

Digital technologies as truthbearers in healthcare

Bartlett, Ruth PhD *

Faculty of Health Sciences, University of Southampton

Balmer, Andrew PhD

School of Social Sciences, University of Manchester

Brannelly, Petula PhD

Faculty of Health Sciences, University of Southampton

Corresponding author:

Ruth Bartlett

Centre for Innovation and Leadership in Health Sciences

Faculty of Health Sciences

University of Southampton

Southampton

S017 1BJ

Abstract

In this paper we explore the idea of digital technologies as truth-bearers in healthcare, and argue that devices like SenseCam, which facilitate reflection and memory recall, have a potentially vital role in healthcare situations when questions of veracity are at stake (e.g. when best interest decisions are being made). We discuss the role of digital technologies as truth-bearers in the context of nursing people with dementia, as this is one area of healthcare in which the topic of truth-telling has been hotly debated. People with dementia have been excluded from research studies and decisions that affect their lives because they are not regarded as truth-bearers – that is, as being capable of giving truthful accounts of their experiences. Also, considerable research has focused on the ethics of lying to and deceiving people with dementia. Given their increasing prominence in healthcare settings, there has been surprisingly little discussion of what role digital technologies might play in relation to these questions of truth and deception. Drawing on theories from science and technology studies (STS) we explore their possible future role in some of the truth-making processes of healthcare. In particular, we discuss the potential value of and constraints on use of SenseCam to support the accounts of people with dementia as part of their care.

Key words

Advocacy care; agency; citizenship; dementia; technologies; truth bearing; truth telling.

Introduction

The role of digital technologies in healthcare has been widely discussed, as has the topic of truth-telling and deception. In this paper we coalesce these two research areas to argue that advanced digital technologies may have a future role to play when truth-making is at stake within a healthcare situation. In particular, we suggest that lifelogging technologies such as SenseCam, which facilitate reflection and memory recall, could be better utilised to support the accounts of people with dementia in the context of caring practices, especially advocacy care and when veracity is at stake during best interest decision-making. To explore this topic we borrow important insights about technology and healthcare from science and technology studies (STS). STS allows for nuanced accounts of how technologies become agents within situated practices and as part of sociotechnical networks (Latour, 2007). As such it provides a useful framework for analysing the process of truth-making between different actors. We also consider the implications of this account for human agency, given that certain STS approaches, such as 'actor network theory', emphasise that human agency is also enacted by virtue of sociotechnical networks and not given in advance of the healthcare situation. Adopting this approach helps to overcome the reductive tendency which often accompanies utopian and dystopian visions of technology's role within healthcare systems.

There has been much discussion about truth-telling and deception in the context of care, especially from the perspective of nurses and other healthcare professionals. For example, the question has regularly been posed as to whether or not nurses should always tell the truth to patients in regard to their diagnosis and illness (Hodkinson, 2008). One review of the literature on truth-telling in clinical practice found that telling the truth was understood to be an 'intrinsic good' (Tuckett, 2004). At the same time, the

importance of nurses 'bearing witness' for people, that is, being present and attentive to the truth of another's experience has been examined. As Naef (2006: 149) argues, 'bearing witness is a distinct way of being and relating to another person' and is an inherently moral process. As such, the nurse's role with relation to truth in caring practices is increasingly regarded as a critical component of providing quality person-centred healthcare and of respecting the patient's selfhood. We borrow the concept of 'truth-bearing' from this work, but extend its application to technological agency, to show that the potential of technological truth-bearing in this context depends upon the particular arrangement of sociotechnical actors to be found within caring practices.

At the same time, as arguments for the importance of truth in the care relationship have been made there have also emerged healthcare settings in which deception and lying have become normalised. Care of people with dementia presents a particularly notable case of such normalisation, for in this context individuals are often characterised as less than full persons, not only by virtue of their diagnosis, which may make conventional forms of communication difficult, but also because of long-standing and deeply ingrained stigmas around ageing and mental health. A person with dementia might struggle to talk, have difficulty remembering people, places or things, lose track of the time or their place in the world, change in personality, emotional or affective disposition, and might eventually find it extremely hard to accomplish everyday tasks such as brushing their teeth. In this case, 'failures' of personhood seem to invite shifts in carers' information sharing, so that nurses and carers of various kinds are more willing to conceal information, misrepresent situations, deceive and tell lies in order to maintain the ease of routines of dressing, eating and visiting, avoid uncomfortable truths and painful memories, and to facilitate smooth processes of medical care. Deception, then, just as much as truth, has become an important issue in

the everyday care of people with dementia, and whilst some work in this direction has been conducted, there remain important questions regarding how the links between personhood, truth, deception and care are negotiated. Most critically for our purposes, the question of how we arrive at a claim to 'the truth' of a person's experience when they have dementia has been under-examined, particularly with regards to the uses of technology in nurses' truth-making practices.

