To tell or not to tell: Managing HIV/AIDS disclosure in a low-prevalence context

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Abstract

The aim of the study was to highlight the challenges confronting health service providers and persons living with HIV/AIDS in facilitating serostatus disclosure to partners at risk in a low-prevalence context. Descriptive qualitative research was employed to obtain data through in-depth interviews with a total of 22 service providers and service users in two sexual health clinics in Dublin, Ireland. A thematic analysis of data was undertaken following transcription of interviews. We describe the barriers to HIV/AIDS disclosure from the perspective of service providers and service users. Findings highlight a range of systemic, cultural, gender and personal issues that regulate HIV/AIDS disclosure in a context of socio-cultural and demographic transformation. Several guidelines for managing HIV/AIDS disclosure are currently in use, but these do not reflect the diverse nature of the population of persons using the sexual health service, and the different professional service providers involved in managing the disclosure process. We recommend the development of standardised guidelines that recognise the diversity and peculiarities of persons living with HIV/AIDS, as well as ongoing training of health personnel managing disclosure.

Keywords: HIV/AIDS, disclosure, prevention, guidelines, Ireland.

Résumé

L’objectif de l’étude consistait à mettre en avant les défis qui se posent aux prestataires de services de santé et aux personnes vivant avec le VIH/SIDA pour faciliter la divulgation de l’état sérologique pour les partenaires à risque dans un contexte à faible prévalence. Une recherche qualitative descriptive a été employée afin d’obtenir des données par le biais d’entretiens approfondis avec un total de 22 prestataires de services et usagers de services dans deux cliniques de santé sexuelle à Dublin, en Irlande. Une analyse thématique des données a été réalisée suite à la transcription des entretiens.

Nous décrivons les barrières à la divulgation de la séropositivité depuis la perspective des prestataires de services et usagers de services. Les conclusions mettent en avant un ensemble de questions systémiques, culturelles, de genre et personnelles qui réglementent la divulgation de la séropositivité dans un contexte de transformation socioculturelle et démographique. Plusieurs directives pour la gestion de la divulgation de la séropositivité sont actuellement utilisées, mais elles ne reflètent pas la nature diverse de la population utilisant des services de santé sexuelle et des différents prestataires de services impliqués dans la gestion du processus de divulgation. Nous recommandons le développement d’une directive standardisée qui reconnaît la diversité et les particularités des personnes vivant avec le VIH/SIDA et une formation continue du personnel de santé gérant la divulgation.

Mots clés: VIH/SIDA, divulgation, prévention, directives, Irlande.

Introduction

Ireland reported its first case of human immunodeficiency virus in 1983 (O’Donell, Cronin & Igoe, 2000). By the end of 2008, when a cumulative total of 5,243 cases were diagnosed, the epidemic has spread beyond the high-risk population among whom the disease was initially concentrated. Statistics from the Health Protection Surveillance Centre (2009) showed an increase of 3.6% in reported cases between 2007 and 2008. In addition, more than half of all new infections were heterosexually acquired and almost all were in individuals born outside of the island of Ireland. Foreman and Hawthorne (2007) suggest that the pattern of immigration to Ireland since 1996 may have contributed to the increase in new cases of infections, especially among migrants from high-prevalence countries, many of whom were diagnosed during routine antenatal screening.

Although with an adult prevalence of 0.2%, Ireland is still a low-prevalence country, far removed from the generalised epidemic seen in other parts of the world, especially in sub-Saharan Africa. However, as experience from these high-prevalence countries suggest, poor management of HIV/AIDS as a public health issue can have devastating long-term consequences.

Testing and notification of partners at risk are among strategies aimed at preventing new infections and slowing the transmission of HIV/AIDS in the general population. The success and
effectiveness of these strategies depend, in part, on the willingness of individuals who are sero-positive to inform partners at risk (Simoni, Demas, Mason, Drossman & Davis, 2000). Despite the advantages inherent in HIV/AIDS disclosure, there is extensive literature documenting the challenges to disclosure in different contexts (Greene, Derlega, Yep & Petronio, 2003; WHO, 2003).

