Feminist Reflections on Home, Digital Health Technologies, and Ethics

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1 Introduction

The provision of care in the home has a long-standing history in nursing, but in recent years societal trends and technological change, including digital health technologies, have brought new ethical challenges. Home care services have the potential to disrupt practices in the home and raise ethical issues because homes are places that are laden with cultural norms and social meanings including associations with love, security, and privacy. Nevertheless, the flipside of these ideals, which includes isolation, abuse, and surveillance, also exist in part, because they are not adequately challenged and are made possible by women's domestic roles. In this chapter, I examine the ethical implications of providing and receiving home services focusing on the use of digital health technologies in the home and their potential implications for the moral practices of the home to highlight a number of ethical considerations related to the provision and receipt of home care services. In particular, I focus on medicalization and surveillance, privacy, autonomy, and family caregiving relationships. Along with feminist ethics, this analysis is informed by feminist relational geography, given that spatial factors are central to the ethics of home care. How these two related perspectives are aligned and how the foregrounding of space and place in geography can enhance the use of feminist ethics will be explained below.

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2 The Compatibility of Feminist Ethics and Feminist Relational Geography

Beyond their attention to the lives of women and less powerful groups in society, feminist ethics and feminist relational geography share a number of characteristics, including their emphasis on a relational ontology, power and politics in everyday care work, and context. Like feminist ethics, central to geographical thought is the understanding that social relations influence the development of identities, experiences, and agency. The notion of space "denotes a dimension in which phenomena are distributed. Conventionally it has been viewed as orthodox geometric space, quantifiable in terms of Euclidean distance" (Curtis and Jones 1998, p. 645). Yet, space can also "be seen as both the medium and outcome of social relations. Space therefore has social significance and is socially constructed" (Curtis and Jones 1998, p. 645). Thus, geographers recognize how spaces are created through social interactions and are viewed to be ever-changing, creating "social space" which describes how spaces are experienced and navigated (Andrews et al. 2013; Hall 2018).

The importance of power and politics in everyday life, particularly with respect to care work, is also understood to be central by both areas of thought. Massey (1991) speaks of social spaces being made by the "geographical stretching-out of social spaces" (p. 24) which refers to the production of the inequities of spaces that are a consequence of changing socio-material aspects of our everyday world, such as technology, transportation, and modes of communication (Hall 2018; Massey 1991). For example, because of neoliberal policies and changes in technology, the boundary that ostensibly separates the home, thought to be a private space, and the state and the market, thought to be a public space, becomes blurry when paid homecare workers provide care (England 2010). These changes impact everyday life in the home, particularly the lives of women who perform the most paid and unpaid homecare work. Dyck (2005) describes women's unaccounted for care work in the home as "place-making" (p. 236) which is the result of neoliberal policies. These seemingly routine and mundane care practices are of interest for geographers (Hall 2018) as they are for feminist ethicists. Geographers, however, foreground place. As Hall (2020) states: "Care also has a *place*, both in society at large, and in everyday routines, relationships and practices, commonly associated within the personal space of home" (p. 3).

Both feminist ethicists and feminist geographers emphasize context, but often describe it somewhat differently. Relational moral theories, such as feminist ethics, conceptualize context, and situatedness in predominantly social terms, with the material relations often ignored unlike what is typical in geography (Whatmore 1997). Yet, the possibility to introduce place coherently into feminist ethics exists if we consider that persons' particularity and location offer the potential to include place because persons can be thought of as located both in sociopolitical and material terms (Peter 2002). Ultimately, while these two areas of scholarship tend not to be brought together frequently, they share many elements and can be combined to address issues in moral life, especially in areas where place is paramount, such as those surrounding home care.

3 Feminist Ethical and Geographical Insights Regarding the Home

Home is commonly understood to be the site in which we live, yet it is much more than this. "Home is also an idea and an imaginary that is imbued with feelings" (Blunt and Dowling 2006, p. 2). These feelings are inherently spatial and can range from feelings and cultural meanings of love and belonging to fear and alienation (Blunt and Dowling 2006). From a feminist ethics perspective, these ideas, meanings, and feelings reflect deeply held values and practices that are rooted in home life and are intertwined with those of society more generally. The morality of home as an idea or imaginary, like morality more generally, can best be revealed by recognizing the practices of responsibility associated with home because these responsibilities illustrate our identities, values, and accountabilities. These are inextricably connected with our social roles and practices making morality a dimension of everyday social life (Walker 1998). Similarly, making home is also a practice. Blunt and Dowling (2006) state, "relational geographies of home require attention to what we term home-making practices. Home does not simply exist, but is made. Home is a process of creating and understanding forms of dwelling and belonging. This process has both material and imaginative elements" (p. 23). Relational geography also recognizes that places, like the home, are not fixed, but develop through their relationships with other spaces and places that exist on multiple scales (Skinner et al. 2015).

