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Dementia care: a test case for the humanity of AI in health and nursing care

Paula Boddington

Abstract

This chapter explores the situation of people living with dementia as a test case to examine the possibilities for implementing AI in health and social care in a manner that fully respects the humanity of all involved. People living with dementia unfortunately already often experience dehumanising attitudes and (often inadvertently) dehumanising treatment. This means that examining the treatment and care of this particular group may alert us to issues that may be present for others but less visibly so. Moreover, there exists a body of work which attempts to counter dehumanising attitudes and treatment for this group which can be drawn upon in considering the use of AI, and there are many existing and proposed uses of AI for the care and treatment of those living or at risk of dementia. We consider the use of AI in dementia diagnosis, and also draw on ethnographic observations within hospital of the care of people living with dementia, from a team focused upon improving the quality and humanity of care and on understanding the patterns of dehumanisation found on the hospital ward. The hospital can be used as a 'small society' to examine institutional forces which affect the provision of care and to identify factors to consider when implementing AI in such a setting. Themes focused on include the observation of people using AI and data; control via AI; and the identification of tasks and goals, as well as the general themes of time and efficiency.

Introduction: AI and human nature

This chapter considers the use of AI and automation in the care of people living with dementia. People living with dementia, and those at risk of dementia, may stand to gain considerably from sensitive use of AI and automation, but are also particularly vulnerable to suffering ill-effects from inappropriate use, and hence may provide a test case where both good and ill may be highly visible.

For the implementation of AI to take a humanistic perspective, a central place must be given to the human person. Many declarations of ethics call for AI to be developed for the 'benefit of humanity', but we need more than some crude utilitarian notion of 'benefit'. If AI is intended to enhance or to replace human agency, thought, and decision-making, we must understand what we really value in human life, in order to appraise whether AI really does enhance us, or really ought to replace us in certain tasks. We must ask questions concerning human nature, as Fioravante and Vaccaro put it in the first chapter of this volume, our ontological status. These questions will include, in the context of medicine discussed in this chapter, how the person is to be understood – simply biomedically, or in terms of the whole person set within a social world (Leonardi, 2018).

It is necessary to ask hard questions about how technological progress may be already impacting us and our social systems; humanistic ethics is concerned not just with technology per se but with the social infrastructure of their design and use (Fioravante and Vaccaro,

2025). For our view of the world, of ourselves, and of what is to be valued, is being moulded in various ways by the very technology in question. Consider, for instance, the myriad ways in which technology directs our attention in various ways – the persuasive technology in the smart phones that most of us carry with us all the time should suffice to illustrate this control of attention, and a key issue to be considered here is how the collection and use of data by technology likewise impacts our attention and our view of the world.

We need also to consider the ideology and implicit values and goals that may accompany technology and its application. The very development of technology such as AI can help to promote certain views of what is best in human nature and what is valuable in human life: the goals that are pursued, the tasks that are seen to be better undertaken by machines than by humans, will implicitly or explicitly make statements about the desirable life for humans – or for certain groups of humans.

Much work in AI focuses upon producing technology to accomplish discrete engineering challenges, but there is also work which focuses on the project of AI conceived in broader and more ambitious terms, with the aims to mimic or to exceed human intelligence, however that is conceived. Such a project thus rides upon assumptions about the nature of intelligence and why it is valued, as well as sometimes making assumptions regarding the place of intelligence as a central or even defining feature of human nature. Intelligence may be conceived in ways which stress certain cognitive tasks, and viewed instrumentally in terms of the capacity efficiently to achieve certain goals: ‘humans are intelligent to the extent that our actions can be expected to achieve our objectives’ (Russell 2019, p.9) (meaning that assessing the goals is not part of ‘intelligence’), although there are robust debates in the field about the nature of intelligence (Larson 2021, Legg and Hutter 2007; Chollet 2019). Some may indeed consider all problems have an AI solution, a view summed up by Demis Hassabis of DeepMind as the ambition to ‘solve intelligence, and then use that to solve everything else’ (Burton-Hill 2016). A technological solutionism or ‘technological fix’ may thus take hold (Weinberg 1966, Morozov 2013). But then, as AI is being developed and becoming more and more integrated into human life, if such attitudes become entrenched, its very deployment may be influencing how we think of human nature, and what we see as valuable in human life, even without any ideological attachment to certain views of the nature and value of intelligence. Conversely, at the same time, intense debate and opposition to certain ideological stances influenced by AI technology are occurring.

As noted, the influence of AI upon our lives may be extended through the ubiquitous ways in which humans and technology mutually interact within socio-technological systems, impacting our perception and knowledge of the world and how we relate to and perceive each other and ourselves, as data about us is collected and analysed through technologies. This means that in examining the impact of AI we need to consider local cultures. Especially within institutions, this will be within a hierarchical context, of particular concern as we consider the culture within hospital wards, a ‘small society’ that has been described as closely reflecting the wider world (Caudill 1958, p.3). The implicit values that may be present in the application of AI, for example, that efficiency, however understood, is a good, that speed is to be valued, that certain goals can be delineated and measured, may or may not be coherent with the values of a humanistic approach to life. Yet we can often see that such goal-oriented, efficiency-led thinking is already present in the institutions within which

much technology is deployed. What will be the impact of adding even more technology to such contexts?

It is clear that we need to ask various epistemological questions about human nature and about AI. This paper takes as a central issue one blending epistemology and ethics, the mutual and reciprocal recognition of other human beings, the capacity for which is one hallmark of human nature, albeit one often sadly lacking. There are many sources of the very real risk of dehumanisation, including the failure to pay sufficient and true attention to the other (Weil 2009, Buber 1970), and technological determinism is multifaceted (Fioravante and Vaccaro, 2025). Our capacity to neglect and to (mis)understand each other as humans relating to other humans suggests that we must ask how well technology can capture and respond to our human condition, and what happens when we rely on technology as a means through which to gaze on the other; what is going on as AI looks at us and as we look at AI? Might technology fail to capture all that is of importance in human experience? For '... no alarm exists for a patient's sense of isolation, yet this does not detract from its importance' (Archibald and Barnard 2017, p. 2478).