Studies show that the decision to disclose sero-positive status can be conscious or unconscious, and influenced by weighing potential advantages and disadvantages (Derlega, Winstead, Greene, Serovich & Elwood, 2004; Emlet, 2008; Serovich, 2001; Valle & Levy, 2009). For example, the competing consequence theory (Serovich, 2001, Serovich, Lim & Mason, 2008) suggests that persons living with HIV weigh the associated costs and rewards before disclosing their status. This decision may be influenced by the need for emotional, physical and social support (Kalichman, DiMarco, Austin, Luke & DiFonzon, 2003; Paxton, 2002; Serovich, Lim & Mason, 2008; Simoni et al., 2000) that would benefit the individual living with HIV. A sense of ethical responsibility and concern for partner's health (Odunsib, 2007; Simoni et al., 2000); younger age (Farquhar et al., 2000); having few sexual partners and personally knowing someone with AIDS (Antelman et al., 2001; King et al., 2008); poor health and desire for social support (MacNeil, Mberesero & Kilonzo, 1999); exposure to counselling (DaRosa & Marks, 1998; Maman et al., 2003); and the need to minimise stress and facilitate preventive behavior (McDowell & Serovich, 2007; WHO, 2003) were also associated with motivations for disclosure. Social capital, ‘the aggregate of actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition’ (Bourdieu, 1985: p. 248), has also been shown to strongly influence the decision to disclose among people living with HIV/AIDS (Kalichman et al., 2003; Waddell & Messeri, 2006; Wouters, Muelemans & van Rensburg, 2009).

While disclosure can be an important strategy for controlling the spread of HIV/AIDS, because of the protective benefits to individuals and the health system, there are challenges that inhibit voluntary disclosure (Maman et al., 2003; Odunsib, 2007; WHO, 2003), and these require measures to help people living with HIV/AIDS deal with them. The prospect of being abandoned, emotionally supported, and the risk of other people knowing about their sero-positive status may discourage disclosure (Antelman et al., 2001; Beauregard & Solomon, 2005; Kilewo et al., 2001; Maman et al., 2003; Medley, Garcia-Moreno, McGill & Maman, 2004; Siegal, LeKas & Schrimshaw, 2005; WHO, 2003). Thus, persons who are aware of their HIV serostatus may choose not to disclose to significant others, especially sexual partners, as a result of such factors or because they are in denial (Galletly & Pinkerton, 2006).

Most studies have examined HIV/AIDS disclosure have focused on the processes and outcomes of disclosure (Black & Miles, 2002; King et al., 2008; Lee, Detels, Rotheram-Borus, & Duan, 2007; Maman et al., 2003; Parsons, VanOra, Missildine, Purcell & Gomez, 2004; Simoni et al., 2000), albeit from the perspective of people living with HIV/AIDS. Health workers are an integral part of the disclosure process, since they provide support, counselling, testing and other related services that facilitate disclosure. Despite their critical role in facilitating disclosure, studies have yet to examine the challenges associated with managing disclosure from the health providers’ perspective, especially in a low-prevalence context where issues of stigma may be more pronounced.

This study aims to describe the issues that service providers deal with in managing HIV/AIDS disclosure; and also to determine measures that are needed for dealing with HIV/AIDS disclosure in Ireland.

Data and methods
Research design and study setting
The study used a descriptive qualitative research design to elicit data, which focuses on observing and describing the behaviour of the target population. The research setting was sexual health clinics located in Dublin, Ireland. Two of the largest sexual health facilities with a long history of specialised service in HIV/AIDS care for people from diverse backgrounds and cultures living in Dublin and the surrounding counties, were purposively selected. Data collection commenced after ethical approval was obtained from both the Dublin hospitals’ joint research ethics committee and the University of Dublin Trinity College. Approval to interview the participants was granted by the Patient Advocacy Committee and the management of the selected clinics, and informed consent was obtained from each participant.

