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My experiences in health science education and research: a community worker's autoethnographic account

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It is essential that strong and mutually beneficial relationships be built among academics, researchers, students, and community liaison officers. Fundamental to this is the importance of a sincere and high regard for the often-invisible role of these community workers, and recognition of the importance of their contribution.

Community liaison officers are a crucial link between universities and communities and they play an important role in health science student training and research processes. Strong and mutually beneficial relationships among academics, researchers, students, and community workers are essential for successful partnerships. Fundamental to this is the importance of a sincere and high regard for community liaisons, who are often 'invisible', and recognition of the importance of their contribution.

While university departments have engaged more actively with communities in recent years, common preventable mistakes are still being repeated, impacting relationships with communities and the sustainability of interventions and research.

Using an autoethnographic research approach, this chapter reflects on the challenges, lessons and experiences of a community worker living and working in the community. These reflections are based on work as a community liaison for health science students participating in academic service learning in a semi-rural community, and on involvement in community-based health research in partnership with various universities. The chapter describes the challenges of university-community partnerships in the context of university teaching and research requirements and the effects of these challenges on students and community members. Recommendations are presented for decolonised and sustainable community engagement in health science education and research in the South African context.

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Introduction

The current emphasis on universal health coverage, interprofessional education and collaborative practice provides an opportunity to reflect on the various interactions between academic institutions and communities. Such reflection is especially relevant given the provision for decentralised or distributed health sciences training at South African universities. Decentralised training has been defined as "training of students outside the central academic hospitals, in district and other appropriate healthcare facilities embedded in the community, in which the students are immersed in the experience of social determinants of health, in understanding the continuum of comprehensive care and the role of context in health and illness, and in addressing the maldistribution of human resources for health".[1]

While the principles of community engagement[2] are well-established at universities, these principles are not always translated into practice, and although university-community engagements are becoming more common, many things could be done to improve the quality, sustainability and value of these interventions.

South Africans often respond to social issues by joining civil society organisations (such as home-based care or support for vulnerable children), mostly without any remuneration. The essential role of a community worker[a] involves linking various stakeholders through providing and maintaining communication between different sectors.[3] As such, community workers serve as a bridge between institutions (such as universities) and the organisations, households, and individuals within a community setting.

The intention of this chapter is to share my experience as a community worker based on several years of work in a non-governmental organisation (NGO), and as a community liaison[b] and research assistant with academic partners in the community, while living in the community at the same time. Through this, I have developed valuable insight into university and community partnerships.

Methods

Personal narratives were used in this retrospective[4] and evocative[5] autoethnographic study. Autoethnography is a qualitative research method that connects the personal and the cultural.[6] Evocative autoethnography allows readers to connect with the feelings and experiences of a researcher through the researcher's introspection on a particular topic.[5] In personal narratives, authors write candidly about their academic, research and personal lives.[7]

I started journalling in 2008 when I became interested in writing and research. In 2015, I shared my desire to tell my story with my co-authors, and we considered the appropriate platform to disseminate the information. At the end of 2018, I responded to the *SAHR* Healthcare Workers' Writing Programme (HWWP), which offers writing skills training and coaching through the publication process for identified first-time authors. Acceptance into this programme encouraged me to continue writing (journalling), and this became the data for analysis.

To ensure that the study was trustworthy, we used the criteria proposed by Le Roux[7] for autoethnographic research. Criteria include showing evidence of subjectivity and authenticity, achieving resonance with the audience, and informing and hopefully inspiring ongoing research that improves practice and contributes to social change.

I have assumed that most readers of this chapter are different from me in terms of experience, type of employment, qualification and position. Therefore, I hope, as Ellis[8] suggests, that reading this will help you to communicate with others who are different from yourself (especially community workers on the ground) and that you will relate to my experience. I have described events as accurately as I remember them and engaged in conversations with my co-authors about my writing to obtain greater reflexivity.

