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STORYAID: NURSING STUDENT RELATIONAL LEARNING WITH YOUNG PEOPLE WITH INTELLECTUAL LEARNING DISABILITIES

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Abstract

Background: Nursing students have expressed fears and anxieties about caring for people with intellectual learning disabilities (ILDs). Educational storytelling interventions could help overcome these concerns and improve nursing care. **Method:** StoryAID was used and developed in the Heritage2Health (H2H) Virtual Art and Drama Project. Eight online sessions followed 'Ubuntu the Lion with the Long Long Mane', a story about difference and connection. Two trained facilitators (storytelling-coach and socially-engaged artist) and academic educators (n=3), supported nursing students (n=13 degree and n=2 masters), young people aged 11-14 with ILDs (n=7), their parents (n=7) and specialist teacher, to deconstruct, reconnect, and rediscover understandings. Rights-based ethnographic evaluation. Thematic analysis. **Results:** Themes- Relating to the story and characters. Participation in the processes of storytelling. Relating to other participants in the storytelling. Relating learning to clinical contexts and professionalism. **Conclusion:** StoryAID and H2H in partnership created safe spaces to engage, challenge assumptions, and develop relational skills.

Key words: storytelling, narrative pedagogy, relational pedagogy, professionalism, nurse identity

Introduction

Nurses and nursing students need to be prepared to care for people with intellectual learning disabilities (ILDs) who are diverse (Ferrell et al., 2004) high users of healthcare (Lindley et al., 2021; Beck, 1992). However, in the United Kingdom (UK) qualified nurses report a lack of knowledge about ILD and feeling too dependent on informal carers (Sowney and Barr, 2006). Nurses working in hospices describe feeling uncertain about assessing mental health needs and caring for children with ILDs (Lindley et al., 2021). The majority of nurses working in intellectual disability care services feel inadequately trained to provide good end-of-life care for people with ILDs (Bekkema et al., 2014). In the community, registered nurses do not feel competent in diagnosing anxiety in people with ILD (Pruijssers et al., 2011) or suitably skilled to prepare families and social care support workers to safely deliver invasive care (Brown et al., 2016). These issues could explain why people with ILDs have far worse health outcomes (PHE, 2020) and are scared of nurses (Pelleboer-gunnink et al., 2017).

It has been suggested that unacceptable differences in the quantity and quality of educational encounters for nursing students with people with ILD, has led to negative staff attitudes, poor care, mortality, and worse health outcomes (Council of Deans, 2017). In the UK a criminal investigation into the death of autistic 18-year-old Oliver McGowan, who suffered seizures and was repeatedly given antipsychotic drugs (<https://www.olivermcgowan.org/>) highlighted the dangers of hospital staff failing to listen to family members who tried to alert them to the fact that Oliver reacted badly to such medication. The death of 32-year-old Ben King who had Down syndrome, because of “inadequate weight management and failure to diagnose obesity hypoventilation syndrome and inadequate consideration of the use of promethazine” (www.inquest.org.uk/ben-king-closes) demonstrates staff failed to fulfil their duty of care and adhere to laws intended to

protect people with ILDs (e.g., Mental Capacity Act, Autism Act, Human Rights Act, Equality Act). In 2022, it will become compulsory for all clinical staff working in health and social care in the UK to receive learning disability and autism training at the right level for their role. However, this requirement does not extend to students in training.

This article argues that educational storytelling interventions could help nursing students to learn to engage and relate to young people with ILD, their parents, and teachers. It describes the StoryAID approach, explains the utility of storytelling in nurse education, and illustrates how StoryAID was used in the Heritage2Health (H2H) Virtual Art and Drama Project. We briefly share some findings to demonstrate how other nursing students and educators may benefit from StoryAID and H2H as an educational partnership. The course described was delivered online during the 2020 COVID-19 pandemic. Hence, the article connects to a growing evidence base for digital storytelling in education (Beck and Neil, 2020; McCabe, 2018; Haigh and Hardy, 2011; Christiansen 2011; Davis, 2016).

StoryAID

StoryAID has been developed and refined in the UK by expert storyteller and coach Eli Anderson (co-author). It is based on 30 years of applied knowledge and expertise in developing and implementing collaborative projects and programmes with public, charitable and private agencies, and institutions (<https://www.storyaid.uk/blog>). StoryAID has previously been used in various contexts, including health workforce education, community outreach programmes, mental health awareness projects, with the aim of supporting dignity, life balance and self-care (Anderson, 2015). However, this is the first time that it has been explored and evaluated as part of an educational intervention. StoryAID is a refinement of the knowledge and practice of storytelling. It is based in a wide range of theoretical perspectives, which include raised consciousness (Ford, 2000; Vambe, 2004; Mehl-Madrona, 2007, 2015;

Chomsky, 1976) individual freedom (Foucault, 1977), anti-oppressive pedagogy (Freire, 1970; 1998), intergenerational epigenetics (Carey 2011), Vygotsky's zone of proximal development (Davis et al., 2016), negotiated story spaces (Bourdieu, 1990), and the medicine of the person (Tournier, 1975).