Our strategy is to examine an group for which dehumanisation already frequently occurs, but where many are already attempting to understand and combat this, the group of people living with dementia, including those at risk of the condition. This can provide material upon which to draw in considering the requirements for the humane introduction of AI, not just for the general mass of humankind, but for each and every individual. We will attempt to do this without adopting a tendency found common within the nursing sphere of assuming an opposition between technology and humanism (Barnard and Sandelowski, 2001, Barnard 2002). In this volume, Fioravante and Vaccaro highlight the importance of the question of human boundaries in relation to technology; the recognition of and appropriate responses to the boundaries of the human is indeed an acute and central issue in humane relationships with and treatment of people living with dementia.

We consider two cases: AI for the diagnosis of dementia, and the situation of people living with dementia in the complex social and institutional world of the hospital ward. These two cases both involve entwined questions of epistemology and ethics. The proposed uses of AI in dementia diagnosis take us into the world of everyday life, for much proposed AI diagnosis would operate ubiquitously on the general population sometimes from many decades before onset. In contrast, the closed world of the hospital provides a world in miniature whose culture can be examined in some detail.

These issues are extremely complex, with multiple interlinking factors and it will thus be impossible to do more than indicate some of the issues and challenges for the successful and humane implementation of AI. This chapter will therefore raise broad themes to consider as background influences, and select certain themes for discussion.

Dementia and dehumanisation

Despite considerable research efforts, much is still unknown about the condition of dementia, its aetiology, and effective prevention and treatment strategies. It often remains undiagnosed, or is diagnosed late, with currently little treatment to the condition, with

major challenges in the provision of appropriate care. A variable condition, many people will live with dementia for a number of years (Liang et al., 2021). This means that there are considerable challenges in caring for this group, especially as dementia can potentially affect all areas of life. Technologies such as AI are perceived as potentially transformative of healthcare including nursing care (Archibald and Barnard, 2017), and in particular there are multiple initiatives for the use of AI in dementia care, treatment, and research. Applications of AI and machine learning in use or development include the diagnosis of dementia, the stimulation of memories of those living with dementia, the use of tracking devices to prevent wandering into unsafe areas, the use of surveillance cameras around the home for safety monitoring, the use of care robots for companionship or the administration of medications or food, and the use of remote devices for monitoring and communication, with mixed reports on their benefits (Astell et al. 2019, Buchanan et al. 2020).

Dementia generally involves problems with memory and cognition and the use of language. Communication problems are common. The key place of reason and language in our understanding of what it is to be human means that people living with dementia are often subject to slights and dismissive language, such as 'death while alive', 'zombies' (Schweda and Jongsma 2022) 'funeral without end' (Mitchell et al. 2020). A common view is dementia 'by definition then seems to threaten the identity and self-hood of the individual at risk' (Higgs and Gilleard 2016, p. 773). The many living with dementia who are trapped in hospitals may be dismissed as 'bed-blockers' (Bates 2004), as if hospitals were really for 'other people'. But dementia represents a possibility for all of us as we age, and thus understanding the basis for such dehumanisation is important for us all. As the value of cognition and high levels of intelligence is increasingly emphasised by the excitement around AI, a close examination of treatment of those whose powers of cognition are in decline should prove valuable.

Humanist traditions have recognised the importance of communication and of understanding languages and cultures from our past, emphasising the study of ancient languages and texts of Greek, Latin, and Hebrew as well as the translation into the vernacular (Davies, 2008). Acute attention to addressing the challenges in communication concerning people living with dementia thus can be seen as echoing this humanist tradition, especially insofar as it represents an attempt to recognise and value those who go before us: in this case, not the ancients, but simply our elders.

Furthermore, the very challenges of care mean that, as indicated above, there is already a robust debate regarding dementia, personhood, and the humanity of care, which presents us with a rich literature and body of evidence on which to draw. Tim Kitwood's work advocating person-centred care for people living with dementia has been very influential in practice (Kitwood, 1997), and following this, there has been considerable work in qualitative social sciences exploring the humanity of care of those living with dementia, much of which rests upon notions of the person which emphasise social and embodied aspects of personhood.

Although there are complex debates within cognitive science, AI, and robotics about the relationship between cognition and the body, popularly the development of AI goes along with notions of a view of the mind as primarily or wholly mental, as inherently individual, as

disembodied in essence, and therefore as being capable of realised within a variety of substrates, with much speculation that AI may develop consciousness or personhood. Such a view thus may go hand in hand with models of the person which emphasise rationality, language, individual autonomy, and cognition, in line with models of personhood developed by philosophers such as Dennett and others (Dennett, 1988). Such an approach to personhood has led to debates about whether or not some human beings who have lessened cognitive capacities might be considered cases of 'marginal personhood' (Wasserman et al., 2017).

But a considerable body of thinking and research within the field of dementia care has taken a firmly different view. For example, the sociologist Pia Kontos (2004, 2005) draws upon the work of Merleau-Ponty and Bourdieu to argue for an embodied and social sense of personhood, demonstrating from long-term observational work of people living with dementia that a sense of self and awareness of social and cultural norms and practices may remain in an embodied selfhood, even with severe decline of linguistic capabilities. There is insufficient space in this chapter to explore different views of personhood in depth, but their significance for how technology is embedded within our social systems will be explored below.

Knowledge of the human being: epistemology matters

Much of the work emphasising person-centred care, the continued humanity and hidden capabilities of people living with dementia, arises from qualitative research methods such as ethnography. This again is relevant to concerns about attention, and may contrast with the different approach to knowledge gained via collecting and analysing data using AI.

