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Not Just another Long Term Chronic Illness — Social Work and HIV in Ireland

Maeve Foreman and Neans Ní Rathaille

This article begins with an overview of the involvement of Irish social workers in the HIV sector over the past 30 years, describing the culturally specific context within which they worked. Drawing on the authors' experience of social work in the area, and on findings from a study conducted with social workers and people living with HIV, a shared perspective on the challenges facing those living with and working with HIV in Ireland is presented. Despite the fact that HIV is now considered a treatable long-term chronic illness, it is suggested that stigma and discrimination, and resulting fears around disclosure, remain key barriers to effective care and prevention. The contribution that social workers can make to support those living with HIV and to challenge such stigma is discussed.

Keywords: HIV; AIDS; social work; medical social work; Ireland

Introduction

The global challenge of HIV continues, with 35 million people infected worldwide, the majority in the developing world (UNAIDS 2014). In Ireland, with a population of 4.6 million (CSO 2014), the number diagnosed with HIV has doubled in the past decade and the cumulative total is now 7353. While the number infected appears low, the rate per 100,000 people is 8.2, compared to an average of 5.7 in the rest of Western Europe (HPSC 2015).

Throughout the nineties, inward migration to Ireland from areas of the world where HIV is endemic contributed to an increase in the detection of heterosexually acquired HIV, accounting for well over 50% of infections for much of the last decade (HPSC 2015).¹ However, mirroring the wider European pattern (ECDC 2010), men who have sex with men (MSM) has more recently emerged as one of the key population groups at greater risk of acquiring HIV. In 2014, 49%

1. The Irish Nationality and Citizenship Act (2004) tightened citizenship laws, reducing the number of immigrants from Sub-Saharan Africa accessing HIV services from then onwards.

(183) of new diagnoses of HIV were among MSM, the highest ever reported in this group, with a threefold increase among MSM since 2005 (HPSC 2015). Additionally, in the European MSM Internet Survey (EMIS), which included the largest ever survey of Irish gay men, 10% of those who had tested were HIV positive (The EMIS Network 2013).

While there have been advances in treatment since the first dedicated HIV service was established in Ireland in 1987, HIV remains more than a medical issue and continues to raise fundamental questions of equity between marginalised groups and majority society, and between regions of the world. Attempts to 'normalise' HIV and see it as just another long-term chronic treatable illness have been criticised because of the ongoing stigma attached to the disease, the difficulties many experience accessing treatment or adhering to complicated treatment regimes, and the fact that for many it is still a terminal condition (UNAIDS 2014). We were interested in exploring whether there was still a need for specialised support, or can HIV be treated like other manageable long-term illnesses requiring ongoing medication?

Beginning with an historical overview and exploration of the role of social work in HIV service provision in Ireland, this article will go on to present some of the results of focus groups with HIV social workers and people living with HIV and, in the light of literature reviewed, suggest some of the issues social workers need to engage with today.

Historical and Cultural Context

The first cases of acquired immunodeficiency syndrome (AIDS) in Ireland were diagnosed in 1982 (HPSC 2015) and following the introduction of the HIV test in 1985 the full extent of the problem unfolded. By then, 60% of those testing HIV positive were intravenous drug users (IDUs) from Dublin's socially and economically deprived inner city, with the gay community and men with haemophilia also initially affected. The high number of families with two or more siblings infected with HIV was a feature shared with other European cities with a high incidence of HIV positive IDUs (Bury, Morrison, and MacLachlan 1992), as was the number of women and children infected (Butler and Woods 1992; Foreman and Mulcahy 1997). This was due in part to restricted availability of drug treatment and the lack of needle exchange. There was no national drug policy and the debate was polarised between abstinence and harm reduction (Butler and Mayock 2005; Cronin 1989). The Irish experience contrasted with most of Europe where 70% of reported HIV cases were gay men (NASC 1992). Many IDUs were already receiving social work services through child and family teams, addiction or probation services. Often HIV was not their most immediate problem and issues related to poverty, addiction and childcare took precedence (Murphy Lawless and Redmond 1993). By 1999, the incidence of HIV among IDUs had fallen dramatically as drug users availed of harm reduction initiatives including methadone treatment and

needle exchange (Seery 1999). Only 7% (27) of new infections in Ireland in 2014 were among IDUs (HPSC 2015), although it is important to note that this is up from 5% in 2013 and is the highest number reported in this group since 2009; 89% were co-infected with Hepatitis C, which remains a huge issue.

