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Perceived Challenges and Social Support for Muslim Women Living with HIV (WLWHIV) in Malaysia

Cabaran dan Sokongan Sosial di Kalangan Wanita Islam Hidup dengan HIV di Malaysia

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ABSTRACT

The unfair social structure that exists in society contributes to negative impacts on women who have been diagnosed with HIV. This qualitative study aims to explore the obstacles faced by Muslim women living with HIV (WLWHIV) in Malaysia. Additionally, this study investigated the perceived social support for those living with HIV in order to improve their overall quality of life. Purposive and snowball sampling techniques were utilised, and semi-structured, audio-taped online interviews were conducted. Eight participants from five different states in Malaysia were involved in the study. The data were analysed using thematic analysis. The survey findings underscored the considerable challenges encountered by Muslim women living with HIV, such as the intricate responsibility of raising children, confronting family stigma, and managing insufficient professional support. It highlights the significance of actively seeking social support, participating in religious and self-care practices, and engaging with supportive peers as crucial elements in enhancing the overall well-being of individuals affected by HIV. Gaining a better understanding of perceived challenges and social support among Muslim WLWHIV in Malaysia will lay the groundwork for crafting effective psychosocial interventions and social policies for this marginalised group. This study can inspire mental health professionals, including social workers, counsellors, and psychologists, to identify the positive qualities of Muslim WLWHIV that can help them advocate for their clients.

Keywords: HIV; quality of life; qualitative; social support; women

ABSTRAK

Ketidakseimbangan struktur sosial yang wujud dalam masyarakat menyumbang kepada kesan negatif kepada wanita Islam yang hidup dengan HIV. Kajian kualitatif ini bertujuan mengkaji halangan yang dihadapi oleh wanita Islam hidup dengan HIV di Malaysia. Selain itu, matlamat kajian ini ialah untuk mengenal pasti keperluan sokongan sosial bagi meningkatkan kualiti hidup wanita dengan HIV mereka secara keseluruhan. Teknik pengambilan sampel snowball dan berangka telah digunakan, dan temuramah secara separa struktur dalam talian telah dijalankan. Seramai 10 peserta dari lima negeri yang berbeza di Malaysia telah ditemuramah. Data telah dianalisis menggunakan analisis tematik. Dapatan daripada kajian ini mendalami cabaran yang dihadapi oleh wanita Muslim dengan HIV, termasuk mengimbangi tanggungjawab dalam menguruskan anak-anak, menangani stigma daripada keluarga dan masyarakat, serta menangani kekurangan sokongan daripada pihak profesional. Dapatan kajian juga mengenal pasti kepentingan untuk mendapatkan sokongan sosial, mengamalkan penjagaan diri, dan berinteraksi dengan rakan sebaya sebagai faktor penting dalam meningkatkan kesejahteraan hidup wanita dengan HIV. Kefahaman dan pengetahuan mengenai cabaran yang dialami dan sokongan sosial di kalangan wanita Islam dengan HIV di Malaysia akan dapat memberikan maklumat untuk menyediakan intervensi psikososial yang berkesan dan menggubal dasar-dasar sosial bagi meningkatkan kualiti hidup populasi ini. Pengetahuan ini juga penting bagi pihak profesional dalam bidang kesihatan mental, termasuk pekerja sosial, kaunselor, dan ahli psikologi untuk membantu mereka memperkasakan hak-hak kesejahteraan wanita dengan HIV di Malaysia.

Kata kunci: HIV; kualiti hidup; kualitatif; sokongan sosial; wanita

INTRODUCTION

The HIV stands for Human Immunodeficiency Virus, which is responsible for causing AIDS, or Acquired Immune Deficiency Syndrome. This deadly virus initially emerged in the 1980s and quickly became one of the most feared pandemics worldwide, eventually claiming millions of lives (Bosh et al. 2021). According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), in 2021, the number of individuals affected by HIV is estimated to be around 38 million worldwide. Out of these 38 million people, approximately 19.5 million are women from various countries across the globe. In Malaysia, there were 125,878 reported HIV cases over three decades (1986–2020) (Tze 2022). In 2021, there were a total of 92,063 estimated people living with HIV (PLHIV) (Ministry of Health 2020). Furthermore, new HIV infection decreased 50% from 2002 to 2020, with 3,146 cases reported, and the incidence rate per 1000 uninfected people decreased from 28 cases per 100,000 population to 9.3 cases per 100,000 population (Tze 2022). Since the start of the HIV epidemic in Malaysia, there has been a consistent trend of more male cases reported compared to female cases, with a male-to-female ratio of 7.5 in 2021, and women represent 10% of all HIV cases in Malaysia (Ministry of Health 2023). However, there is no data that is particular to Muslim women with HIV in Malaysia, particularly due to confidentiality and sensitivity. At the same time, it also highlights the pervasive and significant amount of work that needs to be done to treat and care for Muslim women with HIV.

Within Muslim communities, being diagnosed with HIV poses various complexities, including medical challenges and the intersectionality between cultural, social, and religious aspects (Szaflarski 2013). Islam highly prioritises chastity, purity, and the importance of marriage relationships, akin to other religious traditions. A Muslim women living with HIV (WLHIV) may be seen as violating certain standards, potentially resulting in bias and stigmatisation towards her and the community as a whole (Rai et al. 2020). This perspective may also hinder individuals impacted by HIV/AIDS from accessing treatment or obtaining necessary social and emotional assistance, thus affecting their quality of life. Despite the challenges, Muslim WLHIV have shown exceptional levels of resilience (Hidayanti Ema & Syukur Amin 2018).