Ethnographic observations typically take place over an extended period. The ethnographer embeds him- or herself within an environment, attempting to make sense of the meanings of the social world (Atkinson and Housley, 2003). From a position both within and without a social world, the ethnographer may observe and record interactions between people in ways which capture intent and nuance in a manner that mere recording of 'behaviour' may not. Ethnography may draw upon the researcher's own reactions to a situation. Some work referred to below also draws upon methodologies of rhythm analysis following on from work of Henri Lefebvre (2013), which is currently receiving considerable attention (Lyon, 2020, Chen, 2016). Lefebvre states that everywhere there is interaction between a place, a time, and an expenditure of energy, there is rhythm. Notably, he distinguishes between the cyclical time of the body and the linear time of modernity, which may often be in tension causing a breakdown of rhythms (arrhythmia). Others have likewise made use of a distinction between linear and cyclical time, with Fuchs drawing links between cyclical time and bodily memory, noting the importance of the latter for people living with dementia (Fuchs, 2018, 2020).

For Lefebvre, the cyclical time of the body has its own rhythms with natural cycles of completion; this is felt within the body. Linear time is imposed through the military rhythms of modernity, as for instance, with the imposition of discipline, order, and timetables within institutions (Lefebvre 2013, p.48). This will be of importance below in relation to discussions

of efficiency and timetabling on hospital wards, and to the place of the human being within an institution and in response to technology.

Note the position of the human body as observer and as observed in this methodology. To attend, the rhythm analyst uses their body, firstly paying attention to its rhythms, and from here, appreciating the rhythms of the world (Lefebvre 2013, p. 29). Arrhythmias occur when rhythms clash, which may cause a bodily reaction in the rhythm analyst as observer. Note the embodied nature of the human being as observer of other human beings, in contrast with the gaze of technology. Note that the contrast between linear and cyclical time points to an imposition of order for example within an institution, or via technology, which help or disrupt the natural cyclical rhythms of the human being. This will help to frame a general question of how to introduce technology into an already ordered space in a humanising manner; the significance of the particularities of human embodiment is a major concern in considering the impact of AI.

This paper draws upon ethnographic work examining the care of people living with dementia on acute hospital wards, conducted with a view to finding ways of improving the humanity of care. Observations from this team have taken place over 8 years with, to date, over 500 days of observations in hospitals across different geographical areas of England and Wales. Projects have focused upon examining the refusal and resistance to everyday care (Featherstone et al., 2019); continence care (Featherstone et al., 2022), and the uses of restraint in care practices (Mwale et al, 2024). Of particular interest are repeated findings of inadvertent dehumanisation in care practices. No malpractice was uncovered, yet standard working practices within hospitals frequently led to people living with dementia receiving poor care, contributing to the decline and deconditioning which is very common for this group, who have very poor outcomes following admission to hospital.

Featherstone and Northcott state that 'the profound invisibility of people living with dementia was striking' (p. 37). Issues identified include poor communication, and difficulties experienced by people living with dementia in keeping up with the institutional demands of timetabled care. This frequently led to 'looping' whereby a classification interacts with the people so classified (Hacking 2007). For Goffman, writing of the 'total institution', 'an agency that creates a defensive response on the part of an inmate takes this very response as the target of its next attack' (1961(1991), p. 41). Difficulties in complying with the 'rules of the ward' led to behaviour which produced a doubling down of the treatment which had provoked the very behaviour in question, in a manner very similar to that first observed in classic sociological studies of institutions in the 1960s (Menzies-Lyth 1960). For example, a patient might attempt to leave their bed in order to go to the toilet. A nurse may explain to the patient that this is not necessary, as they are wearing a continence pad; the wards guard against 'wandering' out of fear of falls, for which there is mandated recording. The patient's continued attempts to leave their bed might then be viewed as irrational and the person as non-compliant. The bedrails are raised, yet the patient continues to attempt to climb over the rails, increasing their risk of a fall. Such instances are so common for people living with dementia on these wards that such cases were called 'climbers' (Featherstone and Northcott 2021, p. 126). This purported evidence of 'irrationality' and loss of agency might in at least some instances more truly reflect a determination of agency and the expression of preference.

The complexity of the social world of the ward, with its own rules of operation which may be inadvertently dehumanising, should alert us to the great complexity of introducing technology into such a space in ways that ensures it really advances the humanity of care,, not simply for patients but also for staff.

Some general themes have emerged from this and other work regarding the care of people living with dementia which mirror issues arising in the application of AI, and which also mirror concerns within humanism.

Firstly, questions arise about how people are observed and understood, both by other human beings and via analysis and application of the data that are collected about them. There are many opportunities for misunderstanding whereby the full humanity of the person may fail to be recognised. Here, those living with dementia are especially vulnerable, as indeed their very invisibility on hospital wards makes clear. The use of AI to collect and analyse data about humans thus must be seen within this context of grave potential misunderstandings; dehumanisation does not just 'happen', it occurs within specific contexts, including the context of the hospital whose very remit and ethos is to care. The potential large impact on this vulnerable group of poorly implemented AI, plus the great potential for benefit, again make people living with dementia a valuable group to examine, as the magnitude of possible impacts may help us to spot issues that also occur with others but less visibly.

A second general theme is control. The ethical question(s) of control of AI is well-known; there are many aspects to this problem. AI's autonomous nature produces challenges for our capacity to retain ultimate human control of AI. But we must also address the control of humans by those who use and control AI. Within any hierarchical organisation such as a hospital, issues of control are central and are likely to be impacted by the introduction of technology such as AI. Potential for improvements via the use of such technology exists, but also the possibility that control might be increased or altered with deleterious impacts, especially on those with the least control, those at the bottom of any institutional hierarchy. These are likely to be the most vulnerable patients, as well as the staff who perform tasks of basic care, whose working lives are subject to tight controls of task-oriented efficiency. As we shall see, the control exerted over vulnerable patients is linked to how they are perceived and their behaviour understood within the institutional context of the ward.

