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# Tough Decisions Faced by People Living With HIV: A Literature Review of Psychosocial Problems

*Paulina Bravo[1,2], Adrian Edwards[1], Stephen Rollnick[1] and Glyn Elwyn[1]*

*[1]Department of Primary Care and Public Health, School of Medicine, Cardiff University, Wales, UK; [2]Department of Woman's Health, School of Nursing, Pontificia Universidad Católica de Chile, Santiago, Chile*

## Abstract

***People living with HIV have faced a new situation since the arrival of the antiretroviral treatments. HIV has become a long-term condition, which not only affects physical health, but also causes psychological and social problems because of stigma and discrimination. These challenges present many decisions and dilemmas for people living with HIV, which involve complex emotional and psychological issues. The aim of this study was to examine the psychosocial decision needs of people living with HIV. To undertake the literature review, a search strategy was designed. Sources included databases (Web of Science, Scopus, ProQuest, and PubMed) as well as electronic journals (AIDS and Behavior, AIDS Care, and Social Science and Medicine). The following search terms were used: (HIV) AND (decision making; OR decision need; OR decision) AND (psychosocial; OR psychological; OR social). All languages were included, using articles from 1990 to 2009. The search was conducted from September 2008 to November 2009, and identified 123 articles. After analysis, 46 articles were included for detailed assessment. The results show that people living with HIV face three key decisions: (i) whether or not to disclose their diagnosis to others; (ii) decisions about adherence to treatments; and (iii) decisions about sexual activity and desires about parenthood. Problems associated with these decisions often result in isolation and mental illness such as depression and anxiety, lack of access to social support, and refusal to seek treatment. Despite the importance of HIV and its public health impact, few studies have considered the psychosocial needs of people living with HIV, but the results demonstrated the burden as a consequence of those needs and that greater support would be of benefit to face them in an effective way. Therefore, the results of this review highlight the requirement to develop interventions to support the psychosocial needs of people living with HIV, to accurately reflect the views and needs of the target users.*** **(AIDS Rev. 2010;12:76-88)**

*Corresponding author: Paulina Bravo, bravop@cardiff.ac.uk*

## Key words

***People living with HIV. Decision needs. Psychosocial. Disclosure process. Adherence. Sexual behavior.***

**Correspondence to:**
Paulina Bravo
Department of Primary Care & Public Health
School of Medicine, Cardiff University
Neuadd Meironnydd Heath Park
Cardiff CF14 4YS, Wales, UK
E-mail: bravop@cardiff.ac.uk

## Introduction

Infection with HIV is an important global public health challenge. In the 1980s, infection with HIV was equated with impending death as people developed acquired immunodeficiency syndrome (AIDS). However, the introduction of antiretroviral therapy (ART) in the 1990s transformed the outlook for people diagnosed as HIV-positive. These people now face the prospect of living with a chronic disease and having to reframe their lives and relationships. Being HIV-positive became less of a threat and the term "people living with HIV" (PLHIV) came into common use, to reflect the long-standing and less-risky nature of the problem. Yet, despite the improvement in medical treatment and the adoption of preventive strategies, the spread of HIV continues. It is estimated that approximately 6,000 people become infected with HIV every day at a global level[1].

People living with HIV therefore face long-term challenges to their psychological well-being, challenges that are principally associated with stigma and discrimination[2]. O'Connell, et al.[3] reported that the quality of life of PLHIV is affected negatively because the impact of having the infection extends beyond the physical realm to affect psycho-social-spiritual wellbeing. The challenges PLHIV face are diverse and complex, yet it seems the extent of the psychosocial problems faced by PLHIV have not been rigorously reviewed or described.

Healthcare delivery models are moving away from paternalistic attitudes. They are increasingly based on patient involvement and self-care, where shared decision making ensures that patient preferences are considered[4]. Given that shared decision making rests on making sure that the patient has adequate and accurate information, decision support interventions (also known as decision aids)[5] have been developed. These are being used in an increasing number of healthcare settings to help patients face difficult, preference-sensitive decisions, providing information about the options and possibilities related with the risks and benefits of each alternative[6].

However, whilst there has been increased interest by healthcare professionals in involving patients in care across a range of clinical domains, we found that very little research to date has focused on PLHIV, and we could not readily find work that had fully considered or identified their needs in terms of making decisions about a range of issues[7]. The aim of this study was to determine whether or not PLHIV have decision support needs, and if they do, to describe these needs in more detail in order to consider to what extent they could be met by the development of new services or interventions.

## Methods

### *Search strategy*

A search strategy was designed to identify publications which described the psychosocial decision needs of PLHIV. The research was conducted from September 2008 to November 2009. Studies that focused purely on the views of healthcare professionals who provide care for PLHIV were not considered. We devised a search strategy which included electronic searches of the following sources: Web of Science, Scopus, ProQuest, and PubMed. We also specifically searched the following journals (AIDS and Behavior, AIDS Care, and Social Science and Medicine). The following terms were used: (HIV) AND (decision making; OR decision need; OR decision) AND (psychosocial; OR psychological; OR social). All languages were included, using articles from 1990 to 2009.

### *Inclusion/exclusion criteria*

Articles were included if they described psychosocial needs or concerns of PLHIV. All types of research methods were considered eligible. The titles available were first assessed for relevance; in a second step, article abstracts were scrutinized to assess suitability for inclusion, according to the objective of this review. Literature review articles were excluded, but their references were assessed.