The early social construct of HIV tended to classify women as guilty and dangerous (promiscuous women or prostitutes) or as innocent victims (sexual partners of haemophiliacs or bisexual men) (Khairul Hamimah Mohammad Jodi & Nurul Husna Mansor 2019; Logie et al. 2016). WLWHIV were assumed to be having sex with multiple partners or blamed for contracting and spreading HIV and other sexually transmitted diseases' (STDs) (Fletcher et al. 2015). As a result, women are still being blamed today when they are unable to prevent the transmission of HIV, even though 85% of HIV cases among women across the world are acquired through heterosexual activity with their partners. The discussion of HIV is still considered taboo, and this perception is mirrored within political systems that closely associate the disease with moral faultiness (Halimatusa'diyah 2019; Maman et al. 2014). As a result, PLHIV experience some constraints, such as limited economic opportunity and structural inequities that include poverty, unstable housing, and homelessness (Loeliger et al. 2016; Sarasuphadi Munusamy & Kamal Solhaimi Fadzil 2017). Furthermore, the social issues surrounding women and HIV have resulted in high levels of stigma and discrimination (Logie et al. 2018).

The unequal social structure that exists in society contributes to negative impacts on women who have been diagnosed with HIV. WLWHIV are expected to take care of other family members, including partners and children (Mohd Saad et al. 2018; Paudel et al. 2015). Those who have financial constraints also need to work to earn an income while carrying both the roles of carer and breadwinner (Fletcher et al. 2016). While fulfilling these multiple social roles, WLHIV jeopardises their own health status and has no opportunity to receive proper medical care and support. In many cases, WLHIV are dying earlier than men with HIV, even though women constitute fewer AIDS cases than men (Confronting Inequalities 2021).

The HIV epidemic in Malaysia is classified as a concentrated epidemic, indicating that specific key populations face a greater susceptibility to infection (Ministry of Health 2021). This includes men who have sex with men (Usman 2018), transgender individuals, sex workers, and people who inject drugs. It is important to recognise that research efforts have been directed towards understanding HIV-related concerns among different populations in Malaysia, such as Indian-Malaysian women (Sarasuphadi Munusamy & Kamal Solhaimi Fadzil

2017); Malay Malaysians (Sarasuphadi Munusamy & Kamal Solhaimi Fadzil 2017; transgender women (Barmania et al. 2017; Shrestha et al. 2020; Rutledge et al. 2018; Wickersham et al. 2017); and men who have sex with men (Krishnan et al. 2021). For instance, Sarasuphadi Munusamy & Kamal Solhaimi Fadzil (2017) reported that Indian-Malaysian women living with HIV encountered many forms of mistreatment, including instances of prejudice, marginalisation, and disparities in socio-economic status. In addition, Rutledge et al. (2018) found that transgender women with regular contact with their primary care provider (PCP) are six times more likely to conduct HIV screenings compared to those without contact with their PCP. Furthermore, Malaysia's HIV strategy prioritises sex workers and expectant mothers, with initiatives targeting female injecting drug users (Leoliger et al. 2016).

In Malaysia, studies on women living with HIV/AIDS have unveiled critical insights into the unique challenges they encounter. A study by Mashrom Muda (2021) highlighted the prevalence of stigma surrounding HIV/AIDS in Malaysia, indicating that misconceptions and discriminatory attitudes persist, impacting the mental health and well-being of affected women. According to Ahmed et al. (2017) and Pebody (2019), stigmatisation while assessing HIV screening and treatment in hospitals affecting the timely diagnosis and treatment for women living with HIV/AIDS. Furthermore, studies from Chan et al. (2021), Chong et al. (2021) and Rahman et al. (2020), the intersectionality of gender and socioeconomic factors, illustrates how economic disparities contribute to the vulnerability of women in managing their HIV/AIDS condition in Malaysia. Collectively, these research findings illuminate the multifaceted nature of challenges and underscore the imperative for comprehensive, culturally sensitive interventions to address the needs of this vulnerable population. However, research on the challenges and social support among WLWHIV in Malaysia is limited, and cultural barriers may cause contentious discussions (Sarasuphadi Munusamy & Kamal Solhaimi Fadzil 2017). As a result, the experiences of WLWHIV in Malaysia have received scant attention in the research landscape, with limited studies focusing on this demographic. The dearth of dedicated research on Malaysian WLWHIV underscores the need for comprehensive exploration of their unique experiences and challenges within the Malaysian context. Often, the experiences of WLWHIV in Malaysia and how they cope with this problem are not given the proper attention.

Through the utilisation of a narrative inquiry research design, this qualitative study seeks to fulfil two distinct research objectives. Firstly, it aims to examine perceptions of the challenges of Muslim WLWHIV in Malaysia. Secondly, the study aims to explore perceived social support for Muslim WLWHIV to enhance their overall quality of life. Women are the experts who can tell their stories from their own perspectives (Halimatusa'diyah 2019). Ultimately, their stories are helpful for understanding the forces and conditions that prevent them from achieving the full expression of their health and well-being.

