

Information disconnects for people infected with, or affected by, HIV/AIDS in the United Kingdom

Direct Research Journal of Social Science and Educational Studies (DRJSSES) Vol.2 (2), pp. 38-44, February, 2015

Available online at directresearchpublisher.org/drjses

ISSN 2449-0806 ©2015 Direct Research Journals Publisher

Short Communication

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Accepted 19 February, 2015

This paper describes the results of an ethnographic which set out to generate in-depth knowledge of the real world “lived information experiences”, including the complexities and subtleties of HIV/AIDS related information behaviour and the factors that influence this behaviour within the context of people affected by HIV/AIDS. The ultimate aim is to determine the potential role that information management could play in the fight against HIV and AIDS. The focus of this paper is “information disconnects”, one of the contextual factors that influenced access to and use of HIV and AIDS related information. The results of this

investigation are discussed in the context of the feasibility of developing an HIV and AIDS- related information strategy to address the identified information disconnects by guiding the design, management, and dissemination of usable, accurate, reliable and up-to date HIV/ AIDS-related information required to mitigate HIV /AIDS.

Key words: HIV/AIDS, information overload, misinformation, stigmatising information, information disconnects

INTRODUCTION

HIV is a biological, social and cultural phenomenon; hence attempts to fight HIV cannot focus only on the search for a vaccine, or a pharmacological cure. An HIV diagnosis is a life-changing event hence attempts to manage and prevent HIV must also take into account the complex social and cultural interactions that can both help and hinder the spread of the disease (Seale, 2004). The analysis reported here forms part of a larger doctoral study which seeks to develop understanding of the complex information behaviour of persons infected with or affected by HIV/AIDS, and to identify factors that impede or enhance the effective distribution, discovery and application of appropriate information. By doing so, it aims to illuminate the potential role of HIV/AIDS related information management in mitigating the health, social and economic challenges of the epidemic.

Research aims

The aim of the analysis reported here was to generate a rich picture of problems with information disconnects experienced by people affected by HIV/AIDS. The study sought to generate in-depth knowledge of the real world “lived information experiences” of people affected by HIV/AIDS, in order to try to understand the complexities and subtleties of HIV/AIDS-related information behaviour within the broader context of people’s lives.

METHODOLOGY

The study adopted an ethnographic approach (Bow, 2002; Hammersley and Atkinson, 2007; Pickard, 2007;

Schensul et al., 1999; Twibell, 2005) which was selected since the intention was to understand HIV/AIDS related information behaviour of people affected by the disease as far as possible from their own perspectives. A sample of 40 persons in the UK directly or indirectly affected by HIV/AIDS was selected. It included a range of age groups, disease stages, sexual orientations, and educational and ethnic backgrounds. 26 were people infected with HIV; six were affected by HIV in other ways; and eight were involved in the provision of information and support.

Respondents were recruited through support workers within an HIV/AIDS support group where the researcher worked as a volunteer. In-depth individual interviews were conducted using an open-ended interview schedule. Interviewees were asked to recount specific experiences, and the researcher's intention was to understand the world from the respondents' points of view. Spradley's analytical model of ethnographic analysis (Gorman and Clayton, 2005; LeCompte and Schensul 1999; Spradley, 1979) was employed for the data analysis.

Findings

This paper focuses on disconnects with HIV/AIDS-related information, and looks at how these problems might be overcome to find ways to empower persons infected with, or affected by, the condition to access and use HIV/AIDS-related information in the journey of living with HIV. The following sections present five information disconnects identified in the study.

Lack of information

Many of the persons infected with HIV experienced a serious lack of information. Although they needed information to make important decisions, including when to start medication, how to disclose their HIV status, how to start new relationships, this information was not readily available. For example the following quotes illustrate that persons could not readily access the information they needed, particularly at the time of diagnosis.

"...I needed to know what the medications are going to do. I could not find any of this information. ...I needed more information but I couldn't get it. I had to go through emotions and I would not take the pill unless I knew all about that pill and all that it is going to do to me. That is what I had to fix on my head and it was really hard. Really, really, really hard" Jane [person infected with HIV].

