

'So isolation comes in, discrimination and you find many people dying quietly without any family support': Accessing palliative care for key populations – an in-depth qualitative study

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Abstract

Background: Ensuring palliative care for all under a new global health policy must include key populations, that is, lesbian, gay, bisexual, transgender and intersex (LGBTI) people, and sex workers. Accessibility and quality of care have not been investigated in lower and middle-income countries where civil rights are the weakest.

Aim: To examine the accessibility to, and experiences of, palliative care for key populations in Zimbabwe.

Design: Qualitative study using thematic analysis of in-depth interviews and focus groups.

Setting/participants: A total of 60 key population adults and 12 healthcare providers and representatives of palliative care and key population support organisations were interviewed in four sites (Harare, Bulawayo, Mutare and Masvingo/Beitbridge).

Results: Participants described unmet needs and barriers to accessing even basic elements of palliative care. Discrimination by healthcare providers was common, exacerbated by the politico-legal-economic environment. Two dominant themes emerged: (a) minimal understanding of, and negligible access to, palliative care significantly increased the risk of painful, undignified deaths and (b) discriminatory beliefs and practices from healthcare providers, family members and the community negatively affected those living with life-limiting illness, and their wishes at the end of life. Enacted stigma from healthcare providers was a potent obstacle to quality care.

Conclusion: Discrimination from healthcare providers and lack of referrals to palliative care services increase the risk of morbidity, mortality and transmission of infectious diseases. Untreated conditions, exclusion from services, and minimal family and social support create unnecessary suffering. Public health programmes addressing other sexually taboo subjects may provide guidance.

Keywords

Sex worker, sexuality, gender identity, palliative care, qualitative, stigma, Zimbabwe

What is already known about this topic?

- Key populations are disproportionately affected by serious illnesses, including cancer and HIV, but have significantly lower uptake of essential health services due to marginalisation, stigma and human rights violations.
- To our knowledge, no studies have considered access to palliative care for key populations in low- and middle-income countries, beyond the specific context of HIV.

What this paper adds?

- Participants reported barriers to accessing palliative care due to stigma and discrimination perpetrated by healthcare professionals.

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- Palliative care staff acknowledged intentionally stigmatising key populations with overtly judgmental attitudes and intentional reduction of care and support.
- This study demonstrated that the discriminatory beliefs and practices from healthcare providers, family members and community affected care delivery from the point of diagnosis throughout the illness trajectory to end-of-life care.

Implications for practice, theory and policy

- Palliative care policy must enshrine non-discrimination for key populations with respect to access to services.
- There is a need for accepting, confidential environments, counselling training that is sensitive to diversity, and public health strategies to reduce stigma and improve access to palliative care for key population patients and family members.
- Professional communication skills that enable patients to share key aspects of identity and behaviour must be combined with enforcement of professional standards that ensure anti-discriminatory practice.

Introduction

Palliative care should be founded upon appropriate government policies, adequate drug availability, the education of health professionals, implementation of palliative care at all levels and integration into national healthcare systems.¹ Palliative care is now stated as a part of the Universal Health Coverage goals:² 'all individuals and communities receive the health services they need without suffering financial hardship. It includes the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care'. The need for palliative care and pain relief services has traditionally been missed in global health and death reviews.^{3,4}

There is also a global policy drive towards 'person-centredness' as a marker of quality care.⁵ Person-centredness requires health services to see people as complete individuals, including an understanding of their intimate relationships.⁴ This suggests a shift from volume-based health services to value-based care where providers can improve patient outcomes through getting to know them, their lifestyles and their specific needs, including those living with chronic and terminal conditions.⁶ In Africa, HIV and cancer morbidity and mortality place enormous demands on underfunded over-burdened health systems.^{3,7-9}