LITERATURE REVIEW

ISLAMIC CONCEPTS PERTAIN TO WOMEN WITH HIV

According to Khan and Tahir (2022), Muslim WLHIV can derive a great deal of benefit from the *Ummah*, which is a philosophical concept in Islam that places an emphasis on the significance of communal support and empathy. The concept that underpins this is that these women have the ability to actively seek out and participate in support groups within their communities in order to discover a sense of comfort and connectedness (Fauk et al. 2022). In addition to providing emotional support, groups also provide assistance in practical matters, which helps individuals develop resilience through the sharing of experiences (Razick Ahamed Sarjoon et al. 2022). Ghaffar (2023) states that Islam highlights the significance of maintaining a positive mindset and expressing gratitude for Allah's blessings as factors that can enhance resilience. The approach also promotes taking practical measures to tackle obstacles and conquer difficulties, with an emphasis on enhancing one's circumstances and having faith in Allah. The Quran declares that being grateful benefits oneself. Anyone who rejects His favour, Allah is self-sufficient and deserving of praise. Furthermore, the concept of forgiveness, also referred to as *Maghfirah,* plays a crucial role in Islamic belief (Muhammad 2020). Practising forgiveness towards themselves and others can help these women reduce their emotional burden and enhance their resilience in challenging situations (Van Es 2019). Religious beliefs provide comfort during challenging times. By engaging in dhikr, individuals can establish an uninterrupted link with God through the repetition of particular phrases or

prayers (Affandi et al. 2020). Engaging in *dhikr* not only provides a sense of support from a higher power but also strengthens their inner strength and resilience (Rafique et al. 2019). These resilient women are able to use their faith to draw upon an ancient practice that has helped previous generations navigate difficult times and emerge stronger.

Islam focuses on principles like compassion, empathy, and justice (Rafique et al. 2019). Amidst the rising prevalence of HIV as a social concern across diverse demographics, Muslim women with HIV find empowerment in Islamic principles to combat prevalent misunderstandings about the disease (Tara-Chand 2019). These sets of principles contribute to fostering greater understanding and inclusivity in discussing HIV/AIDS issues and provide a way for Muslim WLHIV to navigate the challenges of living with HIV within their communities (Moghadam et al. 2018). Moreover, Islamic doctrines underscore the significance of privacy and confidentiality, particularly concerning the sensitive health data of Muslim women impacted by HIV. It instills a sense of reassurance in these individuals, knowing that their confidential information remains safeguarded and will not be divulged or disseminated without explicit consent (Juliastuti et al. 2020). The preservation of privacy grants individuals the agency to manage this aspect of their lives while concurrently accessing support and assistance from proficient professionals.

SYSTEMATIC CHALLENGES OF WLWHIV

WLWHIV often encounter systematic barriers that impede their access to comprehensive healthcare, social support, and opportunities, exacerbating the challenges they face in managing their health and well-being (Ahmed et al. 2017; Halimatusa'diyah 2019; Mashrom Muda 2021; Sarasuphadi Munusamy & Kamal Solhaimi Fadzil 2017). A qualitative study by Mashrom Muda (2021) interviewed 20 WLHIV found that women with HIV are facing various challenges such as uncertain health conditions, stigma, discrimination, and negative labeling by family members and community members. The challenges faced by WLHIV affected many aspects of their lives, such as a lack of social support, denial of rights and opportunities for treatment, employment, community activities, limited decision-making freedom, and a constant state of sadness, disappointment, and pressure. Mashrom Muda (2021) suggested that support is crucial for WLHIV to rebuild their lives.

The existing literature on WLWHIV does not position women as themselves but as women in relation to their sexual partners, as mothers of babies who may be born HIV positive, or as carers for people living with HIV (Casale et al. 2015). As HIV and AIDS have begun to spread rapidly among women around the world, they have increasingly been identified as a feminised epidemic by many national governments, international organisations, donors, and non-governmental organisations that constitute the global response to the problem (Carter et al. 2017; Carter et al. 2021). WLWHIV are more likely to live in poverty, with unequal access to basic needs and resources (Barmania et al. 2017; Ngoma et al. 2017). Women with HIV/AIDS also struggle with oppressive cultures and traditions (Campbell et al. 2016; Yourkavitch et al. 2015), the denial of sexual and reproductive choices, and the absence of adequate health care information (Kosia et al. 2016). In addition, HIV status prohibits women from accessing a better quality of life (Gatwiri et al. 2016), and existing policy has been limited in recognising the gendered impacts of the epidemic (Mwatelah et al. 2019).

The faintness of women's voices makes it difficult to address the root of the problem for WLWHIV. One dilemma women face is the decision of whether to disclose their HIV-positive status to their partners (Hatcher et al. 2015; Madiba et al. 2017). On the one hand, if a woman decides to openly disclose her HIV-positive status to her partner or spouse, she might forgo the relationship if the person decides to leave her. On the other hand, if she decides to hide her HIV status, she will forgo a truthful relationship based on trust and intimacy. In addition to self-disclosure, society views a 'good woman' as one who is physically and mentally healthy, can produce a child, and carries the duties of a wife and mother without any limitations (Wangman et al. 2015; Omonaiye et al. 2018). In contrast, society stereotypes HIV-positive women as those who have moral issues, are unable to become pregnant, will transfer HIV to their baby during pregnancy, delivery, and breastfeeding, deal with manageable chronic illness', and are physically ill (Ngoma et al. 2017). The social construction of HIV portrays such women as perpetrators rather than individuals who need support and treatment.

Chong et al. (2021) reported that the perception of insufficient confidentiality and the possibility of encountering discriminatory behavior at public health facilities emerged as significant barriers to

HIV testing among HIV positive patients in Malaysia. While participants expressed satisfaction with HIV treatment, they seldom sought psychosocial support, often choosing to 'safeguard' their privacy. Furthermore, injustices in reproductive health care policies for women with HIV/AIDS and violations of women's rights jeopardise their dignity, health, and well-being. Most HIV and AIDS education and prevention interventions, such as the promotion of safe sex practises, programmes to address the relationship between HIV and intimate partner violence, and advice to reduce one's number of sexual partners', only aim to educate women as agents to prevent HIV transmission (Carter et al. 2021; Patrão et al. 2017). In many parts of the world, condoms have been used as the main HIV prevention method—an approach requiring that women negotiate with their partners to use a condom during sexual intercourse. However, an unequal power dynamic between men and women has made this method a spectacular failure in preventing transmission of the HIV virus (Batchelder et al. 2016; Peasant et al. 2017). Often times, women are blamed for not using condoms and contracting HIV via sexual intercourse, even though both men and women are involved in negotiating condom use (Khumaidi et al. 2021).