"But time and again, I am tired all the time, absolutely tired and that confuses me because I can not know whether it is the diabetes, or my HIV because with

diabetes you fall asleep a lot. I don't I don't think there is enough information at this place, it is only verbal." Ruth [person infected with HIV]

"... the newspapers and TV media are saying lay down and take it, protect yourself first do not get it and then there is no information after that. There is no information saying that if you get HIV it is sustainable, if you get it traced in time, and you have not let your body go down too far down ill. So with them they say do not get it, protect yourself. They do not say if you have it get moving now". Lora [person infected with HIV]

Without the requisite information, persons infected with HIV live with uncertainty because they cannot readily find answers to life issues. Uncertainty makes living with HIV a lot harder. The concerns raised by persons infected with HIV suggest that information is a very vital component as far as living with HIV is concerned. Hence the availability of biomedical information, psychosocial information and practical information has the potential of improving the quality of lives of persons infected with HIV. However, although a lack of information was a problem, so was having too much information.

Excessive information

Information overload was a major problem associated with HIV/AIDS-related information. Respondents complained feeling overwhelmed by the large amounts of HIV/AIDS information, particularly on the internet. They were distressed by too much, and contradictory, information because it was difficult to work out which information to use. Respondents also complained that official websites also bombarded them with too much information. This sometimes resulted in avoiding or destroying information. For example Job [person infected with HIV] was overwhelmed by the weekly emails and resorted to just deleting the emails because the information was too much.

"..... I get my information from very reliable sources, official websites. I do not get them from random websites but because there is so much information. I subscribed to NAM HIV weekly, there is a weekly email that goes out with information and as somebody with HIV that is just too much information. So I now do not look at that information, I delete it off my email.I emotionally panic and get distressed by new information. There is just so much information it is too overwhelming."

Too much information soon after the diagnosis was frightening to persons infected with HIV. For example Justus [Information provider] said that too much information too soon can be dangerous.

“...That is the problem with information on the internet you may get scared from reading it. But if you find information that starts with the basics and continues to complex issues it can make sense. I think it is dangerous to take pieces of information from here and take pieces of information from there because you can come to all wrong conclusions by reading it. Yeah you cannot teach a 5 year old using material of a 16 year old. There is need for some basic information and build from. Too much information too soon can be dangerous”

Julius [person infected with HIV] also expressed a concern that too much information too early can be frightening.

“...The down side or the bad information is taking too much information taking too much detail at once at the beginning of a diagnosis. It can be very frightening. It may also cause damage if you read things on the basis which is happening to yourself and you just to take it in bit by bit on board.

Too much information too soon does not help as people get scared and stop accessing and using information. The need for providing information with support was expressed.

“...You know when people are just diagnosed they are afraid and too much information too soon would not help. Some people are so afraid and as a result they bury their heads in the sand. Others are happy to look for as much information as they can. Sometimes they find so much information that they get so scared. Hence they need guided information, they need information with support, have things explained, and they need the human face” Joy [information provider]

Information providers also expressed frustration that information came out in tremendous amounts and changed frequently. Too much information made it hard to work out what the right information was, and this created uncertainty.

“... The booklets and leaflets, ... they send too many out too often. Do you know what I mean? Update after update. Contradictions in the main articles that come out. That is not always great. Do you know what I mean? and it is quite difficult if you are giving out information that actually changes every now and again and it changes so quick so soon.” Ritah [Information provider]

From the quotations above, information overload is a serious hindrance to accessing and using HIV/AIDS-related information. This was not only frustrating to persons infected with HIV but information providers, who reported that information provision was made difficult by information changing so often. Information overload

early in the diagnosis was frightening and the need to disseminate information systematically, starting with the basics, was emphasized.

