THEMATIC FOCUS: TRANSGENDER ISSUES

Engaging primary health care providers in transgender community health care: Observations from the field

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ABSTRACT
The purpose of this article is to share our experiences when engaging with primary health care providers in transgender community health care, particularly with regard to gender reassignment therapy. Through action research in the form of the implementation process monitoring in the Gauteng Province, it was found that improvements have occurred with regard to the awareness and the better general health care afforded to transgendered people. However, a significant need still exists with regard to the provision of gender reassignment surgery where the necessity for the said surgery has yet to be recognised and provided to eligible members of the transgender community, especially those with a lower socioeconomic status. Lack of access to publicly funded gender reassignment may contribute to the use of unsavoury money acquiring schemes for those who cannot afford private health care costs. Thus, various collaborations with policy makers in South Africa, transgender technical experts, and willing advocates of transgender health, should ensure that the availability of clear guidance in order to provide care for transgender persons at a primary level.

Keywords: gender identity; gender reassignment; primary health care; stigma; South Africa; transgender

There is a conspicuous absence of research on the identity, lives and healthcare
access of transgender people in South Africa. This is typically noticeable in texts that are dedicated to a discussion of gender identity to the exclusion of a discussion of transgender, or the third sex (see, Nduna & Jama, 2001). Transgender people reject their original gender assignment and actively seek to redo their sex and gender, whether by surgical or chemical means, or social performance of their chosen gender (Hearst & Chen, 2004; Mantell et al., 2006; Mungala, Kilonzo, Angala, Theobald, & Taegtmeyer, 2006; Nkabinde, 2008; Prinsloo, 2011). Despite the general and particular health needs of transgender people (Hamblin, Nduna, & Padi, 2011; Nduna, 2012), there is paucity of research with regard to access to health services for transpeople in South Africa. We learn from a book that published life stories of trans people, and from studies of internet use, that transgender people experience challenges related to access to medical needs during transitioning (Morgan, Marias, & Wellbeloved, 2009; Prinsloo, 2011). The unique challenges faced by South African transgender clients who use public clinics are peculiar to the trans community, as indicated in a report by Hamblin (Hamblin et al., 2011). These hindrances are also linked to general poor service delivery, heteronomative attitudes, conflating gender with sexual orientation. All of these negatively affect and contribute to bias in service delivery in some ways (Mdletshe & Nduna, 2011; Van der Merwe & Padi; 2012).

Historically, transgender clients in South Africa were referred to tertiary health care for gender reassignment and other ailments not directly related to transitioning. The Cape Town academic hospital was the preferred service provider. There are reports in South African literature of concerns about “lack of good quality medical resources” for trans persons (Nkabinde, 2008, p. 29). The South African government is addressing inequity and quality in health service provision generally. Thus, with the transformation of the South African healthcare system this has necessitated that health and medical services for trans people be decentralised as well. Policy guidelines and processes have been put in place to enable health care providers to refer or assist transgender persons in primary health care clinics, or both. However, anecdotal evidence suggests that the majority of transgender persons continue to be referred to tertiary care, even though they have presented themselves for minor ailments or processes that can be easily attended to at a local primary health care level. Leo’s story, published in a book about life stories of transgender people in South Africa, displays how healthcare workers do not always have a clear understanding of how to treat a trans person, and at worst, they ill-advice some clients to not consider a sex change on the premise that it is usually unsuccessful (Hearst & Chen, 2004). This gate-keeping of access is unacceptable. The cost of a sex change is quite expensive, as reported by those who have undergone the change. Privileged eligible individuals sometimes travel overseas to have a sex change in other countries (Hearst & Chen, 2004; Mantell, et al., 2006). This means that medical transitioning is invariably unaffordable to the poor working class transpeople who invariably happen to be black Africans from the townships and villages (Mungala, et al., 2006).
The need for trained primary healthcare (PHC) staff in dealing with transgender clients cannot be overemphasised because PHC level clinics are a first point of call for trans people who may present with depression, suicidal behaviour and other mental health problems related to their gender identity (Mungala, et al., 2006; Padian, Buve, Balkus, Serwadda, & Cartes jr, 2008). Experiences such as those described by Lindsay (Mantell et al., 2006), who shot his own penis because she could not accept it, could be abated with proper interventions early on in a child’s life. There is evidence that suggests that even in the specialised tertiary institutional dedicated services, clinical staff do not always understand the needs of trans people, giving a service to clients is blurred by personal values, and some trans people leave dissatisfied and feeling unassisted (Padian et al., 2008). Hence, Transgender and Intersex Africa (TIA) undertook to document experiences, as an organisation, of working with PHC staff on integrating a service for trans people in the Gauteng province.

