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Patients' stories in healthcare curricula: Learning the art of healthcare practice with patients

Journal of Further and Higher Education

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Patients' stories in healthcare curricula: Learning the art of healthcare practice with patients

In our previous paper, we theorised that patients' stories prepare students by allowing them to reflect on their practice in the safety of the academic environment. This paper furthers this theory by arguing that when engaging with patients through storytelling, students grow epistemologically, where they develop knowledge about empathetic practice, and ontologically, where they learn to form and maintain relationships with the patients in their care. These new forms of knowing then inform practice and their professional decision making. Patients' stories galvanise students to think more deeply about their practice and their patient engagement. Through that, they develop their art of healthcare practice, becoming competent, empathetic practitioners who are constantly motivated to developing their practice.

Keywords: patient stories; storytelling; healthcare education; healthcare practice; narrative pedagogy; transformative growth

Introduction

Patient stories, where people with a particular diagnosis or healthcare experience are involved in the education of emerging healthcare practitioners through storytelling, is often part of healthcare curricula in universities. This activity is linked to the current drive in healthcare, aimed at supporting partnerships between patients and professionals. While there is evidence that patient stories are beneficial to meeting the educational needs of healthcare students this teaching and learning approach appears to lack a robust theoretical underpinning to explain why it is valuable for ongoing professional development, how it stimulates such development and how it could fit within healthcare education curriculum and clinical practice (Job, Wong and Anstey 2017; Edwards et al. 2016; Terry 2013; Turnbull and Weeley 2013; The Health Foundation 2011).

Exploring the theoretical underpinning of patients' stories became a passion of this academic team following the incorporation of patients' stories within our own nursing curriculum, specifically, the provision of the first-hand experiences of people affected by cancer, delivered in small groups in the classroom. Students had the opportunity to enter a dialogue with people affected by cancer about the impact of their diagnosis, their treatment, information needs and life now, living with and beyond cancer. It was clear that students were captivated by these stories, their engagement and dialogue with people affected by cancer was reflective and provided a memorable and meaningful learning opportunity for the students (Job, Wong and Anstey 2017, Edwards et al. 2016).

In our previous paper (Job, Wong and Anstey 2017), we argued that patients' stories bring real world experience and practice into the university setting, helping to illuminate patient experience and bridge the disparity between theory and practice. This, in turn, aids the students to be more adequately prepared for the challenges of modern practice emphasising the importance of empathy and a person-centred approach.

In this paper, we aim to add to this series of theoretical critique by exploring the idea of the patients' involvement in the student's knowledge acquisition and its influence on the healthcare practice and, on a wider scale, shifting practice paradigms. We argue that these changes contribute to an overall transformation in the students' learning, about themselves as a practitioner, about their relationship with those they care for and about the students' approach towards healthcare practice philosophy. We see that patients' stories within the healthcare education curriculum are a variant of narrative pedagogy, an approach to healthcare education which features the use of storytelling to encourage professional development. Through this paper, we endeavour to further highlight the importance and relevance of patients' stories in healthcare

curriculum and to issue a clarion call to encourage patients' involvement at all stages in the development and ongoing support of healthcare practitioners.

Knowing *with* patients – participation in knowledge development

Healthcare practices are activities engaged in by human beings, there is a difference between practice that relates to physical objects and those that relate to human beings. This early distinction was first recognised by Aristotle who used the word *poiesis* to describe production or manufacturing based activities and *praxis* that describes activities pertaining to human beings (Anstey 2012). Each of these activities requires different kinds of reasoning and different sets of skills to accomplish them. Making something requires knowledge of the steps and skills for transforming raw materials into an object, described by Aristotle as *techne*. Action, as in clinical medical practice, which aims to support the human good in a specific situation he describes as *phronesis*. This is the practical knowledge required to support clinical activity which can be described as knowing that and knowing how these relate to actions that seek to accomplish good in response to human needs. Related themes emerge in Gilbert Ryle's (1945) distinction between knowing how and knowing that, which emphasises the characteristic between knowing how to do something (for example taking blood pressure readings) and knowing that some particular proposition is true (such as water boils at 100°C) (Anstey 2012).

Patients' stories add another dimension of knowing. We term this as knowing *with*. Apart from knowing that (anatomy, physiology, disease and its aetiology for example) and knowing how (triage patients, assess patient's needs and developing treatment and interventions for example), students take part in a form of knowledge that is deeply empathetic - knowing *with*.

