Patient Advocates journey

THE JOURNEY PROJECT: An evaluation of the Impact of the Kheth’Impilo model on Patient Advocates (PA)

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Background

Kheth’Impilo’s (KI) Patient Advocate (PA) model of community-based care has been cited in the South African Department of Health National Antiretroviral Treatment Guidelines (2004)1 as an effective model of care and support for patients requiring anti-retroviral treatment (ART) and tuberculosis treatment. PAs are hired from their community of residence and play an integral role in supporting patient adherence to a healthy lifestyle, including ARVs. In all cases PAs have completed secondary schooling. These individuals are community role models who act as the link between health facility workers and the community. Although the model has demonstrated improved clinical and psychosocial outcomes for patients, little is known about how this work impacts on the PAs. It is against this background that the Journey pilot project has been developed; it qualitatively examines the experiences of PAs and describes how some PAs have progressed within themselves and outside Kheth’Impilo.

Method

Semi structured interviews were conducted with 3 PAs2 from the Western Cape Province of South Africa. Each interview included a standard set of questions about their experiences that focused on their life history before they became PAs, how they came to work at KI, their experiences at KI and aspirations/prospects for their future.

Results

All PAs indicated that they are passionate about their work and continue to provide care and support to patients after hours. Their work has become a way of life. Working with people living with HIV is not a static experience as some of them hinted but has inspired/stimulated PAs to explore different opportunity vehicles presented by their line of work.

As community role models, PAs empower patients to make positive life choices. Their work experience has given them more confidence and enhanced their respect for clients regardless of HIV status. They desire to pursue careers where they can continue to help others as counsellors, nurses, pharmacist assistants or auxiliary social workers.

Of the 250 PAs employed by KI between 2006 and 2010, 51 PAs (which KI can account for) from 4 provinces have progressed in their careers. Of these 12, 9, 25 and 2 were from the Western Cape, Eastern Cape, KwaZulu Natal and Mpumalanga respectively. The Department of home affairs employed 11 PAs as administration officers, 12 progressed to be auxiliary social workers, the South African Social Security Agency (SASSA) employed 6 PAs as grant officers, one PA was employed as grant officer by the Department of Social Development employed, the Department of Justice employed 12 PAs as administrative clerks, KI career-pathed 5 PAs; 4 as patient facilitators and one as a data capturer. Lastly, 4 joined another NGO as Home Based care coordinators.

Conclusion

The Kheth’Impilo developmental model has inspired PAs and exposed them to different routes for their personal and professional development.

Sustainability of these services is the greatest challenge ahead besides ensuring that PAs are provided with appropriate support for their development.

PA 1: A PA journey living with HIV/AIDS

It is so great seeing the person that you are supporting getting better and standing on their own feet, it’s such a great experience, it is so amazing to see that I like doing it because it’s more like saving a life.

Working with HIV issues gives me a platform to grow and to see the world in the bigger picture. You can see I am young; I am able to reach people that are my age. Let’s say to talk to them, to warn them about this thing of HIV, because it is real. It gives me a platform to spread the word.

When you get into a house, they think that maybe you are bringing something to eat, of which you are not. You are only supporting them to adhere to treatment. Fortunately this year we have been introduced to this social worker, so if we are seeing a patient that has financial issues, we refer them to the social worker. So now we are kind of bringing something to the families who are struggling.

The PA expressed that he has matured because he can manage his own finances without requiring support from his parents which he finds rewarding. Working as a PA has enabled him to finance his part time studies in business at UNISA.

PA 2: Desires an AIDS free generation in our time and believes that prevention (of re-infection) is vital

I heard the news, wow, it was so shocking. I was in denial; I was angry; “where did I get it?” The only thing that strengthened me is that I kept telling myself, “I didn’t ask for it.” At first I was so worried that I was HIV positive, but I told myself I can see there are people that are living with this virus, so why can’t I be strong? I don’t want to die. That is the last thing I want so I am going to take those pills”.

I got weaker and weaker as I was taking the TB tablets and ARVs. I had so many side effects, vomiting, feeling dizzy, but I was very strong at heart. I told myself “I do not want to die”, that kept me strong. I even asked the counsellor, “if I am taking these tablets right, does that mean I will improve?” they said “definitely”, and then I improved and my CD4 count increased.

I thought I should lead by example and be a mentor to people living with HIV. I am in their shoes, so I thought that I would be doing the right thing. I will not just convince them, but will also talk from my experience even though telling them about myself is challenging to me. HIV is not a death sentence. Having to say those words is motivating.

Given the scope of the work of KI, PAs can be career-pathed be pharmacist assistants, phlebotomists, nursing assistants or auxiliary social workers. This particular PA aspires to be an auxiliary social worker.

2. An analysis of a focus group which was comprised of 8 PAs was not included.

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