The connection between StoryAID and H2H came about through a shared interest (EA, TNP) in developing a space of freedom for vulnerable people. Since 2008, the founders of StoryAID and H2H have worked together with the Chair of the Special Interest Group on Inclusion and Social Justice (PP), special educational needs teachers, a socially engaged artist (BO'D), the entrepreneurship team, the Service-Learning Hub, and over 1,200 nursing students and community guests, to create experiential learning courses and inclusive events, some held at National Trust heritage properties. The most recent development in the partnership was to explore the African tradition of *ubuntu* (Downing and Hastings-Tolsma, 2016) and the writing of the story "Ubuntu the Lion with the Long Long Mane" (Nash-Patel, 2021). This illustrated children's book encapsulates ubuntu ideology in a story about one lion's experiences of otherness and discovery of the possibilities of self-actualisation through connection to others and the world. The partnership of StoryAID and H2H, and the writing of the ubuntu story, was a direct response to the pandemic and the need to give voice to people with ILD in hospital settings. The pilot study described here, has enabled iterative and mutual learning and development for the project partners and nursing students through storytelling.

Storytelling in nurse education

Evidence demonstrates that stories and storytelling can support nursing student's learning by developing relationships that reinforce nursing knowledge, skills, and experience (Lindesmith and McWeeny 1994; Bergman, 1999; Banks-Wallace, 1999). In this sense StoryAID can be considered an evidence-based educational intervention, that is based on

processes to ask, acquire, appraise, apply, and assess how storytelling can benefit patient-centred care (Kirkpatrick, Ford & Castelleo, 1997; Lober and Komnenich, 2020), communication and connection (Bergman, 1999; Urstad et al., 2018; Kelly, 1995), and risk management (Brown, 2010). As previous research has demonstrated, the utility of storytelling within the context of patient-centered care in clinical settings has been “to really understand who a person is or was, and in turn provide the care that will suit their unique needs” (Chu, 2006). For example, to promote health (Palacios et al., 2015) or self-management (Gucciardi et al., 2016).

Stories support learning by enabling nursing students to reflect on clinical placements and practice (Timpani, Sweet & Sivertsen, 2021; Crawley, Ditzel & Walton, 2012; Wheeler et al., 2016) and to explore what it means to be a nurse (Wood, 2014). Storytelling can also support relationships between students and educators (Bodine, 2018; Haigh and Hardy, 2011). It can enable perspective sharing with patients and service users (Lindesmith and McWeeny 1994; Hunter and Hunter, 2006; Sabio and Petge, 2019; Walshe, 2013). And it can promote social inclusion, cultural intelligence, and awareness of intersectionality in education (Sinkfield-Morey, 2018) by supporting self-expression, creation, and imagination beyond institutions to engage traditionally excluded groups and communities in teaching and learning (Paliokosta and Kostidakis, 2019).

For some reason storytelling remains a hidden part of the curricula (Attenborough and Abbott, 2020) and there is a need to equip nurse educators with effective approaches (Haigh and Hardy, 2011) that are relevant to specific learning goals such as clinical skills development (Eraut, 1994; 2004). Perhaps it is because storytelling is a more fluid nontechnical approach to curricula (Lunenberg, 2011) that reflects the more esthetic, emotional, political, and visionary elements of nursing, which nonetheless matter to patients (Attenborough and Abbott, 2020) and the human rights of patients (Paliokosta and Nash,

2019). Within a narrative pedagogy, storytelling is the basis for the stimulation of thinking, interpretation, and learning (Diekelmann and Diekelmann, 2009). It accords with Freire's (1970/2001) views of education as a process of *conscientization*, or the development of critical awareness of one's social reality through reflection and action. It positions curricula as the opportunity for creation of knowledge by learners and teachers together (Daniels and Downes, 2016), within the context of their lives (Freire, 1998). The possibility of stories to convey political, social, gender, and personal perspectives, connects the learning approach with critical pedagogy (Giroux, 2011), feminist pedagogy (Crawley, Lewis, & Mayberry, 2008; Shrewsbury, 1997), and transformative learning (Mezirow, Taylor & Associates, 2009).

