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ETHICAL ISSUES OF PERSONAL HEALTH MONITORING: A LITERATURE REVIEW

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1. Abstract

Personal Health Monitoring (PHM) technologies are currently in development to supplement medical care environments with health monitoring outside "brick and mortar" settings to better meet the needs of people with long-term illnesses. This review identifies common themes in the current literature discussing ethics of PHM and gaps in need of further research. Identified themes include privacy, autonomy, medicalization, social isolation, visibility and impact on healthcare providers. An in-depth discussion of the ethical issues of PHM was rarely found in the searched literature. Areas in need of further research include inadvertent monitoring and the impact of PHM on families and patient relationships.

2. Introduction

Personal Health Monitoring (PHM) technologies are currently being developed to supplement medical care environments with health monitoring outside "brick and mortar" settings. A primary factor spurring the development of PHM is the rapid aging of the global population which is predicted to increase the burdens placed on many countries' healthcare systems, potentially outstripping available medical resources (Agree et al., 2005). Although the elderly are a primary force behind PHM, systems are currently in development for a multitude of audiences of all ages and health. This paper provides a review of the literature relating to the development and implementation of PHM technologies that discusses ethical issues.

In the current literature agreement upon a common definition of "Personal Health Monitoring" does not exist, with many synonymous and related terms being used instead including "telecare," "assistive technologies," "ambient intelligence," and "wearable health sensors." For the purposes of the current review a working definition was established that incorporates the related terms: Personal Health Monitoring refers to any electronic device or system that monitors a health-related aspect of a person's life on a constant basis outside of a hospital setting. Recently developed examples include GPS tracking devices used with mental health patients, blood pressure wrist monitors and "smart clothes" capable of measuring physiological signs (Stergiou and Bliziotis, 2011, Lymberis, 2005, Lauriks et al., 2007). PHM devices may have the capability to record data both locally and offsite, or to register an alert in the case of abnormal activity; however, these optional features are not necessary to designate the technology as PHM.

Although the ethical discussion of PHM is still nascent, implementation is already occurring in the homes of elderly people (Zwijsen et al., 2011). This early deployment is partially due to the recognition of the health benefits of ageing at home instead of living in a care facility (Bowes et al., 2011). Unfortunately, monitoring of any type tends to raise questions about privacy, autonomy and independence. When considering these two factors together an in-depth discussion of the ethical issues raised by PHM is both necessary and appropriate at present. To spur this discussion a literature review, to identify common themes within the debate on the ethics of PHM, was conducted.

3. Method

Academic literature available in four databases (Scopus, IEEE, MEDLINE, and CINAHL) addressing the ethical implications of PHM was reviewed over a period of several months. Attention was given to the discussion of ethical issues in each article, with the goal of identifying the themes present in the literature. The databases were searched to identify literature discussing ethical issues relating to development and implementation of PHM technologies. The search was limited to English language articles. No date restrictions were placed on the search, but all results happen to be from 2003 or later.

3.1 Procedure

Articles were located from May 2010 to June 2011 by systematic searching of databases as well as manual journal searching, citation tracking from found papers, and presentation of papers by research colleagues. Recognizing that "Personal Health Monitoring" is an emerging term not yet widely used in the literature, synonymous and related search terms were employed during database searches including "wearable body sensors, " "personalized health," "pervasive health," "assistive technologies," "health surveillance," "ambient assisted living," and "smart homes." All articles matching the synonymous terminology were checked to ensure the technology under discussion matched the working definition of PHM.

Search queries consisting of three categories were employed. The first category included "personal* health* monitor*" and related terms, while the second category used broader information and communication terms such as "ubiquitous computing" and "ambient intelligence" linked to healthcare or medicine with the "AND" Boolean operator. The first two categories were combined using the "OR" Boolean operator. Finally, the third category was a single term: "ethic*" linked to the first two categories with "AND." The desired outcome of the search query was to identify articles directly mentioning PHM or related terms that also directly discussed ethics or ethical issues.

This method was intentionally chosen to identify articles explicitly addressing ethical issues of PHM and to limit the quantity of results. Prior literature reviews on specific ethical issues within PHM involving surveillance technologies and residential or community elderly care settings have used more inclusive search terminology and provided analysis of articles and themes not explicitly addressing ethics, but still involving well-recognized ethical issues such as privacy and autonomy (Zwijsen et al., 2011, Niemeijer et al., 2010). After piloting the database searches including these and similar terms, it was determined that their inclusion resulted in too many irrelevant articles being returned.

