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Intelligent Monitoring of Chronic Illness for the Ageing Rural Population: Opportunities and Cautions

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Abstract. Globally there are an increasing number of older people who require care for a range of health concerns, the most significant of which for our health systems are those with chronic illnesses, or multiple chronic or complex conditions. Even in countries with the best rated healthcare systems, this change in demographics and health care needs poses a significant challenge. Many older people, particularly those in non-urban locations, currently experience a range of vulnerabilities which can impact on their health status. Technological solutions are required to support health systems to be economically, socially and environmentally sustainable. In this context, socially accountable care needs to empower older people to make choices which align with their values, while also taking into account professional and familial care-givers, equitable care provision in what are often large and disjointed systems, and resource constraints. Intelligent technologies offer the potential to reduce some of the burden on health care systems, while simultaneously providing person-centered care, enabling improvements to older people's wellbeing. Through the findings of a relatively simple technology-based health intervention we explore how these benefits will only be realized if such technologies are designed and implemented with exceptional social accountability in place.

Keywords: Ageing, Assistive technology, Vulnerabilities, Social accountability.

1 Introduction

Although the intelligent augmentation of human care has been considered from various perspectives, this article's contribution is focused on how the lens of 'vulnerability' has implications for both the intelligent technological and human care that have yet to be adequately considered in integrated solutions. In response to the rapidly ageing population, the World Health Organization released the first World report on ageing and health in 2015. This report emphasized the need to create environments in which the capacities of older people are maintained. There is a growing demand on primary health care in particular. In Australia, the number of standard GP consultations per person per

year has increased for the over-65 population, while there has been a decrease in these visits for all other age groups [1]. It has also been acknowledged that older people, even those who engage in healthy behaviours earlier in their life, are more likely to experience one or more chronic diseases as they age. Geographic location impacts on the accessibility of primary health care, with waiting times to see a GP increasing as communities are increasingly distant from urban centres, or where there is more socio-demographic disadvantage [2]. This challenge of providing adequate health care as the population ages is a world-wide phenomenon [3]. Moreover, there is an expectation in many parts of the world that health care professionals and health care systems will be accountable to the communities in which they operate [4]. Technology solutions have been proposed in various forms, such as intelligent homes, telehealth and care robots. The main aim of introducing these technologies is to decrease the need for people to present to the GP and local hospitals through prevention and management. To be viable as a solution, all such technology must be capable of providing good care, as defined by the values of the recipients of care, and their support networks. Such care values for the elderly have been shown to include autonomy, security, respect, trust, privacy, social wellbeing, and more [5-9]. The values literature defines the foregoing as 'towards' values, but it also describes 'away from' values [10-12], and one example is that elderly people want to engage in positive ageing, and get away from the vulnerabilities which are frequently associated with ageing and the challenges of managing chronic illness in regional and rural areas. To achieve good care is ideally a mixture of human and intelligent technologies, which together reduce as far as possible the vulnerability of elderly people living in communities. Due to the important role of the family, particularly in community care, interventions are needed that support caregivers who may not be local. Individualised, personal care is possible with emerging technologies. However, being individually-based, these applications of smart technologies have limited integration in the whole life of an older person. For instance, the Australian Productivity Commission [13] identified a range of care needs for older people when accessing aged care and support. These include gateway needs, such as information, advice, referrals, assessment and care co-ordination and management; a range of health services; housing and residential care options; disability services and community services such as transport, social and wellness activities and carer support services. Moreover, studies have identified that the aged care system is complex, and difficult to navigate to obtain appropriate services [8, 14-16]. These care needs are going to be seen globally as policies increasingly favour ageing in-situ for as long as feasible. Thus, it is critical that whole-of-life, community-based options and technology options are developed to meet the care needs of the ageing population. Such technology options offer the potential for health and aged care professionals and systems to continue or increase the social accountability of service provision, assuming that the technologies themselves are designed and implemented with social accountability in mind. Designing socially accountable technology for the purpose of care is complex, requiring that design incorporate care needs and values of individuals and their carers, as well as broader societal needs and expectations [4]. In this paper, we explore some of these complexities through the experience of a telehealth pilot project. We look at this project through a

vulnerabilities framework, as a means for addressing multiple ‘social accountability’ demands.

