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The Double Burden: The Digital Exclusion and Identity Crisis of Elderly Patients in Rural China

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Abstract

The rapid digitalization of China's healthcare system, a phenomenon that accelerated during the Covid-19 pandemic, had two negative consequences for a significant portion of elderly persons in China. The first is an unfortunate practical outcome: their exclusion from many health services such as online medical appointment platforms, e-prescription requests, obtaining e-referrals, and sharing electronic medical records. The second is an emotionally debilitating identity crisis as elderly persons' former status as knowledgeable senior mentors was replaced with social perceptions of them as helpless and ignorant souls reliant on more youthful persons for guidance and assistance. This article adopts a grounded theory to explore the phenomenon from the perception of excluded elderly persons using participatory observation and in-depth interviews of 44 elderly clients of a rural hospital in the Shandong province in eastern China. The study shows that the current focus on direct practical aspects of digital exclusion may fail to capture the impact and ancillary consequences such as a painful loss of self-esteem by the digitally excluded. As the study illustrates, the practical aspects can all be overcome through intervention by those who aid the digitally excluded but this help may exacerbate the rarely considered ancillary harms of digital exclusion. Studies of digital exclusion will make more significant contributions to our understanding of the phenomenon if they look beyond the obvious direct consequences of digital exclusion to consider possible ancillary and flow-on effects.

Keywords

digital divide; digital exclusion; e-health; elderly; health care app

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1. Introduction

If the vision of an omnipresent digital interface offered by Negroponte (1995) had not fully materialized prior to the global Covid-19 pandemic, it was surely realized during the lockdowns and shift to online communications during that episode, particularly in China. Even prior to the pandemic, the Chinese government had prioritized the use of digital technology in the public healthcare system (Jha et al., 2009; Schickedanz et al., 2013) and apps came to rule almost all aspects of citizens' lives in the course of the world's strictest lockdowns. Confined to their residential compounds except for limited excursions, residents of China were reliant on a green health pass on the government health app for any travel outside the home or access to services once outside a residential compound (Yu et al., 2023) and for access to almost all health services (Ke & Hsiao, 2022). By the end of the pandemic, communication for almost all aspects of health services had shifted to digital modes, including booking health appointments, gathering information from and providing information to patients, and demonstrating health status.

Central to the shift to a digital interface for patients to connect with health services in China was the adoption of a "smart hospital system," a program integrating hospital care with digital phone app technology. Hospitals in China are responsible for both primary care that would be handled by general practitioners in many other countries as well as emergency and other hospital services and are, therefore, the first and only port of call for almost all health services, particularly outside major urban centers (Cai et al., 2023). Digital apps have become the gateway to admission at hospitals and medical care and those unable to readily access and use the necessary apps face severe hurdles when trying to obtain medical care.

The study commenced as a conventional investigation of the impact of digital exclusion on elderly healthcare users in China. Originally used in the early days of the internet to signify the divide between those with computers and internet access and those without (Erdiaw-Kwasie & Alam, 2016), the notion of digital exclusion is now commonly employed to refer to groups such as the very poor and the technologically challenged, a group often populated by elderly persons who struggle to access services available exclusively or primarily through digital communication. The phenomenon fits into the wider conceptual notion of a digital divide, a topic that has been the subject of considerable conceptual analysis (e.g., Ragnedda & Muschert, 2018) and that has spawned a vast array of studies (e.g., Lythreatis et al., 2022) that have looked at the impact of the divide between the digitally literate and those who struggle to move past the analog world. Sophisticated studies distinguish up to a dozen different measurements of digital exclusion.

In broad terms, studies of the digitally excluded fall into four camps. The largest group comprises studies that look at the loss suffered by those excluded from the digital world; it was assumed initially that the present study would fall into this collection, with a focus on the impact of digital exclusion on access to health care in China. Rapid urbanization (Yi & Vaupel, 1989) and the dramatic impact of decades of an enforced one-child policy have led to an aging population profile in China (Tatum, 2021), not dissimilar from that of very advanced economies. The increase in life expectancy aligns with a greater incidence of chronic and infectious diseases (Chen et al., 2022), which in turn increases demand for healthcare resources (Chomik & Piggott, 2015; Tsai et al., 2021; Wang et al., 2023), a development amplified by growing levels of multimorbidity (Zhang et al., 2019). The elderly in China, particularly in poorer and more remote rural areas, were assumed at the beginning of the study to be a cohort particularly at risk from the adoption of a digital health system interface, and the focus of the study was further narrowed to digital exclusion in this group. In particular, it was assumed,

consistent with previous studies, that the problem is much greater for the rural elderly than for the urban elderly in China (He et al., 2022).