Carper's (1978) taxonomy of knowledge in healthcare practice delineates four patterns of knowing: empirical, aesthetic, ethical and personal. Empirical knowing draws on the traditional ideas of scientific knowledge, considering underlying principles and techniques often procedural. This form of knowing can be taught through textbooks and lectures and would involve topics such as human anatomy. Aesthetic knowing expects a deep appreciation of the meaning of a situation and its transformation into practice often creatively, the art of professional practice. This form of knowing is conversely more implicit and is often expressed in the practitioner's proficiency and competence in his or her field when dealing with complex cases. Personal knowing is largely autobiographical, acknowledging the validity of feelings, experiences and reciprocity; the knowing of one's own self may enable the knowing of others. This form of knowing requires an awareness of one's beliefs that guide one's practice such as the value of the patient's autonomy in decision making about his or her care for example. Ethical knowing evolved from the moral characteristics of the individual to the professional requirements of duty and responsibility; it is about what ought to be done in practice (Carper 1978). Forty years later this taxonomy still resonates with contemporary healthcare practice.

Knowing with, unlike knowing that and knowing how, carries an element of knowledge that is personal, ethical and aesthetic. It shifts the focus of knowledge development away from knowing about a certain topic, which is empirical or practical which can be taught didactically or developed through self-study methods. Knowing with is the form of knowledge that can only be developed with the participation of others, in this case, with patients.

When students enter into a dialogue with patients it is important to remember that the student connects not only with the patient story but also with their own

experiences of practice, meaning that they use the patient perspective to help understand and refine their own practice and knowledge (Job, Wong and Anstey 2017). The provision of this opportunity in the educational setting arguably helps in this process. The university is home to healthcare practice theory, therefore, patients' story in a classroom helps them to associate this with a learning experience, thereby bridging the theory and practice divide (Job, Wong and Anstey 2017). This associated learning is arguably more difficult when conducted in the practice environment where theories learned can seem unrelatable in the context of real world practice (Eraut 1994, Bosser et al. 1999, Job, Wong and Anstey 2017).

Dialogue is indispensable in the learning environment. Learning that meets the challenges of modern healthcare needs to be firmly established in the real world of practice (Rolfe 2013). Who better to provide this dialogue than the patient themselves? Freire (1970) believed that this dialogue is crucial in the development of critical thinking, which is an essential skill of all healthcare practitioners. Therefore, dialogue between patients and students fulfils a modern requirement for a different type of knowing. The integration of patients' stories encourages the student to critically reflect in order to explore the patients' perspective, their beliefs and attitudes about their diagnosis, treatment and their interaction with healthcare services (Job, Wong and Anstey 2017). This helps the student to know with the patient which in turn helps them to critically challenge their own assumptions, attitudes and beliefs.

Knowing with is deeply empathetic, aesthetic and personal process. It is featured in the reflective dialogue between the student and the patient. This form of knowing is not about facts or skills but about how the facts and skills that the student acquires as part of their education can impact the patients who are on the receiving end of care and practice. While this form of knowing is inherent in placement or practice education

where students practice in a supportive clinical environment, patients' stories, when shared in the university setting enables knowledge development about the realities of practice through reflection in the safety of the university environment (Job, Wong and Anstey 2017). Healthcare education is about learning how to care for others, hence, it is imperative that student practitioners develop such knowledge through knowing with the people that they care for.

As this process of knowledge development is empathetic and personal, there needs to be mutual respect between students and patients in this epistemic pursuit. Ethically, to participate in this process, patients need to be willing to share their experiences, be open to questions posed by genuinely curious students and be empowered to decline to respond as they wish. Students, similarly, need to be sensitive and mindful of their interactions and carry themselves professionally, as they would at the bedside. These ground rules need to be set to ensure a protective and highly educational environment for both students and patients.

It is important to remember that dialogue is a two-way process, therefore, the patient also benefits from taking the perspective of the health professional, making this a mutually beneficial experience. When the goal of healthcare education is the development and understanding of the holistic impact of health or illness, the integration of patient stories can assist in the student developing a deeper empathetic understanding through perspective taking that aids them in their delivery of care and their future communication strategies with patients.

Being *with* patients – flourishing through participation

The benefit of patients' stories in healthcare education is more than epistemological; it is also ontological. Incorporating patients' stories recognises that healthcare education does not just involve students and academic or clinical educators but also patients as

key stakeholders of care. Therefore, students need to work with patients for their own professional development, in other words, know how to be with patients.

