upper and post-secondary education), and “high” (ISCED 5–8 indicating tertiary education). Occupational status was coded binarily as “employed” or “unemployed/inactive.” Income was measured based on the question of whether the household had

enough money to make ends meet and split into three categories: “with great/some difficulty,” “fairly easily,” and “easily.”

As health has been found to be associated with psychological well-being and cognitive functioning, we considered the respondents’ self-rated health conditions, ranging from “excellent” and “very good” to “good,” to “fair/poor.” In addition to physical health, we included the shortened and revised Control, Autonomy, Self-realization, and Pleasure (CASP)-12 scale, which is a commonly used measure of quality of life (QoL) among older people (for details on the initial CASP scale, CASP-19, see Hyde et al., 2003; Wiggins et al., 2008). The CASP-12 scale is based on 12 items and has a range of scores from 12 (minimum) to 48 (maximum), with higher scores indicating higher subjective well-being. Considering that personality is known to be associated with social participation (e.g., Roberts et al., 2007), we also incorporated the 10-item Big-Five inventory (BFI-10), which was introduced by Rammstedt and John (2007) and obtained from the seventh wave of the SHARE survey (2011). This established personality inventory measures five dimensions of personality (openness, conscientiousness, extraversion, agreeableness, and neuroticism) with two items for each dimension (for further information on the measurement, please see Börsch-Supan et al., 2019). Each dimension can be expressed in nine different values ranging from “low” (1) to “high” (5) with increments of 0.5.

As living alone can contribute to feelings of loneliness and social isolation, especially during a pandemic when social distancing is necessary to reduce the risk of infection, we examined whether respondents live alone or not. Previous studies have highlighted the significance of regional differences in the adoption of modern technologies (König et al., 2018). These differences can be attributed to factors such as variations in broadband internet availability and diverse needs and habits related to modern technologies based on the degree of urbanization in the area. While general internet availability may not vary regionally within Switzerland (Seifert, 2022), we considered respondents’ living area by distinguishing between “urban” (big cities, suburbs or outskirts, and large towns) and “non-urban” (small towns, rural areas, and villages) places of residence. Given the geographical, linguistic, and cultural proximity of German-speaking Switzerland to Germany and Austria, French-speaking Switzerland to France, and Ticino to Italy, we made the assumption, based on the spillover hypothesis and previous research findings (e.g., König et al., 2018; König and Seifert, 2020; Seifert, 2022), that internet use, frequency, and/or intensity might vary among the three language regions in Switzerland. Although we are unable to include Romansh (Switzerland’s fourth official language) in our analysis, we acknowledged this phenomenon by differentiating whether respondents live in the “German,” French,” or “Italian” speaking part of Switzerland. Moreover, as migrants are likely to maintain connections with non-resident family members despite often living farther apart (König et al., 2021), they may have developed effective strategies for bridging distances and staying in contact through the use of modern technologies even before the pandemic. Therefore, we also considered cultural differences resulting from migration and included a variable indicating whether respondents were born in Switzerland (“yes” or “no”).

Since the data used in this study were primarily collected during the pandemic, we incorporated various factors that could potentially influence internet behavior in later life. For instance, we examined extensive social distancing situations, indicating whether respondents had never left their home throughout the last 3 months preceding the

TABLE 1 Sample characteristics.

	Min	Max	Mean/Proportion	SD
Age	50.00	96.00	72.51	8.05
Men			46.97%	
Education				
Low			14.11%	
Medium			65.06%	
High			20.83%	
Employed			18.42%	
Income				
With great/some difficulty			7.63%	
Fairly easily			29.54%	
Easily			62.82%	
Health				
Excellent			8.80%	
Very good			31.70%	
Good			42.57%	
Fair/poor			16.93%	
CASP-12	17.00	48.00	40.39	4.96
Big Five: Openness	1.00	5.00	3.70	0.91
Big Five: Conscientiousness	1.50	5.00	4.27	0.72
Big Five: Extraversion	1.00	5.00	3.51	0.96
Big Five: Agreeableness	1.00	5.00	3.68	0.78
Big Five: Neuroticism	1.00	5.00	2.45	0.94
Living alone			26.56%	
Urban area of residence			22.57%	
Language region				
German			73.78%	
French			23.32%	
Italian			2.90%	
Migrant			13.61%	
Never left home			4.12%	
COVID-19 disease: Respondent			5.02%	
COVID-19 disease: Someone close			43.79%	
Attitudes toward technology	1.00	5.00	3.01	0.82
Internet experience (years)	0.00	30.00	18.65	7.36

Notes: SD stands for standard deviation. Source: SHARE Waves 8 and 9, Swiss subsample, release 8.0.0, unweighted, own calculations.

interview (“yes” or “no”). Additionally, we considered whether respondents or individuals close to them had tested positive for the coronavirus between the first and second COVID-19 surveys which encompassed the period between summer 2020 and 2021. These variables were coded binarily (as “yes” or “no” answers) and captured different situations that could potentially impact internet usage during the pandemic.

In addition to sociodemographic factors, living arrangements, and pandemic-related circumstances, individuals’ attitudes toward and experiences with technology and ICT play a crucial in their current internet usage (König et al., 2018). To assess respondents’ attitudes toward technology, we included four statements: “Technical progress

must always go further,” “I could no longer imagine my life without technical devices,” “The increasing digitization has more advantages than disadvantages for society,” and “Robots should be used to care for the elderly.” Response options ranged from “do not agree at all” (1) to “totally agree” (5). In further analyses, these four items were combined using a summative scale score and calculated as the mean of the items ranging from 1 to 5. This scale was labeled as attitudes toward technology (Cronbach’s  $\alpha = 0.67$ ). For models investigating internet intensity, we also included respondents’ internet experience, which was measured in continuous years of past internet usage. Table 1 provides an overview of the descriptive distributions of all independent variables included in our main analysis.

## 6.4. Analytical strategy

Based on the Swiss drop-off from 2021 and merged with information from the second COVID-19 survey conducted shortly before, our main sample consists of 1,560 respondents. Out of this, we excluded all respondents who are younger than 50 years old ( $n=6$ ) and those residing in nursing homes ( $n=10$ ). We also had to exclude 112 interviews that had at least one missing value in one of our dependent variables, including 12 participants with seemingly wrong information regarding their average online activity, which exceeds the possible daily limit. The same applied to 227 respondents who had missing information in one of the explanatory variables used. Considering these exclusions, our main sample included 1,205 complete interviews investigating the different patterns of internet usage among respondents in the later stages of their lives living in Switzerland. Given the different dependent variables, our multivariate analyses were based on logistic (ever and recent use), ordinal (internet frequency), and linear (internet intensity) regressions. Before beginning our analysis, we provided a descriptive overview of the trend of recent internet use between 2011 and 2021 based on information on respondents from previous SHARE Waves aged 50 years or older who did not live in nursing homes. Moreover, based on our main sample, we also presented insights regarding different types of internet use and experiences by gender. An overview of our analytical strategy can be found in a simplified representation in the [Supplementary Table S1](#).

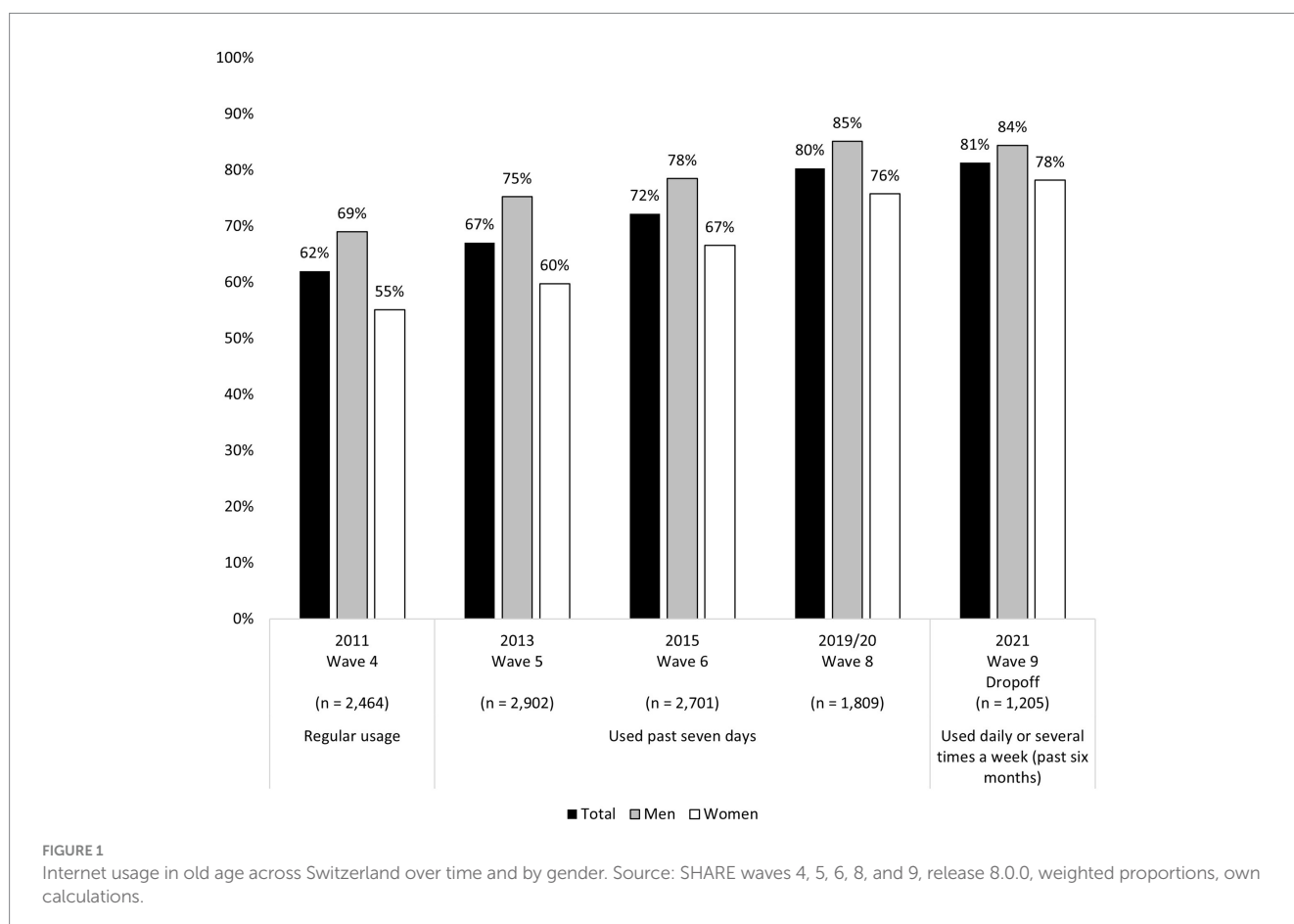
## 7. Results

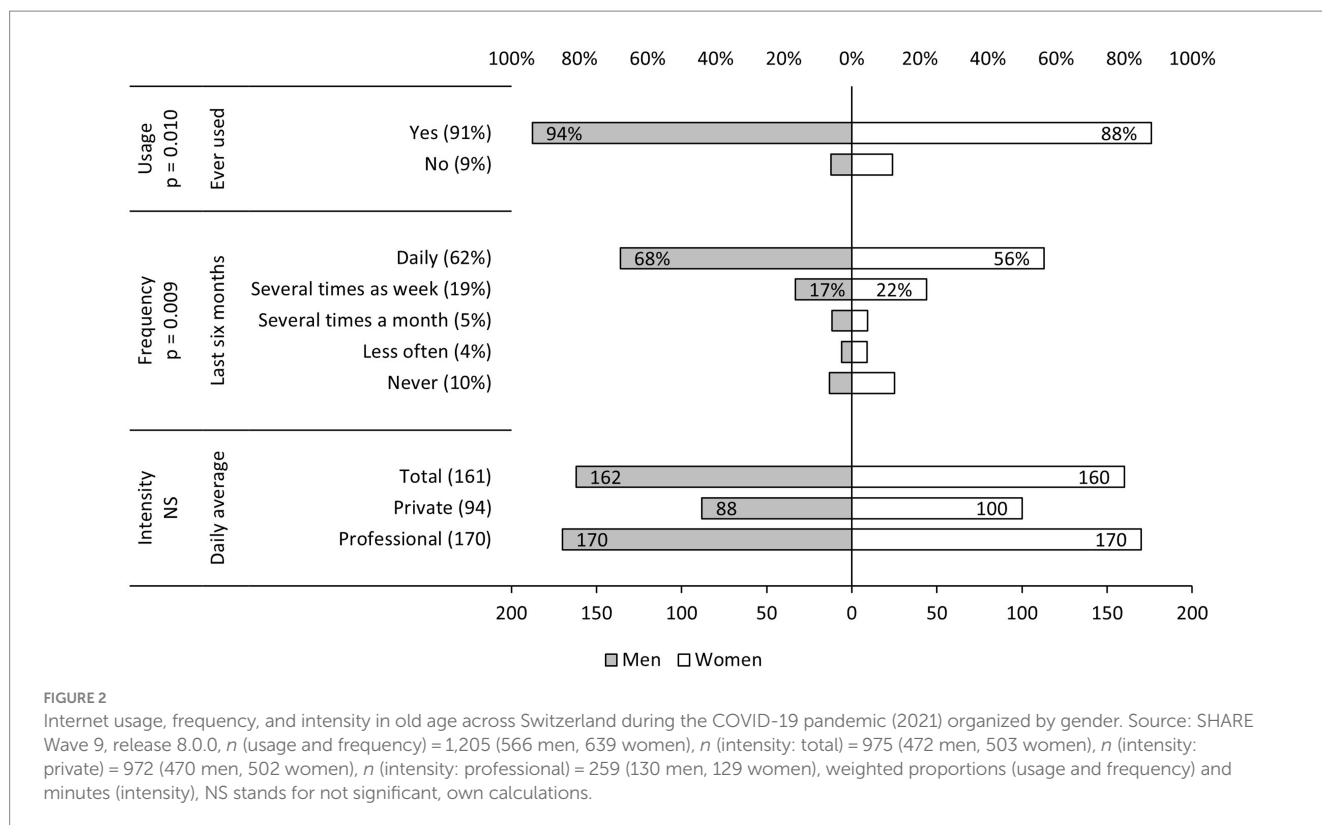
### 7.1. Trends in internet use

At a first glance at [Figure 1](#), the level of recent internet use among older adults in Switzerland shows that the majority of residents who are at least 50 years old are online. Simultaneously, our results reveal a continuous and gradual increase in this number over time. While 62% of those surveyed in 2011 were regularly online, 10 years later, this proportion increased to around 81%. Furthermore, we found evidence for both the persistence of gender differences regarding internet use and their decrease over time. In 2021, the gender gap in internet use was around 14%, but by the summer of 2021, it had declined to 6%, indicating that more women have become aware of the advantages the internet has to offer. However, the differences between women and men remain significant over time and in all observed periods (chi-squared test with  $p \leq 0.010$ ). At the same time, the results indicate that the internet usage among men appears to have plateaued, with around one-sixth not using the internet regularly.

### 7.2. Internet usage, frequency, and intensity: an overview

Based on the previous findings, we expanded the analyses of internet use across various domains: Usage, frequency, and intensity ([Figure 2](#)). The distributions indicated that approximately one in 10





individuals (9%) had never used the internet in their life. Regarding gender differences, we observed that men have significantly more experience with the internet. While 12% of surveyed women reported never having used the internet in the past, this percentage was only half as large (6%) for men. Among those who were online within the last 6 months, most of them were highly active internet users. Specifically, 62% reported being online every day, and an additional 19% reported being online several times a week. Similarly, gender-specific patterns emerged regarding internet frequency, which showed that men used the internet on a daily basis more than women (68% vs. 56%). In terms of internet intensity, we found that Swiss residents aged 50 years and older spend an average of about two and a half hours (161 min) online per day. Moreover, when differentiating between private and professional internet use, we observed that individuals spend more time online for professional reasons (170 min) than for private purposes (94 min). While general internet use and frequency vary by gender, there are no significant differences between men and women in terms of average use (intensity).

### 7.3. Internet experience and COVID-19

In addition to the previously reported recent internet behavior of Swiss residents in the later stages of their lives, the duration and experience of individuals who used the internet could play a decisive role in their current usage behavior. Based on the question “For how many years have you been using the Internet?,” it can be observed (Figure 3) that older people in Switzerland have been using the internet for an average of around 19 years. In addition to more frequent internet use, men also have on average 2 years more experience using the internet compared to women (20 years vs.

18 years,  $t$  test significant with  $p = 0.000$ ). Regarding the influence of the COVID-19 pandemic as a potential push factor for starting to use the internet, the findings in Figure 3 clearly indicate that, at least in Switzerland, this was not the case. Less than 1% of recent internet users reported starting to use the internet in 2020 or 2021. In fact, over 80% had been using the internet for over a decade. However, Switzerland already demonstrates a high level of internet diffusion among older people (Figure 1), both in comparison to other European countries (König et al., 2018; König and Seifert, 2020) and in general, which reduces the proportion of older individuals who have yet to start using the internet both in regular circumstances and in response to the pandemic.

### 7.4. Determinants for internet use, frequency, and intensity

To analyze and compare the factors influencing different patterns of internet use in later life among Swiss residents, we estimated several models considering individual characteristics, living arrangements, and pandemic-related circumstances. Additionally, attitudes and, if applicable, experiences regarding ICT were included in additional models. Table 2 presents the multivariate results for five different measures of internet use. Logistic regressions were used for never use and recent use, while ordinal regressions were employed to assess internet frequency. Linear regression analyses were applied to the models investigating internet intensity (total and private), where the average daily usage was converted to logarithmic minutes beforehand.

In general, the results confirmed previous findings that ICT usage, particular internet behavior, is strongly associated with cohort or age. Specifically, older Swiss residents are more likely to have no prior



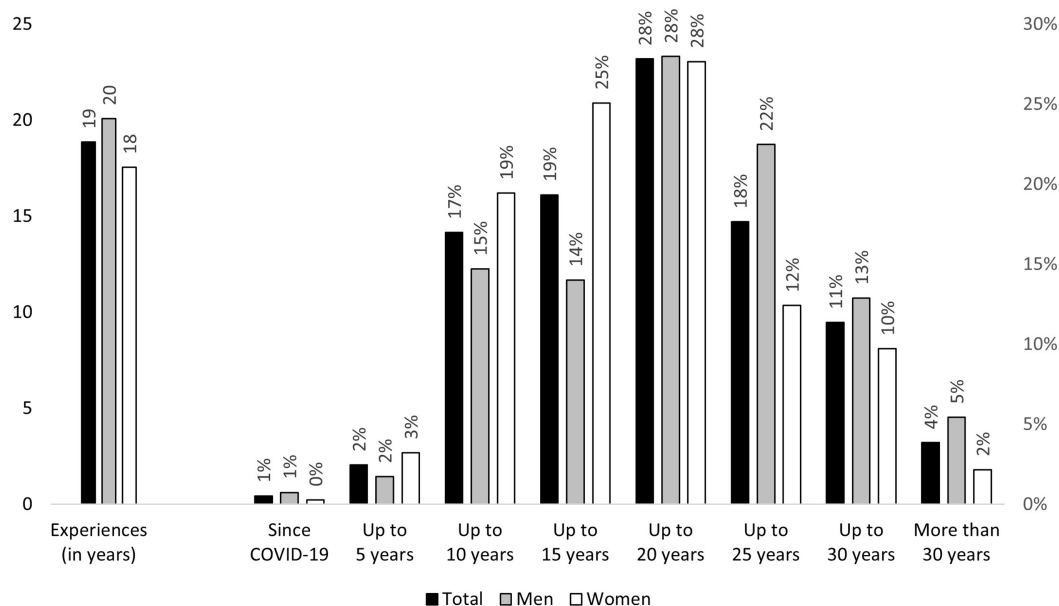


FIGURE 3

Internet experience in old age across Switzerland by gender. Source: SHARE Wave 9, release 8.0.0,  $n = 980$  (503 women, 477 men), weighted, own calculations.

experience with the internet. Furthermore, recent internet use and frequency are negatively correlated with age. However, when considering respondents' experience with the internet, the average daily intensity of being online does not vary by age. In other words, age does not affect internet intensity if individuals had early experiences with the internet. The often-discussed gender gap in internet behavior (Mariscal et al., 2019) was partially confirmed in our analyses, as men were more likely to have recent and frequent internet use compared to women. However, there were no gender-specific differences in terms of overall and daily usage. While the latter finding aligns with our descriptive results (Figure 2), the higher proportion of non-users among women becomes less significant when accounting for respondents' education, indicating the importance of higher educational credentials in determining internet usage experiences.

Our findings for education were similar to those for age, as less educated individuals had a higher likelihood of never being online and used the internet less frequently and less often recently. In contrast, employment did not affect internet use and frequency, but it did impact intensity. We found that employed respondents had a higher overall daily internet intensity but were less intense online for private matters. This suggests that many professions in Switzerland require the use of ICT. Like employment, the financial situation only affected average daily usage. Swiss residents whose households were able to make ends meet (fairly) easily used the internet less intensively in their daily lives compared to those reporting some or great financial restrictions.

Considering their various life circumstances, subjective health did not have a direct impact on internet behavior in later life. In contrast, respondents with a higher quality of life, as measured by CASP-12, were not only more likely to have ever used the internet, but they also used it more often and more frequently recently. However, they exhibited lower intensity in their online activities. Regarding the influence of personality on internet use, the findings indicated that

individuals with a high level of openness were more likely to be open to technology such as the internet and had more often and frequent experience with it. On the other hand, only conscientious individuals with a high degree of self-control, accuracy, and determination used the internet with significantly less intensity in their everyday lives.

We also observed that living arrangements and structural cultural patterns partly influenced individuals' internet behaviors. Respondents who lived alone and thus had fewer social interactions in their home environment spent more time online on average. The urbanization of their living area did not have any impact on the examined measures of internet use, indicating that general internet access did not vary between (big) cities and rural areas in Switzerland. Regarding regional differences within Switzerland, we found that respondents aged 50 years and older living in Ticino were more likely to have no experience with the internet at all. For those with internet experience, there were no differences among the three language regions in terms of recent use, frequency, and intensity. However, it is important to note that while the sample size of Italian speaking respondents roughly corresponds to their percentage of the total population (Table 1), the relatively small sample size may lead to potential under- or overestimations of the observed effects. Regarding differences caused by migration, the results highlight that foreign-born residents of Switzerland spend more time using the internet than the native population in the same age group. However, this effect seems to be true for total internet use but not private intensity. This suggests that non-natives are more likely to be employed in jobs involving internet use.

Furthermore, the inclusion of pandemic-related events at the individual level indirectly affected internet use in 2021. Being isolated at home or personally infected by COVID-19 did not appear to have any effect on internet use. However, if someone close to them was infected, it became important. In such cases, respondents were more likely to be online more often and frequently (though not intensely).

TABLE 2 Patterns of internet usage, frequency, and intensity in Europe.

	Never used		Used in the last 6 months		Frequency		Intensity (total)		Intensity (private)	
	OR	OR	OR	OR	R	R	R	R	R	R
Age	1.14***	1.15***	0.90***	0.90***	−0.06***	−0.06***	−0.01**	−0.01	−0.01	−0.01
Men	0.65	0.65	1.46*	1.46*	0.21**	0.20**	0.07	−0.01	−0.01	−0.07
Education (Ref.: Low)										
Medium	0.35***	0.34***	1.82**	1.81**	0.33**	0.32**	−0.03	−0.01	−0.05	−0.04
High	0.11***	0.11***	4.05***	3.95***	0.80***	0.77***	0.19	0.14	0.17	0.13
Employed	0.38	0.37	1.33	1.36	0.09	0.12	0.60***	0.62***	−0.22**	−0.20*
Income (Ref.: With great/some difficulty)										
Fairly easily	0.94	0.89	0.86	0.93	0.02	0.06	−0.28*	−0.26*	−0.38**	−0.36**
Easily	0.93	0.92	1.10	1.13	0.09	0.09	−0.31*	−0.35**	−0.40**	−0.43***
Health (Ref.: Excellent)										
Very good	1.06	0.96	1.03	1.04	−0.11	−0.09	0.09	0.07	0.06	0.05
Good	2.44	2.09	0.69	0.74	−0.25	−0.22	0.12	0.09	0.11	0.09
Fair/poor	2.17	1.80	0.67	0.72	−0.31	−0.28	0.02	0.02	−0.03	−0.03
CASP-12	0.94*	0.95*	1.05**	1.04*	0.03**	0.02**	0.01	0.01	0.01	−0.01
Big Five: Openness	0.79*	0.79*	1.27**	1.26**	0.13***	0.12**	0.03	0.02	0.01	0.01
Big Five: Conscientiousness	1.16	1.07	0.88	0.92	−0.11	−0.09	−0.09*	−0.09*	−0.13***	−0.12***
Big Five: Extraversion	0.93	0.92	1.03	1.03	0.01	0.01	0.02	0.03	0.03	0.04
Big Five: Agreeableness	0.91	0.92	0.98	0.98	−0.02	−0.01	−0.02	−0.01	−0.04	−0.03
Big Five: Neuroticism	1.07	1.01	0.93	0.97	−0.04	−0.02	−0.02	0.01	−0.01	0.01
Living alone	0.92	0.85	0.96	0.99	−0.02	−0.02	0.18**	0.15**	0.17**	0.14**
Urban area of residence	1.09	1.26	1.11	1.01	0.01	−0.03	0.11	0.09	0.09	0.08
Language region (Ref.: German)										
French	0.81	0.96	1.08	0.93	0.09	−0.01	−0.02	−0.04	−0.01	−0.02
Italian	3.06*	3.20*	0.53	0.53	−0.35	−0.35	0.18	0.24	−0.09	−0.03
Migrant	0.97	1.00	0.89	0.82	0.15	0.09	0.21**	0.17**	0.10	0.07
Never left home	/	/	1.02	0.99	0.12	0.11	0.10	0.06	−0.04	−0.08
COVID-19 disease: Respondent	/	/	0.69	0.74	0.01	0.05	−0.12	−0.13	−0.04	−0.05
COVID-19 disease: Someone close	/	/	1.52**	1.53**	0.19**	0.19**	−0.03	−0.03	−0.04	−0.04
Attitudes toward technology	/	0.44***	/	1.85***	/	0.39***	/	0.13***	/	0.12***
Internet experience (years)	/	/	/	/	/	/	/	0.03***	/	0.02***
N	1,205	1,205	1,205	1,205	1,205	1,205	975	975	972	972
R <sup>2</sup>	0.28	0.33	0.20	0.23	0.12	0.14	0.18	0.24	0.07	0.14

Notes: Logistic (“never used” and “used last 6 months”), ordinal (“frequency”), and linear (“intensity”; total and private) regressions. Odds ratios (OR) and regression coefficients (R) displayed; robust standard errors; / stands for not applicable; significance levels: \*\*\*  $p \leq 0.001$ , \*\*  $p \leq 0.010$ , \*  $p \leq 0.050$ . Source: SHARE Waves 8 and 9, release 8.0.0, unweighted, own calculations.

