**Dr. Tulp Attends the Soft Machine: patient simulators, user involvement and intellectual disability**

**Introduction**

In 2011 we carried out a small pilot study with a cohort of students studying on a combined learning disability nursing/social work degree programme. In a clinical lab setting we used a patient simulator to augment their understanding of epilepsy and its management. Their feedback on the session provided the basis of that paper (X,Y & Z, 2102). We argued there that the development of simulation from the 17th century use of corpses to the twenty first century use of hi-fidelity manikins follows a medical model of skills training that Dr. Tulp would still recognise.

Here we continue that discussion but now switch the focus to consider those more conceptual elements of patient care that challenge the use of simulation as a teaching and learning aid. In particular we explore a concern that while simulation can be very useful for learning how to manage standard clinical procedures it might prove less useful when there is a mis-match between the 'patient' in real life and the representation 'embodied' in the manikin. This is particularly true when the 'real life' patient has intellectual disability.

We suggest that simulation exists on a continuum and begin with a critique of that end of the spectrum which employs patient simulators. We then go on to contrast this approach with the use of 'real' people.

Intellectual disability is simultaneously a diagnosis, a label and a social construction. The term itself operates as a discursive totem which renders those to whom the label is applied susceptible to a variety of inter-disciplinary regimes and social responses (Foucault, 1972). Today a mix of better survival rates and a wider appreciation of the effects of poverty and disadvantage on child development have led to an increased incidence of learning disability (McKay *et al*, 2010). According to Tyler *et al* (2007) this trend suggests that increased numbers of individuals will live into their adult years with increasingly complex needs. This needs to be considered against the fact that people living with intellectual disability experience ill-health at a rate approximately two and half times that of the population at large (DH, 2001; Emerson *et al*, 2005; Hardy *et al*, 2007). People with intellectual disability are also more likely to have genetic syndromes and to live with chronic conditions such as epilepsy or cerebral palsy (Tyrer *et al,* 2009).

This set of circumstances ought to bring them into contact with primary and secondary health services on a regular basis (NPSA, 2004). But despite the increased rates of ill-health these people actually access health services less often than might be expected (DH, 2009). And when they do present in clinical environments they display a higher frequency of health issues (Cooper *et al*, 2004). All of this means that people with intellectual disability are disadvantaged in their access to health care. But what is even more worrying is that the treatment and care they receive when they do attend is often sub-standard.

Dinsmore and Higgins (2011) have found that this continues today, even after the Ombudsman's 'Six Lives' report (DH, 2009). Their investigation found that a recurrent theme was that hospital staff appeared not to have had any training in meeting the needs of people with learning disability (2011:21). The Royal College of Nursing has recognised that learning disability nurses have a key role and in their most recent position statement 'Learning from the Past - Setting out the Future' (RCN, 2011) they acknowledge that changing demographic patterns alluded to above may lead to growing unmet health needs in the population of people with intellectual disability. This might be compounded if health professionals in training learn skills based on their interactions with patient simulators programmed to replicate standard responses in a standard setting.

**Dawn of the Replicants**

The increasing use of technology in healthcare along with higher public and patient expectations has encouraged the development and use of innovative educational methods in healthcare education. The UK Government paper *A High Quality Workforce - the Next Stage Review* (DH 2008) recommended the development of a “*strategy for the appropriate use of e-learning, simulation, clinical skills facilities and other innovative approaches to healthcare education*” (p.42). The use of simulation has also been encouraged in a number of key Government documents worldwide, such as the US Institute of Medicine’s (1999) report *To Err is Human: Building a Safer Health System*. More recently, the UK Government White Paper *A Framework for Technology Enhanced Learning* (2011) argued that Innovative educational technologies, such as simulation provide unprecedented opportunities for health and social care students, trainees and staff to acquire, develop and maintain the essential knowledge, skills, values and behaviours needed for safe and effective patient care.