### *Data extraction*

Included articles were studied for relevance and content. Data were extracted under the following headings: research identification (authors, year of publication, country of study sample, and study population) and research methods. The principal findings of each study were summarized for future analysis and synthesis.

### *Data analysis*

The data for analysis and synthesis were the study methods, findings, and conclusions. Following a thematic analysis method, Paulina Bravo and Glyn Elwyn analyzed these data to identify consistent codes across the studies. Most salient codes, explanations, and the relationships between them were identified for the authors and clustered into themes. This thematic analysis was used as the basis for a model describing the psychosocial needs of PLHIV.

## Results

A total of 3,127 citations were retrieved, and after scanning the titles, 3,004 were removed. The remaining 123 abstracts were read for detailed assessment; 69 full articles were retrieved and subjected to detailed assessment, and 23 of these 69 were removed because of their methodology (non primary studies) or lack of relevance. Finally, 46 articles were subjected to full data extraction and thematic analysis. Figure 1 is a flow chart of included and excluded articles. The earliest included article was published in 1998, and the most recent articles were published in 2009. Twenty-one studies used qualitative methods, the same number used quantitative methods, and four used both approaches; detailed descriptions are given in table 1. Of the studies, 26 had mixed gender samples; there were 16 women-only studies and four studies only included men in the sample.

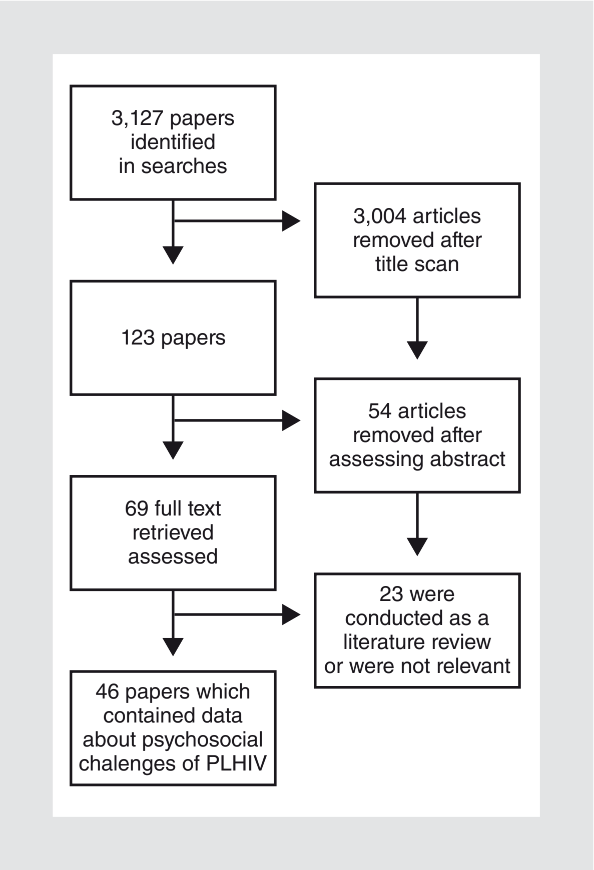

**Figure 1.** *Results of literature search. PLHIV: People living with HIV.*

After thematic analysis, the three most salient psychosocial themes regarding decision making dilemmas were identified in the included studies. These were (i) whether or not to disclose the HIV-positive diagnosis to others, (ii) whether to adhere to ART, based on feelings of physical well-being or denial of the disease, and (iii) decisions about sexual activity in terms of safer sex and desires about parenthood.

### *Fear of disclosure*

Disclosure of the diagnosis, that is of being HIV-positive, is undoubtedly one of the largest challenges facing PLHIV. It was described as a clear decisional conflict in 50% of the articles analyzed. According to Thomas, et al.[8], more than 85% of the sample of Indian women and men living with HIV who participated were concerned about disclosing their illness status. Pierret[9] noted how PLHIV try to control the disclosure process by making judgments about who to tell, and when and how to do so, and that these are difficult decisions, but critical to their being able to adjust to their new roles and lead normal lives. This control also helps them to protect themselves and their families from discrimination, and their HIV status seems to be an important “secret”[10].

After a positive HIV diagnosis, many people experience psychological pain and are at risk of committing suicide. Zhou[10], who studied 21 PLHIV in China, reported that this is because people feel unable to face the distress of social judgment by others. Symbayi, et al.[11] reported that 40% of the study of 1,063 PLHIV in South Africa had experienced discrimination, and one in five had lost a job or a place to stay after disclosing their HIV status. For example, a study of 203 PLHIV living in southern India reported that 97% of women and 96% of men felt stigmatized by their HIV status and, as a result, had a low quality of life[8]. A number of included studies confirmed that stigmatization leads to isolation, especially for those unable to access social or peer support[2,10-18]. In addition, Mak, et al.[2] reported that PLHIV develop a sense of stigmatization if they internalize these feelings and beliefs, a situation that can affect their mental health and social relationships. Simbayi, et al.[11] studied 1,063 South African PLHIV and reported that at least 30% of the participants in their research felt “guilty, dirty, and ashamed”.

