Reflections through the Dialogical Self: A Journey of a Female Surviving HIV Positive Spouse

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Abstract

This study explored the lived experience of a female HIV-positive spouse through the dialogical self-theory framework. The objective was to find out how the complex and dynamic process of negotiating identity, relationships, and self-esteem affect self-perception after an HIV diagnosis. The participant's narrative reveals a multifaceted self, comprising various I-positions that interact and sometimes conflict.

The journey is marked by struggles with internalised stigma, self-blame, and fear, alongside moments of resilience, self-acceptance, and empowerment. Through auto-discourse, the participant engages in an internal dialogue, reconciling her past, present, and future selves. This process enables her to reclaim agency, redefine her life narrative, and forge a new sense of purpose. The study highlights the significance of acknowledging and integrating multiple I-positions in understanding the experiences of individuals living with HIV. By examining the intricate dynamics of internal and external dialogues, this research offers insights into identity negotiation, stigma management, and resilience-building.

The findings underscore the importance of considering the dialogical nature of the self in supporting individuals living with HIV. This study contributes to a deeper understanding of the lived experiences of HIV-positive individuals, informing support services and interventions that acknowledge the multifaceted nature of the self. Ultimately, it sheds light on the participant's journey towards self-acceptance, healing, and empowerment, providing a nuanced understanding of the complexities involved in living with HIV

Keywords: reconciliation, dialogical self, self-identity, self-identity-reconstruction, surviving HIV-positive-spouses, significant others, stigma and discrimination; spoiled-self

Introduction and background to the study

Understanding ourselves and our place in the world is usually a lifelong struggle for most people. This struggle is even more challenging when one experiences a life-changing event, such as the death of a spouse and being HIV positive. Such unplanned for events alter forever the ways that people experience and construct meaning in their lives. This research explored the process of reconstructing one's self following the death of a spouse and being HIV positive,

and the role forgiveness plays through the dialogical self in this process. The objective was to find out how individuals, such as a female surviving HIV positive spouse, perceive themselves, perceive and interact with others, including social relationships.

Traditionally, the development of theories and concepts of the self has come from distinctly separate psychological or sociological perspectives. In psychological literature, Kowalski and Leary (2004) observed that; typically, the self has been studied in clinical laboratories; separated from the experiences, culture, and relationships in which it may develop and be expressed. From a more sociological perspective, the self is viewed as the result and expression of the relationships between the person, society and role performance. Kowalski and Leary (2004) suggest that there has been a narrowing of the gap between sociological and psychological views, however, with a dynamic, multifaceted, contextual-relational view of the self-emerging. Contemporary social-psychologists refer to the multiplicity of identity as encompassing one's social roles as well as personal characteristics. In their review of the psychological literature on the self, Leary and Tangney (2012) suggest that one of the stumbling blocks to linking the self to behaviour has been the view of the self-concept as stable or generalised. Their solution is to view the self-concept as a multifaceted phenomenon that is, as a set or collection of images, schemas, conceptions, prototypes, theories, goals or tasks. Self-concepts are cognitive structures that can include content (being HIV positive), attitudes (how you feel about being HIV positive), or evaluative judgments (what you think and what others are saying about you being HIV positive) and used to make sense of the world, focus attention on one's goals, and protect one's sense of basic worth (Oyserman & Destin, 2010). Thus, the self is the '*I*' that thinks and the '*me*' that contains those thoughts. One important part of this '*me*' involves mental concepts or ideas of who one is, was, and will become. These mental concepts are the content of self-concept and these get affected in the event of one being HIV positive.

Narrativity and self-interpretations in general, include dialectic of innovation and sedimentation. The implicit layers of one's habitual and characteristic orientations are moulded through explicit articulations in narrative and other forms. As a social phenomenon, widowhood has been in existence as long as socially-regulated marriage. Ntozi (1997) observes that between birth and death of a person, marriage is one of the events perceived as important by society; it changes the personalities, the attitudes and life-style of men and women. Berman (2015) postulates that marriage is entered into with great hopes and expectations and becoming a widow or widower often interrupts this anticipated future. The death of a spouse is the most

life-changing event that one is likely to experience. Berman (2015) further postulates that while widowhood is often never anticipated, becoming a widow/widower as a result of HIV is perceived as a failed marital life, and therefore, it has serious repercussions on the individuals, family and the community.