Following the previous section, knowing with is a collaborative venture towards knowledge development. Heron and Reason (1997) saw this process as a means towards human flourishing, an ideal society where humans cooperate and interact freely with each other in a common epistemic pursuit. In their argument, such knowledge development requires mutual participation.

The participatory paradigm answers the axiological question in terms of human flourishing, conceived as an end in itself, where such flourishing is construed as an enabling balance within and between people of hierarchy, cooperation, and autonomy. In our view, social practices and institutions need to enhance human association by an appropriate integration of these three principles: deciding for others, with others, and for oneself (Heron, 1989, 1993). (Heron and Reason 1997, 287)

While clinical practice carries an element of deciding for patients, there is also an important element of deciding with patients, particularly in the modern person-centred care paradigm. Excluding the latter in care provision will result in a regression to a paternalistic model, where the practitioner has full responsibility of deciding on the care provided with no input from the patient (Charles, Gafni and Whelan 1999).

Patients' stories in healthcare curriculum and practice enable a form of collaboration in the knowledge development process. Through knowing with, students learn how to be with patients in their care provision. The following feedback from a student on our course reflects this.

The patient session is a day I will remember forevermore. University-based nurse education can feel isolated from clinical practice...the patient session

allowed us to not only look on but sit with the patients and experience the raw honest emotion of their lives. Prior to the session, empathy and partnership working were words that had a formal definition, now they are feelings that I aspire to achieve during each patient contact. (Nursing student's feedback)

When patients participate in the students' learning about clinical practice collaboratively, there is an opportunity for students to flourish. Collaboration with patients in care provision grounds in practitioner in the real world of practice, where care is always for the patient. Patients participate in the process of knowing with by providing feedback on the care they receive and by offering the perspective of a care-receiver. These experiences that they share is deeply emotional and aesthetic, something that the students can only learn through dialogue with the patients and not by experiencing it themselves as practitioners. We argue that patients have a form of knowledge that is unique to them as recipients of care and this knowledge is crucial to the development of healthcare practitioners. Therefore, they have the right to be co-enquirers with the students in the students' learning about healthcare practice. This right is fundamental (Heron 1996), as is the patients' right to be involved in the decision making process about their own care. In the context of healthcare education, it would be ironic to not involve patients when teaching about person-centred care.

Learning to be with patients is particularly important today. Reason (1998) argued that there is a shift away from a worldview where everyone has a role to play in the universe, a worldview which Skolimowski (1994) calls *Mechanos*, the clockwork universe. *Mechanos* was a result of a long period of scientific pursuit and scepticism brought on by the great minds of Bacon, Galileo, Descartes and Newton (Skolimowski 1994). It resulted in the perspective of individuals such as doctors, lawyers and scientists having distinct specialist knowledge about the operations of the world, hence

have a specific role to fulfil in society. In the Mechanos worldview, patients were perceived as the passive care receiver while the practitioner bore the full responsibility of care provision. However, Reason (1998) argued that modern-day challenges transcend the responsibilities of individual groups of professionals. The issues of healthcare provision, for example, concerns more than just doctors as the world shifts away from the medical model of healthcare provision. The responsibility falls on educators, students, patients, all healthcare practitioners, professional bodies, regulatory bodies, hospital managers, administrators and directors. Modern day challenges require all these stakeholders to work together, in other words, be with each other.

... it has not been possible to see the world as an assembly of separate parts, we have been pushed to see the planet as a living whole, a complex system of separate but interrelated entities – of which we are a part. (Reason 1998, 42)

The mechanical worldview is less relevant now because the modern-day challenges require the collaboration of multiple groups of people. Similar to how practice education or placement helps students socialise into the profession (Eraut 1994; Krusen 2011), patients' stories in the healthcare curriculum help students learn to be with patients.

This kind of flourishing is practical knowing: knowing how to choose and act-hierarchically, cooperatively, autonomously-to enhance personal and social fulfilment and that of the eco-networks of which we are a part. Such human fulfilment is consummated in the very process of choosing and acting. So in the participatory paradigm, practical knowing is an end in itself, and intellectual knowing is of instrumental value in supporting practical excellence. (Heron and Reason 1997, 287)

Learning to be with patients is inherently about interacting, developing and maintaining relationships with them in one's practice. Within the context of healthcare practice, practical knowing refers to the interactive elements of clinical practice such as how to behave, how to act and how to communicate with patients. It inherently carries an emotional and moral element. Practical knowledge construction in this area grounds learners in the emotional and moral dimensions of clinical practice. The focus here is not about gold standard technical proficiencies but about learning about care for patients. Actions, treatments, behaviours on the wards are not just about replicating what is taught the textbooks, rather it is choosing the right action in response to the needs and condition of the patient.