Zhou[10] described that PLHIV become very cautious in their interpersonal and wider social relations, often withdrawing from their family and social networks. Thi, et al.[18],

**Table 1. Descriptions of the studies which identified psychosocial problems in people living with HIV**

| First author Year | Study population | Country | Method | Principal findings |
|---|---|---|---|---|
| Barnes 2009 | 80 women living with HIV | USA | Qualitative, in-depth interviews, grounded theory analysis | Women have to face a negative and hostile environment of pressures and public opinion. Motherhood as a reason to look to the future. |
| Bedimo 1998 | 403 women living with HIV | USA | Quantitative, records analysis, multivariate | Reproductive activity decision-making is a highly complex issue; some related factors are culture, economic situation, and social influence. Rate of pregnancy is less in PLHIV and rate of abortions is higher, compared with non HIV population. |
| Beusterien 2008 | 35 PLHIV | USA | Qualitative, focus groups, content analysis | Themes that influenced adherence to the medication(s): regimen complexity, lifestyle fit, emotional impact, side effects, medication effectiveness, and communication. |
| Bungener 2000 | 32 African and 68 European women living with HIV | France | Quantitative, questionnaires, descriptive analysis | Disclosure of HIV status is significantly higher in European women. Desire to have a child greater in African women than in Europeans. |
| Chen 2001 | 1,421 PLHIV | USA | Quantitative, survey, multivariate | 28% of HIV-positive men and 29% of HIV-positive women desire to have children in the future. |
| Cooper 2007 | 61 PLHIV | South Africa | Qualitative, in-depth interviews, grounded theory analysis | Reproductive intentions of PLHIV and concerns for vertical transmission. Necessity of counseling in reproductive desires is described. |
| Craft 2007 | 74 women living with HIV | USA | Quantitative, questionnaires, descriptive analysis | Majority of women chose not to become pregnant after diagnosis. Younger women more likely to choose pregnancy ($p < 0.01$). The most influential factors on pregnancy decisions: personal health concerns and fear of vertical transmission. |
| DeMatteo 2002 | 91 families living with HIV | Canada | Mixed method, interviews and questionnaires, thematic and descriptive analysis | Relationships in the family and HIV consequences. Parents evaluated both risks and benefits of disclosing the disease. |
| DiIorio 2009 | 236 PLHIV | USA | Quantitative, questionnaire, modeling | There is a direct relationship between self-efficacy and depression and level of adherence. Participants with a high level of social support showed less depression and therefore a higher adherence. |
| Doyal 2005 | 62 African women living with HIV | UK | Qualitative, interviews, content analysis | Nondisclosure can mean social and physical isolation. Peer support is established as a strategy to address the disclosure process. |
| Flowers 2006 | 30 Black Africans living with HIV | UK | Qualitative, in-depth semi-structured interviews, phenomenological analysis | Isolation as a consequence of nondisclosure. Stigma and spoiled identity as a result of HIV status. |
| Gray 2006 | 11 PLHIV | USA | Qualitative, in-depth interviews, grounded theory | Themes related to adherence are “choosing life”, making choices about what is important in life and “realizing the benefits”, understanding the efficacy of the treatment. |
| Harzke 2004 | 137 African American drug users living with HIV | USA | Quantitative, questionnaire, correlation analysis | Association between social support and rates of adherence is positive. On the other hand, social isolation and adherence have a negative association. |
| Hebling 2007 | 12 women living with HIV | Brazil | Qualitative, semi-structured interviews, thematic analysis | Motherhood as reason to live and self-care. Motherhood defined as a woman’s right, but they are afraid of the vertical transmission of HIV. |

*(Continue)*

**Table 1. Descriptions of the studies which identified psychosocial problems in people living with HIV *(continued)***

| First author Year | Study population | Country | Method | Principal findings |
|---|---|---|---|---|
| Hopkins<br>2005 | 402 women living with HIV | Brazil | Mixed methods, clinical records, in-depth interviews and prospective survey, correlation and multivariate analysis, content analysis | Difference in sterilization between women living with HIV and HIV-negative women: women with HIV with higher rates. |
| Kanniappan<br>2008 | 43 women living with HIV | India | Qualitative, in-depth interviews, content analysis | Complex nature of decision making related to motherhood: concerns about death and desires to have a child as a reason to live. |
| Kerrigan<br>2006 | 23 PLHIV | Brazil | Qualitative, semi-structured interviews, content analysis | Sexual activity can be explained by desires for social validation and denial of the illness. |
| King<br>2008 | 1,092 PLHIV | Uganda | Mixed method, in-depth interviews and questionnaires, thematic coding and multivariate analysis | Reasons to disclose include reduce the risk of transmission in sexual relationships and improved social support. |
| Kirshenbaum<br>2004 | 56 women living with HIV | USA | Qualitative, in-depth interviews, grounded theory | The impact of the decision on the new child (growing without a mother if they die; risk of vertical transmission). Experience of pressure from their partners for having a baby. Negative attitude from health care workers and society. But having a baby gives a strong motivation to keep living. |
| Ko<br>2005 | 105 men living with HIV | Taiwan | Quantitative, in-depth interviews and chart reviews, descriptive analysis | Difference in disclosure process depending on the modes of HIV transmission. Men who have sex with men do not disclose for fear of discrimination. |
| Kremer<br>2006 | 79 PLHIV | USA | Qualitative, interviews, content analysis | People who decided to adhere to the treatment discuss it with their physician. However those who decided not to adhere to the treatment will not discuss this decision with health professional based on a lack of confidence. |
| Laher<br>2009 | 42 women living with HIV | South Africa | Qualitative, focus group and in-depth interviews, grounded theory | Fears about a new pregnancy include the risk of vertical transmission and consequences for their own health. Condoms are preferred to avoid pregnancy and other STDs, but it needs negotiation with the partner. |
| Lovejoy<br>2008 | 290 PLHIV | USA | Quantitative, surveys, correlation analysis | Factors associated with unprotected sex included non-stable relationships and loneliness. |
| Mak<br>2007 | 119 PLHIV | China | Quantitative, surveys, multiple regression | Self-stigma as a psychosocial need. Negative effects of self-stigma in mental health. |
| Menon<br>2007 | 127 adolescents living with HIV | Zambia | Quantitative, structured and semi-structured interviews, correlation analysis | Peer support intervention could promote disclosure by providing access to psychological support. |
| Moore<br>2007 | 151 PLHIV | Togo | Qualitative, interviews, content analysis | Sexual behavior concerns include risk of transmission to the partner. Unprotected sex could be explained by desires for parenthood. |
| Morrow<br>2001 | 29 women living with HIV | USA | Qualitative, focus group and interviews, code themes analysis | Women with HIV need psychosocial support to address their problems effectively. |