In this paper we begin to open up the question of how technologies might be used in truth-making practices, set against the background of the normalisation of deception and lying in the care of people with dementia. We propose that nurses and other health professionals might experiment with how technology can be used to 'bear witness' to people's experiences as part of everyday caring practices and during periods of important decision-making. The 'Microsoft SenseCam' is chosen as an example of an advanced digital technology, as it is beginning to find traction in healthcare settings, particularly in the context of people with dementia to facilitate reflection and memory recall (Browne et al, 2011). The SenseCam is an advanced integrated sensor system, or 'lifelogging' technology, which comprises 'a neck worn sensor package, including a digital camera that takes images automatically, without user intervention, and sensors that note change in light, body heat, and a three axis accelerometer' (Bharucha et al., 2009: 96). Exploring the current research on this technology we expand consideration beyond improving memory to examining its effect on the way in which agency and truth are enacted in the care of people with dementia. In doing so we also attend to some of the philosophical and moral complexities involved when digital technologies take on such roles. Developing an STS position on technology, agency and truth-bearing we are able to put forward an account which defends the importance of a situation-specific

judgement of the effects and potential of such technologies, avoiding the traps of 'techno-fix' and 'techno-peril'-type arguments.

Truth and technology

Truth is regarded as a central philosophical notion, 'perhaps the central one' (Engel, 2002: 1). It has been described by moral philosophers as a 'need of the soul' – in that we constantly seek to know the truth about a given situation to feel good within ourselves, and to do good for others (Gaita, 1998). More broadly, whether and how one can know the truth has been *the* central epistemological question of philosophy, and is one which philosophers have been grappling with since the foundations of the discipline. But it is also a practical consideration, one which must be solved by reference to the specifics of many everyday situations, not least of which are to be found in the healthcare system. Most generally, knowledge of a person is often a precondition for quality care. Consider, for example, how important it is for a ward nurse to know the truth about a patient's admission, and the challenges that nurses will face if the patient is too unwell or cognitively impaired to provide such relevant information. How does one ascertain the truth in this situation? There will always be doubt as to whether other informants, such as family members, paramedics or witnesses to an incident are reliable sources. Practices have been developed in relation to the particular aims and functions of different healthcare settings which allow for the resolution of such issues in a timely and orderly fashion. How we make the truth thus varies from place to place.

Over several decades, STS researchers have developed multi-layered accounts of how knowledge-making depends upon the configuration and maintenance of sociotechnical networks. One of the key approaches has been to describe the situated

nature of truth-making processes, detailing how truths are arrived at in a fashion that is dependent upon the particular relations established between material and social actors within a given network or set of practices (Latour 2007). This has had much to do with the recognition that social life is entangled with material life; human agency with material agency (Latour 2007) and that strict philosophical divides between living and non-living, politics and science, nature and society are not reflected in the mess of lived reality.

Such arguments have been known to various strands of sociological and philosophical work, for example in social constructivism. But moving beyond such approaches, STS has challenged the reduction of meaning to 'context', as is common in these prior frameworks, showing instead that it is the practices through which actors are brought together which enacts such things as 'truth' and 'agency'. In this regard, the position is not only epistemological – regarding how we know about things – but also ontological – regarding what things are. As Woolgar and Lezaun (2013: 323-324) explain:

Objects do not acquire a particular meaning in, or because of, a *given* context; they cannot be accounted for by reference to the external circumstances of their existence. Rather, objects are brought into being, they are *realized* in the course of a certain practical activity, and when that happens, they crystallize, provisionally, a particular reality, they invoke the temporary action of a set of circumstances.

The consequence is that what things do and what they are, things like the SenseCam for example, depends upon how they are networked with other material and human actors within specific practices.

Moreover, and perhaps even more controversially, STS has proposed that human capacities are also enacted within such networks – what we can do and what we are depends upon the arrangement of the networks of actors through which we move. Agents and their power are the effect of sociotechnical networks. As Harbers (2005) summarises:

The core of this theory is the principle of radical symmetry between human and nonhuman actors, which dissolves modernist demarcations between living, consciously acting, and communicative subjects on the one hand, and dead, deaf-mute, and merely instrumental objects on the other, that is: between culture and nature, man and machine, society and technology. (Harbers, 2005: 15)

Developing this kind of argument, Cussins (1996) shows that an individual's agency within healthcare practices is enacted not simply by reference to their apriori selfhood, but through a heterogeneous and ontologically complex network of actors, including – for example – medical images, chart records, body parts and samples, numbers and so forth. How their selfhood coheres or is challenged depends upon the arrangements of things beyond their immediate bodily form. This means that people and things differ across sets of practices, or, as some have argued, we live in a multiplicity of worlds (Law and Lien, 2012)

To acknowledge that 'things' are enacted within practices, that they might differ across practices, that things are agents, and that human agency is also enacted, has become a set of key tenets in the contemporary approach to bodies, people and materials in STS (see Woolgar and Lezaun, 2013 for an overview of an important special collection on this subject). However, nursing scholarship has not made as much use of this research as it might do, especially given the increasing integration of digital technologies within healthcare practices. Making sense of how digital technologies like

the SenseCam might figure within care practices and what roles they might play in truth-making must take account of these key insights.