With the emergence of technologies such as the Internet of Things (IoT), Machine Learning (ML), Artificial Intelligence (AI) and integration of data analytics platforms, intelligent aged care solutions can be envisioned to not only assist in providing quality care but to also help reduce the overall cost associated with care facilities [17]. These technological advancements can open the doors for many enhancements within the aged care domain such as clinical decision support systems to improve quality of care and operational intelligence. However a key obstacle in utilising these technological solutions in the health care industry is to overcome the challenges associated with the privacy and integrity of data [18]. A secure framework is required to protect the overall design of such an intelligent health care infrastructure in order to protect against unauthorized access to sensitive personal information.

Intelligent augmentation of human care can address many existing challenges. For example, despite persuasive evidence of our need for connection, and the clear demonstration of the influence of connection on our physiology, there is today, according to Cacioppo [19] ‘a worldwide epidemic of disconnection’. Loneliness and social isolation is far more than a social misfortune. It is a significant problem of health and happiness which is distinct from, but contributes to, the likelihood of depression, functional decline, early entry to hospitalisation and care, and higher levels of dependency. Over time if it is not addressed, loneliness and social isolation can contribute to generalized morbidity and mortality [20]. According to Dury [21] ‘older people are more vulnerable to loneliness and social isolation, and are more at risk of a range of health and social issues which can be directly linked to loneliness’. Various schemes have been put in place to try to reduce the effects of loneliness and social isolation, and there is some existing evidence to support their expansion; however, Dury [21] notes that ‘more research would provide clarity regarding their effectiveness’. Some intelligent technologies are already making significant impact in this area, including telepresence, robotic care, and others [5, 15, 22]. Although this paper reports on a simple technology-based health intervention, some of the learnings are critical as we seek to design and implement more complex or unfamiliar technologies.

The prevalence and impact of social isolation and loneliness in regional and rural areas may be more dramatic than in metropolitan areas [14, 23-25]. Strategies and structures that enable the delivery of earlier intervention in the progression of social isolation, social disconnection, depression, and morbidity/mortality is likely to improve health outcomes and quality of life for aged care clients, and provide greater social and community connectedness.

This article begins with the theoretical framework, which is about the vulnerability experienced by some of the ageing population, before then describing a study involving rural and regional seniors in Australia.

2 Theoretical Framework: Vulnerability

This work is situated within a ‘vulnerabilities’ approach. From an ethical perspective, this approach is located in the area of social accountability. That is, there is a moral obligation on society to care for its elderly population. As such, societal structures need to empower, rather than limit older people, such that their age-related illnesses are cared for, which the person is assisted to enjoy as full a life as possible. The theoretical framework is based on [26] framework of vulnerability, in which vulnerability is defined in terms of exposure to risk, relative capacity or resources to counter risk and meet one’s needs, undermining agency and/or exacerbating powerlessness. This framework proposes that there are three main sources of vulnerability: inherent, situational and pathogenic. Inherent vulnerability captures a range of factors which are attributes of all humans, as finite, fallible beings, subject to fragility [26]. Whereas the literature focus is on recovery from temporary vulnerabilities, some research shows that ageing itself is a cause of inherent vulnerabilities and therefore older people will increase in vulnerability as they age [27]. As can be seen in Figure 1, age and health status are both inherent factors; particularly when an individual’s health status includes complex and chronic illness. Situational vulnerability refers to factors that are external to the individual, embedded in the broader social context in which the person or people group is situated. In the Australian context, living in regional or remote locations compounds age- and health-related vulnerabilities because of restricted access to care compared to urban areas. The final category, pathogenic vulnerability, is related to social and interpersonal relationships. This type of vulnerability stems from dysfunctional social interactions that create or maintain power imbalances and marginalise an individual or people group. Social factors are of interest in the context of older people experiencing chronic illness, insofar as those factors make ageing and chronic illness more difficult to manage, or disempower people to make informed choices about their care.

