

# Research Repository UCD

Title	HIV-positive patients' experiences of stigma during hospitalisation
Authors(s)	Surlis, Siobhan, Hyde, Abbey
Publication date	2001-11
Publication information	Surlis, Siobhan, and Abbey Hyde. "HIV-Positive Patients' Experiences of Stigma during Hospitalisation" 12, no. 6 (November, 2001).
Publisher	Elsevier
Item record/more information	http://hdl.handle.net/10197/4203
Publisher's statement	This is the author's version of a work that was accepted for publication in Journal of the Association of Nurses in AIDS Care. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in Journal of the Association of Nurses in AIDS Care (Volume 12, Issue 6, November–December 2001) DOI:10.1016/S1055-3290(06)60185-4 Elsevier Inc.
Publisher's version (DOI)	10.1016/S1055-3290(06)60185-4

Downloaded 2024-03-13T04:02:15Z

The UCD community has made this article openly available. Please share how this access benefits you. Your story matters! (@ucd\_oa)



© Some rights reserved. For more information

Preproof version. Definitive article available:

Surlis, S. and Hyde, A. (2001) 'HIV-positive patients' experiences of stigma during

hospitalization'. Journal of the Association of Nurses in AIDS Care, 12 (6):45-54.

Contact: abbey.hyde@ucd.ie

HIV **POSITIVE PATIENTS' EXPERIENCES OF STIGMA** DURING

HOSPITALISATION

Abstract

The aim of the research to be presented in this article was to explore, within an Irish

context, HIV positive patients' experiences of hospitalisation, and particularly their

experiences of nursing care. This paper reports on one of the dominant themes to emerge

in the study - the experience of stigma among persons living with HIV during their

hospitalisation. A volunteer sample of 10 former in-patients of hospitals in the Republic

of Ireland's capital, Dublin, were interviewed in depth, and data were analysed using a

qualitative content analysis. Findings indicate that while some participants experienced

stigma from nurses, such stigma was stratified according to the means by which the

disease had been contracted, with drug users expressing the greatest feelings of stigma

from nurses. Data also suggest that the location of nursing care favoured by many

participants was segregated care in specialist units, because it enabled them to avoid

being discredited by other patients who did not have the virus, as well as potentially

1

offering social support from like-situated others. Finally, patients experienced breaches in confidentiality because of institutional policies that made their disease conspicuous, and from some nurses' nonchalance in handling information about their disease. The analysis draws on Goffman's conceptualisations of stigma to explain the social process underlying participants' accounts.

*Keywords*: HIV, AIDS, Nursing Care, Stigma, Confidentiality, Homosexuality, Drug User, Republic of Ireland.

#### INTRODUCTION

When the AIDS epidemic first emerged in the early 1980s, health care providers, like the general public, were frightened and many had reservations about caring for people with HIV/AIDS (Lewis, 1988). Since then, while enlightenment on the issue has appeased much of that early disquiet, Pratt (1995) has noted that fear, ignorance, and prejudice are the major barriers to effective nursing care of patients with HIV/AIDS. This article reports on research that aimed to explore HIV positive patients' experiences of hospitalisation, with particular reference to their experiences of nursing care, within an Irish context. A prominent theme to emerge in the study was the experience of stigma, and this concept is the focus of the paper.

The argument being advanced in this article is that while HIV positive patients experienced stigmatising attitudes from some nurses, the degree of stigma related to the

mode by which the disease was acquired, with drug users reporting the greatest level of stigma. It is also suggested that segregated care was favoured by HIV positive patients in this study because it prevented them from becoming 'discredited' individuals in the face of 'normals' or those who do not have the virus, and also offered the possibility of social support from those in the same predicament. Finally, it is proposed that both institutional policies and nurses themselves were responsible for discrediting HIV positive patients by paying insufficient attention to matters of confidentiality.

#### **Literature Review**

The volume of literature on the topic of HIV/AIDS has escalated greatly in the past 15 years. This brief review will focus on issues of most relevance to the notion of stigma experiences for those individuals living with HIV/AIDS while being 'cared' for by health-care providers, such as nurses. These issues centre on staff attitudes, the location of nursing care (special versus general units), and the issue of confidentiality.

Nurses' attitudes have been found to have an impact on the experiences of persons living with HIV/AIDS (Armes & Higginson, 1999; Beedham & Wilson-Barnett, 1993, 1995; Kermode, 1995; Schietinger & Daniels, 1996). Beedham & Wilson-Barnett (1995) reported that 96% of respondents in their study stated that the aspects of nursing care which were seen as most important related to staff attitudes rather than competence or effectiveness of treatment. Participants in research by Schietinger and Daniels (1996) and more recently Armes and Higginson (1999) also highlighted the importance of health care

providers' attitudes, with both studies suggesting that this was an area in which further training was required.

