I am a Person

How value sensitive design can better support caring relationships for people with dementia, interpreted through the lens of personhood

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Abstract: This paper presents a conception of personhood as both physical and social, and both as radically contingent upon their respective physical and social environments. In the context of age-related cognitive decline, particularly dementia, it supports literature suggesting social personhood is occluded rather than deteriorating with brain function. Value sensitive design (VSD) applied to assistive technologies for people with age-related cognitive decline, has focused upon physical support. The paper concludes that issues of power must be grasped by those in VSD practice in order to reorient VSD in assistive technologies to also support social personhood.

Introduction

The contribution of this article is a reconsideration of Personhood. It is occluded, not erased, in age-related cognitive decline, and therefore value sensitive design (VSD) for

assistive technologies needs to focus especially upon enhancing and revealing person-hood. Thus the research question addressed is 'How can Value Sensitive Design improve assistive technologies to value personhood better than assistive technologies built without VSD?'

Conceptual lens: Physical personhood

The philosophical backdrop to the definition of personhood the authors have discussed elsewhere (Krepset al 2016; Kreps 2018) and we would kindly refer the reader to this discussion rather than repeat it here, beyond a simple assertion of the reality of subjective consciousness. In this paper we wish to stress our contention that human individuals are *both* radically contingent, *and* unique. This seemingly paradoxical state occurs on both the physical, biological and the non-physical, or social, levels of human existence.

The physical part of our personhood, our biological bodies – including our brains – exist within restless ecologies of sustenance, growth, maintenance, programmed cell death, renewal, and waste. Our individual cells are continually growing, maturing, dying off: much of us is completely replaced many times during the course of our lives. (Cooper and Hausman 2007:689-690). Our physicalityis radically contingent upon our continued ingestion of the outer world, its processing into the self-renewal of the cells of our body, and the expulsion of waste back out into the world around us. "Humans possess a total of approximately 10^{14} cells" of more than two hundred types (Cooper and Hausman 2007:689). Red blood cells live for about four months. Colon cells die off after about four days. Brain cells, the inner lens cells of the eye, and the muscle cells of the heart, last for most of our lives. The rest is far more transient, subject to continual self-renewal. All these molecules and cells require elements of the air, sunlight, food and drink we ingest, daily, both for growth and for their various functions, including those functions govern-ing the processing and discard of waste. The essential truism is that our physicality is largely fluid – a collection of temporarily captured solids (in a form that is about 60% water) in a common pattern that defines us as specimens of genus *homo sapiens*.

Yet, of course, our (constantly self-replicating) fingerprints, the patterns of our irises, and a host of other molecular and genetic markers are unique to each of us: for all the radical contingency described above our own special patterning of the flow of matter through us is nonetheless unique. It is our own, unique, 'dissipative structure'. Such dissipative structures occur throughout the living world. Evolutionary biologist Brian Goodwin's simple image of the dissipative structure is perhaps useful, here, as a reminder: picture a tap running into a bath; the water forms a spiral as it runs down the open plughole. The spiral is a dissipative structure. It could be oil or wine pouring down the plughole; the dissipative structure would be the same (with perhaps minor differences in speed and angle). The structure is not dependent upon its contents and exists only as they pass through it (Goodwin 1994:9-10). Such dissipative structures are the very stuff of life,

visible in both the biology and behavior of all living systems. So, the human individual is physically – biologically - a dissipative structure, with only a very few parts lasting its (one) entire lifetime.

Conceptual lens: Social personhood

Our (non-physical) social personhood, similarly, is also radically contingent: our attitudes, our languages, our values, knowledge, skills are all absorbed, not just in childhood, but throughout our lives, and passed on, from and to those around us, through the phenomenon of human communication and socialisation: we are radically social beings. Post-structural thinkers since the 1960s – most especially Michel Foucault – have given us an extraordinarily detailed picture of the myriad ways in which the contents of this social personhood are determined by the social milieu in which we find ourselves (Foucault 1977:135-170). Essentially, the social personhood is defined through our relationships, and specifically through the power relations between us. But, of course, each of us is also unique - our own particular kaleidoscope of the social, our own special fusion of all the influences upon us (and our influences upon others) at any particular time in our lives. One might say that our social personhood, too, is a dissipative structure, composed of the many influences we absorb and extend, growing and changing as we discard aspects of our younger selves and develop more mature characteristics.