The stigma surrounding HIV/AIDS makes life more difficult for Muslim WLHIV because they must deal with societal misconceptions and prejudices about the illness (Ahmed 2003). Muslim women with HIV may face discrimination, social exclusion, or violence because of their health condition. The fear of revealing one's HIV-positive status and the possible repercussions can result in secrecy and isolation, intensifying the emotional weight they bear (Fauk et al. 2022). Furthermore, the convergence of health status with gender and religious identities can affect their healthcare access. Barriers to accessing suitable medical care may arise from cultural and religious sensitivities, language obstacles, or insufficient knowledge about available services (Giwa 2015; Gurmu & Etana 2015). Because of societal misunderstandings and biases, Muslim women with HIV frequently face severe stigmatisation and discrimination within their communities (Balogun 2010). Despite facing difficulties, a study by Rai et al. (2020) reported that WLHIV demonstrated strength and resilience as they confronted the challenges of daily life, persistently fighting against the obstacles they encountered.

SOCIAL SUPPORT FOR WLWHIV

Another related area that past research has examined is how WLWHIV seek and receive social support to improve their overall quality of life. WLWHIV reported family members as the source of informal support, particularly in relation to HIV status disclosure. Often, women disclose their status to a trusted family member first, as highlighted by Maman et al. (2014). This family member helped the PLWHA cope with the news of their diagnosis and prepared them to disclose it to others. However, the dilemma of disclosing one's HIV status hinders social connections, even within religious contexts (Grodensky et al. 2015). Women often yearn for these connections but fear judgement and rejection. Establishing trusting relationships with healthcare providers is also highlighted as an avenue of support (Cuca et al. 2016). Having a good relationship with healthcare providers can potentially influence women's health decisions, including decisions such as abortion due to fear of being discovered (Cuca et al. 2016).

Past studies have highlighted that religion and spiritual practises provide comfort to women experiencing illnesses such as cancer (Adawiyah Ismail 2019). According to Grodensky et al. (2105) and Warren-Jeanpiere et al. (2017), religion can provide support so that women living with HIV/AIDS can experience the full expression of health and well-being. However, studies also found that many WLWHIV were unable to receive the necessary support from mental health professionals (Tuthill et al. 2017), and some were reluctant to use counselling services due to a lack of trust towards counsellors and concerns that counselling would jeopardise the confidentiality of their HIV status (Bhatia et al. 2017). Forming supportive communities becomes paramount support for WLWHIV. Support groups emerge as a vital intervention for countering stigma and discrimination (Paudel et al. 2015). These groups provide a safe space for women to share experiences, find empathy, and gather strength to navigate their challenges.

Coping with HIV and AIDS necessitates resilience, and spirituality often plays a significant role in the lives of women living with the virus. Many turn to religious practises, prayer, meditation, and church activities as sources of connectedness and coping mechanisms (Arrey et al. 2016). A local study by Zainal-Abidin et al. (2022) highlights how religious coping can be a supportive force, especially

when received from family or non-governmental organisations (NGOs). Additionally, spirituality is recognized as a key source of support, although its potential to foster connections with church communities is hindered by the fear of disclosing one's HIV status (Grodensky et al. 2015).

WLWHIV navigates a challenging landscape marked by stigma, the quest for support, and diverse coping strategies. The efforts to counteract discrimination through support groups and trust-building with healthcare providers underscore the crucial role of community and healthcare systems in enhancing the well-being of these women. Furthermore, the intersections of spirituality and religious coping offer profound insights into how women find solace and strength amid adversity. Recognising these challenges and developing comprehensive support mechanisms can contribute to empowering women living with HIV/AIDS and fostering a more compassionate and inclusive society.

Muslim WLHIV face challenges like stigma and discrimination daily, but they show remarkable perseverance and determination by seeking support from friends, family, and community members (Ahmed 2023). According to Fauk et al. (2022), support from significant others will allow WLHIV to access vital resources to manage the adverse effects of HIV and stay engaged in society. Furthermore, support from family members, friends, and religious communities is crucial in helping Muslim WLHIV to deal with the challenges they encounter, to promote a feeling of companionship, and to foster a sense of belonging, which are crucial to aiding WLHIV in navigating their circumstances. Similarly, according to Ismail et al. (2022), Muslim women with HIV can challenge societal limitations and create a beneficial influence by actively engaging in their communities. Engaging in diverse community activities provides an opportunity for WLHIV to defy common stereotypes associated with their condition (Juliastuti et al. 2020). In addition, Muslim women with HIV can improve their own health and educate others who may have misunderstandings about the disease (Ismail et al. 2022).