Until recently, Catholic moral values were central to Irish culture and were enshrined in the laws of the state (Inglis 1998). This impacted on the initial development of AIDS policy and HIV education and prevention interventions, as well as on shaping public perception of HIV and those who were affected (Smyth 1998). Contraceptive devices, including condoms, were only available to married couples on prescription for family planning purposes. The Health (Family Planning) Act 1979 was amended in 1985 to allow restricted sale of condoms to adults over 18 in chemists and doctors' surgeries, but it was 1993 before the sale of condoms was deregulated and their availability became more widespread (IFPA 2014). Attempts to introduce sex education in schools were often challenged until the eventual, but problematic, introduction of Relationship and Sexuality Education in 1998 (Mayock, Kitching, and Morgan 2006). Until 1992, it was illegal to give information and advice to women seeking a termination (IFPA 2014), although medical opinion at the time considered it risky for HIV positive women to proceed with pregnancies (Berridge 1996). Additionally, it was difficult for statutory health services to target gay men as sex between men was illegal, and gay men could not be open about their sexuality. The Criminal Law Sexual Offences Act 1993 eventually decriminalised homosexual acts, making 17 the age of consent for all, but in the meantime, the gay community and non-governmental organisations led the response to AIDS. Gay Health Action, founded in 1985, produced the first safer sex leaflet and helped found organisations such as Cairde, a befriending agency, and AIDS Action Alliance; and the Irish AIDS Initiative Conference, an all Ireland response lead by people living with HIV, resulted in the establishment in 1988 of an AIDS Liaison Forum² for those working with, and affected by, HIV. Social workers were involved in the Forum from the start. Since then, Ireland has become a more secular society. Although Irish women still have to travel abroad for terminations (Bacik 2013), condoms are now available (IFPA 2014), civil partnership was introduced for gay couples in 2011 (GLEN 2014), the recent Marriage Equality Referendum made Ireland the first country in the world to support legalising same sex marriage by popular vote (Yes Equality 2015), and Gay Health Network (GHN) and the Health Service Executive continue to jointly run a national HIV Prevention and Sexual Health Awareness programme targeting MSM (GHN 2014).

2. ALF'S goal was 'to foster excellence in service provision through open sharing and discussion ... and to promote better networking, cooperation and skills development throughout the HIV/AIDS Field' (ALF, 1993). The Forum also published a newsletter, AIDS Inform, from 1989 to 1994, and was replaced by the HIV Services Network in 1999.

Social Work and HIV

Since the early eighties, social workers in hospitals, community care, probation, fostering and addiction services have worked with people diagnosed with HIV and dying from AIDS (Foreman 1988; Jones and Foley 2002; Travers 1996). The profession's pre-existing principles such as acceptance and non-judgmental attitude, commitment to social justice, and strengths-based and anti-oppressive practice approaches were ideally suited to this work (Linsk 2011). From 1989 onwards, social workers in Ireland were appointed to hospital-based HIV counsellor posts to support those diagnosed with HIV, with the first two posts in the National Haemophilia Centre and a hospital-based HIV service (Lindsay 2002). Their role included the provision of pre- and post-HIV test counselling (Foreman et al. 1992) and ongoing psychosocial support. This included making care plans with families living with AIDS, supporting those dying from AIDS to live in their community for as long as possible, developing a planned response for those coping with AIDS dementia, running support groups, providing bereavement support and promoting behaviour change to safer practices. Social workers also attended to issues such as housing, finance and guardianship of children (Foreman and Mulcahy 1997).

The Irish Association of Social Workers' special interest group in HIV was established in 1989 (IASW 1992). In an early initiative, members worked with HIV positive parents to produce a book for children infected and affected by HIV (Fitzgerald 1992). At a broader level, several initiatives in the late eighties by groups like the IASW and the AIDS Liaison Forum challenged the government's lack of action in tackling the growing problem of HIV. Calls for a broad-based national interdisciplinary body to manage AIDS care culminated in the establishment of the National AIDS Strategy Committee (NASC).³ Social workers have sat on the committee from the outset. NASC reported twice, in 1992 and in 2000 and recognised that the most effective way to deliver services was a coordinated civil society and statutory intersectoral approach. The 2000 Strategy guides current policy on HIV but NASC has not, despite recommendations to the contrary, engaged in broader sexual health policy (ECDC 2010; Layte et al. 2006). Its sub-committees have been more active and have advanced policy and practice in education, prevention, care and management of HIV (NASC, 2005, 2011).