Throughout this process, we made sure that my original words were used. The main data are my written and verbal reflections on my work as a community worker and community liaison, which were analysed thematically. The first level of analysis involved the co-authors and myself reading through and discussing my reflections, after which we each separately identified codes. At the second level we came together again to identify common themes from the codes. The third level involved deeper analysis as we proceeded with further introspection and reflection. Finally, we linked my experiences to the literature.

From an ethical perspective, we followed the advice of O'Hara[9] who recommends following the standards of the Belmont Report when review by an internal review board is not possible; these standards advocate for respect for all persons, beneficence, and justice.[10] We also considered the ethics associated with autoethnography set out by Lapadat.[11] Firstly, from a relational ethics point of view, we have taken care not to blame or cast anyone in a negative light and have intentionally written this chapter to encourage growth and offer lessons for the future. However, to make sure of this, I asked those who have been part of this journey to read the chapter prior to submission and provide their input and consent. Secondly, I have been openly vulnerable, and have experienced the therapeutic benefits of writing these personal narratives. But it has been a stressful experience, since this is my first time writing for a peer-reviewed

a Community worker refers to someone (usually a community member) who works for an organisation in the community. This is distinct from a community health worker (CHW), who offers a health-promotion and disease-prevention and management service to households.

b In this chapter, community liaison officer refers specifically to a community worker who works for a university to support students with community engagement.

publication and I feel pressure regarding the outcome and what others will think – both readers and community workers. Thirdly, I have not been intentionally provocative, but do feel compelled to bring awareness to the challenges that exist when training students in interprofessional and collaborative practice or doing research in communities they may not be familiar with. Certain experiences I have had have been painful. However, Denzin[12] agrees that it is necessary to make "visible the oppressive structures of a culture" (in this case, the culture of community engagement and research) and Lapadat[11] affirms that this will "point a way towards more socially just possibilities". My only goal is to create awareness and explore a better way forward.

Reflections on my journey

My personal upbringing is filled with examples of my grandmother caring for people in need, and I always remember extended family staying with us in our home. I heard the African Proverb, *umuntu ngumuntu ngabantu*, which means 'a person is a person through other people', almost every day of my life.

Because of this influence, in 2004 I volunteered as a caregiver at a centre for needy and vulnerable children in a semi-rural community, north of Pretoria. When I arrived at the centre, I was the only young person working with other older volunteers. My job involved doing home visits, usually walking two to five kilometres to visit households of people living with HIV and AIDS and their affected families. I organised identity documents and social grants for those who needed them and helped to get children registered and back to school. Sometimes cases were unusual, for example I organised a funeral for an old lady who was caring for her 15 grandchildren (their parents had died of AIDS). She did not have funeral cover, so I arranged with the local municipality and fundraised for the remaining funeral costs. I managed to reunite a Mozambican man with his family as he was sick with HIV and had no one to care for him. Unfortunately, he died a week after the reunion. The child of a mentally ill patient burnt their house to ashes, so I took care of the child and his siblings at the centre while their mother left to be with her boyfriend 20 km away. I would put my son to bed at night, leave him in the care of my mother, and walk a kilometre to sleep with the children at the centre so that they would be safe.

As volunteers we were not paid, and I worked 12 months with no salary or stipend. My payment was the difference I made in the lives of others. I grew and learned a lot from being a caregiver at this centre, and always felt rewarded by the end results. I learnt patience, love and perseverance, and that helping to improve someone's life is invaluable. In 2005, the centre received funding and I began receiving a stipend of R100 (approximately US$6.8) per month. I started to assist with fundraising for the organisation, such that half my time was caregiving and the other half was marketing the project.

One day, as I was walking to do home visits, I met two fourth-year occupational therapy (OT) students doing their academic service-learning fieldwork in my community. I was interested to hear more about what they were doing, so we exchanged numbers, and I later contacted their lecturer, explained what we did and invited the students to do their fieldwork at the centre. In 2005, the OT students started working with us. My interest in their work grew, and as I connected with the students, they began to share the challenges they were experiencing while working in the community. With matric and no training, I became a source of support, offering my time to help them with their planning. I looked at their projects and interventions and taught them about community culture and how they could approach the community. This input was recognised by the students' lecturer, and more students began attending my sessions.