METHODS AND ORIENTATION

This article reports on a case study of participatory action research using observation of networking carried out over a period of 12 months in and around Gauteng in 2011 by members of TIA. TIA is a newly formed organisation which is based in the township of Soshanguve outside the city of Pretoria in the Gauteng province, South Africa. A “township” in South Africa refers to an urban residential area created for black migrant labourers (Statistics South Africa: Census 2001, 2004). In 2011, TIA began ad hoc networking amongst transgender constituents (http://www. facebook.com/pages/Transgender-and-intersex-Africa/195694323776480).

The objective of TIA was to create an accessible platform from which to address barriers faced by transgender persons when accessing health services. This undertaking was established at a time where the country itself was re-engineering the PHC system in an attempt to readdress imbalances of the past through consideration of the National Health Insurance (NHI) to facilitate universal access to healthcare for all. TIA and other trans activists attempt to ensure that transgender persons are not neglected from these processes. TIA strategically engaged individual PHC providers in order to address basic healthcare needs of transgender persons at a local level in the townships. The aim was to build a referral network of local providers who could be trained to engage in basic transgender care. It is hoped that the trained local primary clinic staff would be able to provide processes for evaluation and recommendation for Gender Reassignment Therapy and possibly hormone replacement. We refer to the process that informed this article as action research because the findings that were uncovered are routinely used in advocacy work by TIA and thereby used to improve the service in clinics. The methods by which data was collected match the image of naturalistic observation because the first author observed people directly as
they carried out their daily duties in their places of employ and other public spaces such as meetings (Alba-Juez, 2009). Observation is regarded as a useful tool for collecting data because people are often unaware of many of their behaviours, and thus, the researcher can observe and link what people say they do (in this case how they should attend to trans people) and what they actually do. Findings from these observations were coupled with anecdotal reports from the TIA constituency.

The objectives of the TIA intervention thus included the following:

- To break down the system of relying on academic hospitals and to decentralise minor procedures that PHC providers can assist with, for example, hormone therapy blood tests and evaluations.
- To increase transgender friendly services within the PHC settings.
- To raise awareness of the medical needs of transgender individuals to the PHC providers.
- To encourage the PHC providers to learn more and understand transgender medical health needs.

Reflections of the authors

The first author of this article, Tebogo, is a transman. He is an activist in the trans movement and started the organisation called TIA. Tebogo is an important stakeholder in the trans community; he is interested in research that builds the movement and especially in the training of healthcare workers. As a participant observer, Tebogo became acquainted with the clinic staff and trans clients and he is an active member of the sector: a method that is appropriate for this type of work (Alba-Juez, 2009). He used his engagement with primary clinic-based healthcare workers as a means to acquire process data regarding promising interventions. Tebogo brings not only practice wisdom to his research but also extensive reading in the field, which supplements his work. This is, an acceptable approach to qualitative research work (Padgett, 2004; Sands, 2004). As a trans person, Tebogo brings an insider perspective, having worked with many other trans people in advocacy, lobbying for rights and services, and having personally encountered some of the challenges addressed in this article. Although some may raise the insider-outsider dichotomy in research, there are no ethical concerns that discourage researching “one’s own group” (Waldrop, 2004). Tebogo presented this article at the Trans Health Conference in Cape Town in November (26–28) 2011. Mzikazi Nduna, the co-author, is a senior lecturer at the University of the Witwatersrand. She was responsible for compiling the literature review for this article, worked on the presentation of findings and the discussion based on the original conference. Mzikazi Nduna has been a volunteer for the transgender advocacy organisation Gender DynamiX since 2007; she met Tebogo during the years when he worked for GDX as an outreach officer and they have maintained collaboration. Data presented here forms part of the monitoring
programme of the TIA and as such did not require ethics approval.

FINDINGS AND DISCUSSION

In this article, the authors report the findings on the observed attitudes of primary health care workers towards gender reassignment, make recommendations to close the information gaps, and address training needs.