This could be attributed to their increased need for obtaining pandemic-related information and news as well as staying in contact with family, relatives, and friends through online means.

Finally, when examining attitudes toward technology and internet experience, specific influences on current internet use were observed. In general, higher levels of curiosity and interest in technology were

associated with a greater likelihood of having used the internet in the past and currently. Similarly, respondents with a stronger affinity for technology were more frequent and engaged in more intensive online activities. Furthermore, a greater affinity for technology could also be inferred from earlier internet usage, which significantly impacted internet intensity. The longer respondents had been using the internet, the more time they spent online every day. Moreover, including both ICT-related items at the individual level yielded the best model fit for each of the dependent variables used. This emphasized that the use of the internet in the later stages of life strongly depends on one's own interest in modern technology and one's personal experiences with it. In other words, technological curiosity accelerates early adoption of the internet and, consequently, its continued use in later life.

## 8. Discussion

This study explored the digitalization processes shaping peoples' everyday life in the 21st century and their impact on individuals' development later in life. It highlights the significance of the person-environment fit in successful aging and emphasizes the role of technology in this context. However, older adults often lack access to and proficiency in using new technologies, which can lead to their exclusion from the digitally dominated society (Hunsaker and Hargittai, 2018). The digital divide, particularly regarding internet use, is still present among older adults based on age and cohort groups. Besides basic access, the frequency and intensity of internet use among older adults are important factors to consider. The COVID-19 pandemic has further highlighted the digital divide, with internet use playing a crucial role in enabling older individuals to communicate and access various services (Seifert et al., 2021). However, those who do not use the internet or have limited internet skills may experience social isolation (Robinson et al., 2020). This article presents three research questions to address these issues: the change in the proportion of older internet users over time, the frequency and intensity of internet use during the pandemic, and the predictors of internet use at different levels.

The findings revealed that the majority of Swiss residents aged 50 and above are online, with a continuous increase over time. Gender differences in internet use persist but have diminished over the years, with an increasing number of women becoming aware of the advantages of the internet, as observed in other recent European studies (Bünning et al., 2023). However, differences between men and women remain significant. The study also explored internet usage, frequency, and intensity. Approximately 9% of individuals have never used the internet, with men having more experience than women. Among recent internet users, a majority are highly active, with 62% being online every day. Swiss residents aged 50 and older spend an average of about two and a half hours online per day, with more time spent on professional use than private use. The duration and experience of internet use play a role in current usage behavior, with older people in Switzerland having an average of around 19 years of internet experience. The COVID-19 pandemic did not significantly influence internet adoption among older adults in Switzerland. Current findings from other studies also suggest that Internet use among older individuals has not significantly increased during the pandemic, in contrast to the expected substantial rise over a 1–2-year period (Gallistl et al., 2021). Factors such as age, education,

employment, living arrangements, and attitudes toward technology are associated with different aspects of internet use.

In terms of determinants of internet use, higher age is associated with no prior internet experience, lower recent use, and less frequency. These results are in line with previous findings (Olson et al., 2011). However, age does not affect internet intensity if individuals had early experiences with the internet. Men are more likely to have more recent and frequent internet use compared to women, but there are no gender differences in overall and daily usage when accounting for education. A lower education level is associated with a higher likelihood of never being online and less frequent and recent use. Employment is related to higher overall daily internet intensity but less intensity for private matters, suggesting that certain professions in Switzerland require ICT use. Subjective health does not directly impact internet behavior, but a higher quality of life is associated with more frequent and recent internet use. Personality traits, such as openness and conscientiousness, also play a role in influencing internet usage. This aligns with previous research among younger adults, which demonstrated that conscientiousness predicts overall Internet use (Mark and Ganzach, 2014). However, research that also includes older adults (born before 1964) has reported that conscientiousness was a significant predictor of internet usage only for the younger individuals (born after 1965), not for the older adults (Roos and Kazemi, 2021). Living arrangements, urbanization, and regional differences have partial effects on internet behavior. Foreign-born residents spend more time online than the native population, especially for total internet use. Pandemic-related events indirectly affect internet use, with individuals being more online when a close person is infected. Attitudes toward technology and internet experience play a significant role in current internet use, with curiosity, interest, and affinity for technology influencing internet adoption and intensity. Overall, the study highlighted the multifaceted factors that shape internet use among older adults in Switzerland.

Given that this study specifically concentrated on Switzerland, the generalizability of our findings to contexts outside of Switzerland may be limited. Nevertheless, the data from Switzerland can serve as a valuable case study. Although the SHARE data allows us to examine internet usage among older adults in various European countries, there are some important variables that were not included in the survey. These variables include technological biographies, technology acceptance, technology use within households, and the reasons for non-use. Future studies using representative data should aim to investigate the factors influencing changes in internet usage status more comprehensively. This can be achieved using longitudinal studies which provide a deeper understanding of how internet use evolves over time. Furthermore, international data is necessary to gain insights into the digital divide, including whether the divide exists among different age cohorts and/or countries as well as how it develops over time.

However, based on the findings, social policy recommendations to promote internet use among older adults in Switzerland could include targeted initiatives to reduce the gender gap and increase digital literacy, particularly among women (Bünning et al., 2023). Additionally, providing accessible digital education programs for older adults with lower levels of education and addressing the specific needs and preferences of older adults in designing online services and platforms can contribute to enhancing their internet adoption and engagement. An example would be providing specific training with

individualized support for older adults. Other studies have demonstrated the moderating effect of technology training and support on the relationship between technology exploration and perceived learning difficulties (Tsai et al., 2019).

## 9. Conclusion

This study examined the digital divide among older adults in Switzerland during a worldwide pandemic. It focused on the proportion of users, frequency, and intensity of use during the COVID-19 pandemic. The findings indicated a growing proportion of internet users over time, although around 9% of individuals involved had never used the internet, while recent users exhibit high activity levels, spending an average of approximately two and a half hours online daily. The study identified age, education, employment, living arrangements, and attitudes toward technology as influential factors determining internet use in 2021. Nevertheless, the COVID-19 pandemic did not have a significant impact on internet adoption among older adults, showing that there was not a big “digital push” among this segment of the population. These findings shed light on the complex dynamics that shape internet use among older adults and underscore the need to promote intervention to aid in the digital inclusion of this segment of the population.

## Data availability statement

Publicly available datasets were analyzed in this study. This data can be found at: the datasets analyzed for this study can be found in the SHARE Research Data Center (<https://share-eric.eu/data/>).

## Author contributions

RK: Writing – original draft, Writing – review & editing. AS: Writing – original draft, Writing – review & editing.

## Funding

The author(s) declare no financial support was received for the research, authorship, and/or publication of this article. This paper uses data from SHARE Waves 8 and 9 (Börsch-Supan, 2022c,d,e); see

Börsch-Supan et al. (2013) for methodological details. The SHARE data collection has been funded by the European Commission, DG RTD through FP5 (QLK6-CT-2001-00360), FP6 (SHARE-I3: RII-CT-2006-062193, COMPARE: CIT5-CT-2005-028857, SHARELIFE: CIT4-CT-2006-028812), FP7 (SHARE-PREP: GA N°211909, SHARE-LEAP: GA N°227822, SHARE M4: GA N°261982, DASISH: GA N°283646) and Horizon 2020 (SHARE-DEV3: GA N°676536, SHARE-COHESION: GA N°870628, SERISS: GA N°654221, SSHOC: GA N°823782, SHARE-COVID19: GA N°101015924) and by DG Employment, Social Affairs & Inclusion through VS 2015/0195, VS 2016/0135, VS 2018/0285, VS 2019/0332, and VS 2020/0313. Additional funding from the German Ministry of Education and Research, the Max Planck Society for the Advancement of Science, the US National Institute on Aging (U01\_AG09740-13S2, P01\_AG005842, P01\_AG08291, P30\_AG12815, R21\_AG025169, Y1-AG-4553-01, IAG\_BSR06-11, OGHA\_04-064, HHSN271201300071C, RAG052527A) and from various national funding sources is gratefully acknowledged (see [www.share-project.org](http://www.share-project.org)). The data were adjusted for this investigation, for which extensive consistency checks were made.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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## Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fsoc.2023.1268613/full#supplementary-material>

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## OPEN ACCESS

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RECEIVED 07 November 2023

ACCEPTED 15 January 2024

PUBLISHED 13 February 2024

## CITATION

Berghs M, Horne F, Yates S, Kemp R and  
Webster A (2024) The indignities of shielding  
during the COVID-19 pandemic for people  
with sickle cell disorders: an interpretative  
phenomenological analysis.  
*Front. Sociol.* 9:1334633.  
doi: 10.3389/fsoc.2024.1334633

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# The indignities of shielding during the COVID-19 pandemic for people with sickle cell disorders: an interpretative phenomenological analysis

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This article seeks to understand the first-hand experiences of people with sickle cell, a recessively inherited blood disorder, who were identified as clinically extremely vulnerable during the COVID-19 pandemic. Part of a larger sequential mixed-methods study, this article uses a selective sample of eight qualitative semi-structured interviews, which were analysed using interpretative phenomenological analysis (IPA). The first stage of IPA focused on practical concerns participants had correlated to understanding shielding and their feelings about being identified as clinically extremely vulnerable. In a secondary stage of analysis, we examined the emotions that it brought forth and the foundations of those based on discriminations. This article adds to our theoretical understanding of embodiment and temporality with respect to chronicity and early ageing. It explains how people with sickle cell disorders have an embodied ethics of crisis and expertise. It also elucidates how people's experiences during the pandemic cannot be seen in void but illustrates ableism, racism, and ageism in society writ large.

## KEYWORDS

shielding, COVID-19, sickle cell disease, pandemic, ableism and racism

## Introduction

On 23 March 2020, a national 'lockdown' was announced in the United Kingdom by the then British Prime Minister, Boris Johnson, in response to the threat from the severe acute respiratory syndrome coronavirus (SARS-CoV-2), now commonly known as COVID-19. While different in each of the devolved nations, in England, 'lockdown' was typified by the public being asked to 'stay at home', limit social contacts, ensure social distancing, and only leave the house for essentials, such as to go food shopping or attend urgent medical appointments. The lockdown was initially introduced for a short period of 12 weeks but lasted for about a year, ending officially on 19th of July 2021. People with compromised immune systems, serious illnesses, disabilities, or chronic conditions were identified, initially by the National Health Service (NHS) and then by their GPs, as 'clinically extremely vulnerable' (CEV) to the COVID-19 virus and were asked to 'shield' by the government. Shielding was a

novel societal concept, defined as ‘extreme isolation’ with the aim of protecting people classified as CEV or thought to be at high risk, such as older people.

The main rules for people who were CEV included: (1) not leaving a household unless urgently required, such as for medical reasons and (2) isolating from other members of the household. To aid people in shielding, many initiatives were introduced, such as the provision of food parcels, virtual GP and consultant appointments, medication deliveries, and working from home policies. While there were provisions made to ensure social contacts, such as allowing families and singles to form ‘bubbles’ with other households, people who were shielding were initially excluded from such measures. Being in bubbles also did not protect people from the effects of ‘extreme isolation’, including increased loneliness as well as anxiety and depression (Carr et al., 2021; Fancourt et al., 2021). For instance, evidence from the English Longitudinal Study of Aging (Di Gessa and Price, 2022) shows that older adults (50+) who were shielding experienced worse mental health.

Despite concerns about the physical and mental health of CEV people who were shielding, a complex picture was emerging. Kemp et al.’s (2020) study in the early days of shielding found that high-risk patients felt vulnerable and anxious but also that they were very resilient in coping. Westcott et al.’s (2021) study with cystic fibrosis patients noted that depression rates were low and remained stable, while there were higher rates of anxiety. Similarly, while they had a small sample ( $n = 25$ ), Kemp et al. (2020) also found that almost half of the patients they surveyed felt that shielding had not really changed their lives, as due to their condition of multiple myeloma, they were already living in social isolation. Robinson et al. (2022), in a systematic review of longitudinal studies, found that while mental health was affected early in the pandemic from March 2020, it decreased mid-pandemic and was comparable to pre-pandemic levels in most population groups.

These studies show nuances in how people experienced shielding but do not investigate the underlying causes of poorer mental health. In this article, we try to understand some of these underlying causes by reporting on qualitative data from a sequentially designed mixed-methods study conducted during the pandemic. We document physical and mental health in a small cohort of participants of African and African Caribbean origin who had sickle cell disease (SCD).

In England, SCD is one of the most common genetic conditions, with estimates of 14,000 people affected (Dormandy et al., 2018). The condition affects the haemoglobin in red blood cells, causing them to form sickle-like shapes, which can cause blockages to the major organs and severe pain, necessitating emergency care, which is called a crisis (Kavanagh et al., 2022). The causes of a pain ‘crisis’ can be exacerbated by a host of different factors, including (1) environment, such as extremes in temperature or strenuous exercise; (2) physiological, like a lack of hydration or proper nutrition; (3) psychological, in terms of stress or excitement; and (4) structural issues correlated to inequalities, such as the inability to access proper housing or good healthcare (Dyson, 2011).

SCD is thus characterised by its uncertainty (Rouse, 2009), in that while there is a severe (HbSS) and mild (HbSC) version, depending on varied circumstances affecting a person, it can be a chronic condition, in others it is a disability, and for some it is life-threatening, but it can also be all these things for one and the same person. As people age with SCD, they will also experience more complications

linked to SCD as well as co-morbidities and impairments due to ageing and this will happen at an earlier and accelerated time than in the general population (Idris et al., 2022). Yet, in day-to-day life, most people with SCD, even if they are experiencing pain or fatigue, look fine, which is why SCD is viewed as an invisible condition or disability (Ciribassi and Patil, 2016) but is often bureaucratically contested as a disability (Das, 2022; Srikanthan, 2023). Within healthcare settings, where people with SCD encounter structural racism, identification with affirmative Black identity and explaining SCD as a serious medical condition often take precedence over any ‘disability’ identity. Even in schools and employment settings, the identification of disability identity and ascription of necessary rights could be a struggle for people who outwardly might look ‘able’ and/or have to deal with other discriminations (see Berghs and Dyson, 2022). The pandemic seemed to be the first time that there was this public bureaucratic and medical recognition of people with SCD as having a clinically serious condition.

We felt it was important to not only try to identify any physical or mental health needs in this population using a validated quality of life measure (SF36) (see Berghs et al., 2022) but also to deploy qualitative, semi-structured interviews to understand how the phenomenon of shielding and identification as a CEV person was experienced. Furthermore, using an interpretative phenomenological analysis (IPA), we explored the emotions that this brought forth and found that participants felt that discriminations within society were heightened during the pandemic. Even though some participants reported health improving, most participants reported worse mental health as the pandemic raised risks correlated to how SCD is embodied, temporality with respect to chronicity, and understandings of ageing and mortality.

## Background

Ableism, disablism, ageism, and racism are all forms of discriminations (Overall, 2006) that became foregrounded during the global pandemic. Lockdown was a divisive policy in the popular press and amongst scientists, with the health of a minority ‘vulnerable’ to COVID-19 pitted against the economic health of the state and the majority who were fit and healthy (Dorling, 2020). Inclusion London (2020) noted how disabled people felt forgotten and ignored during the pandemic despite policies of lockdown. Thus, Arcieri (2022) found that increased anxiety amongst older adults during the pandemic was correlated to ageism and ableism in society. Ableism (Campbell, 2008, 2009), the prioritisation of fit and healthy bodies (Andrews et al., 2021), and disablism, the discrimination against people with impairments causing them to become ‘disabled’ (Oliver, 1983), such as premature deaths of people with intellectual disabilities, were defining features of the pandemic (Walmsley, 2020; Heslop et al., 2021; Chicoine et al., 2022).

The pandemic also exposed how being identified with ‘pre-existing conditions’ in clinical settings could bring up discussions of ‘quality of life’ and curtail rights to life-saving treatments (Abrams and Abbott, 2020). The medical rationing of ventilators, triaging with limited access to treatment, and negative psychological impact of shielding language and practices on older populations in the early pandemic highlighted ageism in society (Monahan et al., 2020; Ramirez et al., 2022). Ableism was also foregrounded in how previously inaccessible hybrid and flexible working policies, as well as reasonable

accommodations and equipment to be able to work from home, were granted during the pandemic (Ocean, 2021; Samuels and Freeman, 2021). Masking mandates and the refusal of some people to wear masks to protect populations made 'vulnerable' were also deemed ableist (Grunawalt, 2021).

Older and disabled people also argued that the way in which their health and social care was organised, for example, in care homes, by support workers, or in hospitals, did not allow for shielding, necessitated embodied contact, and left them more vulnerable to the risks of COVID-19 infection and death (see Shakespeare et al., 2021). This also indicated unequal class and other privileges in society, with some population groups able to shield, maintain social distancing, stay at home, and mask, while others could not shield or had to work, for example, as frontline healthcare workers. Goodley et al. (2023) note that this also heightened the feelings of vulnerability in the chronic and disabled populations and brought to the fore anxieties and fears. Yet, they also note how the pandemic also brought with it affirmation of life and resilience in mutual aid groups, peer interventions, and adaptation (Goodley et al., 2023). Samuels and Freeman (2021) found that the pandemic highlighted 'crip-time' in that disabled and chronically ill people often experience time differently from the 'chrononormative' and ableist way that time is used to structure and control life. They found that 'crip-time' (Kafer, 2013, 2021) was what everyone began to experience during the pandemic; in that time was no longer linear but unpredictable. They argue that while crip-time can be liberating, it can also feel enforced as it becomes predicated on the disabled body-mind and how temporality is interlinked to 'race', colonialism, gender and sexuality' (Samuels and Freeman, 2021).

Goodley et al. (2023) and Samuels and Freeman (2021) thus mostly highlight an elitist positioning in resistance to 'slow time', noting how some disabled people are not granted any 'time' nor 'survival'. Furthermore, Levy et al. (2023) argue that the pandemic exacerbated a crisis of ageism in how policies and language used during the pandemic created such vulnerabilities, which affected some people over others. The way in which the pandemic was spoken about was often in militaristic terminology; for instance, as an invisible enemy, people had to 'fight' with healthcare workers viewed as self-sacrificing individual 'heroes' (see Cox, 2020). The militaristic language also brought to the fore the able-bodied warrior as the patriarchal ideal productive norm of late capitalist society. Tremain (2023) argues that this is 'disaster ableism' in how the pandemic could be exploited to normalise the norms, values, and beliefs of ableism. The militarised language hid the fact that it was inequalities and structural violence in a lack of welfare provision that made certain population groups more vulnerable, which was in turn, caused by government neoliberal economic policies (Lohmeyer and Taylor, 2021). Barrett et al. (2021) found that the language of sacrifice on Twitter, during the pandemic indicated a 'calculated ageism' in that the older population was deemed worthy of sacrifice for the younger generation and the economic needs of a country.

Thorneycroft and Asquith (2021) thus theorise that the pandemic brought to the fore and made visible fears of societal and structural 'violence' in becoming disabled, abject, and thus disposable. Like other scholars, they argue that the pandemic represented a necropolitical (Mbembe, 2003) continuum of neoliberal capitalism, where the state becomes sovereign in deciding which bodies matter and which do not (Thorneycroft and Asquith, 2021). This necropolitical order was also underpinned by class and racial inequalities, which were made more visible during the pandemic in the deaths of minoritised populations

(Sandset, 2021; Ramirez et al., 2022), as well as amongst frontline healthcare workers. Early in the pandemic, Laster Pirtle (2020) contended that even in a supposedly 'deracialised' neoliberalism, COVID-19 was another feature of racialised capitalism, noting that it was racialised and economically deprived groups that would be impacted the most. These concerns became highlighted with the death of George Floyd on 25 May 2020 and the Black Lives Matter movement during the pandemic (Sobo et al., 2020). Black people have always suffered unequal violence in structural discriminations in embodied distress, chronicity, disability, illness, and deaths, but the pandemic made these disparities more visible (see Carney et al., 2023). The embodied impacts of inequalities, stress, and discriminations that lead to adverse life outcomes, bad physical and mental health, as well as accelerated ageing and disability, have furthermore been linked to bodies 'weathering' such traumas and accelerated ageing (Geronimus, 2023).

While ableism, racism, and disablism can exist together, they must also be seen as separate from each other. Adopting an intersectional lens (Crenshaw, 1991) means that we can differentiate between (1) ageing with physical, cognitive, sensory, and emotional impairments, (2) gaining impairments as we age, and (3) discriminations, such as becoming 'disabled' which, according to a social model of disability, is when society discriminates against people with impairments (Oliver, 2013). Similarly, van der Horst and Vickerstaff (2022), using Thomas's (1999) social-relational model of disability, describe how, for them, ageism is a form of social oppression. Thomas (2012, 2019) argued that disablism allowed disability to come to the fore through avoidable discriminatory practices and oppressions. She also made a distinction between 'restrictions of activities' that were not disabilities. Instead, Thomas (2012, 2019) argued that impairments and impairment effects (the direct and unavoidable impacts of impairments on embodied functioning), were bio-socially and culturally constructed, in that while they may be predicated on biology or the body, they were also socially and culturally created too. Hence, van der Horst and Vickerstaff, (2022) argue, "Ageism would be differential treatment based on age, not based on impairments. Differential treatment based on (real or expected) impairments would be ableism." Ageism then becomes separated from the effects of ageing or 'age effects', which may be different from 'impairment effects' and ableism.

In the pandemic, discriminations and oppressions worsened, and it seemed as if they could have an impact on age and impairment effects. Yet, the evidence from the pandemic also seems to indicate that we view age and impairment effects as monolithic when people can have multiple age and impairment effects. Similarly, age effects, like co-morbidities, might worsen because of worsening impairment effects. We also note how evidence seems to suggest that discriminations can accelerate ageing and impairments. This also calls into question ageing as visible and temporally constructed to a norm, as there may be forms of disability that are correlated to early ageing. In what follows, we try to contextualise the above literature and theory to the experiences of people with SCD as CEV and shielding during the pandemic.

## Methods

The study was conducted in the Midlands region of England between June 2020 and June 2021, during the COVID-19 pandemic. The Midlands region encompasses the city of Birmingham, which had

some of the highest rates of COVID-19 deaths in NHS Trusts outside of London, as well as having some of the longest periods of lockdown with the city of Leicester (see [Berghs et al., 2022](#)). Ethical approvals for this project were given by the De Montfort University Faculty of Health and Allied Health Sciences Ethics Committee in 2020. The project was co-produced with two voluntary organisations based in the Midlands, OSCAR Birmingham and OSCAR Sandwell, who were also responsible for sharing information about the project.

We used a sequential mixed-method design to explore the perspectives of people with SCD towards shielding during the COVID-19 pandemic ([Berghs et al., 2022](#)). The qualitative phase of the study used interpretative phenomenological analysis (IPA) due to the methodological need to understand the phenomenon of shielding from participants' perspectives ([Smith and Fieldsend, 2021](#)). IPA has been used successfully in previous SCD psychology research using smaller sample sizes ([Erskine, 2012](#); [Coleman et al., 2016](#)). Semi-structured interviews were conducted at different points throughout the pandemic, with one being conducted after the end of shielding to ensure comparison. All interviews lasted around 50 min to an hour and a half and were audio-recorded, with verbal and written consent being given by all participants ([Bryman, 2016](#); [Lobe et al., 2020](#)). We also ensured that a Black person with SCD who had a background in counselling was available for interviews and that we could signpost participants to the voluntary sector for further support if needed.