When the occupational therapy technician (OTT) who supported students in their community fieldwork resigned, the lecturer supervising the students asked if I would be willing to extend my services by working part-time for the university's OT Department. Because I did not have any tertiary qualifications, the university was not sure how to appoint me. Thus, I worked with the OT Department for six months without being officially appointed, while the Department motivated for my appointment. In 2006 I was finally appointed by the university as a 'community liaison'. My duties were to facilitate connections and relationships between the OT Department and community organisations, to find clients requiring OT intervention in households so that OT students could do home visits, to do translation for students where necessary, and to do follow-up visits to community partners to determine the efficacy of the students' work. Knowing the challenges of community engagement, I used my skills to educate students about the community, and I organised cultural events where they could have fun, enjoy local food and experience the culture of the community. Students learned a lot and began to see themselves as part of the community.

Being a community liaison improved my communication skills. Opportunities arose for me to connect to research projects, and I joined a national, multi-site research project, which opened further opportunities for me. I became an independent research coordinator, a research fieldworker, and data collector, which also improved my academic writing. I found myself part of a team of different cultures, coming together in the spirit of *ubuntu* with the shared goal of community development. We got on well and being in the team motivated me to further my studies. Because of my connections with several researchers and academics, I developed networks with other universities in South Africa, and got an opportunity to travel overseas to present research results.

Unfortunately, in 2010, the university authorities suddenly terminated all academic service-learning programmes in my community in order to focus on a peri-urban site closer to the university. The OT lecturer and I received the news two weeks before the beginning of the new service-learning period. Although the Faculty of Health Sciences tried to convince the university management to remain in the semi-rural area, as there had been over 20 years of investment in my community, the decision was not reversed. This changed my life. I felt humiliated and dehumanised by the institution, and lost my income, which took away the opportunity to build my academic skills (at the time I was registered with a distance-based university as a part-time student for a degree in Development Studies). The situation negatively affected my life and that of my then-11-year-old son and we were faced with big adaptations.

In the years that followed I worked for two NGOs in two different peri-urban communities and opted to move to those communities in order to understand them better. I also tried to continue with my part-time studies, but this remained challenging due to financial constraints. I stayed in contact with the OT lecturers I had gotten to know, and because of those connections, I became a research assistant on several research projects. Most recently, I worked with a PhD student on food security for HIV-positive women with disabilities. In 2018, I presented a poster on my experiences as a community worker at an academic conference, and in 2019 I facilitated a panel discussion with community workers at an academic conference on the theme 'hearing community worker voices and experiences'. From these connections came the opportunity to be awarded a bursary by the Bigen Africa Group to do a degree in Development Studies at North West University on a full-time basis, which I am currently busy with as a first-year student.

Key findings

The main themes identified following analysis were: qualities of a community worker; the value of a community liaison person; personal growth and skills development; and partnerships, power, and privilege. These are discussed in detail below.

Qualities of a community worker

An essential characteristic of a community worker is a sense of humanity, or in other words, *ubuntu*. A genuine concern for people in the community and deep compassion for them has been the driving force behind my work. Being passionate about people and recognising their needs has often made me go beyond the extra mile for them. While working with the PhD researcher, there was a time when due to injury she could not walk or drive. I travelled by taxi to her home, drove her in her car to the research site, later took her back to her home, and then took public transport to my house. It was important to me that the research outcomes be achieved, and the extra effort was worth it. Placing community first has always been non-negotiable.

Value of a community liaison officer

I have seen how important it is to have a community liaison person in partnership between community members and those from outside. Initially I did not have a defined set of tasks, but my role and relationships developed over time as I became a link between the OT Department and the community. My value lay in being a reliable and important support system for the students. I assisted with developing cultural sensitivity and understanding, monitoring project implementation, and helping to overcome language barriers. This was especially important as lecturers were often not able to be with students full-time in the community during fieldwork. In addition, NGO staff often had a large workload and could not take on the extra work of supporting students. As community liaison, I was able to lighten the workload of lecturers and community workers.