Additionally, vulnerability may also be “assumed” or “imposed” [27]. That is, vulnerability may be imposed by the deliberate actions or neglect of others (for example, through government policy or deliberately inflicted interpersonal harm), whereas “assumed” vulnerability acknowledges that some vulnerabilities are intrinsic to situations into which people willingly enter, for instance, trust-based relationships. In both cases, vulnerabilities are avoidable [27].

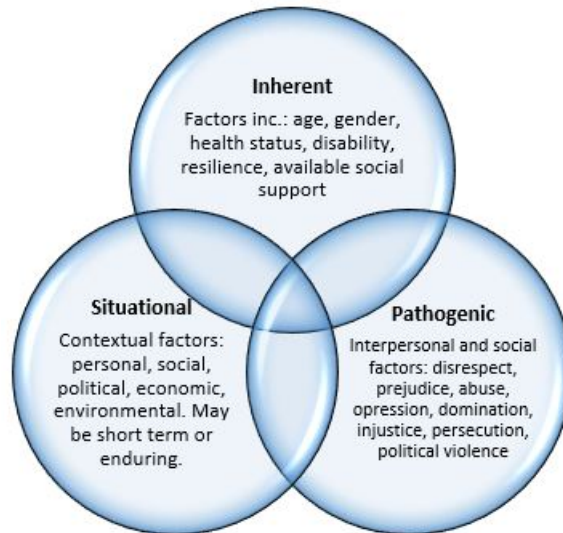


Fig. 1. Vulnerability Framework, based on [26]

Thus, under this framework, older people with chronic health concerns may experience multiple sources of vulnerability. This framework also allows for the variety of experiences of ageing and health status which exist. Not all older people are vulnerable, and those who are will experience vulnerability differently, and to different degrees. The framework, depicted in Figure 1, shows how different factors overlap. Therefore, appropriate approaches to mitigating vulnerability and increasing agency requires tailored, value-sensitive strategies to address overlapping sources of vulnerability. These include inherent factors (particularly where social supports are lacking and/or health status is in decline), and situational factors including personal, social, economic and other circumstances. Solutions to the growing health care needs of the ageing population need to be designed and implemented with care, so as to take into account the values and needs of older people, and enhancing their capacities [3] – that is, taking care not to contribute to vulnerability. Using this framework, we suggest, is a helpful approach to designing socially accountable technology to support the delivery of socially accountable health care to older people.

3 Background to the Telehealth Project

Although the overall results of the telehealth project were previously reported [5], here we revisit specific findings to explore the implications for social accountability. In particular, this project highlighted that ‘social accountability’ has multiple dimensions when technology is being applied in the context of caring for vulnerable, older people with chronic illness, whose data is being captured and monitored. In our data driven

world there is an increasing emphasis on intelligent monitoring, in which there is promise of more fulfilling lives, whilst at the same time personal liberties, such as socialising face to face, privacy and other considerations are being eroded.

It is well established that if older people maintain strong social and community connections they also maintain higher levels of wellness and functionality [30, 31]. Older people face barriers in retaining their social and community networks because:

- Relatively small changes in health and function (e.g. deterioration in their vision or hearing, deterioration in continence or balance) can lead to discontinuing social activities, and
- Physical, attitudinal and social barriers in the community challenge the capacity and motivation of older people to maintain community activities and/or taking up new opportunities. [32]

The aim of the telehealth project was to (1) evaluate the use of Telehealth hardware and software in the homes of older people with chronic illnesses living in a regional community (Orange, NSW, Australia) and to (2) review the social and economic impact of the use of this equipment. In order to achieve this interviews were conducted prior to the installation of the equipment and at the completion of the trial. The first aim could only be met through an analysis of the final interview data, whereas contrasting and comparing the data for participants from pre and post interviews led to the achievement of the second aim.

Tunstall Telehealth monitoring equipment was installed for at least two months in the homes of clients who consented to participate in the study. The monitoring equipment assessed a core set of measurements (such as blood pressure, heart rate, and weight) and obtained custom measurements depending on each client's health condition, e.g., heart failure, chronic obstructive pulmonary disorder, hypertension and diabetes. The clinical/triage team from LiveBetter Services Ltd (LiveBetter) ascertained the custom measurements for each client. Clients who consented to installation of the telehealth monitoring equipment were further given the choice to participate in the research.