We felt this was ethically important due to the sensitive issues that came to the fore around racism and deaths in NHS services. For the same reasons and increasing pressures on the voluntary sector as the pandemic progressed, we decided to switch to IPA, allowing us to recruit a smaller sample size (6–8 people), but that would allow a deeper understanding of a phenomenon from the participant's perspective ([Smith and Fieldsend, 2021](#)). In total, eight participants with SCD took part in the interviews, comprising six women and two men. The in-depth, semi-structured interviews occurred via the online platforms of WhatsApp, Zoom, and Teams and were audio-recorded ([Lobe et al., 2020](#)). Participants were selectively sampled ([Bryman, 2016](#)) to determine whether their physical health deteriorated, improved, or remained the same during the pandemic. We also chose to recruit an even split of people with SCD who had caring responsibilities and people who did not, as well as those employed and unemployed, although one person was experiencing furlough and another was having a break from work. Three participants were in their 20s, three participants were in their 30s, one participant was in their 40s, and one was in their 60s.

We used the qualitative software analysis programme NVivo to organise and code our data according to a dual hermeneutics, which ensured we stuck closely to participants' understandings ([Pietkiewicz and Smith, 2014](#)). The emergent themes were also checked against any theories or findings correlated to shielding ([Layder, 1998](#)). We checked data analysis and thematic coding with a clinical psychologist and other members of the research team to ensure interpretation was sticking closely to how participants were making sense of their experiences of CEV and the phenomenon of shielding. We also triangulated the data with the findings from the survey to ensure further rigour, validity, and contextualisation ([Bryman, 2016](#)). Initially, we thus examined NHS treatment and care as those were significant codes and themes in our data analysis and triangulated strongly with the quantitative data ([Berghs et al., 2022](#)). However, to understand those experiences, we had to contextualise

being identified as CEV and what shielding entailed for people. We initially examined emotions but realised that those became connected to experiences of racism and ableism. In this article, we report on those wider thematic findings from the semi-structured interviews using IPA.

## Findings

In our quantitative analysis, we found that there was worse quality of life and mental health during the pandemic, and this was linked to discrimination ([Berghs et al., 2022](#)). In the IPA of the qualitative data, we identified three themes that came out of people's experiences of shielding that were also strongly correlated to understanding the intersectionality of those oppressions ([Crenshaw, 1991](#)). First, the indignities of the recognition of embodied vulnerabilities that had once been contested and invisible ([Ciribassi and Patil, 2016](#); [Srikanthan, 2023](#)). Second, the importance of time and temporality to understand the context of the pandemic ([Samuels and Freeman, 2021](#)) for a chronic condition typified by uncertainty and early ageing ([Sheppard, 2020](#)). Finally, chronicity brought into context temporality and fears of mortality.

### Indignities of recognition: embodiment and vulnerabilities

Despite SCD being the most common inherited genetic condition in England, it has been historically neglected and misunderstood by healthcare professionals as well as members of the public, pointing to entrenched inequalities in terms of structural racism ([Dyson, 2011](#)). With the introduction of shielding, it became visible, and participant 2 (female, 20s) stated, "I feel like it was the first time that sickle cell was actually recognized by the government as a serious condition." Recognition was a double-edged sword; as participant 1 (female, 30s) pointed out, it was because COVID-19 could 'kill' them. SCD was mentioned on government websites, people were being contacted by the government or their GPs, and some were able to receive charitable aid, such as food parcels.

As noted by [Shakespeare et al. \(2021\)](#), recognition was also felt to be superficial in nature, as some participants initially reported not being able to get information about shielding rules or not being contacted by GPs, consultants, or SCD centres at hospitals. Participant 4 (female, 30s) explains, "And I was petrified, And then I did not have no one to turn to." Participant 2 wondered: if they were so vulnerable and at risk, why could they not have free prescriptions? Additionally, the food parcels ignored their cultural and religious backgrounds, as well as impairment and age effects impacting on activities like being able to open canned goods or even cook. Participant 3 (male, 60s) stated, "I mean, I'm in the survival mode." And he also reminded the interviewer of the uncertainty of impairment effects in that, "We have a time where we cannot even stand up."

Some participants, while not naming it, mentioned ableism ([Campbell, 2008, 2009](#)), for example, how flexible working from home had not been an option but was now possible for their employers and made accessible ([Ocean, 2021](#); [Samuels and Freeman, 2021](#)). Participants noted that individual self-management of the risks was how they coped with shielding, especially during tiers 3 and 4



lockdowns, which were the highest levels. Participant 3 (male, 60s) explained:

“If I go to the shops, I've got disposable gloves. You know once I get in the car. I take them off, sanitize and then I will hold the steering wheel. I won't go through the shops, that is like a cattle market for some reason (...) you would never think there was a pandemic. So, during this, especially during this three-tier system I've driven to (town) to go to (supermarket) you're talking an hour, an hour, 40 minutes-drive one way, you're talking a five-and-a-half-hour journey. That's how I cope in my head.”

In this way, conceptions of time became interwoven with greater vulnerabilities and ‘survival’ as practical acts of ‘taking time’ in resistance and affirmation (Goodley et al., 2023). Despite the emphasis on individual self-management, there was also the gradual realisation that shielding would not be possible due to the kinds of embodied care they had to give, for instance, as mothers, and the relational support they depended on from others for their healthcare and other needs, as noted by Shakespeare et al. (2021). Participant 5 (male, 40s) stated:

“I have a support worker, here in the house. But she just comes like in the morning and goes shopping and does the dinners, but just the dinner, not lunch. So even, like they said to me to shield myself, like just stay in the room. I couldn't, I had to do my own shopping and go to the pharmacy to collect my medication and all that.”

He explains being really scared at the start of the pandemic because he was living with people who were not shielding. This was often contrasted by participants who were living with family members and had to adopt extreme measures to ensure shielding. Participant 7 (female, 30s) explained:

“So as soon as they used to finish work, when they, when they get home, they will change up by the door, strip right off, put things into black bags, straight to the washing machine, going upstairs to go have a shower and just, you know, before even like talking to me, they've done all of that.”

Despite the lengths taken to ensure shielding, many participants also related how the rules had to be ‘broken’ to go into hospitals for regular blood transfusions, pain management, or emergencies. For example, participant 8 (female, 20s) noted shielding was an illusion:

“I had to leave my house during the shielding period, because I had to go into hospital and I remember thinking, oh, my gosh, I don't think I could go to the hospital because as soon as I step out the door it's going to just hit me, like this coronavirus is airborne and like, you get really scared and paranoid. And I remember feeling so scared.”

Shielding thus heightened feelings of vulnerability but also a sense that the authorities had not taken their condition seriously before nor provided the necessary health and social care services (Lohmeyer and Taylor, 2021). As participant 3 (male, 60s) stated:

“There's a lot of contradiction, so on paper, I'm vulnerable (...) They'll recognize that I'm vulnerable (...) But at the same time, immediate social services are not there.”

Participant 6 (female, 20s) also related feeling the same way:

“Me as an individual who is a single person, as part of the BAME community, who's got health conditions, who's classed as vulnerable and recognized as vulnerable by the government, by the system, is treated like I've got nothing.”

This meant that most of our participants felt different from other populations who were CEV because of the intersectional nature of their vulnerabilities. Participant 8 (female, 20s) brought up inequalities and the prioritisation of people who had cystic fibrosis or cancer and how they had funded services even during the pandemic. We noted that this feeling of neglect also became correlated to understandings of time in shielding and to how ill a person was. Participant 8 states:

“And because I felt like, I had to be going into hospital, and see doctors and stuff like that regularly. It kind of, it made me feel like I wasn't shielding in a way. That meant that, like I didn't feel like shielding in the same way. I felt like I was in a different kind of phase.”

## Temporality

As illustrated above, the importance of time and timing for pandemic preparedness and support (Shakespeare et al., 2021) came up a lot during the interviews to understand why shielding was not possible. Some of the participants brought up the suddenness at which shielding began and how it was different from social distancing, like participant 1 (female, 30s):

“It all happened really quickly. Really, I just thought I'll be socially distancing like everybody else you know, then it turned into, actually you have to shield and you can't even leave your house at all. So, I did not get much time to get my head around things, before that was what we were meant to be doing.”

However, participants 2 (female, 20s) and 6 (female, 20s) noted how people with SCD and their families live in anticipation of a crisis, explaining how their mothers prepared and stocked up on food and essentials. Many participants noted that for them, just to be ‘normal’ means precision timing and planning for any impairment effects (Thomas, 2012, 2019). Participant 1 (female, 30s) explains this well:

“You'd be like, “Okay, what should we do today?” It's a bit chilly, so that means we can't go here, we can't go there, we've got to go somewhere inside, to live normally takes a level of military planning, like make sure I am wearing the right things, make sure I have my medication, making sure to keep hydrated, how long is the walk, can I park, is it steep, you know you've got to go through this almost like mental checklist anytime you go anywhere.”

Normal time outside of the pandemic, or ‘chrononormativity’ as mentioned by Samuels and Freeman (2021), entailed that people with



SCD could physically not always have time to rest their bodies and look after themselves; thus, some participants reported having better health during the pandemic. Participant 7 (female, 30s) said that they were able to feel ‘well-rested’ and thus, “I think it’s better. I think it actually is better this year.” This was echoed by participant 4 (female, 30s):

“It was better this year. I would say it probably the best I’ve been as an adult. I don’t think I’ve actually experienced a crisis. I think I had one earlier in the year. But what I’ve noticed is, with me not going out to work. I wasn’t as tired, and my body wasn’t as stressed out. And I think that actually helped to, like being able to work from home and I noticed the difference.”

Participants related that they also tried to avoid going into the NHS as they felt as if they were always being treated as if they were ‘wasting the time’ of healthcare workers, or as participant 5 (male, 40s) explained, being a ‘burden’. Pain management was thus mostly done at home, but there were participants who stated that their health got worse and they needed to go to the hospital.

With respect to ‘normal’ time (Samuels and Freeman, 2021), some participants related keeping to routines, especially if they had children and work to do. Like participant 4 (female, 30s), “I usually get up the normal time I’d get up to go to work, I kept that routine.” This was different for participants 2 (female, 20s) and 5 (male, 40s), who overturned norms of time. Participant 5 stated that this helped with his shielding. “At the moment it’s a bit upside down. Like, I sleep a lot in a day (...) it is in reverse. So, I sleep during the day in and go, like going around more at 2 am, 3 am, 4 am I’m still awake.” All participants related that people with SCD needed to take time to sleep, rest, and slow down to manage their conditions, but also because they could forget things due to impairment effects (Thomas, 2012, 2019), like, fatigue. For instance, participant 5 noted that not having face-to-face consultations and check-ups was a problem, “on the phone it’s different because it’s so quick and sometimes you forget stuff.” The importance of taking time and living in each moment was also related by participants as important to resilience and affirmation of life (Goodley et al., 2023). Participant 3 (male, 60s) stated: “That’s how I cope with it, I just took it day by day. Do not look beyond that day, though. (...) As you know, Christians will say in the cultural background, tomorrow’s not promised to nobody.”

If every moment of time is precious, giving time to someone also shows their importance, and not giving time seemed to illustrate ableism and disablism in services and a lack of understanding of SCD. This was highlighted by participant 6 (female, 20s) observing triaging of patients: “I feel like COVID had an impact as well, I feel like they were so busy and stuff like that (...). And then try to tell you that you are not as important as this person.” The lack of improvement in NHS services over time and the fact that some people felt that they were treated worse during the pandemic meant that some participants felt that time was not moving forward. Participant 5 (male, 40s) asked: “In the COVID situation, it has not changed. Like, what is my life? It is not changed much. Because the way they treat me in 2020, is what a treatment in 2019 is, or 2018.” This lack of change in NHS services and understanding of SCD by healthcare professionals, as well as triaging, heightened fears of chronicity and mortality.

## Mortality and chronicity

While time seemed to slow down during the pandemic, some participants noted a speeding-up of time or blurring of time because days were always the same. Crip-time is not always ‘slow’ but can, due to the way in which mind and body interact, speed up (Price, 2015), or collapse completely into loss of time in a pain crisis. Understandings of time became connected to the emotions, such as anxieties and fears correlated to why they had to shield and what they heard was happening in clinical settings to older and disabled people who did get COVID-19, as found in the literature (Monahan et al., 2020; Shakespeare et al., 2021; Ramirez et al., 2022). Participant 8 (female, 20s) explained:

“It’s crazy when you think about time and I feel like this last year has just been a whirlwind (...) I was thinking about this and I think it’s what has my experience of shielding been like and I think it’s been really varied. So right at the start, I was really scared, I think I think we saw 12 weeks. And I was like, What? That’s three months not going anywhere else. I don’t think I could do that. I think just the fear, you heard all these things on the news saying that, actually, they’re going to be rationing ICU and oxygen.”

Many participants found ‘triaging’ and disablism in services very emotionally triggering, but it was only when both participants 8 and 6 explained how their mothers had watched over them and protected them in NHS services that we understood why. Participant 6 (female, 20s), when recounting how she was watched over in an intensive care unit, recounted:

“In fact he was always telling my mom, we’ve used all our equipment, you know, basically he’s saying we’re wasting our product, there’s no brain activity, no nothing, nothing is working, if she were to wake-up, you would wish she was dead because she is not going to be able to be on her own, forever, she’s just going to be in a wheelchair for the rest of her life. So why would you want to make her be in that result? You know she’s independent, stuff like that.”

The above quote illustrates disablism and ableism in healthcare services and gives credence to the fears and anxieties that participants had linked to going into the hospital during the pandemic with nobody to watch over them as adults. Heightening the fears even more was the lack of control that they had over the severity of a pain crisis. Participant 8 (female, 20s) explained chronicity as ongoing:

“I live with a chronic illness (...) I cannot tell you after this crisis this is the last crisis I am ever going to have my life. That is a lie. Even if I tried to say that, it would be lie because I will have a crisis again, you will, sadly have a crisis again, whether we like it or not, that is part of the disease.”

Furthermore, participants also noted that for them, the intersectionality of the ethnicity of healthcare professionals who were at greater risk was ‘unsettling’ as they were from the same minority ethnic background. So, participant 9 (female, 30s) stated:

“And I think when it showed that the healthcare workers that were dying, they were either Black or Asian, you know. It was very worrying, very worrying, very upsetting because you just think what’s happening and what is the reasons for all of that? And it just seemed like all we knew was that you’re more at risk but no one was really explaining why?”

The lack of information was also distressing because most of the participants had lost family members or knew people who had died during the pandemic. The risks of death were correlated to inequalities and racism in broader society, and several of the participants made links to the Black Lives Matter Movement (Sobo et al., 2020). Participant 3 (male, 60s) noted that it was nothing new:

“So, there’s a lot things that I experienced, you know what I mean but like I says, that’s why I felt it when George Floyd got killed. I turned off the news feed. I didn’t want to know because until you until you know or identify the brutality, discrimination, inequality, the harrasment as a Black male ...”

The issues of racism in the NHS were often connected to pain management and treatment because they intersected with racist stereotypes as well as ableism in the invisibility of pain, which was contested (Berghs et al., 2022). Participant 6 (female, 20s) noted how she was viewed as a drug addict and told by a nurse, “Oh, you have just got a habit.” Similarly, participant 8 (female, 20s) noted that when seriously in danger of death and disablement, a nurse told her, “Oh, you could look a bit more ill.” Participants explained how difficult it was to know what to do in such situations. Noteworthy, is that the older male participants felt that they either had to acquiesce and become ‘smaller’ or ‘passive’ while the younger female participants wanted to fight for better treatment but then became labelled as ‘aggressive’. Yet, participant 2 (female, 20s) explained how it was important to talk about racism but also how to know when to ‘give time’ mattered:

“I’m adding to the problem. If I don’t say anything, or if I don’t question it, or try and get out of that mindset, I just have to accept it, then nothing will ever change. So even I’m learning how to have these conversations. And like, think of me now, what I feel like is racist or figuring out who am I going give the time to educate? And who am I just going to ignore? Like, it’s kind of learning on both sides?”

However, she also noted that there would be times when she could not ‘give’ that time. As such, participant 2 said it was important to always have a family member or advocate present when arguing:

“Even though, especially this is more for adult care, even though we are adults from ages 16 and that sort of transition, even if we’re 35, or 40, whatever. And we’re in a crisis we’re like extremely vulnerable, like we can’t talk about ourselves. So, the same way that you would give an older person, like they use like this assessment called DoLS, which is like they assess, if that person can make decisions for themselves in the present moment, things like that, we should have that same assessment.”

We did not expect any correlations to be made to age and ageing, but the highlighting of the ages of 35–40 was significant in this participant’s account as she identifies the vulnerabilities people with SCD experience at that age, like older and disabled people. We also noted that the older participants brought up the greater risks of co-morbidities and early ageing. Many also had additional needs for medical care for co-morbidities, such as diabetes, which they argued healthcare professionals seemed unaware of. This increased the risk of diagnostic overshadowing with no clear understanding of the boundaries between age and impairment effects (van der Horst and Vickerstaff, 2022). We also noted that participants understood this early ageing and could explain how it impacted impairments, like participant 5 (male, 40s):

“We have problems (...) getting worse and worse and worse. Because now I use glasses just to read or to (...) But I know like, people with SS, we have more, like the problems with the lungs, with the eyes, with the bones and stuff.”

Living with a chronic condition also has a mental health connection to understanding the impact of early ageing as participants explained how the pandemic heightened fears of risks and thus death. Participant 4 (female, 30s) explained why she suffered from anxiety:

“When I was younger, I was quite healthy, to be fair, but when I would fall sick, it would get me down. Because there were people who were my age, and I felt that I should be doing what they were doing. So, I think that’s something that professionals need to take into consideration. And then when I had my (child), my anxiety really went sky high, because then all I was thinking about was my mortality to be to be fair, because if I had a crisis, and I passed away, who would look after (them), and I think it’s things that people who don’t have an illness like we do, don’t think about at this age, but it’s something that we do think about.”

All the participants explained that regardless of their physical health, they had mental health needs that were not being met and that were poorly understood. The pandemic also brought out a need for bereavement support, which some of the youngest participants, 2 and 6, felt had been ignored and needed a culturally sensitive response. Participant 6 (female, 20s) said:

There needs to be some form of grief counselling as well for the other patients that have sickle cell because we are really close knit and we all depend on each other and the majority of us was known to each other (...) some of us will be in hospital when another person with sickle cell passes away. So, it’s sad for that person and their family. But then you as a person with sickle cell think, is that going to be me? Like that person was only 30? Is that what is going to happen to me when I’m 30 but nobody talks about it. So, I think there needs to be like a recognition that there needs to be some kind of grief counselling.

Noteworthy are the connections being made to the death of a person with SCD at age 30, the heightening of fears of mortality, and the lack of recognition of grief and the need for psychological support. All participants noted how they were living with ‘chronicity’, a chronic illness that was becoming progressively more complex and uncertain

(Rouse, 2009), which had a mental health impact. It could also at any time become acute and life-threatening, the fears of which the pandemic was amplifying.

## Discussion

In the findings, there are commonalities to many of the threads woven in the literature on the pandemic and how it impacted people identified as CEV, like the creation of vulnerabilities in older and disabled populations and the lack of disability and culturally inclusive services (Shakespeare et al., 2021). However, people with SCD experienced intersectionality of discriminations (Crenshaw, 1991) and clearly used words like racism and oppression to make sense of their experiences during shielding, within NHS services, and also in British society. We found that multiple discriminations were understood and highlighted through concrete examples, even if participants did not necessarily use words like ableism (Campbell, 2008, 2009) or disablism (Oliver, 1986). They understood the connections to disability and the lack of human rights being afforded to people like themselves. For instance, the inhumanity of triaging, the hierarchy of illnesses, and the prioritisation of some conditions over others in hospitals were all mentioned (Abrams and Abbott, 2020). Similarly, while nobody mentioned necropolitics (Thorneycroft and Asquith, 2021), some participants did note the loss of lives of ethnic minority people and disabled people due to multiple discriminations that can also impact people with SCD. While most disability models see disability as a central experience and the removal of barriers leading to emancipation (Oliver, 1983, 2013), we found that disability was one of many discriminations that people could experience. This may point to needs within disability politics and models for a greater conceptual understanding of intersectionality (Crenshaw, 1991) to ensure inclusion.

While we also found that people with SCD had worse mental health during the pandemic, there were nuances in that some people reported better physical health and resilience in coping, similar to Kemp et al. (2020). We did not find a decrease in mental health needs mid-pandemic (Robinson et al., 2022), but this might have been due to the longer periods of shielding and lockdowns that people in some parts of the Midlands experienced. We did find that anxieties and fears were connected to the multiple discriminations that people noted during the pandemic, which were heightened due to people's inability to properly 'shield' but also because there was a lack of psychological support in services. We noted there was some evidence of 'weathering' traumas in hospital settings in the examples given by participants, which were also correlated to growing up with a chronic condition and experiences of structural racism (Geronimus, 2023). However, we could not assess if this had an embodied impact or not in accelerated ageing which then impacted on SCD, or if it was SCD that then impacted the body. We also struggled with how to conceptualise the embodied impact of weathering (Geronimus, 2023), when it was possible that it was caused by multiple discriminations across the life course as well as disadvantage. We found there were discriminations based on invisible forms of early ageing that perhaps services were unaware of, which participant 4 understood as affecting all the organs in his body. Was this an accelerated third or fourth part of life typically seen in later life ageing and disablement (Gilleard and Higgs, 2011) or a second transition

we should prepare for in services? Our participants noted that ageing and death could happen earlier for people with SCD, but it was not clear if we could separate 'age effects' from 'impairment effects' as van der Horst and Vickerstaff (2022) argued. Another issue was how to conceptualise a pain crisis that could act as both acute and chronic. This revealed limitations within models of disability that tried to separate impairment from disablement (Oliver, 1983, 2013), as a pain crisis could severely disable but also lead to death. This could happen in the best-case scenario, where all medical assistance and support were provided. Similarly, a person could also have a severely disabling condition when younger that became manageable as chronic as they aged, meaning a lessening impairment and, thus, progressively less disabling.

None of our participants mentioned 'crip-time' (Kafer, 2013), which we did not expect, but they seemed to have an implicit understanding of it by living with differing forms of chronicity. All participants explained that to prevent impairment effects and serious pain crises, timing life events and understanding an embodied temporality (connection between mind and body in body-mind; Price, 2015) were critical to living life well (Sheppard, 2020; Samuels and Freeman, 2021). The older that our participants became, the more they understood how their environment and emotional states were linked to their physical and mental health, as well as differing SCD physical, sensory, and cognitive symptoms or impairments and age effects (van der Horst and Vickerstaff, 2022). It was often our older participants who explained how time was linked to caring for oneself and others, for instance, to plan time to be well with family, to rest, or that time was needed to guard good health and anticipate a pain crisis. Participants also related living in the moment, and participant 3 correlated this understanding of time to his Christian beliefs.

Participants were thus expressing an embodied ethics correlated to how to live well with SCD and cope with periods of acute crisis. Akin to Bailey's (2021) conception of 'ethics of pace', they noted the ethical and existential need to 'pace' oneself in life to protect their wellbeing. This is different from the 'pace' that Sheppard (2020: 45) describes in rehabilitative services, which is about ascribing to a 'normative way of moving through time' ending with an 'inevitable failure to do so' and is also more than non-normative self-care. Tremain (2023) argues that we now need an ontology and epistemology of crisis, but this already exists for people with SCD. As participant 8 states, "I will have a crisis again, you will, sadly have a crisis again, whether we like it or not, that is part of the disease." They explain that this is 'inevitable' but they are 'more' than their pain. In statements like this, an 'ethics of crisis' is embodied in values and norms correlated to temporality and notions of the self as body-mind emerge. Participants normatively learn how to physically and psychologically exert control over their environment, ensure support, and cope with an uncertain condition. They also noted times when they would be 'on the floor' or be incapacitated during a pain crisis, like a disabled and/or older person, exposing them to the risks of unethical treatment and care, not only to racism but also to ableism, disablism, and ageism. They understood these limits and that they had no control over a pain crisis or even mortality, but they had embodied ethics of how to live with the inevitability of crises before the pandemic. Both impairment and age effects are invisible and can be contested (van der Horst and Vickerstaff, 2022), but they are also masked by one impairment effect (pain) over all others. Just as a person with SCD goes into crisis and loses control over the body and

time, the pandemic and indignities of shielding as a CEV person meant a loss of control of embodied vulnerabilities and temporality, heightening individual fears of early ageing, disablement, and early mortality that society and services were contributing to.