The Heritage2Health Virtual Arts and Drama Project

In this pilot project, StoryAID was chosen as an approach to support a relational learning experience for nursing students and young people with ILDs. All H2H projects are based in relational pedagogy and in particular perspectives from relational inquiry, including attention to intrapersonal, interpersonal, and contextual relationships (Doane, Hartrick-Doane and Varcoe, 2020). In the project StoryAID and H2H united on three key points, which could be thought of as implicit learning objectives. First, these approaches enable *direct engagement* of young people with ILDs in nurse's learning which benefits student communication skills and social and cultural competencies, as well as student understanding of the ethical issues, safety, and risks involved in caring for people with ILDs. Second, storytelling in a relational context could help to *prepare students* for the uncertainties and complexities of the workplace and the formation of positive future relationships with patients in practice. Third, they *support inclusion* of a diverse group of participants through

partnerships and opportunities for participants to voice their own situations and lived experiences as impetus for learning and understanding (Unwin et al., 2018).

Participants

Nursing students on degree and masters level courses in adult, child, mental health, learning disability fields were invited to register for the elective. In the UK pre-license nursing students chose to specialise in either child, adult, mental health or learning disability nursing at the start of their course and upon graduation they gain registration in that field. The pilot was carried out with the first cohort of 15 self-selecting students (BSc Year 2=10, Year 3=3, MSc=2) in June/July 2020. There were no control or comparator groups. The facilitator/educator to student ratio was 4:15. The recruitment of student participants was coordinated by a Student H2H Ambassador and overseen by TNP. No incentives or reimbursements were provided to the learners. The recruitment of the young people aged 11-14 with ILDs (n=7) and their parents (n=7) was supported by the partner special school, who sent out letters inviting families to take part and explaining the aims and objectives of the project.

Intervention

Delivery of the intervention comprised:

- 8 online storytelling sessions, each 45-minutes long held weekly at 4.30pm
- Facilitation by a storyteller coach and drama specialist (EA) and a contemporary artist (BO'D) who also created pictures and artistic materials to support storytelling (see full report)

- Sessions followed the story of ‘Ubuntu the Lion with the Long Long Mane’ (research copy available from TNP) and story books were made available to the young people and their families prior to the sessions
- Participants were encouraged to reflect on their learning using personal journaling, but this was not a formal requirement
- Supervision of learning was provided by two nurse lecturers and a special-school teacher, who is connected into the project partnership through membership of the Inclusion and Social Justice Special Interest Group (see above)

The number of sessions, their frequency, timing, and duration were delivered as scheduled. No significant modifications were made during the course of the study and learning from group reflection was fed back into the project. The teaching and learning strategies focused on creating the conditions for multi-disciplinary learning and co-producing understanding between facilitators, educators, students, and other stakeholders through the shared experience of storytelling.

StoryAID was applied as a facilitated approach to storytelling to encourage nursing students to deconstruct, reconnect and rediscover their assumptions and to build understanding in relation to young people with ILDs. For example, by exploring notions of ability/disability, and what it means to be healthy. Facilitators (EA and BO’D) with experience in socially-engaged learning and facilitation methods, and with the support of academic educators (TNP, PP) encouraged participants to explore various physical, emotional, and spiritual perspectives of the story and their self (Stern, 1985). The StoryAID methodology is illustrated by the Enhanced Consciousness Wheel (ECW) which has been further developed and refined through the project (Figure 1).

The careful use of prompts alongside the story unfolding, invited participants to deconstruct their assumptions about ‘who they are’, ‘who they are being’, and ‘how they are

choosing to participate' in the storytelling process (Daniels and Downes, 2016). For example, the facilitators invited participants to reflect on their beliefs about the difficulties Ubuntu the Lion faced about how he perceived the world (Ventegodt et al., 2003a, 2003b). The experience of deconstruction can be unsettling for students as they begin to see the extent of their assumptions about the world and their limited perspective on it (Bourdieu, 1990). Therefore, alongside the telling of the actual story, participants were encouraged to reconnect with their understanding, by telling their own personal stories (Hydén and Antelius, 2011) and what it means to them to live with authenticity (Bourdieu, 1990). The facilitators were prepared that in some cases this opening-up can reveal trauma and negative past events and therefore they encouraged participants to see storytelling as a way to disrupt a cycle of negative thinking, rumination, or retraumatisation (Anderson, 2015).