*(Continue)*

**Table 1. Descriptions of the studies which identified psychosocial problems in people living with HIV *(continued)***

| First author Year | Study population | Country | Method | Principal findings |
|---|---|---|---|---|
| Nam<br>2008 | 32 PLHIV | Botswana | Qualitative, in-depth interviews, grounded theory | Good adherence is association with illness acceptance, the ability to avoid internalized stigma, and identification of a confidante. |
| Nelms<br>2008 | 8 women living with HIV<br>6 HIV healthcare workers | USA | Qualitative, in-depth interviews, phenomenological analysis | Needs of HIV-positive women in the disclosure process to children included that they are unsure how to go about the process and fear their children's reactions. |
| Nóbrega<br>2007 | 229 women living with HIV | Brazil | Quantitative, questionnaire, cross sectional | 39.9% desire children; women who desire to have a new child are more likely to be in a stable relationship ($p = 0.04$) and their partners know about their status ($p = 0.03$). 88% think their doctor would react against the decision. |
| Nöstlinger<br>2004 | 628 parents or caregivers living with HIV | Netherlands | Mix approach, structured survey, descriptive analysis | Obstacles when disclosing to children about their parents or caregiver's HIV status. 10% have disclosed. Obstacles that may affect disclosure: (i) emotionally too disturbing for the child and (ii) anticipated negative consequences related to stigma. |
| Ostrom-Delaney<br>2008 | 66 women living with HIV | USA | Quantitative, structured interviews, descriptive analysis | Decide to disclose parent's HIV status to children; decision based on the children's ability to handle the information. Reasons for not disclosing include concern for the child's wellbeing. |
| Paiva<br>2003 | 250 men living with HIV | Brazil | Quantitative, structured interviews, descriptive analysis | 43% of participants want to have children in the future, 52% answered no and 5% did not know. Men without children and single people want significantly more to have children ($p < 0.05$). |
| Paterson<br>2000 | 81 PLHIV | USA | Quantitative, questionnaire, clinical assessment, prospective | 22% of participants adhere ≥ 95% to the treatment. |
| Peretti-Watel<br>2006 | 2,932 PLHIV | France | Quantitative, survey, correlation analysis | Factors associated with nonadherence included socio-economical indicators, age and drug use. |
| Pierret<br>2007 | 118 PLHIV | France | Qualitative, in-depth interviews, content analysis | A normal life for PLHIV is experienced when they can have control over the disclosure process and can maintain a normal sexual life. |
| Relf<br>2009 | 18 men living with HIV | USA | Qualitative, in-depth interviews, grounded theory | Avoiding sexual intimacy avoids need for disclosure. Decision could cause sexual isolation. Traumatic experience of disclosure affects future disclosure decision. Casual sex seems to be a way to have sex avoiding disclosure. Stable relationship motivates disclosure. |
| Sherr<br>2008 | 502 PLHIV | UK | Quantitative, questionnaire, multivariate analysis | Adherence rates and factors associated (social isolation, economical problems). Stable relationships can support adherence |
| Simbayi<br>2007 | 420 men living with HIV<br>643 women living with HIV | South Africa | Quantitative, survey, regression analysis | Discrimination experience: more than 25% have lost their job after disclosure. Internalized stigma is a common experience for PLHIV. |
| Simoni<br>2000 | 373 indigent African-American and Latina women living with HIV/AIDS | USA | Quantitative, face-to-face questionnaire, multivariate analysis | Associations between social support and psychological and physical adaptation suggested the necessity to invest in interventions in order to foster it. |