METHODOLOGY

STUDY DESIGN

This study employed a qualitative research design based on these two reasons. First, the qualitative research design provided participants with the opportunity to share their stories and to express their voices. Secondly, the exploratory nature of qualitative methods allowed the researcher to capture participants' thoughts and gain a deeper perspective on participants' interpretations (Tashakkori et al. 2007). This fits with the goal of this study, which is to shed light on the challenges and social support among WLWHIV in Malaysia. Furthermore, narrative inquiry research methodology was adapted in this study. The researchers deemed that narrative inquiry was an appropriate methodology for this study because it allowed and enabled a rich, deep, and intimate study of individuals' experiences over time and in context (Josselson et al. 2003). Secondly, narrative inquiry provided an optimal way for the researchers to understand the lived experiences that WLWHIV would be telling in a way that participants could interpret and make meaning of their own stories (Kaushik et al. 2019). Finally, narrative inquiry viewed social phenomena in a broader context by focusing on the subjective meaning of participants' reality and contexts in their naturalistic settings (Tashakkori et al. 2007), allowing study participants to construct their stories as WLWHIV in Malaysia using their own interpretation.

SAMPLE AND SAMPLING

A combination of purposive and snowball sampling techniques were used to recruit the participants from non-profit organisations providing social services, centres, and shelters to women and children living with HIV, starting from the top five (5) states with the highest HIV cases in 2019: Selangor, Wilayah Persekutuan Kuala Lumpur, Johor, Sarawak, and Penang (Ministry of Health, 2021). The author requested an updated list of women and children centres or shelters (government and non-government) and made initial contact via email or phone with the person in charge from the shelters or centres to explain the research objectives and request permission to share information about the study with their staff members and clients. To recruit a diverse set of the population, the author also used purposive and snowball sampling, where at the end of the online interview, respondents were asked to inform others of the research who may have had this experience and invite them to participate. In this study, the term Muslim WLHIV refers to any Malaysian women with HIV who consider herself to be a follower of Islam, regardless of their race and/or cultural traditions are.

DATA COLLECTION

The author conducted online, semi-structured, in-depth interviews with each participant using Google Meet and a passcode to collect data. The data collection took place at the end of 2021, during Malaysia's ongoing recovery from COVID-19. Consequently, the data were gathered through Google Meet, a video conferencing platform that facilitates real-time virtual interactions, rendering it a practical choice for interviews, focus groups, or meetings when face-to-face interactions are not feasible (Pratama et al. 2020). As highlighted by Nesir et al. (2023), Google Meet serves as an effective platform for data collection, with researchers able to employ strategies that include addressing ethical concerns, identifying and selecting potential participants, choosing the appropriate type of remote interview, preparing for the remote interview, and establishing rapport with participants.

During the online interviews, open-ended questions were asked to explore the perceived challenges of living with HIV and the use of social support by WLWHIV. Prior to the interviews, respondents were asked to complete a short socio-demographic and background self-administered questionnaire to provide background information. Each interview lasted for approximately one hour. All participants were provided with a gift of appreciation after the first interview. The author developed an interview guide that comprised questions about participants' experiences of living with HIV, the effects of HIV on them personally, and concrete measures that were or could be put in place to increase social support and increase the quality of life among WLWHIV.

DATA ANALYSIS

The paid transcriber verbatim transcribed all recorded online interviews. After checking the accuracy and validity of the transcribed online interviews, the author then analysed each interview transcript based on Fraser's (2004) guidelines for analysing personal stories in narrative research. First, the audio-recorded interviews were listened to and re-listened to, aiming to avoid producing "overintellectualized" personal stories and to think critically about the stories. Secondly, the transcribed information was categorised into themes or patterns and organised into coherent categories. Finally, all the similar and different themes that emerged from the data were combined to create in-depth stories about shared experiences of WLWHIV.

RIGOUR AND TRUSTWORTHINESS

Immediately after these interviews, the author wrote memos about what was working or not during the interview process and shared the memos with other researchers in the team. Memos also assisted in creating probes where necessary. The author also utilised member checking in an effort to guard against our own bias and requested that participants look over emerging themes and subthemes to ensure interpretations were accurate. To assist in reflexivity, Marshall et al. (2011) suggested the use of epoche, in which the interviewer wrote a full description of their own experience with the research topic and bracketed these experiences from those of participants. This allowed the researcher to gain clarity from preconceptions and assisted in addressing researcher bias. Data triangulation was also utilised by requesting that a worker working at the non-profit agencies serving WLWHIV and another individual with a background in qualitative research assist in reading and reviewing the transcripts and coding.

ETHICAL CONSIDERATIONS

Participants were asked to review and sign a written consent form. Before starting the online interview with participants, the objectives and scope of the study were discussed, including voluntary participation and the participants' rights to discontinue and/or withdraw from the study at any time without penalty. While there was likely little risk to participants, psychological discomfort might have been felt if participants recalled a time(s) where they did feel or experienced traumatic events related to the study questions.

LIMITATION

The sample comprised a group of individuals who were diverse in their geographical areas, which can be described as rural and urban, and age, thereby giving voice to an often-understudied population. Some limitations of this study, however, bear mention. Given that all the data for the current study were drawn from self-reports, participants may be subject to recall bias. Sample consist of only eight participants, and findings may not be generalised to a larger and more diverse community in Malaysia.

RESULT

The final sample included eight Muslim WLWHIV. Their ages ranged from 31 to 48, with a mean age of 38.5. Of the 10, six participants have children, and two are remarried with husbands who are HIV-negative.

The results highlighted many challenges experienced by Muslim WLWHIV, including balancing roles as a mother and as a wife and dealing with stigma and discrimination from community members. For participants in the current study, seeking social support by sharing their status with trusted family members, practising self-care, and talking with supportive peers are crucial components of enhancing their quality of life.