A second set of studies looks at how the impact of digital exclusion can be mitigated, particularly for the elderly left outside the digital world (e.g., Holgersson & Ellgren, 2020). Often studies in this group consider the possible role of organizations, particularly government bodies, in filling in the gaps and providing information and support for those unable to access services by digital means such as alternative communication and identification formats—that is, hard copy substitutes—for use by the digitally excluded elderly (Y. Song et al., 2021). The general conclusion is that, with respect to the digital divide in China on access to health care at least, these programs, such as government directions to service providers to develop simpler user-friendly apps for the elderly (Chen et al., 2022), have had very limited impact. These studies were considered in the design of interview questions used in the study with the findings largely confirming the conclusions of earlier investigations that suggest little has been done by institutions to provide workarounds to digital exclusion.

A third group of digital exclusion studies investigates the role of family, particularly children, in overcoming barriers faced by the digitally excluded. A range of variables that might affect the level and value of support provided are considered, including children's gender (Yi et al., 2016), the number of children (Warmenhoven et al., 2018), children's education level (Cui et al., 2021; Lei et al., 2023), internal migration of adult children (Q. Song, 2017), and a country's position as developing or developed (Mubarak & Suomi, 2022). This group of studies played an important role in the design of the current study, prompting a deeper investigation into the role of family in assisting the digitally excluded.

Finally, a further group of studies reviews the ancillary benefits of digital literacy available to the elderly who master access to digital health services. These include the role of digital media in maintaining closer intergenerational relationships that contribute to elders' subjective well-being (J. Li & Zhou, 2021) and the psychological satisfaction that comes to elderly users who can take pride in their technological mastery (P. Ren & Klausen, 2023). However, few studies seek to explore the ancillary negative consequences of digital exclusion apart from ageism, the phenomenon that rises when the digitally literate shun the elderly who are unable to communicate with them through digital devices (Seifert, 2020).

Based on the existing literature, the initial intent of the present study was to investigate the impact of the digital divide on a particular subset of elderly health patients, those residing in a poorer non-urban area of China, taking into account the studies that discussed the role of children in mitigating digital exclusion in the health sector. The focus of the study was thus on the outcomes of the digital divide rather than its causes or illustrations of its manifestation, a topic that has been referred to as the third level of the digital divide (Scheerder et al., 2017). Also excluded from the study were parallel exclusions such as the social exclusion of digitally excluded elderly in long-term care facilities (Seifert et al., 2020). As explained in the methodology section that follows, the study was based on interviews with patients at a district hospital. Where information in the study is directly attributable to a patient's comments, the patient is identified in brackets by reference to their number in the table of interviewees in the Supplementary File, followed by their age and gender.

At the commencement of the study, it became obvious that the digitally excluded had not been excluded from health care—as the cohort of interviewees at the regional hospital chosen for the study demonstrated,

the digitally excluded have found ways to overcome the hurdles. The initial interviews suggested, however, that the solutions may have led to unanticipated and not insignificant personal costs, namely a serious, and potentially very unhealthy, loss of esteem by the elderly forced to rely on others for assistance with access to almost all aspects of basic health services. This revelation led to the adoption of a new focus for the study, to investigate whether the digital health divide caused a loss of self-esteem and pride for digitally excluded elderly health patients in rural China.

There was, certainly, support for the supposition regarding this ancillary consequence in the key literature on gerontology and aging. An elderly person's perception of themselves as aged and what that encompasses depends to a large extent on the spatial setting in which they find themselves, with views of those living in diverse urban environments likely to be different from those living in homogenous environments far from large urban centers (Enßle-Reinhardt & Helbrecht, 2022). It would be expected that long-time residents in a relatively poor and very homogenous regional environment would have much stronger ties to traditions (Y. Ren, 2023), particularly Confucian traditions of respect for and veneration of the elderly (Muyskens, 2020) in this case. Notwithstanding two violent and comprehensive revolutions since China's millennia of feudalism, many cultural norms persist and one of the most enduring is the concept of filial piety, a notion embodying both responsibility for supporting the elderly and recognition of the elderly as the primary source of wisdom, knowledge, and advice (H. Li & Wu, 2022). The revised direction of the study thus directly considered the possibility that reliance on others, particularly the young, for the most basic communication tasks, could not only lead to feelings of cultural impotence but could trigger feelings of disassociation as elders lose what they may perceive as crucial aspects of their societal roles.