Reconnection involved facilitators encouraging and reflecting on *the active witnessing of self* (Paliokosta and Kostidakis, 2019) a process whereby other participants, family members, peers, and educators see the person go through the process of questioning self in context(s) and go through the process with the person as they form a new more complex understanding of their identity (Bourdieu, 1990). The facilitators used the same ECW cycle of prompts to help participants to rediscover their self by acknowledging that the story they are living through is shaped by archetypes, stereotypes, dogma, and rules, about what it means to be 'a patient' 'a nurse' or 'an educator' (Pfeifer, 2010) rather than a unique person with a unique identity (Goodrich and Cornwell, 2008). Rediscovering and renegotiating relationships through the facilitated StoryAID space aimed to allow openness and trust to develop in the group so that participants could experience the world through the intersubjectivity of other human beings (Bourdieu, 1990). Group reflection exercises at the end of sessions were important for checking that the materials and the educational strategies were being delivered

as originally planned and that participants were moving towards the intended learning objectives.

[Figure 1 To go near here]

Evaluation

An ethnographic rights-based evaluation (Parker, 2007; Hydén and Antelius, 2011) was used to enable a volunteer nursing student researcher, with support and supervision of the educators (TNP, PP) to take a fully inclusive approach to assure the rights of the young person to be involved in issues that affect them (Callus, 2017). Ethical approval was sought and granted by the university (Ref-1581 2020). Nursing students and all other participants gave their consent to the evaluation (Parker, 2007) and were given the choice to opt out of the evaluation but still participate in the programme at any time. In the post project evaluations, the socially-engaged artist (BO'D) undertook semi-structured interviews with nursing students (n=5), parents of young people with ILDs (n=4), storyteller-coach facilitator (n=1), educators (n=2), and the school-teacher (n=1) 2 to 6 weeks post programme. Interviews included questions about concerns, needs, involvement, session timings, improvements, learning, and suggestions for future planning. Additionally, all participants were requested to contribute to record their learning using photographs, notes, digital posts, and narrative formation (Hydén and Antelius, 2011).

Data captured by the evaluation were analysed (BO'D, TNP) using thematic analysis which included familiarisation with the data, coding issues, generating themes from the data, reviewing themes, and writing up (Lyons and Coyle, 2001). To support rigour in the analysis interview data was read independently to identify issues and cross check meaning (American Educational Research Association, 2006). A further level of the analysis (BO'D, EM) drew

on relational inquiry perspectives (intrapersonal, interpersonal, context) (Doane, Hartrick-Doane and Varcoe, 2020) to explore different dimensions of nursing student's learning, with selected findings from the report illustrated below.

Results

Thematic analysis of the evaluation data revealed four key themes about nursing student's learning in this project:

- Relating to the story and characters
- Participation in the processes of storytelling
- Relating to other people participating in the storytelling
- Relating shared learning to clinical contexts and professionalism

(i) Relating to the story and characters

Over the 8 sessions, participants read, listened, exchanged experiences and types of knowledge. The ubuntu story was a stimulus for student reflection (Eraut, 2004) particularly notions of discovery and becoming a nurse (Downing and Hastings-Tolsma, 2016; Wheeler et al. 2016) and the pressures of being a nursing student, during the time of the pandemic. In the evaluation students talked about “being in someone else’s shoes”, “being a nurse”, “being the uniform” and “being in the shoes of the character in the story”, “being Ubuntu the lion”. The experience of vulnerability in self and others is important in nursing and was made possible through relating to the story and characters.

(ii) Participation in the processes of storytelling

Nursing students talked about the experience of being collectively with others in the storytelling and how this helped them to learn about dis/ability and be less fearful. All

nursing students actively participated and were invited to read, listen, act out, reflect, and recreate elements of the story together with drama. It should be noted that the participating students were self-selecting and therefore possibly more open to the storytelling approach and participative learning. A lesson for H2H is to try and widen participation in the future with the support of this first cohort of students, and their contributions as co-producers of the project and advocates for learning in partnership with young people with ILDs:

“Students that participate in a project like that are really engaged anyway. To extend it to other groups it needs to be embedded into the curriculum or specific modules, where it would be up to course directors and lecturers to deliver it. It is quite a resource intensive form of teaching unless you work with the students and get them involved in running it.” (Nurse academic)

As nursing students behaved in new ways (e.g., pretending to be Ubuntu the lion) they learnt how a person exists outside of a stereotype or identity label (Mehl-Madrona, 2007). It was then with a sense of urgency, that students desired a professional identity (Eraut, 1994) that aligned with their ‘authentic self’ (Nietzsche and Zimmern, 1997) and allowed them to care in ways that connected with their self (Lindesmith and McWeeny 1994).