One of the areas of need for transpeople is psychological services; this need stems from various psychosocial pressures that trans children, youth and adults face (Oloyede, 2010). Field work carried out by TIA reveals that the response of the PHC staff is lacking in this regard. A concern, as observed, was the attitudes of most of the PHC staff towards trans people. For instance, some seemed to believe that gender reassignment or confirmation surgery was a luxurious choice, a cosmetic undertaking, or a luxury reserved for the privileged. This condescending attitude communicated by certain nurses at clinics resulted in some clients shying away from accessing treatment from their nearest clinics. It has been observed by TIA and reported by certain members in the network that the feelings that were evoked by being turned away because of such attitudes possibly resulted in some trans people resorting to accessing finances in an underhand manner, or ways that are not in the best interests of the person concerned, so that they could finance visits to private clinics. The ignorance, negative attitudes and the resultant feeling of being shunned evidently caused frustration as well as feelings of helplessness with regard to ever accessing proper healthcare, including receiving an assessment for gender reassignment or hormone replacement, or both.

Closely linked to the negative attitudes of nurses was a discovery by TIA that some mental healthcare providers, including psychologists and psychiatrists, lacked essential information regarding transgender issues. Psychological services to a large extent have not been established in most of the South African district hospitals, let alone at local primary healthcare clinic levels and specialised services, which are concentrated at tertiary hospitals (Pillay, 2006; Pillay & Mkhonza, 2004; Robertson, 2004; Williams et al., 2008). A few clinics receive visitations, which are not always regular, by a psychologist. It was evident from the engagement of TIA with nurses that, most of the time, some of the members of the PHC staff were not adequately equipped with the necessary skills to offer adequate health services to trans people beyond the generalised services that affect all patients. This indicates a lack in the training of clinic staff. The clinic staff in South Africa is trained using what is called the “supermarket” approach or primary care orientation, which suggests that they should be trained to be able to handle most problems with which most people present, most often. This approach is cost effective and responds to the health needs of communities; however, this approach tends to marginalise health care needs that are not regarded as common or burning issues; this includes trans health needs. Of note is the reality that transgender persons reported in TIA networks that they
often ended up taking responsibility for educating the professionals, invariably nurses, during consultations. It has been observed that this can be very stressful and difficult for transgender individuals and their families as they visit the clinics with the hope of obtaining further, correct information. It is disappointing to have to educate the service provider. The ignorance of healthcare workers and an attitude to be oblivious become critical, especially during the transition, because at such a time of the visit to the healthcare worker, trans clients need confirmation that they are eligible and ready for the requested surgery. Another disappointing finding was that there were no readily available practice guidelines with respect to how to address a transgender person who presents in the waiting room or the clinic. While not entirely surprising, these findings with regard to the aforementioned negative attitudes and lack of knowledge displayed by some PHC staff, reflect a lack of training; nonetheless, this is concerning. This is especially so in the light of the parallel reports on problems regarding access to health for general ailments not related to transitioning such as depression, HIV and Aids, et cetera. Whilst not wanting to address transgender persons only through a lens of HIV, it is revealing that there is a paucity of engagement regarding basic health services for transgender persons (Hamblin et al., 2011; Mdletshe & Nduna, 2011; Nduna, 2012).

Some of the findings drawn from the field that are recorded by TIA have been communicated through a press statement as part of the advocacy work of TIA. An example of one of these findings raises concerns about inadequate service at one of the largest Johannesburg-based hospital. At this hospital, TIA noted that certain healthcare workers attending to clients used out-dated standards of care (Harry Benjamin, SOC), and no clear medical guidelines are available on site regarding trans patients. All South African hospitals should align their standards of care with national norms. Based on this experience, it is imperative that every hospital should have clear and accessible guidelines on how to deal with specific trans patients. In certain cases, constituents at TIA reported that they were denied access to medical care and were referred to an expensive private psychiatrist for evaluation and diagnosis before the hospital could accept them as their patients. In order to circumvent such prohibitive costs for clients, psychologists and psychiatrists could be trained to perform assessments. In this regard, this article argues that it is unfair for a public hospital to refer underprivileged patients to a private doctor before they can be accepted as clients. In addition, refusing referral letters from other respected professionals devalues the contribution of these health practitioners.