2. Methodology

The study utilized qualitative research methods based on participatory observation and semi-structured interviews with 44 elderly patients attending a regional county hospital in Shandong Province, a province in the east of China stretching from a poorer hinterland to a more prosperous coastal area. The participants were all over 60 years of age (the mean age was 72.7 years), had relatively low literacy levels, were in poor health (details of their health problems are set out in the Supplementary File), lived in geographic areas several hours by train from a large urban center, and were socially disadvantaged with no access to commonly available urban amenities. The research was conducted over three non-consecutive time periods—June–August 2022, February 2023, and June 2023—to capture data from a range of calendar points. Audio recordings collected by the investigators were transformed into text and imported into Nvivo 12 software (Woolf & Silver, 2017) to build an analytical framework for elucidating the behavior of smartphone health app use among elderly patients.

Both one-on-one and focus group semi-structured interviews were conducted in the study, with each interview lasting more than 30 minutes. The group interview sessions catered to interviewees who felt more comfortable in a group of fellow patients. Similar questions were asked in both types of interviews and the similarity in responses suggested the alternative formats had no impact on the views offered by respondents. Both the identification of interview subjects and interview locations were randomized to cover all possible activities of elderly patients and activity areas within the hospital, including wards, hospital corridors, consultation halls, cafeterias, waiting rooms, plazas, and nearby waiting areas. One-on-one interviews provided privacy which in turn encouraged frank and confidential communication and opportunities to

explore in depth issues of interest to interviewees (Muraglia et al., 2020). Focus group interviews provided opportunities for interviewees to discuss broader topics among themselves and bring up issues not anticipated by the investigators (Barbour & Morgan, 2017; Kitzinger, 1995).

With the consent of the interviewees, interviews were recorded to ensure the accuracy of post-processing content and the authenticity of the data. Interviewees were informed of the intended use of the interview content both during and after the interviews. They were assured that if they decided to withdraw from the study in the course of the interview, the interview would be suspended and the recorded information deleted, but none of the participants withdrew. To assess the conditions and behavioral orientations of elderly patients regarding smartphone app use in the context of hospital services, in addition to statistical information about the interviewees such as age, education level, area of residence, health status, and occupation, the interview process covered issues such as intergenerational support, social interaction, daily media use, payment habits, medical accompaniment, independence of the diagnostic process, and smartphone use during the visit to the clinic.

The data content analysis used a grounded theory methodology (Glaser & Strauss, 1967; Heath & Cowley, 2004). The methodology is designed to derive accurate findings from qualitative data by adopting a bottom-up approach in which the explanatory framework and most plausible theory emerge from the process of collecting, inducting, deducing, and validating texts rather than from established concepts and theories. The text of interviews was transcribed, organized, proofread, and checked against the recording before being imported into the Nvivo program, where the text content was coded at three levels (open coding, axial coding, and selective coding) using nodes that formed the hierarchy of the coding to form a subordinate relationship.

A potential risk of grounded theory methodology is that the theoretical framework derived from the collected data may be distorted by incomplete data that was collected before the final theory or vision was known. In other words, the outcome might have been different if the questions were asked of respondents after the theoretical framework had been developed—a case of "if we had known then what we know now, we would have asked different questions." The solution to this risk is to revisit some interviewees with revised questions and discussion to see whether the new information would lead to a revised theoretical framework, exploring issues that had not been dealt with in depth initially but which had been raised by other interviewees. This was done by random selection of four patients (just under 10% of the cohort) for revised interviews. The revised interviews were then coded and analyzed to test for possible new significant categories and relationships. None were revealed and it can be assumed that the theoretical model obtained from the initial interviews represented a comprehensive model supported by available evidence.