If we return to the ward nurse example, it is now possible to begin to see how the truth-bearer role and process of making the truth is enacted within the particular practices of bureaucracy, admission, nursing, observing, caring and visiting within an everyday healthcare setting. Any number of technologies, from computers and clipboards to syringes and stethoscopes might be involved in such practices and will play a significant role in how the truth of a patient's illness is produced. In particular, the entanglement of bodies and technologies within specific sets of healthcare practices shows how a truth about a patient can come about without that person themselves having a say in the truth-making process. Many actors and technologies have a voice in the healthcare situation, but not always the patient, an issue that is particularly acute in the context of care of people with dementia.

On this note, healthcare research has shown how power relations are shaped by the relations between people and things. Moreover, it has shown that it is important to analyse how truth used in relation to particular healthcare outcomes. A good example from nursing research is Ceci's (2006) study of what it means 'to know' within distinct caring practices, specifically as regards the day-to-day practices of case managers. Ceci (2006) found that multiple truths about a client's situation could emerge through processes involving the care manager, client, and the system of devices, reports, principles and so on. However, due to organisational and economic constraints care managers tend only to 'see' and use certain forms of knowledge and communicate certain truths to decision makers and funders (Ceci, 2006: 93). Drawing this research together with STS insights further emphasises the ways in which truths are made in relation to people, materials and power, highlighting the importance of attending to

how patients' agentic status and capacities are enacted as part of situated practices. Different sociotechnical relations help to bring about more or less politically and ethically-desirable outcomes as regards the silencing or highlighting of particular agents' voices.

This is particularly important in the context of caring for people with dementia, and moves us away from purely philosophical ideas into the realm of citizenship. Here, the practice of truth telling is considered integral to being a 'good citizen' and 'subject of government; it is crucial to citizenship because it is what enables one to produce specific truths about oneself and therein show 'care for one self' (White and Hunt 2000: 95). Thus, individuals have the right to expect opportunities for truth-telling in order to be considered as full citizens, which is never more pressing than when they are the actors about which truths are being made, and which might have powerful implications for their lives (for example, when decisions are being made about whether a person should be placed in a care home or discharged from hospital). It follows that whenever a person is denied the opportunity to play an agentic role in the truth-making process they are denied such citizenship. This is because they are deprived of the opportunity to take care of themselves. With the STS perspective we begin to see how an individual's citizenship and their ability to contribute to the truth about their situation is something which must be arrived at through the particular arrangement of actors in the relevant set of practices. All of which raises, for us, three interrelated questions (1) how is the truth currently denied to people with dementia (how are they deceived and lied to); (2) how are they discredited as agents and as truth-bearers about themselves; and (3) what role might digital technologies have to play in helping to rearrange the sociotechnical practices which enact agency in this context? We now turn our attention to these questions.

Selfhood, truth and deception in the context of dementia

Historically, the diagnosis of dementia has meant an immediate assumption of incapacity, an expectation that people were not able to contribute meaningfully to social relationships and society more generally due to cognitive impairment (see for example Berrios and Porter, 1995). Over recent years, this assumption has been challenged, with the introduction of presumed mental capacity (in England and Wales Department of Health 2005), legislated to protect the right to self-determination where possible, resulting in decision-based assessment of capacity. This shift has been welcomed as a protection for people with dementia to be involved in decision-making for as long as possible, capacity allowing. But inclusion in decisions is offered through care relations, where the legacy of assumed incapacity may well endure as a cultural norm. The way in which existing care practices are organised might constrain the opportunities for people with dementia to be treated as agential subjects in truth-making processes, excluding them from bearing the truth on their own behalf.

Being seen as a viable witness to bear truth in a given situation is compromised not only by the material, often neurological effects of dementia, which might affect – for example – language and the reliability of a person’s recall, but also by the ways in which practices of care tend to concretise this disqualification of agency of a person with dementia. Stigma and norms around mental health, as well as an implicit neurological determinacy tend to result in people with dementia being understood as being in continual decline, so that they are less and less able to take up a position in truth-making process. They are positioned according to certain expectations of their capacity (Sabat, 2005) such that their ability to bear the truth is often questioned irrespective of how capable they might be at any given time and in any given situation. What we have

seen from the STS literature, however, is that the agency of a person with dementia may change if the particular set of agents in their immediate network changes. Whilst this is theoretically the case, in practice exclusion from agency is quite commonly fixed, rather than experimented with.