An initial response to widowhood is a sense of lost identity (van den Hoonaard, 2010). Particular triggers, like having to fill out marital status on a form, or being introduced as someone's widow, or the sudden self-realisation of being a widow, start the course of action of acquiring a personal and social identity as a widow (van den Hoonaard, 2010). This process is described by an old widower: "I have to recreate my life, have to recreate my thinking" (Moore & Stratton, 2002, p. 87).

Review of literature

HIV in marriage

HIV presents a unique, complex phenomenon within the context of marriage. Though marriage has legal and customary definitions, which vary depending on location and context, it is taken to include a matrimonial union between partners who share special expectations, privileges and obligations between themselves, their children and their immediate families. HIV, when introduced within marriage, brings forth reality challenges that are less frequent outside of marriage. The most dominant mode of marriage in Zimbabwe is the heterosexual monogamy marriage; polygamy unions are present, but not as common and homosexual marital unions are not provisioned for by the law (Hallfors, Iritani, Zhang, Hartman, Lusenzo, Mpofu, & Rusakaniko, 2016).

Research by Borquez, Cori, Pufall, Kasule, Slaymaker, Price et al. (2016) and Nalugoda, Guwatudde, Bwaninka, Makumbi, Lutalo, Kagaayi et al. (2015) cemented the assertion previously made by Population Action International (2008) that individuals within marriage, for a huge part of sub-Saharan Africa, are at a far greater risk of being infected with HIV. Cultural practices and societal expectations, according to Kposowa (2013), often place individuals in marriage alliances at a risk that is 4.3 times more likely to contract HIV. Extramarital sex remains one of the predominant means through which HIV infects persons within marriage. Sub-Saharan Africa continues to hold a relaxed attitude towards extramarital sex particularly regarding males in marital unions and the negative attitudes towards condom use within marriage places individuals at a greater risk of HIV infection. Research conducted in Kenya cited in Zakarsa, Weiser, Hatcher, Weke, Burger, Cohen, Bukusi & Dorkwin (2017)

and the Population Action International (2008) revealed that 11 per cent of males who undertook the study reported to have had extramarital sex with an extramarital sex partner compared to two per cent of females within the past year. Higher incidences of extramarital sexual relations predispose individuals in sexual unions to a greater risk of being infected with HIV.

Persons infected by their partners often report having observed, suspected or having had evidence of infidelity of the other partner. To these couples, diagnosis of infection does not necessarily come as a shock due to reduced level of trust after observing incidences of infidelity. However, the response to diagnosis are also usually negative with respondents in a research by Wagura (2015) expressing feeling disappointed even though they had suspected that a similar fate would befall them. Chief among the reasons cited for remaining in the marriage union in spite of being seemingly betrayed and infected was that desertion would not change the acquired HIV status. Peta (2017) states that the major reason for women staying with their husbands after being infected with HIV was that they are economically heavily reliant on them. Respondents also cited concerns over raising children from broken homes, highlighting that it was important for the future of their children that both parties continue with their marital union.

The position of women within marriages in sub-Saharan Africa impedes their ability to negotiate safe sex (Peta, 2017). Women are heavily dependent on their husbands for upkeep and financial resources. This, combined with gender based violence and societal expectations of sexual behaviour in marital unions, represent a trend that remains prevalent in sub-Saharan Africa. Women, who are not infected with HIV, within marital unions which are sero-discordant, can end up infected with HIV. Traditional gender roles impact the women's decision-making powers and influence while increasing their vulnerability to HIV infection. Discordant couples interviewed in a research by Bunnell et al. (2007) highlighted that one of the challenges they faced was with regards to negotiation of condom use and abstinence. Though facing challenges similar to any other married couples, they have remained steadfast building productive relations and maintaining a family of children who due to following medical advice were born without HIV infection. Petronio (2012) discusses how couples who immediately embrace the reality of their situation and adopt an alternative lifestyle that strengthens positive health outcomes have a greater chance of living fulfilling lives where they can set lifelong goals together and attain them.

Individuals seek to develop an understanding of the self in response to the appraisal motive. This is an inherent desire held by individuals to know more about themselves. Individuals possess a desire for accurate and certain evidence regarding their traits and abilities and evidence that confirms their self-assessments (Cohen & Sherman, 2014). This is born out of the need to reduce uncertainty by increasing consistency, as such, gaining more ability to predict and control the environment (Stanghor, 2013).