Participant selection
Given the sensitive nature of the issues being investigated and concern for anonymity and confidentiality, it was decided to conduct in-depth interviews on a one-to-one basis, using purposive sampling to select respondents. Two categories of respondents, (i) service providers and (ii) service users, were included in the study. Although service providers were the main subjects for the study, service users were also included, in order to determine the extent of similarities or otherwise of the issues around HIV/AIDS disclosure previously highlighted in literature. Selected service providers were aged between 32 and 39 years and included physicians, nurse managers, advanced nurse practitioners, nurses and HIV/AIDS counsellors who had worked in the clinic for a minimum of 3 years. Eligibility criteria for service providers included working in the selected clinics, and directly with service users living with HIV/ AIDS. The selected service users included indigenous Irish and immigrant respondents, with the majority being females from sub-Saharan Africa. The length of confirmed HIV serostatus ranged from 3 months to 8 years. Eligibility criteria for service users were confirmed HIV serostatus, in a relationship at the time of the study, and may or may not have disclosed their status to partner(s) at risk. Prior to data collection, service providers who fulfilled the inclusion criteria were contacted by telephone and invited to participate in the study, while service users were randomly recruited from the patients’ list obtained through HIV/AIDS counsellors who acted as gatekeepers to ensure that the clinic remained a safe environment where anonymity was not compromised. The involvement of HIV/AIDS counsellors in the recruitment of service users did not influence their decision to participate.
Data collection

Qualitative data, in the form of in-depth interviews and case studies, were obtained from both service providers and service users. Two interview guides (one for service providers and the other for service users) were prepared. The semi-structured nature of the guides ensured that researchers had the flexibility to pursue other lines of inquiry that may have emerged during the interview. The interview guide covered issues regarding the management and experiences of disclosure, both from the service providers’ and services users’ perspective. Among service users, interviews focused on identifying the barriers to disclosure, to highlight issues that are peculiar to the Irish context. The service providers’ interview guide was designed to capture information on their experiences in facilitating and managing disclosure, as well as the availability or use of professional guidelines in facilitating disclosure.

Using the guide, in-depth interviews were held with a total of 22 participants comprising 14 service providers (including specialist consultants, HIV/AIDS counsellors and nurse specialists) and eight service users (equally divided between males and females). Before interviews commenced, participants were briefed about the purpose of the study, confidentiality of the information being given, their anonymity, as well as the right to withdraw at any stage during the interviews. After the briefing, written informed consent was obtained from each participant. Interviews with service providers lasted about 90 minutes on average, while service users’ interviews lasted about 60 minutes on average.

Data analysis

Tapes from the interviews, which were digitally recorded, were transcribed verbatim and subjected to thorough scrutiny and consistency checks with the recordings. Verbatim transcriptions of the recordings were done by the author, and verified for consistency by other independent consultants, and then imported into NVivo™ qualitative data analysis software file to aid thematic analysis. The author independently reviewed the transcripts several times in order to become familiar with the content before the process of sorting, coding and identifying themes (Maykut & Morehouse, 1994; Pope & Mays, 2006). Prior to data coding and theme identification, transcripts from participants were sent back to the interviewees for validation and to ensure accuracy.

Data analysis was based on a thematic framework. Themes emerging from individual interviews were developed through an inductive and deductive process (Gray, 2009; Green & Thorogood, 2004; Pope & Mays, 2006). Following theme identification, relevant codes generated by NVivo™ were systematically applied to the identified themes. This process facilitated the mapping of themes and interpretation of the data in respect of the study objectives. A joint decision was made on which themes and sub-themes to report on, and relevant quotes from the data were extracted to support the presentation and discussion of results. In order to aid the interpretation of data relevant verbatim quotes were extracted from the transcripts in support of the themes being reported. Pseudonyms were used in place of participants’ names to hide their real identities.