One key dimension to this concretisation of their exclusion as full agents is that once individuals are understood to be incapable of truth-telling this often leads to those individuals being lied to and deceived, for they become excluded from the regime of truth more broadly. The relation between an individual's truth telling status and the willingness of others to engage in deception has thus become a burgeoning topic in research related to the care of people with dementia.

Kitwood (1997) noted that the culture of care for people with dementia is not malicious, it has just gone unchallenged and has thereby embedded certain norms and allowed breaches of other norms where otherwise they would be corrected. As regards our immediate interests, for example, current evidence suggests that lying and deception are common practice in the care of people with dementia, albeit often well-intended to prevent distress to the person with dementia. For example, Elvish et al. (2010) found that 97% of people in paid care for people with dementia lied for various reasons. These included protecting the person from distress, for example to avoid retelling them of the death of a loved one, or to encourage them to do something that would avoid potential harm at a later stage, such as keeping a chiropodist appointment. Carers may ask the person to get dressed as their relative is visiting, although they know they are not. In these situations, people with dementia are viewed as being less than full persons, as they are deemed unable to discern a truth from a lie, which can lead to them being discredited from participation in conversation according to common conventions of information sharing.

Seaman and Stone (2015) conducted a qualitative meta-synthesis to examine the practice of deception in the care of people with dementia, noting that more research had been conducted with medics, health professionals and family members than with people with dementia. Perhaps partly because of their exclusion from such research, all of the studies found that there was a general acceptance that deception was a therapeutic intervention when conducted in the best interests of the person, and that it was usually done to eliminate or decrease the chance of distress. The motives, modes and outcomes of deception occur in contexts that have many influencing factors, cognitive capacity being just one of them. For example, Seaman and Stone's analysis identified two assumptions: that particular actors only deceive in particular institutional contexts; and that people with dementia are understood to be incapable of deception and as such lack agency. Ceci (2006: 96), showed that in a specific exchange between a care manager and a woman caring for her husband such 'assumptions are taken to represent the truth'. That is, that the assumptions of the care manager come to constitute the truth of the situation, thereby discrediting any other claims to truth partly by discrediting the person with dementia from having agency and thereby as being capable of bearing truths about themselves.

The effects and ethics of such routine deception are yet to be fully explored. It is important that they are, for systematic networks of deception might operate not only to protect people with dementia (from harm or emotional pain) but also to conceal truths from people with dementia in more dangerous ways, for example when major decisions are being made about their lives, such as in treatment decisions or when considering placing a person in residential care.

Organisational norms and cultures, alongside the values of practitioners are likely to influence how individual practitioners approach honesty and deception in

caring practices. But it is also true that they are not the only people with values involved in this situation. Barnes and Brannelly (2008) noted that cognitive decline in dementia might mean that people may not easily remember what their relationship is to any given person around them, but the intuition of the person with dementia may remain, and be used to assess how trustworthy another person is, for example when they appear to be offering help. People with dementia may not always be able to contribute to decision-making processes in the conventional form of conversation but this does not mean that their sense of trust in those around them is also unavailable. We must not use instances or more general loss of single capacities as evidence for a lack of full agency of people with dementia. Instead we should work to reorganise relations within the given situation of care in order to help sustain the agency of a person with dementia.

This body of evidence suggests widespread deception facilitates the censure of people with dementia, reducing their opportunity to contribute as truth-bearers to practices of truth-making. It calls for consideration of how to assist people with dementia to have their voices not only heard but made to count in the decision making process. Mechanisms are clearly required that enable individuals with dementia simultaneously to influence key decisions regarding their future as much as possible, and to establish and maintain trust in care relationships. Finding ways of supporting people with dementia, through digital technologies may offer one route (alongside others) to challenging the normalisation of deception in the culture of care, open opportunities for people with dementia to exercise certain forms of agency and speech, and to thereby improve advocacy care.

Digital technologies as truth-bearers

Advances in modern digital technology in terms of recording, capturing, and transmitting information - or 'truths' - have the potential to reconfigure how truth-telling and knowing occurs in a range of situations. The explosion of web 2.0 and intelligent digital devices, which allow for measurement, recording, feedback and communication of data and information, sometimes in a context-sensitive fashion, are already proving influential. Take, for example, the broader changes occurring in everyday life, where the 'internet of things' assembled within smart homes, neighbourhoods and cities is gradually becoming a socio-technical reality (Atzori *et al.*, 2010). Increasingly, governments across the world are recognising the potential of these technologies and looking to a future of digital welfare (From, 2015).

Manifestly, digital technologies already play a role related to truth and trust in many social relations, where they might act as a 'token of trust' between parties who have no intimate knowledge of each other, but who need to have faith in each other's supply of information, their identities or intentions (Lyon, 2002). Biometric passports, contactless payment cards, magnetised access swipe-cards and LinkedIn profiles are just a few examples. Such relationships are increasingly common as social interactions occur in more fleeting ways and at greater temporal and geographical remove, and indeed professional caring relations are also increasingly characterised by haste and impersonal connections. The role of digital technologies in bearing the truth has perhaps never been greater.