3.1 Research design

The research questions were:

- What is the impact of the Tunstall telehealth systems on user perception of well-being and social functioning?
- What is the economic impact of the use of these systems?

These questions were answered in a mixed methods approach, involving pre and post interviews, observations, and through the use of a national standard instrument, the Depression Anxiety Stress Scales (DASS), though the DASS results are not reported here. Approval to conduct the study was granted by the University's Human Research Ethics Committee.

The client organisation, LiveBetter, identified and recruited 18 participants for the pre-phase and 11 for the post-phase. Pre and post data reported here only relates to 11 of the 18 participants in common to both phases. Seven pre-participants did not participate in the post-evaluation for various reasons. At the time of the study the majority lived in Orange and the surrounding region and the furthest participant lived 120 km outside Orange.

The transcribed interviews were analysed using thematic analysis with QSR NVivo, a software package for managing data.

4 Findings

The full thematic findings have been previously reported [5]. Here the focus is on social accountability and thus the economic and data driven aspects affecting vulnerable older people are focused on. Three themes emerged, ‘service delivery’, ‘social impact’, and ‘technology’. Within the first was a category of ‘economic impact’ and within the last were categories that included ‘equipment’, ‘hardware’, and ‘interface’. Exemplary quotations related to these are presented next, and then discussed in the following section.

4.1 Economic impact

People on retirement pensions can find even small costs, such as the cost of batteries, difficult to manage.

The oximeter apparently takes a lot of battery power to connect with all of the other things that I use. So it always used to be the first one that I did in the morning, which I was very glad about that because having heart problems your fingers aren't hardly warm enough in the mornings ... then they rang me the other week and said “It was using too much batteries that way” so she said “Don't worry. We have reversed the order so it's actually the last test.” And I said “I just needed that” I thought to myself. So – and they were trying to save on the batteries so they're obviously trying to run it economically.

Pensioners often go without what most people consider basic necessities. This is important to note because it has significant implications on the affordability of telehealth systems.

Oh the girls can take me shopping if I want to go shopping. So they had to take me ... I don't feel safe enough to walk up the – get out of the car and walk up the street myself ... you don't get enough money to go shopping on the pension, by the time I pay everything out, and it's just enough – more or less just to last you a fortnight ... this month's been a really bad month for me because I had to pay \$408 out for my car green slip. And then I had a lot of other expenses on top like

the rent, the money from phone, the money for my insurance on the furniture ... by the time I got the pension that week I had nothing left, probably had about one week – one fortnight there in this month I had about 5c to last until Thursday.

In some instances the cost of help is prohibitive, even though it would improve the quality of life.

I don't have much in the way of friends or social activities, or anything like that. I feel too bloody useless like I can't do anything because I can't walk properly, I can't use my hands the way I used to because they shake all the time. I want to try and do some walking up and down in the pool, but that's a bit expensive.

4.2 Equipment

There are physical barriers to using some telehealth systems.

I'm only doing ... the temperature and sugar. I mean, the weight, I can't do it because I have a wheelie and I can't see the scales.

The ability to self-monitor gives reassurance to some people.

I would never know my blood pressure was up without it, because you can't go up the doctor every day. I hadn't been up the street for about probably three years. So I find that very handy – very good.

4.3 Hardware

In addition to the battery example, above, another hardware limitation was identified by the following participant concerned how best to self-monitor when the equipment was not reliable.

The two things that I did find, is there are some IT issues with it. We had to reboot it, the machine, once. And secondly, a week ago, or something, I tried to use the screen to make a phone call to the people and it said this page cannot be sourced, or some such thing, and then it just froze. Had to turn the whole thing off. And then for a while it stopped talking to the scales, and all this sort of thing.

4.4 Interface

Human computer interaction, as seen in the hardware example, above, was also challenging in regards to interpreting interface messages.

It said “Please take you ECG reading now” you take it and you press the button, and then you go onto the next one, and you finish the four. And then when that’s all finished you just press the finish button, and then you just watch for the – I always watch for the signal little round piece – red piece that goes round and round to make sure it’s gone to Brisbane.