Feminists underscore that power relations are omnipresent in the home, creating identities and hierarchies. Practices of the home, manifested through both caring and domestic work, are gendered and often are attributed to the so-called private as opposed to the public world. Yet, these worlds are mutually constructed. While traditionally, men have viewed the home as a haven from public life, the home for many women is a workplace, illustrating how norms and ideas are infused across places (Blunt and Dowling 2006). In a similar vein, Walker (1998) calls us to critically reflect on these forms of moral–social arrangements and their practices to ensure that they are coherent to those who engage in them and that they are not coercive or marginalizing.

4 Digital Health Technologies

Digital health technologies have become increasingly prevalent in society, including those that are in the homes of those receiving healthcare services. These technologies can involve telehealth to offer consultations, education, and support remotely; digitized devices for medication delivery and the enhancement or regulation of bodily functions, for instance, cardiac monitors and insulin pumps; health informatics, for example, electronic health records; wearable technologies for monitoring blood sugar, heart rate, and emergencies; blogs and social media sites for patients; and digital health promotion for the dissemination of health education (Lupton 2014). These innovations, while often developed as solutions to health-related problems, have wide-ranging ethical and social implications that require reflection.

Any attempt to generalize regarding the impact of these technologies, however, is difficult because of the degree of variability in the nature and purpose of these technologies and the variability among the people who rely on them. Moreover, new technologies are continually emerging along with research studying their impact, further adding to the challenge of making any definitive statements. Moreover, homes, unlike institutions, are diverse and spatially dispersed, resulting in the experiences of users of technology being similarly diverse (Andrews 2003). As such, a feminist particularist approach, which examines the unique strengths, vulnerabilities, and preferences of people along with their contexts, is ideal in this regard because it permits an examination of each person's individual needs and situation.

It is also important to consider vast differences that exist in terms of accessibility to these digital health technologies. Differential access to these has been referred to as the "digital divide," which has been defined as "the gap between individuals, households, businesses and geographic areas at different socio-economic levels with regard both to their opportunities to access information and communication technologies (ICTs) and to their use of the Internet for a wide variety of activities" (OECD 2001, p. 5). This gap is the result of many factors related to equity, including lower levels of education, health and digital literacy, and income (Lupton 2014). Even in high-income countries, there are geographical differences in the availability of technologies depending on the quality of data infrastructure between urban and rural areas with less availability in rural communities despite their need being the greatest (Salemink et al. 2017). This gap is of most concern when certain health services and information are only offered digitally. Nevertheless, fears of oversimplification and generalization aside, I raise some possible ethical implications here that require a nuanced interpretation when examining particular situations.

5 Medicalization and Surveillance

Feminist ethicists not only have a long history of questioning the medicalization of childbirth, they have also been concerned with the excessive medicalization of aging and other human experiences. Over 25 years ago, Liaschenko (1994) expressed concern regarding the rise of technology in the home that could bring the "gaze of medicine", or medicalization, with its emphasis on the biomedical view of disease, into the landscape of the home, potentially impacting home practices that foster and maintain human agency. Liaschenko (1994) argued for the "gaze of nursing,", which embraces both the "gaze of medicine," if that is in keeping with patients' values, along with a perspective that supports the view of patients as persons who live particular lives in particular places. She, like Conrad (2005), was concerned that technology has the potential to further encroach on the everyday lives of people allowing normal human experiences such as aging and death to be understood through a medical lens and to fall under the control of health care professionals. It is important to recognize, however, that how individual patients experience the constant surveillance of wearable technologies, whether it be self-surveillance or that of the surveillance by health professionals, is for some reassuring and for others a source of anxiety (Lupton 2014). Moreover, while technologies can enhance quality and quantity of life for some, these technologies can encroach on what has, at least previously been believed to be, the private domain of the home (Poland et al. 2005).