Study limitations

While this research provides a valuable insight into management issues regarding disclosure of HIV status within a low-prevalence context, especially as it affects an immigrant population, we recognise its methodological limitations and applicability in contexts where HIV/AIDS is more prevalent. The nature of qualitative data, and the size and selective nature of the sample, may limit the extent to which the results are generalisable to populations in other contexts. Furthermore, since respondents were selected from two sexual health clinics, only the views of those with access to these clinics would have been reflected in the data, and this may imply a restricted perspective regarding management issues around disclosure for service providers working across sexual health facilities in Ireland. Thus, while there are limitations to the extent to which the findings reported could be generalised to similar sexual health clinics within and indeed outside Ireland, the findings reported in this paper provide valuable insights into critical issues in the management of HIV/AIDS disclosure in low-prevalence contexts, especially as published data relevant to low prevalence contexts are scant. Moreover, the sizeable number of immigrants from high-prevalence countries represented in the sample highlights issues that might constrain HIV/AIDS disclosure among similar populations in a low-prevalence context. These limitations warrant caution in interpreting the results.

Results

The aim of this study was to describe the challenges confronting service providers in managing disclosure on a day-to-day, case-by-case basis, and what is done to resolve this. In addition, we wanted to explore how the challenges associated with HIV serostatus disclosure in a low-prevalence environment mirror those of high-prevalence contexts, and how these are navigated. Consequently, we focus on two major themes that appear prominent in the data: (i) challenges associated with using guidelines to facilitate disclosure; and (ii) dealing with patient’s concerns and strategies for disclosure.

Challenges associated with using guidelines for managing disclosure

Service providers were unanimous in their opinion about the importance of disclosure. However, the lack of standardised guidelines on the modalities for managing disclosure constituted one of the most important challenges. Participants reported the existence of different guidelines, which are often contradictory, for dealing with HIV/AIDS-related disclosure. Existing guidelines include: the Irish Sexual Health Service Guidelines; the 2007 UK Guidelines for the Management of Sexual and Reproductive Health for People Living with HIV Infection; the US/CDC HIV Partner Counselling and Referral Services; the Medical Council’s Guide to Ethical Conduct and Behaviour; and the Code of Professional Conduct for Each Nurse and Midwife. Multiple guidelines may offer the advantage of alternative courses of action when dealing with disclosure, but there is also the likelihood of confusion among service providers who may favour guidelines recommended for use by their professional association, irrespective of their appropriateness for managing a specific case. For instance, HIV
counsellors would often refer to the *Irish Sexual Health Service Guidelines*, aspects of which differ from the UK Guidelines for the Management of Sexual and Reproductive Health for People Living with HIV Infection, which is favoured by physicians in general practice. This sometimes create tensions when a team of different professionals work together in managing disclosure, thus requiring the need for consensus, sometimes with considerable delay, before progress is made. As some service providers noted:

There are different guidelines that exist … with, I suppose, the main one coming from the HSE [Health Services Executive]. Therefore, we would often draw up our own guidelines in the clinic that would suit others in the team who might prefer to work with guidelines recommended by their profession (S, 36-year-old female service provider).

In the opinion of several of us, waiting to achieve consensus, given the difference guidelines can be a difficult and long process through which precious time is wasted (M, 38-year-old male service provider).

When achieving consensus was difficult, service providers would normally follow the recommendations of the appropriate guidelines for their profession. As one participant asserted:

Where confidentiality and disclosure overlap … and recommending or suggesting disclosure would breach confidentiality, I would take guidance from the Irish Medical Council guidelines (F, 40-year-old female service provider).