## Conclusion

People with SCD understand that they will have times in their lives with a worse quality of life and periods when they need care and support. They explained how a relational, embodied ethics of crisis was helpful to manage the chronicity and medicalisation of SCD. They, and their families, had developed ways and embodied expertise to cope with and temporarily manage the condition. This ability to adapt to SCD had also been formed within a society and NHS services where they experienced structural racism as well as discriminations like ableism, disablism, and even ageism. This meant that the ethics of crisis management became embodied, hypervigilant, and incorporated into a necessary pace of caution and anticipation. Anticipation of crisis of pain, which was also a crisis of time in that it meant a total loss of temporality and self. The pandemic as a crisis writ large had a psychological impact, which our participants related to as affecting them and their families and which became heightened and linked to fears of early mortality.

## Data availability statement

The datasets presented in this article are not readily available because due to the sensitive nature of the discussions around health, morality and racism we have restricted access to the data to only team members. Requests to access the datasets should be directed to [Maria.Berghs@dmu.ac.uk](mailto:Maria.Berghs@dmu.ac.uk).

## Ethics statement

The studies involving humans were approved by the De Montfort University Faculty of Health and Allied Health Sciences Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided

their written and verbal consent informed consent to participate in this study.

## Author contributions

MB: Conceptualization, Data curation, Formal analysis, Funding acquisition, Methodology, Project administration, Resources, Writing – original draft, Writing – review & editing, Investigation, Software, Supervision, Validation. FH: Conceptualization, Data curation, Formal analysis, Methodology, Software, Writing – original draft, Writing – review & editing. SY: Conceptualization, Formal analysis, Investigation, Methodology, Writing – original draft, Writing – review & editing. RK: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft. AW: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – original draft.

## Funding

The author(s) declare financial support was received for the research, authorship, and/or publication of this article. Funding for this research study was given by De Montfort University.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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RECEIVED 18 January 2024

ACCEPTED 20 February 2024

PUBLISHED 07 March 2024

## CITATION

Simmonds B (2024) From bare life and necropolitics to a feminist care ethic: ageism in the COVID-19 pandemic and future directions.  
*Front. Sociol.* 9:1372926.  
doi: 10.3389/fsoc.2024.1372926

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# From bare life and necropolitics to a feminist care ethic: ageism in the COVID-19 pandemic and future directions

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This perspective paper begins with discussing how COVID-19 magnified the pre-pandemic ‘bare life’ conditions which exposed older people’s lives to risks and indignities in the health and social care system. Then, by using the concept of Necropolitics, the life and death decisions, based on age as a proxy measure for population health during the pandemic, are discussed. This discussion includes examples of ‘exceptional’ practices that were implemented in the UK during the first wave, including ‘Do Not Resuscitate’ orders, unsafe hospital discharges, not transferring to hospitals, and denying access to treatment for older people. It then goes on to renew the call for a feminist care ethic to be central to the ways in which our future health and social care systems are configured. Arguing for the need to politically reframe ageing, health and social care provision towards a radical alternative system that rethinks care relations and addresses inequality.

## KEYWORDS

ageism and age-based discrimination, necropolitics, feminist care ethics, bare life, COVID-19, risk, health and social care

## Introduction

When COVID-19 hit in March 2020, the NHS in the UK had gone through the most challenging set of circumstances since its inception in 1948; it occurred at a time when health and social care institutions were underfunded, understaffed, fragmented, and poorly coordinated with each other (Simmonds, 2021). Thus, the ageist practices described in this paper are not unique to the COVID-19 pandemic but did magnify the ‘bare life’ conditions which exposed older people’s lives to risks and indignities in the health and social care system (Waring and Bishop, 2020). The result was devastating for older people in the UK, particularly the tragedy of numerous deaths in care and residential settings.

What did change during the COVID-19 pandemic, however, was the necropolitical decision-making became explicit and exposed in the ‘care’ conditions that some older people found themselves in during the COVID-19 pandemic in the UK, particularly those in residential care settings. For instance, it illuminated a spatialised control of populations, where the state implemented modes of exception in relation to who can live and who can be left to die (Mbembe, 2003). In this paper, I discuss examples of some of the ‘exceptional’ practices which were implemented during the UK’s first COVID-19 pandemic wave, which determined based on age, who could live and who could be left to die. These included inappropriately applied ‘Do Not Resuscitate’ orders, unsafe hospital discharges, not transferring to hospitals, and denying access to treatment.

In this perspective paper, I am advocating for [Tronto's \(1993\)](#) position that instead of employing universalistic impartial ethical frameworks like utilitarianism to guide decisions about care in a detached distanced manner using standardised protocols, a feminist care ethic needs to be central to the ways in which our future health and social care systems are configured. However, I start by providing the context into which the treatment of older people in the COVID-19 pandemic can be situated.

## 1.1 Bare life: older people in pre-pandemic health and social care systems

Since the 1980s, health and social care systems in the UK, as well as other countries in the Global North, have been neoliberalised and impacted by globalisation inasmuch as welfare state systems have to a greater or lesser degree been undermined by the deregulation of social and working protections, and previously publicly run services have been outsourced to large multinational conglomerates ([Simmonds, 2021](#)). The resultant reduction in the quality-of-care services in the UK was significantly affected by 'caretalisation' ([Scourfield, 2011](#)). Cartelization is where large companies buy up and merge small care organisations ([Scourfield, 2011](#)). At a time when more funding should have been provided to address the growing numbers of older people needing care, austerity measures were hitting local authorities with a 21% reduction in funding per person between 2009–10 and 2015–16 meaning social care budgets were cut and eligibility criteria tightened ([Harris et al., 2019](#)). During the austerity years, 600,000 fewer older people received social care per year ([Darzi, 2018](#)), leaving them at risk of getting stuck in the hospital or facing unsafe discharges and likely readmissions.

Furthermore, [Waring and Bishop \(2020\)](#) highlight how, before the pandemic, older people's rights in large bureaucratic organisations like hospitals, particularly when being transferred into the community, were being eroded. They found that the social organisation of discharge inadvertently exposed older people's lives to risks and indignities, which were normalised. However, this was less to do with state power and more to do with the product of complex unworkable systems; nevertheless, they argue that these systems reduced older people's lives to 'bare life' ([Agamben, 2005](#)). 'Bare life' is the product of the state implementing legal exceptions to the treatment of groups that are not recognised as citizens and therefore can be legitimately killed ([Agamben, 2005](#)). 'Social-cultural organisations' determine the thresholds for what is considered a life of value and what is not, and these modes of exception have become normalised in institutions, particularly where there is spatialised control of disempowered and disenfranchised populations ([Waring and Bishop, 2020](#)). Therefore, even before the pandemic, the lives of older people in the health and social care system in the UK were devalued and put at risk, what changed during the COVID-19 pandemic, is this necropolitical decision-making became explicit and exposed.

## 2 Biopower and necropolitics

Biopolitical power, as theorised by [Foucault \(1978\)](#), describes a shift in the way the state protects the sovereign's life, from the use of the gallows to protecting the 'social body' or general population via

disciplines like epidemiology: 'It is no longer a matter of bringing death into play in the field of sovereignty, but of distributing the living in the domain of value and utility' ([Foucault, 1978: 144](#)). Thus, biopower encapsulates the transfer of power from the sovereign's right to kill, to managing populations to ensure the survival of the perceived stronger group; therefore, following the industrial revolution, the focus of state power was on control of populations' health (1978).

Necropolitics ([Mbembe, 2003](#)) extends Foucault's conceptualisation of biopower to argue that the state also implements modes of exception in relation to who can live and who can be left to die. This control over decisions of life and death is enabled via categorisations that mark out those who matter and those who do not, and the differential spatialised control of these segregated populations. [Mbembe \(2003\)](#) argues that biopower is insufficient to capture the techno-spatialised capability of power of late modern state to exert death over the living. Mbembe writes as a Cameroonian scholar living in South Africa, about the impact of colonialism. Thus, in using his theorisation of necropolitics, it is acknowledged that, while both racism and ageism kill people, they are not the same thing. For instance, not all of his theorisation can be applied to the experiences of older people during the pandemic. Although arguably the spatialised control of populations—enabling conditions inferring on people the status of the 'living dead' ([Mbembe, 2003](#))—is relevant to the 'care' conditions that some older people found themselves in during the COVID-19 pandemic in the UK, particularly those in residential care settings.

[Robertson and Travaglia \(2020\)](#) and [Travaglia and Robertson \(2021\)](#) extended the work of [Mbembe \(2003\)](#) and [Waring and Bishop \(2020\)](#), examining the necropolitical assumptions made in decisions of who got treatment and who did not during the pandemic. They called into question social-cultural assumptions about the value of different groups of lives in times of crisis ([Robertson and Travaglia, 2020](#)). Although decisions over treatment based on, what is considered a life of value and what is not, occurred prior to crises like COVID-19, and during the pandemic, utilitarian medical philosophical decision-making was magnified. This is where 'need' is assessed based on the overall benefit to society and the extent to which existing chronic health conditions will impede clinical benefit ([Robertson and Travaglia, 2020](#)). However, during the pandemic, life and death decisions were based on age as a proxy measure for population health, without considering the social implications, human rights, and dignity of groups at the receiving end of intersecting structures of inequality ([Colombo, 2021; Travaglia and Robertson, 2021](#)). What follows are examples of how a state can implement modes of exception, determining who can live and who can be left to die.

## 2.1 Examples of COVID-19 'exceptional' practices

The necropolitical practices that were originally described by [Mbembe \(2003\)](#) are evident in some of the decision-making of British state, particularly during the UK's first COVID-19 pandemic wave. One of the more publicly discussed discriminatory practices involved discharging older patients into care and residential homes without testing for COVID-19. During a legal challenge in the High Court, lawyers for the Department of Health and Social Care stated that they implemented this policy because they were unaware, at the beginning of the pandemic, of asymptomatic transmission and infections and

were not made aware of the dangerous repercussions of discharging older patients into care homes with unknown infection statuses (Booth, 2022). However, asymptomatic transmission and widespread deaths in care homes were widely reported in several other countries, including Spain and Italy, in March 2020 (Amnesty International UK (AIUK), 2020; Horton, 2020) and were discussed by the chief scientific advisor of the government on the radio in mid-March 2020. Although infection procedures were put in place before the second wave in September 2020, the spread within care homes due to these unsafe discharge practices had already taken its toll; by the end of June 2020, 31 per cent of all registered deaths in the UK were in care homes (Bell et al., 2020). In 2022, the High Court ruled the policy to be unlawful (BGS, 2022; Booth, 2022).

Another practice, documented by both Amnesty International UK (AIUK) (2020, 2021) and Calvert and Arbuthnott (2021), involved older people, living in both the community and residential settings, not being transferred to a hospital despite it being clinically necessary. These decisions were based on their 'older' age status alone. For example, in the first wave, some ambulance services were advised not to admit any 'elderly' [sic] patients to the hospital; indeed, some crews saw only a handful of older patients during the peak when, pre-2020, they would be frequently attending patients in this demographic group. Indeed, even when an older patient was admitted to a hospital ward, Calvert and Arbuthnott (2021) report, a 'score of three domains' triaging tool was used to ration access to intensive care treatment, including ventilators. Nine points were originally given for being over 80 years old, which was enough to pass the threshold for being refused treatment; however, this was readjusted to allocate more points for existing health conditions and fewer points for being over 80. Nevertheless, there were reports of this revised tool being rigorously applied even when beds and ventilators were available. People over 80 were confined to what one family member called 'death wards':

Vivien says that inside there were eight elderly [sic] men infected with the virus whom she describes as the 'living dead'... lying 'half naked in nappies' on their beds in stifling heat looking 'drugged and dazed'. The scene was heart-breaking: 'To see people just dying, all around you' (Calvert and Arbuthnott, 2021: 245).

At the time, only 2.5 per cent of those over eighties were provided with intensive care treatment, while 50 per cent of those dying were over 80; however, for those that did receive intensive care treatment, the chance of survival was 40% (Calvert and Arbuthnott, 2021) and those without any chronic health conditions were predicted may have lived for another 7 years (on average) if they had not contracted the virus (Hanlon et al., 2021).

Legal orders put in place to signal someone does not wish to be resuscitated should be discussed with the individual and the family, then agreed upon as part of an advance care plan designed to empower individuals, ensuring their wishes are met at the end of their lives. However, during the COVID-19 pandemic, end-of-life care policies were inappropriately applied to groups of residents based on age and/or because they live in a residential care home (Amnesty International UK (AIUK), 2020, 2021; Care Quality Commission (CQC), 2020, 2021; Stevenson, 2020; Wearmouth, 2020; Calvert and Arbuthnott, 2021). Amnesty International UK (AIUK) (2020, 2021) and Calvert and Arbuthnott (2021) both reported that local councils had asked GP surgeries to search and apply blanket 'Do Not Resuscitate' orders for all

residents in residential and care home settings. When this was leaked to the media, there was an outcry, and these directives were withdrawn. Although rationing of healthcare based on intersections of age and disability is not unique to the pandemic, it intensified, and in many ways normalised its practice, no longer being seen as 'exceptional'. In fact, some practices, like inappropriately applied 'Do Not Resuscitate' orders, have been left in place (Amnesty International UK (AIUK), 2021), due to a lack of training and the presence of appropriately qualified staff (Care Quality Commission (CQC), 2021). 'Do Not Resuscitate' orders have also in some cases been misinterpreted to mean that residents should be denied any medical care, including being taken to hospital (Care Quality Commission (CQC), 2021).

The misuse and misapplication of these end-of-life practices during the pandemic, which are designed to promote, rather than remove agency, have highlighted the ways in which they can be applied to discriminate based on age. They have reduced and rationed health resources, when there would be significant clinical benefit, and when, on average, someone over 80 with no co-morbidities, without contracting COVID-19, may have lived for a further 7 years on average (Hanlon et al., 2021). Nevertheless, as Travaglia and Robertson (2021) state, the utilitarian medical philosophical conceptualisation of 'need' is not just based on the individual assessment but on the overall benefit to society, and age has been used as a blunt proxy measure for health. The Equality Act (HM Government, 2010) legislates for age as being a protected characteristic, like gender, disability, and ethnicity, which cannot be used to discriminate. However, when it comes to healthcare provision, age can be used to justify not providing healthcare services, if there is a good rationale for doing so (HM Government, 2010). This presents healthcare providers in the UK with a legal loophole if challenged in the courts. Furthermore, the discriminatory practices discussed in this paper can be seen as examples of how older people in healthcare spaces and times can be seen to inhabit 'death worlds', where spatialised control of populations is at the whim of states deciding over their life and death (Mbembe, 2003).

### 3 Discussion: transforming the health and social care system using a feminist care ethic

The concept of bare life (Agamben, 2005) has been used in this paper to highlight the impact that neoliberalising health and social care, then austerity measures, had on normalising institutional decision-making, which risked the lives of older people when discharging them from hospital. This discussion was followed by an examination of necropolitical decision-making (Mbembe, 2003), exposing how modes of exception have been applied to the lives of older people (amplified in the first wave of the COVID-19 pandemic in the UK). Practices that contravene older people's human rights, such as withdrawing lifesaving treatment via techniques such as triage tools or legal orders originally designed to empower people at the end of their lives, can be seen as examples of the state making decisions about who can live and who can be left to die. Those at the receiving end of these practices were spatially controlled in residential care homes or hospital wards, and policies were employed to ration healthcare underpinned by utilitarian medical philosophy, which argues that need should be assessed on a societal, rather than an individual basis (Robertson and Travaglia, 2020).

In this perspective paper, I am advocating for Tronto's (1993) position that, instead of employing universalistic impartial ethical frameworks like utilitarianism to guide decisions about care in a detached manner using standardised protocols, a feminist care ethic needs to be central to the ways in which our future health and social care systems are configured. An 'Ethic of Care' is difficult to define, but some of the characteristics include attentiveness, responsibility, competence, and responsiveness, and these to be integrated through all the phases of care, from organising and doing care, to receiving feedback (Tronto, 1993). The care ethic, according to this approach, is a practice which is possible, in a society which has a strong sense of justice, open discussion, and one which acknowledges the need to equalise power relationships; therefore, care involves political discussion and consensus (Tronto, 1993). Thus, the value of women's care work and inequalities of access to resources based on age, gender, ethnicity, and disability must be taken into account in care decision-making (Tronto, 1993).

Since the 1980s, neoliberalism has shaped institutions and justified cuts to public spending, in the NHS and social care in the UK (Simmonds, 2021). Currently, in England—and to some extent the rest of the UK—older adults are treated as care commodities (as beds which are allocated tariffs and then bought and sold in a market) and are dependent on large-scale care systems in which their needs are exploited by multi-national conglomerates (Simmonds, 2021). The care of older people in the UK is not valued or resourced, arguably because women are still providing most of the care for older relatives in the family as well as in outside agencies (Bunting, 2020), and the historical injustices of care work being of low value and feminised have continued. Care systems and nuclear family configurations that rely on the exploitation of women's labour are 'unreliable and unjust' (Care Collective, 2020: 17). This, coupled with endemic ageism in society (Ayalon and Tesch-Römer, 2018), is arguably how neoliberal governments have successfully justified the low value and pay associated with health and care work and the low political priority given to the care of older people.

In conclusion, this perspective paper aims to renew calls to understand one's relationship to caregiving and receiving as fluid and interdependent, rather than viewing the human condition as a binary between either being dependent or autonomous (Tronto, 1993). Care communities need to be reconfigured to interdependently care for one another (Care Collective, 2020; Simmonds, 2021). These networks do not need to be familiar; they can be intergenerational or community based (Care Collective, 2020). The focus of care provision must be shifted to relational, therapeutic, and reciprocal approaches, which integrate the care ethic characteristics of attentiveness, responsibility, competence, and responsiveness within caring networks (Tronto, 1993; Care Collective, 2020; Simmonds, 2021). There are plenty of examples of alternative care models that have been trialled and have been successful in the UK, yet not widely commissioned, from intergenerational housing schemes to therapeutic care homes and

age-friendly cities (see Simmonds, 2021 for further details). I suggest that the pandemic could be a moment in time where the impetus gained from the associated failures of the state is politically harnessed to renew the impetus to design a just and reliable system, which enables ethical care practice.

## Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## Author contributions

BS: Conceptualization, Writing – original draft, Writing – review & editing.

## Funding

The author(s) declare that financial support was received for the research, authorship, and/or publication of this article. My gratitude goes to the Department of Geography and Earth Sciences at Aberystwyth University for their payment of the open access fee and the School of Education and Sociology at the University of Portsmouth for contributing the cost of copyediting earlier drafts of the paper.

## Acknowledgments

This paper is dedicated to all those (older) people who died during the years of austerity policies and the COVID-19 pandemic.

## Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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RECEIVED 11 January 2024

ACCEPTED 05 April 2024

PUBLISHED 17 April 2024

## CITATION

Alnamnakani A (2024) A narrative case study  
of an older disabled Muslim woman during  
the COVID-19 pandemic in the UK.  
*Front. Sociol.* 9:1369188.  
doi: 10.3389/fsoc.2024.1369188

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# A narrative case study of an older disabled Muslim woman during the COVID-19 pandemic in the UK

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This paper explores the experiences and perceptions of Zora, an older Muslim woman living with a disability in the UK. Older disabled Muslim women in the UK often face multiple discriminations based on disability, age, gender, religious, and racial grounds and this has arguably been intensified by the COVID-19 pandemic. Drawing on multiple narrative interviews with Zora, this paper focuses on the intersections of disability, ageing, gender, race and religion within a particular social context during the COVID-19 pandemic in the UK. The paper describes the complex ways in which Zora experienced various modes of everyday disablism which were not related to the COVID-19 virus itself, rather the consequences of the movement restrictions associated with it. Much of the oppression and barriers she described were socially determined, both through direct discrimination, stares and prejudicial attitudes, and indirectly through stigmatization and an embodied fear of the reaction of others in public spaces. Nevertheless, Zora did not present herself as a victim. Instead she portrayed herself in affirmative terms, as a 'brave' woman who resisted and overcame daily social challenges and movement restrictions as part of working toward creating a more accessible, inclusive and age-friendly society. One that is inhabitable for herself and other older disabled women facing an uncertain future.

## KEYWORDS

COVID-19, pandemic, ageing, disablism, racism, religionism, sexism, chronic illness

## Introduction

The evolution of COVID-19, declared a pandemic by the World Health Organisation (WHO) in March 2020, had a devastating impact on different people all over the world (United Nations, 2020; Yan et al., 2022). Following the second wave of the pandemic, which began on September 2020, several UK wide measures were implemented. For example, rules on face masks, social distancing, a staying at home order, cancelation of mass gatherings, school closures and larger lockdowns to control the spread of the disease, and mitigate the negative impacts of a crisis (BBC, 2020a,b). In this regard, disabled women, older women, and Muslim women have specific vulnerabilities as the pandemic produced new forms of vulnerability in addition to the vulnerabilities that existed previously.

Disabled women, often more intensely than women in general, have been cast in the collective cultural imagination as inferior, unfit, useless, undesirable, asexual and incapable of independence (Hanna and Rogovsky, 1991; Garland-Thomson, 2005). They face double discrimination on the basis of gender and disability disparities, these combine to produce poor outcomes such as lack of access to healthcare, low employment, education, low income levels,

and fewer opportunities for vocational training (Schur, 2003; Ekblom and Thomsson, 2018; Schalk and Kim, 2020). Moreover, disabled women are vulnerable to sexual violence because of the stigma and prejudice associated with their disability. As such, they are among the most vulnerable and marginalized social groups of society (Dockerty et al., 2015; Ekblom and Thomsson, 2018; Kirk-Wade, 2023). Yet, Asian or Black disabled women face the triple oppression of sexism, racism and disablism and, as a consequence of these social categories, they are socially excluded and placed in an extremely marginalized position (Begum, 1992).

Older women are often expected to experience more disadvantages than older men (Yan et al., 2022). For example, it is suggested that a tension exists for older women in attempting to access employment, they often face a disproportionately increased risk of job loss due to automation and technological change as well as being subjected to gendered ageism (Sargeant, 2011; Yan et al., 2022). Yet, findings from a meta-analysis study revealed that older women were more likely to be abused than older men, and such gender disparity is more evident in non-Western populations than their Western counterparts (Ho et al., 2017). These aspects of discrimination, bias, and marginalization create barriers to older women's social participation. Such barriers are further compounded for disabled older women who are systematically overlooked and underrepresented in initiatives, development policies, programmes, legislation and humanitarian efforts. However, ageism, ableism and gender inequality are further exacerbated by other forms of discrimination on the basis of religion, race, and migration status amongst other factors (UN Women, 2022).

For example, Jawad and Benn (2003) suggested that most Muslim women experienced double oppression, as a result of the culture of their community and the culture of their religion. In the community, Muslim women were amongst the targeted victims of anti-Muslim hate crime encountered by Muslims living in the UK because they wear one of the most recognizable symbols of Islam - the hijab (Jawad and Benn, 2003; Dodd, 2019). This symbol has become riddled with racial meaning such as 'foreign', 'violent', 'oppressive', and 'misogynistic' (Siraj, 2012; Selod and Embrick, 2013; Al Wazni, 2015). Taken together these stereotypes result in the belief that a Muslim woman's body is incapable of Western ideals and values (Selod and Embrick, 2013), this explains why they also experience racial discrimination. Only 1.2% of Muslims in the UK described themselves as being of White British origin (Ali, 2015). Regarding the culture of their religion, Muslim women have traditionally been assigned for motherhood and homemaking roles. This is the case despite the fact that Islam states that such roles are neither exclusive nor inflexible (Islam House, 2013).

However, given that relatively few studies have examined the impact of the COVID-19 pandemic on older women, disabled women and also Muslim women in the UK, the literature used in this study was mainly from other countries. For instance, in a nationwide survey of older women in the United States, VoPham et al. (2022) found notable changes in lifestyle factors during the COVID-19 pandemic. Over half of older women reported less physical activity or exercise compared with before the pandemic, this may have both short and long-term effects on the health and wellbeing of these women (VoPham et al., 2022). In a large, population-based study of community-dwelling older women in Hong Kong, Yan et al. (2022) revealed that psychological abuse was the most prevalent form of

abuse against older women during the COVID-19 pandemic, this was followed by financial or economic abuse and physical abuse.

According to the UN Women (2020), disabled women often face additional challenges in their attempts to flee violent situations, such as sexual exploitation and consequential economic deprivation, or to access protection orders or essential services which offer refuge, such as lockdown or quarantine. The COVID-19 pandemic resulted in an increased burden of domestic violence and unrecognized unpaid domestic labor for Muslim women (Safdar and Yasmin, 2020; Jailani, 2022). As a consequence they became the backbone of their family economy, acting as household managers, taking the main role in children's care and education, and becoming a leader within the family, this caused anxiety and mental stress (Safdar and Yasmin, 2020; Jailani, 2022).