Now, the relationship between these dissipative structures - the physical body and brain, and the non-physical, social personhood - has been focus of debate amongst philosophers and scientists for centuries, but some contemporary philosophers and neuroscientists are approaching common ground from their respective corners, to acknowledge that our psychical life, while bound to its motor accompaniment, is not governed by it. Or, as neuroscientist Benjamin Libet puts it, the "determinist materialist view" that would reduce us to 'a pack of neurons' "is a belief system; it is not a scientific theory that has been verified by direct tests". On the contrary, "the nonphysical nature of subjective awareness, including the feelings of spirituality, creativity, conscious will, and imagination, is not describable or explainable directly by the physical evidence alone" (Libet 2009:5).

But, of course, although not determined by the motor accompaniment of body and brain, our mental and emotional lives are nonetheless bound to them. The biological process ofself-renewal is not fixed, or even the same from individual to individual, and its efficiency changes with age. The processes of apoptosis by which cells undergo programmed cell death begin to accelerate, as we grow older, internally protecting against tumour growth. But at the same time many cells also become senescent – "the state where cells have irreversibly lost their proliferation ability" and become resistant to apoptosis (Lu et al 2012). Molecular damage in cells begins to proliferate, too; many cells try to go on undertaking their function longer than they were meant to, unable to self-renew; prob-

lems mount up. "The number of senescent cells increases in tissues with aging" (Lu et al 2012).

Age-related cognitive decline occludes social personhood

Fascinatingly, underlining the description made above of the relationship between our physical and non-physical personhood, age-related cognitive decline – the processes of aging taking place in the brain - has been shown, in the literature of recent years, not to erase, but to occlude our social personhood (Kitwood 1997:54-69). Essentially, as the physical motor accompaniment to our mental and emotional lives begins to deteriorate, our social personhood, that separate non-physical reality made up of our relationships, does not itself deteriorate, as if it were somehow contained or made up of the physical cells whose life-processes are coming to an end: instead it becomes harder to reach, shining in moments of lucidity *through the relationships* those with cognitive decline maintain with their relatives and carers. The common picture of dementia from decades gone by, that as the mental processes gradually collapse an individual's personhood also vanishes, therefore, is a misconception, and indeed it has been challenged in the medical literature since at least the 1990s (Jenkins and Price 1996; Tappen et al 1999;Kontos 2005; Fazio & Mitchell 2009; Palmer 2013).

Assistive technologies, then, those smart devices of the internet age appearing in every nook and cranny of the social world, and already marching boldly into the care of elderly people, can be designed in one of two ways: to support the physical functioning of bodies whose self-renewal mechanisms are almost exhausted; or to support the continuing relationships and social personhood of the individual whose motor accompaniment is reaching its natural end. The former approach focuses too exclusively upon the physical and belongs to the misconception of dementia of past decades. The latter approach acknowledges fully the persistence of social personhood in those with cognitive decline and seeks to support their relatives, carers, and all the relationships that maintain personhood in its last years, months and days.

Value Sensitive Design

VSD employs an iterative, tripartite methodology that integrates conceptual, empirical, and technical investigations. It takes an interactional stance toward technology and human values, in which values are sought from both direct and indirect stakeholders. It distinguishes these from designer values and seeks to explicitly support these human values by the technology, in an integrative manner which involves a co-evolution of technology and social structure (Friedman et al 2015; Friedman et al 2016; Friedman et al 2017; Miller et al 2007).

It is focused on moral and social values discovery and designing technology to ensure those values are met. Therefore,it is particularly relevant to assistive technology for social personhood. Yet this does not appear to be a consideration at present in the VSD literature. As a technology development approach focused upon human values, it should, when applied to assistive technologies for people with dementia and those with age-related cognitive decline more generally, focus upon supporting relationships, and upon respecting the personhood of those at the end of their physical lives.