Linked to this, a third general theme concerns the identification and pursuit of goals and tasks. The goals of any AI must be the right goals, adequately identified, and the impact upon a system as a whole of employing AI in achieving such goals must be considered. But the goals of technology may not always be in harmony with the goals of those swept up in its path. The tasks undertaken on a hospital ward may be in some dispute: problems so produced also may again disproportionately impact people living with dementia, as shall be indicated below. Goal-oriented management of medical conditions may not always be sympathetic to other values, including communication, tasks of basic nursing care, and everyday actions which help to humanise and to assist people to be recognised fully within the social world of the ward (Barnard, 2002). Moreover, the hierarchical system of the hospital gives priority to certain kinds of tasks and to the pursuit of certain goals; any

introduction of technology must of necessity consider how tasks are viewed and understood within this hierarchy, noting that 'official' narratives of institutional goals may not truly reflect reality on the ground.

These themes linked to questions of time: time taken to observe and understand others, time saved by AI, time in the swift pursuit of technological and scientific progress and quest to implement such, time in the drive for efficiently completing identified tasks; notions of speed and efficiency as noted are indeed embedded into understandings of artificial 'intelligence'. It is commonly claimed that AI will free human beings up to perform other more 'human' tasks such as interaction with people. This claim will be assessed below in the context of findings about time management on hospital wards.

AI in the diagnosis of dementia

We now consider the proposed uses of AI and machine learning (ML) in the diagnosis of dementia. This will demonstrate how the collection and analysis of data by AI technologies may be beneficial, but may at the same time produce significant shifts in how we view ourselves and others, creating profound individual and social questions: the 'control question in AI' is often not so much how do we control any particular AI, but how we address the cascading network of impacts of its routine embedded use. Similar issues may arise in the diagnosis of other conditions, but the diagnosis of dementia via AI and ML produces a plethora of wide-ranging and particularly acute issues concerning how we understand disease, how we understand and respond to the human being, and what happens when AI is introduced into the equation. The use of AI in dementia diagnosis could be seen as nothing other than the application of AI in the dispassionate search for information; but this view sits uneasily with the profound human significance of a disease diagnosis. This discussion also acts as a general introduction to many of the challenges facing people living with dementia as a prolegomena to our discussion of hospital care, and indeed, we draw upon ethnographic data from hospital care in our discussion of the potential impacts of a dementia diagnosis, to add useful context to the impact that a diagnosis of dementia may have on how a person sees themselves and is seen by others.

Speed and urgency

First, note that much technological development is trumpeted with claims of the urgency and severity of the problem to be addressed, hence the need for speed in efficiently tackling a problem; this may seem like harmless enthusiasm but may interfere with a humanistic approach. The literature around the use of AI and ML in dementia diagnosis likewise emphasises the severity of this condition, its prevalence and projected increase, stressing the healthcare, social, and economic costs (Amini et al., 2022; de la Fuentes Garcia, 2020; Danso et al., 2019), with many describing dementia as a 'burden' (Kourtis et al, 2019) or as 'devastating' (Dashwood et al, 2021), with a climate of 'urgency' (Li et al., 2021). Indeed, there worries are sometimes expressed that concern with ethics in the face of such urgent challenges is unethically hindering technological progress for the benefit of humanity.

While such descriptions of the challenges of dementia may be broadly accurate, it is notable that such a presentation of the condition contrast starkly with the approach of the care

sector, which has worked hard to counter characterisations of those living with dementia as a burden or as in a hopeless situation, and often as, in some sense, no longer ‘fully persons’ (Kitwood 1997; Kitwood and Brooker 2019). Note then two very contrasting approaches, one stressing dementia as a medical condition, the disorder understood in biomedical ways, one stressing the *person* who must *live* with dementia.

The use of data

Understandings of human functioning and ill-health produced via AI depends upon data. The collection, analysis and sharing of large volumes of data has been also a notable feature of research into Alzheimer’s disease for many years (Milne et al. 2022), and ML and other technologies being used greatly facilitate the collection and analysis of a very wide range of data types and of modes and places of data collection. The variety of data used reflects the complexity of the condition of dementia, which can affect many aspects of functioning, and also reflects the uncertainty regarding the causes and biomedical manifestations of the various dementias (Dekkers and Rikkert 2006; Weller and Budson 2017).

The data may include various biomarkers and/or behavioural or cognitive function; may be data that may be broadly thought of as ‘medical’, collected in a clinical context, or outside the clinic; and may be collected at a discrete time, or over an extended period of time. The wide variety of behavioural data used includes gait analysis, mood, heart rate, sleep, navigation, and a person’s capacity to undertake everyday tasks such as making toast, as well as individual patterns of technology use, in ‘digital phenotyping’ of clinically relevant behaviour (Insel 2017; Jain et al. 2015). Much work uses ML to analyse linguistic data, such as conversations, medical notes, and test results (Astell et al. 2019; de la Fuentes Garcia et al. 2020; DHSC 2020; Mullard 2021; Shibata et al. 2019; Shimoda et al. 2021; Spichak 2021). Cognitive tests may include traditional tests (such as the classic ‘clock drawing test’ (Jiang et al. 2021) as well as digital versions of standard tests, or newly designed digital tests. There is work underway attempts to bypass language difficulties, e.g. with tests requiring one to classify photos as ‘animal’ or ‘not animal’ (Kalafatis et al. 2021; Khaligh-Razavi 2019). Medical data used varies (Berisha et al. 2021) and includes administrative health data (Park et al. 2020), various physiological measurements (Reith et al. 2021), and imaging (Cope et al. 2021). ML is used to improve interpretation of established tools of dementia diagnosis, such as MRI scans of the brain, or to find new tools, such as retinal scanning (De Fauw et al. 2018).

Crucially, technology thus facilitates the creation of a picture of dementia risk from potentially any facet of life and behaviour.