MOTHERHOOD AND STIGMA FOR MUSLIM WOMEN WITH HIV

The study's findings brought to light a myriad of challenges that Muslim WLWHIV face, casting a stark light on the intricate intricacies of their lives. Juggling the role of a mother while also caring for children who are living with HIV adds an additional layer of complexity. One participant shared her heart-wrenching struggle, stating that:

"Every day is a battle to ensure that both my own health and my children's health are maintained. It's an overwhelming responsibility that never lets up."

This poignant quote encapsulates the relentless effort these women invest in ensuring their children's well-being while navigating their own health challenges. Compounding these burdens is the weight of stigma and discrimination emanating from relatives and family members. This forms a distressing reality that many Muslim WLWHIV grapple with daily. This first-hand account exposes the profound emotional toll of familial stigma, eroding the support networks that are crucial for these women's well-being. participant's sombre reflection resonates deeply:

"It's painful to witness my own family treating me differently after learning about my HIV status. Their avoidance and whispers cut deep."

Moreover, the absence of adequate support from counsellors or social workers magnifies the challenges these women face. Muslim WLWHIV often rely on professional guidance to navigate the complexities of their condition, but when that support is lacking, their struggles are exacerbated. A participant's frustration is palpable as she shares:

"I sought help from a counsellor, but their lack of understanding about HIV left me feeling even more isolated. It's disheartening when those meant to support you are unaware of your unique needs."

These challenges often intersect, creating a complex tapestry of experiences that shape Muslim WLWHIV's lives. The dual burden of maternal responsibilities intertwined with the stigma encountered within their own families compounds their emotional turmoil. As one participant expressed:

"Being a mother to children who are also HIV-positive while battling discrimination feels like an insurmountable mountain. There are days when I feel utterly defeated."

SOCIAL BONDS AND SELF-CARE IN HIV JOURNEYS

The findings of this study revealed that the act of seeking social support had a significant impact on the participants' overall quality of life. Numerous individuals derived comfort by disclosing their HIV status to close family members, thereby experiencing emotional relief and fostering a sense of comprehension. One participant shared her experience, stating:

"Sharing my status with my sister lifted a weight off my shoulders. She stood by me, and we started researching together on how to manage my health better."

A participant further highlighted the significance of telling family members if one has HIV:

"Despite feeling apprehensive, informing my parents about my diagnosis proved to be one of the most advantageous choices I made. They provided me with support and facilitated my comprehension that I was not alone in this endeavour."

Some respondents shared that they made the decision to remarry and received social support from their spouses. One participant articulated her experience, stating that the pivotal moment in her life was to finally find a spouse who exhibited understanding and support despite her HIV status:

"Finding a partner who was understanding and supportive despite my HIV status was a turning point. His acceptance and willingness to stand by me made a tremendous difference in how I viewed my own life."

Moreover, the participants underscored the notion that the pursuit of social support extended beyond the realm of intimate familial and conjugal connections. The support and companionship of friends and peers were crucial in offering emotional solace and cultivating a feeling of inclusion. The act of engaging in the sharing of personal experiences with those who had a deep understanding of their unique path fostered a support network that effectively mitigated sentiments of seclusion. One more participant expressed her viewpoint, stating that the act of establishing connections with other women who were also experiencing HIV infection provided her with a sense of reduced isolation:

"Connecting with other women who were also living with HIV made me feel less alone. We became like a family, sharing our challenges, victories, and advice. It's a bond that gives us strength."

The incorporation of self-care practises has been identified as an additional essential element in enhancing the overall quality of life for these individuals. The significance of placing emphasis on the maintenance of both physical and mental well-being in the face of HIV-related difficulties was underscored by the participants. One participant had a similar viewpoint, stating that they came to the realisation that prioritising self-care is not an act of selfishness but rather a vital necessity:

"I realised that taking care of myself isn't selfish; it's necessary. Engaging in activities I enjoy and making time for relaxation have helped me regain a sense of control."

Furthermore, the act of participating in discussions with peers who provided support was found to have a substantial impact on enhancing the overall well-being of the individuals involved. Through the act of exchanging personal narratives, individuals fostered a collective spirit of camaraderie that surpassed feelings of seclusion. One participant remarked:

"Being part of a support group where I could openly discuss my concerns made me feel understood and less alone. We learned from each other's journeys and offered mutual encouragement."

The aforementioned tactics frequently exhibited interdependence, resulting in a holistic approach that significantly improved the participants' overall well-being. The act of disclosing one's own circumstances to family members fostered a more profound sense of connection and acceptance. In addition, social support from the husband and spouse was identified as crucial, thereby reinforcing the significance of engaging in self-care practises. Participants in this study shared that they derived validation and gained insights from their participation in support groups as a gratifying experience that helped them in spite of the obstacles posed by the community members.

DISCUSSION

The HIV/AIDS pandemic affected diverse communities worldwide, regardless of their economic status, gender, or geographical location. Nonetheless, cultural attributes like religion, stigma, customs, and gender exert influence over every facet of HIV, encompassing vulnerability and healthcare accessibility (Fauk et al. 2021). This study aims to explore the challenges faced by Muslim women living with HIV in Malaysia. Additionally, the objective of this study is to investigate the perceived social support for those living with HIV in order to improve their overall quality of life. Findings from the study highlight the significant difficulties faced by Muslim WLWHIV, including the complex task of managing children, dealing with familial stigma, and coping with a lack of support from professionals. It also shed light on the importance of actively seeking social support, engaging in self-care practises, and interacting with supportive peers as integral factors in improving the overall well-being of those affected by HIV.