Patients' stories in healthcare curriculum are about empowering patients and encouraging their involvement in the education of emerging healthcare practitioners, practitioners who will eventually be responsible for their care. It offers students an avenue to learn how to be with them, constantly grounding students in the realities of practice and develop knowledge within the emotional and moral dimensions of care provision. This is particularly salient in today's person-centred care paradigm where decisions on care are the patient's responsibility, as much as they are the practitioner's.

Practising *with* patients – moving beyond evidence-based practice

The emphasis on evidence-based practice and the hierarchy of evidence in practice has arguably led to an undervaluing of clinical judgement and experience, and this can act as a potential barrier to individualised care (Gabbay and le May 2016; Greenhalgh and Maskrey 2014). This is not to dismiss the importance of consulting the evidence base when making decisions that will affect the care and management of a person with healthcare needs, yet this alone should not form the basis of decision making. Each person has individual circumstances that make them unique and the experienced health

professional needs to draw on more than research evidence or guidelines when making decisions (Greenhalgh and Maskrey 2014). The top priority in any given situation should be the priorities highlighted by the patient themselves and can be elicited by asking “what matters to you?” This, in turn, supports the practice of shared decision making, and this is different from the health professional running through a list of options in a set of guidelines or an algorithm (Greenhalgh and Maskrey 2014). This requires the health professional to reform their reflections in the reflection of the patient, meaning the patient should not be a passive listener but a critical co-enquirer in the dialogue with the health professional (Freire 1970). The health professional presents information but must be prepared to reconsider their view point as the patient expresses their own. This leads to an unveiling of reality and an individualised plan of care.

Gabbay and le May (2016) pointed out that in practice professional decision making is complex and not simply a linear application of a set of guidelines. This is illustrated in the figure below.

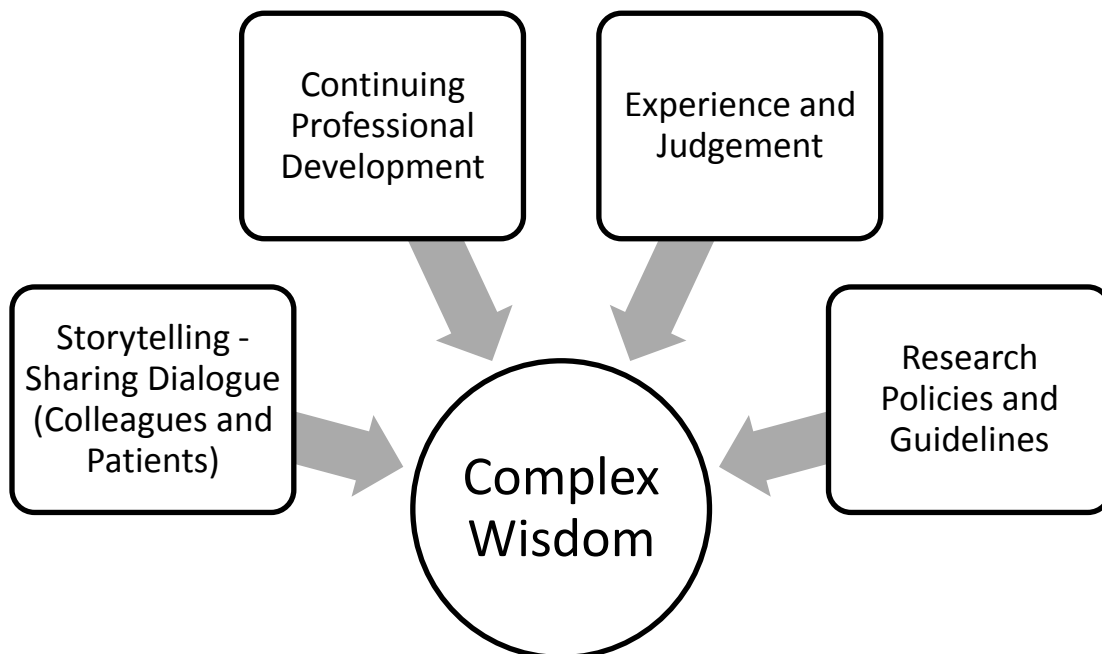


Figure 1. Complex wisdom (Gabbay and le May 2016)

Many different avenues of work and clinical experience contribute to complex wisdom and good practice. Gabbay and le May (2016) named this learning and decision-making process ‘mindlines’, as an outcome of their ethnographic study exploring the decision making and knowledge gathering of healthcare professionals. They discovered that health professionals acquire their mindlines through training, but also their own and each other’s experiences, their interaction with colleagues and patients; coupled with an understanding of local circumstances, health systems and the management of conflicting demands.