'Key populations' as described in public health include lesbian, gay, bisexual, trans and intersex (LGBTI) people, including men who have sex with men and women who have sex with women, who may or may not identify as gay or bisexual, sex workers (people who exchange sexual services for money or gifts) and injecting drug users.¹⁰⁻¹² Discrimination against any socially disadvantaged groups is a significant risk factor for stroke, heart disease, psychological distress and depression.^{12,13} Discrimination against LGBTI people in particular is known to lead to poorer health outcomes.¹⁴ Fisher (2014) describes potentially lethal health outcomes for sexual minorities in legally sanctioned homophobic countries, where those who provide

healthcare to key populations may be criminalised. Key populations are disproportionately affected by some serious illnesses (such as HIV, other sexually transmitted illnesses and some cancers), often under-diagnosed due to the failure of health workers to explore sexual preferences.¹³ Men who have sex with men have an HIV prevalence four times that of heterosexual men,¹¹ but they and other key populations have significantly lower uptake of essential health services due to social marginalisation, legal and social conditions, stigma and human rights violations.¹⁵ Access to health and psychosocial care is generally poorer for these marginalised populations,¹⁶ and especially so in African countries like Zimbabwe with seriously discriminatory socio-political climates. Barriers to palliative and end-of-life care for LGBT people have been described in a high-income setting,¹⁷ but not previously in a low- or middle-income country. Other factors such as social class may also affect access to care, and where potential sources of discrimination coexist, as in the case of poverty and homelessness, for example,¹⁸ there is the potential for double stigma.

Estrangement from family and stigmatisation from healthcare providers reinforce widespread discrimination against key populations.¹⁵ There is global variance in acceptance of homosexuality, with widespread rejection in Africa, including Zimbabwe, and in poorer and/or highly religious countries.¹³ The Zimbabwe Criminal Law (Codification and Reform) Act¹⁹ does not refer to gender and sexual identities, but criminalises same sex intercourse 'with indecent intent' (p. 366), and this is fueled by public debate. The same Act also criminalises soliciting, procuring and living off the earnings of sex work.

Currently, in low- and middle-income countries nothing is known about the palliative care needs and experiences of these key populations. This study aimed to identify the attitudes and experiences of sex workers, sexual minorities, and health and palliative care providers regarding accessibility and quality of palliative care for key populations within Zimbabwe.

Methods

Study design

Cross-sectional in-depth qualitative interview and focus group study.

Recruitment

Using the above definitions, key populations were defined as adult (aged at least 18 years) sex workers and sexual and gender minorities (LGBTI people and other sexually non-conforming people). The selection was focused on those socially excluded populations whose behaviours led to higher incidence of infectious and non-communicable life-limiting illness.¹³ As the socio-political context precluded a conventional recruitment strategy via health centres, these legally vulnerable and hard to reach populations were accessed through non-governmental organisations that support sex workers and LGBTI people. The researcher met with all representatives to introduce the study and the sampling frame. They approached eligible individuals about the study to avoid any potential coercion from direct contact with the researcher at this stage. Purposive sampling criteria including sexual orientation, gender identity, age and sex worker status, guided recruitment. Representatives were not offered training to recruit for this study but were familiar with the process and all succeeded in recruiting requisite numbers. Data regarding refusal to participate were not collected by support agencies, therefore it is not possible to know whether there were any patterns to non-participation.

Due to non-response from the Ministry of Health, government health professionals were not included in the sample. Health and palliative care providers and representatives of support and programme agencies were purposively sampled across palliative care, sexual health and support agencies. The sample was drawn from those living in two urban areas as well as smaller centres near border posts, mines and truck stops known to attract high-risk populations in Zimbabwe.

Ethical considerations

Ethical approval was obtained from the Medical Research Council of Zimbabwe on 24 September 2014 (Ref: MRCZ/A/1881). Recruitment was undertaken with clear safety protocols to minimise risk to participants and researchers. A distress protocol was developed in case any interviewee became distressed, fatigued or unable to continue for other reasons. A representative from a relevant support organisation was available to address any adverse events. Interviews were conducted in places considered safe by our partner organisations. These included their own secure premises, or at alternative spaces considered low risk with no link to key populations. Before

commencing the interview/focus group discussion and having received an explanation of the study, each participant signed consent forms to participate and to audio record. Confidentiality was ensured throughout the analysis and reporting process by using pseudonyms and removing identifying information.

