Reciprocity in Knowledge Production: A Cornerstone for Disability Inclusion

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Contents

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M. H. Rioux et al. (eds.), *Handbook of Disability*,
https://doi.org/10.1007/978-981-16-1278-7_18-1

Abstract

The chapter is divided into three linked contributions by authors who discuss their experience of, and thinking about, reciprocity in different health care and educational settings. Christina described how the disrespectful attitude of health care staff toward her as a new mother with a disabled child led to her active engagement with community projects. Gubela has looked at a history of coloniality that dismissed the local knowledge and wisdom related to health thereby which has ruthlessly impacted on the well-being of a rural community. Lindsey and Lucia have described the process of "learning from" each other in a PhD supervision partnership.

Keywords

Reciprocity · Disability · Indigenous knowledges · Cooperative learning · Common humanity

Introduction

In Casement's introduction to his seminal book "On Learning from the Patient" (1985) he states, "*there have been some genius analysts, such as Freud and Winnicott, who learned naturally how to learn from their patients… Opportunities for learning from the patient are there in all caring professions*" (pg. x). This belief in the value of learning with and from the "other" is a cornerstone of reciprocity in knowledge production. It values the coming together of two or more minds to inquire, explore, and attempt to understand experiences that are essentially those of being human. With the world still reeling from the COVID-19 pandemic, this chapter seems ever more prescient as we recognize that we will not survive without knowledge exchanges across borders, community cooperation in creating safe spaces, and neighbors reaching out to those who have become isolated or unwell. Reciprocity relies on a respect for another's knowledge and experience and the recognition of a shared humanity, in other words to survive we need each other.

The following chapter in divided into three linked contributions by authors who have discussed their experience of, and thinking about, reciprocity in different health care and educational settings. Christina describes how the disrespectful attitude of health care staff towards her as a young new mother with a disabled child led to her active engagement with community projects that can assist parents and children with disabilities learn from each other and demand their rights. Gubela has looked at a history of coloniality that dismissed the local knowledge and wisdom related to health thereby creating a split system of health care, traditional knowledge, and "Western medicine" that has ruthlessly impacted on the well-being of a rural community. Lindsey and Lucia have described the process of "learning from" each other in a PhD supervision partnership.

Our hope is to add to the scholarship in critical disability studies (Vehmas & Watson, 2014) that goes beyond binary notions, of who is able and who is disabled, to considering how creating a third space of knowledge benefits all. This chapter explores how relationships built on reciprocity move beyond "doer and done to" (Benjamin, 2018) to one of shared learning and a recognition of a common humanity.

The chapter concludes with the four authors considering how reciprocity becomes more than an exchange of "goods," as it facilitates disability inclusion that is part of an overall "ethic of care" (Tronto, 1993). Some of the barriers to relationships based on mutual respect, fear of vulnerability, and an acknowledgment of the need for the other will be addressed. The authors, through the use of personal and political accounts of the barriers to, and rewards of, sharing knowledge, hope to show that moving beyond the rigid professional boundaries held by clinical staff, academic researchers and educators can provide new knowledges and nurture the emotional well-being of all.

The following section begins with Christina describing, in vivid detail, her experience of having a child with disabilities as a new young mother in a rural South Africa setting. The narrative is followed with some of Christina's theoretical reflections on the experience, with suggestions about improving the system of health care. She states there should be more joint working between parents of children with disabilities and health care staff, a form of reciprocal learning from and with each other.

The Experience of Parenting a Child with Disabilities in a Rural South African Setting

My child was born 8 months premature and was in an incubator for 1 month. When I was discharged from the hospital, I did not know that my child was disabled. I thought my child is normal like other children I did not see anything wrong to him. He has all parts of his body like other children. After some few months, I discovered that my child was not physically developing like other children of his age. He was too weak to sit upright on his own, he continued to fall occasionally, and his age group were about to crawl. I suspected that something was not right, and the health professionals would be the right people to assist. I took him to my nearest hospital and explained the situation of my child to the health professionals.

When I realized that something was not right to my child, I approached my nearest hospital, and my first point of contact was the doctor and the nurse. I presented the health condition of my child in my vernacular and the nurse translated to the doctor in English.

I was told that all he needed was to practice certain exercises and that with time he would be able to walk. I was advised to take him to physiotherapy and occupational therapy every second week of the month, but their reasons were not clear to me. I tried to ask what the cause of the disability and I was told not to worry “the child will be fine.” I felt irritated because I was told the same thing over and over again, and I did not see the progress to my child.

The Emotional Impact of Parenting

I felt ashamed because I was such a young mother and I used to ask myself constantly, why I gave birth to this kind of child? What was the cause? It God’s punishment? I am bewitched? These are some of the questions I cried over every day. The most painful part of all was that I could not find anyone with whom I could share my misery. I was given false hope, reassurance that his situation would get better which sounded promising. I was in and out to the hospital for therapy sessions without seeing any improvement to my child. They keep on telling me “Do not worry, he will be fine.” Those words strengthened my hope because I had trust in the therapist as they know best about health issues.

The father of the child was still at school. When my mother suspected that I was pregnant she informed my aunt, and I was approached by my aunt to confirm with me if indeed I was pregnant. I confirmed with her that is true. My family took me to the boyfriend family to inform them that I am pregnant. My boyfriend refused and told his parents that he does not know anything about my pregnancy. This meeting was before the child was born.

My elder brother told me to take my child to Nthume institution for persons with disabilities because he is disabled. I felt powerless because there was no support from anyone until I was introduced to Disabled Children Action Group. There was no support from anyone, family, friends, or adequate knowledge about parenting a disabled child. It was an emotional straining to find myself being disconnected from the people I love and trusted most.