Although the pandemic illuminated the experiences of older women (VoPham et al., 2022; Yan et al., 2022), disabled women (UN Women, 2020) and Muslim women (Safdar and Yasmin, 2020; Cahyaningtyas et al., 2021; Jailani, 2022) in the world's strictest lockdown, the intersections, convergences and the connections of these identities have been under-researched. Literature addressing the impact of COVID-19 in relation to gender, age, disability and religion identity, has largely overlooked the concerns of older disabled Muslim women and debates about these identities often take place in isolation from each other. Yet, these markers of difference need to be considered in relation to each other to bring to the fore the paradigm of intersectionality and to show that disability identity does not function in isolation from other social categories. Rather, they accentuate each other contextually and as a process.

Older disabled Muslim women, irrespective of impairment, are often disadvantaged on multiple fronts, they face discrimination in everyday life situations and within different contexts/societies (Hanna and Rogovsky, 1991; Turmusani, 2001; Jawad and Benn, 2003; Schur, 2003; Dossa, 2009; Sargeant, 2011; Alnamnakani, 2022). Discrimination against these women is not merely a function of the women's subordinate position in society (Dossa, 2009), but is a result of the intersections of ageing, gender, race, religion and disability identity. While few studies have examined the experiences of Muslim women with disability across the world such as Hussain (2005) in the UK, Dossa (2009) in Canada, and Turmusani (2001) in the Middle East, there do not appear to be any studies which explore the everyday life and experiences of older disabled Muslim women during the COVID-19 pandemic in the UK. The goal of this study, therefore, is to address this gap in the literature. The study explores the lived experience of an older disabled Muslim woman, taking into account her racial background, in the context of the COVID-19 pandemic in the UK. In this study, Zora shares her story of what it is like to be subject to discrimination as a result of having multiple identities.

Based on multiple narrative interviews which took place over a period of 18 months, this study addresses how Zora makes sense of and copes with the challenges associated with her multiple identities during the COVID-19 pandemic in the UK. Yet, since there is neither a single method for narrative analysis nor the analysis of the intersectional identities (Nasheeda et al., 2019; Turan et al., 2019), it was necessary to develop the 'narrative intersectionality' approach, this aimed to craft an analytical tool that would be sensitive to the intersectional identities of the participant throughout her narrative.

Following a discussion of methodological approaches, the article explores Zora's experience of her multiple identities in the context of

the COVID-19 pandemic in the UK. This is covered in one subsection and is preceded by an overview of Zora's upbringing and diagnosis: it discusses her experience of vulnerability whilst traveling by train, a public place where attitudes such as stigma, prejudice, and discrimination are derived from people's beliefs and ideas related to disability, ageing, race, and religion. This is followed by a discussion of the findings and the conclusion of this paper.

## Methodology

For the purpose of this article, the present data includes a subset of information for one participant taken from an original study which explored the lived experiences of five disabled Muslim women of varying ages in the UK (Alnamnakani, 2022). The study, however, is not concerned with generalizing the result and is dedicated instead to developing an in-depth understanding. Including fewer participants enabled more in-depth information to be collected about the phenomena under exploration. In the context of this paper, the participant's name has been replaced with a pseudonym.

This study utilises a narrative inquiry as a form of qualitative research, this focuses not only on "*individuals' experiences*" but also on exploring "*the social, cultural, and institutional narratives within which individuals' experiences are constituted, shaped, expressed, and enacted*" (Clandinin and Rosiek, 2007, p. 43). Narrative inquiry was selected for this study because of the role that it plays in giving a voice to silenced and marginalized people (Bruner, 1991; De Fina, 2015). It is a way of creating and sharing meaningful content from which people's experiences can be transmitted (Muylaert et al., 2014). The term narrative carries many meanings and it is often used synonymously with story (Riessman, 2008), such as in this study.

Parker and Shotter (1990) described narrative as the verbal recounting of life events as a story. Narratives allow people not only to tell what happened in the past, but also to enhance people's understanding of the present and possibly their future as well (Mattingly and Garro, 1994). Thus, people use narrative to understand and make sense of who they are and who they may become, by reference to where they have been and what they have been throughout their life. Selecting narrative inquiry in this study enabled me to focus on personal narrative, to start with participant's situation from the onset of her disability up until the time when she tells her story. This in turn enabled me to view the whole web of this woman's experiential reality of living with her multiple identities, particularly in a crisis time such as the COVID-19 pandemic.

A purposeful sampling was used to recruit participants with different experiences, ages, backgrounds and educational levels in order to reflect the diversity of these disabled Muslim women (Patton, 1990). The eligibility criteria included Muslim women who were residing in the UK, were at least 18 years of age, spoke English or Arabic, and self-identified as disabled. The rationale for selecting the narrative of one participant in this article was that her experiences demonstrated how approaches to older age and disability intersect with gender, race, and religion, and how these have been intensified by the COVID-19 pandemic. Once ethical approval had been granted by Cardiff University, School of Healthcare Sciences Research Ethics Committee, participants were recruited from various sources including disabled people's organizations, feminist organizations, Islamic mosques, Muslim women's networks, women's groups, as well

as personal Instagram accounts and snowball sampling (Alnamnakani, 2022).

Data were collected through multiple narrative interviews combined with semi-structured interviews, observing nonverbal communication and note-taking data. Narrative interviews are considered as a form of in-depth interview which emerges from the life stories of the participants and their context (Jovchelovitch and Bauer, 2000). According to Muylaert et al. (2014, p. 184) "*they allow the deepening of research, the combination of life stories with socio-historical contexts, making the understanding of the senses that produce changes motivates and justify the actions of possible informants.*" Hence, using narrative interviews can lead to a better understanding of the participants' perceptions and their social world.

According to Anderson and Kirkpatrick (2016) narrative interviews can be conducted together with semi-structured interviews and observation. Semi-structured interviews seek to uncover the person's lived experience (Walker, 2011). It permits the researcher to use open-ended questions which then allows the participants to respond in their own words and to describe the richness of their personal experiences in relation to their context (Bryman, 2012; Polit and Beck, 2014). Three in-depth interviews were conducted with the participant in this study. Each interview lasted between 45 and 90 min, depending on the interest, willingness and availability of the participant. The initial interview was conducted in-person, but the following interviews were conducted via virtual platforms (Zoom video meeting) due to COVID-19 restrictions.

Observing nonverbal communication and the effect of the context was used during the interviews to enrich the data with the meanings that are taken for granted. For example, facial expressions, gaze, silence, gesture, posture, tone of voice and other nonverbal interactional communication and body languages that could not be captured in an audio recorded interview. Interactions which occurred during the interview were observed and then reported in detailed notes immediately after each interview. The note-taking included nonverbal communications, information given by the participant in the concluding talk when the recorder had been switched off, what was seen/observed during the interview and any impact that the presence of the researcher may have had on the situation.

The data analysis methods were comprised of manually transcribing the recorded interviews and developing the 'narrative intersectionality' approach to analysing and interpreting the collected data. The 'narrative intersectionality' approach, was developed based on Chadwick (2017), and Blackie et al.'s (2019) concept of narrative intersectionality. The aim was to craft an analytical tool that would be sensitive to the intersectional identities of the participants throughout their narratives. The 'narrative intersectionality approach' conceptualises a participant's narrative as multidimensional and comprised of multiple analytical layers concerning multiple identities. The story is co-constructed between the participant and other actors within a particular social context and at specific intervals in her life.

The analytical process using the 'narrative intersectionality' approach included 7 steps, these were organized into 4 stages. The first stage involved 3 steps. Step 1 was the initial reading of the transcript and broad coding, and step 2 was re-reading and making initial notes on a story. Step 3 was listening to the participant's voice in her own words and reconstructing a story, the codes from step 1, as informed by notes from step 2, led to the development of emerging plots or

storylines, outlining the main elements of the participant's story. These first 3 steps were descriptive, focusing on understanding and developing the participants story and seeking to develop its initial plots.

The second stage was interpretive, aiming to produce meaning by engaging the emerging storyline with the related theory. It discussed the data with theory, and the theory was then used to fill the meaning-gaps in the emerging storylines and explain the story. The third stage involved 2 steps, further data collection and repeat process. These steps were interactive and aimed to interweave between the data collection and analysis process. This process was reiterated until a meaningful narrative was constructed. The fourth stage involved writing-up, aiming to refer to the conceptual framework which relied on the intersectionality theory to illuminate the complexity of the participant's experience and engage the co-constructed narrative in a critical discussion with the relevant theories.

According to Evans (2016) and Samuels and Ross-Sheriff (2008), intersectional studies should recognize the ways in which social context can affect social inequalities, particularly the way in which historic, economic and political conditions can shape participants' experiences, and can cause resistance to marginalization and exploitation across various contexts. In other words, intersectionality aims to address the manner in which sexism, ageism, racism, class and other systems of discrimination create inequality. As such, intersectionality calls for women to be viewed as whole beings; to recognize that not all women experience their womanhood in the same way. Many women face multiple forms of oppression but not all are rendered powerless (Samuels and Ross-Sheriff, 2008). It was felt important, however, to push this concept further and suggest that individually disabled Muslim women in the UK experience their multiple identities and various interlocking oppressions differently in different social contexts at different intervals of their lives, such as during the COVID-19 pandemic.

To enhance the credibility of this study prolonged engagement with the participant was used to support rigorous data collection, and gives a better understanding of the research context from the participants' point of view (Creswell and Miller, 2000; Shenton, 2004; Ryan et al., 2007). Data collection occurred through meeting and interviewing the participant on three occasions over a period of several months. There was at least a 4–8 month period between each interview and it was essential to maintain contact with the participant during this time to reduce attrition. Maintaining engagement with the participant facilitates a building of trust in the relationship. Member checking also occurred during each interview. Shenton (2004, p. 68) termed the provision of the accuracy of the data during the interview course as “*on the spot*” check. I re-framed questions or expanded on them using probing questions to explore issues the participants were describing in more detail. I also feedback to the participant to ensure that the constructed narrative reflected her perspective.

With regard to the ethical considerations, the participant was offered time to ask questions and consider her decision to take part in the study before signing the consent form. The participant voluntarily consented to sign the form which involved the following point: (I understand that the direct quotations from my story and the findings and potentially secondary analysis of the findings and associated data from this study may be presented at conference and published in scientific journals. I understand that these will be used anonymously and that no individual respondent will be identified in such report).

With respect of issues of anonymity, pseudonym was allocated and some of the minor details about the participant were changed. Some personal and demographic information was concealed such as using an approximate rather than exact age of the participants. In addition, anonymity was further maintained by omitting some of the data in the interview transcript or by judging what should be left out in the analysis based on the interview.

## Findings

The following findings aim to highlight how an older Muslim woman experienced life with disability, how she perceived herself in her local context and how she coped with the challenges she faced during the COVID-19 pandemic in the UK. This, however, does not mean that the narrative provides an exhaustive account of the participant's experiences of living with disability. More specifically it foregrounds some parts of this woman's experiences with disability in her local context and in a specific time frame of the pandemic, where other parts of her experience are not given the same attention.

Meanwhile, the narrative also brings to the fore the paradigm of intersectionality to show how differences of gender, age, race, religion, and disability accentuate each other. This should be understood contextually rather than viewing disability as a master category under which other categories are subordinated. Consequently, the narrative that follows does not make any claims for the generalisability of older Muslim women's experiences of living with disability, rather it highlights the experience of a specific older disabled Muslim woman in the context of the COVID-19 pandemic in the UK. Yet, for the production of generalization, there are a number of issues that could be explored with social groups of disabled women. Several stories of other disabled women in the UK remain unknown, untold and unheard.

The findings tell Zora's story, an older disabled Muslim woman in her 60s. Zora is a retired nurse who is married and had two children from a previous marriage. In 2003, Zora contracted HIV from her first husband. Following the HIV diagnosis Zora was diagnosed with a number of mental health conditions, these included bipolar and borderline personality disorder. At the same time, Zora described practising her religious traditions more, and began to wear a niqab (a veil covering all of the face apart from the eyes). In 2009, Zora developed chronic back pain, osteoarthritis, chronic IBS (irritable bowel syndrome) and stomach ulcers. She was also diagnosed with fibromyalgia after suffering long-lasting pain, which affected her mobility. As a consequence, Zora had to use crutches to walk short distances both indoors and outdoors.

Zora lived with her mother as her husband was working in another city. Throughout her narrative, Zora described how she was frequently stared at because of the way she walked and because of other categories of her identity, such as being “*Black*” and a “*lady with a niqab*.” In spite of this, she described how she tried to cope with people staring, as an older disabled Muslim woman with a niqab, in an attempt to carry on her daily activities independently and feel a sense of belonging, but this was not always successful. Zora described feeling “*vulnerable*” to sexual harassment on the train due to general hostility toward body differences, one of her everyday life contexts during the COVID-19 pandemic. The discussion section describes how the narrative provided a response to the objectives of this study and illustrates how the participant in this study resisted and overcame



daily social challenges to recreate a better world for herself, other older disabled Muslim women, and the next generation of disabled people.

## Zora's upbringing and diagnosis

When Zora was 6 years old, and whilst playing with her siblings, she recounted that they used to have “a very short person” walking around in their neighborhood. As children, Zora described how they tended to stare at this person. In response to their behavior, Zora stated that her

“mum used to say, don't stare, don't laugh at people because you don't know what's your future is going to be, so we were raised like that”.

Staring is fastening one's eyes on someone as a way of strongly expressing response and reacting to others (Garland-Thomson, 2006, 2009). It is a more sustained form of looking than glimpsing, gazing and other forms of normative looking, which registers intense interest and endows it with meaning. That interest can take many forms ranging from curiosity, wonder, disgust to hostility (Garland-Thomson, 2006). Zora described how her mother taught her and her siblings at an early age that anyone had the potential to become disabled or look different, including them, in the future. This familial context encouraged Zora to volunteer her time after school and at weekends to look after older people, “the disabled, people with learning disabilities, children, [and] teenagers with learning disabilities.” Thus, she became a volunteer “carer” at the age of 16 years. Her experience of looking after people developed further during her university placement, prior to working as a nurse in the NHS. She said:

“I worked for the NHS for 30 years. I'm proud of the things that I've contributed in the past”.

Zora was proud to work at NHS hospitals where she looked after people for many years. She told me that she wanted to do a postgraduate course to specialize further in mental health nursing, but she felt that the mental health problems due to her first marriage prevented her from doing so. Zora found it difficult to talk about her own mental health.

Zora: “I wanted to specialise, and I wanted to do mental health, but I have a mental health issue”.

Amani: What mental health issue?

Zora: “So, basically a bipolar and then I have a borderline personality disorder, but I think, I have, I was married, I'm married now, but I was married before to someone else, and he was an HIV positive”.

In 1997, Zora got married. She stated that her first husband was HIV positive, but he did not inform her about his health condition when they got married. “He kept it secret,” she said. When Zora was expecting her second baby in 2003, she “started to feel really sick” and visited the hospital. She explained that she had a medical check, including a blood test, but they told her:

“You are okay. And then, two weeks later they called: ‘you have to come back to the hospital now, now, now, now’ [emphasis by Zora], so they can stop the baby from getting this [HIV] condition, so basically then I was diagnosed with post-traumatic stress disorder because of what he did”.

When Zora was first diagnosed with HIV, she described being “very stressed out”. The challenge was not merely accepting HIV and living with it but also what to do with her husband. She told me that her ex-husband was arrested and was taken to court. Going to court for the trial was stressful for Zora, and the struggle was evident in her words when she spoke:

“The trial was like, made me, I was, I was very stressed out, they said, you have post-traumatic stress disorder, but I forgive him, and I leave it to Allah [God]”.

Following her diagnosis with post-traumatic stress disorder, Zora described how she resorted to two strategies: forgiveness and reliance on Allah. Worthington and Scherer (2004) stated that forgiveness could be used as an emotion-focused coping strategy to reduce a stressful reaction to a transgression. Thus forgiveness was a form of coping used by Zora to help alleviate stress caused by the traumatic events described above, and which affected her mental health. Secondly, Zora also credited her faith in God for getting her through that stressful time. She described laying her trust in “Allah” and leaving the rest to him because she believed nothing is difficult for Allah. Accordingly, after obtaining a divorce, Zora explained how she tried to start a new life.

“I moved and stayed with my two children. I just started to practice my deen [religion] more. I started wearing a niqab ... so now I wear a niqab, but I'm still the same person who goes to the shop, says good morning, and then the person there goes, ‘good morning, how are you?’ ‘I'm fine;’”

Underlying her action of continuing to work, going to the shops and moving with her children was a vision of life where being a HIV positive Muslim woman would not mean living in isolation. These actions enabled Zora to subvert the stigmatized identity of a Muslim woman who had HIV both for herself and others. Zora also described remaining “the same person” who loved interacting with others in the community. She believed that HIV and the niqab did not change who she was in terms of her social behavior and interaction with other people in the community. In addition to HIV, Zora also developed chronic back pain, osteoarthritis, chronic IBS and stomach ulcers between 2009 and 2011. She described being in a lot of pain due to these medical conditions:

“The pain is like I've been stabbed with a knife and I would stay on this couch, and I can't move, I can't get up for salah [prayer], I can't get up to go to the toilet, and I can't even umm eat because of the pain”.

The pain did not only affect Zora's everyday life activities, such as eating, toileting and praying; it also affected her ability to work. Zora had worked until 2012 when she retired on health grounds. “That's how bad it was all the pain in my body,” she said. Therefore, Zora



believed she was disabled from the time she began to experience the pain in 2009, this started several years after the HIV diagnosis. She explained that her support worker tried to help her apply for a disability allowance, but she did not qualify at that time.

“They said that just because you are in pain doesn’t mean you can qualify for it, and PIP, which is personal independent payment, concentrates on your mobility”.

Zora did not qualify for the PIP, to help her with the extra cost of living with a disability, until fibromyalgia affected her mobility, a diagnosis which was confirmed in 2015. She described how pain due to fibromyalgia, combined with osteoarthritis, chronic back pain and stomach ulcers, resulted in her having to use crutches and “*start to be very slow and then every step agony*”. As such, the following section describes Zora’s experience of her identity as an older Black disabled woman who wore a niqab and used crutches in one of her everyday life contexts during the COVID-19 pandemic: public transport.

## On the train; “I realised I’m vulnerable”

During our conversation, Zora spoke of her feelings about the way she walked and how people reacted toward her within her local community. She said:

“I feel awkward because of the way I’m walking, it’s like I’m walking down a hill, and the way I’m walking with my crutches is extremely slow, and people are staring at me, and I don’t know why they’re staring at me, I don’t know if they’re staring at me because of that or because I’m Black, or because I’m Muslim, or because of my disability, or because my age [laugh]”.

At the heart of Zora’s words is the matter of her body appearance. Walking slowly, older adult, Black skin, niqab, and crutches – all of these are body characteristics and embodied practices. She began by describing her walking as “*extremely slow*,” she believed this to be a primary reason for people staring at her. Garland-Thomson (2017) argued that stare indicates a disabled identity about the body when markers, such as Zora’s crutches, are conspicuous to people. In this case, Zora’s body disrupted the body norm expectations and invited the stares that constituted her as other. But Zora also said she was unsure if her disability was the only reason for being stared at. Her uncertainty was complicated by the presence of other categories of her identities, which she believed invited staring; namely, being an older, Black and Muslim woman with a niqab.

An older woman could be stared at, as Cecil et al. (2022) suggested, because they are subject to both sexism and ageism, and consequently be stigmatised as their appearance looked dissimilar to societally favored youthfulness. Wilkinson (1969, p. 191) referred to situations in which Black people find themselves receiving the “*Black hate stare*” in various forms in public, such as frowns and glances. Zempi (2020) reported that Muslim women in the UK who wore the niqab experienced stares from strangers in public places due to their visible religious identity and gender performance. In the following extract, Zora explained how she responded to a staring incident on the train during the COVID-19 pandemic:

“When I was on the train, I was sitting in a carriage where there was no one else and four rows ahead of me there was a man, this man came behind me by my seat and then he just didn’t talk but WOOH [loud voice expression], like that. I just went Ahh [panic expression], he was holding his private part and staring at me. When I saw him holding his private part, I turned to look through the window, and when I was looking through the window, I couldn’t see if I can see anything, I stared at the window, and for me, it took like an hour, but it would be three minutes or so, and then while I was staring he was laughing. After three minutes of staring at the window, I finally could see his reflection. I don’t know whether because we entered to the tunnel and there was dark, and you can see, and it’s like a mirror now, it’s not like you’re looking to trees or anything, and he was shaking his private part and staring up and down at me”.

Blocking a person’s path, making sexual gestures through touching oneself in the presence of another person, and looking at a person up and down, are all non-verbal examples indicating Zora’s experience of sexual harassment on the train. Sexual harassment involves unsolicited and rejected verbal or nonverbal sexual gestures that happen in different ways by a male stranger toward a female, solely based on her sex, in a public place (Laniya, 2005; Ludici et al., 2017; Mason-Bish and Zempi, 2019). However, to understand any woman’s experience, Davis (1994) and Mason-Bish and Zempi (2019) emphasized the importance of thinking of her as embodied and not as a person experiencing sexual harassment on various, nonintersecting axes, and then thinking about the particular meanings assigned to that embodiment in her context.

Dalton et al. (2021) and Martin et al. (2006) found that non-White women were more likely to have experienced sexual assault, to have been judged unfairly and blamed for the occurrence of the assault. Disabled women were among those who suffered most from sexual crime in the transport environment as their impairment limits their ability to defend themselves. This may lead the perpetrator to feel that disabled women would be relatively powerless to resist (Martin et al., 2006; Casteel et al., 2008; Ludici et al., 2017). Older women, however, face particular barriers to disclosure of sexual assault, this results in their experiences remaining hidden (Fileborn, 2017).

On the other hand, Haddad et al. (2006) argued that Muslim women had been historically portrayed as either hypersexual women or silent images of oppressed victims of male brutality. Yet, women who wear the hijab, in particular, were subjected to sexual harassment based on stereotypes about their gender, religion and race. This positions their bodies as passive and incapable of resisting male offence (Alimahomed-Wilson, 2017). In this regard, wearing the niqab marked Muslim women out as more readily visible and as soft, easy, and convenient targets for attack (Mason-Bish and Zempi, 2019). Zora acknowledged that she was vulnerable, as an older Black disabled Muslim woman with a niqab who was traveling alone in an empty train. Measures to restrict movement had been introduced by authorities during the pandemic, this had led to a drop in passenger demand (Marra et al., 2022). As a result she described her thoughts and her response to the man’s behavior whilst she was traveling on the train:

“I was just holding one hand on my bag and the other hand on my crutch. With my crutch, I thought in my head should I hit him

with my stick? What if I hit him with a stick, he might get hold of the stick and beat me with the stick, so I can't hit him, I was frozen, and then he just walked away. So then I had my suitcase, the next stop I got off, and it took like maybe 20 minutes to get to the exit, for somebody that would take them five minutes. And as soon as I saw the person behind the window at the station, I burst into tears and I said please I need to report something to the police, and then I thought I should never get on the train again on my own for the rest of my life. Although I video what happened to prove this, and I thought maybe the video would be evidence to the police, and that's when I realised I'm vulnerable, it hits me like a COVID".

Zora's expression "*I was frozen*," meant she resorted to the fight, flight and freeze response in the presence of a stressful threat (Samra, 2019). At first, Zora described thinking about the fight response. She thought of hitting the man with her crutch, but realised she could not protect herself if he took the crutch and started beating her. Bearing in mind that he stood by her seat and she could only walk slowly on her crutches, due to her age and physical impairment, neither fight nor flight and escaping from him seemed possible. Thus, Zora described finding herself in a situation where she could not act or move at all; she froze until the man walked away.

According to Owen (2021), reports of sexual harassment on public transport in the UK increased by 63% in 2021 when compared with the figures for 2019, prior to the pandemic. Yet some women were still hesitant to report crimes, this was due to their mistrust of the police and the way age shapes the experiences of older victims of sexual harassment (Lazar, 2020; Owen, 2021). On the contrary, Zora did not present herself as a passive victim in the face of the perpetrator. Zora recorded a video during the stressful few minutes of her experience of sexual harassment so she could use this as evidence in police investigations, the carriage was empty and there were no witnesses. Then, when she managed to reach assistance at the station, she immediately reported the incident.

Concerning COVID-19, a report by OECD (2021) demonstrated the fact that the virus had a devastating impact on people's physical health. It also showed that the crisis affected people who were already struggling the hardest, such as the ethnic minority community. In the same way Zora described how being alone and vulnerable, due to the pandemic movement restrictions, had strongly affected her well-being. On reflection, however, Zora referred to herself as a strong and brave person. She said:

"I don't feel vulnerable in general before that day and thought I was a strong person who is brave, I'm not afraid of anyone, and then I realised that because I froze that means that I'm not. Ah, but I videoed it".

For Zora, being a strong person did not mean having physical strength. Rather, it meant having the confidence to make choices, have freedom of mobility, and travel independently without requiring assistance. This was despite having a physical impairment which limited her mobility and resulted in her needing crutches. However, this incident placed Zora in a socially vulnerable position, encapsulated in the case of sexual harassment that lowered her self-esteem and made her feel weak and devalued. Swinton (2012) argued that belonging goes to a deeper level than inclusion. The term

'inclusion' means that all people should feel welcomed and incorporated into the fabric of their society without any kind of restrictions or limitations (D'Eloia and Price, 2016). Thus, to be included, Zora just needed to be present so that the transport system fulfilled some social or legal standards of inclusion and diversity. On the other hand, belonging can follow from broader environmental cues that indicate one's identity is compatible with, or appropriate in, a given context (Slepian and Jacoby-Senghor, 2021). As such, to belong Zora needed to be seen as a valued human being and feeling able to be her true self.