3. The Cohort of Contributors to the Study

There is, to be sure, no single definition of the "elderly" and, clearly, chronological age alone does not accurately identify a group whose members perceive their age in relative terms drawing on personal experiences and narratives (Baars, 2007). However, the combination of chronological age and health conditions necessitating hospital visits was considered sufficient to identify an appropriate cohort for this study.

A total of 44 elderly patients participated in the interview process including 25 females and 19 males. Fourteen participants were in the age group of 60–69 years old, 21 participants were in the age group of 70–79 years

old, and nine participants were in the age group of 80 years old or above. The average age of all participants was 72.7 years. Twenty-six of the subjects were involved in one-on-one interviews and 18 subjects were involved in focus group interviews. Most of the participants (84%) were suffering from chronic illnesses such as gastroenteritis, heart disease, bronchitis, hypertension, etc.

Twenty-three elderly patients used smartphones, 14 elderly patients used older-style feature phones (mobile phones with press-button-based inputs and a small non-touch display), five elderly patients used both smartphones and feature phones, and two elderly patients did not have a cellular device.

4. Findings: The Three Cohorts of Elderly Healthcare Users

The study sought to investigate, first, the extent to which patients accessing health care had suffered digital exclusion and consequently been forced to rely on others to obtain the care they needed and, secondly, the extent to which the revelations of their limitations and digital ignorance in turn would lead to a significant loss of self-esteem. The findings revealed a much more nuanced set of relationships between the elderly and digital health services than originally anticipated, particularly with respect to those wholly excluded from the world of digital communication.

There is no universal test for digital literacy and scholars in different contexts rely on a variety of benchmarks to determine levels of digital literacy (Oh et al., 2021; Padilla-Góngora et al., 2017). The survey found, however, that it was possible to divide elderly patients attending county-level hospitals in China into three broad groups: adopters, partial adopters, and wholly excluded persons. The three groups corresponded, respectively, with persons able to use apps related to their hospital visit and other apps, those able to use the apps related to the visit with assistance, and those wholly reliant on other persons to navigate app usage. Of the 44 persons interviewed for the study, nine were considered adopters, nine partial adopters, and an overwhelming majority, 26, wholly excluded persons. The third group in turn comprised three distinct camps, each with its own reasons for exclusion. While the study looked only at the impact of digitalization and shifts to mobile apps on health care for the elderly outside large urban centers, the findings could likely be extended to all other services that have shifted or are shifting to app-based programs or to any of the other life challenges faced by the elderly (Whitbourne, 1999).

We did not find a significant correlation between adoption categories and age or gender, but correlations were noted between digital app use and child companionship, literacy, health status, and socio-culture. The latter is a commonly used Chinese notion referring to the extent insular individuals are wholly integrated into the historical local rural culture (Fei, 1992), used in contradistinction to those who have been exposed to and adopted attributes of the broader urban society. A further important determinant for smartphone app usage was cost, with the digitally excluded generally aligning with the poorest segment of hospital users.

An interesting and unanticipated observation drawn from the study was a differentiation in learning approaches between respondents with some digital skills and those who taught them. It is commonly assumed that the learning process postulated by Bandura (1962), one of learning through observation, imitation, and modeling, applies to learning across the board. The quick mastery of digital technology by the very young, freed from inhibitions and assumptions and able to apply learned logic to self-learning by trial and error, revealed new ways of acquiring skills in the digital era. References to help by children and

grandchildren by full and partial adopters suggest the digital device education of these participants was similar to that used to learn non-digital life skills, a process consistent with that described by Bandura. Quite likely, the youngest teachers cited by participants mastered their technology skills through a very different learning process.

4.1. Adopters

A common characteristic of adopters of digital interaction for health care is their prior use of smartphones and digital communication for other reasons. Not all elderly persons are retired, and the self-employed in particular may be comfortable with digital communication from business use (42-65M). Better-educated persons with white-collar backgrounds such as teachers were also included in the group of prior users (40-82F). More common, however, are elderly persons who were taught how to use smartphones for various purposes by children (12-76M).

Those familiar and comfortable with smartphones and digital apps used them for common smartphone purposes apart from health features, including online shopping, managing finances, and social communication. The non-health and health purposes merged to an extent for those facing lengthy hospital stays, with digital entertainment and family video conversations being important tools to break the monotony (12-76M). An important sentiment reported by some smartphone users is the feeling of self-empowerment, with users able to directly participate in their health care by taking responsibility for aspects of their care such as arranging appointments, registration, and so forth, rather than relying on health administrators (6-67F). A further source of self-esteem derives from the ability to assist and tutor those less familiar with digital technology.