The personal and social significance of a dementia diagnosis

Such data collection and analysis raises profound questions about how people living with or at risk of the condition are seen and labelled. There may be radical divergences between the view of the subject garnered via technologically mediated data collection, and that of the care sector operating at its best and most humane. Data collection and analysis leading to diagnosis may be of profound individual significance. A disease diagnosis or risk assignment may be seen as more or less determining of one’s future, more or less threatening to one’s

sense of agency and of self. The impact will vary depending on many factors, among them, the very ways in which the condition is conceptualised, how an individual sees their personal risk, who seeks a diagnosis and why, what care and treatment is available, and how society in general views different risk and disease groups. A dementia diagnosis is far more than a biomedical label: it can lead to a cascading loss of membership of a social community.

The reach and impact of AI

AI can significantly alter the data landscape of everyday life. Data may be collected in unanticipated ways, in a manner below conscious awareness; information can be extracted from data once thought to be trivial or meaningless. Routine medical information becomes relevant to a dementia diagnosis. Data collected for recreational purposes in tracking activities is potentially revealing of a diagnosis with serious implications for one's future, turning the everyday into a location for medical hazard. An expanding range of data suddenly become 'medical' data; going about one's everyday business, one can leave a trail of 'data exhaust' holding clues to one's dementia risk. Wearables may collect both behavioural and physiological data and may be used both for diagnosis and for ongoing monitoring to detect progression (Astell et al. 2019; Frey et al. 2019; Kourtis et al. 2019). Ambient data may be collected from everyday use of smart devices. The class of those at risk will be moulded by the capacity of the technology and of developments in scientific understanding. This issue presents itself forcibly with research ambitions to diagnose dementia 'decades' before symptoms appear (Frey et al. 2019). This will raise questions about what it is to have the condition; given the widespread stigma associated with dementia, this is a troubling issue indeed, especially as attempts to combat stigma in various areas are often doomed to failure, as the source of stigma may simply shift elsewhere (Buchman and Reiner, 2009). Research also aims to distinguish dementia from normal cognitive changes that may occur with ageing, and of course this may be extremely beneficial, but note that it comes with constant monitoring of normal cognitive changes with age. The irony of potentially constantly monitoring a population for cognitive difficulties via a technology that heralds and promotes the value of intelligence is noted.

Classification, accuracy, and perception

Likewise, much research is driven to improve accuracy of diagnosis, to detect sub-categories of dementia, and to finely monitor disease progression. This is laudable, but the context of application of diagnostic knowledge should be noted; the ambition of fine-grained diagnosis contrasts sharply with research findings on the ward. In some wards, symbols, such as a forget-me-not or a butterfly, are placed above certain patients' beds to alert staff to a dementia diagnosis. But not only may these symbols sometimes fail to match the patient, staff generally interpret symbols as indicating advanced dementia, as a result often underestimating capacity, with even those capable of self-care constructed as high dependency (Featherstone and Northcott 2021, p.71). Ironically, communicating disease status via these 'technologies of attention' then sometimes led to staff failing to communicate with a patient (Featherstone et al. 2020).

Data collection, disease diagnosis, and control

The impact on the self

We need to consider the type of data collected and its analysis, but also the relationship of the data subject to this data. Work on the 'data self' provides a useful tool for analysis (Lupton 2016). Contrast two cases, that of early adopters of health tracking wearables and other devices, who may use this actively to increase their autonomy, gain self-understanding, and improve fitness and health (Ng and Kong 2016); with those labelled with dementia or seen in a high-risk category. The question of who is doing the surveillance and why is critical: the individual, the healthcare system, relatives, others: is the one under surveillance the active data self, or the mere object of the gaze of others? Note that for those considered at risk of dementia, talk is almost exclusively that of monitoring by others, and systems may be designed so that those monitored are unaware, for example via automatic monitoring of routine health data (Miled et al. 2020). These raise complex issues that are genuinely hard to resolve but as we shall see below, in some ways mirror the experiences of those living with dementia.

Control by AI and by others

Passive data generated in everyday activities is especially welcomed for application to groups who are considered to be 'nonadherent' to treatment plans (Insel 2017). It is argued that passively collected data better reflects the true nature of the condition, in contrast to data collected in artificially designed cognitive tests. Ecological validity is a central concept of digital phenotyping (Jain et al. 2015), that passively collected data is a means to achieve 'real world' objective tracking of 'reality' (Milne et al. 2022). But notions of the 'ecological validity' of data may increasingly reify the concept of disease. Such data collection techniques potentially mould the understanding of a 'diagnosis' from a label applied to an individual, by examination of that individual, at a specific time; to assigning an individual or entire class of people into a risk category, a predictive model, formed from extrapolation from a population group (Milne et al. 2022). By such means, the very understanding of what it is to have a 'disease' could be transformed.

Moreover, the potential ubiquity of data collection, especially if passive, raises serious issues of individual control by the data subject; an issue which is already a feature of life experienced by many living with dementia (Armstrong and Byrne, 2011). For some, medical information is liberating, but not for all (Milne et al. 2022). Loss of control may thus be extended to a far larger group of those 'at risk' of an earlier and earlier diagnosis. In the field of genetics, there have been long-standing discussions of 'genetic responsibility' – the question of whether individuals have a responsibility to find out and act upon genetic information (Leefmann et al. 2017). These questions could then be expanded via the diagnosis of disease more generally via data collected in everyday life by AI, with particular significance for different conditions.

Agency and the 'disobedient' patient

The so-called 'nonadherent' patient is a category into which those suspected of dementia are likely to fall. Debate within medical ethics about 'adherence' to medical regimes should

warn us of the dangers of seeing patients as ‘noncompliant’ (Resnik 2005). Moralisation of the data subject impacts their epistemic status as the object of data collection. To be passively monitored for signs of cognitive decline may have tangible benefits but seems in tension with a reciprocal relationship of belonging within a social world. The embedding of such data-collecting capacity into everyday technology and the interrogation of this data to produce a diagnosis or a risk score makes passive data subjects of us all. This may heighten agency for those who seek this self-knowledge, but for others, passively collected data may reduce agency, and all the more so, the more that the information so derived is considered of superior validity to other forms of knowing the human subject. Which is the ‘true’ patient, the potentially hyper-real person constructed from digital data, or this human being here and now? How does the person viewed in this way, reacting to this view of themselves, compare to the person observed under the attentive gaze of another human being?