Family and Friend’s Attitude

I struggled immensely at that time as I received no support from my family and friends. There was no one I could turn to for advice or even simply to talk to about the attitude from my family and friends. Inadequate emotional assistance led to an escalation of the stress I already suffered due to the circumstances. My best friends laughed at me and used to tell me that having a child is a burden, because you must carry the child wherever you go like a “handbag.” At that time, the analogy seemed too moderate as my child was more than a handbag, like a big suitcase filled with stones. The burden seemed to be more I could bear. Crying was part of my daily routine as my parents were constantly angry because they expected me to go to school not to have child. Since it was my first child, I experienced stress as well as feelings of depression, anger, shock, denial, self-blame, guilt, and confusion. It was not easy at all because you have no life, no life at all. I could not go anywhere; I had not enough time to be social because I did not have anyone to help; and I was overwhelmed with stress, frustration, and fear of parenting a disabled child.

Fear of Health Professionals

I experienced a deep fear of health professionals because they were reputed to scold those who asked too many questions. The hardest thing to deal with, however, was the false promise that the child would eventually be able to walk. I really trusted health professionals and were very few in my area during that time. I thought that they knew everything, well-educated doctors who had all the answers to the problem of my child. I had expectations for my child as great as any other mother’s, but as time went on, I realized that what I was told by the health professionals, mostly physiotherapists, could not come to pass.

Diagnosis Discovered Professionals Quantifying and Naming the Disability (Parents and Therapist)

I learnt the name of my child’s disability was cerebral palsy (CP) when I was queuing with other parents of children with disabilities at the physiotherapy department. One of the officials came outside and said “parents of CP children should move from this queue and queue to the other side of the building.” I told myself that my child’s disability was CP, now I know, it was a big English word to hear it for the first time in my life, I did not realize the two letters it stood for Cerebral Palsy. When it was my turn to get in the consultation room, I explain the condition of my child and asked will he be able to walk one day? The response was “Don’t worry he will be fine!!!!!”.

I was told how I should stretch the hands and feet of my child when I am at home. Every time when people ask me “why you are carrying your child at your back going in and out to the hospital?”, my response was my child has a “CP” problem, and that was the only answer I could give. I did not ask anything because I believed that professionals know better, well-trained medical doctors and highly qualified to do their job, and, as a result, I have to listen to and take their instruction.

Educational Assessment

When my child was 8 years old, I took him to my nearest special school for admission. The process for admission was long, because you have to take an application form to the psychology department to assess the IQ of the child. The day I visited the hospital for the psychologist to assess the child, I realized he was a white man who spoke English and I was not fluent with my English. I was stressed because there was no translator, and I could not express myself confidently in English. I put the form on his table and pointed for him to complete his part in the form. He did so without asking any questions and at the last part he wrote 48% IQ.

There was no instrument that he used to assess my child as having a 48% IQ. Because of this score, his application to the school was rejected and I was told that his IQ level was too low for admission. I went back home worried about the IQ score because the difference was 12% to make 60% for my child to get admission. I wanted my child to go to school, then I could look for a job. I went back to the psychologist after 3 months to tell him the IQ he wrote was too low for the school to accept my child. He asked me what he must write. I told him that he can write anything above 60% IQ and he then wrote 68% IQ. The head of the school then accepted the application of my child and I was just over the moon about the admission of my son. I felt helpless because at that time I could not read English or write English as a parent. I had to rely on the goodwill and actions of "expert" others.

Negative Experiences of Parenting

In writing this narrative and revisiting this painful past, there are questions I have about how health care services can meet the needs of parents who have children with disabilities. This response is particularly important when parents, as I was, do not come from privileged backgrounds of race, class, education, and socioeconomic security. Parents may not speak the English language of the medical staff, they may have little or no previous experience of disability, and they may live in rural communities that hold negative views of disability. Yes, rural areas hold negative views. My experience is more of the rural area I come from than in the urban areas.

Having no clear explanation for my child with disabilities made me vulnerable to ostracization by family members and the community. Callery (1997) claims that the integration of parental and professional knowledge has potential benefits in the management of children's health problems. It was easy to internalize the negative comments thrown at me, when there was no other plausible explanation that I could use to explain my child's disability. Studies have found that parents are also dissatisfied because they do not feel that they are respected as partners who have parental expertise and competence (Balling & McCubbin, 2001; Fisher, 2001). As a parent of a child with a disability, I was not given an opportunity to share my observations and experience of parenting my child. I was afraid to ask questions, I just have to take what I was told to do. Gona et al. (2018) assert that health professionals underestimate the emotional distress and need for information experienced by parents and carers of children with disabilities. I remember when the physiotherapy gave me pamphlets to read that were written in English with pictures of children and persons with disabilities, but I could not read the pamphlet. The information was of no use, because I could not understand the language. It was not my first language, and I could not find any help.

Fear of Societal Stigma

Having a disabled child means the destruction of parents' dreams of their ideal child (Schmitke & Schlomann, 2002). I had no social or emotional support when raising my child with a disability, and I avoided public places with him to keep him away from the community. If people saw him crawling outside, I would rush to put him on my back and hurry into the house. Dura-Vila (2010) suggested that raising a child with a disability has significant consequences for parents and family. The major problem with this system of avoidance came in the child's need to visit the clinic. On those days, I knew that the child and I would be exposed to the public, and everyone will know that I have a child with a disability. So, I devised a plan to avoid many questions.