Articles were reviewed to determine relevance to the current review. Articles were excluded if they only discussed development, implementation or technical specifications of PHM technologies. No requirement was set for length or depth of ethical discussion, and there was no restriction on the type of article included.

3.2 Data Analysis

All selected articles were reviewed at least twice to identify discussion of ethical implications of PHM. Key terms were identified and combined into themes present across multiple articles. In all, eight themes were recognized based on their usage in the literature. The themes and subsequent analysis were used to identify areas for future research within PHM.

4. Results

A total of 297 articles were returned during the search of databases. After combination with hand-searched papers, 39 met the inclusion criteria of explicitly discussing ethical issues of PHM. On detailed examination of the papers, eight common ethical themes emerged.

4.1 Privacy

Two types of privacy emerged from the articles: personal privacy and data privacy. In general, personal privacy was interpreted to mean the right to be left alone or not monitored by a third party. Several articles identified a gradual loss of personal privacy from increased implementation of PHM technologies, particularly smart home systems (Remmers, 2010, Dorsten et al., 2009, Demiris et al., 2009). The loss of privacy was based on a feeling of constant monitoring among users.

From the collected articles data privacy was interpreted to mean the right to control one's data, including controlling access and use by third parties. Concerns over the usage of data gathered by PHM were more common (Tiwari et al., 2010, Kosta et al., 2010, Agrafioti et al., 2011). In one article an ethical protocol was developed to address concerns by building anonymization features into the data collection process of a wearable health sensor to prevent third party identification of the user (Agrafioti et al., 2011).

Regarding data privacy, it is not clear if the UK's Data Protection Act 1998 governing personal and medical data will apply to all data collected by PHM devices. In particular, it is not clear if data collected by lifestyle monitoring systems which can record "every move, every action, many bodily functions, activities of daily living, whereabouts, [and] comings and goings from the house," will fall under the definition of "personal data" as defined by the Act (Bowes et al., 2011). As a result, the possibility of misuse or undesired access to personal data is raised. This could be a significant ethical issue following widespread implementation of PHM (Bowes et al., 2011). One solution proposed by an American "reality mining" research team facing similar worries of data misuse involves giving patients ownership of most or all of their PHM data (Pentland, 2009).

Personal privacy tended to be seen in the literature as being given up in favor of the perceived benefits of using PHM, which is discussed below. However, in one Swedish example privacy, a sense of being cared for and liberty were improved among elderly users of a PHM device which provided monitoring data to individual caregivers (Essén, 2008).

4.2 Visibility

Visibility or "obtrusiveness" was identified as relevant to the acceptance and long-term use of PHM, although a definition of either term was rarely offered (Robinson et al., 2007, Hensel et al., 2006)). Visibility appears to refer to the degree to which a PHM device is noticeable by the user and other individuals, both at home and in public. In accepting the use of tracking devices for dementia patients, cognitively intact older adults identified ease of use, size and weight as important in accepting a tracking technology (Landau et al., 2010b). As proof of

the importance of these criteria, dementia patients discussing the risks and management of wandering believed monitoring devices may place them at greater risk for theft when wandering outside, demonstrating a potential misunderstanding of GPS tracking devices which are designed to be small and unobtrusive (Robinson et al., 2007). This study suggests that patient education on the range of available devices and their use is central to reducing concerns over visibility.

An example of a PHM device achieving low visibility occurred in a Swedish study of adults who reported, following extended use of PHM, that the system faded into the background and was not perceived during daily use. Instead, it was imagined that their caregiver was monitoring them through the device, meaning the caregiver was perceived as "present" in the home on a constant basis (Essén, 2008).

An issue related to visibility is "covert" surveillance. Monitoring devices, particularly smart home technologies, are designed to be inconspicuous to facilitate blending into the home environment. While this may initially promote acceptance of the technology and personal comfort, elderly users who experience increasing cognitive impairment may eventually forget entirely about the monitoring equipment, leading to a form of "covert" monitoring that raises questions of consent (Bowes et al., 2011).

4.3 Medicalization as applied to PHM

Medicalization was rarely used as a term in the collected literature, although several articles described issues that can be interpreted as medicalization of the home environment.

In the context of PHM, medicalization means the devices have the effect of reminding the user or occupants of a medical condition in a non-medical environment. To this end there exists a risk for developers of PHM technologies to view the home environment as a blank canvas for medical monitoring technologies, or "just a machine" (Gentry, 2009). In this case the home could be turned into a medical environment or "de facto intensive care unit," eliminating the public-private divide between home and "brick and mortar" medical environments (Demiris and Hensel, 2009, Chan et al., 2008, Bowes et al., 2011).