The hollow ‘future promise’ of AI for some?

Milne et al. (2022) usefully discuss a notion of the ‘data shadow’, a picture of the self which is derived from data which may mar one’s future hopes. The future promise of individual empowerment through digital technologies may be real for some, but for the person living with dementia, or with a diagnosis of future dementia, there may be no ‘data self’ but only a data shadow, a data ‘non-self’, to whom the glittering future promise of technology is only a future threat. You have just successfully argued a case at the High Court, or had a paper refuting string theory accepted in Nature; on the other hand, an app on your phone alerts you to signs of cognitive decline undetectable by either you or your colleagues. Note again the dementia patient’s invisibility (Featherstone and Northcott 2021, p. 37).

On the other hand, there may be room for optimism. Milne et al. (2022) show how the continual monitoring and tracking makes room for a future projection of change of the digital self over time, counter to ideas of the constant self. Dementia is generally seen as an inevitable progressive decline. Yet results from routine testing may show variability in scores over time. Could this help counter the trope of the ‘inevitable slide downwards’ and lack of hope of dementia?

The interpretation of behaviour

As should now be apparent, a general issue we must address is the context and meaning of data and information. A technologically mediated view of the world and of data may fail to understand the meaning that such data has for individuals. The picture of a person, the diagnosis of a disease, constructed via technology will depend crucially on how data sources are interpreted. There is an especial hazard if a diagnosis achieved through new technologies is simplistically assumed to have the epistemic power fully to capture the condition; yet the scope and variety of data potentially used in AI dementia diagnosis may well nudge towards such a biomedical view of the disease. To move towards a position where growing numbers of individuals and groups will be given risk labels for cognitive decline would have profound implications which need to be discussed, debated, and predicted before technological and informational revolutions become embedded into our health service, care, and everyday infrastructure. We need to consider both how the technology may ‘see’ the person, and also how people, including the data subject, may use

the findings of technology. Human behaviour is not bare bodily movement but requires understanding to read (Anscombe 1957; Taylor 1968). The same behaviour can be read in quite different ways by different human beings, so even human oversight of ML may not fully address the issues. Interpreting behaviour is a particular issue for those seen as deficient cognitively or in executive functioning and social awareness. We shall also note below the priority of data and metrics on the ward as what can be readily measured takes priority over many care concerns.

Consider the remote monitoring of movement for those at risk of dementia (Astell et al. 2019; Ng et al. 2016), and compare this with the actual monitoring of movement that occurs on wards. Ethnographic research finds that for those with a dementia diagnosis, attempts to exercise agency, such as getting out of bed, walking around a hospital ward, or attempting to leave the ward, are likely to be seen as 'wandering' and ipso facto as lacking in agency or intent (Featherstone and Northcott 2021). This perception then loops back to confirm a diagnosis, and perceptions of a possibly worsening condition, meaning any further attempts by the person to communicate and act are also seen as lacking clear agency. Yet a patient may simply be trying to stretch his or her legs, to talk to another patient, or relieve the unrelenting boredom of the ward. The 'future promise' of a person living with dementia may be modest indeed compared to many others, yet careful observation finds that even this little may be taken away.

AI, dementia, and the hospital ward

We are seeing how complex the consequences of a dementia diagnosis might be, something of the significance for the individual person and for how others see them, and how these might be compounded by the prospect of passive mass screening of a population for signs of dementia using AI. Issues that stand out include the question of how we are seen by others, and how we are seen by the data collected via technology. The small world of the hospital ward mirrors these issues, but at the same time provides us with a smaller stage in which to observe, as research finds that the experiences of those living with dementia in hospital are not simply the consequences of their condition, but of their place in the complex social world around them.

And so we turn to the hospital ward. There is much that could and should be said, and unfortunately much will be skimmed over. For reasons of brevity we will use the time promise of technology as a linking framework for the three themes identified above: how people are observed and seen including the use of metrics and data; the various questions of control; and the identification and prioritisation of goals and tasks. We start by examining technology's promise of freeing up time for other more human tasks, moving on to discuss the need for flexibility in timing, considering what needs to be in place for such promises to be made good, considering how tensions might arise from the introduction of technology into a complex social and institutional system. Fears have long been expressed that the introduction of technology into nursing may produce merely technical provision of care through adoption of protocols and metrics (Locsin 2016); in response there have been calls for a proactive approach that reflects the central role of technology while also fostering person-centred care (Archibald and Barnard 2017, p. 2475) and for a move away from focus on adverse effects of technology to positive outcomes from nurse patient relationship

(Kitson et al. 2014). People living with dementia can be shown to be an early warning system for fault lines which potentially could impact all of us, and research which carefully observes their care can provide some clues about what might help or hinder the humane introduction of technology.

Freeing up staff time: the promise

One of the biggest claims for AI in general and within the nursing and medical spheres in particular is that by taking over mundane or routine tasks, and/or by performing tasks faster and more efficiently, its use will free up time not simply for more medical procedures and to clear waiting lists, but also for more human and interpersonal contact (Wise 2022; Buchanan et al. 2020, Mieronkoski et al. 2017). The benefit of added time for the humane details of patient care have also significant potential for the wellbeing of staff. Staff burnout in nursing and care staff is closely associated with feelings of being unable to care for patients to the high standards to which staff aspire (Vahey et al., 2004). There are complexities however; the potential clash between precision and efficiency which come with the introduction of technology, and attributes of nursing such as care and compassion has been noted (Archibald and Barnard 2017). The introduction of AI health technologies may result in nurses spending less time with patients and an increased workload (Buchanan et al. 2020).