Data collection

A focus group discussion for sex workers and another for LGBTI people, each lasting approximately 1.5 h, was conducted in the four centres ($n = 8$ focus group discussions in total) using a semi-structured topic guide. The proximal towns of Beitbridge and Masvingo were combined as a single centre focus group discussion. Individual interviews of approximately 1 h were conducted with a small sample of participants from the focus group discussion, who self-identified as having a life-limiting illness. A further 12 interviews were conducted with health professionals: five palliative care nurses, three doctors, two support organisation administrators, one programme coordinator and one outreach worker across the sites. Data collection was undertaken from November 2014 to January 2015.

The topic guides were developed with reference to the study objectives and review of the literature on LGBTI people and sex worker health. Two pilot focus group discussions helped refine phrasing and sub-headings (data not included). The broad areas of enquiry were illness history and experiences of accessing health and palliative care, exploration of sexual identity in clinical consultations, communication and sexual identity, involvement of partner/significant others and support structures during serious illness and after death. Interviews were conducted and audio-recorded primarily in English with questions and topic guides translated into the vernacular (Shona or Ndebele) by the research assistant as required. The lead researcher (J.H.) is Zimbabwean female, fluent in English and conversational in Shona; the research assistant (S.C.) is Zimbabwean female, and fluent in all three local languages (English, Shona and Ndebele). It was not possible to return translated transcripts to participants for checking due to the challenges and sensitivities of re-approaching participants.

Analysis

Data were transcribed verbatim (with translation into English where required) by the research assistant and analysed using thematic analysis²⁰ with five key stages: familiarisation, coding, theme development, defining themes and reporting. Analysis was led by J.H. The first stage of analysis was familiarisation in which the researcher(s) read, reread and annotated the transcripts alongside research questions. Transcripts were coded line-by-line within the sub-headings of the interview

Table 1. Sample characteristics.

Key populations	60	Health professional	12
Site		Site	
Harare	17	Harare	8
Bulawayo	16	Bulawayo	1
Mutare	15	Mutare	2
Beitbridge/Masvingo	12	Beitbridge/Masvingo	1
Age		Age	
<35	32	<35	3
35 and over	27	35 and over	8
Info not provided	1	Info not provided	1
Gender		Gender	
Male	18	Male	4
Female	42	Female	8
Ethnicity		Ethnicity	
Shona	39	Shona	10
Ndebele	16	Ndebele	1
Other	5	Other	1
Sexual orientation/ gender identity		Status	
Lesbian	6	Palliative care nurse	5
Gay	15	Doctor	3
Bisexual	3	Director/administrator	2
Transgender	2	Coordinator	1
Intersex	1	Outreach worker	1
Sex worker	33		

schedules; however, inductive coding was undertaken within each theme to identify emergent patterns and sub-themes, and across transcripts for higher level overarching themes. Subsequently, a coding frame was developed to demonstrate emergent patterns and themes. The coding frame and transcripts of three interviews/focus groups were reviewed by the research team. After discussion, themes were developed and the coding frame revised and applied to the full data set. During subsequent analysis, the themes were developed further and refined with particular attention paid to non-confirmatory cases, where emerging themes contradicted more common ideas. Additional themes not captured under the sub-headings were also noted during this stage of analysis and added to the thematic compilation. Themes were defined and finalised through discussion (J.H., K.B., R.H.), and all researchers agreed with the final analysis, interpretation and reporting.

Results

Participants

A total of 72 individuals participated (see Table 1): from key populations ($n = 60$) recruited for focus group discussions, and from healthcare providers and support organisation representatives ($n = 12$) recruited for interviews. Focus group discussion participants who self-identified as

living with a life-limiting illness were also interviewed ($n = 1$ sex worker in Mutare, $n = 1$ sex worker in Beitbridge and $n = 1$ lesbian woman in Masvingo).