Working relationships were established by social workers with self-advocacy and peer support groups such as Body Positive and Irish Frontliners,⁴ non-governmental HIV/AIDS organisations, community drug projects, HIV Services and the GHN. Examples of collaborative practice include the provision of HIV

3. NASC was launched at a 'Sharing the Challenge' conference in 1991, which had been jointly organised by civil society and the Department of Health.

4. Irish Frontliners' magazine *Frontline*, produced in 1989/1990 provides a record of the devastation caused by AIDS, and the early activism of the self-advocacy movement.

awareness training by hospital social workers with GLEN's Gay HIV Strategies and the Gay Men's Health Service (a statutory community service managed by a social worker) in gay clubs and saunas in Dublin (Hayden 1998); provision of late night testing and counselling in gay pubs, clubs and saunas following an outbreak of syphilis (Gay Men's Health Service 2011) and outreach with community drug workers to prevent further infections among young IDUs following an increase in HIV in an inner city area (Clarke et al. 2001). Social workers also took part in the National Stamp Out Stigma Campaign 2007–2008. More recently, the IASW collaborated with GLEN to produce a handbook on social work and LGBT issues (IASW 2011).

Today, despite medical advances, individual decisions to change risk behaviours remain the most viable way to prevent HIV infection (UNAIDS 2014), and the importance of developing prevention interventions with people who are HIV positive has been highlighted (Collins and Sheehan 2005; WHO 2011). The introduction of routine HIV testing in sexually transmitted infection and antenatal clinics has led to a change in services being provided by social workers/counsellors, who now concentrate on working with those who are at high risk or who have a multitude of problems (NASC 2000).

Living with HIV in Ireland: Methodology

We set out to explore the impact of developments in HIV treatments and the conceptualisation of HIV infection as a treatable chronic illness on those living with HIV in Ireland. Locating our qualitative study in an interpretivist paradigm and employing purposive sampling, we conducted two focus groups with fifteen members of Irish support organisations for people living with HIV. In all, nine Irish men (five of whom were gay and four ex-IDU) and six women (three of whom were Irish, two Sub-Saharan Africans and one South American) participated. The majority of the women had contracted the virus heterosexually and two women were ex-IDUs. Participants reflected the changing demographics of those affected by HIV in Ireland. Currently new diagnoses occur most frequently amongst young gay men, and infections among men now outnumber women three to one. In the 1980s drug users were the largest group testing positive whereas in the late 1990s and early 2000s heterosexual women, in particular women from SSA, were the largest single group testing positive. Participants self-selected following written approaches to the organisations concerned, and gave written consent to take part in the study. As one of the authors is currently a social worker in a clinic attended by some of the participants, these focus groups were lead by the university-based researcher. Questions asked to prompt discussion included 'What is it like for you now living with HIV? What about relationships? What about support?'

In addition, we conducted two focus groups with nine social workers and counsellors who were members of the HIV counsellors' group, which has a membership of approximately 15 social workers and addiction counsellors, with

one representative on NASC. Participants' views were sought on past and current psychosocial issues facing those living with HIV. Focus groups were held in May and June 2011, and all sessions were recorded, transcribed, analysed for repeated themes and coded accordingly. A clear limitation of the study is that all participants were involved with peer support organisations or employed as HIV counsellors and therefore may represent a particular perspective of those who have significant commitment and involvement with HIV issues. For example, a study of people living with HIV who are not linked in with HIV organisations may present a different picture of stigma management and HIV disclosure, and resulting experience of discrimination (Poindexter and Shippy 2010). Together with the small number of participants this means that the findings cannot be generalised to the wider population of people living with HIV. Additionally as the two researchers have a background in HIV social work, we were challenged to maintain a position of 'not knowing' and avoid inputting our own views on the topic.