Within the hospital ward, this future promise could lead to hopes of time for attention to personal and individual needs, to personal grooming, and for entertainment and conversation with patients, within an environment which is often one of unremitting boredom for patients within an atmosphere of constant busyness for staff. People living with dementia may especially benefit such time and attention, and thus observations of their experiences on hospital wards provides useful material to consider what must be in place for this promise of extra time to materialise. As research indicates, much must be in place.

How might extra time help? Ethnographic observations shows considerable evidence that greater attention to addressing issues such as grooming and dress can potentially have significant impacts upon the mood and behaviour of individuals. Research demonstrates the importance of familiarity including the familiar feel of a person's own clothes to ground people living with dementia in their present reality and aid memory and cognition (Buse and Twigg 2015, 2018), and that individuals living with dementia may retain an acute sense of their appearance and place in their social world (Kontos 2004, 2005) hence highlighting the importance of paying attention to this aspect of a patient's care, rather than purely to basic medical and physical needs. Neglect of appearance may add to inadvertent dehumanisation and assumptions regarding capacity (Twigg and Buse 2013).

But people living with dementia on wards were found often to have personal grooming neglected, often with false teeth and glasses missing, with men unshaven, beards unkempt, and were less likely than other patients to have personal possessions on their bedside cabinets, adding to the unfamiliarity of the environment for a group less likely than other patients to be able to cope well in such a setting (Featherstone and Northcott 2021). Those living with dementia, and indeed, older patients in general, are less likely than other

patients to be dressed in their own clothes, wearing instead ill-fitting hospital gowns which may fail to provide adequate coverage; loss or absence of familiar clothing on the ward sometimes produced considerable distress (Featherstone and Northcott 2021, pp. 50ff; Boddington et al. 2021). Featherstone and Northcott describe the 'stripping practices' (Robb 1967) on admission to the ward for people living with dementia, compared to other patients, when personal possessions are removed or hidden away: Roth and Eddy (1967: 69) wrote of the 'process of stripping the patient of moral and social identity'. The significance of this is underlined by observations which have shown significant improvements in behaviour following time taken to address such issues, such as improved communication and alertness (Boddington et al. 2021).

But for this to eventuate, the staff involved have to see any time devoted to the personal appearance of patients as well-spent, and they have to be free to choose to spend time in this way; such choice may be restricted by those higher in the hierarchy, by their own perceptions of what tasks are valuable within the setting, and by time pressures which persist despite – and in some cases because of – the introduction of technology. Featherstone and Northcott find the nurses subject to a fast-paced timetable of constant busyness, and that the hierarchical structures of the ward appear to prevent communication, reinforcing the invisibility of both the patients and the lower grade staff (2021, p.105). Moreover, there is considerable evidence that nurses have preferences for task-based care over the psychosocial needs of patients (Kitson et al. 2014; Mieronkoski et al. 2017) but that the fragmentation of tasks may interfere with care provision (Feo and Kitson 2016).

Observations have shown that such barriers to freeing staff time persist within hospital wards, with pauses in work discouraged, continual self-surveillance as well as close monitoring of colleagues to enforce acceptable busyness (Featherstone and Northcott 2021, p. 117, 144). In illustration, during periods of quiet on a ward, a healthcare assistant arranged for three men who were each living with dementia to have a 'race night' with a horse races on a games console, only to be reprimanded by senior nurses, following which a doctor arrived who publicly scolded the healthcare assistant for slowing his timetable and insisted patients be put back in bed (ibid.). Other examples could be given. Implicit attitudes towards more person-centred aspects of care can also be seen in how technology was used on the wards. Medical technology was in constant use, yet the wards frequently contained technology such as TV sets which were rarely if ever used (Featherstone and Northcott 2021, p. 24); attempts to use these could be foiled because nobody knew the password (Featherstone and Northcott 2021, p. 145).

Time and communication: when slow is good

It is important to understand that the potential benefits of any saved time should also apply to tasks currently undertaken but under time pressures which hamper communication for those who have difficulties in comprehension or simply operate more slowly, a frequent issue on the wards. Let us examine one example, the medications round. The medications round is signalled as possessing a particular urgency, with nurses wearing 'do not disturb' tabards, and with the understandable requirement for careful logging and checking of the administration of medications. But people with dementia admitted to hospital are usually

already on a regime of medication at home, which is often changed upon admission, hence often prompting queries or resistance, which staff may not have time to address or may explain simply as what the doctor ordered, and which resistance they may attempt to overcome (Featherstone and Northcott 2021). The person living with dementia thus also frequently becomes the 'non-adherent' patient in respect of medications. (The implications for the use of care robots for the administration of medications will be obvious and merits further consideration outside the scope of this paper.) The process of helping a patient with food is equally complex.

The institutional culture of time, task, and efficiency

But for technology to be used in a way that frees up time for communication by the use of technology, the need for this must be recognised on the wards, including the validity of many often 'irrational' seeming forms of resistance and questioning, and including recognition of how tasks higher up the pecking order may be interfering in such a process. Spending time with patients in communication and personal care would need to be valued as one of the recognised 'tasks' of the hospital. But to do this requires certain views of the role of the hospital and the task of medicine, as well as certain views of the person. We need to see the whole human being in a humanistic way.

Providing food and medication to individuals is not simply getting fuel or drugs into a body, but involves interacting with a human being in a socially embedded way. The privations of the hospital ward may be harder to bear for some than for others, and again the group of people living with dementia – unfortunately for them – act as an indicator of neglect. It has been noted above the material familiarity of one's environment, such as clothing, can aid in the orientation and alertness of a person living with dementia, and likewise the social rituals of mealtimes may help a person maintain orientation to their place in a social world. Kontos (2004, 2005) has found that the rituals of dining and dress may be well understood even by those with profound cognitive difficulties. For some patients, this may be an added extra, a 'luxury'; for others, something more deeply necessary, especially as we remember the rapid decline and deconditioning that routinely happens to people living with dementia on hospital wards. Attention to such details is the warp and weft of a humanistic approach, and we must ensure that technology respects and enhances this, especially in the face of experience to date which shows how technology itself can become the focus of attention (Barnard 2002, p.21). The introduction of technology itself needs to be cognizant of such issues, especially as the general institutional aim of efficiency which might spur its introduction assumes a task- and speed-oriented social world.