According to TIA’s assessment of feedback from constituents, at this hospital, the staff used unfair criteria to determine which trans patients could gain access to their services. For instance, those who were subjectively assessed as having “passed” the assessment received better treatment than those who do not pass in terms of stereotypical gender binaries. It was also noted by Tebogo and his colleagues that the hospital did not recognise the importance of dispensing hormonal treatment to trans
individuals, regardless of their financial background. Most importantly, and barring access to treatment, the hospital did not give the patients an opportunity to express themselves in their mother tongue, which influences the outcomes and the decisions taken during the evaluations. These are inherent problems which deny patients the opportunity to express themselves in their mother tongue. This raises concerns about the informed consent that patients are expected to give, as not all of them are comfortable expressing themselves in English or Afrikaans – the dominant languages which are not home languages for most Black people using public services. All of these issues were viewed as very serious limitations and shortcomings of service delivery and are known not to be unique to this observed hospital.

Nonetheless, there are some signs of progress which need to be acknowledged. Tebogo had access to the TIA records which indicate that approximately half of the trans people whom TIA had assisted with applications for gender reassignment and hormonal replacement during this period, received assistance through the public health sector. Based on his personal experience, and those of other TIA staff and volunteers, they noted that there are healthcare providers within the public sector who are willing to engage with, learn about, and support the transgender community.

This is indeed encouraging for the transgender community that despite the difficulties, there is hope that someday transgendered individuals will enjoy fair treatment in the public health sector.

CONCLUSION

Given this momentum, TIA is exploring the possibility of introducing the international guidelines to PHC providers as laid out in the World Professional Association for Transgender Health (WPATH) standards of care. Ongoing partnerships between existing transgender organisations and local clinics, government hospitals, and private practitioners are being pursued and fostered. TIA is also involved in an annual lecture for undergraduate students registered for psychology at the University of the Witwatersrand in order to create awareness early in their prospective careers as psychologists, social workers and other health practitioners. Such collaborations are encouraged and cost-effective. There is a need to support and sustain the engagement of transgender technical experts and willing transgender individuals and advocates to continue to be involved in the various policy and protocol processes taking place in South Africa in order to ensure that there is clear guidance regarding care for transgender persons, whether at a primary, secondary or tertiary level of care. Publishing reports on experiences of both trans individuals and organisations is also encouraged as this will contribute to literature and knowledge. However, publishing reports is difficult owing to a lack of systematically collected, recorded, and managed data, and lack of research funding for such. Bridging finance could be secured by encouraging more collaborative efforts between non-governmental organisations as
well as research and academic institutions. This article and other conference reports published here constitute a first step towards putting forth a research agenda on transgender issues in South Africa. We are hoping that these papers issue a call to academics, researchers and funders to seriously consider making a contribution to this field. Experiences encountered by Transgender and Intersex Africa (TIA) encourage a formation and stretching of a movement that incorporates healthcare workers and builds the capacity of volunteers and professionals. If this is achieved, trans people would be afforded better and proper healthcare access and services at a primary healthcare level.

NOTE


BIOGRAPHICAL NOTES

Tebogo Nkoana is a black post-op transsexual man. He started his human rights activism in 2007. He is passionate about gender, sexuality and HIV and Aids issues. He worked as an outreach officer at Gender DynamiX from 2008 until 2011. Tebogo is a founder and director of Transgender and Intersex Africa (TIA). Tebogo is also the co-founder of Transitioning Africa which mainly focuses on supporting a growing transgender and intersex movement in the Southern Africa region. He sits on the board of Iranti, a young media advocacy organisation based in Johannesburg.

Mzikazi Nduna (PhD) is a senior lecturer in the Department of Psychology, University of the Witwatersrand, South Africa. She has research interests in Father Connections; sexual and reproductive health, gender and gender-based violence and psychological distress pertaining to women, children and sexual minorities. She is an alumnus of the Sexuality Leadership Development and the Carnegie Fellowships and currently holds the ICP CHANGE fellowship Award. She has co-authored more than 27 peer reviewed journal articles, presented at international and local conferences and reviewed articles for more than five international journals. She is a member of the gender-based violence Prevention Network for the Horn, East and Southern Africa, Management Committee of Gender DynamiX and the SANAC Women’s Sector Expert group.
REFERENCES


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