Keynote 2500 word paper

Educating for Connected Health – sustaining personhood in a digital world

Introduction: The relentless growth and diversity in technology aimed at automating healthcare delivery arguably challenges nursing's central position in care delivery as new technologies augment or replace nursing activites. Whilst not a new phenomena, this paper argues that the scale of change in the triadic relationship between the person receiving the service, the nurse and the computer, needs us to rethink our relationship with technology. The emergence of a digital humanism provides nursing with the opportunity to be active influencers rather than passive bystanders, to ensure that personhood remains central to how care is delivered.

Main Text: It is somewhat of a cliché to say that technology is having a transformative effect on our everyday lives. From communication to transport and from retail to entertainment, much of what we take for granted today, is unrecognisable from even a few years ago.

Some say we are in the midst of a 4th industrial revolution, which is said to be more rapid and impactful than any of the previous three. Klaus Schwab, Founder and Executive Chairman of the World Economic Forum in 2016 suggests this digital revolution is:

> *"a fusion of technologies that is blurring the lines between the physical, digital, and biological spheres."(Schwab 2016 p1)*

There has been no president for the speed, scope, and impact of this revolution, which perhaps explains why society struggles with some of the effects and unintended consequences.

Of course healthcare has been transformed too. Many aspects of the person's journey through diagnosis and treatment potentially has a digital 'solution'. From automated triage that improves access to treatment, to diagnostic devices that automate previously manual readings; from robotic surgery with reduced human error to automated drug dispensing and delivery; from data supporting clinical decisions to the supply of predictive analytics.

We have also seen the emergence of connected health, which uses technology to provide an increasing number of services remotely. The possibilities seem endless and the availability in particular of big data has the potential to enable targeted prevention, improved efficiency and strengthened treatment protocols.

For a person like Jean, 52 with a diagnosis of type-2 diabetes, digital technology can be a useful adjunct to everyday life. It allows her to track her blood insulin and adjust her dosage to suit her level of activity; to easily access information relevant to her specific circumstance; to chat to people in her same situation via social media; to consult experts through telephone or video-conferencing and to receive reminders to exercise if she has been sedentary.

The opportunities for interdisciplinary coordination, continuity and management are also significant. The remote involvement of nurses, nutritionists, GPs and consultants etc, enables Jean's team to interact and share records of interventions thus avoiding duplication or worse, oversights.

When effective, Jean can be fully involved in treatment decisions and can receive 'nudges' that remind her of appointments, follow-up and new innovations/treatments, so that her condition is carefully monitored and her health maintained.

However despite the rapid uptake of technology in areas such as mobile banking, e-commerce and music/video streaming, uptake in health has been somewhat slower by comparison. One explanation for this is a generational issue in that many current teachers and senior leaders have had to adapt to the new digital environment and may be less inclined to embrace new technology.

Mark Prensky (2001) coined the term 'digital immigrants' for those who he considers speak an out-dated language (that of the pre-digital age) and who struggle to relate to a digital generation who speak an entirely 'foreign' language. The digital or 'net' generation, described as 'digital natives', are familiar with the language of computers, gaming and the internet.

Whilst this native/immigrant argument provides a useful perspective, it seems too simplistic to explain the whole story. However, there is a body of research exploring specifically why take up of health technology is relatively slow. Using the Technology Acceptance Model (TAM) (Davis et al 1989), which is an information systems theory that models how users come to accept a technology and how they use that technology, studies are being conducted to understand barriers and enablers to technological engagement.

The TAM model suggests key factors influence our decision to use technology including perceived usefulness, which is the degree to which it is perceived the technology will enhance job performance, and perceived ease of use and relative effort involved. But in health, knowing whether peers would adopt it or service users would value it are just as important.

Understanding attitudes and perceptions of technology is critical in healthcare. As long ago as the 1980s writers such as Sherry Turkle, (1984) the Abby Rockefeller Mauzé Professor of the Social Studies of Science and Technology at the Massachusetts Institute of Technology, were warning of the potentially dehumanising effects of technology which increasingly defines the way we think and act in this digital age. In her book 'The Second Self - Computers and the Human Spirit' she talked about the computer's relentless threat to the "I".

Similalrly, Joseph Weisenbaum another MIT professor of computer science and the father of modern artificial intelligence, suggested that the computer—linear, logical, and rule-governed— encourages us to think in these ways, which, he argues, makes us privalege instrumental reasoning over human engagement and interaction. He asserts, "it is the capacity to choose that ultimately makes us human" (p10) and in healthcare it is these choices, interactions and person-centred interventions, that are critical to the care of those who are vulnerable due to ill-health or disability.