The use of digital health technologies also raises questions about the meaning of embodiment and the relation between humans and the ever-changing nature of technology and the normalization of the creation of what have been called cyborgs, or beings with both biological and technical components. As prosthetics, these devices can enhance bodily capacities by providing data that can be used to inform people of their limitations and strengths. They also allow people to work on themselves and to present a particular identity (Lupton 2014), such as person who derives a positive sense of self by achieving a high number of daily steps. While on an individual level this might improve quality of life, it is important that the social implications are taken into account, because as Poland et al. (2005) have argued, health technology has the potential to have profound effects on the self, identity, and personhood. For example, Boström et al. (2013) studied the perceptions of older adults who wore monitoring technology and had sensors in their home to maintain their independence. The main theme of their research was "maintaining a sense of self" that represented older adults' need to maintain their identities and control over their lives, given the loss of privacy they experienced. Yet, overall, they believed they could accept the surveillance if they could maintain their autonomy and sense of security.

6 Privacy

Surveillance also has ramifications for privacy. Privacy is a complex and deeply problematized concept in feminist ethics which DeCew (2018) argues can be best understood as a cluster concept which embraces interests in: "(1) control over information about oneself, (2) control over access to oneself, both physical and mental, and (3) control over one's ability to make important decisions about family and lifestyle in order to be self-expressive and to develop varied relationships" (p. 2). In this way, the concept does not only pertain to informational and physical privacy but also can contest the traditional dichotomy of the public and private spheres, which protects the private sphere from state interventions and scrutiny (Allen 2011). This problematization is necessary because privacy is not always ideal because it can foster unchosen seclusion and the hidden domination and abuse of women and others. Yet, it is also important to ensure that the state does not interfere with the most personal aspects of life in unwanted ways (DeCew 2018). Consequently, cyberfeminists, who have an interest in examining and theorizing the internet, digital technologies, and cyberspace, argue that the impact of adopting digital technologies must not be taken up uncritically at both the level of individuals and also at the level of culture (Consalvo 2002). On the one hand, they argue that these technologies give people the opportunity not to be isolated in their homes and to be politically empowered, yet on the other, the anonymity can lead to a lack of accountability and potential safety (Allen 2011).

With respect to informational and physical privacy, concerns have been expressed regarding the unauthorized sharing of data, the intrusiveness of the equipment, and the disruption of daily routines by technology. Yet, home care recipients have expressed that these issues are of less consequence to them than having to move out of their homes. With respect to older adults living in the community, some have concluded that the ethics of the use of assistive technology requires that a balance be struck between the violation of privacy and the protection of people in their homes (Zwijsen et al. 2011). From a feminist perspective, the balance can only be struck by assessing each person in their unique situation and assisting them to understand the implications of their choices. These conclusions also require that long-term care environments are not so unappealing that people have no other real choice than to remain in the home, even if they find that the experience of receiving care in the home is unacceptably intrusive.

7 Autonomy

Conventionally, little attention in ethical theory has been given to the significance of place to the self. Instead, ethics has tended to equate the self with the mind—a thinking thing that is immaterial, nonspatial, and separate from the body (Waymack 2001) with notable exceptions arising from phenomenology and feminist philosophy. In a similar way, in bioethics, conceptualizations of autonomy have not fully considered the implications of an emplaced self which is not surprising because the roots of bioethics are in mainstream ethical theory and because bioethics has tended not to concentrate on ethical issues that arise in homes. Hospitals, unlike homes, tend to be more generic in nature, allowing their spatial features to become invisible to professionals who occupy them regularly (Peter 2002). Feminist ethics along with insights from feminist geography, however, make it possible to understand the emplaced nature of autonomy because they recognize that people are not only socio-politically situated, they are materially situated which is an important consideration with respect to home care. Without this sense of autonomy as being emplaced, how different settings, like the home, situate autonomy can be overlooked (Andrews and Peter 2006). As Malpas (2003) states, "Since all human life, and with it human illness and suffering, is essentially lived in place, so any attempt to engage with human life that ignores its placed character will inevitably fail, to some degree or another, in that engagement" (p. 2347). The saying "he is the king of the castle" typifies the imaginary and cultural values of the home that express autonomy and agency, along with gender, which can become altered when digital health technology enters the home because of the requirements of patients to conform to the demands of healthcare professionals who have decided to use these technologies (Lupton 2014).

In many instances, however, the restriction of autonomy may be a matter of degree because the technology may free people from not needing to attend medical appointments, to be in hospital, or to have healthcare workers coming into the home.