According to Wilson and Van Antwerp (2021), having a psychological sense of belonging within a particular social context is essential for positive psychological and performance outcomes. They found that women in an under-represented group were particularly vulnerable to not belonging as their minority status, based on their gender, race, social class, religion or other under-represented status, can contribute to a negative feedback cycle associated with unmet belonging needs (Wilson and Van Antwerp, 2021). Zora described being a "*vulnerable*" commuter within the transport system during the COVID-19 pandemic, her belonging involved not only making the transport environment physically accessible, but also re-emphasising the need for a monitoring system which would make public transport safe for her as an older, disabled and Muslim woman.

As such, Zora believed she was vulnerable, as an older disabled woman she could not control these situations and could not shield herself adequately from their consequences. Older women are in general easily victimized and cannot defend themselves due to their reduced mobility and physical impairment (Block, 1983). In addition, Arstein-Kerslake (2019) and Scully (2014) affirmed that disabled women are at greater risk of experiencing specific types of harm or being a victim of hate crime or abuse.

Scully (2014) identified two types of vulnerability in relation to disability: inherent, and contingent vulnerabilities. Inherent vulnerabilities are those which are often due to physiological or biological characteristics directly resulting from the impairment itself. For example, Zora's impairments are associated with mobility problems such as poor balance and risk of fall when walking. Contingent vulnerabilities are those which are directly created by the social environment, they are contingent upon social and cultural responses to embodied differences which instigate and perpetuate situations and create vulnerability (Scully, 2014).

For example, an environment, such as public transport, that has not been made emotionally safe (the visceral feeling of being accepted for who you are and what you feel and need) to use for Zora, who used crutches, needed to walk slowly and required another person to guard her during attack. This environment left Zora vulnerable to the perpetrator, because when she was faced with the need to feel secure or escape safely she was dependent on the presence of another person or other passengers on the train. However, the train was empty as many people worked from home and avoided travel during the coronavirus pandemic. Thus, the perpetrator held power in this situation, and she believed that he might abuse that power. The perpetrator's power was demonstrated through using some tactics to control Zora by intimidating, threatening, and causing fear by blocking her way. The utilization of these tactics, according to Crowley (2022), could place a heavy burden on the female victim based on the particular features of the setting and the characteristics of the victim.

This is the vulnerability that is contingent on an inaccessible environment (Arstein-Kerslake, 2019).

If the public transport were made accessible with automated surveillance, older/disabled passenger alarms and other appropriate mechanisms to detect parameters such as unsafe behavior, then Zora might be able to use the train independently and would not need to depend on another person to guard her. To put it another way, the railways provide emergency buttons in the toilets of trains. Similarly, safety alarms could be provided on the train's carriage for disabled and vulnerable people to draw the train crew's attention to emergencies. Zora would, therefore, not be vulnerable to the potential for other people to use their position of power and to harm her. But against a background of such vulnerability, Zora was inherently and contingently vulnerable in the context of public transport.

Whilst it might not be possible for changes in the social environment to fully negate the impairment-related inherent vulnerabilities from the lives of disabled people, contingent vulnerabilities could, in principle at least, always be altered (Scully, 2014; Arstein-Kerslake, 2019). Thus, to eliminate her vulnerability, Zora described her decision not to “get on the train again on [her] own for the rest of [her] life”; this decision restricted Zora's autonomy by limiting her independence in traveling alone. “Under such circumstances, any inner reflections on who one is are eclipsed by the external definition of what one is in the eyes of others” (Jackson, 2002, p. 68). Zora wanted to live in a way that positively acknowledged the difference of her age, religious tradition, physical ability and gender-based identity, but this was not possible in every situation.

Zora's experience on the train reflected the ecological approach to disability. According to Nathan and Brown (2018), the ecological approach provides a useful framework for modeling dis-ability. They argued that disability cannot be reduced to the experience of an individual, caused by biology, society, or a combination of both because disability is not a property of an individual. Disability is only part of the story which cannot be analyzed independently without including the environmental features of the underlying context (Nathan and Brown, 2018). That is, the disability itself is not a disease or impairment existing within Zora's body but only exists in the gap between her capabilities and the demands of the environment and context. In other words, Zora had the physical potential to travel independently, but when the perpetrator threatened her there were no measures on the train to ensure her safety, thus the person-environment interaction created a disability.

## Discussion

Much of the attention so far has focused on the implications of the COVID-19 pandemic on a single group of women, such as older women (VoPham et al., 2022; Yan et al., 2022), disabled women (UN Women, 2020) or Muslim women (Safdar and Yasmin, 2020; Cahyaningtyas et al., 2021; Jailani, 2022). However, the experiences of older disabled Muslim women has not been given the same attention. In this study, older adult, gender, race, religion and disability augmented one another in the participant's display of herself to form a spectacle of embodied otherness that is simultaneously sensational and pathological. Zora, therefore, shared her story to demonstrate how she coped as an older disabled Muslim woman with a niqab, one

who is independent and “brave” despite the challenging times presented by the pandemic restrictions.

Zora's narrative touches upon her feelings of exclusion and vulnerability in one of her everyday contexts during the COVID-19 pandemic. Zora located her narrative in the context of public transport to highlight how one can be an actor and also a person who is acted upon. In this sense, she suggested that the bridge to accommodate her differences could be crossed through a context-specific sense of humanity implying respect for diversity as an outcome variable to crisis management, and ability to promote genuine harmony throughout the wider society.

Zora did not want to change her body or herself; she wanted to change the collective negative perceptions of old, disabled, ethnic and Muslim women as members of minority groups, particularly, during the COVID-19 pandemic (Armstrong and Watson, 2021; Walubita et al., 2021; Claus et al., 2023). Zora wanted people to recognize these facets of perception as socially constructed barriers and not as inevitable or natural. Accordingly, she did not only resist defining herself in terms of the stereotypes and preconceptions, observable in wider society, but insisted that another socially positive identity was appropriately descriptive of her. For example, she commented on how “brave” she was when she videoed the incident and reported it, she did so in order to support communities in developing solutions that would enhance vulnerable women's safety, particularly during crisis times.

By portraying her life in this way, Zora asserted her agency in the sense that her resistance operates across the individual and collective levels and is enacted through self-reflection coupled with action (Gabel and Peters, 2004). Through these acts of resistance she celebrated a unique version of herself, as an older disabled Muslim woman, which she reconstructed from the perception of society about her identities as invisible, negative, passive, oppressive or without agency as described by Amini and McCormack (2021), and Turmusani (2001). Zora described being discriminated against and feeling vulnerable due to stigmatization which excluded her and set her aside as less important due to her multiple identities, it is an example of a situation which Oni-Eseleh (2021) described as social rejection.

The elements of social rejection which Zora experienced included being stared at, stereotyping based on cultural beliefs and denial of access to equal opportunities within her community. Knowles et al. (2014) found in their study that social rejection motivated people to distance themselves from the sources of rejection. In the same way, Zora reported that she would not use the train again on her own. This was due to her fear of people's unpredictable reactions to her multiple identities. This may lead to lack of functioning and increased dependency, with a potential negative impact on her health and wellbeing. Adopting this coping mechanism, however, brings to the fore the idea that the goals of the stigmatisers are achieved and the unjust world is left intact.

As such, a social life was no longer hers to participate in and enjoy independently, it was dependent on how other people would perceive and react to her, also the availability of someone to accompany her. To put it in another way, Zora expected to arrive safely at her destination. Instead, she experienced a stressful situation and performed painful physical activities (i.e., carrying her suitcase while walking slowly with crutches to get to the nearest exit where she could get help) in her efforts to avoid such hostility, in the same sense as discussed by Block

(2020) regarding the precarity of spirit when a person's body and mind are under extreme stress due to a hostile living environment.

However, the aim of using the narrative intersectionality approach for this case study was to bridge the boundary between the medical model of disability and the social model of disability. Research has shown that healthcare students initially adhere to the medical model of disability, this views disability as something that must be fixed or cured in order for the disabled person to better fit into society and live a full life (Hirschmann, 2012; Cuff et al., 2016). I would argue that focusing on the body, as a disabled body needing a cure, can undermine the social issues that disabled people experience.

On the other hand, the social model of disability puts the onus of change on society, saying that inability to participate fully in social interaction is intrinsic to the society that is structurally, attitudinally and systemically inaccessible (Cuff et al., 2016). Yet, focusing exclusively on the social barriers in society obliterates the body from view, it overlooks the pain and suffering caused by the physical impairment that cannot be addressed through accessible society (Hirschmann, 2012).

As Shakespeare and Watson (2001) argued, the distinction between impairment and disability can be demonstrated by understanding where impairment ends and disability starts. While impairment is often a cause of disability, disability may itself produce or exacerbate impairment (Shakespeare and Watson, 2001). Therefore, incorporating the narrative intersectionality approach can develop a mutually beneficial integration of the two models, it creates a critical framework for discussing the medical and social factors that shape the individual experience of disability represented in the participant's account. It can also transform practice for social change and view disabled people as whole beings: to recognize that not all disabled people experience the same multiple identities in the same ways; many encounter multiple forms of oppression, but not all are rendered powerless (Samuels and Ross-Sheriff, 2008).

## Conclusion

This paper provides an insight of the intersected experience of aging, disability, gender, religion and race for a specific older disabled Black Muslim woman during the COVID-19 pandemic in the UK. The paper explores the strategies that the participant used to combat the deleterious effects of her multiple identities and strengthen her sense of agency in a lockdown world. Engaging with the narrative of this woman, this paper argues that the participant in this study endured a challenging context where social barriers related to her multiple identities left her not only unable to integrate but, more importantly, feeling vulnerable within the context of her everyday life. Her vulnerability was not related to the COVID-19 virus itself, restrictions imposed during the pandemic made her vulnerable in terms of her personal safety and wellbeing, not only in terms of health outcomes. To sum up, the present findings are of significance for understanding the long-term consequences of the COVID-19 pandemic restrictions on people living with multiple identities, such as older disabled Muslim women. To optimally serve them, attention should be given to their lived experience, daily social challenges and the lasting impact of the COVID-19 restrictions on their wellbeing,

social lives, lack of freedom and independence, particularly if future lockdowns were to occur.

## Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found in the article/supplementary material.

## Ethics statement

The studies involving humans were approved by the Cardiff University, School of Healthcare Sciences Research Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

## Author contributions

AA: Writing – original draft, Writing – review & editing.

## Funding

The author did not receive financial support from any organization for conducting this study or the preparation of this article. Research discussed in this article was carried out as part of a PhD thesis.

## Acknowledgments

I am grateful to my academic supervisors at Cardiff University. Dikaos Sakellariou, Reader at the School of Healthcare Sciences, and Gareth Thomas, Reader at the School of Social Sciences, they provided me with extensive professional guidance throughout the original study as well as during the writing of this paper.

## Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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RECEIVED 24 June 2024

ACCEPTED 23 September 2024

PUBLISHED 04 December 2024

## CITATION

McFarland J, Rice C, Changfoot N, La Rose T, Alfaro-Laganse C, Badri S, Smith K and Katz B (2024) Graying arts access: crafting creative online programming to promote older adults' artistic engagement in and beyond pandemic time. *Front. Sociol.* 9:1454143. doi: 10.3389/fsoc.2024.1454143

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# Graying arts access: crafting creative online programming to promote older adults' artistic engagement in and beyond pandemic time

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**Introduction:** Declared a global pandemic by the World Health Organization (WHO) in March 2020, the COVID-19 virus and attendant patchwork of local, regional, and national government-initiated public health responses to it unexpectedly opened possibilities for greater access to culture for disabled and chronically ill people in ways that were unimagined in pre-pandemic times. During the “emergency” period of the pandemic, the fields of critical disability studies and aging studies independently demonstrated the importance and value of shifting to digital technologies for disabled people and older adults respectively; however, to date, little scholarship has considered the value of digital technologies for older adults aging with and into disabilities beyond pandemic time.

**Methods:** Informed by the theoretical insights of scholarship exploring critical access and the aging-disability nexus, this paper draws from empirical data collected during Phase 2 of Direct[Message]: Digital Access to Artistic Engagement, a collaborative, community-based, arts-informed research project based in Southwestern Ontario (Canada). Drawing from 50 qualitative interviews with aging adults from un/under/represented communities, findings explore the intersections of older age and disability, including dynamics related to gender, sexuality, migration, size, race/ethnicity, and other differences, as these relate to access to and enjoyment of creative spaces before, during, and “after” the COVID-19 pandemic.

**Results:** Results show that older adults aging with/into disabilities in Southwestern Ontario express an overwhelming desire and even urgent need to access interactive arts programming from the relatively safe spaces of their homes both within and outside pandemic time.

**Discussion:** As the normative world pushed for a return to ableist normative life in 2022, a year marked by “severe” rates of the highly infectious Omicron variant and the loss of effective public measures, such as community masking and widely available testing, participants described the need for continued access to creative and social participation via remote options that sidestepped

socially exclusive and physically inaccessible spaces. Findings indicate a need for increased investment in digital arts programming for older adults aging with/into disabilities.

#### KEYWORDS

aging, aging-disability nexus, arts access, remote access, COVID-19, underrepresented older adults

## Introduction

Declared a global pandemic by the World Health Organization (WHO) in March 2020, the COVID-19 virus and attendant patchwork of local, regional, and national government-initiated public health responses to it unexpectedly opened possibilities for greater access to culture for disabled and chronically ill people in ways that were unimagined in pre-pandemic times (Barden et al., 2023; Brown, 2021; Introna, 2023; Rice et al., 2021). Because the pandemic posed a threat to coded-as-abled/healthy populations, “emergency” measures (Ellcessor, 2022) or temporary forms of access proliferated and “many disabled people noted that the pandemic made for a ‘cripping of the world’—where for perhaps the first time the vast majority of humanity ‘dwelled in disabled reality’” (Piepzna-Samarasinha, 2022a, n.p.; Croft et al., 2024; Ignagni et al., 2020; Keegan, 2020; Rice et al., 2024; Wong, 2022). For example, for millions of disabled and older people, orders to shelter-in-place or stay at home were “ironic” since confinement to the home has historically been the default reality for many disabled people, including older adults experiencing changes to hearing, sight, memory, and/or mobility; and loneliness and social isolation were, prior to the pandemic, viewed predominantly as a social problem affecting older communities (Clayton et al., 2023; Goggin and Ellis, 2020; O’Sullivan et al., 2021). During the emergency period, however, such confinement was experienced by young, nondisabled, and healthy populations as a “new normal” or temporary reality that generated some promising yet *temporary* solidarity with disabled and aging communities (Nowakowski, 2023; Piepzna-Samarasinha, 2022b). Pandemic emergency responses necessitated the widespread adoption of digital technologies to support remote working, learning, and socializing, and marked a period that some critical disability studies scholars have described as “pandemic time” or “COVID time,” a “time that [for normative life] has to be endured rather than settled into” (Ignagni et al., 2020, para 9; Croft et al., 2024; Ellcessor, 2022).

At the beginning of the pandemic, some scholarly and public discourses framed emergency measures (e.g., restricting in-person interactions) as constituting a time of increased recognition of “crip” culture and access practices (e.g., digital/remote access), and thus ushering in a period of greater inclusion for disabled people—“crip,” a reclaimed pejorative term, conceptualizes disability not as dysfunction, but rather as possibility (Clare, 1999; Rice et al., 2021). During these same years, however, counter-discourses emerged to simultaneously frame emergency measures and the swift turn to the digital as instituting a time of intense isolation, loneliness, and exclusion—essentially, a time of no access to cultural or social

life—for older adults, generally (Berg-Weger and Morley, 2020; Moore and Hancock, 2020; Reneland-Forsman, 2020; Seifert, 2020; Shan et al., 2020; Zapletal et al., 2023). The shift to virtually delivered services, while beneficial for some (e.g., young disabled and/or chronically ill communities), has highlighted a critical need to promote the digital engagement of older adults who disproportionately encounter unevenly felt “digital divides,” or barriers to digital/remote access that can compound the risk of experiencing social isolation in later life, and exponentially exacerbate crosscutting digital inequalities (Beaunoyer et al., 2020; Cosco et al., 2021; Losada-Baltar et al., 2021; Zheng and Walsham, 2021). Although access to and use of technology among older adults increased during the pandemic (Clayton et al., 2023; Murciano-Hueso et al., 2022; Sixsmith et al., 2022), especially among those with family members or caregivers who could assist with technology training and use, many older adults continue to face an array of barriers, including digital anxiety, fear of new technologies and cybercrime, low digital competencies, and a lack of digital skill-building opportunities (Kim et al., 2023; La Rose et al., 2022; Schlomann et al., 2020; Tomczyk et al., 2023). For multiply marginalized older adults who experience additional barriers to social participation, such as discrimination and cost, the inaccessibility of creative digital spaces has emerged as especially harmful (Jonsson et al., 2023). Such work has highlighted a critical need in aging studies to take seriously older adults’ use of technology and the digital inequalities they experience, a problematic that the pandemic and emergency responses to it both accentuated and aggravated. Although numerous studies have demonstrated the role technology and the arts play in decreasing social isolation, establishing and sustaining social belonging, promoting lifelong learning, and improving the well-being of older adults (Castora-Blinkey et al., 2010; Cohen, 2006; Guthell and Heyman, 2016; Klimczuk, 2017; McFadden and Basting, 2010; Noice et al., 2014; Peine et al., 2021; Todd et al., 2017), few studies with a focus on aging have considered how cultural and artistic participation could be facilitated using digital technologies prior to the pandemic (La Rose et al., 2022).

In contrast, critical disability studies has demonstrated the value of digital technologies and environments before, during, and beyond pandemic time by evidencing the *political* significance of digital access to artistic engagement and creative participation for disability-identified communities (Cachia, 2023; Chandler, 2019; Chandler et al., 2018; Orsini and Kelly, 2016; Rice et al., 2015, 2016, 2018, 2024, 2023). Researching during pandemic emergency conditions, some critical disability scholars have uncovered and highlighted the creative possibilities and unanticipated benefits of digital and/or remote options. This includes the Narratives of



Neurodiversity Network, a neurodivergent academic, creative, and educator collective, who explain:

As the pandemic mainstreamed remote collaboration to an unprecedented level, we realized the possibilities an online space could offer neurodivergent individuals outside the oppressive and pathologizing structures of societal institutions, including the classroom, the courtroom, the psychiatrist's chair, and the academy. (Betts et al., 2023, p. 64)

Indeed, remote access, according to Johnson et al. (2024), comprises “an example of crip technoscience and a crip ritual—a transformative practice that is ‘repeated and reiterated within disability culture’” (p. 218). Remote access events or parties, whereby participants come together and interact in virtual space in ways that sidestep the inaccessible dynamics and/or harmful effects of gathering in-person, offer vivid illustrations of disabled community-building (Gotkin and Hamraie, 2024; Hamraie and Williams, 2023; Johnson et al., 2024). As well, since the start of the pandemic, chronically ill and disabled people have depended on digital platforms (e.g., Twitter and Instagram) to find community, track COVID-19, make its symptoms and after-effects visible, tackle misinformation, and circulate life-saving resources (Callard, 2020). At the time of writing, social media accounts (e.g., DoNoHarm BC) and COVID trackers, such as the Canadian COVID-19 Hazard Index (COVID-19 Resources Canada, 2024), continue to circulate in online disability communities as educational tools that resist the increasingly dominant socio-temporal construction that “the pandemic is over” (Archie, 2022, para. 2). Such online communities also document the development of a living archive of sick, ill, and disabled knowledges, or what Piepzna-Samarasinha (2022b) calls the “work of our survival,” throughout the pandemic (para 15). Technological affordances, specifically remote opportunities to participate, have thus been invaluable to people with disabilities and chronic illnesses during the pandemic.

The obvious overlap between disabled *and* aging populations notwithstanding, separate bodies of scholarship have independently demonstrated the critical importance of art and technology for older adults and disabled people. Despite this, few studies have considered the value of digital technologies for artistic practice for people aging with longstanding disabilities and people first experiencing disability in later life—two unique yet overlapping intersections of aging and disability we refer to as *aging with/into disabilities* (Changfoot and Rice, 2020). Unlike the separate fields of aging and disability studies, which “often fail to recognize that people with disabilities age and that aging gives rise to disability,” the aging-disability nexus attends to the inter- and intra-sectional experiences of people aging *with* and *into* disabilities (Aubrecht et al., 2020, p. 7; Changfoot et al., 2022; Grenier et al., 2016; Korotchenko and Hurd Clarke, 2016; Lamb, 2015; McGrath et al., 2016; McFarland and Taylor, 2021). This paradigm challenges dominant aging discourses that define “successful aging” (Rowe and Kahn, 1997) as the prevention of disability and the maintenance of physical and cognitive function, and disability discourses, policies, and activism that overlook age-related disabilities, such as age-related vision and mobility differences (Jonson and Larsson, 2009; McGrath et al., 2016).

Put simply, the aging-disability nexus and by extension the concept of aging with/into disabilities conceptualizes disability as a *part of* rather than *distinct from* the aging experience (Aubrecht et al., 2020; Changfoot et al., 2022). To this end, we use the term disability to refer to disabilities experienced across the lifespan, including those developed in earlier life, those acquired in later life, and those anticipated to arrive in the future. In this usage, we reject the dominant convention of reductively associating disability with *young* bodyminds, who are predominantly assumed to exist outside of the normative linear life course (e.g., education, work, marriage, childrearing, etc.) and thus expected to have “no future,” and impairment—often configured as normal and expected—with aging or *old* bodyminds (Grenier et al., 2016; Changfoot and Rice, 2020; Kafer, 2013).

While few studies have considered the potential of digitally mediated creative spaces for older adults aging with/into disabilities, even fewer studies still approach this topic from a crip perspective that does *not* conceive of technology as a fix or cure to the “problem” of old age and/or disability. In one rare exception, Temple Jones et al. (2021) conducted a narrative literature review of disabled and aging people's experiences with technology and access design, or what they call “TechnoAccess” (p. 2). Building on the critical insights of crip technoscience and critical access studies (Chandler et al., 2023a,b; Hamraie, 2015, 2017, 2018; Hamraie and Fritsch, 2019), the concept of TechnoAccess rejects, or pushes *against* “technoableism,” the notion that technology can “solve” disability and thus “save” disabled people from disability itself (Shew, 2023). A TechnoAccess approach recognizes instead how technologies may misfit with disabled and abled bodies and produce their own disabling effects (e.g., technologies such as diagnostic testing or the written word producing learning disabilities: see Rice et al., 2024). TechnoAccess prioritizes non-normative bodies, including disabled and aging embodiments, in technological development and scopes the “ongoing sociotechnical lives and corporeal realities of people's intersectional experiences, understanding that access is contingent upon social, structural, and technical barriers that are felt unevenly among users” (Temple Jones et al., 2021, p. 2). In their systematic review, the authors found that studies that implement storytelling methods, such as ethnography, most explicitly center “mad, disabled, and Deaf people's corporeal attunements in inquiry” (p. 9). Importantly, the authors note that, while the research they reviewed often reported on technology development *for* disabled and/or aging people, studies rarely worked *with* and their results were rarely drawn *with* and *by* disabled and aging people. To this end, our study aims to address a gap in the literature about age, disability, and technology, while responding directly to Temple Jones et al.'s (2021) imperative to “improve arts access in ways that centralize disabled, aging, and other marginalized people's multimodal experiences with technology” by eliciting and incorporating older adults' rich stories across all aspects of technology development and research design (p. 3).

Promoting a deep desire for social change, storytelling is an important and complementary approach to researching the needs and lives of underrepresented populations, including disabled and/or older adult populations (Chazan and Baldwin, 2021;

Charise, 2022; Fraser, 2004; Nyboe and Drotner, 2008; Kaare and Lundby, 2008; Smith and Sparkes, 2007). Indeed, storytelling, particularly during the pandemic, played a significant role in shaping the identities and artistic expressions of older adults aging with/into disabilities, while opposing master COVID-related narratives, including “the pandemic is over” (Archie, 2022, para. 2). For instance, COVID in the House of Old uses wooden storytelling chairs to remember grief and outrage with the countless victims of Canada’s eldercare system at the onset of the pandemic (Davies, 2022)—a time of mass eldercide, when older adults were often reduced to statistics in dominant news reporting on the effects of COVID-19 (Badone, 2021; Parekh and Underwood, 2020). Micro stories can challenge “generalizing and totalizing impulses” that disappear minoritized perspectives, and instead “tell small, situated stories that centralize the embeddedness of our embodiments” (Rice et al., 2022, p. 252), including those of older and disabled communities, which can trouble the violent necropolitical logics that undergirded global responses to and dominant narratives about the pandemic (Rice et al., 2022).