There’s the blood pressure, then weight, and then ask me about salt, and how I feel today. But see it’s only got better, worse, or something on the thing. Well it doesn’t have in-between, so every time I press it I’ve got to press – same, same is the word. I just put the same because some days I feel in between it and I can’t put worse down, but I could say not as well or something like that.

Then the questions come up ... asking about have you diarrhoea or vomiting ... probably diarrhoea about three times ... I’m not sure of the relevance.

4.5 Further findings

In addition to the above quotations from the categories most relevant to this article, the following ones also illustrate the positive nature of the outcomes of this monitoring, and thus what the potential is for intelligent monitoring in the future to augment human care, as will be seen in the discussion section which follows.

In the initial interviews, several participants reported a relatively low level of awareness about self-management or interpretation of basic measures such as blood pressure, pulse, and blood-oxygen. When feeling unwell participants would consult a health professional. Understanding of medication, and its impact, was at the lower end of health literacy. This changed with the follow-up interviews. Several participants had been recording in notepads, or sheets of paper, their vital signs and had become comfortable in linking the recording of changes to how they felt. They were not using any recordings of their measurements but a technology, pen and paper, which they were comfortable with. Despite not starting with a clear level of comfort with the proposed technology at the initial interview, most were converts and wished to keep the equipment in the follow-up interview. Exceptions were those participants with diabetes who were used to having regular self-testing with their own instruments, and who were more comfortable in self-managing at the commencement of the study and reported little change as a consequence of the use of the tele-health equipment. Examples of self-assisted monitoring:

It good service because daily, ten o’clock in the morning, eleven o’clock - between ten and eleven I got a chance to check my data because sometime it is different.

When I first had the equipment I thought, ... well it won't be much use to me. But in the last few months I've found it's been excellent, because I've been able to monitor a bit more and (nurse clinician) said "If you can take your blood pressure twice a day." But I've been taking it three times now, if I didn't have that equipment I wouldn't be able to do that, and they wouldn't be able to compare whether my blood pressure was dropping, or whether it was too high ...

Telehealth monitoring also provided social connectivity, with 46% of the participants living alone. The nurse clinician called all the participants at least once a fortnight, including participants with stable vital signs and well-managed conditions. Participants expressed their appreciation of these conversations with the nurse clinician. These phone calls provided social connection and reassurance of remote monitoring for older participants.

Through the observations journaled during the project the following outcomes were also noted. The participants expressed to the nurse clinician that they valued their partnership with the nurse, who helped set health goals and provided advice for health-related decisions. Most importantly, this relationship provided access to a trusted nurse clinician. The participants would initiate conversations with the nurse clinician to clarify health information they had received from medical specialists and seek help to solve health-related issues. One client with heart failure stated that "the telehealth nurse has become one of the pillars in my health along with my General Practitioner (GP) and my Cardiac Nurse".

Telehealth played an important role in chronic disease management by facilitating interdisciplinary care. The nurse clinician shared information with and collaborated with GP's, Nurse Practitioners, Registered Nurses, Pharmacists and home-care workers. Data obtained from Telehealth monitoring influenced medical management decisions related to medications and identified the need for further investigations. In one case, data from the ECG Telehealth peripheral contributed to investigations which led to a more invasive procedure, significantly improving the participant's quality of life. Finally, preventable admissions/reduced emergent medical and health consultations were also reported by participants. Several participants reported a stabilization of their vital signs, such as blood pressure, with improved compliance with medications and the ability to interpret "good" from "poor" health days. When blood pressure and/or weight was up adjustments to activity ensued, with increased activity and socialisation on good health days, and adjusted activity levels on poor health days. Participants generally reported better awareness about how they felt based on the measurements, and that meant overall they felt that they were doing more. Participants reported taking ad hoc measurements, outside of designated reporting times, just to "check" how they were measuring up against their perceptions. This suggests an improved health literacy and an ability to self-monitor and better manage their daily living. Participants were more likely to discuss trends and/or examples of good/poor days and what they felt were different about them. Medications had been reviewed and adjusted and several participants indicated that ad hoc medical and health consultations were not as frequent. They generally expressed a greater degree of comfort with their ongoing management of their

condition than the health professional directed management previously. To what extent preventable admissions have been avoided could not be ascertained, and nor could frequency of contact with health professionals be verified without access to personal health records, but participants were more confident in reduced reliance on direct visits to monitor their health status than previously.