According to Lupton (2016: 3) 'people are now encouraged, obliged or coerced into using digital devices for monitoring aspects of their lives to produce personal data' in relation to healthcare. This might include, for example, self-monitoring of blood pressure or physical activity levels. Since such technologies 'create and recreate certain types of digital data assemblage' (Lupton, 2016: 3) they have been enrolled into the

broader structures of (self-)surveillance that characterise contemporary social order and certain mechanisms of social control. Against a purely dystopian image, we argue that digital technology may have some potential to play a more positive role in the truth-making process, especially for people with dementia who are routinely disbelieved and positioned as incapable of bearing the truth on their own behalf.

As a 'life-logging' technology, comprised of a digital camera and sometimes other passive recording devices, the SenseCam can be used alongside a custom-designed browser (Doherty *et al.*, 2011), which enables users to engage with the data (images, locations, time, people present) collected in particular ways. For example, they can view the many thousands of pictures taken by the SenseCam according to date, but also using techniques of 'event segmentation', which separates one event from another using particular ways of conceptualising 'an event', as well as by use of tools which draw associations between similar events, automatically identifying events that might exhibit personal salience and highlighting those events that might be most important. Given this suite of possible methods for logging someone's everyday life, researchers and health practitioners have begun to use the SenseCam in a range of care situations, including in the context of dementia (Browne *et al.*, 2011; Hodges *et al.*, 2006; Piasek *et al.*, 2011; Piasek *et al.*, 2012; Piasek *et al.*, 2015; Piasek and Smeaton, 2014). We draw on this emerging literature to think through one potential application of the SenseCam, namely as a truth-bearer, and show that when implementing new digital technologies within healthcare practices it will be important to attend to the way in which technological and human agency is brought about in relation to existing care practices.

In a review of intelligent assistive technologies and their use in the context of care of people with dementia, Bharucha *et al.* (2009) found that the devices were being used as cognitive aids, physiological sensors, environmental sensors, as advanced

integrated sensor systems and as geospatial tracking tools. Furthermore, artificially intelligent assistive technologies have also been used to engage people with dementia in creative occupations (Leuty *et al.*, 2013) and a number of artificially intelligent ‘assistive robots’ are currently being developed (Metzler *et al.*, 2016). However, we found no evidence of advanced digital technologies being used explicitly in a truth-bearing role to support the enactment of people with dementia as full agents within truth-making processes.

That being said, within relations of care, advanced digital technologies are beginning to play a role in maintaining the identity of and supporting the accounts produced by people with dementia. Most notably, researchers are reporting on the value of using technologies like SenseCam to supplement a person’s memory and ability to narrate biographical information (see work by Piasek *et al.* 2011; 2012; 2015). These researchers and others have suggested that a person’s memory and personhood could be at least partially maintained within caring practices through use of the SenseCam device and software.

However, in our view, the functionality of technologies like SenseCam is currently under-utilised and has not been considered in enough philosophical detail. They could be used more to support and empower people with dementia at transitional points on the journey when veracity is at stake; for example, when judgements about a person’s care and treatment options are being made. STS insights help guide us in this work by pointing to the importance of paying attention to how the introduction of such a novel digital technology forms and deforms the agency of a person with dementia by regard to how it takes up a role in caring practices by relation to other actors. To exemplify this we turn to Hodges *et al.*’s (2006) study. They show that one woman with dementia found the SenseCam technology useful:

Mrs B said that seeing the beginning of a clip brought memories ‘flooding back’. Her descriptions of events demonstrated that she remembered the events themselves, rather than the SenseCam pictures alone. For example, she would remark that someone had been rude to her on a particular day, or that the food hadn’t tasted nice – clearly this information is being recalled from her own memory (Hodges et al., 2006: 190).

In this study, the SenseCam technology was being used to elicit Mrs B’s recollection of past experiences; events had been recorded passively by the camera, and selected out of the mass of pictures using software to stimulate her memories of the recent past. Hodges et al. are impressed by the ability of SenseCam to help support the memory of a person with dementia, and thereby to slow decline in memory. However, it is clear from the excerpt that the technology also helped in as much as Mrs B’s account of her experiences could be better believed by others and used in her ongoing care by virtue of the way in which the SenseCam was being treated as a truth-bearer. It is this latter point that is particularly important for our claims regarding its potential because it highlights the issue of how human agency is enacted alongside that of the technological actors involved in situated practices. Introducing SenseCam into the practices of care helped bring about a shift in the agency of Mrs B with regards to the specific set of actors involved in her caring situation. SenseCam might help to support the agency of people with dementia more broadly.