Achieving consensus might be difficult when there is a perception that some guidelines lack specific recommendations for dealing with a peculiar situation. For example, some participants asserted that only one guideline, the *Irish Sexual Health Service Guidelines*, made specific recommendations regarding a time frame of 3 to 6 months within which disclosure must be achieved. Other guidelines were vague about timelines, thus leaving individual counsellors who refer to them to independently determine a timeline for disclosure that might conflict with the opinions of others in the team. Apart from the tension that was generated, this might also lead to inconsistencies in the standards applied by different service providers. While disclosure should be made as early as possible, the 3 months recommended by the Sexual Health Service guidelines was considered too short by some service providers who subscribe to the view that disclosure is ‘a process rather than an event’ as described by other guidelines (BHIVA, BASHH & FFPRCH, 2007, p.39). Those who opposed this view thought that it might prolong the time frame within which disclosure would be beneficial to those at risk.

The majority of the women who were clients at the clinic were pregnant women whose sero-status was confirmed following testing during routine antenatal visits. Our data revealed that existing guidelines were vague regarding how to manage disclosure and when to do this in the case of pregnant and positive women, among whom concern is for both the partner at risk and the unborn baby. In facilitating disclosure for such women, service providers have had to resort to different measures in the hope that they would not compromise their duty of care. They suggested that these different situations required consensus in managing the process, taking into account the specific circumstances of each patient.

The lack of standardisation constituted a source of frustration for service providers, as they struggled with achieving a balance between various disclosure guidelines and their duty of care to patients. Some service providers felt that guidelines required that the disclosure process was rushed, without consideration for duty of care to patients living with HIV/AIDS. Consequently, many service providers would resort to what was considered a ‘best’ approach to dealing with disclosure that takes account of duty of care to patients. This sometimes required approaching disclosure with an ‘indirect and soft’ approach, persuading and encouraging the client to disclose to those at risk; or alternatively a more ‘direct and forceful’ approach, where the provider would insist that the at-risk partner be brought in and notified. Two service providers’ accounts best illustrate these two approaches:

I would obviously encourage safer sex all the time to reduce risk. I think the individual has to make a decision about when to tell … there’s a bit of negotiating, communicating that needs to be done while ensuring that the situation is not further complicated (S, 36-year-old female service provider).

Sometimes, I think the bolder approach works, as in, they would never have brought the partner in unless you literally dragged them and say … right, you are coming in … rather than give me a ring when you are ready to come and have a chat (D, 39-year-old female service provider).

Thus, given these different approaches, the existence of several guidelines may further complicate the management of disclosure and/or achieving standardisation in the disclosure process. This may also explain the difference of opinions regarding the effectiveness of existing guidelines. Some providers reported that the guidelines were effective, but others felt that guidelines only existed to protect those working within the system, in case legal issues arose:

These guidelines probably exist so that if someone sued a health provider or the department of health, they can tick a box to say that guidelines have been followed even though such guidelines are [woolly] … they are not hugely helpful because they are just there to cover something, but not a lot (S, 36-year-old female service provider).

Sometimes you are faced with a peculiar situation … where your best judgment indicates that you take a different approach that will benefit all the parties involved, but you are constrained because you want to be covered in case there are legal issues … so you just follow the guidelines even though it’s not the best. (P, 45-year-old male service provider).

Such comments raise questions about having guidelines which may not be particularly beneficial to facilitating disclosure, but only fulfil the need to block a legal loophole. Generally, there was consensus that the guidelines could actually constrain service providers from applying their initiative when dealing with individual cases, which might involve circumstances not covered by the guidelines.
In view of the foregoing, participants suggested that effective management of HIV serostatus disclosure would require harmonised guidelines suitable to the Irish context, as well as education and training of service providers on using such guidelines. Participants acknowledged that, where guidelines did not adequately account for all possible scenarios, there should be freedom for service providers to use their initiative when peculiar circumstances warranted it.

Dealing with patients’ concerns and strategies for disclosure

A challenge regarding patients’ concerns with and strategies for disclosure was another major theme that surfaced in interviews with service providers and service users. Generally, stigma, fear and anxieties associated with disclosing to at-risk partners and the wider social network were common issues that affected all service users. Female service users reported anxiety about possible violent reactions from male partners, stigma, and the loss of economic and social support from both immediate family and significant others as barriers to disclosure. Male service users, on the other hand, would mention a concern with non-violent reactions from at-risk-partners, and stigma from their friends and colleagues at work knowing about their status. These issues often created a dilemma for service providers in managing aspects of the disclosure process.