Alarming, worrying, upsetting information

Many informants reported finding HIV/AIDS-related information alarming, upsetting and worrying. Biomedical information, including information on medications, their side effects and information on quality of life, e.g., possible physical and mental deterioration could create uncertainty which left persons infected with HIV alarmed, scared, disturbed and frustrated. Information on side effects of medications planted a seed of fear in the minds of persons infected with or affected by HIV and AIDS because when they read about complex conditions such as dementia or meeting premature death they thought this would happen to them.

“I could die from a heart attack I could die from diabetes, I could die because my medications stopped working, but I am doing everything within my power from the information provided. I mean there is new information coming and the big thing for me that terrifies me absolutely is developing dementia sooner” Job [person infected with HIV]

Respondents found information on drugs worrying, confusing and unhelpful:

“I find the various information on drugs frustrating and unhelpful. You know there are so many different research projects going on,... there being so much information is a bit frustrating and unhelpful because you get very confused, and very worried because of contradictory information.” Jack [person infected with HIV]

Jane [person infected?] also described the scary information she received from books:

“The worst information for me was the books that they give you, you read about the worst stages of HIV. It said when you get on medication you will suddenly get so ill. They talk about people who have had it for so long. The bad experiences they have had. The books talk about that quite a lot”

The information providers in this study also acknowledged that HIV/AIDS-related information tended to scare people infected with HIV.

“...we have clients who when they read something for instance one of them opened an article and read something which said ‘Increased risk of cancer from HIV medications’ and he froze, because he thinks that everything that can happen will happen to him. So he

just saw this headline, increased risk of cancer and he started sweating worrying, freaking out” Justus [Information provider]

Stigmatising information

Respondents reported Stigmatizing information as a major problem as far as HIV and AIDS-related information is concerned. HIV and AIDS related information was stigmatizing when information portrayed HIV in a negative light, especially when HIV and AIDS related information was used as a signifier of guilt.

“... The newspapers are saying all these ugly things regarding HIV There has been a lot of bad press saying: someone has infected somebody else, they have gone to court and they are being sentenced to 5 years imprisonment and it wouldn't make things brighter for people who have got HIV because it puts people in a depressive state of mind where they isolate themselves, they feel they can't go and do what they want to do, they feel they are quite limited of things they can do.” Julius [person infected with HIV]

Ritah [information provider] also suggested:

“The other times you can get it [HIV] in the press, is when an HIV person is facing prosecution for transmission. And so often you may also see it is a side column saying “Immigrant gives somebody HIV”, or man “purposely gives woman HIV”, now obviously that does not always help stigma. So you do see that HIV only features in papers when somebody has given it to somebody.

Popular culture only reported about HIV when it was linked with something that already had stigma such as immigration or crime. Hence, popular culture was described as portraying HIV as a signifier of guilt shame and crime.

“HIV is something that is not put in under consideration unless they already link it with something that already has stigma such as Immigration. In news papers every time I hear about HIV is like , an immigrant has infected someone with HIV. This one with HIV has raped the other one”. Claire [information provider]

Respondents also reported that popular culture was not interested in disseminating the vital basic information on HIV and AIDS. Hence the way HIV was represented in popular culture was not beneficial as far as the prevention and management of HIV is concerned.

“You can never hear information teaching about HIV or research findings about HIV. Actually it is an ignored area. People still think HIV and AIDS death. It is an

“African thing”, it is “Gay thing” it is not for you and me. Supposedly asylum seeker or gay rapes girl, you know kind of things like that so it becomes a signifier of guilt. You know but the TV programmes have been sensational. They have given the visibility but they have not challenged the stigma. So where HIV has featured in popular culture it has not been necessarily beneficial. In the 1980 HIV was associated with fear, guilt and this has not been challenged today because it is still something that is attached to gay men, African people and young people” Sarah [person affected by HIV]

Unpleasant terminology and strong metaphors, including “killer disease”, “deadly plague”, “HIV positive”, and “germs” that are used when referring to HIV were felt to be extremely stigmatizing to people infected with HIV and embarrassing to members of the community. Use of such strong metaphors created unnecessary and unfounded fear about HIV and persons infected with or affected by HIV. As Hope [person infected with HIV] suggested:

“.... They say that it is a killer disease. That is it. You know!!! KILLER DISEASE!!! They say it's a killer disease. Can you associate with someone who has got a killer disease? [Respondent laughs] Can you eat with somebody who has got a killer disease? You can not. Why should you come near, he is got a killer disease, you never know maybe by touching him you will catch it, so the way HIV is called described, they need to use professional words, you know that KILLER DISEASE is a strong word to use. [Respondent laughs]”

Respondents felt that popular media employed terminology that apportioned blame to persons infected with HIV. This information more often than not influenced members of the community to stigmatize persons infected with HIV.

“You see the media uses terminology like the HIV victim or innocent victim; you know the terminology used is like it just puts blame to the HIV positive person. It is the other one who got it who is innocent, ‘is the poor them’; the one that transmitted the disease ‘is the guilty one’, ‘the bad one’. So we see in that way, media has greatly influenced communities to stigmatise people with HIV because of the terminology they use. There is also the case of using terms like oh it is a gay plague. ...they just say whatever they want to say like last time there were saying, “ooh a cure might be found for this deadly plague. Something which brings fear to people.” Susan [Information provider]

Persons infected with or affected by HIV became stigmatized when HIV and AIDS related information only emphasized sex. This was reported to create a negative feelings among persons infected with HIV because it

created an impression whoever contracts HIV must have been promiscuous.

“Information on the TV may be scary to the sufferers, because you can get stigmatised from it. I mean at the end of the day, the TV, when it came on TV it was purely sex they were throwing out. They weren't saying you can get it through this; you can get it through that. We have had to learn that along the way. I think if there is going to be anything on TV it would have to be some kind of documentary that is explain everything. That puts everything there, not that one thing just sex, because people automatically become stigmatised by that. You get a cold status. You know, she sleeps around with anybody or he sleeps a round with anybody and that is not always the case. I mean it may be true for some cases but it is not true for every case”. Lora [person infected with HIV]

The popular media were also accused of disseminating simplistic, racist, sexist, stereotyped and stigmatizing information. For instance, Joy, who did her PhD on HIV and communication, focusing on media houses told me that:

“when I did my PhD noticed that people dealing with disseminating HIV and AIDS information especially in the popular culture do not have adequate knowledge about HIV. The information they provide some times perpetuates stigma; the information is full of stereotypes of the 80s and there has not been enough work done to update the public that HIV has now transformed from a death sentence to a chronic manageable illness. HIV is portrayed as a disease for black Africans and it is sometimes too simplistic.”

The above multiple voices concerning stigmatizing information demonstrate that persons infected with HIV get emotionally disturbed by information portraying HIV and AIDS in a negative light. In contrast, disseminating positive information about HIV and AIDS has the potential of reducing the stigma, fear and prejudice surrounding HIV.

Misinformation

Respondents expressed their frustration with misinformation associated with HIV and AIDS. In some cases, respondents reported that they received wrong information about important aspects of life, for instance whether a person infected with HIV can have children or not, whether a person infected with HIV could be buried or cremated. These were important issues in people's lives, hence misinformation on those issues was distressing and frustrating. The quotes below illustrate this:

“...when I was diagnosed they told me I couldn't have

any children that were 14 years ago, so why do positive people now get pregnant? And they said to me unless you have £5000 to spend we cannot do it for you. If you don't have money, go away. I can't understand why they did this to me” Juliet [person infected with HIV]

“I thought that we have to be cremated. I thought we did. I thought that that's what happened that we have to be cremated. In the olden days that's what happened. You had to be cremated. In the olden days they thought that if we were buried we would contaminate the earth. That's right. When I told her about that and she did not want to be cremated she looked so disturbed. I said you know don't take my word as gospel truth, come and ask at [organisation]. That is old information I have read long time ago, I never questioned it and I took it as gospel truth” Jane [person infected with HIV]

False information was frustrating and distressing to persons infected with HIV hence the need to disseminate correct and up-to-date HIV and AIDS related information cannot be over emphasized.