Findings

There was consensus between social workers and those living with HIV on four dominant themes that emerged from an analysis of the data, namely:

- Ongoing existence of stigma and discrimination
- Difficulties around disclosure of HIV status
- Continuing need for pre and post test counselling
- The role of peer support in building resilience and challenging HIV stigma

These will be presented jointly below. Other issues raised by participants related to living longer with HIV across the lifespan, such as how to have children safely, coping with side effects of long term treatment, the transition of adolescents to adult HIV services, ageing with HIV and specific issues facing migrants within the asylum system and the homeless. These are reported separately (Foreman 2014; Foreman and Ní Rathaille 2013).

Ongoing Existence of Stigma and discrimination

Several participants talked about prejudice and stigma experienced in online chat rooms like Gaydar, mirroring the reported growth of HIV-related stigma within communities of gay men (Smit et al. 2012).

Oh yes well from a medical point of view obviously it's moved on a lot, but at the same time I think the stigma to do with it hasn't moved on really ... I've told people who don't know that I'm positive that, yes, I had cancer in the past, because it's kind of acceptable, but HIV is not socially acceptable (Person living with HIV (PLWHIV))

Participants also thought that the public remains ignorant about advances in HIV treatment, and the newly diagnosed still react with shock and worry that they are going to die of AIDS.

It's the same as it was in the 80's and the 90's. We're aware of the available treatments, but the newly diagnosed are not ... Those from Sub Saharan countries still see it as a death sentence because that's their experience of HIV (Social Worker (SW))

Participants argued that while treatments have improved, the psychosocial issues and social repercussions of a diagnosis have not, although in some inner-city communities this is not always the case.

It's more openly spoke (about) and it's more accepted in the working class community because when I was diagnosed every second neighbour had a son, a daughter (with HIV) so it was widely accepted there (PLWHIV)

In the past, people with HIV in Ireland have faced discrimination in health care services, in financial and insurance matters, in employment, education and travel and by social exclusion (Murphy Lawless and Redmond 1993; O'Gorman 1999). Participants stressed that this remains an issue, citing experiences of discrimination within the health services, particularly being left 'to the end of the list' by dentists and surgeons. People living with HIV raised the need to keep HIV alive in the public consciousness to tackle stigma and discrimination. They wanted HIV to be more visible, not just on Irish or World AIDS Day.

It's like this is the only time that it comes about you know, that you will hear stuff being done, you know, about the media wanting to do interviews for World AIDS day, or Irish AIDS Day, and after that then it's gone again (what's needed is) the same commitment every day, not just one day a year, then maybe something would change (PLWHIV).

Difficulties around Disclosure of HIV Status

All participants discussed the difficulties of disclosure to sexual partners, for example, one participant talked about the insults that she endured when she told a new partner of her diagnosis. People managed sexual encounters differently with some telling all partners, casual or long-term, and others believing that you need to know that you can trust someone first.

If you didn't tell the person from the beginning, what happens like later on when you decide to tell them, aren't they going to feel betrayed that you never told them? (PLWHIV)

Earlier studies have shown that stigma and discrimination within migrant communities can prevent people disclosing their status and accessing support (Foreman 2008; Foreman and Hawthorne 2007), a point echoed by one South African female participant:

If you tell a friend, she's going to tell another friend, and the other friend is going to tell another friend, and it keeps going and then they'll be saying 'oh she has AIDS, she has AIDS' and that's the stigma (PLWHIV)

In participants' experience, the majority of parents do not tell young children of their own or their parents' diagnosis, which can inhibit their use of support services. The toll of living with a parent with HIV, and of keeping such a secret, has been shown to place a heavy burden on children (Cree and Sidhva 2011). While the national paediatric HIV team encourages parents to tell positive children by the age of 12 parents are afraid to tell, afraid the child will blame them, echoing earlier accounts of difficulties around disclosure to children (Travers 1996).

The stigma and discrimination still affects parents, the secrecy, they put a lot of energy into keeping the diagnosis a secret from everyone, the isolation ... we had one case where the other children in a school knew the diagnosis and the child with HIV was the last one to find out (SW)

Most clinics adopt a multidisciplinary approach if there is concern about non-disclosure to an unknowingly 'at risk' partner (UNAIDS/UNDP 2008), and follow either the Irish guidelines drawn up by a social worker for NASC (Jones 2001), or British HIV Association guidelines (BHIVA 2008). Some believed that there was no need to tell partners if their virus load was undetectable because of evidence that HIV treatment greatly reduces the risk of transmission (Lancet 2011), echoing studies that show a correlation between non-disclosure and those with 'HIV health optimism' (Murphy et al. 2015). To date, there have been no prosecutions in Ireland for sexual transmission of HIV, although all participants were aware of the increased criminalisation of HIV transmission and the growing number of prosecutions abroad (Bernard 2010). Social workers emphasised the fact that even where sexual partners were told, risky behaviour can still take place because of the many contextual and social factors involved.