As described above, technological agency has been well-documented in the field of science and technology studies (STS), which has shown that technologies certainly do act as agents within a given situation due to their place within locally-situated practices that join together different actors, objects, concepts, ways of knowing and so forth,

allowing them to take on quite different properties from place-to-place and over time (Barad, 2007; Law and Lien, 2012; Woolgar and Lezaun, 2013; Mol, 2002).

Using this work we see that SenseCam's agency is enacted through taking pictures according to its own schedule, determined by algorithms in the firmware, and combined with the software's agency (in selecting out significant events) which together can combine to support the agency of a person with dementia, not simply by confirming their memory of events but facilitating their ability to speak about their experiences as an agent bestowed with truth-bearing capability. What is most salient for our purposes here is that the technology's agency combines with Mrs B's agency to support her truth-bearing role as well, but only as part of the situated relationship between Mrs and Mr B and the other actors involved. The carer himself pointed out that the device helped him to trust the accounts that Mrs B provided as veracious and not simply as being learned by repetition or randomly produced. In this way SenseCam was understood to provide independent confirmation of her statements because of the way in which it took its images, and how the software helped to order those images according to particular timelines or themes. Given this role, the technology fostered a corresponding relationship between representations of Mrs B's experiences and her statements, which brought Mrs B's narrations into the realm of sense for those around her, helping to challenge the assumption that her previous failures to make sense when documenting her experiences had permanently discredited her as a bearer of truth. The implication being that Mrs B was perhaps still able to discern truth from lie. In this regard, integrating the SenseCam into caring practices can help to enact the agency and citizenship of people with dementia by challenging the way in which they are discredited as truth-bearers. This might not always be the case, for a person's capacities might shift from situation to situation and the set of actors will change from place to

place, meaning that how SenseCam works and how the images are interpreted will also change. But on some occasions SenseCam might support people to bear the truth about their experiences. And by showing that this is possible, it might help to foster a retreat from the normalization of deception, misinformation or lying to people with dementia, helping to reinstate them as citizens with rights to the truth about what is happening to them.

On this account it might seem that such use of technologies as truth-bearers is inherently helpful for challenging lying and discredited agency, but of course digital technologies are also often a part of a global assemblage of surveillance devices (Haggerty and Ericson, 2000), which may have quite nefarious purposes and at the very least have immediate implications for privacy (Lyon, 2003), identity (Barnard-Wills, 2012) and freedom (Los, 2006). But we cannot adopt either a naïve dystopian vision nor a naïve utopian one. Technological agency changes by virtue of how it is enacted within different sets of practices. Digital technology's use in care practices is thus bound to be characterised by ambivalence. As Barnard (2016: 9) recently summarized:

Technology is both good and bad and will be used in ways to bring about expected and unexpected outcomes. This tendency towards ambivalence highlights its lack of neutrality. It can be both enabling and oppressive (witness, for example, the debate(s) in midwifery around 'natural' and 'interventionist' birthing). It works often as planned but sometimes leads to unforeseen outcomes (e.g. thalidomide; excessive machinery in nursing environments) and often places requirements on us to upgrade knowledge and alter skills. Technology is political[.]

We can demonstrate this ambivalence in the context of SenseCam and dementia. In another case of using the SenseCam to support memory, Piasek et al. (2011) used the device to help elicit talk from John, a person with dementia, as part of a therapeutic

intervention as with Mrs B, but the researchers found that other coping practices that John used with his wife interfered with this. John's wife, Mary, would often bring her way of interacting with John, in which she would support his accounts, correct him and encourage him, into the therapy situation with them. What the technology could do was therefore changed by the specificity of the relationship and how the caring practices were organized in the therapeutic situation. The researchers found that:

As the therapy continued it became apparent that similarly to John mirroring his everyday coping mechanism, Mary mirrored her interactions with John from outside of the therapy time into the sessions. This happened despite the clear rules of CST [the therapeutic intervention] being explained in the plain language statement, prior to and throughout the therapy (Piasek et al., 2011: 312)

Here, then, the technology's ability to act as truth-bearer and to facilitate an increase in John's agency was constrained by the use of other kinds of caring techniques within John and Mary's everyday practices and by the stubbornness of their everyday (caring) habits. Mary's actions did not allow for SenseCam to provide a supportive account. What this means more broadly is that technologies like the SenseCam might be able to take on an empowering, truth-bearing capacity to alter entrenched practices which enact people dementia as discredited agents, and to challenge the corresponding information concealment, deception and lying, but only in situations where such empowerment is possible or sought, according to the existing sociotechnical relations established in those situations. For SenseCam to work, people have to be willing to work with the images it produces, to learn how to make use of its mechanisms within their existing practices, and to be willing to consider it a support to the person with dementia's agency. It will not do so just by virtue of its presence.