More importantly mindlines are shared, checked and adjusted as professionals enter into a dialogue with trusted colleagues and their patients; stories are swapped, experiences shared, problems solved together, and this leads to sense-making and creative thinking. Arguably the formation and reformation of mindlines are a process of reflection and involve people in relation with the world. This transformative thinking and learning facilitates person-centred care and regards dialogue as indispensable to the act of cognition unveiling reality (Freire 1970).

Plausibly then in order to provide the student health care professional with the tools to become a critical decision maker they need exposure to the lived experience of people with health care needs. Greenhalgh and Maskrey (2014) pointed out that a re-balancing of evidence-based practice needs to begin at the undergraduate level with a reorientation away from rule-following, emphasising that realigning ‘professional relationship-based care’ is important. Greenhalgh and Maskrey (2014, 4) suggested one aspect of this work would involve “reflective case discussion with input from patients who want to articulate their experiences, choices and priorities”.

Learning the art of healthcare practice through patient storytelling

Knowing with, being with, and practising with patients encourage a form of learning

that is deeply transformative. Healthcare education is beyond scientific knowledge and therapeutic skills. Students must learn how to care.

We were all attracted to a healthcare profession because we are caring people.

We value caring relationships, and the healthcare arena provides the structure within which our natural feelings and skills can find expression. (Devereaux 1984, 791)

Healthcare practice is an artistic expression of innate compassion. This artistry materialises in the form of excellent practice and professional competence. The job of healthcare educators is to equip students with the required skills and knowledge, to provide the appropriate environment to cultivate such artistic practice and allow room for its expression. Healthcare educators use many teaching approaches to achieve this goal, ranging from didactics to dialectics and experiential learning.

While didactics can be effective for teaching scientific knowledge and therapeutic skills, a dialectical approach is more appropriate to teach students how to care (Rolfe 2013). Patients' stories provide a supportive environment for such reflective dialogue to occur in the university (Job, Wong and Anstey 2017). They fit well within other dialectical approaches used within healthcare education such as practice placements, clinical supervision, problem-based learning and experiential learning. We see patients' stories as a variant of narrative pedagogy used in nursing education (Diekelmann 2001).

Narrative pedagogy is an interpretivist pedagogy that is concerned with exploring different ways of thinking and understanding experiences. It encourages educators and students to learn from their own experiences by contributing to converging conversations about their embodied experiences of learning, teaching and practice (Diekelmann 2001). These conversations cultivate interpretive thinking, helps

teachers and students learn, unlearn and relearn by exploring new possibilities within their own practice as practitioners or as educators (Ironside 2006). There are many methods of using narrative pedagogy and creating opportunities for reflective converging conversations to occur such as using drama and roleplaying (Ekebergh, Lepp and Dahlberg 2004), storytelling (Swenson and Sims 2003), metaphors (Taylor et al. 2018) and writing (Ironside 2006). We believe that patients' stories are a suitable addition to this list of narrative pedagogical methods.

Patients' storytelling argues that patients can be effective educators for healthcare students and their wealth of experience of receiving care can be valuable materials for learning and reflection (Job, Wong and Anstey 2017). Listening to patients' stories and asking questions, students actively engage in a reflective process with their own experiences of practice and understanding of care provision.