In fact Weisenbaum, in his article of 1976 *Computer Power and Human Reason* he argued that Artificial Intelliegnce technology should never be used to replace those people who work in positions that require respect and care, such as nurses, police officers, soldiers, judges, therapists or customer service representatives.

But despite these warnings, in recent years we have seen technological design move towards much greater automation, with arguably little consideration of the experience, attitudes, beliefs of the end user. One only needs to consider the example of the telephone answering machine to see how little attention was paid to what it feels like to be kept hanging on the line in a queue for hours listening to distorted, piped music.

In healthcare, any number of service user surveys emphasise the necessity of person-to-person interaction and human contact. As Youngson (2016) points out we have good evidence from randomised controlled trials that compassionate person-centred care improves clinical outcomes. For example we know it is our ability as nurses to provide empathic and supportive preoperative consultation that improves wound healing and surgical outcomes, halves opiate requirements, and reduces length of stay in hospital. Further we also know that people receiving treatment in emergency departments are 30% less likely to return if treated with human compassion (Youngson 2016).

We are also aware from recent surveys into why people leave the profession, that it is the opportunity to deliver compassionate caring which provides meaning and satisfaction to those delivering care. Such care also aligns with professional practice ideals, and therefore helps to defend against risk of burnout, which are typical reasons for choosing to remain or leave a job (Tee and Scammell 2018). Person-centred care is therefore a positive force for good not just for service users, but professionals and service providers too.

But, whilst we are in the midst of a digital revolution, the question must be asked, can compassionate, person-centred care be delivered within an increasingly automated, digitally driven world? How does this stack up in an environment in which more and more practice, services and treatment will become automated, detached from human experience and alien to service users?

We only have to look at some of the recent tragedies and appalling standards of care, when what Galvin and Todres (2012) call 'humanly sensitive care', is missing. Bournemouth University has been researching and promoting humanising practice as a key theme in its nursing curriculum for some years. It is essentially about listening to and acting on what people that use services are telling us. Too often they feel they are not engaged as human beings.

Within the debate, following the tragedy that was Mid Staffs (Francis 2013) ([5]see footnote), about how to restore humanly sensitive care, the view taken at

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[5] Mid Staffs is shorthand for The **Stafford Hospital scandal** which highlighted poor care and high mortality rates amongst patients at the Satfford Hospital, England. Between 400 and 1,200 patients died as a result of poor care over the 50 months between January 2005 and March 2009. The final report was published by Sir Robert Francis in 2013 http://webarchive.nationalarchives.gov.uk/20150407084231/http://www.midstaffspublicinquiry.com/report

Bournemouth was that the restoration of humanly sensitive care is not just about 'more time' or 'better leadership', but how the 'humanising focus' is clearly articulated and 'kept alive' as a primary focus for practice, particularly within this digital age.

Galvin and Todres suggest maintaining a humanised focus is based on two foundation pillars on which to build other strategies such as leadership; resources; organisation and training:

> Pillar 1 - A distinctive and simple 'vocabulary' that keeps the focus on 'humanising' issues as a central concern and
> Pillar 2 - Ensuring that such a focus is coherently championed at all levels: political, organisational, practical and educational.

In their research, the main question asked by Galvin and Todres was simply What makes people feel 'more human' or 'less human' when engaging in health and social care systems and interactions?

The outcomes of which is a Conceptual Framework of the Dimensions of Humanisation articulating eight bipolar dimensions (Todres, Galvin & Holloway, 2009) that describe what constitutes health and social care processes and interactions that are 'humanising' or 'dehumanising' (see figure below).

Forms of Humanisation	Forms of Dehumanisation
Insiderness	*Objectification*
Agency	*Passivity*
Uniqueness	*Homogenisation*
Togetherness	*Isolation*
Sense – making	*Loss of meaning*
Personal journey	*Loss of personal journey*
Sense of Place	*Dislocation*
Embodiment	*Reductionist body*

The humanising dimensions are those characterized by maintaining personhood and include Insiderness, Agency, Uniqueness, Togetherness, Sense – making, Personal journey, Sense of Place and Embodiment. Whilst the polar opposite are the dehumanising dimensions, where personhood is diminished, which include Objectification, Passivity, Homogenisation, Isolation, Loss of meaning, Loss of personal journey, Dislocation and Reductionist body

If we look at just two of these in more detail firstly - Uniqueness vs Homogenisation - Our uniqueness as human beings, Galvin and Todres point out, cannot be reduced to a

list of characteristics, such as age, gender, ethnicity; each of us is unique in relation to our relationships and our context, and this is how we see ourselves. De-emphasising our uniqueness through automated systems and digital processes potentially separates individuals from the context of their life. In other words we need to consider an individual's context, carers, friends, family and home and balance any generalisations that hide characteristics that make people uniquely who they are.