The case of C and A illustrate the dilemmas that service providers often faced when dealing with patients’ concerns regarding disclosure, especially among women. C is a 28-year-old mother of three children originally from a high-prevalence country in sub-Saharan Africa. She had lived in Ireland for more than 5 years before she was diagnosed during a routine antenatal visit. Although her current partner and children are all negative, she was abandoned when the partner fled from the home they shared after learning that his test returned negative. C suspected she must have been infected by her former partner who migrated to Ireland after learning that his test returned negative. In view of the foregoing, participants suggested that effective management of HIV serostatus disclosure would require harmonised guidelines suitable to the Irish context, as well as education and training of service providers on using such guidelines. Participants acknowledged that, where guidelines did not adequately account for all possible scenarios, there should be freedom for service providers to use their initiative when peculiar circumstances warranted it.

The results also demonstrate that migrant service users appear to face additional challenges with disclosure. Concern about economic survival was not restricted to migrant female patients. Male service users were also concerned about the implications that disclosure would have for their status within their social network and their livelihood. T is a 33-year-old service provider who reported a difficult encounter with a male client whose livelihood was based on providing sexual services for MSM (men who have sex with men) community in the city. According to him:

> I once had this patient, emm… [names withheld] of south east Asian origin. Initially, when we started the consultation, he was quite reluctant in disclosing the details of his personal life, including the work he is doing. When he realised that we needed certain information without which it would be difficult to proceed, he confided to working in the sex industry, providing services for the MSM community. When the conversation shifted to partners at risk, he excused himself to say he was going to the toilet. I haven't seen him since then and he couldn't be traced at his address. It's been two years now (T, 33-year-old male service provider).

Issues around immigration status, especially among irregular migrants, appear to complicate not just the disclosure, but also the therapy process. Undocumented migrants would often not use the health service or disappear soon after being diagnosed, because they feared service providers would report them to the immigration authorities, leading to deportation. One service provider reported that:

> I have seen a few cases of people who are diagnosed as positive and would refuse to report for follow-up activities. The moment they realise they are positive, they move from their known address, making it impossible to locate them. The fear of being deported makes them forgo the benefits of early diagnosis and treatment, thereby increasing the risk for them and those around them including their unborn children (E, 34-year-old female service provider).

These challenges may have serious implications not only for the disclosure process, but also the physical and mental health of
migrants, as there were reports of people who had depression or suicidal thoughts following diagnosis.

Religious belief is another barrier to managing disclosure among migrants. Denial was more common among migrants with strong religious beliefs in ‘miracle healing’ or a ‘divine cure’. Moreover, perceptions of HIV/AIDS as an infection resulting from sexual immorality might have also contributed to the unwillingness to disclose serostatus within their religious circles.

Migrants also encountered challenges arising from limited language skills. English is the official language of communication in Ireland, and migrants who have limited language skills would require the services of an interpreter to facilitate communication with service providers. Thus, apart from sporadic availability of this service, those who may have required an interpreter to receive the results of their test would often not show up for the appointment, given the likelihood that the interpreter was someone known to them. This increased the risk of patients being lost to follow-up because, as one participant puts it:

*By the time you take steps to go and locate them in their physical address, the experience is that large number of them would no longer be at the address that they registered (E, 34 year-old-female service provider).*

The foregoing calls attention to the systemic, cultural, gender and religious dimensions of HIV/AIDS disclosure. While men in stable relationships are more likely to disclose to partners at risk without anxieties about negative outcomes, women are often inhibited from disclosing because of possible violence from their partners. Moreover, stigma is still a pervasive concern not just among migrants, but generally in Ireland. Service providers would therefore need to work closely with AIDS activists, community leaders and policy makers to address stigma, and support people living with HIV/AIDS. Furthermore, existing guidelines and the environment of service provision do not recognise the diversity of individuals presenting with HIV/AIDS, thus the blanket approach that is applied to all cases irrespective of their peculiarities will further complicate the disclosure process. As one participant reported ‘service users cannot be managed in a protocolised manner’, meaning that no single set of guidelines will account for the complexity of cases presented.