A related issue is that of stigmatization associated with being monitored, which is especially pertinent in community settings for the elderly (Courtney, 2008). Participants reported that using PHM devices could lead to a feeling of frailty based on the need to be monitored, although it was suggested that such a problem could be solved through community wide implementation of identical PHM setups (Courtney, 2008). Attractive as this solution may be, it violates the principle that PHM solutions should be deployed to fit the individualized needs of the user to avoid "monitoring for monitoring's sake"(Bowes et al., 2011).

4.4 Social Isolation

Concern over increased social isolation was present in several articles based on the possibility that visits from medical personnel may be less necessary if daily monitoring is controlled by a PHM device (Stowe and Harding, 2010, Tiwari et al., 2010, Demiris et al., 2004). In particular, if PHM is viewed as "caring" for an elderly user in the sense that medical personnel will be alerted in case of an emergency, human caregivers may feel less responsibility towards the user which could lead to reduced social interaction. This situation may lead to a lack of personal touch between patients and medical personnel which is problematic considering the health benefits of regular social interaction and physical touch (Chan et al., 2008).

While a concern over increased social isolation was common, one article suggested that social networking features built into PHM devices could enhance a user's social contact with other members of a patient group (Magnusson et al., 2005), but this depends on these features being built in, and used.

4.5 Autonomy

Although autonomy was mentioned in several articles as an important ethical consideration, it was rarely elaborated as a concept. Within the literature a common notion of autonomy was the right to make decisions for oneself. In these terms a potential problem exists if PHM is deployed on a community level using an opt-out system for participation because it violates this sense of autonomy, as imagined in a scenario involving a "smart pillbox" that automatically reveals dosing information to physicians for the patient's safety (Kosta et al., 2010) .

A related issue is the potential for alteration of behavior of recipients of PHM based on the perceived expectations of the technology. In the case of smart homes, recipients may go so far as to alter their daily routine based on the presence of monitoring, for example by sleeping at certain times or not leaving the house for fear of being viewed as wandering (Tiwari et al., 2010). This alteration of behavior can be interpreted as the monitoring systems exhibiting a passive control over the recipients. Further, users of lifestyle monitoring which feeds back suggestions for improved behavior, such as reality mining systems, could actively be influenced to change their behavior based on these suggestions (Pentland, 2009).

A problematic reliance on PHM may also be viewed as an issue of autonomy, particularly regarding smart home technologies that may carry out such tasks as turning off taps and stoves (Stowe and Harding, 2010, Tiwari et al., 2010, Demiris and Hensel, 2009). Monitors that alert medical personnel in the case of emergency may take the decision to call for help out of the hands of the user which could lead to decreased autonomy and reduced self-care among users (Bowes et al., 2011).

4.6 Balance of Principles

The themes mentioned above highlight several "principles" seen as relevant in the current literature on the ethics of PHM. In line with the Beauchamp and Childress (2009) approach these principles are not absolute, but rather are commonly balanced in the literature both by authors and research participants. In several studies with elderly individuals monitoring technologies identified by the participants as problematic were welcomed by current (Courtney, 2008) and potential recipients on the basis that the technology fulfills an important need that outweighs its downsides in the eye of the user (Ding et al., 2011, Courtney et al., 2008, Demiris et al., 2008a, Demiris et al., 2008b, Melander-Wikman et al., 2007). In the case of residents of a long-term care facility concerns over personal and data privacy were overridden by a perceived need for the monitoring technology (Courtney, 2008). An "inherent duality" appears to exist in the views of participants relating to surveillance technology. This duality centers around the moral conflict between freedom and safety, again implying a moral tradeoff in implementing PHM technologies involving third party access to data (Niemeijer et al., 2011). This balancing act or application of the technology within an individualized context was identified as the determining factor in assessing the morality of PHM applications, implying the technology is inherently value neutral (Welsh et al., 2003), which contrasts with the morally-loaded terminology used in advertising the technology to potential users (Nordgren, 2011).

The importance of remaining at home over moving to a care facility such as a nursing home may begin to explain the balancing act seen in several articles. In one study data privacy, personal autonomy and freedom were all promoted by PHM which allowed users to live at home (Essén, 2008). The ability of third parties (caregivers) to view personal health data was not viewed as a violation of the user's privacy or capacity to make autonomous decisions, despite the caregiver being likely to give behavior advice based on the data (Essén, 2008). Rather, the move to a nursing home was viewed as violating the individual's data privacy and freedom to escape monitoring because multiple nursing home caregivers would be perceived to have access to their PHM data. In this sense PHM was seen as promoting rather than violating data privacy (c.f. Fairweather and Rogerson, 2001).