Secondly - Embodiment vs Reductionism, which suggests we experience the world through our bodies in a range of positive or negative ways. Therefore an individual's biology cannot be understood without considering the psycho-social-cultural aspects. The term Embodiment, Galvon and Todres suggest, relates to how we experience the world and this includes our perceptions of the psycho-social-cultural context and its possibilities or limits. It may be affected by illness, or changes in body image or ability.

Consequently an excessive emphasis on digital processing and not recognising the individual within their social context, can limit or inhibit our ability to respond to another human being in a caring and dignified way.

Applying this analysis to all dimensions of Todres and Galvin's model clearly reveals that greater automation creates a greater risk that some form of dehumanisation and loss of personhood may occur.

However this paper is not arguing that technology is inherently a bad thing as it provides huge and recognisable benefits in healthcare.

BUT it is highlighting the insidious risks, indicating that we as nurse academics, researchers, educators, clinical leaders and students, need to engage, shape, inform and influence the future. In other words to be what Todres at al (2007) describes as 'a humanising force that moderates technological progress' (p60).

So how do we do this?

One powerful way in which we can engage is through the lens of digital humanism which suggests (Pettey 2015) that people are (or should be) the central focus in the manifestation of digital workplaces.

Milad Doueihi (ref), a French professor of digital humanities at Paris-Sorbonne University defines Digital Humanism as:

" the result of a hitherto non-experienced convergence between our complex cultural heritage and a technology that has produced a social sphere that has no precedent."

"This convergence, instead of simply forming a link between antiquity and now, has redistributed concepts, categories, and objects, as well as behaviours and associated practices, all in a new environment."

"Digital humanism is the affirmation that current technology, in its global dimension, is a culture, in that it creates a new context, on a global scale."

What Doueili is saying is that the current revolution in technology creates a new **culture** in which we as nurses need to engage more forcefully. We have an opportunity because designers and technologists are recognising this dehumanising effect and are looking for help. Digital Humanism is the move away from computer-literate people to people-literate technology.

Whilst not everyone accepts this view of a new culture, for example a blog by Prof Feisal Mohamed of City University, New York, in 2012 argued that:

"The sense that technology is inherently a form of progress, rather than a platform for consumerism, is one of the most insidious ideologies of our time, and one that distracts us from meditating on the true sources of human flourishing."

However the reality is that Technology is here to stay and we in healthcare need to better understand how technology interacts with how we as humans live, work and play.

Martin Recke (2017), Corporate Editor, at SinnerSchrader, suggests that recent developments in machine learning and autonomous agents (Alexa, Siri or the self-driving car) and smart robots are all taking us along the same route – with increasing sophistication and inter-dependence on the interaction between humans and machines.

As Recke points out, in short, Digital Humanism refers to our long-held concern to put humankind, in all its facets, at the centre of tchnological development. This includes our work as health professionals, as a good humanistic design would place the desires and needs of humans ahead of the most convenient or most accurate solution.

We know from history that the early 14th century humanists started a cultural revolution that peaked in the Renaissance era and so as we survey the landscape and anticipate the technological future, perhaps now is the time for a new cultural revolution, a new Renaissance in a humanized digital healthcare.

Of course before this can happen there are many practical challenges not least of which is the preparation of the healthcare professionals who will need to engage with and take advantage of new technologies.

In the UK if we look at what the nurses regulator body says about technology in the recently published NMC UK (2018) ([6]see footnote) education standards, registered nurses must:

- *"demonstrate the numeracy, literacy, digital and technological skills required to meet the needs of people in their care to ensure safe and effective nursing practice"*

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[6] The NMC regulate nurses and midwives in England, Wales, Scotland and Northern Ireland and have a role in protecting the public. They set standards of education, training, conduct and performance so that nurses and midwives can deliver high quality healthcare throughout their careers.

- *"demonstrate the ability to manage commonly encountered devices and confidently carry out related nursing procedures to meet people's needs for evidence-based, person-centred care"*

- *"effectively and responsibly use a range of digital technologies to access, input, share and apply information and data within teams and between agencies,"*

Whilst engagement with technology is acknowledged it hardly pushes the boundaries and there is little or no mention of the specific skills or leadership required to engage. It seems rather passive rather than helping to shape the future. More encouragingly, in 2016, The Royal College of Nursing launched a campaign in the UK entitled "Every nurse an e-nurse".