There have been three previous reviews of VSD, but none of those examined issues of cognitive decline with ageing. One examined applications, adaptations and critiques of VSD (Davis and Nathan 2015); both the authors of this examination received their doctorates at the VSD laboratory in Seattle, under the supervision of Prof Friedman, the founder of VSD. Another reviewed methods and theoretical aspects of VSD (van der Hoven et al 2015); that author did an internship at the VSD laboratory in Seattle, under the supervision of Prof Friedman. The third was a review of information systems, science and technology studies, media studies and computer ethics, involving VSD (Snyder et al 2016).

More recently there was a comprehensive survey of VSD, for which the lead author was its founder (Friedman, et. al. 2017). This tome reviewed the development of the field and listed all major areas of VSD focus, citing key authors and contributions to the literature for each such area. Thus, it has been possible to examine contributions in those areas relevant to this study, and in that process to look at works published by those same key people, since the time of the survey in 2017. Pertinent to this study, there has been a significant focus on studies involving people with dementia (Burmeister, 2016; Felzmann et. al. 2015; Koldrack et. al. 2014; Kreps et. al. 2016; Niemeijer et. al. 2014; Pakrasi et. al. 2015; Schikhof et. al. 2010; Teipel et al., 2016), as well as cognitive decline with ageing more generally (Alzheimer Europe, 2010; Begum et. al. 2015; Burmeister, Bernoth, Dietsch, & Cleary, 2016; Castillo et. al. 2011; Castillo et. al. 2014; Cremers et. al. 2014; Fukushima et. al. 2005; Harvie et. al. 2016; Jenkins & Draper, 2015; Koldrack et al., 2014; Schikhof & Mulder, 2008), and more recently, there have been attempts to reformulate VSD to caring for people more generally, through a variant known as Care Centered VSD (CCVSD)(Poulsen &Burmeister, 2019; Sharkey, 2016; van Wynsberghe, 2013, 2015).

These areas of VSD research have revealed many complexities in designing assistive, monitoring, and other care technologies for people with age related cognitive decline. The recent focus on CCVSD, and its associated focus on engineering care robotic assistance, has shown that there are many areas that still need further exploration in relation to the social dynamics of robotic interaction with humans, when providing care. However, all of the work to date has followed the paradigm of supporting physical function and appears to accept the view that people with dementia in particular will experience further decline in capacity, mental and physical. The idea that personhood also has a social di-

mension is not yet reflected in the VSD literature and this is a contribution made by the present article. As is borne out by the above VSDliterature, the focus of VSD to date has been on physically supportive technology - designed to support the physical functioning of bodies whose self-renewal mechanisms are almost exhausted – rather than supporting the continuing relationships and social personhood of the individual whose motor accompaniment is reaching its end. Clearly, more is needed in the area of social personhood support, which is not addressed in any of those articles. The question, then, is why has attention in VSD circles been so exclusively upon the physical? Our contention is that issues of power in the understanding and application of technology are at play, and that a better understanding of such issues is required if VSD is to overcome this deficit.

Power and technology

The multiple tendrils of the network of relationships - the web in which the spider of our social personhood sits – is, as Foucault underlined(1977:135-170) - a network of power relations, where the exercise of individual Wills is always relative, always contingent, never in isolation from the Will of 'the Other'. Power relations are everywhere, and in VSD, particularly when applied in the context of age-related cognitive decline where personhood is frequently so occluded that the scales of such relations lie heavily against the independence of those in the midst of them, attention must be paid to weighting such independence for the person with dementia as carefully as possible. Technologies, including assistive technologies, are always pregnant with power relations. VSD, therefore, must understand power, and operate within a framework that is sensitive to its workings (Kreps 2018).

Brey's (2007)framework for a critical understanding of technology's impact upon the social is instructive and useful in this context: "A critical theory of this sort requires the development of an answer to four questions: (1) *the theoretical question*: how can technology play a role in the distribution and exercise of power? (2) *the factual question*: What is the role of technology in the distribution and exercise of power in contemporary society? (3) *the normative question*: What role should technology have in the distribution and exercise of power in society? and (4) *the practical question*: What steps can be taken to move closer to this ideal?". The first three questions - theoretical, factual and normative - enable us to develop and envisage "policies and practices for the realization of a society in which technology is a force for empowerment rather than for domination".