**Discussion**

Disclosure of HIV-positive status offers considerable benefits from both an individual and a public health perspective (WHO, 2003). However, the advantages inherent in HIV serostatus disclosure must be preceded by a willingness to share the information with others (Simoni et al., 2000). Because disclosing HIV serostatus is fraught with risks, including stigma, it is important to understand all the ramifications of telling other people about one’s sero-status (Lee, Rotheram-Borus & O’Hara, 1999; McDowell & Serovich, 2007), and the challenges encountered by service providers who facilitate disclosure.

While there is extensive literature documenting the dynamics of disclosure from the perspective of people living with HIV/AIDS, few studies have examined the important role of health service providers in facilitating and managing disclosure (Da Rosa & Marks, 1998; Maman et al., 2003). Thus, this study was aimed at examining the challenges of disclosure from the perspective of service providers and service users in a low prevalence context. Two major themes: (i) challenges associated with using guidelines; and (ii) dealing with patients’ concerns and strategies for disclosure emerged from our data.

With regard to the first theme, our findings suggest that health providers are confronted by both systemic and personal challenges when managing disclosure. Such challenges can be overwhelming and may limit service providers’ capacities in facilitating or managing the disclosure process. The absence of standardised guidelines, coupled with the diversity of health professionals who may hold divergent opinions, exacerbates the systemic difficulties with managing disclosure. For example, different professionals working in the same team may find it difficult to achieve consensus on how to handle different aspects of disclosure. Addressing this problem would require the development of standard HIV/AIDS disclosure guidelines that recognise not just the particularities of the HIV/AIDS scenario in Ireland, but also the circumstances of individuals needing disclosure.

The risk of mother-to-child transmission of HIV, which can rise as much as 30 - 45% with prolonged breastfeeding (Joint United Nations Programme on AIDS, 2006), can be reduced to less than 2% with appropriate interventions (Dorenbaum et al., 2002). Statistics from the Health Protection Surveillance Centre (2008) show an increase in the rate of mother-to-child transmission. Therefore, HIV-positive pregnant women will be able to benefit from existing interventions when significant others around them know their status and are able to support them to benefit from existing interventions. Perhaps service providers should be equipped with the skills for assessing both the bonding and bridging social capital (Putnam, 1995; Wouters et al., 2009) available to HIV-positive pregnant women, which might facilitate the disclosure process. Managing disclosure for this category of women remains challenging, and needs to be appropriately handled to minimise consequences for the woman and the child.

Findings from this study corroborate earlier studies that suggest that women carry a disproportionate burden of HIV/AIDS disclosure (Deribe, Woldemichael, Wondafrash, Haile & Amberbir, 2008; Forbes et al., 2008; Serovich, McDowell & Grafsky, 2008) including stigma, physical abuse and lost social and economic support. Pregnancy may complicate the situation for women, and as the results show, current guidelines do not specifically recommend how to handle disclosure among pregnant women. As a result, service providers adopt different strategies that yield different outcomes, and of concern are cases where, particularly among migrant women, pressure to disclose forces them to stop attending the clinic or discontinue antiretroviral therapy, with severe implications for the unborn child.

Another manifestation of systemic challenges is the lack of training with respect to handling disclosure among health workers interviewed. In the absence of standard guidelines, such lack of training will pose a significant challenge. Although participants reported ‘learning on the job’ and ‘sharing information with colleagues’ as a means of updating their knowledge and improving their skills,
it might be worthwhile to organise training for those who need it, so as to improve the efficiency of the disclosure process.