Since the first discovery of HIV in Malaysia, the Ministry of Health (MOH)in Malaysia plays crucial role in providing support to WLHIV, regardless on their religion and race Over the last two decades, Malaysia successfully reduced new HIV cases from 6,978 in 2002 to 3,177 in 2022. In May 2023, the MOH granted RM5M grant to the Malaysian AIDS Foundation (MAF) to combat combating HIV, sexually transmitted infections (STIs), and hepatitis C in the country (Pillai 2023). MOH's main responsibility is to provide easily accessible and thorough healthcare services, including HIV screening and antiretroviral therapy (HAART). Since 1990s, MOH has been actively involved in implementing prevention and education initiatives, with a particular emphasis on raising awareness through campaigns, encouraging HIV testing, and addressing stigma. Despite progressive efforts to enhance the quality of life among WLWHIV across the world, WLWHIV are still encountering various

challenges as a result of the prevailing stigmatisation and discriminatory attitudes (Maurice et al. 2022; Ngoma et al. 2017).

According to Cotton et al. (2006), religious beliefs and practices will influence coping mechanisms, support networks, and views on health and illness. Furthermore, the psychological well-being of individuals can be significantly impacted by the attitudes and opinions conveyed by their relatives, members of their community, and healthcare providers. There have been documented instances wherein individuals living with HIV, specifically women, have encountered familial exclusion as a consequence of their HIV-positive status. Certain individuals within the familial unit may exhibit a tendency to disengage both physically and emotionally from the afflicted party, perceiving the condition as a deficiency in moral character rather than a manifestation of a medical nature (Khumaidi et al. 2021; Peasant et al. 2017). In contrast, the findings of this current study revealed that family members, including parents, sisters, and husbands, actively provided social support for WLWHIV by offering emotional understanding, practical assistance, and open communication channels, underscoring the pivotal role of familial relationships in enhancing the well-being of individuals living with HIV.

The intersectionality of gender, religious beliefs, and health status profoundly shapes the realities of women grappling with HIV. Societal norms, cultural pressures, and gender disparities can compound the difficulties they encounter (Hearld et al. 2021). In Malaysia, WLWHIV experience emotions of isolation and marginalisation within their social networks (Azreen Abdullah et al. 2019; Nor Asyikin Fadzil et al. 2016). The observed phenomenon can frequently be attributed to a dearth of knowledge pertaining to the transmission and management of HIV within these particular communities. The perpetuation of adverse stereotypes and misconceptions serves to exacerbate the marginalisation of the virus, leading to the exclusion of specific individuals from religious congregations and social gatherings (Lemin et al. 2022). The occurrence of societal rejection can give rise to significant emotional distress, thereby intensifying sentiments of isolation and detrimentally affecting their holistic psychological well-being.

As outlined by Ghaffar (2023), Islam underscores the significance of maintaining a positive outlook and expressing gratitude for the blessings bestowed by Allah, actions that foster resilience. Additionally, it advocates for taking concrete steps to confront obstacles and surmount adversity, prioritizing efforts to enhance one's circumstances while placing trust in Allah's guidance. In the context of Malaysia, WLWHIV encounters obstacles as a result of prevailing stigmatisation and discriminatory practises (Nor Asyikin Fadzil et al. 2016). The emotional well-being of individuals can be greatly impacted by the adverse attitudes and judgements they encounter from their family, community members, and healthcare providers. The findings of the research underscore the pivotal significance of engaging in social support as a strategy for managing stress. Disclosing one's HIV status to close family members helps alleviate the weight of concealment and cultivate an environment characterised by comprehension and empathy, similar to studies from Azreen Abdullah et al. (2019), (Nor Asyikin Fadzil et al. (2016), and Zainal-Abidin et al. (2022).

Muslims are advised to turn to Allah for guidance and exercise *sabr* (patience) to surmount life's trials (Ghaffar, 2023). In the context of Muslim women living with HIV, spiritual resilience has been noted to be of paramount importance (Arrey et al. 2016). Losing a partner or husband will affect the overall quality of life among women (Lyndon & Riyadh, 2020). Similarly, the findings of this study are unique due to the fact that Muslim WLWHIV reported receiving substantial support from their husbands and partners, irrespective of their partners' HIV status. This phenomenon shows a notable change in public attitudes and an increasing comprehension of HIV dynamics in intimate partnerships. The participants expressed that the acceptance and support of their partners posed a challenge to traditional societal norms and had a positive impact on their overall well-being. Moreover, the participants placed significant emphasis on the notion that this assistance exhibited a broader scope, extending beyond the realm of the individual and thereby yielding favourable consequences for familial dynamics. Similarly, a study by Meari et al. (2016) emphasised that spouses' engagement in conversations pertaining to their partner's health and overall well-being will result in enhanced familial unity and improved interpersonal communication.

Engaging in self-care practises and actively participating in supportive peer groups offer alternative pathways for emotional solace and individual empowerment (Abu Hassan Shaari et al. 2023; Warren-Jeanpiere et al. 2017). Rafique

et al. (2019) also shared that engaging in the practise of *Dhikr*, reinforces strength and resilience. Moreover, engaging in collective endeavours among individuals of the same age group fosters a feeling of inclusiveness and community, thereby mitigating the pervasive sensation of isolation commonly encountered by PLHIV (Grodensky et al. 2105). For example, those who choose to participate in a support group that is specifically tailored for WLWHIV are afforded the opportunity to establish connections with fellow members who possess a deep understanding and empathy towards the unique issues they face. The act of exchanging narratives, perspectives, and guidance within this secure environment can mitigate the psychological weight of seclusion and provide a forum for productive dialogues regarding the management of well-being, interpersonal connections, and social interpretations.