In all, 49 participants were of Shona ethnicity, 17 were of Ndebele and 6 were of 'other' ethnicity. Of the participants, 50 were female and 22 were male. Focus group discussion participants self-identified as lesbian ($n = 6$), gay ($n = 15$), bisexual ($n = 3$), transgender ($n = 2$), intersex ($n = 1$) and sex worker ($n = 33$).

Findings

Two dominant themes emerged from the data: (a) minimal understanding of, and negligible access to palliative care significantly increased the risk of painful, undignified deaths and (b) discriminatory beliefs and practices from healthcare providers, family members and the community had wide-ranging effects on care for those living with life-limiting illness and their wishes at the end of life.

Theme a: Minimal understanding of and access to palliative care significantly increased the risk of painful, undignified deaths.

Few key population participants had heard of palliative care. Understanding was incomplete and generally linked to anti-retroviral therapy adherence. Some participants had heard of a local hospice, but were unclear what was offered there:

Maybe it's for people who are tired of pain and go there to die. Maybe get injected and die. (FGSWB3 Sex worker female, 21, focus group Bulawayo)

Healthcare providers had limited experience of providing palliative and end-of-life care for key populations:

I haven't had terminally ill patients. Most of the patients who are presenting are still at a manageable stage. (KIIH8 doctor male, 30, interview Harare)

Despite HIV being a common reason for palliative care referrals in Zimbabwe, exploration of sexual risk behaviours, particularly among key populations who are known to be at risk, was uncommon. Health professional assumptions of heterosexuality and monogamy enabled LGBTI people and sex workers to remain 'undercover' and access health and palliative care along with mainstream populations:

Our social history just goes to, 'are you married?' If yes then we take it that they have one sexual partner. (KIIH7 palliative care nurse, female, 33, interview Harare)

Hiding sexual risk behaviours, however, resulted in untreated symptoms. Together with inaccurate self-diagnosis,

this was likely to increase transmission of infectious diseases, non-adherence to treatment, risk of co-morbidities and mortality:

[When] they die within a week you wouldn't have done a lot of work because they were a late referral ... because they would be hiding ... and you wouldn't have achieved much. (KIIH1 palliative care nurse female, 59, interview Harare)

Pain assessment and management were lacking in personal testimonies and anecdotal accounts of others who had died in their communities. Participants had access to only basic pain medication regardless of severity. Most were unaware of medications for severe pain and described scenarios of friends dying in pain, partly due to their resistance to seek healthcare.

Theme b: Discriminatory beliefs and practices from healthcare providers, family members and the community had wide-ranging effects on support for those living with life-limiting illness and their wishes at the end of life

The six healthcare providers associated with palliative care organisations were conversant with palliative care principles, but some acknowledged personal difficulties in applying the approach to key populations. Attitudes to key populations were strongly determined by religious beliefs and personal experience:

... we tend to intertwine [unfinished personal business] with what the patient brings and at the end of the day it will impact negatively on the type of treatment that we give a patient. (KIIM2 palliative care nurse female, 42, interview Mutare)

Healthcare providers reported less experience with, and more prejudice against, sexual minorities than sex workers, a population they were familiar with in their personal lives:

The commercial sex workers I don't think I will have much fuss with them but the gays and lesbians. I think I am not used to them. (KIIM2 palliative care nurse female, 42, interview Mutare)

That familiarity also jeopardised care for seriously ill sex workers:

... they are corrupting and taking our husbands ... they are looting from our husbands and we are now running short of finances because of these commercial sex workers ... if you are a female nurse and a sex worker comes as a patient and sometimes your husband, it happens doesn't sleep at home and sleeps elsewhere or books a room for him and a sex worker then you won't be good to that lady ... and you would

rather say let her die because she is corrupting my husband and disturbing my marriage. (KIIIB1 coordinator male, 48, Beitbridge)