This means that we must simultaneously address the culture of the institutions including the local culture of wards onto which technology is introduced. Yet Featherstone and Northcott's findings showed the culture of the ward was profoundly shaped by its timetables and by the need for completing tasks efficiently, and concluded that roles which could not be quantified or reduced to data, such as talking to patients, were invisible (p. 86 ff). 'Value was placed on the prompt completion of a routine timetabled task, rather than the interactions with patients (or missed opportunities to do so) around them. Stopping to talk to a patient, to listen or to reassure them, despite its value for staff, patients, and the wider work of the shift ... was typically overlooked and unrecognised. *These interactions*

could not be quantified or recorded with the available mechanisms, lacked organisational value, whereas the timing and completion of task-based care would be highly visible and documented.' (p. 90, emphases added). We see then, the long arm of data and metrics.

Time and timetables

Observations on the wards also reveal the need for flexibility in the timing of care. Here attention to the clashes or arrhythmias arising from the imposition of linear institutional rhythms upon the cyclical time of the body is useful, showing the necessity of understanding the full person living in their body within a social world including attention to local culture in integrating technology. Here the institutional context of the hospital is pertinent. Osborne, Lowe, and Meijering used rhythm analysis to examine informal care practices for people living with dementia at home, finding that 'in dementia care, the body's circadian rhythms take precedence instead, broadly resisting dressage - with the only exception being for medical appointments' (2023, p. 5). In contrast, Northcott and Boddington (2024) found that the linear rhythms of the hospital ward frequently overrode the cyclical bodily rhythms of the person living with dementia. This had implications not simply for the provision of particular tasks, but for the dignity and social standing of the person.

Take for example, continence care such as the fitting of catheters and the changing of continence pads (which were often used even for continent patients 'just in case'). It was not simply that these means were used to help facilitate ward timekeeping; it was not simply that patients might be made to wait for pad changes or that they denied or discouraged from accessing the toilet; tasks which were seen to be 'medical' could interrupt other tasks, and tasks arising from hospital timetables, such as the provision of meals, were given priority over personal care tasks arising from the cyclical rhythms of the patient's body. Catheters caused discomfort and confusion and men living with dementia frequently removed them, meaning that they would then be refitted. The timing of this could be an issue. Catheters might be fitted, even though a patient had visitors or was in the middle of eating. Likewise, a patient in a soiled pad might be made to wait to have it changed, because lunch had arrived. The patient living with dementia suffers indignity with the socially inappropriate situation possibly adding to any confusion and disorientation. The ethnographer observing this is acutely aware of the social transgression and insult. It must be emphasised that these studies found no instance of abuse by staff but nonetheless, the routine nature of such events, otherwise acutely out of kilter with due respect for a person's social standing, renders them invisible to those swept up in the ever-present demands of busyness and the medical mandates of the hospital. Technology surely has the potential to help provide care that reflects the needs and rhythms of the individual person, but again, attention to such issues is vital for the adequate and humane implementation of technology.

Time, technology, and the construction of 'disobedience'

Lastly, a few observations. We have noted the driver of efficiency both within the institution and implicit within many uses of AI and other technology. Observations on the hospital ward alert us to the fact that the notion of efficiency also helps to create the notion of the 'disobedient' patient, the one with the most trouble fitting into the timetabled efficiency of

the ward, who requires too much explanation about why their tablets now look different, and so on, with the consequent hazard of a worsening of status and of behaviour via looping. People living with dementia have provided a useful test case to alert us to this possibility which surely lurks for many if not all of us as technology proliferates into the infrastructure all around us. We face a world where those most resistant to the use of particular applications of technology, or to the medical imperative, to passive data collection perhaps, are also, perhaps unknown to them, seen as disobedient or non-adherent, possibly then subject to further attempts at control. This possibility does not seem compatible with a humanistic approach to the adoption of AI and should be guarded against. It represents one of the many ways in which the use of AI may exert control in profound ways which arise from the socio-technical system into which it is embedded and hence, which might escape notice.

We have seen above concern that patients living with dementia were 'wandering' and strategies to prevent this, arise at least in part because of the necessity of preventing falls, including the mandated recording and reporting of falls. Especially given the vast capacities of AI to capture and analyse data, this should alert us to the potential of recorded data to be used in ways that might assist patients but which might also be used to add to practices of discipline and control, especially if the recorded data feeds back into an institutional system of rigid hierarchically nested tasks, where attention is drawn to metrics and to technology at the expense of the person.

'Disobedience' is a strong term but can also be understood in terms of Lefebvre's notion of 'dressage', the ways in which linear rhythms are imposed via discipline upon the recalcitrant cyclical rhythms of the body, especially when arrhythmias occur. This was found to operate frequently for people living with dementia on the hospital ward in particular who had difficulty in otherwise 'obeying' the rules of the ward. 'Dressage is achieved in a number of ways: by the physical layout of the ward and its furniture; by the actions of staff such as repeatedly tucking patients into bed or raising the bedrail to prevent movement; by the use of objects and technologies, such as catheters and pads to discourage use of the toilets, and so on' (Northcott and Boddington 2024). Featherstone and Northcott (2021) found that on the wards, technology often had a dual use function to control the 'imperfect' patient. Any introduction of AI technologies into such a situation must be alert to such possibilities. To do so involves far more than simply abstract concern with 'autonomy' but will necessitate careful observation and critique. Even something so basic as the desire to use the toilet instead of a pad is worthy of attention and inclusion in any project to use AI in a way consistent with humanistic principles.

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