Finding a Way Forward: The Value of Local Support Groups

The coming together of mothers of children with disabilities was a platform to share life experiences collectively to promote acceptance and equality for our children to be recognized as part of the South African future and society. The formation of Disabled Children Action Group, parents' organization, restored my dignity, gave me confidence, and reduced the stigma of the community. The organization was of vital importance because it helped to normalize my experiences of parenting by meeting together as parents of children with disabilities. Through our joint efforts as parents of children with disabilities, we share challenges, solutions, and developed strategies towards affirmation of integration and equal participation in our society.

Today, I walk tall, an active proud mother of an adult son with a disability, committed to advocate equal opportunities for and able to mentor other parents and persons with disabilities to advocate for their rights. I salute Disabled Children Action Group for having played a significant role with a wealth of information acquired from sharing knowledge through parents' empowerment workshops, trainings, seminars, and conferences. Today, I am a disability inclusion activist, and I obtained my Master's degree in Disability Studies and Doctor of philosophy.

The Future Practice for Health Professional and Parents of Children with Disabilities

Health professionals as change agents can make a difference in the lives of children with disabilities and their families in a number of ways. By using the social model of disability, health professionals in partnership with people with disabilities and parents can address sociopolitical constructs that create challenges for persons with disabilities. As can be seen in my narrative, I cannot emphasis enough the importance of the provision of early diagnosis and information to parents in the process of care and rehabilitation of their child with disability. In providing diagnoses and information related to disabilities, family members should be included wherever possible. This inclusion could limit blaming and attitudes from families and could strengthen the support base for the parents. The social model promotes opportunities for Disabled Children Action Group, parents' organization, to advocate and lobby for the rights of children with disabilities, remove societal barriers, attitude experienced, and critique the manner in which society perceive children with disabilities and their parents. The attitudes towards children with disabilities impact parents' experiences and challenges parenting children with disabilities.

The formation of local support groups at grassroots levels to provide for the sharing of challenges and information could have a positive impact on parents and the community. Continual efforts to raise awareness about the rights of children with disabilities within the society through traditional councils and community radio stations would reduce the challenges of stigma and attitudes experienced by parents within their communities. Parents of disabled children have a great role to play in the development and well-being of their children, because parents know their children better and are able to inform the health professionals about their child's development. They can help health professionals to understand their children better, they can give advice about individual behavior, and they can contribute to the design and implementation of joint learning and support strategies. It is for this reason that health professionals and parents of children with disabilities should work together to close the gap existing between parents and health professionals for the betterment of the child.

This collaboration is an appropriate responsibility for health professionals, seeing that the core values of health professionals include service delivery and the enhancement of dignity, worth of children with disabilities, parents, and society. The health professionals incorporated to local parents branches to create social networks on disability and diversity awareness programs for social cohesion. Parents share their own experiences of parenting children with disabilities to health professional forum meetings. The provision of adequate and effective information about disability management which is relevant to children with disabilities in their vernacular language through seminars. Appropriate counselling at the grassroots levels, i.e., at the local clinics. Training on food security income generating projects to unemployment parents of children with disabilities.

In this next section, Gubela Mji highlights the impact that "Western" medicine, religion, and education have had on the traditional healing practices of an indigenous African culture, the AmaBomvane, in the Eastern Cape Province of South Africa. The AmaBomvane experienced a prolonged period of symbolic violence through a process of colonization, which viewed their languages, education, health care systems, and spiritual practices as inferior to those espoused by the white Western world. The lack of respect shown by the West towards knowledge that existed over generations that are part of the healing traditions within an African context provides a powerful example of how the lack of reciprocity can lead to damaging health outcomes. Gubela ends her discussion with some considerations of future possibilities, and in this way, joins the call for decolonized learning in all health, education, and social environments. This decolonial learning is only possible if there is a genuine sharing of knowledges without privileging some as being “superior” to others, i.e., that “Western” medicine is viewed as better than traditional and/or local practices of health care. Gubela suggests that there is much to be learnt and shared with the “other,” which are the elders of the AmaBomvane clan.

Hope Amid Symbolic Violence

The hegemonic knowledge of the “West,” i.e., the USA, the UK, and Europe, which promotes “scientific knowledges” that are based on medical diagnosis of a single cause of a disease, which frequently is addressed by either surgical or pharmacological cures has negative impact to indigenous peoples who see health and sickness in a relational manner. This approach to patients tends to apply colonial power of imposition whereby the body of the indigenous person is something to be studied and divorced from seeing the body as belonging to a human being. This approach is described by Jansen (31 Jan 2021, cited in Mji, 2013) when describing how colonial doctors managed indigenous patients: “The crisis in western medicine is that investigations concentrated upon certain mechanisms, upon special organs, and systems to good purpose. The patient was provisionally ignored: he was merely the incidental battlefield of bacteriological conflict, or irrelevant container of a fascinating biochemical process” (Mji, 2013, pg. 46).

Unfortunately, the colonizers used this lens of imposition on all aspects of life in countries which were colonized. This colonization resulted in a tendency of choosing to be arbiters of existing indigenous knowledges systems, frequently viewing these health knowledge systems as inferior forms of health care, and describing some indigenous healers, such as amaxwele (herbalists) or amagqirha (diviners), as charlatans who use a mixture of witchcraft and trickery. It appears that Western medicine saw itself as superior, which created mistrust of the traditional practices of the village healers.

The way these new knowledges systems were introduced throughout South Africa during the period of colonization and which continued during apartheid has been seen by indigenous peoples as a form of symbolic violence. Burham (31 Jan 2021, cited in Mji (2013) shares this concern about the Xhosa people who are part of AmaBomvane:

> We are getting too one-sided in our development of the rational side of our being and getting psychologically impoverished and also severed from roots which nourish us. How can we claim to be healers when we have become technologists? Especially healers of people to whom technology has less meaning and the human being is still supreme? This difference might be partly because western technology is moving away from the essence of being human and from participating creatively with the rest of the world. The Xhosa healer is not only essential for his own people but, to some extent, for all of us (Mji, 2013, pg. 47).