As such, it might only be appropriate to use these devices in particular places and at particular times and for particular purposes. The question thus becomes not whether we should use these technologies in the future or not, or whether they will bring about utopian or dystopian ends, but rather how and when we should use them within a given situation, relationship and set of caring practices, on a case-by-case basis. We have to do so by attending to the ways in which SenseCam can be used in a given situation to support the agency of a person with dementia and not in a one-size-fits-all manner. This would take heed both of the ambivalence of technology, how its agency is enacted through situated practices, but also of the limits of the technology to shift the existing ways of enacting a person's agency, which might sometimes be found to be quite difficult to change in any given caring scenario. SenseCam and other digital technologies do not present a utopia of care, they cannot be an easy fix, but nor are they just another technique of domination.

Conclusion

As we have argued in this paper, digital technologies may help to support the truth of people's experiences of care; they might help to assist the person with dementia in their role as truth-bearers, for example by helping them to relationally construct a coherent and trustworthy account. Although the use of deception within professional care environments may not be malicious, and could be the result of strains on a system that increasingly depends upon haste and momentary or fragmentary caring relationships, it is nonetheless inimical to the full appreciation of a person with dementia as a full person. The latest digital technologies provide a new possibility for aiding the person with dementia, and to help shift the sociotechnical relations through which their agency is enacted, allowing for them to be reinstated as having agency,

personhood and citizenship, especially in paid care contexts. Such a shift might help change the culture of deception and lying for the better, by changing how truth-making practices are arranged so as to support better information sharing in both directions of care.

Although we have focused on people with dementia, the argument applies to other groups whose capacity to provide factual accounts of their everyday life might be called into question, including, for example, adults with a learning disability. Advanced digital technologies might have an advocacy role to play here as well.

At the same time, it must be recognised that technologies such as SenseCam also threaten to further disempower and silence people by replacing their agency with the apparent objectivity of such technologies. All of which is to say that we must integrate new technologies into caring practices *carefully*, ensuring that it is done in order to improve the agency of those in care and not to displace it.

Such ambivalence of technology is unavoidable, but rather than posing a fundamental problem for the introduction of digital technologies into healthcare practices in the future, this complexity instead calls upon nurses and other healthcare professionals to ensure that technologies are used as part of caring practices to help support and empower people in ways that are tailored to the existing arrangement of actors in a given situation.

More evidence is needed before digital technologies like SenseCam can be effectively integrated into advocacy care in this manner, for digital technologies would inevitably influence safeguarding practices and procedures in significant ways. Nevertheless, as Barnard (2016: 8) has argued in this journal, nurses have a duty to 'respond in practice to the errors, advantages, difficulties, and temptations of technology for the benefit of those who most need assistance and care'. We need to

research new ways of bringing about the agency of digital technologies like SenseCam in caring practices that take heed of key insights from STS regarding the entangled enactment of the agency of persons and things.

References

- Atzori, L., Iera, A. and Morabito, G. (2010) The Internet of things: A survey. *Computer Networks* 54 (15): 2787-2805.
- Barad, K. (2007) *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Duke University Press, Durham NC.
- Barnard, A. (2002) Philosophy of technology and nursing. *Nursing Philosophy* 3 (1): 15-26.
- Barnard, A. (2016) Radical nursing and the emergence of technique as healthcare technology. *Nursing Philosophy* 17 (1): 8-18.
- Barnard-Wills, D. (2012) *Surveillance and identity: Discourse, subjectivity and the state*. Ashgate Publishing, Farnham.
- Barnes M. and Brannelly T. (2008) Achieving care and social justice for people with dementia. *Nursing Ethics*, 15 (3): 384–395.
- Beebe, H., & Dodd, J. (2005) *Truthmakers: The contemporary debate*, Oxford: Oxford University Press.
- Berriis G. and Porter R. (1995) *A History of Clinical Psychiatry, the origin and history of psychiatric disorders*. London, Athlone Press.
- Bharucha, A.J., Anand, V., Forlizzi, J., Dew, M.A., Reynolds, C.F., Stevens, S. and Wactlar, H. (2009) Intelligent assistive technology applications to dementia care: Current capabilities, limitations, and future challenges. *The American Journal of Geriatric Psychiatry*, 17 (2): 88-104.
- Browne, G., Berry, E., Kapur, N., Hodges, S., Smyth, G., Watson, P. and Wood, K. (2011) 'SenseCam improves memory for recent events and quality of life in a patient with memory retrieval difficulties. *Memory* 19 (7): 713-722.

Cash, M. (2003) Assistive technology and people with dementia. *Reviews in Clinical Gerontology* 13 (4): 313-319.

Ceci, C. (2006) "What she says she needs doesn't make a lot of sense": Seeing and knowing in a field study of home-care case management. *Nursing Philosophy* 7 (2): 90-99.

Cussins, C. (1996) Ontological choreography: Agency through objectification in infertility clinics. *Social Studies of Science* 26 (3): 575-610.

Dahler, A.M., Rasmussen, D.M. and Andersen, P.T. (2016) Meanings and experiences of assistive technologies in everyday lives of older citizens: A meta-interpretive review. *Disability and Rehabilitation: Assistive Technology* 11 (8): 1-11.