It is important to partner with a community liaison who understands the community culture well, and who is able to bridge the communication and knowledge gaps.[13] There are significant cultural dynamics in communities, for example in my community it is believed that disability is caused by bad blood and a razor blade is used to draw blood from affected areas, for instance in children with cerebral palsy. I also saw that some student interventions were not culturally appropriate, such as ironing and cooking activities for older black male clients, as these are not things they typically do. I made sure that students used acceptable strategies to approach families, and that they were able to use the right words and be culturally appropriate. An example of this is given in Box 1.

Personal growth and skills development

Being a community worker has empowered me and I have experienced personal growth, developed critical thinking skills, and found my purpose. Qualities I have developed include patience, love, perseverance, and adaptability, and my communication, marketing, leadership and academic-writing skills have all grown. Being part of projects gave me the opportunity to learn how to design and conduct research. This in turn made me recognise the importance of writing, especially in observing and communicating community needs. When a research project leader believed in me as the community worker facilitating a project, it gave me confidence. My presentation skills developed as I disseminated research outcomes, which empowered me to be able to speak publicly and to stand up for my rights. Being part of research teams has opened opportunities for me. My interest keeps growing, I ask questions and want to learn, and researchers and students learn from me, all of which encourages me to want to uplift my community further.

Partnerships, power, and privilege

I have observed the benefits of positive partnerships and the value of good relationships. Long-lasting friendships were built with some lecturers and researchers over years, and once I became a visible research team member, I felt the regard we had for each other, which was wonderful. Equality between academics and community workers needs to be upheld, as each brings a diverse range of skills and abilities.[13] Greater learning and improved outcomes occur when all team members are included and see themselves as part of the community.

I have noticed that exchange of services, namely university students getting experience and community members receiving free care services, has great impact in the community. Because I saw how beneficial the students' work was, I was concerned that if students were not satisfied (or not meeting the expectations of the university degree requirements) we might lose them. It was for this reason that I went in depth with them, to help ensure that their programmes continued and succeeded.

One of the biggest threats to partnerships is not understanding where the other person is coming from. As I connected with the students, they shared their challenges in the community, such as losing clients, some clients not liking the services offered, and some clients not wanting to see students after a certain number of sessions. Community members pride themselves on their culture and traditions, and if someone approaches them inappropriately it is likely that they will withdraw from the partnership.

Another challenge was mismatched expectations. Students must comply with certain training requirements; however, academic outcomes and community expectations do not always correspond. Students need to attend to both aspects, which often leads to overwhelm and affects learning. As such I felt concern about students burning out due to workload; choosing inappropriate community projects; failing to adapt; experiencing culture shock; and becoming confused about where to start in the community.

For me, lack of finances was not just an obstacle but a great barrier to my involvement in partnerships. I understood that I could only get paid at the end of the fieldwork period (seven weeks), but there would then be a delay in payment, and I would have to borrow money so that I could meet the students at the beginning of the next fieldwork. I could not expect the students to fetch me from my home initially because they did not yet know the community.

Once we were involved in a car accident while driving to one of the homes. Because I did not have medical insurance, I lay on the roadside for almost two hours waiting for an ambulance. I did not receive professional counselling, which would have helped me deal with the trauma. While the Department tried its best to help me, the incident raised the question for me: 'How should an institution take care of its community engagement partners when there is a crisis?'

I have also reflected on how community workers could be integrated more fully into their teams. For example, I was not invited to the farewell function of one of my colleagues. I thought this may have been because I was 'just a community worker'. Leon et al.[14] talk about 'the invisible worker', and this is how I felt. It reminded me of the situation described earlier when the university terminated academic service-learning programmes and I felt powerless for my voice to be heard.

Something that has been difficult for me has been working part-time for the university for almost five years but receiving no benefits and no opportunities to be appointed full-time.

Box 1: Mina's story

Mina (not her real name) was a 15-year-old learner with epilepsy and cognitive deficit. She attended a mainstream primary school but was still in Grade 5, with learners four to five years younger than herself. There were no other suitable placement options for her as family members worked during the day.