(iii) Relating to other people participating in the storytelling

The storytelling space gave a place for the active witnessing of self-identity formation (Heavy, 2018). Nursing students described how the expression of their personal truths about preferred ways of being created trust and acceptance of self and others as authentic, fallible, feeling, and caring beings. We found that intellectual disability can positively challenge social norms and values because people with ILDs do not experience the world in the same ways as professionals (Callus, 2017): the nursing students said they became more aware of how young people with ILD might see them as scary professionals and how “acting silly” and

“having fun” and “laughing together” helped to break down barriers (Hydén and Antelius, 2011) that could benefit future care. In a digital environment the learning space became a mix of interconnected and intersectional spaces (Heavy, 2018) where ability to use technology could in some cases overcome dis/ability (Davis, 2019) and illness (some young people were in hospital receiving treatment during some sessions but were still able to participate). This generated empathy between participants by witnessing people in situ (Beck and Neil, 2020). However, some students felt “left out” in the digital space to begin with, but as sessions progressed the facilitators adapted to be more inclusive of the whole group (checking everyone appeared on screen or contributed) and ensuring retention of all students. As noted by one facilitator:

“Through storytelling you are able to open up and facilitate a space for navigating uncertainty. The space has a quantum dynamic, a spatial architecture that can be shaped, formed, pushed, changed, and crafted by emotions or gestures. The space is a changing, interactive space. It can be felt, it has colour, and texture.”

(Storyteller facilitator)

Within this emerging diverse story group community, students felt safe to question “what kind of nurse do I want to be?” and “What kind of a world do I want to create?” The co-creation of a shared new story, the story of participation in the group, progressed participant’s sense of togetherness in creating more inclusive and more meaningful understandings of self, disability and caring (Parker, 2007; Anderson, 2015).

(iv) Relating shared learning to clinical contexts and professionalism

Nursing student feedback during and soon after the sessions indicated benefits for student knowledge about disability and confidence to work with young people with ILD in clinical settings. At 3-months post course, students were able to provide examples of how

they had taken learning from the project into practice and personal development, as recorded in the reflective evaluation:

“The experience of being together alters and creates something new. There was a strong sense of creating and becoming something new and different, something better than before, because of going through the story together and sharing that experience.” (Facilitator, BO'D)

Learning about inclusion was taken into clinical placements as students reported noticing when patients seemed overlooked, misunderstood, or excluded from ‘difficult conversations’ (Browning et al., 2007).

Together these selected findings indicate that StoryAID enabled H2H to deliver an educational intervention that helped nursing students to interrogate and challenge power relations held in identities and assumptions about themselves and others (Chow, et al., 2003). The approach shifts the focus from didactic learning about meta-theoretical sociological concepts such as disability, ethnicity, gender, and culture, to student’s experiential examination of their own subject positions, discourse, contestation, and local action. The telling and exchange of stories based on ubuntu, and the imagining of new stories about ways of being (McCabe, 2018) encouraged student socio-political awareness, the exploration of moral agency (Beckett, Gilbertson, and Greenwood, 2005) and possibilities for change (Cameron et al., 1995). StoryAID help set and manage the conditions for a nuanced and complex awareness of the young people’s experiences of marginalisation on the one hand, and agency (especially the support of parents and teachers) and willingness to contribute to changing nursing and nurse education for the better, on the other (Dillon, 2019). This awareness included us all questioning who was the ‘educator’ in the learning process and the value of the authentic self in teaching. Thus, support for nurse educators to tell their stories is

an important emerging issue for professional development and future research. Inspired by the StoryAID approach, we have told the story of the project in an accessible summary written from the perspective of a young person with autism (included in the final report).

Conclusion

In this pilot project StoryAID and H2H combined the benefits of storytelling with experiential learning and service user engagement, to build nursing student's relational skills and empathetic understanding of young people with ILDs. There is good reason to believe that other nursing students at other universities, educators, and young people with ILDs, could equally benefit from using StoryAID and H2H to deliver a relational learning experience. The StoryAID methodology and its enhanced consciousness wheel help structure the storytelling processes and could be the basis for future exploration of storytelling as an educational intervention. Nursing students experienced moments of uncertainty, exploration of self, frustration, and scepticism, which StoryAID and the multidisciplinary approach helped to address by providing them with a safe space to connect with each other, young people, educators, and other participants. Students became aware of their critical abilities to question assumptions and opportunities to relanguage and recontextualise their developing identity and confidence to be a nurse. Going forward, the story of Ubuntu the Lion with the Long Long Mane, gives participants a story to keep in mind in their work with patients and their families to create a health service that supports belonging and acceptance.

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Figure 1: StoryAID Enhanced Consciousness Wheel (ECW)