For example, it is important to take into account that despite the popularity of so-called patient-centered care, the experience of receiving care in an institution, such as a hospital or nursing home, can restrict autonomy even more than receiving home care services because of the regimentation and spatial limitations often inherent in them. As opposed to the idealized practices of home, in which the identities of people are built and preserved and the unique needs of people are respected when providing care, institutions can be regimented reflecting an ethos of efficiency. As a consequence, caregiving including meal provision, bathing, medication provision, and even recreational activities can be highly scheduled and regimented (Andrews and Peter 2006), which limits the everyday autonomy of care recipients. This phenomenon has been called the "task and time" (p. 332) approach that has been described as depersonalized and mechanistic (Kitson et al. 2014).

Even if home care provision avoids such mechanistic efficiencies, however, the entry of care workers into the home can be experienced as an intrusion, interfering with the freedoms and everyday routines and choices of the home's occupants. They also often experience an erosion of their autonomy because they can become passive objects of care without the necessary voice to direct their everyday lives as others care for them (Jacobs 2018). Autonomy understood relationally emphasizes that the "exercise of personal autonomy is enabled or constrained by social relationships and by social norms, structures and institutions" (Mackenzie 2019, p. 4) which reflects the many possible scales of analysis needed to understand autonomy. How autonomy is exercised is a reflection, not only of micro influences but also of social policy as it impacts the nature and amount of support that is provided by the state, which may or may not include the availability of digital health technologies. It is important to recognize that autonomy can also be enhanced by the provision of services that allows for choice and control and by the nature of relationships among care recipients and caregivers (Bjornsdottir 2017; Öresland et al. 2009). For example, Jacobs' (2018) research, which incorporated a feminist ethics lens, found that home care nurses could promote autonomy by adapting to patients' unique needs, values, and preferences; by activating their strengths, and by collaborating with them and their informal caregivers. While care can result in dependence and restricted autonomy of patients, it is a needed prerequisite for the enhancement of their autonomy because the relational support makes autonomy possible (Jacobs 2018). To what extent this can be meaningfully supplied in a virtual fashion through technology is necessary to explore.

8 Family Caregiving Relationships

Family caregiving in the home is virtually synonymous with practices in the home, such as the domestic and caring work which maintains not only the physical well-being of its occupants but also fosters their identity, belonging, and privacy (Blunt and Dowling 2006; Hall 2020). In recent years, this caregiving has greatly expanded as the responsibility for the provision of many healthcare services has shifted from the state to the home, especially in countries such as Canada, New Zealand, the

United Kingdom, and the United States (Milligan 2009). While, traditionally, women have held a disproportionate degree of responsibility for the everyday caring for family members, including for those who are sick and dying, they, along with men and even children, have become progressively more responsible for providing care that heretofore would have been provided in hospitals and other institutions by paid, professional nurses. This privatized caring is supported by a neoliberal ethos, which rests on the assumption that families are and should be available to provide care without sufficient attention to their ability and willingness to do so, and it is reflected in the social policies of many countries (Milligan 2009; Peter and Liaschenko 2014; Peter et al. 2007; Tronto 2006).

This shift in social policy has had a profound impact on home-life disrupting home routines and practices as those practices of formal health care are overlaid onto those of the home. Family caregivers and their care recipients must adapt to changed places with not only the invasion of the often ever-present medical equipment, but also with the presence of formal homecare providers who, on one hand, make necessary care possible, but on the other, can be unwelcome (Angus et al. 2005; Seto-Nielsen et al. 2013). The nature of this transformed family caregiving can be extraordinary, encompassing a full range of care, such as support with activities of daily living, emotional care, technical nursing care, and service coordination and supervision, often with minimal available public support and training. As a consequence, many caregivers experience reduced quality of life, distress, physical burdens, and needs that are not met by healthcare systems (Dionne-Odom et al. 2017; Martín Martína et al. 2016). Furthermore, there can be significant out-of-pocket costs and lifelong income losses for informal caregivers (Canadian Cancer Network 2017).