A person's self-concept has great influence on their self-esteem. Self-esteem refers to the judgment upon evaluation a person has of their self and is usually defined as high or low depending on whether an individual evaluates him or herself positively or negatively (Stanghor, 2013). Self-esteem is often a product of how individuals perceive the reaction of other people to their behaviour, how they evaluate any comparison to others and the value they give to the roles and behaviours they perform. Self-esteem has the potential to impact the content and nature of evaluation a person has whilst engaging in self-talk and is an essential influencer in the self-identity reconstruction.

Self-identity stems from the differences that we have as individuals in the context of others (Karamouzian, Akbari, Haghdoost, Setayesh & Zolala, 2015). Arendt (1958), as cited by Hermans (2013), proposed that, if people were the same, there would be nothing to say about our existence, if they were somewhat not the same, there would be nothing understandable about being human and the more similar experiences we have as humans help us understand each other through inferences on experiences. Hermans and Hermans-Konopka (2010) aver that the self and self-identity operate in a similar fashion; these two entities utilise the alter ego as an intrinsic feature of the self-extended in the social environment. Hence, self-identity becomes an attribute shaped by the social status quo and the receptivity in the individual labelled as such (Karamouzian et al., 2015).

Self-identity among people living with HIV was observed to have been altered and that alteration seen as a result of personal choices by most people (Kleiber, Hutchinson, & Williams, 2002). This was mostly attributed to what is perceived as bad behaviour, that is, extramarital sexual encounters (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012), injecting of drugs through needles (UNAIDS, 2013) and random and opportunistic sexual behaviours (Rhodes, Malow, & Jolly, 2010). The perception that the contraction of HIV is due to a preferred lifestyle has a significant impact on internal dialoguing individuals go through. The choices, the decisions and opportunities that an individual chooses become a reflection of how

they choose to live in harmony with society (Friedman & Rossi, 2011). Internal dialoguing provides a basis for justifying why others do not disclose their statuses, how the widowed or widowers chose to live after losing a partner to HIV-related illness (UNAIDS, 2013), how they build or destroy relations that interfere with their psychological wellbeing and happiness (Ekstrand, Bharat, Ramakrishna, & Heylen, 2012) and; lastly, how they determine what is good for them independent of societal expectations.

Hermans' (2003) theory of the dialogical self provides a rich and insightful framework for understanding the forgiveness in self-identity reconstruction among the surviving HIV positive spouses. In the extended dialogical self, there is no clear boundary between the inside and the outside of the mind. The self and its contents are radically open and accessible to the world and the various social and cultural voices present therein. A person who is HIV positive does not live alone, his/her status is likely to be known soon or later to significant others and this changes his/her position in relation to his/her significant others as a result of his/her HIV status. The collection of these utterance and perspectives, known individually as "positions", constitutes a decentralised self with many different, relatively autonomous, voices existing within it simultaneously. Hermans (2003) terms the collection of these positions within the self's psychological space a repertoire. Repertoire, although composed of separate autonomous positions, is united by the individual's personal sense of temporal continuity (Hermans (2003). Thus, the multitude of different voices that comprise a given individual are nonetheless experienced as a single continuous consciousness.

Dialogue, which occurs among the positions within the self, can be understood in terms of exchange and power (Hermans, 2004). Dialogical relations are always more or less asymmetrical with regard to the power vested in one position over another at any given time. Camlin (2017) observes that the self that is HIV positive (spoiled self) becomes less powerful in its conversation with the external source (culture) that views the 'spoiled self' as having transgressed against the society. The power of organisation of positions in the dialogical self can be more precisely understood in terms of spatial movements (Hermans & Hermans-Konopka, 2010). However, these movements also provide an opportunity for re-organisation of the self, if new dialogues can be formed between positions in the self that allow for flexible and constructive responses to the changing environment (Kahn, Preis & Hermans, 2012).