Of particular importance in terms of identifying areas in need of further research were two articles examining the family as a morally relevant stakeholder in the implementation of PHM (Gammon et al., 2009, Landau et al., 2010a). Relational aspects of decisions to monitor the health of a family member were identified through the example of parents valuing the health and safety of a child that may favor freedom and autonomy (Gammon et al., 2009), or caregivers valuing safety over the autonomy and freedom of their family member with dementia (Landau et al., 2010a). This balancing of principles within a relationship may be a worthwhile avenue of research regarding PHM's effect on doctor-patient and family-patient relationships.

Other articles examine the balancing of principles by third parties. In one study involving cognitively intact older adults, participants favored implementing tracking technologies for dementia patients on the basis that patient safety was more important than their autonomy or freedom (Landau et al., 2010b). This view was shared by caregivers of people with dementia when addressing patients under their direct care, but the reverse was true for the patients of others, suggesting the primary concern in opinion formation was the "peace of mind" of the caregivers (Landau et al., 2010a).

4.7 Informed Consent and Development

Several articles identified the need for ethical reflection during development and implementation of PHM technologies, but offered little in the way of ethical discussion (Rigaud et al., 2011, Frisardi and Imbimbo, 2011, Kosta et al., 2010, Gentry, 2009, Demiris and Hensel, 2009). In terms of research and development of PHM, it appears impossible to obtain informed consent from recipients of PHM because full understanding of the implications of using PHM cannot be gained without actually using the technology (Demiris and Hensel, 2009, Stowe and Harding, 2010). Piloting methods such as storytelling and prototyping may present a possible solution to this problem.

4.8 Impact on Healthcare Providers

A small number of studies discussed the impact of PHM on medical personnel. One paper examined the problem of engagement and skills development among care workers when a standardized IT system is used to process and categorize medical data (Gerdes, 2008). Although not explicitly discussing PHM, the conclusions reached in this paper suggest that use of PHM systems that involve extensive categorization of data within a standardized template could lead to stunted skill growth among caregivers. Additionally, if PHM devices attempt to provide both care and social interaction, reduced caregiver visits for elderly users could lead to a reduction in recognition of non-monitored symptoms (Gerdes, 2008). In another study examining caregivers and power relationships it was determined that surveillance in a social care setting (both home and community based) can lead to new power

relationships among caregivers and recipients, often changing the activities and interaction during caregiver visits (Vuokko, 2008). Finally, one article examined perceived threats to job security among the medical workforce based on PHM taking care of routine daily tasks, particularly among care workers (Tiwari et al., 2010).

5. Discussion

A limitation of the review was the broad definition of Personal Health Monitoring as a restriction on the database search method. Without a common definition in the literature the search method included as many synonymous terms as possible, meaning an exhaustive list of articles addressing all potential ethical issues (e.g. privacy, confidentiality, freedom) was prohibitively large. The database element of the search therefore had to be limited to articles explicitly addressing ethical issues through use of the "AND ethic*" search modifier. Some articles addressing potential ethical issues that did not appear through the search with "AND ethic*" have been identified through the other methods mentioned. Despite this limitation, the current review identifies articles explicitly addressing ethical issues of PHM and areas in need of further research, which will hopefully contribute to common terminology and responsible implementation of Personal Health Monitoring.

The majority of the reviewed literature addresses ethical issues encountered by elderly users of PHM, especially people with dementia. For studies gathering data directly from elderly users few objections to using PHM were found, although a tradeoff between privacy, autonomy and other values to gain the benefits of PHM was frequently mentioned by potential and current users. This balancing of principles suggests that developers of PHM need to be aware of the "human goods" affected by their devices, and to take all appropriate measures to reduce these effects. Smart home and assistive technologies for the elderly have received the majority of attention in this review based on database results, and prior literature reviews focusing on these technologies in residential and community care settings have turned up a wealth of data (Niemeijer et al., 2010, Zwijsen et al., 2011). Although many articles mention these issues, few discuss them in-depth and ethical consensus is far from reached (Niemeijer et al., 2010, Niemeijer et al., 2011, Zwijsen et al., 2011).