The moral responsibilities of nurses in the home are also not always straightforward as social policy directing home care services has increasingly shifted the moral responsibility for care from the state to the family, thereby altering the kinds of relationships nurses have with patients and families. Ward-Griffin and McKeever (2000) and Milligan (2009) have provided typologies of relationships that assist in conceptualizing the evolving and sometimes conflicting types of relationships. The first type the “nurse-helper” has become least common, although it is the type of relationship most commonly idealized in nursing. Its sustained face-to-face nature allows nurses to preserve the identities of people who are vulnerable, which, in turn, allows nurses to maintain their own sense of identity and value (Peter et al. 2018). It is the type of relationship in which nurses provide and coordinate most of the care with the family playing a supportive role, but this relationship, as a consequence of social policies that have limited the amount of nursing care provided, has become increasingly uncommon (Ward-Griffin and McKeever 2000). Given that nurses often view this kind of relationship and the kind of care that flows from it as reflecting their moral identities and responsibilities, it is not surprising that they experience moral distress when they cannot provide this type of care in their practice (Brazil et al. 2010; Peter and Liaschenko 2013).

The second type of relationship is one in which family caregivers are viewed as a resource—they are coworkers alongside nurses, or, they are workers who are managed by nurses. These caregivers often acquire a high level of skill and knowledge as they assume responsibilities that would normally be in the domain of professionals even though many feel unqualified and fearful and would prefer assistance from nurses (Milligan 2009; Ward-Griffin and McKeever 2000). Despite their skill and knowledge, unlike professional caregivers, family caregivers do not have the power and privilege of nurses who are socially recognized for their expertise and exercise significant power in healthcare systems. When they are not provided the supports of professional networks and associations, they can be left feeling relatively isolated and powerless (Pauley et al. 2018). Unsurprisingly, the second type of relationship frequently evolves into the third type in which the family member also becomes a patient as their own health deteriorates as a result of substantial caregiving and preexisting health conditions. As the needs of the caregiver become more evident, they may come to conflict with those of the patient and complicate who is the focus of care in the relationship, i.e., the patient or the caregiver (Milligan 2009; Ward-Griffin and McKeever 2000).

The current evidence we have of the distress of patients and family members can inform what Walker (1998) calls an "empirically saturated reflective analysis" (p. 11) to evaluate whether the moral understandings embedded in home care arrangements are intelligent, coherent, and morally habitable to those involved in them. Morally habitable environments are those that are characterized by mutual recognition and cooperation as opposed to suffering and the uneven distribution of responsibilities (Walker 1998). The experiences of those involved in home care make it evident that the current moral–social arrangement of the delivery of home care services is not creating morally habitable environments, in this case homes, because this arrangement is not supporting sustainable moral practices for many. While families and friends may want to care, without outside support, they often cannot do so without falling ill themselves or becoming exceedingly distressed. They, like all people, are interdependent and require support to continue to provide care.

Digital health technologies have been found, however, to bring improvements to some of these problems. In their review of the literature examining the role of digital technologies to enable aging in place, Kim et al. (2017) found a number of benefits that are relevant to the well-being of both home care participants and their caregivers. While there are a number of definitions of aging in place, they use one that focuses on the ability of older adults to live in the community and their own home while maintaining their quality of life. This technology has made possible the early detection and management of health problems, the self-management of hypertension and diabetes, and safety monitoring (Kim et al. 2017). It also has decreased the social isolation of older adults and has provided a way for caregivers to receive additional support from health care professionals and watch over their loved ones remotely. While these relationships are not as ideal as face-to-face encounters because older adults fear losing the physical contact of others (Sundgren et al. 2020), technology can make possible what might not otherwise be possible at all. Some have spoken about the unprecedented compression of time and space as the "death of distance" in the capacity of telemedicine and the internet to breakdown both social and physical barriers (Andrews et al. 2013) and enhance the abilities of families and friends to extend their relational capacities to hold and maintain the identities of older adults in the community (Parks 2015).

9 Conclusion

While digital health technologies in the home may hold much promise in improving the quality of life, enhanced autonomy, and decreased social isolation for many, continued ethical scrutiny is needed particularly with respect to concerns regarding privacy and surveillance. It is also important to consider the broader societal changes these technologies may bring, including an emphasis on self-care and self-monitoring that neglects the impact of the social determinants of health, the potential impact on the evolution of the institution of the family and practices of the home, and the effect on our identities as humans as we become increasingly wed to technology. Further research and scholarship and a heightened awareness of these issues and the possible solutions these technologies can bring will help bring about informed use of these technologies. Feminist ethics coupled with relational geography can permit this type of ongoing and rich ethical analysis of home care issues, given their capacity to address an array of concerns combined with their recognition of the significance of place.

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