Participants offered reasons for delayed presentations at health facilities such as lack of finance and anticipated discriminatory behaviours from health workers. When patients did seek care, judgmental and inconsistent medical care led to patients defaulting on treatments, with consequent incremental effects on co-morbidities and mortality:

They get questions like, 'why are you doing this? Have you read the bible?' Or the nurses would scream 'look at that homosexual', 'is this a woman?' and you get those giggles. And people feel like next time I won't go. They default on treatment. They do that. Sometimes people get stressed and default. (KIIH3 Director male, 42, interview Harare)

Some participants chose to visit private doctors who they felt were professional and confidential. Others sought advice and medicines from pharmacists. Many relied on colleagues and friends. None reported relationships with healthcare providers that supported their specific needs. Untreated symptoms, uncontrolled illness, lack of health monitoring and social support led to painful, lonely and undignified deaths:

I had a friend of mine ... she had a cancer on her leg and she went to the Apostolic church. So they used some herbs to heal the wound. So they used to take some [local grain] and put it in there saying that there were worms in the wound that needed to eat the food they put rather than eat her flesh ... the whole room would be filled with a bad smell. So people started to run away from her until they stopped giving her food, then one day when we went to pay her a visit we found no one there, flies everywhere and the moment we opened the door we discovered that she had passed away. (KIIIB2 Lesbian, 40, interview Masvingo)

Stigma from family members and the wider community further compromised support for the ill and dying. Discrimination in this environment was described as extreme to the extent that lives were in danger:

They can be killed or burnt alive. Because people regard them as animals and not as human beings. (KIIM2 palliative care nurse female, 42, interview Mutare)

Patient care appeared contingent upon attitudes of family and community towards key populations, regardless of the severity of illness, even at the end of life. Some participants preferred to die in hospital as they could not count on family support:

So isolation comes in, discrimination and you find many people dying quietly without any family support ... They will

say you were doing your gay things on your own that's why now it's payback time for your sins ... People will look at you and say it's now punishment for not having reproduced, getting married and not following the family tradition and going against God. (KIIH3 Director male, 42, interview Harare)

Spiritual support was also compromised by discriminatory views of some religious leaders:

... when the pastor comes ... and you say this is my wife and he is a man the pastor will definitely freak out. 'This is a taboo, an abomination. What are you doing? No wonder you are in this situation'. (KIIH6 palliative care nurse female, 48, interview Harare)

Participants believed final wishes at the end of life would not be respected because of their 'bad behaviour':

I would want my partner to stay with some of my things, but if you are staying with your partner and you die, your family will just come and take away your things and just say you were a friend and this property belonged to my daughter. (FGLGB3 lesbian 42, focus group Bulawayo)

Discussion

The research highlights that for sexual and gender minorities and sex workers living with life-limiting illness, the care and support provided by healthcare providers, family and community members was negatively affected by discriminatory beliefs and practices, closely reflecting stigma research results in India.²¹ Poorly informed health professionals influenced by misconceptions and limited experience with key populations were identified as drivers of fear and prejudice in an environment that discouraged early presentation, diagnosis and treatment. This potentially increases the risk of transmission of infectious diseases, morbidity and mortality.

Unwillingness and inability to explore sexual orientation and gender identity with patients has important implications for the effective implementation of palliative care. An African Palliative Care Association standards document²² and the Zimbabwe National Palliative care Policy²³ both promote inclusion of 'special needs populations' but do not specify sexual minorities and sex workers in that definition. Our data which highlight diversity and inclusivity, add weight to the growing call for value-based care, where providers spend quality time with patients, listening, identifying and addressing their needs which, in the case of key populations, may be complex.