The AmaBomvane People and Their Obligations

The AmaBomvane people are proud indigenous people. The highest determinant of health and well-being for the Bomvana person was to live and exist as an embodiment of the Bomvana culture, as a spiritual being who honored and practiced the beliefs of the Bomvana. The AmaBomvane believe that the highest indicator of good health is to live and exist as a Bomvana, and as such, there are certain obligations for the status of being a Bomvane. These responsibilities include ensuring that there is sufficient food to feed all families until satiety, peace, and security, looking after children from conception until maturity and giving reverence to ancestors. Since the introduction of the Western practices of education, religion, and medicine to this area, the Bomvane people now live below the poverty line with their community blighted by diseases such as malnutrition, tuberculosis (TB), and human immunodeficiency virus (HIV and AIDs).

The current Chief of AmaBomvane laments that the modern (Western) knowledge systems of delivering health, religion, and education that entered their calm existence had overlooked their daily cultural practices, which contributed to the health and well-being of AmaBomvane. The indigenous people of this area regard themselves as having been practicing education, religion, and health for the well-being of their families long before the foreign entry of Western medicine. They believe that the colonizers' introduction of Western-based knowledges undermined their civilization by introducing Western understandings and interpretations of education, religion, and health. The blatant disregard of the indigenous knowledge system of AmaBomvane by the imposition of Western knowledge can be interpreted as being a form of symbolic violence.

This Chief believes that the enforcement of these three aspects (health, education, and religion) by external agents who seemed to have assumed that the AmaBomvane communities were "blank slates" who had no knowledge and wisdom at all. This belief resulted in a fractured ill community struggling with their "beingness" and becoming, i.e., being part of an evolving community.

The Relationship Between AmaBomvane Community and Allopathic Health Care Providers

The section of this chapter will focus on the relationships between the "western" health care providers in the district hospital, their nine satellite clinics, and the AmaBomvane community.

The AmaBomvane community currently receives health services from two set of health providers, namely the allopathic health care practitioners in secondary hospital and the clinics and the indigenous health practitioners embedded in the Eastern Cape indigenous community of South Africa. These two health systems run parallel to each other, but the allopathic health care providers have assumed they are being the "better" health providers. In many respects, this high moral ground assumed by the allopathic health providers has been reinforced in the colonial education practices that are so vehemently contested in the struggle against the apartheid government.

Due to these separate and parallel health systems, there exists a subtle conflict between the indigenous health practitioners and the allopathic health practitioners that operate in the areas of Bomvaneland. Patients from this area who seek to utilize both indigenous and allopathic health strategies to manage their illness are negatively affected by the tensions with allopathic medicine and its practitioners belittling the indigenous health practitioners. The AmaBomvane view health as dependent on the status of relationships between the individual, the family unit, the community, the ancestors, and the environment. Illness is seen as result of these broken relationships (Mji, 2013). For the AmaBomvana, it is more important to prevent illness rather than to cure it, so their indigenous health system is focused on strengthening these relationships rather than curing physical disease (Mji, 2013).

Due to the general level of mistrust between the allopathic health professionals and the indigenous healers, many patients and their relatives try to contain the health situation "on the quiet" by using indigenous health advice before visiting the hospital or the clinic. This practice frequently results in them being chastised by health professionals for attempting to use what is seen as an "inferior" medication when their relatives are sick. What is misunderstood is that many households are located quite far from the hospital and the indigenous healer is the only resource available to them, especially at night. The condescending attitude and critical approach by health professionals creates a deep mistrust, with health professionals perceiving the patient as having used some form of "voodoo muthi" prior to coming to the health center. Because of this situation, people using these services opt for a veil of secrecy as they feel stigmatized, chastised, and ashamed of the indigenous health knowledge (IHK) they have sought and used prior to coming to the allopathic health center. In many ways, they feel silenced by the allopathic health providers who appear to be the knowledge holders on the issues of allopathic medicine and the power it exudes in the area on matters related to health. This conflict makes it appear that there is no will to accommodate other approaches to health care, including IHK, which is still widely practiced by this community. As the battle to take control of health matters by the allopathic health providers and to silence the people of this area of the IHK continues, within the Bomvane culture, there is a group of older women who see themselves as practicing healing from a standpoint of humility and without duress. They are the valued and valuable IHK practitioners. They have carried the traditions and knowledge from generations of their forefathers, and they practice a deep wisdom of knowledge that connects the environment with the health and well-being of its inhabitants.

Elite Older Women as Agents of Health and Care

I draw this proposition from an ethnographic study that explored the IHK carried out by the Bomvane older women in their home (Mji, 2013). This study revealed a wealth of health-related knowledge carried by the Bomvane older women in supporting their relatives when they are sick. It was further ascertained that these Bomvane older women, when their IHK strategies were not helpful in improving the health status of their relatives, went out of the home to consult other older women who are known in their villages for dealing with the type of illness that had afflicted their relatives. Mji (2013) classified these women as the elite older women. Elite groups comprise influential, prominent, and well-informed people who occupy important positions and whose behavior is associated with those positions. They are expected to hold the basis of expertise, valuable information, and an overall view of the social organization in their villages. I argue that the older people in indigenous communities such as KwaBomvana can become more powerful and autonomous in old age, taking on new roles and duties.