*(Continue)*

**Table 1. Descriptions of the studies which identified psychosocial problems in people living with HIV *(continued)***

| First author Year | Study population | Country | Method | Principal findings |
|---|---|---|---|---|
| Stirrat<br>2006 | 215 PLHIV | USA | Quantitative, self-administered survey, correlation analysis | Positive association between social and treatment adherence. |
| Thi<br>2008 | 53 PLHIV | Vietnam | Qualitative, focus groups, content analysis | Avoid social contact as a consequence of stigma and discrimination. |
| Thomas<br>2005 | 203 PLHIV | South India | Quantitative, survey, multivariate analysis | Perceived stigma rates (97% women, 96% men). Negative relation between internal stigma and quality of life. Disclosure as an important concern. |
| van Kesteren<br>2007 | 296 men living with HIV who have sex with men | Netherlands | Quantitative, self-administered questionnaires, correlation analysis | Sexual behavior for men living with HIV. Men who have sex with men reported an inconsistent use of condoms in casual relationships. |
| Wood<br>2004 | 36 women living with HIV caring for children < 18 years | USA | Qualitative, focus group and in-depth intervie ws, thematic analysis | Role of interpersonal relationships in adherence (positive relationships stimulate treatment, negative relationship with opposite effect). Children as facilitator in adherence. |
| Zhou<br>2007 | 21 PLHIV | China | Qualitative, interviews, phenomenological analysis | Effects of social construct (stigma and discrimination) of HIV and status disclosure of PLHIV. |

PLHIV: people living with HIV.

in a study of 53 Vietnamese PLHIV, confirmed that they avoid social contact with family, friends, the healthcare system, and public services for fear of stigmatization and discrimination and this leads directly to low self-esteem and self-isolation.

Mayers, et al.[19] emphasized that isolation and subsequent loneliness is one of the most salient and difficult emotional problems associated with being HIV-positive. Flowers, et al.[13] explained that many PLHIV cannot access community and social support unless they disclose their status. Moreover, the research conducted for Relf, et al.[20] with 18 HIV-positive men showed that some of the participants have chosen to avoid sexual intimacy in order to avoid the need for disclosure, a situation that can cause frustration and sexual isolation. Only one study out of 36 reported a different view where nearly 90% of the 1,092 Ugandan participants, who were clients of a PLHIV support organization, said it was not difficult for them to disclose their disease. This may be explained partly because participants have gained access to medical or home care more easily and obtain social support by declaring their HIV status[14].

It is clear from the included studies that the decision to disclose the HIV status is not a simple phenomenon and PLHIV agonize about who to tell, and how and when to do so. Individuals might first disclose their HIV status to their sexual partners if they are in a stable relationship[15-20]. Ko, et al.[15] reported that PLHIV also tend to inform family members, but that there is disparity in whether they inform siblings or parents first. It seems that cultural issues influence this pattern of disclosure. A study of a 100 women living with HIV in France noted that European women disclosed their HIV status more readily than African women, and that European women inform their siblings before their parents[21].

The situation has special issues when PLHIV have children. Ostrom-Delaney, et al.[17] reported that 66 affected women in the USA wanted their children to first hear about the problem from themselves, declaring that it is a child's right to know and that they want to reassure the child. The authors also reported that 90% in their study of women living with HIV did not regret disclosure of their disease to their children. However, Nöstlinger, et al.[16] reported that in their study of 628 PLHIV in the Netherlands, only 10% had disclosed their HIV status to their children. They found that PLHIV believe that their children deserved a carefree childhood and that this information could emotionally disturb them. This statement is supported by Nelms, et al.[22].

**Table 2. Disclosing HIV-positive status: the factors that are considered in the process**

| To whom | Advantages of disclosure | Disadvantages of disclosure |
|---|---|---|
| Partner | Possible support from partner | Possible loss of the relationship |
| Siblings | Potential support of brothers and sisters | Judgment and exclusion from social contact and support |
| Parents | Support of family members | Discrimination, rejection by family and isolation |
| Children | Children's right to know<br>Better to find out from their parents | Disrupted relationship with children<br>Rejection by children<br>Disturbance of the child's emotional and social wellbeing |
| Friends | Support | Judgment and exclusion from social contact and support |
| Healthcare providers | Access to healthcare | Stigma and discrimination |

In addition Ostrom-Delaney, et al.[17] and Nöstlinger, et al.[16] reported that PLHIV do not want to worry or scare their children and want to avoid the negative consequences related to stigma. Nevertheless, PLHIV are often not convinced that they have taken the right decision in the disclosure process to their children, expressing their need for professional support and to be better prepared for this process[16]. Those articles exemplified how the disclosure process involving children can be difficult and how more support and guidance might be helpful.

The consequences of the disclosure process are very significant, with possible loss of a personal partner, reputation, and occupation[13,16]. Simbayi, et al.[11] described that 60% of 1,063 PLHIV in South Africa had not told others about their status because of fear of their reactions. This nondisclosure leads to a poor mobilization of their social support[23] and may result in physical and emotional isolation[12]. Moreover, PLHIV who disclosed their status to someone who they did not regard as a confidante reported they were not able to access emotional support, showing symptoms of depression[24]. Advantages and disadvantages identified for PLHIV during the disclosure process to different parties are summarized in table 2.

People living with HIV identified participation in peer groups as positive in terms of the disclosure process and access to psychological support. Morrow, et al.[25] studied 29 American women living with HIV and found that they required psychosocial support in order to effectively address their problems and disclose their diagnosis. This finding is supported by Doyal, et al.[12] who studied 62 African women with HIV living in the UK. The participants highlighted the positive influence of peer support on their decision to disclose. A study conducted in Zambia with 127 adolescents living with HIV showed that peer support interventions could promote a disclosure process because the participants felt they were supported by people who had lived through the same experience[26].