The accounts in this study of painful, humiliating and lonely deaths, disenfranchised relationships and disrespect for inheritance wishes represent the tragedy of living with life-limiting illness without the benefits of

palliative care. The evidence from this research identifies distinct palliative care needs of key populations. These include appropriate medical and supportive treatment after a comprehensive, holistic assessment with access to all levels of pain control; equal access to care without judgement or discrimination; access to information and safer sex materials, to protect against contracting life-threatening conditions as a result of high risk behaviours; and support for family members and partners in managing the often difficult issue of disclosure. Findings from this study can be used by policymakers to specify inclusion of sexual minorities and sex workers as key populations in the national palliative care strategy as it is developed. From a public health perspective, examination of marketing strategies that identify the best practice for addressing sexually taboo issues, such as HIV and male circumcision, is encouraged to optimise social acceptance.¹⁵ Further research with wider gender diverse representation could contribute to the limited data available on key populations in sub-Saharan Africa.

Strengths and limitations of this study

This was the first study undertaken in low- and middle-income countries to describe palliative care experiences for sexual and gender minorities and contributes to the growing body of research on sex workers. It is likely that palliative care issues experienced by gender diverse minorities were under-described as only two transgender and one intersex persons were included in the sample; therefore data saturation is unlikely to have been achieved. In this socio-politically punitive environment, their recruitment, however, was a positive achievement and addressed the absence of this demographic in other research.²² The sexual orientation of sex workers was not recorded, therefore, we may have missed the opportunity to explore experiences for those with both LGBTI and sex worker status. Diagnosis information was not included when recruiting key population participants, beyond a request for participants with life-limiting illness to volunteer for individual interview. Data regarding refusal to participate were not requested from the support agencies who all successfully recruited requisite numbers, therefore, it is not possible to know whether there were any patterns to non-participation. Information surrounding serious illness, dying and death was often based on witnessing deaths of colleagues and friends. Permission was sought from the Ministry of Health and Child Care to interview government health workers, but non-response in the time available excluded them from this study. Recruitment of 12 other health workers to discuss care for key populations was challenging given the socio-political situation. Translated transcripts were not returned to participants for checking, due to the challenges and sensitivities of re-approaching individuals.

Conclusion

The findings from this study have informed the following recommendations which, given the risks for individuals associated with these key populations, focus on palliative healthcare services and staff:

1. Enhance clinical interviewing skills using history taking forms reflecting culturally appropriate terminology to explore sexual orientation, gender identity and relationships to enable person-centred care for key populations faced with life-limiting illness.
2. All palliative care training and service implementation should include information regarding health and human rights of key populations to promote person-centredness and values-based care in order to comprehensively address the needs of all patients and their families affected by incurable illnesses.
3. Practitioners must ensure confidentiality and safety which is culturally and context-specific while facilitating disclosure, and ensure access to appropriate treatments and support from diagnosis of life-limiting illness to death and bereavement.
4. Recognition of the challenges that key populations may experience in managing the interface between members of their support network and their own family members demands a broader interpretation of 'family'. This would decrease the isolation of patients and disenfranchised partners, and increase access to care throughout the life-course.

To our knowledge, this is the first study to describe palliative care experiences of both sex workers and sexual minorities in low- and middle-income countries. As was found in a similar study in the United Kingdom, patients must make a risk assessment to determine if the benefits outweigh the risks of revealing their identity to health professionals.¹⁷ Given the legal context and public discourse, and the very real threat of violence, this risk assessment carries serious implications in Zimbabwe. Discrimination from healthcare providers discourages key populations from accessing palliative care services, potentially increasing the risk of morbidity, mortality and transmission of infectious diseases. Untreated conditions, exclusion from services, and minimal family and social support create unnecessary suffering in an environment characterised by poverty and under-resourced health facilities. Recommendations from the study confirm the continuing need for research and enhanced education of practitioners.^{22,23} These are necessary to address the public health implications of discrimination in health and palliative care, especially in countries where inequality is

legally or religiously sanctioned. Public health programmes addressing other taboo subjects such as HIV and male circumcision may provide guidance.

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Declaration of conflicting interests

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