Methodology

A dialogical self—constructivist paradigm assumes the existence of multiple realities, in which the participant and researcher are co-creators of understanding in the natural world. Smith (2008) observes that, according to narrative theory, we are born into a storied world, and we live our lives through the creation and exchange of narratives as we face any phenomenon in life. A narrative can be defined as an organised interpretation of a sequence of events. Gardner-Neblett and Iruka (2015) define a narrative as an account with three components: a beginning, middle and an end. Within the dialogical self-constructivist framework, identity theorists such as Oyserman and Destin (2010) define identity as the expression of the roles and narratives that people use to express their self to themselves and others. Dialogical self-constructivism directs the narratives of the social person termed the "self" as the key conceptual variable in the explanation of social behaviour. Research design focused on a single case to gain a detailed understanding of a single participant's experiences was used.

Sample and sampling procedure

This study used biographical research design. The approach emphasises the reconstruction of the single case and the development of experiences in the life course. The present self-representation has to be analysed by the central difference of experienced life history and the narrated life story. This approach is particularly interested in the things not mentioned in an interview, but existing under the surface of the self-presentation (Rosenthal, 2004). A female surviving HIV positive spouse was purposively selected for an in-depth semi-structured interview. The empirical research strategy aims at the case structure. It is assumes, that the link between social context and individual could be best analysed by single case and individual experience (female surviving HIV positive spouse). It tries to do justice to the person and one's personal experience. The central form of interviewing in the approach is the narrative interview (Hermans, 2013).

The core structure of the interview is a division in a first step of free narration and second step of further questioning. In the first step the interviewee is asked to give a full extempore narration of events and experiences from their own lives. In the second part of the interview "the period of questioning" the interviewer initiates with narrative questions, more elaborate narrations on topics and biographical events already mentioned. In addition, the researcher asks about issues that had not been addressed. Text and thematic analyses were used, that is, structure of self-presentation, reconstruction of the life story and narrated life, were looked into

in depth. The purpose of the research was explained to the participant and thereafter, she was requested to sign the informed consent form. In order to maintain the anonymity of the research participant, she was given a pseudonym, MaNkosi.

The participant was interviewed in private to avoid being labelled and stigmatised. She was told that during the interview session, if she developed some discomfort, the session would be stopped immediately and, if she so wished, she could withdraw totally from the research without any negative consequences. That was also indicated in the informed consent form that she had signed. Participation was voluntary and there were no monetary benefits for participating in this research. A number of measures were put in place to ensure non-maleficence and protect the autonomy of the participant. Thus, no harm was inflicted on the participant directly or indirectly, intentionally or unintentionally as a result of the research.

Reflexivity

As a male researcher, I acknowledge my privilege and positionality in studying the experiences of women living with HIV in Zimbabwe. My personal connections to the topic stem from my interest in women's health and empowerment. I recognise potential biases in my approach. Emotionally, I am invested in the topic and may be drawn to narratives of resilience and hope. Through this research, I aim to amplify the voices of women living with HIV, while acknowledging the power dynamics at play.

Discussion of findings

MaNkosi is a 50-year-old widow who went as far as Grade 7 and grew up in a broken family in a rural area staying with relatives. She saw marriage and sex as means of having children and she had several boyfriends. She was not sure of herself; her knowledge of HIV and AIDS was limited and she never had a good upbringing. She got married customarily at the age of 20. She remained at her husband's rural home while her husband worked in the mines and she had two sons aged 30 and 26 years old. They used to live a happy family life and never used any form of protection in their sexual life. She used to think that HIV and AIDS were for the prostitutes. Her husband was always sick at work and he was taken to the hospital where he was tested and found to be HIV positive. She also went for testing and found that she was HIV positive as well. Her husband later died from HIV related complications.

Self-identity track

Self as a mental representation of one's identity is revealed through the journey travelled by an individual from early life values. Self-identity is affected by one's past behaviours and what significant others are saying about an individual (Petronio, 2012). The process of self-identity reconstruction involves understanding the embarked journey, and identifying the role one played at each and every stage of that journey.

The idea of marriage and sex

MaNkosi found it difficult to live with the idea that she was HIV positive at the beginning of knowing her status, but gradually came to accept her status. Being shunned, gossiped about, stigmatised and discriminated against affected her a lot at the beginning. Some of the difficulties are articulated in the following excerpts:

MaNkosi had this to say:

> At the beginning it was tough and difficult, but now I am fine….. I have grown to accept what I have….. I live with my medication; it is a daily thing! People are always looking at you with suspicion…… you do not trust anyone eish …. They laugh with you now and the next time you a subject of gossip so how do you trust them …….