5 Discussion

In this discussion section we are applying the model discussed in Section 2, and findings from the telehealth project to how intelligent assistive technologies might augment human care to support the healthcare needs of the ageing population. In particular, we highlight that such technologies have the potential to address or reduce vulnerabilities or add to or compound vulnerabilities. That is, designing and implementing such technologies are a matter of social accountability.

Utilising technology to support positive ageing is not in itself a new concept. Intelligent architectures have been investigated for the potential solutions they offer for older people experiencing disabilities and chronic illnesses [7, 8, 34, 35]; and being geographically isolated from health services [15]. Moreover, numerous studies have suggested that such technologies contribute to the wellbeing and self-concept of older people [36]. These findings were consistent with what was found in the telehealth project.

5.1 Inherent Vulnerabilities

Factors identified in the framework in Section 2 as examples of inherent vulnerabilities include declining health status, disabilities and available social support. Assistive technology, such as that used in this telehealth study assumes a one-size-fits-all approach. The human client has to adapt themselves to the technology. As seen, this has some success. Better would be intelligent technologies that are self-adaptive, and can be tailored to each individual client. To successfully integrate technical solutions to address inherent vulnerabilities, some steps that need to be taken with careful consideration are:

- Increase familiarity and skills with technology through facilitating regular use, either in-home or at a senior-friendly tech hub, including familiarizing older people with security options such as password managers or thumb print access.
- Measure the impact and perceptions of technologies among older users, with particular focus on their experience of wellbeing and enhancing capacities.
- Design educational programs for older people and their care-givers to empower consent and choice.

5.2 Situational Vulnerabilities

Several challenges emerged from the project. The chief of these were the cost of the service and the security of data. The benefits of the telehealth service are undermined

if the cost is prohibitive. That is, if people are unable to access the service due to economic factors, or will forgo other things (such as regular meals or adequate heating) in order to afford the service, it will increase vulnerabilities for some sections of the community.

Similarly, if the personal data captured in real time, across multiple networks is not secure, this will increase the vulnerability of older people using the service. This security may be an issue in the design of the software or hardware, but may also result from users being unfamiliar with securing devices in their own home. These challenges can be addressed from a social accountability perspective. Public resourcing could be used to ensure equitable access to such services, particularly if it is reducing the economic and capacity constraints on the health system. There are also reasonably simple solutions to in-home security, such as biometric access options.

5.3 Pathogenic Vulnerabilities

As the use of assistive technologies is on increase, their implications on the lives of our most vulnerable people is debatable, particularly in addressing dysfunctional social structures. Even if we set aside the issues of human rights and their legal obligations, the social accountability perspective is worth consideration. The concept of social care is related to trust, respect, dignity, privacy and security, and assistive technologies pose huge risks in each of these aspects. For instance, use of artificial intelligence is related to losing of trust. When rural elderly people interact with a machine that has human characteristics and treats that machine as if it were a care giver, do their expectations change? And, is there a level of deception involved that makes the use of such machines unethical [35]. Similarly, there is concern, for instance, that using robots for elder care could end in increased social isolation, and could involve deception and loss of dignity [36]. How far does the concept of smart home invade ones privacy [36] and how secure are our elderly? More needs to be learnt about how rural elderly people feel about their confidential information in terms of cybersecurity threats in this highly connected world of cloud, IoTs, and mobile devices. All such implications are debatable in different perspectives, viewpoints and ever-changing technological landscapes.

6 Conclusion

There are lessons to be drawn from this project for how we can design and implement intelligent technologies in a data-driven society which is both human-centric and socially accountable. Human care will always be needed, but given the increasing percentage of older people, compared to the overall population, the cost of such care requires intelligent technological augmentation. It is critical that such technologies be designed to address multi-faceted social accountabilities, to older people and the community, so that health and aged care service provision can, likewise, meet the numerous and complex needs and expectations of older people, their carers, and the communities in which they live.

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