The elite older Xhosa women of KwaBomvana have shown excellence in the management of the health of the home by developing a bridge between natural indigenous herbs of their area and the home. They have strengthened the concept of "humility," health, and survival as a collective by sharing their knowledge of healing practices within their community. However, with the imposition of Western health knowledges, the voices of these older people, especially women, are rarely heard now in debates about health. Consequently, there has been little research that explores the ways in which the older women contribute to the health economy and social capital of their communities. In Bomvanaland, the "new knowledge" holders that have entered carrying their perception of a superior way of dealing with knowledge related to health, education, and religion have disrupted the quiet existence of the AmaBomvane people.

As a result, the education on matters of health and spirituality that has been delivered to the young by the Bomvane older women has been ignored and frequently criticized by the allopathic health care professionals in the area. Alongside this dismissal of the wisdom of these women, South Africa has a high prevalence of HIV and AIDS frequently related to the economic migration patterns of young adults living in rural communities. The high prevalence of HIV/AIDS and migration patterns has meant that many older people, specifically women, have become the pillars of their communities and carers for orphans whose parents were lost to AIDS.

Clough (1998) suggests that the talents of women have been carefully integrated into their day-to-day activities, so much so that these talents have been classified and simplified as part and parcel of "the role" woman are seen to fulfill in society, for example, terms such as "labour of love" are commonly and loosely used. Boneham and Sixsmith (2005) suggest that women's dual roles as caregivers, especially those caring for persons with disabilities, have been underestimated. They claim that a gendered evaluation of health and health care is more likely to position the older women in a more positive light and construct the older women as active agents in health matters, especially concerning their family. The role that the older women take on in fostering a spirit of belonging, participation, and identification of local assets, such as IHK, in their local community needs to be recognized by allopathic health providers and claimed by the community as a legitimate health resource. The women's contribution to the young in facilitating the unlocking of internal power and resilience through storytelling, which further builds character, deserves recognition by all.

According to the Bomvane older women, there is a strong relationship between relationships and sickness. They see nurturing relationships through respect, with older people respecting young people and vice-versa, as the cornerstone to good health with healthy homes making healthy villages. They see part of their contribution to healthy villages is to assist in nurturing the youth to be respectful individuals who understand the culture of AmaBomvane and participate respectfully in the activities of their villages. Like the Maori (Durie, 2004), by whom health was measured according to their participation in tribal activities, being included in family celebrations and the ability to make Bomvane beer for ancestral reverence served as a yardstick for wellness. Being healthy entailed being fully engaged in the functions of AmaBomvane people in a respectful culturally acceptable manner (Jansen, 1973; Bùhrmann & Gqomfa, 1981, 1982); Bùhrmann (1983, 1984, 1987). This participation in village activities was and is the yardstick that is used for measuring the health status of an individual in their villages.

Lately, the healing vocation and knowledges of the Bomvane older women are at risk of being lost because of the changing mores within their community. The migration of the middle generation of AmaBomvane families to the cities for economic security, with some dying of HIV and AIDs, has left the Bomvane older women having to change their roles. Previously, they were the educators of the young, and now they must undertake the heavy duty of caring for the home and their young grandchildren.

In view of the challenges that the Bomvane older women are currently facing, I have considered if the current (and Western) education systems in the area could assist with supporting the older people in these rural communities in managing the pressures, risks, and anxieties of this modern living? In other words, can there be a reciprocal sharing of resources and knowledge that can allow for a mutual exchange of wisdom. For example, can the social media resources of Snapchat, WhatsApp, and Facebook as mobile technologies that can deliver information and offer support networks, be of assistance for the older people in indigenous communities such as KwaBomvana? Can the existing allopathic health care systems and educational institutions in this area respectfully join hands with the older people of this community through a mutual enhancing of the health of the home? While there is also a possibility of doctors and health professionals trained in Western medicine working collaboratively with the elite older Xhosa women and indigenous healers. As part of decolonizing the curriculum, elite women could be integrated within the school system, teaching the youth of their culture and health remedies. One of the biggest challenge is that the carriers of indigenous health knowledge are dying with this knowledge system. Could the new technologies capture and transform the important role that is played by the older people as knowledge holders and reservoirs of experiential knowledge for future generations? These technologies could be used to capture oral history and stories as knowledge and evidence of health practices which could be used as reservoirs of indigenous health knowledges and used to decolonize the health science curriculum.

In the final section of this chapter, Lucia (a PhD student) and Lindsey (one of her two supervisors) discuss how they have worked together and learnt from each other. This journey of mutual learning was in many ways unexpected and has brought many rich rewards for both. Lucia has more confidence in her self-knowledge and thinking, and Lindsey is now less fearful of serious long-term mental illnesses, her own and those of the students and clients that she meets.

Learning from and with the Other

The supervision of a PhD project brings many rewards and challenges. As the journey begins, it is never clear how it will develop, and so many different factors can come into play in a process that can take between 4 and 8 years. To our knowledge, there has been a PhD thesis written about the experiences of students in a supervisory relationship (Kirkland, 2018), and a psychosocial understanding of the parallel dynamics that can occur in supervision alongside the topic (Jervis, 2012). In many ways, what Lucia and Lindsey are writing about is echoed in the seminal work of Casement, published in 1985, “On Learning from the Patient.”

In this section, Lucia and Lindsey look at what reciprocity means in their work together as supervisor (Lindsey) and PhD student (Lucia). The study is on trauma and psychosis, and Lucia has chosen an autoethnographic methodology that uses a psychoanalytic analysis of her lived experience of psychosis and recovery. Lindsey begins with her reflections on being a PhD supervisor, and Lucia continues the story with her experience of being supervised. The reason for Lindsey to “go first” in this section is to contextualize a pivotal moment in their relationship, which, before writing this chapter, neither Lucia nor Lindsey had fully recognized or discussed with each other!