The potential risks to patients associated with learning 'at the bedside' are becoming increasingly unacceptable, and the search for education and training methods that do not expose the patient to preventable errors from inexperienced practitioners continues (McGaghie et al 2010). As Hobgood et al (2009) note, all the evidence shows that a significant proportion of adverse events in health care are caused by problems relating to the application of the 'non-technical' skills of communication, teamwork, leadership and decision-making. These are the cognitive and social skills that complement technical skills to achieve safe and efficient practice.

Simulation may be seen as an effective educational strategy to address the growing moral and ethical issues around 'practicing' on human patients, and indeed Ziv et al (2003) argued that there is actually an ethical imperative to use simulation wherever possible. Simulation may provide an effective way to increase patient safety, decrease the incidence of error and improve clinical judgment (Beamson and Wiker, 2005). Some authors, however, assert the unique selling point of high fidelity simulation is that it may be used to recreate patient care scenarios that are rarely experienced in clinical practice, to test how health professionals behave in challenging and/or crisis situations, and to carefully replay or examine their actions during that scenario (McGaghie et al 2010; Issenberg et al 2005).

**Fidelity and Realism**

When learning occurs in a realistic environment related to work, learning is retained and reproduced; simulation works best when ‘micro-worlds’ are created related to the learners workplace (Wilford & Doyle, 2006). The more realistic the environment is to the learners’ own area of work, the more successful the learning will be. When considering how 'realistic' a simulated scenario can be student perceptions have generally been reported as being high (Devitt et al., 2001; Feingold et al., 2004; Reznick et al., 2003). Maintaining a realistic environment is a key requirement for successful simulation (Hotchkiss and Mendoza, 2001). This not only means having a manikin capable of adequately reproducing the patient's condition, but also creating a learning environment that looks and feels like the real world. In simulation, the ultimate achievement is what is termed the willing *suspension of disbelief*. It is at this point the participant becomes so involved in the scenario that it feels 'real'. In order to achieve this, it is clear that the manikin should approximate very closely to the human condition, in appearance as well as in 'reality'.

From the students' perspective, if the simulation is to work it must be believable, and the student must be able to take on the role of the 'nurse' and feel the responsibility for the care, assessment, and delegation necessary to meet the needs of this 'real' patient. If the patient deteriorates, the students need to believe that their actions or omissions may lead to an adverse outcome for the patient. The true advantage of simulation is that it provides a safe environment in which to learn the skills necessary for the prevention of adverse outcomes. It should provide an environment that allows the learner to embrace their role and act confidently with the necessary critical reasoning to accomplish their objectives.

**Simulators, Skills and Student Learning**

Issenberg *et al* (1999) argue that simulation is a valuable educational tool for healthcare professionals for the following reasons:

 *“…unlike patients, simulators do not become embarrassed or stressed; have predictable behaviour; are available at any time to fit curriculum needs; can be programmed to fit selected findings, conditions, situations, complications; allow standardised experience for all trainees; can be used repeatedly with fidelity and reproducibility , and can be used to train both for procedures and difficult management situations..*.” (1999: 864).

It is clear that the student experience of simulation will be much richer if the students are able to reflect from a perspective that their actions and decisions really made a difference in the outcome of care. However, limitations in simulation technology, particularly related to the manikin, may have a correspondingly negative impact upon learner perceptions. Halamek *et al* (2000) evaluated the effectiveness of a delivery room scenario with neonatal resuscitation, and found that the majority of the negative comments were directed at the lack of fidelity in the neonatal manikin, although the participants did rate the environment as a whole and the general nature of the simulations very favourably.

Although it may be difficult to argue with this simulation works much less well where the technology is unable to replicate the 'bio-fidelity' associated with real life situations. Our previous work (XYZ, 2012) found that the patient simulator was unconvincing in its attempts to 'mimic' an epileptic seizure. And it is also the case that due to the standardised production process the patient simulators currently in use all approximate to an 'ideal' physical shape. Those who work with individuals with intellectual disability know that not all of their clients will conform to these parameters. For someone living with scoliosis, or cerebral palsy, for example, their body shape and associated health needs would put them well beyond the range of movement and positions that a manikin could mimic.