4.2. Partial Adopters

The common feature of partial adopters of digital apps for healthcare purposes is the general lack of use or interest in the digital app features of smartphones other than for health purposes. But for the need to access services via smartphones, these users would likely not exploit the app features of the devices. Two factors in particular have driven the take-up of digital technology by this group. One is a practical concern—obtaining access to services such as doctor appointments or prescriptions is very problematic without the use of digital apps (44-74M). Much of the health system is predicated on patient initiative (Chen et al., 2022) and, for those without access to close family support, mastering health-related apps is a prerequisite to getting health service. Absent access to services, the partial adopters envisage a genuine, and possibly fatal, risk to their health care.

The second factor driving partial adoption is concern over the burden on children who would otherwise assume responsibility for the organization of healthcare services if the respondents did not move to a degree of digital self-sufficiency. Confucian responsibility norms prevail in Chinese society (Zhao, 2022) and elderly parents strive to minimize burdens for care imposed on children. A prime motivation for the partial adoption of digital apps for health care was to reduce children's responsibilities for the adopters (12-76M).

4.3. Digitally Excluded

The disadvantages for older adults resulting from digital exclusion have been well documented globally (Friemel, 2016; Jaarsveld, 2020; Loges & Jung, 2001). At the same time, and somewhat ironically given the ability of the internet to overcome the tyranny of distance and isolation for rural communities, the growth of the medium may exacerbate these phenomena for the disenfranchised digitally excluded rural dwellers (Warren, 2007). The rural respondents in this study experiencing this double whammy readily rationalized the reasons for their failure or inability to adopt digital communication but differed in their stated views on the extent to which they were emotionally impacted by the exclusion.

As noted, the digitally excluded fall into three camps. The first, a small minority in the group, seems to genuinely believe they are not disadvantaged from their exclusion, asserting it is possible for them to rely on other means to acquire services usually available by app (23-70F).

The second cohort, accounting for most of the digitally excluded group, comprises the digitally abandoned—elderly facing what they perceive as unscalable barriers to digital access. Financial constraints were an obvious factor for some of these—ironically, the impact of the high cost of medical care on the limited budgets of the rural poor left them with little disposable cash for what would be the luxury of a smartphone and digital access to programs that could aid their access to health services (3-70F). Unfamiliarity with technology and a perceived inability to learn new digital skills is cited by others (13-80F; 1-71F), a factor that might be compounded by fading vision and consequent difficulty reading small screens (14-78M).

A much smaller group are the digital rejecters, elderly persons not faced with the attributes of the excluded but deliberately rejecting the use of digital media to access health services. This group makes a conscious calculation (or possibly an after-the-fact rationalization) that the benefits of the use of digital apps do not outweigh the cost of learning. The time lost mastering the skills needed is time lost to actual in-person socialization with friends or neighbors while the benefits may be inaccessible in any case in the event of severe illness and hospitalization (18-81F).

5. Findings: The Personal Identity Crisis of the Digitally Excluded

Max Weber once described traditional Chinese villages as autonomous areas without officials, and village autonomy as the rule of "custom" (Weber, 1951). The social and political revolution that ultimately saw the overthrow of the feudal system and feudal norms at the national level did not percolate down through all parts of Chinese society (Meng, 1969), with significantly different impacts in large cities, in which intellectuals and political leaders lived, and rural areas (Johnson, 2009). Prominent among the feudal ethics that persisted in rural society was the principle of "filial piety," a concept that goes beyond responsibility to care for parents materially and spiritually (Yeh & Bedford, 2003; Yeh et al., 2013) to include demonstrations of respect for the wisdom and guidance of the elderly. The interviews revealed a sharp divide in views between digital adopters and the digitally excluded about the flow of generational responsibility.