Additionally, engaging in communal activities with peers fosters a sense of community and inclusivity, which can counteract the prevalent feelings of isolation often experienced by individuals with this condition. This is parallel with studies from Bhatia et al. (2017) and Paudel et al. (2015) that highlight the significance of establishing and advocating for environments to facilitate persons' access to emotional assistance and resources for self-empowerment in order to tackle the diverse array of obstacles associated with HIV status.

The process of empowering these women necessitates the deconstruction of societal stigmatisation, the cultivation of comprehension among professionals providing support, and the establishment of an inclusive milieu that recognises their distinct challenges and capabilities. Equality, personal freedom, and self-determination are crucial to revealing the invisibility of women's voices, including WLWHIV. Thus, it is important not only to recognise the biological differences and characteristics of women and men but also to understand how social and gender roles interact in both the construction of identities and in the allocation of expectations and responsibilities for WLWHIV.

IMPLICATIONS AND RECOMMENDATION

Given all the potential challenges and stressful experiences that increase the vulnerability of WLWHIV, it is vital to examine the circumstances that contribute to building resilience in this population. For example, the implementation of tailored interventions that acknowledge the diverse roles of WLWHIV will equip them with the skills and resources they need to manage their obligations while placing their health as a top priority. At the same time, awareness initiatives aimed at countering misconceptions and prejudices and fostering empathy need to be implemented across communities (Abu Zahrin et al. 2022). Finally, the provision of psychosocial care specifically designed to address the emotional consequences of stigma has the potential to enhance the overall quality of life for women living with HIV.

For adherents of Islam, their faith transcends mere religious convictions; instead, it constitutes a holistic lifestyle that permeates every facet of daily life (Mabvurira 2016). Furthermore, given the context of Malaysia, culturally sensitive interventions that take into account the diverse religious and sociological practises prevalent among the populace. Engaging in partnerships with religious institutions can contribute to the elimination of social stigma and the promotion of a conducive and affirming atmosphere, as described by Zainal-Abidin et al. (2022). These collaborative alliances have the potential to foster empathy and understanding among their members, establishing a solid foundation for communal backing. In addition, the provision of tailored psychosocial counselling services to those living with HIV, including WLWHIV, can support them in overcoming specific challenges they face, including addressing instances of discrimination, navigating their social roles, and enhancing their overall well-being.

Collaborative efforts between healthcare professionals, religious organisations, and powerful local personalities will cultivate an environment that promotes the empowerment and support of WLWHIV as they navigate the many intersections of their various roles and identities (Cuca et al. 2016). Together, advocacy can be used to integrate awareness with choice and participation for WLWHIV and their family members in creating positive change.

Faith-based interventions have demonstrated effectiveness in supporting Muslim women living with HIV in managing the psychological stress associated with their diagnosis (Ismail et al. 2022). These interventions connect women to their religious beliefs or spirituality through practices such as prayer or religious gatherings. This connection allows them to find solace, seek

hope amid life challenges, and reaffirm their faith in God's compassion. Faith-based approaches emerge as a promising strategy tailored to the needs of Muslim women contending with HIV, integrating Islamic doctrines and customs to enhance resilience (Adawiyah Ismail 2019; Zakaria & 2017). Utilizing the spiritual aspects of Islam, these interventions aim to provide direction, strength, and significance to the lives of Muslim women facing HIV, encompassing activities like prayer sessions, meditation, Quranic recitations relevant to illness, and participation in faith-based community events. Such interventions offer a means for Muslim women living with HIV to strengthen their connection with their religion while finding comfort amidst the challenges posed by their medical condition.

CONCLUSION

Upholding Islamic principles, combating prejudices against those with HIV, and offering culturally and religiously informed support are essential for fostering a supportive environment (Himelhoch & Njie-Carr 2016). In additon, gaining a better understanding of perceived challenges and social support among Muslim WLWHIV in Malaysia will set the stage for the development of effective psychosocial interventions and social policies for this marginalised population. Psychosocial interventions such as support groups, individual or group counseling services, and educational workshops on HIV/AIDS awareness and coping mechanisms can provide vital platforms for WLWHIV to share experiences, acquire coping skills, and enhance their mental well-being. Additionally, empowerment programs, peer mentoring and community outreach efforts can contribute to building resilience and reducing societal stigma towards WLWHIV. In addition, legal support services, family counseling, and health navigation programs further address specific challenges WLWHIV may face. Leveraging online support platforms for virtual connections and information-sharing adds an additional dimension to these interventions, ensuring accessibility and flexibility. The success of these programs hinges on cultural sensitivity, community collaboration, and an overarching commitment to fostering a supportive environment for WLWHIV in Malaysia. Focusing on the life experiences of WLWHIV provides an opportunity to examine the women's personal experiences and their connection with the institutions that confer power, privilege, and resources.

This research reveals the complex experiences of Muslim WLWHIV in Malaysia as they navigate the challenges of parenting, societal discrimination, and insufficient assistance. In the face of intersecting and compounding obstacles, the efficacy of seeking social support, prioritising self-care, and engaging in supportive networks becomes evident as prominent sources of resilience. The aforementioned results emphasise the critical need for comprehensive therapies that encompass not just the biomedical elements of HIV but also its significant psychosocial components. Through the promotion of comprehension, empowerment, and a feeling of inclusion, these approaches present a promising prospect for the development of a more empathetic and all-encompassing community for individuals grappling with the complexities associated with HIV.

AUTHOR'S CONTRIBUTIONS

Conceptualization, methodology, data analysis, writin original draft and preparation: Azahah Abu Hassan Shaari; resources, review and editing: Ibrahim A Alghamdi. All authors have read and agreed to the Published version of the manuscript.

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