In the scenario described we can see that the use of a patient simulator as an aid to teaching and learning benefits the learner in the acquisition of skills. This benefit is then immediately passed on to the patient who receives good care and treatment. However, this is just one aspect of the use of simulation. And even here the success of the patient simulator can be challenged on two fronts: its approximation to reality, expressed as a level of technological sophistication and its ability to convince as a 'patient' expressed as a level of responsiveness. There appears to be a gradient along which the efficacy of the manikin as a teaching tool decays. For example, if we place a real live human being at one end of an imagined continuum and an hi-fidelity patient simulator at the other then the simulator will be best able to replicate the human condition when the target state is unconsciousness and the interventions are invasive and/or surgical. The simulator's ability to replicate reality will be most severely tested when the target state is fully consciousness and the interventions are more social.

**Pushing the Limits of Simulation**

So far we have taken patient simulators, which form one end of a continuum of simulation approaches available to educators, as the focus of our discussion. It seems from our reviews of the literature and from our earlier study (XYZ, 2012) that this approach has its limits. The essential drawback for the patient simulator is not so much its inability to replicate some clinical conditions/syndromes, but its complete failure to respond as a 'social animal' to the narrative aspects of caring. This may seem an absurd charge to put before a machine but an old piece of research on nurse-patient communication carried out by Sheppard (1993) makes a very relevant point - communication in the patient-professional dyad is about more than transmitting information or attending to administrative details. Feelings too are communicated and no matter how sophisticated the simulator even those designed to provide real-time voice responses provided by an operator cannot truly reciprocate when asked a question such as 'How do you feel today?'.

And of course it is a recognised fact of life for practitioners in the field of intellectual disability that may of their clients will have no verbal communication at all. Some will be able to use formal and/or informal signs but for others communication will rely on support staff to demonstrate a close understanding and interpretation of visual cues (Purcell *et al,* 2000; Bradshaw, 2001; Murphy, 2006).

The spoken word occupies much less of the content of our interpersonal communications than might be supposed (Mehrabian, 1981). For people on the spectrum of autistic disorders even this will vary (Saulnier & Klin, 2007). The patient simulator is limited to the 'instrumental' side of communication and cannot provide the 'affective' aspects noted by Kruijever *et al* (2001). Precisely this concern was voiced by our students. They noted the lack of communication and inter-personal behaviour available to the manikin which they would normally expect to observe when caring for clients. In the lab-based scenario where they were to manage an episode of epilepsy some struggled with the absence of feedback. When asked for feedback on whether they had engaged the manikin in conversation we had differing responses:

*'I found that I did not talk to the manikins but this did not stop me from talking to real live people when using the same skills in practice'.*

*'I did, as I told the manikin the process in which I was going to go through when practising clinical skills'.*

In order to cope with the 'softer' side of communication it is necessary to take a different approach to simulation which escapes the self-imposed limitations that come with the patient-simulator. Thacker *et al* (2007) describe such an approach to the care for individuals with intellectual disability. In this study the individuals with intellectual disability themselves took on the role of 'patients' who were being assessed by trainee doctors. The session was part of an Objective Structured Clinical Examination (OSCE) designed to test the ability of the doctors in training to obtain informed consent. It is worth noting that the original programme of training which preceded this used real actors too, but these were non-disabled actors who then not only had to mimic the agreed set of symptoms but also had to mimic intellectual disability. As with the patient simulator, the approximation to reality was compromised in this approach. The engagement of trained individuals with intellectual disability then meant that the student doctors had the very best patient simulators that money could buy: they had real people.