In addition to receiving false information, respondents received over-dramatized information, including myths about HIV transmission. In the context of this study, over-dramatized information refers to exaggerated information. Respondents reported instances when HIV/AIDS-related information was exaggerated. Over dramatized information also resulted in excessive fear for persons infected with HIV which was demonstrated through destroying beddings, cups and other items used by a family member infected with HIV. In other cases people feared to share cups or even touch a person infected with HIV.

“People fear sharing cups, even others when they touch somebody who is HIV positive they say oohh nooo!!!. You know like I had a friend she was complaining. She went to the brother's house, and she was HIV and they said "whatever she used, take them and bin them we do not want to transfer it to our children". So they had to bin all the beddings and everything she used. Because they were scared that she will transmit HIV to them. That was terrible. She said I will never go to my brother again, I said no its just lack of knowledge you do not have to hate your brother because of that. He doesn't know anything about it but once he finds out the truth he can't do that. So most of these people don't know anything. And that makes them treat people with HIV badly.” [Hope Person infected with HIV]

Over-dramatized information was threatening to persons infected with HIV. This quote from Jane bears witness to this:

“It was over dramatised how you can catch it. About the tooth brush. Before I had my THT course I had thought

my daughter could get it by using my toothbrush. ... I thought that you could get it like that. I thought if you used the same fork you could get it like that, I don't know where it comes from but misinformation is the worst. It sends you a bit crazier". Jane [person infected with HIV]

Provision of correct information about the routes of transmission of HIV can go a long way towards reducing unnecessary fear and hostility that surround HIV and AIDS. Accurate up-to date information has the potential to demystify HIV/AIDS. Hence members of the community will gain the confidence to relate with persons infected with HIV.

Stereotyped information was also another form of misinformation that persons living with HIV experienced. The stereotypes also created a sense of hopelessness as persons infected with or affected by HIV always thought of an impending death.

"...especially at the beginning I did not have any clue, neither me nor my mom really knew what it [HIV] meant. Because my dad found out really late and he was really ill. It was a hard time because all we had were the stereotypes of what HIV was in the 80s, that it was a death sentence]." Sarah [person affected by HIV]

Mary [information provider] discussed the stereotypes regarding HIV.

"...it's really, really hard to break cultural beliefs or beliefs that people have held for so long. Like when the first cases of HIV came out, basically, the first cases were homosexuals, so people held onto that message that it's just for homosexuals. And some still up to now because today [at the conference]it came in a message that it's for hetero sexual who are promiscuous and other people held onto that. Up to this day people hold on to that message that, no, you can't get it if you are not promiscuous ,or if you are not gay or anything like that."

Respondents reported that stereotypes of the 1980s were mainly perpetuated by the popular media, including the TV and Newspapers. These quotes illustrate ways in which popular culture perpetuate stereotypes of HIV.

"HIV isn't really visible in Britain today you know it's not on the news not on TV programmes very often and when you do see it is very much sidelined, like a, ummm, used to dramatise a storyline on a soap. It's not a main story, ...that is why the AIDS stereotypes of the 80s seem to be perpetuated. People are more reminded of being gay, sex deviant and so the fear still exists because it is not publicised." Claire [information provider]

Stereotyped information, especially one portraying HIV as a death sentence, resulted in hopelessness which

made living with HIV so depressing. Provision of up-to date information, particularly about new medications that have transformed HIV from being a death to a chronic illness can go a long way to restoring hope for persons infected with, or affected by, HIV/AIDS.

RESULTS AND DISCUSSION

Key findings that emerged in this study indicated important problems with HIV/AIDS-related information making it extremely daunting. Respondents not only experienced both a lack of information and excessive information, as well as alarming, and upsetting information, stigmatising information and misinformation.