Continuing Need for Routine Pre and Post Test Counselling?

While post-test counselling is still routinely offered in the majority of specialist clinics, in some hospitals social workers said that they had seen an erosion of their role, with clients who are newly diagnosed with HIV no longer being routinely referred, unless they reacted badly and clearly needed support.

Post test counselling (is) only done if the doctor decides that the person isn't responding well to the diagnosis and needs intervention (SW)

This mirrors concerns expressed elsewhere regarding the depletion of the role of the HIV specialist social worker (Cairns 2011), even though specialist social work support, peer support and counselling are regarded by some health

professionals as the most beneficial interventions for those living with HIV (NAT 2011). Without routine referrals, social workers were concerned that mental health issues might not be picked up early and necessary support work around HIV prevention conducted. One social worker's views mirrored findings of a recent UK study of specialised HIV services where social workers complained about getting referrals as a last resort (Pearmain 2011):

It's frustrating if you get a late referral when the person is in crisis, and have to pick up the pieces, work with the client later. It'd be easier if everyone was referred when first diagnosed and known to the social worker (SW)

Those who had been attending clinics for longer, in some cases for up to 25 years reported that they had good relationships with social workers. However, some participants described getting little if any support when told of their diagnosis, particularly in outlying hospitals, which they stated added to their sense of stress, anxiety and isolation. Even where families were aware and supportive, the need for access to counselling and support was expressed:

All my family know, but I don't think they know what to ask, they just ask how are you doing? Same as anything else, like being gay, they know, but they don't want to know and I don't like to worry them (PLWHIV)

One man diagnosed in 2005 eventually sought counselling through a non-governmental organisation six years after diagnosis:

I never got counselling when I was diagnosed in the hospital. No, so I had to go and get a counsellor myself ... it's helped me ...I was just met by the doctor and he told me and that was it (PLWHIV)

Others want an allocated social worker and would welcome mental health checks at the same time as routine medical checkups. As one person said that it would be good to be asked on a regular basis by a social worker or nurse 'Well, and how are you?'

You see a different doctor every month, they open a file and they start all over again. Would you ever read the notes, a total pain in the arse. But the social worker it's the same person who deals with you (PLWHIV)

Some multidisciplinary teams (MDT) within Irish HIV services have expanded to include clinical nurse specialists, and in some cases psychologists and psychiatrists, disciplines that were not much evident in the eighties. While social workers said that this enhanced the service, collaboration, building relationships and being assertive were all cited as key. It can create an overlap or blurring of boundaries with social workers no longer being involved in helping parents with disclosure to a child and feeling that their role has been reduced to more practical/social or child protection issues. As in other studies (Pearmain 2011), those social workers with offices sited in HIV clinics and in dedicated posts were more integrated into the MDT.

You have to be there. If they have to go looking for you, it'll impact on accessibility and familiarity and how involved you are (SW)

The largest Irish HIV clinic currently has four social workers in post as HIV counsellors. The smaller consultant-led HIV clinics in hospitals outside Dublin do not have dedicated HIV social worker posts. While the hospitals' social work departments can and do respond to any demands made on them by clients with HIV, they cannot offer the proactive service requested by HIV positive participants in our study and available in larger centres (NASC 2005).

The Role of Peer Support in Building Resilience and Challenging HIV Stigma

In exploring what made a positive difference in their lives, those living with HIV identified some clear coping strategies. All participants agreed on the power of peer support, especially in addressing internalised stigma.