## Materials and methods

*Direct[Message]: Digital Access to Artistic Engagement* (*Direct[Message]*) is a collaborative, community based, arts-informed research project working within three mid-sized cities in Southwestern Ontario, Canada: London, Hamilton, and Guelph. In partnership with the Re•Vision Center for Art and Social Justice at the University of Guelph and the Schools of the Arts and Social Work at McMaster University, a Hamilton-based, community arts organization called *Centre[3] for Artistic and Social Practice* leads *Direct[Message]*. In keeping with the principles of TechnoAccess (Temple Jones et al., 2021), the project aims to make the arts more accessible and interactive for older adults through developing innovative digital technologies and environments with/by aging communities, especially those at the intersections of disability and other difference. To this end, *Direct[Message]* employs a community-based, co-design model that facilitates collaboration between older adult community members, artists, facilitators, academics, and staff from local community- and arts-based organizations and studios, including Museum London, VibraFusionLab, Cinematronics, and CreativeAge Network.

The project, which began near the end of 2019 and start of the pandemic, engages older adults from underrepresented communities in Southwestern Ontario. Shaped by the contours of a global pandemic (La Rose et al., 2022), Phase 1 (2019–2021) established strong and lasting collaborations with community partners through identifying barriers and supports that informed older adults’ engagement with the arts. Phase 1 also involved the development of an easy-to-use keyboard and an easy-to-access web-based platform as prototypes to better support older adults’ virtual arts engagement. Phase 2, the focus of this article, iteratively evaluated and developed these digital devices, including the easy-to-use keyboard with asynchronous art content and synchronous online art activities, that we thought would enhance older adults’ access to and participation in the arts. This paper draws from interview data collected during Phase 2 of *Direct[Message]*.

TABLE 1 Disability characteristics of study participants (N = 51).

Participants identify as living with a disability	
Yes	24 (47%)
No	26 (51%)
Prefer not to answer	1 (2%)
Participants with disabilities identify in the following ways	
D/deaf or hard of hearing	2 (4%)
Blind or visually impaired	1 (2%)
Living with a physical disability	8 (16%)
Autistic	1 (2%)
Neurodivergent	0 (0%)
Living with cognitive difference or challenges	3 (6%)
Living with a combination of disabilities	7 (14%)
Prefer to self-identify as [fill in the blank]	10 (20%)
Prefer not to answer	0 (0%)

The University of Guelph’s Research Ethics Board (certificate number: 20-06-027) reviewed and approved the Phase 2 (2022) study in Spring 2022, while the initial study received ethical approval from McMaster’s Research Ethics Board in 2019. Participants could participate if they identified as an older adult (i.e., 60 or older) or an E/elder (a title determined by cultural stature rather than age); experienced barriers (e.g., cultural, financial, physical, social, technological) to arts engagement; lived in or around London, Hamilton, or Guelph; and could understand and speak English. In keeping with the study’s aim to prioritize underrepresented older adults, we used a “Recruitment Matrix” (Rice et al., 2020), a form of purposive sampling related to equity and inclusion, to recruit older adults with diverse embodiments and identities, including those from disabled, Two-Spirit, lesbian, gay, bisexual, trans, and/or queer (2SLGBTQ+), Black, Indigenous, and people of color (BIPOC), and newcomer, immigrant, and refugee (NIR) communities. Four 2SLGBTQ+, 11 BIPOC, and 13 NIR people participated. Several Arabic-speaking participants joined the study and chose a community translator to translate. Notably, nearly half (24) of participants self-identified as disabled, defined broadly to include mobility, sensory, and learning disabilities, chronic illness, neurodivergence (e.g., autism), mental health conditions (e.g., depression, anxiety, PTSD), and facial and physical differences (Table 1).

During Phase 2, we invited older adult participants in the catchment cities to test a technology-based prototype (i.e., an easy-to-use keyboard) and a web-based platform (<http://www.seniorsartlink.com>), both of which were developed by *Direct[Message]* in collaboration with older community members to better support older adults’ virtual engagement with the arts. We asked participants to test the keyboard and website by exploring at least one art-related activity offered by the platform. For example, participants could visit a virtual art gallery, attend a pre-recorded artist talk, follow step-by-step instructions to create an artwork, and/or explore relevant resources about digital literacy, such as instructions for creating a Zoom account. Ten older

adults tested the keyboard/platform and participated in follow-up interviews about their experiences of using the keyboard to access art content/activities. We designed interviews to assess the potential of this type of digital technology to help older adults develop new digital skills, increase social interaction, and engage in artistic practice. These participants responded positively to the asynchronous content (i.e., the online platform) offered through the keyboard but explained that it was limited in that it did not connect them with other creative older adults. While participants generally expressed excitement about the wide diversity of digital content, including topics such as Deaf arts and the artistic exploration of the legacies of slavery and colonialism in Canada, they commented on how the keyboard's asynchronous format constrained social interaction. Put simply, participants wanted to create art synchronously (in real time) with others online, rather than creating art through asynchronous instruction. Based on the insights gleaned from the first round of data collection (i.e., the interviews in Phase 2), we focused on developing the digital platform's interactivity for further testing and paused keyboard development and testing.

To improve the digital platform's effectiveness for older adult communities, *Direct[Message]* in collaboration with older adult community representatives and artist-facilitators developed a series of online art activities for/by/with older adults. Forty-One older adults were invited to participate in one of six activities led by older adult artist-facilitators. In the summer of 2022, we offered the following online art activities: tribal [Sudanese cultural] doll-making, photography, an art crawl, drawing, digital storytelling, and collage. Each online art activity consisted of two parts: Part I oriented and prepared participants for the art activity and familiarized them with each other and the group's facilitators, researchers, and community consultants; and Part II provided context/instruction and engaged participants in an interactive art activity. Following art activity completion, we invited participants to take part in a 1–2-hour interview about their experiences of participating in the online art activity and other creative activities both online and in-person. Forty of the 41 participants who participated in the online art activities took part in a follow-up interview. In total, 51 older adults and E/elders living in Southwestern Ontario participated in Phase 2 of the study; 10 tested the keyboard, 41 tested the online art activities, and 50 participated in semi-structured interviews following their respective activities. Participants' first names are used to identify their individual responses and stories throughout. In instances where participants share the same first name and spelling, an initial was used to distinguish them (e.g., John F and John S). In instances where participants did not want to use their name, a pseudonym was assigned.

All interviews were conducted and recorded online, using a teleconferencing platform, by the first author between April and September of 2022, a time when federal and provincial COVID-19 protections (e.g., masking protocols and capacity limits) were being removed (Ontario Public Service, 2022). Notably, this context profoundly shaped the study's dynamics. Whereas previously, Canadian university research ethics boards were mandating virtual methods *only*, suddenly studies that sought to maintain social distancing practices to protect the health of researchers and participants alike and minimize the spread of COVID-19 were

pressed to justify the use of virtual methods. Aside from contending with the changing expectations of research ethics boards, we also experienced internal disagreement among academic and community researchers about the online format, which as some highlighted would inevitably constrain the type (and success) of art creation and facilitation possible, as well as the social dynamics involved in a group setting. Ultimately aligning with a disability justice ethic of community care and interdependence (Berne et al., 2018; Piepzna-Samarasinha, 2018, 2022a), community and academic researchers collectively decided to continue conducting research activities online. The research team concluded that virtual research, though limiting for some older adults (e.g., with limited access to a stable internet connection and/or digital literacy skill-building opportunities), comprised the more responsive-to-difference ethical approach, given the ongoing spread of COVID-19 and its grave, disproportionate impact on disabled, aging, migrant, low-income, and racialized communities (Azeez et al., 2021; Garcia et al., 2021; Kamrul Islam and Hallstrom, 2023; Neely and Lopez, 2022)—many of the same communities at the center of our research.

We analyzed interview data using a combination of thematic and narrative analysis (Braun and Clarke, 2006, 2020; Reid et al., 2016). This approach allowed us to track “collective or shared meanings and experiences,” especially “*meaningful pattern[s]*” (emphasis added, Braun and Clarke, 2012, p. 57), across data, while attending to each individual's personal narrative (see Table 2 for a small selection of participants' diverse personal narratives, which are unique and overlapping). Our analysis is informed by critical disability studies and the theoretical insights of scholarship exploring the aging-disability nexus (Chandler et al., 2023a,b; Aubrecht et al., 2020), for as Braun and Clarke (2012) remind us, the production of themes is not a neutral or indifferent process; it is:

not like archeologists digging around, searching for the themes that lie hidden within the data, pre-existing the process of analysis. Rather, analysts are like sculptors, making choices about how to shape and craft their piece of stone (the “raw data”) into a work of art (the analysis). Like a piece of stone, the database provides the material base for analysis, and limits the possible end-product, but many different variations could be created when analysing the data. (p. 63)

Indeed, a commitment to valuing disabled and ill embodiments and knowledges, or “cripistemologies” (Johnson and McRuer, 2014), including those produced through the aging process, such as hearing, memory, and mobility differences, informed and animated our creation of themes. A commitment to disability justice, an intersectional and activist framework rooted in the experiences and perspectives of racialized, queer, trans, fat, and poor communities of disabled people also shaped the creation of themes (Berne et al., 2018; Clare, 1999; Lorde, 1997; Kafai, 2021; Piepzna-Samarasinha, 2018, 2022a; Schalk, 2022; Tidgwell and Shanouda, 2021). With the goal of attending to the specifics of, and advancing access and inclusion for, multiply oppressed disabled people, including those aging with/into disability, disability justice builds on the gains of the disability rights movement and critical disability studies by valuing and centering the leadership of those most affected by the outcomes. To this end, in prioritizing

TABLE 2 A small selection of stories from older adults aging with/into disabilities.

<b>Don</b> , a Black, Indigenous Two-Spirit person in his late 60s, is passionate about and an advocate for Indigenous issues, including the ongoing legacies of the Canadian Indian Residential School System, Two-Spirit culture, and Indigenous men’s health. He enjoys using art, including painting, beadwork, and diamond pin art, to explore and celebrate his multiple identities as a double leg amputee and person aging with HIV. Don wants to visit local art galleries; however, as a wheelchair user, he regularly contends with environments that do not anticipate disabled people. Don is also restricted by the cost and location of such activities.
<b>Ida</b> , a woman in her late 60s living with post-traumatic stress disorder, enjoys the performing arts (e.g., tap dance) and textile arts (e.g., knitting). At the beginning of the pandemic, Ida learned how to upcycle old furniture and she participated in a few online arts classes (e.g., painting); however, she felt out of place because many of the other participants had advanced knowledge and skills. Despite having limited experience, Ida enjoys online options to participate in the visual arts, especially when navigating tough days with her mental health.
<b>Bernie</b> , a trans non-binary person in their late 70s who “transitioned late in life,” struggles to find activities that are not divided by binary notions of sex and gender (e.g., woman/man). During the height of pandemic lockdowns, they attended several programs and research activities that offered free arts-based content to seniors and/or people with mental health conditions. Living alone and grieving after the loss of their beloved cats, Bernie depended on these online activities for their social aspect, despite feeling “zoomed out” and stiff. Bernie generally seeks activities that explicitly display 2SLGBTQ+ inclusive symbols.
<b>Dorica</b> , a woman in her early 60s who has mobility issues and “a really big stomach,” uses a walker and a local paratransit service to get around and lives with a mental health condition that affects her sleep cycle—factors that shape her ability to participate in creative endeavors outside of the home. Prior to the pandemic, Dorica attended some creative in-person programs (e.g., coloring) primarily for the social aspect and enjoyment these activities provided. Dorica would like to visit art galleries in person; however, in such spaces, she needs access to spacious washrooms to accommodate both her body and walker and free or low-cost activities.
<b>Lynne</b> , an immigrant woman in her early 60s living with spinal disabilities and chronic pain, is a retired cake decorator and bakery owner. Living with an autoimmune condition, Lynne remains COVID-cautious because she caught COVID twice within the span of 6 months. As a chronically ill person, Lynne identifies as feeling “extremely lonely” and limited, especially as others around her started to return to in-person activities. She is interested in participating in art activities that help her combat loneliness and distract her from “looking out the window to see if anyone’s come to see you.” The extensive time commitments and pacing of in-person activities, as well as the transportation to and cost of such activities, are challenging for her.
<b>Anthony</b> , an immigrant man aging into cognitive differences in his late 80s, has had a life-long passion to be an artist, but was pressured by his father to take up a more lucrative career in the trades instead. Once retired, Anthony returned to his passion and enrolled to take watercolor classes at the local library and became a Master Gardener. During COVID, Anthony attends online activities with the help of his wife, who increasingly provides greater assistance to him, including technological assistance.
<b>Radia</b> , a Black immigrant woman in her early 60s living with mobility and heart issues and recovering from cancer treatment, used to attend a weekly local knitting class, a treasured activity that reminds her of Sudan (her place of origin); however, Radia stopped attending when she experienced anti-Black racism. Radia wants to learn more about how to participate in online arts programming because getting around by foot is increasingly difficult and she has lots of free time; however, Radia worries that texting or writing in English may be a challenge.

an intersectional lens, disability justice rejects biomedical and individualized understandings of disability and instead conceives of disability as a biological, social, and structural phenomenon informed by powerful intersecting structures (e.g., colonialism and racism).

Finally, in addition to our activist and social justice-seeking focus, our positionalities as authors, as intergenerational and interdisciplinary researchers and artist-facilitators engaged in researching, cultivating, and actively participating in aging and disability arts, also informed our analysis and the knowledge we produce. Our social positions as old/er, aging, disabled, racialized, queer, immigrant, ill, and allied co-authors inform our experiences with and understandings of aging and disability, the questions we ask, and concepts we explore in this study.

Results

The current study investigated the stories that participants aging with/into disabilities told about their relationships to creativity and experiences accessing creative programming in-person and online. Drawing from 50 qualitative interviews with aging adults from un/under/represented communities, findings explore the intersections of older age and disability, including dynamics related to gender, sexuality, migration, size, race, and other differences, as these relate to their access to and enjoyment of creative spaces before, during, and “after” the COVID-19 pandemic.

Existing creative opportunities are limited

Results suggest that existing creative/artistic opportunities are limited for older adults, both those experiencing disability for the first time in later life and those aging with long-standing disabilities developed earlier in life. Participants aging with/into differences described feeling unwelcome, discriminated against, and/or excluded when accessing artistic spaces and activities in their local communities. Specifically, participants reported how intersectional aspects of their nonnormative embodiments and identities, including but not limited to considerations of old age and disability, were neither adequately anticipated nor expected in existing local arts programming and thus rendered incongruous or “misfitting” (Garland-Thomson, 2011). The feminist materialist disability concept of misfitting “emphasizes the particularity of varying lived embodiments and avoids a theoretical generic disabled body” (p. 591), enabling analyses of multiple and intersecting identities and embodiments, including those uniquely experienced in later life *as well as* those experienced across the life course and compounded by the aging process.

Participants described how ageist and ableist stereotypical understandings about the interests and capacities of older adults resulted in few affordable opportunities specifically for seniors aging with/into disabilities. Lynne (see Table 2), for instance, recalled attending a creative activity designed for older adults where facilitators distributed children’s coloring books and crayons, and instructed attendees to color. Thankful for the opportunity to meet and socialize with other older adults, Lynne said, “we were glad to do it, you know, it was lovely to sort of get together with people,



it was lovely to do something artistic, but the level was childish.” “Because I’m over 60,” Lynne said, it is assumed “that I have regressed to three [years old].” Feeling infantilized by the type of creative activity and condescended to by the younger coordinators, Lynne expressed the need to feel “like an ordinary person having a lesson” and desired art programming that had “a little bit of an older person’s point of view” to help minimize ageist and/or ableist sentiments. In another instance, Betty, a woman aging into cognitive difference, described aging out of the conventional art spaces/events she once enjoyed; she said, “I’m kind of a lost artist. As I get older, I don’t have access, I don’t have... I’m not surrounded by people who appreciate the same things that I do, and I feel isolated [sobbing].” Ageist and ableist attitudinal barriers, as well as a lack of creative opportunities tailored to the needs and interests of older adults who variously age into mobility, cognitive, and/or sensorial differences, produced environments and communities in which aging participants increasingly felt they could no longer fit into, both materially and socially.

Some aging and disabled participants described experiences of non-belonging or “misfitting” in local arts settings through discussions of race, migration, and language. Radia, a Black immigrant woman (see Table 2), stopped attending free knitting classes after she experienced anti-Black racist comments, and struggled to find other affordable, local activities once she left. Similarly, Dihnorath, an immigrant woman of color with a neurological condition that affects her gait, described how she felt she was being purposefully excluded from participating in some local musical and theatrical venues precisely *because of* her multiple differences. As a Columbian immigrant aging with mobility restrictions, Dihnorath explained that the stakes were higher for older immigrants because they have fewer opportunities to leave their homes, and thus fewer opportunities to practice English in ways that might foster their participation in the arts, unlike younger and presumably non-disabled immigrants. Ethnocentric language norms (e.g., Anglocentrism) worked in tandem with ableist and ageist structures to limit her opportunities to access the arts. In parallel, several Arabic-speaking newcomers, immigrants, and/or refugees reported language as a barrier to participating in local creative opportunities. For instance, a Black refugee woman who moved to Canada in 2020 during the pandemic’s onset, Ibtisam E said, “in Lebanon it was easier, there was no language barrier.” Where she once ‘fit’ into senior handiwork activities, she no longer could fit within a Canadian context due to a lack of linguistic diversity within local sewing/knitting classes. Stories of participants, especially racialized and migrant older adults aging with/into disabilities, reveal how racist, colonialist, and xenophobic assumptions structure who is assumed to physically and socially belong to (or fit into) creative spaces and, by extension, exclude “others” who fail to occupy those normative identities and embodiments, contributing to and intensifying experiences of exclusion related to age and disability.

Participants also described how they experienced misfitting related to gender and/or sexuality, which exacerbated their feelings of invisibility and alienation as older and disabled bodyminds. For example, Bernie (see Table 2), a non-binary person, felt they had no other option but to leave their gendered choir after transitioning, and now avoids creative activities that use gender exclusive language. Bernie explained:

I sing with [a gendered choir]. Well, I’m not going back there; I refuse to go back... people are asking. And I said, ‘no, I can’t because it says [‘women’ in the title].’ ‘Yes, but they accept non-binary [people, someone claimed].’ I said, ‘that’s not the issue’. They’ll still classify me as a woman; they’ll say, ‘these *women*’, and ‘*she*’—there will always be ‘*she*’ spoken. And I said, ‘No, I’m not [going unless]... it’s a mixed choir or something... where I can make sure they know who I am. So, it’s just trying to get away from things like that, where they [the organizers of creative programs] definitely make it male or female—nothing in between.

Similarly, Dana, another gender-variant participant described feeling alienated by both generational and intergenerational arts activities and events that were narrowly constrained by gendered expectations (e.g., feminine arts) and divided by gender. Feeling “invisible” as an aging Two-Spirited person in such spaces, Dana wanted to see arts programming and communities intentionally acknowledge gender variant artists/creatives and challenge gender binaries, saying, “I know that now there are even washrooms that are gender neutral. We don’t [only] want washrooms; we want community that’s gender neutral.” Additionally, Dana asserted that 2SLGBTQ+ communities in general are unseen or overlooked in the arts, maintaining, “we just are not targeted. We’re not looking at Two-Spirited people, queer, trans, gay, bi people having art. And it’s especially needed for these communities because we have a story to tell, and it needs to be shared.” These instances make plain how cis- and hetero-normative assumptions (i.e., oppressive ideologies that promote various normative ideas about aging, disability, gender, and sexuality, including sex and gender binaries—not to mention assumptions about which generations and/or age groups need and want non-binary spaces), structure creative programs in ways that can produce exclusionary dynamics for and amplify ageist and ableist notions about underrepresented older and disabled communities.

Participants embodying ability and size differences also reported experiencing physical, affective, and attitudinal obstacles when attempting to access existing arts spaces in the community. For instance, Don (see Table 1) detailed how environmental features, like stairs, actively exclude him from participating in creative local spaces:

I actually have to make sure it’s wheelchair and handicapped accessible. If it isn’t, that stops [me] from wanting to be part of [it]. There might be stairs going down. We had... [an event] and I couldn’t attend [because] I had to stay upstairs because there’s no way I can get downstairs to where the actual full event was housed. You know I’d like to [go] by myself and even listen to young guitar players doing recitals. I used to love doing that, but I can’t get up and down from where I used to sit.

Recalling a time when he was younger and less disabled by the creative spaces he occupied, Don can no longer access the artistic communities he once fit neatly into because environments with only stairs anticipate and thus welcome people capable of ambulatory movement, actively excluding those who use assistive devices at any age. Relatedly, in rare instances when participants’ stories detailed supportive

experiences of accessing arts spaces/communities, these were generally presented in the past-tense, indicating that at one point in their lives, when they were younger and non-disabled, surrounding structures and relations enabled their participation. In another example, Dorica (see Table 2) described how narrow washrooms limit her ability to visit local art galleries as someone who has “a really big stomach” and uses an assistive device:

if it's not accessible then I can't use it...[and] if I do [visit a place] by myself I can't leave my walker unattended. And, plus, sometimes I can't use a washroom if it doesn't have a bar and enough space, I can't use it, physically use it, unfortunately.

Like the normatively exclusionary contours of stairs, narrow washroom stalls in art galleries assume that the enjoyment of art hinges on thin embodiments that *are* and *remain* unassisted by assistive devices, like walkers, wheelchairs, and scooters. Such examples illustrate how the material-discursive arrangements of a creative space/program can actively produce misfits and intensify experiences of alienation, non-belonging, and isolation felt by those aging with/into differences.

## Digital participation can promote access to creative engagement

Results from the current study also suggest that digital participation is “fitting” for older adults aging with/into disabilities and can foster and enhance access to creative engagement. Participants described virtual options as helpful and, in some instances, life-saving both before and during the pandemic, namely because remote options reduce physical barriers and eliminate distance/geography, expanding access. Moreover, those experiencing age-related mobility challenges (e.g., muscle weakness, joint tenderness, and swelling, etc.) and/or restricted access to community mobility (i.e., various forms of transportation that enable them to stay connected), described digital formats as promoting greater access to creative engagement because these can reduce a dependence on walking and getting around, especially in spaces that do not presume and thus anticipate people who use assistive devices. For instance, John F, a man aging into mobility differences, explained, “I’m having problems with walking and sometimes I have to use a walker. And going to Toronto, if you’re going to see an exhibit then you’ve got to deal with subway stairs...so it can be more difficult.” Digital participation, he suggested, “would be very good for people like me who’ve just given up on going through the physical manifestations, wanting to watch it digitally.” Marianne, a woman who described “having a real hard time with [her] feet,” a change she attributed to getting older, reiterated this point: “I don’t walk all that well anymore. So, it [virtual arts programming] was nice for me, like I said, to go around and not have to [walk]...to see the different things.” Radia (see Table 2) similarly explained that virtual arts programming was ideal for her: “I prefer if I have something to do from my home online... because my leg is still swollen.” Indeed, virtual options may support access for people like Margaret, who explained that walking with an arthritic knee to visit or move around an art

gallery had become less of a possibility in later life, since even necessary outings, like getting groceries and attending medical appointments, had become taxing: “my mobility is restricted; it’s painful for me to go any distance because of my knee.” As other participants indicated, digital options to participate (e.g., visiting a gallery or watching a performance) hold potential for those whom getting to and around materially inaccessible venues (e.g., with no elevators or accessible parking) is, perhaps, no longer realizable because the activity no longer fits their changing embodiment.

Virtual environments also allow older adults, including those without disabilities, to avoid the constraints of place and distance and enrich their creative engagement. For example, John S (a non-disabled man who finds virtual environments to be too “static”) said, “the benefit [however] continues to be that you meet with people in far flung areas... And if you’re meeting with people across the globe, they’re bringing experiences to the meeting that you wouldn’t have in any other way.” Similarly, Victoria, a woman aging with mobility differences, explained, “online is an amazing tool right now...I’m grateful for it because I could do something over in Europe and I wouldn’t have to go there. I don’t like travelling, so [laughs]. I don’t like going on the airplane, it’s too claustrophobic, but I could if somebody set up a Zoom thing over there.” Digital arts enabled participants from all over, including places where resources and/or supports were more limited (e.g., towns and rural areas) to participate in activities that might otherwise be out of reach. As these responses suggest, online environments can bridge the physical gaps between spaces and, to an extent, democratize participation, benefiting both disabled and non-disabled older adults.