In summary, the research shows that disclosure is a difficult step to take, but it is a fundamental and necessary process in terms of accepting the illness and gaining access to services and support.

## *Initiation and adherence to treatment*

Ten of 46 included articles reported dilemmas around the initiation of and adherence to antiretroviral treatment (ART). Kremer, et al.[27] conducted semi-structured interviews in 79 PLHIV, and described 10 criteria that seem to predict adherence. These criteria include side effects, beliefs about resistance, experience of HIV-related symptoms, quality of life, ease of regimen, spirituality, body-mind beliefs, and preference for, or use of, complementary medicine. Furthermore, the participants who decided not take the treatment anticipated that their physician would not agree with such a decision, based on lack of trust in the health professional support and opinion[27].

Sherr, et al.[28], in a UK-based study of 502 PLHIV, showed that 43% had not taken their ART according to the timing indications and nearly 30% had not followed the instructions about the relationship to meals requirements for the treatment. Similar findings were reported by Paterson, et al.[29] in which only 22% of the 81 participants had adhered to 95% or more of the treatment. Peretti-Watel, et al.[30] reported that nonadherence was more common in younger PLHIV who had higher levels of alcohol abuse and poor living conditions. In addition, Wood, et al.[31] reported that some of the 36 American women living with HIV participants of their study denied their illness, and that this led to nonadherence because taking the medication reminded them of their HIV status. In addition, some women reported that they only took the ART when they felt ill, revealing that they misunderstood the rationale of the therapy.

People adhering to treatment argue that the physical benefits associated with ART provide a good motivation to adhere to the therapy[32,33]. According to Nam, et al.[24], the key predictor of high adherence is a general acceptance of the HIV status and a belief that the treatment is beneficial. Furthermore, Gray[33] stated that PLHIV in the USA who decide to adhere to treatment have done so because they have made a positive decision "for life" rather than to not take the medication, which would "cause death". In addition, people adhering stated that they felt they were involved in the decision making process about the treatment when their wishes were considered and they agreed with their physician[28].

Interpersonal relationships may also play an important role in adhering to treatment. A psychosocial model for adherence, tested in 236 American PLHIV by DiIorio, et al.[34], suggests that social support is directly related with a higher level of adherence. For example, feelings of support from family and partners or women with children may motivate individuals to take medication. Similarly, interpersonal conflicts or the disruption of a relationship is more likely to lead to nonadherence[31]. Harzke, et al.[35], who surveyed 137 African PLHIV in the USA, reported that social support is associated with good adherence, and that social isolation has the opposite effect. Simoni, et al.[36] also reported that social support is correlated with better psychosocial and physical adaptation. It is interesting that Stirrat, et al.[37] found that adherence is also associated with disclosure, i.e. good adherence is associated with higher levels of disclosure to family members and personal contacts.

In summary, the research shows that adherence to treatment is contingent on a good understanding of the illness and its consequences, on developing productive relationships with clinical and other services, and being able to secure and maintain a network of social support and effective relationships.

## Decisions about sexual behavior

Nineteen of the 46 included studies described sexuality as a difficult area for PLHIV. According to Bungener, et al.[21], PLHIV reported two important issues. Firstly, decisions about sexual relationships with others, and secondly, decisions about parenthood. Pierret[9] stated that attempting to continue a normal sexual life is the most difficult challenge for PLHIV and that the risk of spreading the virus dominates their emotional life. The immediate period following diagnosis of HIV status is reported to be the time of greatest personal confusion, involving distress, suicidal ideation, personal loss, and disruption, particularly of their sexual life. Men report a loss of confidence, and women report feeing dirty and undesirable[38].

The PLHIV who remain in heterosexual relationships report many conflicts. Knowing that one person has HIV introduces the need for constant protection for the other partner. According to Laher, et al.[39], for some of the 42 African women participants, condoms are preferred as a contraceptive method, considering the lack of side effects and the protection against sexually transmitted infections. However, women often report having to negotiate with their partners to use condoms, which is difficult[38-39]. Moore, et al.[40] reported that HIV-positive men did not see the necessity of using condoms when having sex with their wives, indicating a total lack of understanding of the risk of spread. This type of behavior could be a result of denial, anger, or a lack of concern for others[41].

Sexual practice among HIV-positive men engaging in sex with other men is inconsistent and related to context. In a study conducted in the Netherlands of 296 HIV-positive men who have sex with men, about 50% reported using condoms when having anal sex, while 30% reported consistent use during oral sex[42]. In addition to this, heterosexual HIV-positive men are more likely to have unsafe sexual relationships when they are lonely and lack social support[43].

Decisions about parenthood are another difficult area for PLHIV. Chen, et al.[44] studied a representative population of men and women living with HIV in the USA. They showed that almost 30% of the participants desired children in the future. According to the Centers for Disease Control and Prevention (2001), most women living with HIV are between 13 and 44 years old, i.e. at their reproductive age[45]. A study conducted by Nóbrega, et al.[46] with 229 Brazilian HIV-positive women found that almost 40% of them would like to have another child. In the case of 74 American HIV-positive women, 26% chose to become pregnant, a decision that is more likely to happen in younger women ($p < 0.05$)[46,47], in stable relationships ($p = 0.04$), and in those who have disclosed their status to their partners ($p = 0.03$)[46].