Learning that one is HIV positive can be one of the most difficult experiences a person goes through in life. Embarrassment, humiliation, stigma and discrimination appear to affect MaNkosi most as she tries to figure out what it is like to be HIV positive. However, it is important to note that MaNkosi was able to live happy and fulfilling lives. Ultimately, everyone's lives are different; how you cope with your diagnosis and how you move forward is dependent on how you dialogue within yourself.

MaNkosi reported being shunned by her family, peers and the wider community. Baltazar (2014) posits that stigma and discrimination limits the people living with HIV access to HIV testing, treatment and other HIV services. From MaNkosi's views, HIV and AIDS are always associated with death, with disapproved behaviours and that HIV infection is the result of personal irresponsibility.

The epidemic of fear, stigmatisation and discrimination has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those affected. This hinders, in no small way, efforts at stemming the epidemic. It complicates decisions about testing, disclosure of status, and ability to negotiate prevention

behaviours. An unwillingness to take an HIV test means that more people are diagnosed late, when the virus may have already progressed to AIDS (Walque & Kline, 2009). This makes treatment less effective, increasing the likelihood of transmitting HIV to others, and causing early death.

Relationship with the significant others

A successful and humane HIV cure requires not only the science of eradicating pathogens, but also the art of healing to restore harmony between mind and the body. Healing in the context of HIV cure is personal and interpersonal, biological and social, and would involve rebuilding connections between HIV patients and their social environment. Doka (2002) suggests that reconnecting HIV patients with their significant others is a necessary component of HIV cure, as this would help patients engage more fully in the HIV healing process. The significant others in an HIV positive person's life often need help themselves to come to terms with their own fears and prejudices, and the implications and consequences of their loved one's sickness and ultimate death. The relationship with significant others play a pivotal role in the life of a HIV positive person right from disclosure, their reaction to disclosure, the blame games on the sources of infection, the support system to the sharing and discussions on HIV issues.

On being HIV positive and engaging significant others

Disclosure of HIV positive status to sexual partners or close relatives and friends (significant others) is an important act because it offers a number of benefits to the infected individual and to the general public. Sleap (2001) argues that disclosure to significant others would provide emotional and psychological support to HIV positive persons whereas disclosure to sexual partners could lead to the partners also understanding HIV counselling and testing services. MaNkosi added:

> My husband tested first after he was urged to do so at his work place in the mine. In the mine, they want a physically fit worker. My husband was always absent from work due to illnesses. This prompted the mine to ask him to undergo a thorough medical examination, which included HIV testing.

Disclosure creates the awareness of HIV risk to untested partners; it subsequently leads to greater uptake of HIV counselling and testing services. Disclosing positive HIV status can be stressful. While a person may receive love and support from some of the people they tell, others may not be as accepting.

Kross et al. (2014) argue that there is a growing body of literature that examines the relationship between social support and HIV health processes and outcomes, particularly in such specific areas as medication adherence, clinical outcomes, and mental health outcomes. Social support is generally characterised as an enabling factor for engagement in HIV care. The relationship between the HIV positive individual and significant others are very important in the management of HIV; support during illness is very important for HIV healing.

Aryle (2015) argues that human health is tied to a sense of connection to social environment, healing a patient means rebuilding the connection between the patient and his/her community which could have been broken by illness. Support from significant others becomes key in the healing process. In the practice of HIV healing, social integration and social norms play an important role during the process of reconnecting HIV patients with their community.

Forgiveness as a way of moving on

There are many reasons why some relationships become long distance; however, most of them are due to work commitment by one of the spouses. Fitness (2001) suggests that one of the myths around long distance relationships is that they are always or more likely to fail than other kinds of relationships. However, there is actually no evidence to suggest that this is true; the threat is that these relationships are at risk of HIV. Magweni et al. (2015) observe that evidence from research findings shows that sexual intercourse within marriage puts partners at risk of HIV infection, most commonly from their partners' extramarital liaisons. Factors such as labour migration involving the separation of spouses exacerbate partners' HIV vulnerability.