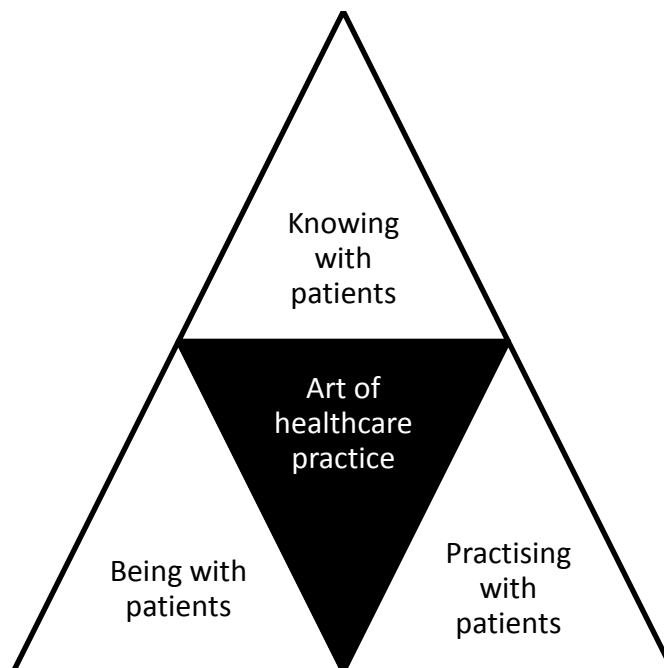


Figure 2. Art of healthcare practice

The figure above shows the contribution of patients' stories towards developing the art of healthcare practice. By engaging in the patients' stories, students participate in a process of knowledge construction that is deeply empathetic, aesthetic and personal.

In addition, students learn how to be with patients, developing practice that is more than evidence-based or experience based; they learn to become person-centred practitioners. Such growth and professional development through patients' stories are transformative for students because students do not just simply expand their knowledge base or sharpen their skill proficiencies. They engage, epistemologically and ontologically, in the deep philosophical questions of healthcare practice to grow beyond becoming competent practitioners; they become artistic practitioners.

Students question themselves as practitioners, becoming deep thinkers of their own practice. Patients' stories afford students space within the university environment to refine their art of practice (Job, Wong and Anstey 2017) and when they find the opportunity to demonstrate this, they become artistic practitioners. Such artistic practice is competent, professional and imbued with a deep sense of empathy and values. This is the type of care provision that is required in modern-day healthcare practice (Gabbay and le May 2004) and teaching this is the goal of healthcare educators.

Fundamentally, patients' stories in healthcare education are an opportunity for converging conversations to take place. These dialogues are deeply reflective and bridge the theory and practice divide (Job, Wong and Anstey 2017). In addition, it facilitates the creation of caring communities of students, educators and patients (Nehls 1995). Such conversations do not end in the university environment. Rather, students, as active agents of change within their own practice, carry on these conversations with their peers, clinical supervisors and their future patients and colleagues as qualified professionals. The learning that emerges from these dialogues about their practice contributes to their continual professional development and refinement of their art of healthcare practice.

As a method of narrative pedagogy, it shares a similar critique. Storytelling contributes little to the learning of scientific knowledge (Heinrich 1992; Hunter 1986; Sarbin 1986) however patients' stories allow students to develop tacit knowledge about their practice that cannot be taught didactically (Job, Wong and Anstey 2017). Some may also argue that, through interpretation, it is as easy to use storytelling to reinforce bad practice as it is to promote good practice. This can be circumvented by supporting patients' stories with ample facilitation and ensuring that students are guided in their reflection. The continuous reflective conversation the student engages in with his or her peers, educators and patients can help prevent the perpetuation of poor healthcare practices by providing moral and professional guidance. The interpretive and reflective nature of patients' stories proffers students the opportunity to make moral judgements about their own practice. Though potentially dangerous in extreme cases, it is not an issue that healthcare educators should avoid since it is an inherent component of professional practice. It would be more advantageous to allow such conversations to occur in the safety of the university such that they do not become future malpractice.

Conclusion

Through patients' stories, students engage in a personal, aesthetic and empathetic process of knowledge development. They develop knowledge about their own practice with the involvement of patients through reflection and storytelling. In addition to knowing with patients, students also learn to be with them in the own practice. This refers to the ontological development of their own practice where they learn to engage with patients and care for patients as opposed to merely demonstrating competent practice. The epistemological and ontological growth that students experienced manifest in their practice with patients, where they make decisions with their patients in careful consideration along with various other elements of their professional practice. Knowing,

being, and practising with patients contribute to a transformational growth in the student, from being a skilful or knowledgeable practitioner to an artistic healthcare practitioner – one who is competent, empathetic and always striving to become better. Such a reciprocal approach towards education and healthcare practice breaks down the hierarchy between the practitioner and patients, resulting in a more equipoise dynamic. Through synchronising reflection and action, the erosion of empathy in the real world of healthcare practice can be prevented.

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Figure 1. Complex wisdom (Gabbay and le May 2016)

Figure 2. Art of healthcare practice