Men's views were studied by Paiva, et al.[48], who found that 52% of the participant Brazilian men living with HIV (n = 250) do not want to have children, principally because of their own status and for fear of stigma and discrimination for the child. On the other hand, 43% of the respondents would like to have a child in the future, especially when they have no previous parenthood experience or if they are single ($p < 0.05$)[48].

In addition, advances in ART have made it possible for couples where only one partner has HIV (serodiscordant couples) to become parents. The Swiss National AIDS Commission[49] has stated that HIV-positive people are sexually noninfectious when they are completely adherent to treatment, have an undetectable viral load, and have no associated sexual transmitted disease. This statement could have implications in the reproductive desires of serodiscordant couples who might decide to conceive in a natural way, acknowledging the low risk of transmission for the HIV-negative partner and the newborn[50,51]. On the other hand, assisted reproductive techniques are available for serodiscordant couples, ensuring protection for the HIV-negative partner. However, there is still a risk for the child who can be infected during birth[52]. The debate about which reproductive method – natural or assisted – should be followed still continues and researchers have focused their interest in providing effective counseling to couples when they are facing this decision[53,54].

People living with HIV argue that couples should be supported to have at least one biological child, as it can bring hope and happiness to their lives. Hebling, et al.[55] noted that HIV-positive women in Brazil say that taking care of their own child is their main reason for living. This statement is shared by some of the American women who say that a new child gives a strong motivation to keep living[45,56]. Nevertheless, reasons that may inhibit the decision to have children are (i) the likelihood of vertical transmission of HIV[39,45,47,55]; (ii) fears that pregnancy may damage women's health[47,55]; (iii) the impossibility of breastfeeding their own child; and (iv) thoughts about their own death[45,55]. All these reasons can cause feelings of incompetence as mothers[55].

Several authors report that women often feel criticized by health professionals when they state their intention to become pregnant[45,46,57]; this criticism is experienced by almost 90% of women living with HIV[46]. Paiva, et al.[48] reported that 50% of the male participants believe health professionals would react negatively to their desire for children. There is evidence that women with HIV are put under pressure to be sterilized; Hopkins, et al.[58], in a study of 402 HIV-positive women in Brazil, found a higher rate of sterilization in HIV-infected women. Cooper, et al.[57] interviewed 61 HIV-positive women and found similar results, and noted that women are encouraged not to have children. Bedimo, et al.[59], by doing a record analysis, found that HIV-positive women had lower rates of pregnancy and higher rates of sterilization and abortion.

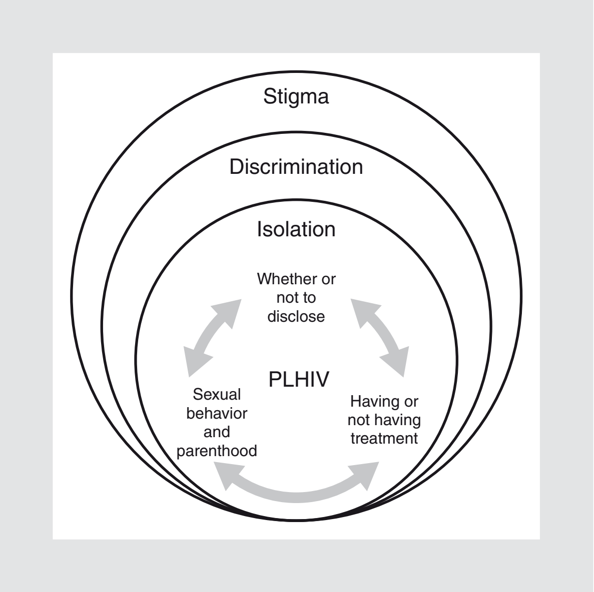

**Figure 2.** *Psychosocial decision needs for people living with HIV: a proposed model. PLHIV: people living with HIV.*

In summary, the research reports that sexual behavior is an important concern for PLHIV. High-risk behavior and spread of HIV are the main concerns related to safe sexual practice. In addition, parenthood seems to be a difficult decision to make, where conflicts between the desires of PLHIV and social judgment play an important role.

## *Psychosocial decision needs of people living with HIV: a proposed model*

Based on the results and the thematic analysis of the included studies, a model was generated (Fig. 2), which describes the psychosocial decision and support needs for PLHIV. Psychosocial decision needs of PLHIV are shown as a vicious circle; the stigma attached to HIV appears as one of the key factors surrounding the lives of PLHIV and their decision making challenges. The Joint United Nations Programme on HIV/AIDS (UNAIDS)[60] has defined HIV-related stigma as a process of devaluation of people who live with HIV or others who are associated with it. As a result, PLHIV may receive unjust treatment and be discriminated against by others. Discrimination related to HIV has been identified as one of the most important problems surrounding the spread of the virus; it has been identified as a critical barrier, complicating the diagnostic process and prevention initiatives[16]. The consequences of discrimination and judgment that PLHIV face leave them in lonely and isolated situations, and social support and networks – important resources when facing dilemmas in any kind of decision – are usually absent. In some cases, PLHIV have "self excluded" themselves in order to cope with HIV in a silent and anonymous way.