The fourth – *practical*– question gives rise to the practice of VSD. What is most crucial, however, to draw from Brey's framework, is that practitioners of VSD should be well versed in understandings of the first three questions, if they are to avoid reinforcing power structures within society opposed to the "human well-being; human dignity (respect); justice; welfare…; human rights …; and freedom" (Burmeister et al 2011)valued by VSD. VSD practitioners need to be clear about the exercise of power, which for the de-

signer of technological artefacts should always be as intentional as possible, rather than intuitive or unconscious, in order best to steer clear of the potential traps of the politics of artefacts(Winner 1986:2-10). For Winner, technology is infused with politics: it is at the very least politics by other means. Technological artefacts are often nothing less than objects created to "enhance the power, authority, and privilege of some over others."(Winner 1986:2-10). Brey'sframework, again, is instructive, here. "The preliminary answer to the normative question is… that the role of technology should be such that it aids in the arrangement of power so that the ideals of democracy, freedom and justice are attained as well as possible"(Brey 2007).Assuming that "power relations are both established by the actions of agents and by the workings of social structures," (Brey 2007) VSD practitioners should also note that, "although power *relations* do not require intentionality, the *exercise* of power always does"(Brey 2007). Such exercise is often opaque, and more complex than it may at first seem.

As Brey reminds us "Technology can help agents exercise power over others by either giving them new powers or by improving the efficiency, effectiveness, reliability and ease by which existing powers are exercised"(Brey 2007). Brey distinguishes between 'power *over*,' whereby power is exercised for the control of others, and 'power *to*,' a personal empowerment towards achievement. VSD needs at times to navigate very complex interfaces between sometimes competing pressures and be prepared to reach sometimes imperfect compromises where the requirements of social structures (power over the process) constrain the scope of design (power to influence relations). Thus, an awareness of power relations amongst practitioners of VSD is crucial to reaching the best compromise, however imperfect, if VSD is to achieve any progress towards "the realization of a society in which technology is a force for empowerment rather than for domination"(Brey 2007).

VSD, in other words, needs a critical understanding of technology's impact upon society, and to be clear whether it is either (a) making 'inherently political technologies' that promote disempowering social power structures more socially acceptable and accessible, or (b) contributing to technologies that aid the "arrangement of power so that the ideals of democracy, freedom and justice are attained as well as possible"(Brey 2007). It is precisely for these reasons that this paper uses the lens of personhood to interpret the literature on VSD usage for technologies addressing the domain of cognitive decline in ageing.

Conclusion: Power, Technology and Personhood in VSD

Those experiencing age-related cognitive decline, for whom social personhood is becoming gradually concealed, and for whom lucidity is most often associated with their relationships with their relatives and carers, are uniquely vulnerable within the network of

power relations exercised by both those around them and the webs of technological apparatus in which they sit, both medical and assistive. As pointed out above, VSD ought to focus upon supporting relationships, and upon respecting the social personhood of those nearing the end of their physical lives. It must also, in light of the above discussion of power with respect to technologies, do so in a manner that acknowledges the inherently political potential of technologies, and aligns the politics of assistive technologies not just towards relationships but towards equal and just relations with relatives and carers, that respect the autonomy of patients for whom, on the physical level at least, there is often little freedom left.

In the regimen of hospitals, of care homes, and of sheltered housing, where it is always time for something, in the busy schedules of those charged with the care of people no longer able to fend (entirely) for themselves, assistive technologies need not only to free-up time for busy professionals to attend to other patients, care home inmates, or sheltered housing tenants. They need also to work towards empowering those they are assisting, and especially in the case of age-related cognitive decline, they need to work towards revealing, rather than inadvertently supporting the concealment, of social personhood. They can achieve this not only by supporting the relationships, but by supporting continued choice and autonomy within those relationships. These, in short, are the values that VSD should be sensitive to, in respect of assistive technologies for age-related cognitive decline.

In the final analysis, there is the possibility that those experiencing age-related cognitive decline may see improvements and enhancements in what could be described as their social capital (Coleman 1988), in contexts where the use of VSD in the design of assistive technologies in place in their care regime are working effectively to support their social personhood in the face of the concealments brought on by physical decline.

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