This campaign sought to involve nursing staff in the design and implementation of information technology, increasing access to education and training, and using data to improve care. This was supported by NHS Digital, which exists to improve health and social care in England by making better use of technology, data and information.

In support the Chief Nurse of NHS Digital, Anne Cooper (2017) said:

"Embracing new technology is a help, not a barrier, to improving patient care. It is important that the professions respond positively to these opportunities and that's why being a modern nurse, in other words an 'e-nurse', matters."

After the launch the RCN published insights in 2018, from a consultation on the digital future of nursing following the every nurse and e'nurse campaign. They found that whilst there were examples of nurses taking leading roles in the use of technology, it was patchy and nurses complained that technology was inadequate or technologists did not understand their world.

They concluded that nurses needed to be empowered to take a leading role to bridge the gap between the world of healthcare and technology and that it was no longer sufficient for either side of the debate to complain about being misunderstood.

So what should we do to respond? For me there are several key questions:

How can we protect our service users best interests and ensure personhood is central to the care we deliver, whilst embracing the possibilities technology offers?
How can we prepare healthcare professionals betters for engaging with and leading healthcare in this digital age?
How can we shape the future of technology in a digital world larely designed by well-meaning technicians focused on solution rather than process?

There are few easy answers but my emerging thinking is as follows:

For nursing and healthcare to be part of and further shape the digital healthcare future I would argue that we need to tackle the three areas of 1. education, 2. research and 3. partnerships:

1. We need think carefully about workforce preparation and CPD as we need people who can work with/understand technology but can also work at the service user interface.
   a. Introducing digital humanities within pre-registration nursing curriculum
   b. Providing in service Digital Champions who can deliver one to one, learner led support to build confidence and skills
   c. Creatinging customised programmes on digital therapies, to create new specialisms of digital healthcare professionals who understand the key components: coding, app development, data analytics – but also the nature of a humanised healthcare.
   d. Developing masters courses that merge healthcare and digital technology to produce hybrid practitioner/researchers, who not only understand the technology and care, but also how innovation gets diffused.

2. We need to strengthen our nursing research base to more deeply understand and influence the service user, nurse and computer triad, through a digital humanist model through:

   a. Further developing the theory around digital humanism in nursing
   b. Creating well designed studies that incorporate human/person centred principles,
   c. Sponsoring studies that employ improvement and implementation science principles and methods in order to determine what technologically driven improvement strategies are effective
   d. Support match-funded PhDs with university's and service providers that answer key digital humanist questions

3. We also need to explore wider partnerships with health, gaming and technology industry in order to support companies who are placing humanistic-based approaches and architectures at the centre of their design solutions and who understand the principles of co-design and co-creation. This is about asking nurses the question "what is the clinical problem you are trying to solve and how can we work with you?". Thus avoiding what currently happens which is companies coming to health providers saying "here is a product we have already created, how can you help us implement it?"

As Sian Kiely the Knowledge & information Manager at RCN Scotland put it

"Digital health is about more than the technology ….it's about making effective decisions about patient care "

This means nurses having the opportunity to develop the essential skills and capabilities for working, influencing and indeed thriving in a digital society. Health Education England and RCN (2017) categorise these competencies under the following:

- digital identity, well-being and safety

- communication, collaboration and participation
- teaching, learning and self-development
- technical proficiency
- information, data and media literacies
- digital creation, innovation and scholarship.

In April, this year in the UK we have seen the launch of the NHS Digital Academy and enrolment of the first cohort of digital health leaders, in partnership with Imperial's Institute of Global Health Innovation (IGHI), the University of Edinburgh and Harvard Medical School. Whilst this is a positive step forward, unfortunately recruitment was targeted at Chief Clinical Information Officers, Chief Information Officers, and senior operational, technical and clinical managers with five years informatics or digital experience, which didn't seem very inclusive or likely to have a major impact on the wider agenda.

Its crucial that we, as nurses, don't get left behind and are purposefully, not tokenly, involved in the research, design, implementation and testing of new digital technology through which we can develop digital capabilities but within a framework of humanly sensitive care.

Through a lens of digital humanism we can develop a distinctive and simple 'vocabulary' that keeps the focus on 'humanising' as a central concern in the development of health technologies.

Perhaps only when this happens will nurses and other healthcare professional develop greater confidence and competence to take advantage of the opportunities that technology affords.

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