One of the first decisions that PLHIV must make is whether or not to disclose, and if so, to whom, when, why, and how. How others handle this is also important. It is unknown how many PLHIV do not disclose and therefore how many may not receive the required support. Secondly, adherence to treatment can be a key to maintaining HIV status under control, but only by high adherence to ART and good monitoring. The studies reveal generic issues of adherence difficulties with taking medication, but the issue of accepting the value of treatment – i.e. long-term prevention of fully developed AIDS – is critical. Therefore, being able to disclose, to feel supported not stigmatized, and to find supportive contexts for helping adherence seem even more critical for PLHIV than for other chronic conditions. Thirdly, sexuality implies a need to understand transmission and to engage in discussion with sexual partners to minimize risk and also to consider reproduction issues. The latter may be seen as a right of human beings, but it also generates practical dilemmas and challenges. These probably need to be addressed by a mix of decision and behavioral support interventions.

These three salient decision areas are themselves interconnected. While someone living with HIV may decide not to disclose, difficulties in terms of treatment could arise in both the initiation and adherence stages because they prefer to avoid or stop medications and maintain their status as a secret. A similar situation is shown in sexual behavior, where conflict over disclosure could lead to high-risk sexual intercourse, increased isolation, self discrimination, and internalized stigma. On the other hand, someone who has chosen to initiate or maintain treatment must depend on a valid and effective social network and therefore disclose to relatives, partners, friends, healthcare providers, etc.

## Discussion

A model of the psychosocial decision needs of PLHIV is proposed. People living with HIV often face dilemmas regarding decision making related to their long-term condition. Our literature review shows three most salient aspects of decision making that are relevant to the quality of life of PLHIV: whether or not to disclose the HIV status, whether or not to adhere to the medication, and how to manage their sexuality. Those decisions are accompanied and influenced by stigma and discrimination, which are key factors at the time of making any decision.

The findings of the current study have some methodological limitations. First of all, it seems clear that no articles specifically describe the psychosocial decision needs of PLHIV, and the synthesis was interpreted from the phenomena described in the research. Despite that limitation, the results have important implications for PLHIV. These results have not been reported so far in the literature, and could mean new challenges in order to help PLHIV in the way they face this chronic illness and to improve their quality of life. Even though some researchers have studied the psychosocial needs of PLHIV, such as loneliness related to HIV[19], life experience of PLHIV and social effects[61-62], and sexual needs of PLHIV[63-66], those works have mainly focused on health professionals' perspectives, excluding the role of PLHIV in the decision conflict. Therefore, this review provides a first approach and understanding of the psychosocial decision needs of PLHIV and may contribute to the development of interventions to help and support PLHIV with making decisions in the psychosocial domain.

From the research perspective, it seems necessary to systematically assess the psychosocial decision needs for PLHIV and to engage them in the difficult task of creating and developing new strategies to support them in the decision making process, according to their desires and requirements. The stigma attached to HIV certainly affects the control of the disease. Moreover, although diagnosis was not examined in this review, it would also be valuable to examine the influences on undertaking or not undertaking HIV tests and the decisions around this.

Our analysis has shown three most frequent psychosocial decision needs for PLHIV, each associated with fear of stigma and discrimination. The first decision is whether or not PLHIV should disclose their status to others – partners, family and health professionals[9-10,15]. This decision is charged with worries related to judgment and being treated in a different way, i.e. stigma and discrimination, which excludes PLHIV from social support and makes them live in an isolated world where quality of life is affected[13-14,18]. The second decision, which involves whether or not PLHIV choose to follow treatment, could be explained for different reasons as desires to deny the illness[31], not feeling sick, interpersonal motivations such as the wellbeing of the relationship[31,35-36], and having children who play an important role in hope and wishing to live. The third decision concerns whether or not PLHIV decide to maintain an active sexual life and how to manage it. This is an important issue, which includes decisions related to safer sex, i.e. condom use, negotiation between the couple, and considering protection of their partners[38,40,42-43]. Parenthood emerges as a decision experienced in the sexual activity context. Couples living with HIV consider parenthood as a right and a new hope, which could bring happiness and desire to live[55], but they are aware of the health and psychosocial risk that this could mean for the newborn, the mother, and the HIV-negative partner in case of serodiscordant couples. In this last point, people face decisions regarding which reproductive method should be followed[54], whether a natural conception, acknowledging the Swiss National AIDS Commission statement about sexually noninfectious successfully adherent HIV-positive people[50-51], or an assisted reproduction.

To break this vicious circle of psychosocial decision problems of PLHIV, it seems necessary to provide rapid support around the time of HIV diagnosis, helping people with disclosure issues and providing guidance for all other behavioral decisions. The potential intervention should incorporate elements to reduce stigma and discrimination against PLHIV, incorporating them in all the development process in order to empower them and provide a sensitive and effective psychosocial intervention.

According to the proposed model, three main decision needs can be predicted for PLHIV by looking at the time and the adaptive process of living with HIV. These decisions regarding disclosure, disease therapy, and sexual behavior should be evaluated and supported by healthcare professionals in active participation with PLHIV in order to improve the psychosocial implications of this disease.

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