The popular media in England disseminated information which portrayed HIV/AIDS in a negative light. The respondents reported that popular media not only employed metaphors such as killer disease, gay plague, victims, when reporting about HIV and AIDS but they also employed stigmatising imageries which portrayed HIV as an invisible contagion, a moral punishment for sinful behaviour and a signifier of guilt. HIV was also portrayed as a disease of a few and a threat to many. This, in some cases, not only stigmatised persons infected with or affected by HIV by depicting them as the guilty, dangerous and deviant others, it also deluded the public into believing that they are safe from contracting HIV/AIDS. Hence HIV was perceived as an unseen influence transmitted by virtually any contact with an infected person –whether this contact was with the body surface, body wastes or even with the air that they breathe.

Popular media sometimes disseminated sensational and incorrect information and this was not useful as far as the prevention and management of HIV is concerned. For example Helman (2001) commented that that the metaphors of HIV and AIDS have serious implications from a medical anthropology perspective as they may impede rational assessment of the risks of HIV and how it is to be prevented and managed. Hence interventions geared towards disseminating the basic information basic information on HIV and AIDS, including the prevention and management of HIV are urgently required. Accurate and up-to-date information about HIV should demystify the myths surrounding HIV and empower persons infected with, or affected by, HIV/AIDS, as well as service providers in their dealings with the condition.

Respondents were frustrated by the large amounts of HIV and AIDS related information found on the internet, leading to information overload, and information being contradictory and incorrect. This resulted in negative information behaviour, including destroying or deleting information and avoiding information. The internet contained information which could be upsetting and frustrating to persons newly diagnosed with HIV. Information providers as well as persons infected with HIV reported instances when information from the

internet panicked people. Information on the internet is not regulated. The above observations about information from the internet imply that information overload hindered persons infected with HIV and AIDS from effectively benefiting from the information from the internet.

The final interesting finding was that disconnects in HIV/AIDS-related information ultimately resulted in a dire lack of HIV/AIDS-related information. Lack of information resulted in double-sided dimension fear: the fears of people who have HIV and the fears of the rest of the society about people with HIV and their own perceived risk of infection. For persons infected with HIV, the lack of information resulted in uncertainty including acute fear of developing AIDS, guilt, fear of the unknown future and painful death, fear of other people's reaction mainly rejection. For people without HIV lack of information resulting from misinformation, stereotyped information and over dramatised information resulted in apathy and excessive fear of persons infected with HIV. Ignorance about HIV was reported to perpetuate prejudice and stigma around HIV.

CONCLUSION

This paper has demonstrated that persons infected with HIV/AIDS face a number of information disconnects including lack of information, information overload, stigmatising information and misinformation which in most cases resulted in ultimate lack of information. The findings indicate that information disconnects not only made living with HIV/AIDS very difficult but it jeopardised efforts to prevent and manage HIV and AIDS. In view of the information disconnects and the associated effects on efforts to prevent and manage HIV/AIDS, we conclude that there is an urgent need for a clear HIV and AIDS information. Interventions should be geared towards addressing the disconnects associated with HIV/AIDS-related information in order to educate, and empower communities with knowledge about HIV/AIDS. A clear HIV/AIDS-related information strategy could potentially empower persons infected with, or affected by the condition in the following ways by:

- (1). Knowing that there is information help have good quality of life.
- (2). Knowing that the information is simple and readily available.
- (3). Knowing that information they receive is correct and reliable.
- (4). Knowing that the information will not scare them.
- (5). Knowing that the information will be appropriate, relevant and understandable.

On the other hand, an HIV/AIDS-related information strategy would potentially provide for structures, policies,

practices and tools geared towards potentially empowering members of the community in the following ways:

- (a) Making available correct and up-to-date basic information about HIV/AIDS to demystify the condition.
- (b) Educating people that HIV/AIDS is an illness which can infect anyone.
- (c) Helping people understand that they need information on HIV/AIDS.
- (d) Reducing the stigma prejudice and fear surrounding HIV/AIDS.

Such an information strategy would be of benefit both to persons infected with, or affected by HIV/AIDS, but also to the rest of the population.

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