Participants also described digital participation in the arts as desirable because it reduces dependence on using personal, private, and public transportation for local travel, which can be unreliable, costly, dangerous, inaccessible, or simply inconvenient for those aging with and into disabilities:

I find it [online arts programming] very, very convenient. Because I don’t have to travel anywhere to get there. (Jessica)

It’s convenient. You don’t have to travel; you don’t have to park. You don’t have to bring all your supplies with you. (Doris)

You don’t have to go anywhere. You don’t have to drive. You don’t have to dress up and go to the theatre. (Bernard)

Zoom was excellent...because it took the barriers of geography out of [creative participation]. (Janice)

We’ve got everything here. We don’t have to put everything in a bag and transport it to where we’re going and set it all up on a desk. (Anthony)

Some participants also expressed wariness about the unfavorable conditions of public transit, which confine large crowds in spaces with limited or no COVID-19 measures left in place to protect them and support their travel to and from creative engagements. Increasingly dependent on walking to get around and thus limited by distance, Jerome described avoiding public transit; he said, “you got to be cautious, got to be careful. I don’t

ride the buses like I used to before...because there again in the buses, you're sitting next to other people who maybe are having the [COVID-19] infection. So, I do a lot of walking" (an activity that he described as becoming more difficult for him as he aged). Online, he concluded, is "more convenient." For Jerome and his wife, and others like them, online activities reduced a dependence on unsafe public transit and enabled them to access activities that might not otherwise be accessible by foot. Thus, participants who could regularly and easily get around their communities as well as those whose mobility was constrained for various reasons (e.g., lacked vehicle access and/or someone to assist, had caregiving and/or work responsibilities, etc.) similarly described a fit between digital participation and their older and/or disabled embodiments.

Participants also described becoming increasingly wary of and altogether avoiding unfavorable conditions as they age with and into disabilities. Less likely to drive or walk in the snow and/or at night, participants described virtual options as supporting their participation generally, and arts engagement, specifically. Nancy, for instance, said, "in the winter, you got to go out and the weather's bad, the roads are bad, the sidewalks are bad and that just puts you off altogether. So, having something online like this, it's a great thing to offer." In parallel, Lynne preferred online options, explaining "if it was snowing or raining or whatever, I couldn't go. I can't risk falling because of the state of my spine, so I don't go out when it's icy." Other weather events also posed a threat to older adults' creative engagement. Bernardine explained, "some places are not easy to reach, right? In summer it's particularly hard on hot days to walk. It takes 45 minutes for us to walk from [home] to [the local arts venue]."

While some participants described virtual formats as imperfect substitutes and incompatible with in-person arts environments, many others, especially those constantly or gradually misfitting with creative communities and spaces, detailed how virtual environments supported and expanded their participation in the arts. In these instances, participants understood online environments as safer for older adults with existing and recently acquired disabilities and health concerns, and for those actively trying to avoid losing vitality as a consequence of COVID-19. For instance, several participants reported wanting virtual options to negotiate the risks of the pandemic, including Sheila, a non-disabled woman who had regretted a recent visit to a crowded indoor art gallery:

People were too close to each other. There was no six feet apart and everybody's wearing masks and you're like, 'Okay, don't stand too close to me', and...if I had been able to watch that online I would've enjoyed it a lot more. And tours of galleries like online, I'd like that.

Despite some remaining pandemic controls to protect the public (e.g., community masking), which have since been rescinded—regardless of the continued circulation of the SARS-CoV-2 virus and the documented threat of the virus's mass disabling effects (Davis et al., 2023; Amisi, 2024), Sheila felt anxious negotiating indoor spaces during the pandemic. Several non-disabled older participants, though equally exhausted with lockdowns and other pandemic controls (e.g., proof of vaccination rules and capacity limits), expressed frustration and concern

with removal of pandemic controls in public settings—a decision that, many disability justice advocates argue, makes public space more dangerous and less accessible for everyone, generally, but ill, disabled, and/or older communities, particularly (Piepznar-Samarasinha, 2022b; Rajkumar, 2022; Adler-Bolton, 2023; Amisi, 2024). For instance, Rob, a non-disabled man of colour, explained that he had not yet returned to his favorite creative program, despite its recommencement, because, he said, "I'm not feeling confident around the controls around COVID these days with the numbers going up and up."

Participants aging with disabilities (i.e., those acquired earlier in life) also described digital environments as safer and thus preferable. For instance, Ida (see Table 2), a woman living with post-traumatic stress disorder, explained how virtual formats enabled her to "talk freely about [her] past" in a creative storytelling workshop. The digital format "with the little screen," she said, "helped me in...that I could tell my story in front of men." Alluding to a relationship with gender-based violence, Ida explained, "because of my past, I tend not to search out [men] for an audience." The online environment, which afforded her the comfort of her home and physical distance from men, "made it seem safer" to present her story to a mixed group. Additionally, she explained, "because I have PTSD... some days, I just don't feel like getting out of bed. It's quite limited what I can do. And so...I love doing things online because I can stay at home, [and] that helps with those days that I'm not feeling that terrific." Similarly, Janet, a woman with sensorial and mental health differences, described online arts spaces as "really important" for herself and others who were aging into disabilities that restricted their movement:

After my car accident, I had balance problems and vision problems and a ton of vertigo, so going out when you can't walk, or you might fall over, doesn't feel safe. And I have friends who have now developed Parkinson's, ALS; they don't get out anymore at all. So, the online stuff just feels so much more accessible.

Janet described digital spaces as essential, explaining, "It [a virtual environment] just opens up my world." In another instance, Jo-Ann, a woman who reported having social anxieties, said she found the online experience of both facilitating and receiving art instruction as "a lot easier." She explained that in-person, in a big room with multiple people, "you get kind of nervous," whereas "when you're just online, you're just seeing one person most of the time...so you feel a little bit more relaxed and at ease to do it." Digital environments shrink expansive physical spaces and the social threats they hold, which for both Ida and Jo-Ann produced a comfortable "fit" and expanded their capacity to participate fully. Highlighting another benefit of the online experience, Jo-Ann said, "I actually like learning online now better than even going to a studio because you can pause it [a recording] and go back." The ease in which online videoconferencing platforms, like Zoom, enable audio and video-recordings, benefited older adult participants, especially those with learning and other disabilities and/or illnesses that could suddenly, yet chronically, interrupt their ability to participate in-person. Dana, for instance, said, "online is ideal because anything I would register for, they would have a replay and that would be so ideal" for "when I'm in pain and then I need to

go into therapy.” Also beneficial for those with learning differences, Penny said, “for me, the way I learn and the way I process my learning experiences is I listen, I mull things over, munch my way through it and then I actually probably need to hear it again. So, for me, online works really well because I can back that video up.”

Finally, some participants conceptualized virtual environments as beneficial because they afforded them permission to comfortably sidestep certain taken-for-granted expectations of meeting in a physical environment, such as remaining seated or attentive for long periods of time. Jane, a woman living with chronic pain and learning disabilities, described how some online environments enabled a passive or relaxed form of participation that she found fit her bodymind. She explained, “I do like online, too, where you like turn off your video, go make a cup of tea or do something and... you can still listen, but you don’t have to be present for the whole time. You can do some self-care.” Similar to relaxed performance (LaMarre et al., 2021), where the atmosphere and unspoken “rules” or “norms” of a creative environment (e.g., a theater) are relaxed for people with sensory and cognitive differences, online spaces, with features to adjust volume and turn cameras on and off, have the potential to promote relaxed participation.

## Digital arts that multiplied *then* are now disappearing

Results from the current study also indicate that older adults benefited from the flourishing of digital arts during pandemic time. Participants described experiencing an explosion of free and affordable virtual activities during the first two years of the pandemic, including arts-based research activities that governments in Canada supported as part of COVID-19-related funding allocations. For instance, Janet, a participant who used virtual options both before and during the pandemic, reported witnessing virtual opportunities to view art increase substantively during pandemic time; she explained, “It’s when most of these galleries opened up and put all their artwork online.” In some instances, participants described having unprecedented access to exhibitions in otherwise out-of-reach venues and artistic skill-building opportunities/instruction that programmers previously made available in only particular cities or neighborhoods, where they had registered demand for such activities. However, participants’ responses indicated that whilst those living outside major centers enjoyed newfound access to these opportunities, they soon realized that they could not count on these life- and culture-expanding access affordances to continue.

Indeed, although digital arts multiplied during the first couple of years of the pandemic, these opportunities started to disappear as “pandemic time” began to wane, despite the predicted threat and felt consequences of new variants. Participants described experiencing the loss of digital opportunities, arts-based and otherwise, as the pandemic was slowly, at the time of interviewing, being discursively constructed as ending (Archie, 2022, para. 2). Bernardine, for instance, explained that her opportunities to participate in creative programming were decreasing because a knitting class she was once able to attend online was, at

the time of the interview, returning to in-person participation exclusively. When the class moved back to in-person, Bernardine could no longer attend as often because of distance, cost, lack of access to a vehicle, and the danger public transportation posed to her health. Relatedly, lamenting the transition from online to in-person, Lynne described the value of online virtual arts programming and emphasized the long-lasting potential it holds for the health and wellbeing of older and disabled communities, especially lonely and/or isolated populations, both within and outside of pandemic time:

If I could wave a magic wand and decide what [the program] should do I would say, ‘don’t get rid of the virtual things because there were, and I include myself in this, some lonely people who looked forward to it at least once a week, seeing some faces and having a chat, right?’ So, that was very important, that aspect of it. I don’t get out much and some of the seniors that joined the group don’t get out at all, so for them going to the in-person sessions is not that practical and especially with the colder weather... Or if it’s raining or, you know, if they’re not well that day or whatever, you know, they won’t be going at all and then it will be two months until they have some interaction with somebody.

Similarly, Katherine described how the conditions of the pandemic produced possibilities for her as a person aging into physical disabilities, noting the effect the return to “the way it was” would have on people who were disabled prior to the pandemic:

The pandemic really stood out for me, as someone who was becoming more physically limited, at how much [was] accessible; things were being made for people. And now that everything is moving back—most things are moving back to in-person experiences—I’m sort of sitting here going, “well, what do I do with myself?” And it really hits home for people who have accessibility issues, and mobility issues, [for whom] this was their whole life before the pandemic, and they were given a bit of a lease on life through the pandemic, and now they’re being shut out of spaces. I see this, particularly with the two [craft/art groups] I’m a member of—about how people have been kind of desperate to get back to in-person meetings. And a small number of people [are] saying, ‘the only reason I could come to every meeting was because it was online’. So, it’s been an interesting time, I think, to think about these things. But I’m pretty sure we’re going to just try to go back to... the way it was.

As Katherine indicates, a return to “normal” creates the real risk that many disabled people, including those aging with disabilities, will lose critical access to creative communities that, for perhaps the first time in their lives, produced a “fit,” rather than a “misfit.” Even when participants, especially those who faced few mobility barriers, expressed a desire to return to preferred in-person creative events, they acknowledged people’s differing perspectives and the continued need for virtual options for older and disabled communities rendered less mobile by inaccessible infrastructures, including their future bodyminds, which (failing a transformation of the built environment) they imagined as less physically mobile



and more confined to the home. For example, explaining that online activities were less relevant for him, given his ability to get around with the assistance of his wife, Anthony said, “we’re not shut in.” Nonetheless, he described value in having such options because, as he explained, “one day, I’m going to be shut in. I don’t drive anymore, so it’s [my wife’s responsibility]—if ever [my wife] gives up driving, I don’t know what we’re going to do.” In another instance, Penny, a passionate advocate for aging arts and artists, noted that among her older adult membership there was a desire to remain online for reasons that pertained to and exceeded the pandemic and COVID caution:

I got resounding ‘yeses’ to go back to Zoom. They [older adults] don’t want to worry about, “Is it [the class] on today?” “Do I come today?” “It’s snowing in [the city], should I come?” You know, “there’s going to be an ice storm at 4 o’clock, will we be done by then?” You know, they don’t want to worry about that. I get that. So... we’ll probably go back to Zoom. And they seem to be quite happy with that.

Reiterating the significance of transportation infrastructures and weather events to the community mobility and creative engagement of older and disabled communities, both Anthony’s and Penny’s commentaries point to a collective demand for digital options to engage in the arts both during and after the pandemic, now and in the future, and for others and their own older embodiments, which they imagined as becoming more disabled in time.

## Discussion

Results show that older adults aging with/into disabilities in Southwestern Ontario express an overwhelming desire and even urgent need to access interactive arts programming from the relatively safe spaces of their homes both within and outside pandemic time. As the normative world pushed for a return to ableist normative life in 2022, a year marked by “severe” rates of the highly infectious Omicron variant and the loss of effective public measures, such as community masking and widely available testing (Ontario Public Service, 2022; Public Health Ontario, 2022), participants described the need for continued access to creative and social participation via remote options that sidestepped socially exclusive (e.g., racist and cissexist) and physically inaccessible (i.e., ableist, ageist, and sizeist) spaces. Participants also described experiencing disparities related to in-person and virtual art activities for older adults in Southwestern Ontario. Prior to the pandemic, underrepresented groups of older adults, including those with disabilities, experienced “misfitting” or non-belonging in creative spaces that were designed with a normative user, or “normate template” in mind (Hamraie, 2017, p. 19; Garland-Thomson, 2011). According to critical access scholar Aimi Hamraie, far from an “average” or “universal” user, this template presumes and is made in the image of a “white, European, nondisabled, youthful, and often masculine figure whose features remain unmarked” (p. 20). Neither neutral nor universal, spaces and environments created with a “normate template” produce a seamless or seemingly natural “fit” between specific users and their environments. Those whose bodies and ways of

being deviate from this norm (e.g., older people, people with disabilities, and people of color) will experience a “misfit” with an otherwise neutral appearing environment, reifying the notion that particular bodies or subjects are the “problem” (Garland-Thomson, 2011). Participants described how the design and delivery of creative in-person environments were, prior to the pandemic, exclusionary primarily because they presumed and anticipated specific unmarked bodyminds (e.g., white, anglophone, thin, cisgender, heterosexual, ambulatory, etc.). For instance, non-binary and Two-Spirit older adults aging with/into disabilities experienced “misfitting” in creative activities that presume binary and Western gender norms (and thus anticipate cisgender, heterosexual, and settler users), while older adults who use assistive devices, like wheelchairs and walkers, experienced “misfitting” in artistic environments that privilege normative bodies (and thus anticipate thin and nondisabled users). The inaccessible social and built environments of in-person artistic communities, and the limited options for traveling to and from such places, foreclosed in-person participation for many participants who do not reflect the “normate template.” And, if cultural and social service organizations had created online opportunities for older adults to participate in the arts during “pandemic time,” participants described—often with sadness and despair—how these opportunities were temporary and/or stopped as pressures to return to normal mounted.

These findings indicate a need for increased investment in digital arts programming, as well as digital skill-building opportunities, for older adults aging with/into disabilities. Celebrated for their life-sustaining potential, such programs, as one participant explained, “got a lot of us [older adults and people with disabilities] through the pandemic” (Lynne). They provided opportunities for various older adult communities to socialize, develop digital and artistic skills, build community with others, and care for one another. Although generally associated with (younger) crip and disabled access-making communities (Gotkin and Hamraie, 2024; Hamraie and Williams, 2023; Johnson et al., 2024), remote access offered many participants aging with/into disabilities the chance to experience the value of and glimpse the potential for digital participation both during and beyond pandemic time. For older adults considered “vulnerable” to COVID-19, those with mobility and/or mental health disabilities, and those with caretaking duties, online opportunities allowed them to participate comfortably from their homes. Digital forms of arts engagement may be particularly promising for those aging *into* disabilities (i.e., those who were non-disabled for most of their lives and are now experiencing ableist exclusion). Remote options and communities may possibly provide a sense of belonging to those newly coming into a disability and/or disabled identification and consciousness, potentially offsetting the shame, guilt, and alienation experienced when aging in an ageist and ableist culture that propounds the imperative to age “well” or “successfully,” that is, without cognitive or bodily change and dependence, which are predominately conceptualized as markers of decline, failure, and weakness across the life course (Aubrecht et al., 2020; Grenier et al., 2016; Gullette, 2004; Lamb, 2015; Leahy, 2023; McFarland and Taylor, 2021). For as some have demonstrated, there is reluctance from many older adults to align with disability in part due to the triumph of “successful aging” paradigms (Leahy, 2023; McGrath et al., 2016; Oldman, 2002).

Indeed, remote access holds possibility for many marginalized groups outside of a pandemic-context, *as well as* for those who are disabled by the presence of COVID-19 and a lack of federal and provincial COVID-19 measures (e.g., community masking) to support their in-person participation. However, despite the value digital arts hold for multiple communities of aging and disabled people, hegemonic orders arguably only ever intended the online pivot to comprise a temporary “emergency” response that, as Ellcessor (2022) demonstrates, governments and corporate interests designed to provide protective access to life/work for a young, healthy, nondisabled majority. Older adult participants found use for technology, specifically remote access, in ways that both fit comfortably within and exceeded the contours of pandemic time. Within pandemic time, some disabled older adult participants experienced what some call “crip utopias” and “crip hope,” whereby disabled communities “hope that some of our adapted practices taken from disability culture, including access practices, will stick around outside of the disability community after COVID time” (Ignagni et al., 2020). In particular, our findings point to the value crip remote access practices hold for older adults aging with or into disabilities. The return to normal and the attendant “snapping back” to in-person creative activities both increases aging, disabled, and ill people’s risk of contracting the virus and excludes them/us from environments and spaces that were only ever constructed with a “normate” user in mind. In important ways, older adults’ creative engagement with accessible remote access environments takes a lead from crip culture in offering another pathway that nonnormatively embodied people can take to repurpose technology for their own anti-ableist and -ageist ends (Rice et al., 2024). In this case, by proliferating material (affective, sensorial) and social connections between bodies and worlds, *Direct[Message]* expanded possibilities for aging and disabled embodiment and life.

As many critical disability scholars, activists, and artists have demonstrated, non-disabled people directly benefited from the knowledges and strategies of disabled communities during the COVID-19 pandemic (Chandler et al., 2023a; Johnson et al., 2024), despite the violent exclusion of disabled people and their needs from national health emergency preparedness and planning (Pearce et al., 2022). The findings from this study indicate that underrepresented communities of older adults may be one such group that has benefited from remote access during pandemic time and would continue to benefit from such access after pandemic time. An AGE UK report (2018) found that having access to wealth and transportation, especially a vehicle, is strongly associated with older adults’ creative and cultural participation. They recommend that arts organizations “take transport into account in their programming, and consider how they can get their activities out into more accessible locations, including care homes” (AGE UK, 2018, p.12). Our findings indicate that accessing creative activities and content virtually, comfortably in the home, may be one desirable possibility, which reduces a dependence on poor transportation or stressful travel (i.e., driving at night, in poor weather, and/or for long distances) for supporting older adults’ engagement in creative and cultural programming. Fluharty et al. (2021) similarly suggest that the digitalization of cultural and artistic events, like museum tours, may be one way in which barriers, like cost of participation and dependence on transportation, may be reasonably mitigated for

those navigating exclusionary systems. However, digitalization can also, they surmise, “bring further age related inequalities among those with low digital literacy” (Fluharty et al., 2021, p. 13).

Indeed, digital technologies and environments are not free of power dynamics, nor social inequalities, and can reinforce harmful and exclusionary biases and structures (Zheng and Walsham, 2021; Jonsson et al., 2023). As many studies have indicated, including some of our own (Hand et al., 2024; La Rose et al., 2022), remote participation using digital technologies is not without its own set of barriers for older adult and/or disabled community members. As Charise (2022) reminds, “it is important to challenge assumptions about access to the internet, which is clearly affected by class, socio-economic status and, indeed, age,” while recognizing the harmful effects of the very existence of digital communication tools (e.g., search engines) and infrastructures, which literally invade and harm Indigenous territories and communities, including disabled people, E/elders, and those who will hopefully become old (p. 241). Therefore, it is vital to recognize how forms of structural disadvantage, like colonialism and poverty, also affect aging, disability, and digital arts access. Further, even with reliable access to the internet, older adults and disabled communities can face challenges navigating videoconferencing technology and etiquette. For instance, Hand et al. (2024) found that out-of-date software and digital devices, misunderstandings regarding the conventions of videoconferencing (e.g., muting microphones to reduce background noise), and inadvertent cross-talk and trouble with turn-taking posed problems for older adults’ remote participation. As well, Clayton et al. (2023) found that inaccessible software, including videoconferencing platforms, and the pace in which technology and accessibility equipment evolves and older and disabled bodyminds change, to be challenging for older and disabled people using technology during the pandemic. It is also necessary to recognize that some older adults will never engage with digital technologies (Clayton et al., 2023). Thus, although the current study found strong evidence for remote creative participation, there cannot be a “one size fits all approach” to the creative and social participation of older adults aging with/into disabilities because bodyminds are diverse and have diverse needs. Indeed, crip and disabled practices and ontologies—not unlike those experienced in later life—remind us that an accessible world is possible, and that access is “an iterative and co-designed process” (Chandler et al., 2021, p. 230; Chandler et al., 2023a,b). To this end, a hybrid model that offers multiple forms of communication and participation, including remote (e.g., mail, phone, digital) and in-person, might better support more older adult and disabled people.

Aside from presenting an evident need for remote options to support older adults’ artistic engagement, the current study’s findings advance scholarship exploring the aging-disability nexus, art, and technology in the following three ways. First, building on critical age studies literature that exposes and challenges the ableism and ageism of successful aging initiatives and scholarship, the findings extend crip, critical disability, and TechnoAccess insights to the study of aging and later life in ways that do not devalue nor seek to “correct” the so-called “problems” of aging and disability through engagement with technology and/or art. Second, the findings offer valuable qualitative data about aging and disabled people’s participation in artistic activities and experiences with technology. Attending to some of the gaps identified by Chacur

et al. (2022) in their scoping review of the existing literature on older adults' artistic engagement, the current study contributes important knowledge about some of the attitudinal, material, environmental, and structural barriers older adults aging with/into disabilities experience when attempting to access the arts. As they note, such practical knowledge is necessary to successfully promote older adults' artistic participation. The current study also privileges the experiences and voices of older adults and centers the most underrepresented voices aging with/into disabilities. Chacur et al. (2022) found that "other minority groups such as older people belonging to ethnic or racial minorities, older immigrants, older adults with disability, older members of the LGBT community, or the oldest-old people are underrepresented in this topic research, if not absent" (p. 940). This study responds directly to this gap, offering diverse qualitative data. Finally, the current study complicates dominant ageist and ableist notions that older adults and disabled people are digitally incompetent and/or unwilling to learn new technologies and invites crip access-making communities and spaces to consider and take seriously older adults as a community who may also require or want digital access.

Importantly, these findings are limited by a sample population that overwhelmingly identified as "very" or "somewhat" confident using digital devices (e.g., laptops, smart phones, tablets) and digital platforms (e.g., Facebook and YouTube). Most participants in the current study reported using digital devices and platforms daily, indicating relatively moderate to high digital literacy levels. Notably, all digital skill levels were encouraged to participate, technical coaching and phone and masked in-person support were offered, and internet-enabled devices were loaned to those who lacked the digital tools and/or knowledge necessary to participate. Only three participants loaned iPads and four required additional technical support (e.g., learning how to use a new type of technology, creating a Zoom account, and/or recovering a lost password). To this end, research with older adults with low to no digital literacy would allow for better understanding of some of the barriers to and supports for remote access, generally, and digital arts, in particular.

Finally, to better meet the needs of a growing number of older adults aging with/into disabilities in Canada (and beyond) and increase the effectiveness of cultural and artistic resources and programs, our findings indicate the importance of meaningfully engaging with arts and culture programmers (e.g., art museums, libraries, and seniors' programming, etc.) and end-users. Findings suggest that prioritizing end-user experiences, including those of older adults, disabled people, and members of BIPOC, 2SLGBTQ+, and immigrant communities, can help providers better understand how to equitably anticipate and serve diverse user communities. Finally, we recommend and advocate for the inclusion of older adults aging with/into disabilities throughout all levels of decision-making regarding artistic and cultural policy development and program implementation.

## Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## Ethics statement

The studies involving humans were approved by the University of Guelph's Research Ethics Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

## Author contributions

JM: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – original draft, Funding acquisition, Project administration. CR: Conceptualization, Funding acquisition, Supervision, Writing – review & editing. NC: Supervision, Writing – review & editing, Funding acquisition. TL: Conceptualization, Funding acquisition, Writing – review & editing. CA-L: Conceptualization, Methodology, Writing – review & editing. SB: Methodology, Writing – review & editing. KS: Methodology, Writing – review & editing. BK: Methodology, Writing – review & editing.

## Funding

The author(s) declare financial support was received for the research, authorship, and/or publication of this article. This work was supported by Canada Council for the Arts Digital Strategy Fund, the Social Sciences and Humanities Council of Canada (Grant #895-2016-1024), and Mitacs through the Mitacs Accelerate Program.

## Acknowledgments

First, we thank the older adults who participated in this research as co-researchers, co-authors, and participants in this project. We thank the artist-facilitators (Suad Badri, David Bobier, Tobi Bruce, Angela Busse, Becky Katz, Judy Major-Girardin, Katherine Matthews, Colina Maxwell, Kathy Smith, and Dan Zen) who enlivened our virtual spaces with interactive creativity and engaging discussions; the creative technologists Jim Ruxton and Simon Lebrun, who developed accessible digital devices/platforms based on participants' needs/wishes; and finally, we acknowledge and thank Centre[3] and the Re•Vision Centre for Art and Social Justice for their social justice-seeking leadership and support.

## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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