Department of Health (2005) *Mental Capacity Act*. London, HMSO.

Dodd, J. (2000) *An identity theory of truth*. Basingstoke, Macmillan.

Doherty, A.R., Moulin, C.J. and Smeaton, A.F. (2011) Automatically assisting human memory: A Sensecam browser. *Memory* 19 (7): 785-795.

Elvish R., James I and Milne D. (2010) Lying in dementia care: An example of a culture that deceives in people's best interests. *Aging and Mental Health* 14 (3): 255-262.

Engel, P. (2002) *Truth*. Canada: McGill-Queen's University Press.

From, D-M. (2015) With a little help from a...machine. *Digital welfare technology and sustainable human welfare. The Journal of Transdisciplinary Environmental Studies* 14 (2): 52-64.

Gaita, R. (2000) *A common humanity: Thinking about love and truth and justice*. New York: Routledge.

Haggerty, K.D. and Ericson, R.V. (2000) The surveillant assemblage. *The British Journal of Sociology* 51 (4): 605-622.

Harbers, H. (2005) Introduction: Co-production, agency, and normativity. In: Inside the politics of technology: Agency and normativity in the Co-production of technology and society. Amsterdam: Amsterdam University Press.

Hodges, S., Williams, L., Berry, E., Izadi, S., Srinivasan, J., Butler, A., Smyth, G., Kapur, N. and Wood, K. (2006) Sensecam: A retrospective memory aid. In: Proceedings of the 8th international conference of ubiquitous computing Verlag, Springer.

Hodkinson, K. (2008) How should a nurse approach truth-telling? A virtue ethics perspective. *Nursing Philosophy* 9 (4): 248-256.

Kitwood, T. (1997) Dementia reconsidered, the person comes first. Buckingham: Open University Press.

Latour, B. (2007) Reassembling the social. Oxford: Oxford University Press.

Law, J. and Lien, M. (2012) Slippery: Field notes on empirical ontology. *Social Studies of Science* 43 (3): 363-378.

Leuty, V., Boger, J., Young, L., Hoey, J. and Mihailidis, A. (2013) Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology. *Assistive Technology* 25 (2): 72-79.

Los, M. (2006) Looking into the future: Surveillance, globalization and the totalitarian potential. In: *Theorizing surveillance: The panopticon and beyond*. London: Routledge.

Lupton, D. (2016) *The quantified self*. Malden, MA: Polity Press.

Lyon, D. (2002) Everyday surveillance: Personal data and social classifications. *Information, Communication & Society* 5 (2): 242-257.

Lyon, D. (2003) Surveillance as social sorting: Privacy, risk, and digital discrimination. London: Routledge.

Metzler, T.A., Lewis, L.M. and Pope, L.C. (2016) Could Robots Become Authentic Companions in Nursing Care? *Nursing Philosophy* 17 (1): 36-48.

Mol, A. (2002) *The body multiple: Ontology in medical practice*. London: Duke University Press.

Naef, R. (2006) Bearing witness: a moral way of engaging in the nurse–person relationship. *Nursing Philosophy* 7 (3): 146-156.

Piasek, P., Irving, K. and Smeaton, A.F. (2011) Sensecam intervention based on cognitive stimulation therapy framework for early-stage dementia', 1st International Workshop on Pervasive Care for People with Dementia and their Carers (PCPDC-2011), held with International ICST Conference on Pervasive Computing Technologies for Healthcare, 23-26 May 2011, Dublin.

Piasek, P., Irving, K. and Smeaton, A.F. (2012) Case study in Sensecam use as an intervention technology for early-stage dementia. *International Journal of Computers in Healthcare* 1 (4): 304-319.

Piasek, P., Irving, K. and Smeaton, A.F. (2015) Exploring boundaries to the benefits of lifelogging for identity maintenance for people with dementia. *International Journal of Mobile Human Computer Interaction* 7 (4): 76-90.

Piasek, P. and Smeaton, A.F. (2014) Using lifelogging to help construct the identity of people with dementia' presented at the Irish Human Computer Interaction Conference 2014, 1-2 Sept 2014, DCU, Dublin, Ireland.

Sabat, S. (2005) Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry* 39: 11-12.

Seaman A.T., Stone A.M. (2015) Little white lies: Interrogating the (un)acceptability of deception in the context of dementia. *Qualitative Health Research*, DOI: 10.1177/1049732315618370.

Tuckett, A.G. (2004) Truth-telling in clinical practice and the arguments for and against: A review of the literature. *Nursing Ethics* 11(5): 500-513.

Vision, G. (2005) *The correspondence theory and its critics*. Cambridge, MA: The MIT Press.

Woolgar, S. and Lezaun, J. (2013) The wrong bin bag: A turn to ontology in science and technology studies? *Social Studies of Science* 43 (3): 321-340.