Perhaps even more pressing in terms of areas requiring discussion are the implications of PHM use among younger or non-elderly patients, families and medical personnel: of the 39 articles reviewed, three discuss non-elderly patients, three discuss families, and four examine medical personnel, few of which feature in-depth discussions of ethics. Each of these groups is likely to interact with PHM directly or indirectly (i.e. through a patient), so further research is needed to determine what role these stakeholders play in ethical issues arising from its use.

Regarding non-elderly patients, further research is needed because many emerging PHM systems target healthy individuals (lifestyle and behavior monitoring) or disorders not exclusively affecting the elderly such as diabetes or hypertension (MilenkoviÄ‡ et al., 2006, Agrafioti et al., 2011, Stergiou and Bliziotis, 2011, Lymberis, 2005, Stowe and Harding, 2010). PHM systems developed for the elderly may also be useful for younger users, such as smart pillboxes or sleep pattern monitors. The assumption cannot be made that younger participants are less likely to experience ethical issues by using PHM, especially feelings of stigma and medicalization for younger individuals lacking experience with having medical devices in the home.

Families frequently play a role in caring for the ill, and may therefore be involved with any medical technologies used by the patient as part of their care. Further research is needed to unpack the effect of PHM use within the context of a family and similar support

communities. Possible issues include medicalization of the home environment and interfamilial relationships, reduced contact between family caregivers and the sick, and increased freedom for family caregivers. A "balancing of principles" may lead families to accept PHM devices in their home that inadvertently monitor them and guests, thereby affecting a tradeoff between personal privacy and freedom of the family and the benefits of PHM.

Inadvertent or covert monitoring may affect all people coming into contact with a PHM user, not just their family or caregivers. Any person entering a PHM environment may be automatically monitored without their consent. This issue may be avoided through filters on monitoring devices which are capable of differentiating between strangers and intended monitoring targets through physiological signs, physical traits, etc., meaning strangers could automatically be ignored. Even if a potential solution exists, it is imperative for developers and users of PHM to be diligent about avoiding inadvertent monitoring of non-consenting individuals. This problem could be magnified through the community-wide implementation suggested as a solution to avoid the stigma and social isolation of using PHM.

With regard to social isolation, one proposed solution is to build social networking capabilities into PHM devices to allow patients with similar issues to socialize remotely. While this may help reduce feelings of social isolation, it can also lead to medicalization with an individual identifying themselves as a "patient" or member of a patient group. Further, the user is giving up some of their privacy by sharing personal data or anecdotes with others, something which may not have been necessary prior to using PHM because they were not experiencing social isolation or reduced caregiver visits. In this sense PHM is passively guiding the actions of the user, raising questions of autonomy. It would appear privacy, autonomy, medicalization and social isolation are intricately linked in some uses of PHM in a problematic way.

Multiple papers involved interviews with cognitively intact adults regarding implementation of tracking devices for individuals with mentally degenerative disorders. These studies showed a preference for patient safety over autonomy and freedom. It must be noted that in light of repeated calls for the increased inclusion of people with dementia in empirical research, any attempts to justify implementing tracking technologies in dementia care based on the opinions of healthy older adults or caregivers is inherently problematic and perhaps in violation of the autonomy of people with dementia (Hellström et al., 2007, Cubit, 2010, Mozley et al., 1999, Nygard, 2006). Individuals in early stages of Alzheimer's and other degenerative conditions often fear loss of autonomy more than death, so it seems counterintuitive to use autonomy-inhibiting devices to ensure their patient safety (Cohen-Almagor, 1996).

Access to data collected by PHM may be given to medical personnel, yet little has been said how this may affect the relationship with patients or paying medical organizations. Regarding physicians, decontextualization of patient symptoms may occur in clinical encounters. Automation of routine tasks may also be possible freeing up medical personnel for other tasks, such as patient interaction. Continuing in the tradition of analysis of doctor-patient interactions, research is needed regarding the effect of PHM on this relationship.

6. Conclusion

In general, ethical issues relating to development and implementation of PHM technologies were given inadequate attention in the reviewed literature. Although several ethical themes were identified, few were given more than cursory treatment in the literature because the

explicit goal of many papers was not ethical analysis. Further research into these areas is both appropriate and necessary (preferably) prior to the widespread implementation of these technologies to ensure they are used in an equitable and beneficial manner. This work contributes to this need for scholarship by suggesting further ethical issues that may arise in the development, implementation and widespread use of PHM.

Additionally, examples of PHM technologies are reviewed and common features are identified in an attempt to contribute to the development of a common definition of PHM. Although this is not the primary purpose of the paper, it is recognized that a common definition would be beneficial to the field.

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