Our results further highlight the challenges that both service providers and service users deal with regarding strategies for and outcomes of disclosure. Although these challenges are similar to those previously identified in the literature, the circumstances differ for Irish and non-Irish service users. For instance, Irish service users may worry about the implications of disclosure to at-risk partners, close family members and colleagues at work. Migrant service users, especially women, also have to worry about the cultural, gender, economic and immigration implications of disclosure. Fear of violent reaction from male partners, lost economic and social support, not being able to access service because they lack appropriate communication skills, and stigma from those around them may complicate the disclosure process for migrant service users. In addition, they distrust service providers because they perceive them as agents of the state who would report them to immigration officials, particularly when they are irregular migrants. The fear of arrest and deportation might discourage following through with disclosure, and accessing or fully utilising treatment services.

Furthermore, service providers should be aware that women who disclose their status and are at risk of violent physical abuse from their partners will require effective case management that closely monitors them, and refers them to appropriate social and legal services. As the WHO (2003) recommends, cross-training in HIV/AIDS and domestic violence for health workers involved in managing disclosure could be an effective strategy to assist women affected by both epidemics. The threat of real and perceived risks should be carefully assessed, so that appropriate advice is given with regard to timing of and strategies for disclosure (Galletly & Pinkerton, 2006; Maman et al., 2003; McDowell & Serovich, 2007).

Similarly, it has been advocated that the processes of disclosure should focus on couples rather than individuals (King et al., 2008; Ndase et al., 2004; McDowell & Serovich, 2007), to avoid the uncomfortable task of the infected partner breaking the news to the partner at risk. The benefits of focusing on couples, among others, is to increase confidence in the disclosure process, help them jointly deal with the negative consequences of blame and anger that often follow disclosure, increase the proportion of couples seeking VCT services, increase access to family-oriented care and treatment programmes, and encourage sustained behaviour change (Maman et al., 2003; Painter, 2001; McDowell & Serovich, 2007).

Negotiating difficult cultural, gender, economic and immigration issues as well as religious beliefs about HIV/AIDS and antiretroviral medications, especially among migrant service users, was a challenge for service providers. Similarly, the conflict between the need for disclosure and duty of care to at-risk partners often strained relations between service providers and service users. Applying pressure on service users to disclose may be counterproductive, as they could then tend to completely avoid either the counsellors or the service.

The consequences of disclosure have been extensively documented in different cultural contexts, and as studies have shown, disclosure of sensitive information is regulated by cultural considerations (Elford, Ibrahim, Bukutu, & Anderson, 2008; Mansergh, Marks & Simoni 1995; Mason, Marks, Simoni, Ruiz & Richardson, 1995; Rubin, Yang, & Porte, 2000; Zea, Reisen, Poppen & Diaz, 2003). Service providers need to bear in mind the cultural inhibitions to disclosure among African migrants, who make up a sizeable proportion of clients. As many cultures in Africa discourage open communication about sexuality, appropriate methods as suggested by King and colleagues (2003) need to be developed to help female clients deal with disclosure. The challenges that service users face have serious implications, not only for the disclosure process, but also their physical and mental health (Sherr et al., 2008).

Conclusion

In summary, both systemic and personal constraints contribute to the difficulty in managing HIV/AIDS disclosure in Ireland, especially among immigrants, who now constitute a sizeable proportion of cases being diagnosed. To this extent, an important step towards addressing the issues raised in this study is the need to harmonise the guidelines used by service users, so as to achieve standardisation in managing HIV/AIDS disclosure. Such guidelines should also be flexible so that they are applicable to the diversity of cases presented. Moreover, it is important that service providers have opportunities for training in managing disclosure, and interaction to share their experiences so that important lessons are learnt. In addition, service providers should develop skills for assessing both bonding and bridging social capital available to service users, and encourage them to take advantage of these in the disclosure process. Finally, in line with the greater involvement of people living with AIDS (GIPA) principle, service users who are key players in facilitating the disclosure process need to be included in planning the direction of service provision.

References