I've been coming here (support agency) for a year and before that I was oh yeh it's a manageable chronic disease and that's kind of all I thought about it, I didn't realise how much of a mess that I was because I couldn't tell anyone and how much it was affecting me. I only realised that after I came here, and I was more open about it, I had totally pulled back from other people (PLWHIV)

I think I get my biggest support from other people who are positive ... and maybe over the years I don't realise how supportive we've actually been — you can actually be yourself, you're not careful about what you're saying, you can just be one hundred percent yourself (PLWHIV)

The resilience of those living with HIV for 20 years or more was particularly striking. Those who had disclosed their status to at least some family, friends and partner appeared to cope well. Those who had accepted their HIV status as part of who they are and refused to be defined by it displayed 'stigma resistance' (Poindexter and Shippy 2010).

Discussion: Just another Long-term Chronic Illness?

Despite the advances in medical treatment, our study indicates that stigma and discrimination remain ongoing challenges for people living with HIV. Although the majority of those interviewed who were living long term with HIV have adjusted well, some clearly continue to struggle with disclosure and resulting discrimination and those more recently diagnosed still seek help with adjusting to a stigmatising condition.

The impact is different to cancer, it's not the same. It takes longer to adjust, because of the stigma and fears around disclosure, to partners, to families (SW)

Goffman (1963), who defined stigma as any attribute that carries a negative social identity, influenced early interventions to combat HIV stigma (Herek 1999). However, Parker and Aggleton (2003) have argued that Goffman's emphasis on stigma as an attribute rather than as a constantly changing social process has limited past interventions which aimed to increase tolerance and understanding of those living with HIV, and reduce fear and anxiety by providing 'correct' information. They argue that Foucault's (1978) work more clearly illustrates the cultural production of difference in the service of power, and suggest that an understanding of power, culture and social inequality are essential to properly combat HIV stigma, particularly when marginalised or socially excluded groups such as IDUs and MSM are affected. Link and Phelan suggest that stigma exists when 'elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold' (2001, 382) and as a result any approach to change stigma must be multifaceted and multilevel.

The reasons for HIV related stigma, and the discrimination that can follow it, are clearly complex. While they can include a lack of understanding about HIV and its transmission they can also reflect prejudice, social fears about sexuality, drug use, migration, illness and death as well as irresponsible media reporting (Parker and Aggleton 2003), and HIV discrimination can be reinforced by and dependent on racism, xenophobia, sexism and homophobia (Dodds 2006).

Challenging Stigma

The Irish Stamp Out Stigma report on public attitudes and personal experiences of stigma found that people living with HIV experienced significant levels of stigma and discrimination from families, friends, at work, and in accessing health and social care services. Interestingly, those living with HIV thought that they were viewed more negatively by society than they actually were (Public Communication Centre 2008). Thus as Deacon (2006) remarks, even when there is no discrimination present, individuals may expect to be discriminated against and become more withdrawn. Internalising stigma can result in a poorer quality of life, depression or lack of self-esteem, preventing people from testing, seeking treatment or disclosing their HIV status (Jeffries et al. 2015).

Although it is accepted that stigma can be a major barrier to effective HIV prevention and care (ECDC 2010), HIV stigma reduction efforts are often relegated to the bottom of HIV programmes (Mahajan et al. 2008). A review of Ireland's HIV Education and Prevention Strategy was mixed. While advances have been made in several areas, with some action in relation to awareness raising and training on stigma and discrimination, implementation has been limited and patchy (NASC, 2011). Study participants called for more awareness raising campaigns and while there is no evidence to suggest that such campaigns

change attitudes, they may contribute to change if they are part of a larger action plan with targeted projects, creating the right environment for change to take place (Parker and Aggleton 2003). Reidpath et al. (2005) argue for the development of strategies that will increase the social value of those who are stigmatised. Interventions which have been shown to prevent stigma and challenge discrimination include empowering those living with and affected by HIV through education, counselling and community mobilisation to resist stigma and discrimination and, adopting a rights-based approach and supporting challenges to discrimination through existing laws (Deacon 2006). To date, there has been two successful legal cases on the island of Ireland. One case, taken against a chiropodist who refused treatment to a person with HIV, was regarded as groundbreaking in tackling stigma and ensuring access to health services (Equality Authority 2009). In the other, a HIV positive person successfully sued a Northern Ireland hospital through the Equality Commission after he received less than optimum treatment because of his HIV status (McDonald 2009). Both cases confirm that as well as having negative health consequences stigma can result in the provision of services of a lesser quality (Reidpath et al. 2005).