Lindsey Writing About Her Relationship with Lucia

What has been essential, in my experience of postgraduate supervision, is a need for an authentic relationship between the student and the team of supervisors, and a genuine interest in the topic. To date, I have been very fortunate with regards to these “essential” elements. Each student and each topic have illuminated my knowledge and understanding of the subject, and all the research projects have endeavored to understanding human beings and their relationships with the world.

In a recent Times Higher Education (THE) article, Buitendijk (2021:2) suggested that “universities should partner with students instead of treating them like passive recipients of our supervisor knowledge.” These seemingly glib words, which echo much of the popular call for “student led” education, do not convey the wonder and delight that I can have experienced in learning with and from Lucia. It also does not express the deep fears I had as the PhD began about Lucia’s well-being and the times when I have taken comfort from her discussions on the lived experience of her psychosis.

Meeting Lucia

In 2012, a university colleague, Professor Wendy Bryant, asked me if I could meet with one of her research assistants, Lucia Franco, who had written an account of her psychosis. In her essay Wendy had told me, she had mentioned Freud. “You know about that Lindsey,” she said, and left Lucia and I to make contact. I read Lucia’s account of her psychotic illness and her exploration of its origins. It was remarkable, Freud was indeed mentioned in it, and Lucia had written a description of a traumatic event that occurred when she was a young woman and followed on with an in-depth analysis of its long-term consequences. Lucia and I had many conversations over her writing style, not the content, and the following year Lucia had it published in a journal (Franco, 2013). Lucia asked me one day, “do you think I could do a PhD on the topic of how the unconscious layering of trauma could lead to psychosis (her hypothesis)?”. “Absolutely,” I answered. What I had not anticipated was the hurdles created to her registration by health science research committees that were afraid she would cause harm to others by exploring their experience of psychosis and that her methodology would not lead to empirical evidence. She was finally accepted by the social science faculty, whose senior researcher, Professor Dany Nobus, said he had seldom read such an eloquent and well-reasoned PhD proposal.

Lucia is in the final part of writing her thesis. We meet regularly and I enjoy our conversations. She never takes knowledge at face value and has read the original work of key psychoanalytic authors to make sense of their theories. She has seen links between Bion’s work on thinking with Winnicott’s formation of the “false self.” She has read the work of Ferenczi (recently “back in fashion” in psychoanalytic thinking) and she has summarized and interrogated their work. She has explored the work of Searles and recently she and I read Bollas’s description of his analytic work with people in the acute stage of their psychosis: “Catch them before they fall” (Bollas, 2012).

Lucia, having experienced many psychotic episodes, has recovered and returned to explore their meanings. She is a person whose experience is applied to theory, and not the other way round. She will argue that in her experience it is important to know the cause of a breakdown, not simply say “it cannot be known.” She does not accept that all emotional vulnerabilities develop in childhood and her long-term goal is that health professionals should listen out for the experience of trauma which may be hidden within psychotic symptoms. Without this knowledge about the meanings of the symptoms, the illness may persist. All these things I have learnt from Lucia. I did not know them before. She has used theory to test it against her lived experience. At times, it seems to have given her validation and words to express her understanding; at times, it frustrates her because she knows something different.

There is a term used in the UK for people who offer educational programs insights based on their experience; they were previously called “service users” and now the term is “expert through experience.” I think that this too can be a glib term, unless like Lucia, they have used their experience in the service of further knowledge. Her methodology is autoethnographic and so she tests her experience against the published knowledge of others. She has said that doing much of this work has allowed her to recover.

Breaking Down and Breaking Through My Fear

There was a moment last year, when I had met Lucia to discuss her work, when I felt a wave of deep sadness pass over me. She had told me that with the work she was doing, many of her symptoms were receding and, with it, she was able to feel connected to others and could enjoy things again. I began to think this was more than surviving her illness but moving beyond it into a world of color and appreciation. I asked her “Do you feel joy now?”, “Oh yes” she said, “I have the full range of feelings now.” I began to cry, I could not stop it; Lucia smiled at me. I was pleased that she was well and remaining well, and at the same time, I was filled with a sadness that for many years she had suffered from an absence of recognition of her illness and, at times, outright discrimination because of her “diagnosis.” This discrimination was time lost, never to be recovered. Perhaps it was also my sadness that I could have done more, done better, if only I had known what I had come to learn from her about people who had psychosis. I had been afraid of psychosis because of the way the symptoms had been explained (taught) to me with an emphasis on medical language, e.g., “delusions of grandeur,” “paranoid features.” This medical model language does not describe or seek to understand the experience of that person, or their attempt to communicate with others. Now I see psychosis as a symbolic language, and an attempt by the person to communicate their distress and confusion, in other words, an attempt to connect with another mind that is willing to listen.

Lucia Writing About Working with Dany Nobus and Lindsey

One of the consequences of being diagnosed with paranoid schizophrenia is that suddenly you are not considered a valid and responsible human being. “What I say may not be real, I do not know what I am talking about.” Things are changing compared to 40 years ago when I was first diagnosed with paranoid schizophrenia; at the time, an old-fashioned psychiatrist said to me “You are abnormal now and you have to accept you will be abnormal for the rest of your life.” While I do not think anyone would say that to me now, I find that a little of this attitude is still in many.

Confidence and Self-Belief Building

When I started working with Lindsey, I did not believe it entirely when she complimented me on my work or my understanding. I had lost belief in myself, and it was hard for me to accept her words as real. However, Lindsey's initial work with me on an article I had written gave me the courage to try and publish it. I trusted that if she thought that my work was good enough to publish, then I had to try. I was also feeling more confident about her having helped me with the writing. Gradually, over the years, I was doing my PhD research, under Lindsey and Prof. Dany Nobus's supervision; I have become more confident, more able to believe in myself, in my abilities, and in my work. This confidence is something that I understand to be normal when doing PhD studies with regular supervision. In my case, however, my being taken seriously, my gradually realizing that I was indeed understood and valued by Lindsey, contributed greatly to my improving my mental health and, in turn, I believe, my academic work abilities.