This affected Mina emotionally. For example, she had a seizure during her menstrual period and some learners made fun of her. This demotivated her so that she did not want to proceed with her schooling.

Although she was on epilepsy medication, her family had certain beliefs regarding her condition, such as that becoming pregnant and having a baby would improve her condition.

Mina was introduced to final-year OT students during their home visits. They provided OT intervention, including rehabilitation and education on Mina's condition, and she became more independent and positive about life.

Throughout this journey I ensured that students used suitable strategies to approach the family, used the right words, and were culturally appropriate.

Together with her parents, the students assisted Mina over time, and she was later placed at a youth vocational centre. Her independence in being able to travel to and from work, socialising with her peers, and being able to contribute financially to her family has built her confidence.

Recommendations

It is true that community workers and other frontline workers (such as community health workers) are now increasingly accepted as essential team members in health systems. University staff and researchers should also ensure that community workers are equal partners and that good relationships are fostered between them. Community engagement not only improves student learning and comprehension, it also impacts the wellbeing of community members. It is necessary to continue learning from community-oriented partnerships so that our work together can grow from strength to strength.

Going forward, I recommend the following:

- Where projects have failed in the past or there have been negative outcomes, we need to go back and determine what went wrong and what could have been improved. Learning from our mistakes will motivate and sustain the community, assist project leaders, and facilitate change where possible.
- Universities should use an action learning cycle approach[15] with their students, which includes journalling as a means of reflective learning. This will help to ensure that projects are relevant, and that institutions are conscious of where they need to change in terms of power and privilege.
- Employment of community liaison officers in health science education and research should be based partly on the candidates' skills and qualities, and not solely on their credentials. This will allow someone like myself with 'just a matric' to be easily appointable by a university.
- When community workers are employed, it should be borne in mind that they may not have any other source of income. It may therefore be difficult for them to fulfil certain requirements (such as taking public transport to get to a specific site). It will help if a down-payment or stipend is given at the beginning of the partnership so that they can participate fully.
- It is important for community workers to be empowered. However, they are often not provided with accredited certificates for their training, or trainers come from outside the community and leave after the basic training, which impacts on community relationships and thus sustainability. It would be ideal if universities could help community liaison officers get an accredited qualification.
- Before a project commences, community liaisons should be informed about the process, including time frames, finances, and who is going to be involved.
- The perspective of community workers should be included when planning community engagement curricula.

Conclusion

Having shared my story, I feel vulnerable. I know that it is worth it since I am giving a voice to many who have come before me, to those who are with me now, and to those who will do this work in future. I have summarised the key qualities of a community worker and the value that a community liaison brings, shown how my personal life and work skills have developed doing this work, and discussed issues around partnerships, power, and privilege. I acknowledge the challenges that exist in finding solutions, especially regarding the economic concerns highlighted. However, I believe that others can learn from my experience, and trust that we can discuss the recommendations made here and lay out clear plans to improve community engagement.

Community workers are key in health science student training and research processes. It is essential that strong and mutually beneficial relationships be built among academics, researchers, students, and community workers. Fundamental to this is the importance of a sincere and high regard for the often-invisible community liaisons, and recognition of the importance of their contribution. If this is done, health science education and research, and the communities served, will benefit from the reciprocity that comes from these valuable, collaborative partnerships.

Acknowledgements

I would like to thank the following people and organisations for helping me to become the community worker I am: my son Stephen Mahlangu, my family and friends, Michelle Janse van Rensburg, Helga Lister, Theresa Lorenzo, Tshwaraganang Orphanage Centre, the Foxley family, the class of 2005 OT students, Victor Litlhakanyane, and the Bigen Africa Group. Thank you to all the other community members, students, staff, and colleagues who have in some way, big or small, contributed to my journey.

The following author contributions are acknowledged: JNM wrote the reflections on her work as a community worker, community liaison and research assistant, and JNM, HEL, and MNSJvR analysed the reflections, drafted the manuscript and reviewed it iteratively.

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