Digital adopters, as noted above, viewed their self-sufficiency in accessing and managing health care services through digital apps as a positive aspect of their relationship with children, ensuring they would not be a

burden for the children and freeing the children to pursue their own achievements and goals. The view of digital avoiders was more complex and dialectic in nature. While the group includes some fatalists who have simply resigned themselves to a life of exclusion and perceived suffering the result of fate (7-65F), the starting point for most in the group was their relationship with children, the group that could have a direct impact on the exclusion of elders. Almost all affirmed a traditional view that children have a primary responsibility to look after their parents (15-77F; 26-67M). At the same time, however, interaction between child and parent must respect that duty in a way that does not require parents to admit to their limitations or shortcomings. As one respondent explained, it would be fine for a child to take the initiative and show a desire to demonstrate and explain the use of an app needed by the parent, but it would be an inexcusable loss of face for the parent to have to take the initiative and ask for help (26-67M). As one interviewee explained, "if we bow down to our children, we will not be able to hold our heads up outside the home" (33-67M).

The despair of the digitally excluded unwilling or unable to turn to children for instructions and assistance with the request initiated by the parents extends beyond the breakdown of filial norms in their view. It reaches a much broader sense of loss, the dismantling by the internet of "thousands of years of cultural traditions" (2-71F; 19-80M; 9-78F). This despair over the loss of tradition and rural social norms was a theme that emerged time and again in interviews. Its impact was significant for respondents.

6. Limitations

The study is not without limitations. One is the exclusion of the very elderly from the inquiry. While interviewees were limited to a minimum age of 60 years, no maximum age was set. However, both doctors and family intervened to prevent interviews with elderly patients over the age of 90, suggesting extended interviews might carry some risk. It might be assumed that digital capabilities and the social role of the very elderly will differ from their younger counterparts. Given the views of doctors and family, collecting data from those over the age of 90 through interview methodology is not possible. Future researchers might explore alternative means of communication with this group, perhaps by enlisting family members as aides.

The second limitation of the study is its geographic reach. The study was conducted within a county-level hospital in Shandong Province and the findings may not apply to similar non-urban center locales across China. Excluded from the study were other non-urban elderly such as nomadic and mountainous populations. The logistical challenges in extending the study to groups such as these would be significant.

7. Conclusion

This study explored digital health services app use and consequential views of elderly patients at a county hospital in Shandong Province, China, that had adopted digital apps for many aspects of its services. The hospital and most allied health services have turned to digital apps as a means of extending services to healthcare users in a semi-rural county setting. An important target of the digital services is the elderly who are also, ironically, the group most likely to be excluded from the services, with potentially serious compromises to their healthcare access. Equally, and perhaps more significantly, excluded elderly persons often experience (sometimes severe) dislocation as the foundations of the social and cultural system they grew up with and expected to see for their lifetimes crumble. As digitization provides younger generations

with newer and very expanded sources of information, the position of the elderly as senior respected authorities falls away and the social constructs that brought comfort disappear.

The loss, as well as the challenge of accessing health services available only through smartphone apps, in effect creates a double burden for the rural elderly. Possibly, the phenomenon will diminish over time as current internet users who are not only familiar and comfortable with digital communication, but also accustomed to confronting and mastering new and continuously evolving digital communication challenges, age and become the next generation of elderly persons. There are no obvious easy fixes for the double burden. Changes or simplifications of apps will not lead to behavioral change by persons who have not acquired smartphones or are resolute in their opposition to mastering their use. Nor is it likely there is any reason to presume the government will restore old systems for this one segment of the population when it has pursued digitization as a strategy to provide health services more efficiently in rural areas. This may simply be a case of observing a previously undisclosed cost of the shift to digital communication for the benefit of many causing compounded harm for the few.

The findings do provide a useful lesson for future digital exclusion research. Research on this topic most often focuses on aspects of the phenomenon itself, particularly who is excluded (for example studies of exclusion by income levels or age or other demographic features nationally or country development levels internationally) and the consequences of exclusion. Rarely does it look further into the possible consequences for the excluded as a result of the methods they use to overcome the constraints of exclusion. The particular consequence that participants in this study attributed to their inability to master digital apps—personal loss of self-esteem suffered by the elderly in a more remote non-urban part of China—may be restricted to persons in a similar situation in this particular culture and area. The study alerts us, however, to the importance of looking further down the results trail to identify all flow-on effects from digital exclusion and responses to that exclusion.

Conflict of Interests

The authors declare no conflict of interests.

Supplementary Material

Supplementary material for this article is available online in the format provided by the authors (unedited).

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