That day, when I could see the tears in Lindsey's eyes, at my expressing my newfound ability to experience joy and other feelings, was perhaps the most crucial moment that told me that she had understood how my condition affected me and how much I was improving. My feeling understood by Lindsey has played an important part in my being able to feel connected to others. My alienation from people, which was a consequence of prejudice (mine and others) and my condition, started to diminish considerably after that event. That meant that my research felt more real and meaningful, but also my life with others became more meaningful. This shift happened gradually, but it came from feeling really understood.

I never felt a psychiatrist to be understanding when I spoke of my improvement, nor did I normally feel them believing in the self-analytical work I had been doing. I think that believing what people with psychosis say, and believing in their capacity to understand themselves, can contribute both to their mental health and increase other people's understanding, while reducing prejudice. It can also improve sufferers' abilities to achieve better work and status in society.

One aspect of my research focuses on how a false self becomes central in psychosis and how the true self remains hidden and unable to find expression. Researching other theorists has given me more insight into my psychosis that has allowed me to progress further in my recovery. The entire process of doing the research has helped in recentralizing my true self.

Continuing Prejudice and Discrimination

I once tried to publish in a journal that focuses on psychosis; one reason why I was rejected was that as an autobiographical article, it had to be shorter and only academic articles could be that long. I am still puzzled, as I thought that doing PhD research studies qualified me as an academic. Other journals give the reason for rejecting my papers, as they are not publishing auto-ethnographical works but focus on professional writings. I am still puzzled. I have accepted that this battle will continue. It has been the focus of my life to go against discrimination and prejudice. In my research, I try to make psychosis intelligible and not a crazy, meaningless phenomena.

Where the Difficulty Can Lie

When the university initially had difficulties accepting my research, I was not particularly affected by their attitude. This was not because the matter was not upsetting, but rather because, since my diagnosis, I have repeatedly encountered resistances from the whole of society from recognizing and accepting my skills and abilities. I have learned to live with it.

Society said, and largely still says, I am potentially dangerous, I cannot be relied on, and I cannot be trusted. The university was only following what the medical model has repeatedly said about schizophrenia. Society fears schizophrenia and often fails to see the human being behind the diagnosis. Who I am and what I am capable of was not in focus.

I am not advocating a total disregard of the knowledge provided by medical science concerning schizophrenia or psychosis, but I am advocating a more holistic approach where the individual is considered from its entire humanity, not only from the partial, incomplete view of one model of understanding. We still do not fully understand psychosis, and many of society's fears are fears of the unknown. An open attitude of wanting to learn from the other is necessary, rather than the defensive approach of a medical diagnosis, predetermined treatment solutions, and prognosis predictions that can prevent knowledge and understanding emerging from the coproduction of knowledge between patient and therapist.

Some Further Reflections

The PhD research has been a source of difficulties; I had a psychotic episode at one point and some of the writing on the topic I found contrary to my understanding in general. It is hard work to study and research, especially in the recent COVID-19 situation, where being isolated and not seeing my supervisors in person often felt discouraging and reduced my motivation to persevere in my research studies. It has also been a source of joys and rewards. I have overcome the difficulties with the help of my supervisors, and the joys and rewards have been made more possible by the relationship of mutual respect and understanding provided by the supervision relationships I have had.

Concluding Comments

In Saban's (2019) book "Two Souls Alas," a critical reflection on the work of Carl Jung, he quotes:

> For two personalities to meet is like mixing two different chemical substances: if there is any combination at all, both are transformed. In any effective psychological treatment, the doctor is bound to influence the patient; but this influence can only take place if the patient has a reciprocal influence on the doctor. You can exert no influence if you are not susceptible to influence. (Jung, 1929, para.163)' pg. 182.

This quote supports the emphasis in this chapter that to learn with and from the "other," there has to be an acknowledgment of vulnerability on the part of the "doctor," i.e., therapist, health professional, academic researcher, etc. In the field of disability studies, this reciprocity of vulnerability has been an ongoing concern since the "nothing about us without us" political slogan became an embedded philosophy in academic institutions and an ethic of care in all health care organizations. But here is the rub: many people in positions of power and privilege find it hard to forgo their sense of importance, even a belief in their omnipotence. What may lie behind this sense of ultimate authority is a projection of frailty, neediness, and vulnerability onto those who are seen as "other." Hoggett (2000) has described the "hatred of dependence" that is embedded in neoliberal cultures of individualism and competition with others. Vulnerability is seen as existing in others, not ourselves, and this view perpetuates the notion of "survival of the fittest," as Benjamin in her later work describes, only one can survive. What this way of thinking and being in the world does not recognize is how we are irreconcilably interdependent on each other, a world view encoded in the African term "Ubuntu," encompassing a value of our humanity being bound up in each other "I am because you are" (Archbishop Desmond Tutu). How then can we move beyond the binary positions of able and disabled, or as Benjamin (2018) puts it, of "doer and done to"?

We have proposed that by establishing authentic and reciprocal relationships, we can learn from and with the "other," which potentially creates new knowledges, and perhaps more pertinent offers health care providers and academic institutions with the emotional support to continue their work. This notion of establishing reciprocal relationships moves beyond the idea of work having an emotional cost or being an "emotional labour" (Smith, 1992). We have described the emotional gains and intellectual benefits of such partnerships; it is what we have termed "love's labour found."