Another very telling point made by the study reported was in the way that the students were able to demonstrate empathy by mimicking the actions of their 'patients' (Thacker *et al* 2007:19). In this case the action of mimicking differs from that of the patient simulator. The simulator can 'mimic' certain symptoms by replicating outward signs (raised respirations, for example) but this is a purely mechanistic reaction. The student doctor who rubs their own abdomen in response to their 'patient' doing the same is responding on a different level entirely and in doing so shows that they have understood something about the condition described. This is the empathy unavailable to the machine and referred to by McCabe (2004) along with 'attending behaviour' as a key element of communication that patients value in their clinical encounters (2004:45).

**Discussion**

In recent times there has been a broad acceptance of simulation in healthcare education, although the studies attempting to assess its worth have found hard data to confirm the effectiveness of simulation elusive, particularly in relation to non-technical skills (Gant 2007). It should be remembered that in comparative terms simulation is still a relatively new educational strategy in healthcare education, and consequently the evidence base for simulation is comparatively small, although growing. As Gaba (1992) noted, no other high risk industry in which human lives depend on skilled performance by professionals, has actually waited for unequivocal proof of the benefits of simulation before adopting it.

However, it is not our intention to appear Luddite or sound like doomsayers by issuing warnings about the rise of the machines. But we do feel the need to add a corrective to the notion of simulation as a universal panacea, able to augment the education of the student health care professional in all circumstances, at all times and with all patient populations.

The type of high fidelity simulation that relies on sophisticated technology to replicate the human body in the shape of a manikin clearly has its place but it would be a mistake to believe that the same equipment can be programmed to do anything beyond mimic physiological reactions via microprocessors.

Students must be able to see beyond the equipment and connect their learning to actual human beings. We suggest, based on our previous work and our reading of the literature, that this can become problematic when students without previous experience have to treat people with intellectual disability. Patient simulators patently cannot prepare the student for the lived experience of disability. The point is reinforced by Campbell (2010) when she suggests

 'Medical practices, organized around the medical model, presume the doctor’s task is to diagnose diseases, discover their causes and symptoms, and design treatments. Any knowledge standpoint of the patient is diminished' (2010:222).

This problem is not confined to doctors. An American study revealed that nurses too are not receiving adequate training in meeting the needs with individuals here identified as having Intellectual or developmental disabilities (ID/DD). Sanders *et al* note that

'Nursing education programs should strive to address negative stereotypes through inclusion of curricula that specifically target the needs of individuals with ID/DD' (2007:459).

Patient simulators form just one aspect of simulation as an approach to teaching and learning for health care professionals. They appear at one end of a continuum which has a real live patient at the other. They DO have benefits:

* Their use is best displayed in their ability to recreate highly controlled situations (such as exist in an operating theatre) where the patient is passive and the clinical interventions are invasive.
* They have great value in providing a 'safe' environment in which student learners can practice their clinical skills.
* In a lab setting they go some way towards replicating the clinical environment and care scenarios practitioners will eventually encounter.

However, patient simulators in particular and the idea of simulation in general operate on a pre-conceived idea of what is statistically 'normal'. This can be traced as far back as Quetelet's original idea of the 'average man' (Quetelet, 1835). This can mean that they are much less effective in some circumstances and with some patient groups. We have shown this to be true for the patient population of people with intellectual disability. It may also be the case that very young and very old patients, those with a range of physical impairments and those who live with mental health problems might also be disadvantaged when they receive care from professionals whose skills were acquired partly from work with patient simulators.

**Conclusions**

Patient simulators are very useful when the student learner needs to practice invasive techniques on an unconscious patient. Their utility rapidly diminishes, however, when the patient is conscious, has communication difficulties, and when the clinical interventions are more 'social' in nature.

The use of patient simulators is now wide spread but we conclude that their utility for some patient groups must be questioned. The situation of people with intellectual disability, living in community settings and with a wide range of impairment, communication and mobility issues possibly puts their care beyond the immediate scope of those professionals educated to tend a soft machine. To paraphrase the slogan, people with intellectual disability are 'people first' to which we add, and in some circumstances, patient simulators come a distant second.

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