MaNkosi had this to say:

> My husband was working at a mine far away from our rural home…. He was a good man truly and you know with these good and nice men….. you are not the only one who is interested in them. I think women could have seduced my husband at his work place to have engaged into casual sex, especially with the life in the mines……. I wish I could have stayed with my husband…..eish… These things come unexpectedly. You just find yourself in this mess …… Whatever happened to my husband…. I don't know for sure…but I know he loved us….. It was this long distance relationship that put my man in trouble…… I know him…..well men with women…. It is always a problem……

Couples who stay separately are likely to be involved in wrong decision-making for the family due to many factors. Adonis (2015) argues that research findings indicate that life choices play a pivotal role to an individual's life, especially to those with HIV. It is very important that they dialogue within themselves before they engage in an activity in their lives be it travel,

investment in business, saving for school, seeking treatment or planning to marry. There is a need for the surviving HIV positive spouses to find a health care team that is knowledgeable about HIV care that would assist in decision-making because any decision taken or to be taken should be in cognisance of HIV positive status.

Turning to God

One of the reasons people judge those who are living with HIV is that the disease is related to sex. Living with HIV is often associated with sexual immorality, promiscuity and a curse by God. Testing positive for HIV often leaves a person overwhelmed with questions and concerns. It is important to remember that HIV is a manageable disease that can be treated with HIV medicines (Bunnell et al., 2007). HIV medicines cannot cure HIV, but they help people living with HIV live longer, healthier lives and reduce the risk of HIV transmission.

Pastoral and spiritual support is vital. People with HIV need reassurance, encouragement and acceptance from their Church. HIV in Church raises uncomfortable issues such as anxieties around sex, sexuality, disease and sin. The contours of the struggle to make sense of intimacy with God, oneself and others after HIV, become familiar. Relationship and sexual intimacy come into question, perhaps with particular issues around immorality, disease and death.

MaNkosi had this to say:

> I don't trust men anymore …… My sons are grown up now and I am able to fend for myself…. I am not very sure about forgiving my husband, but I am no longer angry now….. I think I have managed to move on with my life…….

Forgiveness moves towards the offender through kindness and generosity in the hope that the other will change. The motivation in moving on is to look forward, to get on with one's own life, whether or not that includes the offending person. However, when you forgive, the focus is on the other; when you move on, the focus is on the self. Forgiveness actually helps a person move on. The participant has not achieved both in their case.

Conclusions and recommendations

This study explored the lived experiences of a female HIV-positive spouse through the dialogical self-theory framework. It delved into the complex and dynamic process of negotiating identity, relationships, and self-perception after an HIV diagnosis.

In the self-conversations, the research found out that the life of a surviving HIV positive spouse was affected by a plethora of events happening in their environment, such as life with HIV, relationship with significant others, view of past self and possible future self, and forgiveness

as a way of moving on. There are surfeits of challenges that widows encounter following the death of their spouses from HIV related illnesses. Being HIV positive brings about life values shift, the shift in terms of what we eat, in terms of what we perceive, in terms of our significant others, our physiological physique, medication and our lifestyle. The diagnosis that brings HIV positive status results devastate the body reducing it to a 'spoiled self' that is looked down upon by the self under the self-hate of being damaged and feeling of being wasted. In this crushed self, there is a need to build a strong self-identity that will propel an individual to a better future.

The surviving HIV positive spouse seeks to develop an understanding of the self in response to the acquired HIV positive status. Cohen and Sherman (2014) agree that individuals always search for evidence to know themselves better. Stanghor (2013) believes that, when individuals know about themselves and have developed a positive self-concept they can modify and suit their behaviour for a better future and hold self-conversations that can lead to knowledge based decisions that reduce cognitive dissonance.

It can be concluded that life with HIV in self-identity reconstruction track is very difficult as it is still associated with stigma and discrimination. Significant others play an important role in their relationship with their HIV positive relatives as their supportive behaviours create confidence and high self-esteem, which are good ingredients for self-identity reconstruction.

The current study recommends that future studies should explore the lived experiences of couples when both spouses are still alive and taking note of the influence of the past self on the decision made by the current self. It is further recommended that forgiveness and reconciliation be made integral part of HIV recovery plan in HIV medication. Future research could explore the experiences of men living with HIV in Zimbabwe, examining the intersection of masculinity, identity, and health-seeking behaviours.

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