To return to the work of Benjamin (1990), she has said that when the dynamics of opposition, oppression, and hatred can be survived, there can be an emergence of love and an appreciation of what the "other" can bring.

> Winnicott's thesis suggests a basic tension between denial and affirmation of the other (between omnipotence and recognition of reality) . . . The wish to absolutely assert the self and deny everything outside one's own mental omnipotence must sometimes crash against the implacable reality of the other. . . .When the destructiveness damages neither the parent

> nor the self, external reality comes into view as a sharp, distinct contrast to the inner fantasy world. The outcome of this process is not simply reparation or restoration of the good object, but love, the sense of discovering the other. (Benjamin, 1990, p.192)

The last 2 years of COVID-19 has shown us how much we need to rely on each other, from neighborhood schemes and support networks to check on vulnerable or shielding persons through to sharing worldwide research evidence and hopefully, very soon, the distribution of resources from countries who have an excess of vaccines to those who do not have enough. We, the authors, sincerely hope that by sharing our experiences and knowledges within this chapter, we will encourage all therapists, researchers, and persons with disabilities and their family members to form active and critical partnerships that extend what is known, understood, and communicated about (in essence) being human.

References

Balling, K., & McCubbin, M. (2001). Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *Journal of Pediatric Nursing, 16*(2), 110–119.

Benjamin, J. (1990). Recognition and destruction. In S. A. Mitchell & L. Aron (Eds.), 1999. *Relational psychoanalysis* (pp. 181–210). New York: The Analytic Press.

Benjamin, J. (2018). *Beyond doer and done to: Recognition theory, intersubjectivity and the third*. Routledge.

Bollas, C. (2012). *Catch them before they fall: The psychoanalysis of breakdown*. Routledge.

Boneham, A., & Sixsmith, J. A. (2005). The voices of older women in a disadvantaged community. *Social Direct – Social Science and Medicine, 62*(2), 269–262.

Buhrmann, M. (1983). Community health and traditional healers. *Psychotherapeia., 30*(1), 15–18.

Bùhrmann, M. V. (1984). *Living in two worlds*. Human and Rousseau.

Bùhrmann, M. V. (1987). Initiation of Xhosa indigenous healers (Amagqira) healers: In L. C. Mahdi, S. Foster, M. Little (Eds.). *Betwixt and between* (pp. 439–456). Open Court.

Bùhrmann, M. V., & Gqomfa, J. N. (1981). The Xhosa healers of Southern Africa: The songs sung in a healing ceremony: A Xhosa healing ritual. *Journal of Analytical Psychology., 26*(4), 297–312.

Bùhrmann, M. V., & Gqomfa, J. N. (1982). The Xhosa healers of Southern Africa: 3. A family therapy session with a dream as central content. *Journal of Analytical Psychology., 27*(1), 41–57.

Buitendijk, S. (2021). The future of the traditional lecture is up for debate one more. *Times Higher Education, 20*, 2021.

Callery, P. (1997). Maternal knowledge and professional knowledge: Co-operation and conflict in the care of sick children. *International Journal of Nursing Studies, 34*, 27–34.

Casement, P. (1985). *On learning from the patient*. Routledge.

Clough, P. T. (1998). The end(s) of ethnography: Now and then. Qualitative inquiry. *Sage Periodicals, 4*(1), 3–14.

Dura-Vila, G. (2010). A gain not a loss: Parental beliefs and family life. *Children with Intellectual Disability, Clinical Child Psychiatry, 15*(2), 171–184.

Durie, M. (2004). Understanding health and illness: Research at the interface between science and indigenous knowledge. *International Journal of Epidemiology, 33*(5), 1138–1143.

Franco, L. (2013). The causes of one case of schizophrenia and implication for other psychoses. *Free Associations, 64*, 64–84.

Fisher, A. (2001). *Critical thinking: An introduction*. Cambridge: Cambridge University Press.

Gona, J. K., Newton, C. R., Hartley, S., & Bunning, K. (2018). Persons with disabilities as experts-by experience: Using personal narratives to affect community attitudes in Kilifi, Kenya'. *BMC International Health and Human Rights, 18*, 18. https://doi.org/10.1186/s12914-018-0158-2

Hoggett, P. (2000). Hatred of dependency. In Emotional life and the politics of welfare (pp. 159–180). Palgrave Macmillan.

Jansen, G. (1973). *The doctor patient relationship in an all African tribal society.* Van Gorcum & Comp. BV.

Jervis, S. (2012). Parallel process in research supervision: Turning the psycho-social focus towards supervisory relationships. *Psychoanalysis, Culture & Society, 17*(3), 296–313.

Kirkland, M. A. (2018). *Professional doctoral students and the doctoral supervision relationship: Negotiating difficulties*. Stirling University. @dspace.stir.ac.uk https://dspace.stir.ac.uk/bitstream/1893/27852/1/Margot%20Kirkland%20-%20Thesis%20-%20April%202018.pdf

Mji G. (2013) Exploring the health knowledge carried by older Xhosa women in their home situation, with special focus on indigenous knowledge [PhD thesis].

Saban, M. (2019). *'Two souls alas': Jung's two personalities and the making of analytical psychology* (Vol. 2). Chiron Publications.

Schmitke, J., & Schlomann, P. (2002). Chronic conditions. In N. L. Pott & B. H. Mondleco (Eds.), *Pediatric nursing: Caring for children and their families* (1st ed., pp. 493–515). Delmar.

Smith, P. (1992). *The emotional labour of nursing*. Macmillan Press.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. Psychology Press.

Vehmas, S., & Watson, N. (2014). Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society, 29*(4), 638–650. https://doi.org/10.1080/09687599.2013.831751