To Tell or Not to Tell

Having control over if, how and when to tell others about one's HIV infection is seen by many as one of the basic principles of a human rights approach to HIV (Dodds, Keogh, and Weatherburn 2004). The stigma and discrimination experienced or feared by study participants living with HIV continues to impact on whether they disclosed their HIV status to partners, families or friends, mirroring Bravo et al.'s (2010) review which highlighted disclosure as one of the most difficult decisions facing people living with HIV. As well as HIV health optimism (Murphy et al. 2015) factors affecting non-disclosure to partners are known to include fear of relationship breakdown, of loss of confidentiality and of domestic violence (Ní Rathaille et al. 2004; WHO 2004). Disclosure and concealment of HIV status can have both positive and negative consequences. While disclosing to family and friends has been shown to be of benefit, promoting health, social support and psychological well-being (Smith, Rossetto, and Peterson 2008; WHO 2004), disclosure of HIV status to partners, family or friends has also resulted in rejection, abandonment and isolation (Cairde 2004; Doyal and Anderson 2005). In the EMIS survey of MSM, only 57% of Irish gay men were 'out' about their sexuality, and 68% of Irish men living with HIV reported that they avoided telling others about their diagnosis. Additionally, over a quarter had been treated less favourably or had been shunned or avoided sexually when someone learnt that they had HIV (The EMIS Network 2013). While the majority of those living with HIV in our study manage stigma by selectively disclosing, others openly disclose and refuse to accept negating images, thus resisting stigma (Poindexter and Shipley 2010).

Implications for Social Work Practice

'Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, communities and nations' (United Nations 2001:13)

People with HIV are living longer and the number of those infected continues to grow. In Ireland, as in the rest of the Western world, while there have been many advances in HIV care, our small study indicated that some of those living with HIV still experience stigma and discrimination which can impact negatively on their mental health, affecting disclosure of their HIV status to family and sexual partners, and their ability to engage with treatment regimes. Similarly, BHIVA (2011) have reported that psychological problems in people with HIV have not reduced in line with medical problems. The centrality of the role of social work in supporting those infected with and affected by HIV since the late eighties has changed in that pre- and post-HIV test counselling no longer routinely occur. There is now a danger that in the rush to normalise HIV as a chronic treatable illness, people are being left on their own to cope with its broader psychosocial impact and many no longer feel cared for. Social workers need to ensure that stigma is addressed in assessments, and should advocate for continuing resources for psychosocial support for those living with HIV as they adjust to difficult life transitions. Additionally, social workers who understand the broader context within which people take risks can be a powerful resource in HIV prevention. Despite medical advances such as PrEP (pre-exposure prophylaxis) and providing HIV treatment as prevention (Lancet 2011), it remains essential that those engaged in risky behaviours are given the option of counselling to allow for focused discussion on risk behaviours. Social workers can draw on existing frameworks to help clients make decisions around disclosure to future and existing sexual partners and their broader social network (Chaudoir and Fisher 2010; Serovich 2000).

The social workers in our study had good insight into the issues facing those living with HIV but their emphasis was on working with clients and families. Despite their membership of the HIV Services Network and NASC, there was a lack of discussion on engagement in wider policy issues such as advocacy for the implementation of the National Sexual Health Strategy (Layte et al. 2006), which is still in development. The freeze on public sector posts in Ireland, cuts in health service budgets and the increase in those being diagnosed with HIV and remaining well on treatment all impact on social workers' time and their ability to engage in wider policy issues. Adopting a human rights approach (UNAIDS and OHCHR 2007), social workers should strive to share their knowledge from practice and continue to work in partnership with peer led HIV community-based organisations, to identify shared issues, lend support to those advocating to change discriminatory social policies and challenge culturally borne prejudices. With support, people living with HIV can build 'stigma

resistance' (Poindexter and Shippy 2010) and in the process shift responsibility for addressing HIV stigma and resulting discrimination, rejection and exclusion to society as a whole (Link and Phelan 2001). Positive Now, an all Ireland network of people living with HIV which was established in 2010, has highlighted the shared responsibility of society, institutions and health care professionals as well as people living with HIV to challenge HIV-related stigma and discrimination, and invites all of us to take part in a continuing conversation about these and other issues, 'as equals beyond client-professional relationships' (Positive Now 2014, 24).

I've no problem with being who I am, because it is who I am, so if I need to tell someone and they reject me that's not my problem, that's their problem (PLWHIV).

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