In a qualitative study, Kermode (1995) explored patients' perceptions of nursing interventions during hospitalisation with their AIDS-defining illness. Being touched, being checked on, the friendliness of nurses, together with comfort-giving and a sense that nurses cared, were identified as most helpful nursing interventions. A later study by Cederfjall and Wredling (1999) of gay HIV-infected men's encounters with health providers echoed much of Kermode's findings in relation to how participants constructed good experiences of nursing care.

Several studies identified nurse respondents who felt that people with HIV were to blame for getting their illness (Armstrong-Esther & Hewitt, 1990; Breault & Polifroni, 1992; Eliason, 1993; Kelly, Saint Lawrence, Hood, Smith, & Cook, 1988; McCann & Sharkey, 1998; Melby, Boore, & Murray, 1992). Furthermore, it been demonstrated that there is a significant association between nurses' attitudes to HIV/AIDS patients and attitudes towards homosexuals (Cole & Slocumb, 1993; Eliason, 1993; Kelly et al., 1988; Kemppainen, Dubbert, & Williams, 1996; Melby et al., 1992; Preston, Forti, Kassab, & Koch, 2000; Young, 1988) and intravenous drug users (Carroll, 1993; Melby et al., 1992). In a quantitative study about nurses' attitudes regarding homosexual patients with a diagnosis of either HIV or leukaemia (Kelly et al., 1988), homosexual patients were evaluated much more harshly than heterosexual patients, regardless of the diagnosis. In contrast, a qualitative study by Breault and Polifroni (1992) found that homosexuals were

granted some leniency by the belief that they were not to blame for having AIDS. In the same study, some respondents held that intravenous drug users and prostitutes were partly responsible for their illness. Preston et al. (2000) found that among rural nurses, attitudes about homosexuality significantly impacted upon their willingness to nurse HIV/AIDS patients.

Despite these reportedly negative attitudes of some nurses towards people with HIV/AIDS, there is also evidence in the literature that justice and fairness mediate nurses' perceptions of those living with the virus. For example, nurse respondents in a number of studies indicated that people with HIV/AIDS deserved fair treatment (Armstrong-Esther & Hewitt, 1990; Dols & Bradley-Magnuson, 1996; Eliason, 1993; McCann & Sharkey, 1998). Furthermore, while some studies have found considerable levels of homophobia among nursing students (Eliason, 1998; Schlub & Martsolf, 1999), others have reported relatively low homophobic scores among nurses (Erlen, Riley & Sereika, 1999). In observing nurses' interactions with AIDS patients (primarily homosexuals) compared to general medical patients, Siminoff, Erlen & Sereika (1998) noted that nurses' used eye contact and touch more frequently with the AIDS patients. The researchers concluded that nurses' attitudes had no effect on whether AIDS patients were eluded by the nurses. Preston et al. (2000) found that while attitudes about homosexuality and societal and professional reservations all significantly related to nurses' willingness to care for persons living with HIV/AIDS, 81.5% of their sample (n=731) reported that they were open to caring for those with the disease.

Findings from studies that have explored the issue of whether nurses would leave the profession if they were compelled to care for HIV/AIDS patients are also heartening. Generally, these studies found only a relatively small proportion of nurses declaring that they would leave (Melby et al., 1992; van Wissen & Siebers, 1993). Indeed nurses who opt to work exclusively with HIV/AIDS patients have been found to value the close nurse/patient relationship and the distinctive nature of AIDS care (Hayter, 1999). It has been noted that better education on HIV/AIDS in nursing programmes may be shaping nurses' attitudes in a positive way, and there is some empirical evidence to support this contention (All & Sullivan, 1997; Carney, Werth, Martin, 1999; Dimick, Levinson, Manteuffel, & Donnellan, 1996).

The issue of the most preferred location of care for patients with HIV/AIDS was addressed by participants in several studies (Beedham & Wilson-Barnett, 1993; Cederfjall & Wredling, 1999; Kermode, 1995; Ong, Clarke, Dunbar, & Mandal, 1993; Schietinger & Daniels, 1996; van Servellen, Lewis, Leake, & Schweitzer, 1991). With the exception of Ong et al.'s (1993) study, this literature suggests that most HIV/AIDS patients have a preference for being cared for in special care units. Reasons for this preference include protection from anti-HIV and anti-gay prejudices, as well as being cared for by staff with positive attitudes and adequate knowledge of the disease.

Given the stigma of HIV/ AIDS, a major concern for many people who are HIV positive is the respect for privacy and confidentiality on the part of health-care providers (Armes

& Higginson, 1999; Beedham & Wilson-Barnett, 1995; Moneyham et al., 1996; Ong et al., 1993; Petchey, Farnsworth, & Williams, 2000; Schietinger & Daniels, 1996). Ong et al. (1993) found that 84% of individuals did not tell their general practitioners of their HIV diagnosis because of fear of transgresses in confidentiality. Moneyham et al. (1996) and Armes and Higginson (1999) found that fear of breaches in confidentiality often prevented participants in their studies from using resources and services they needed. In Beedham and Wilson-Barnett's (1995) study, 14 out of the 85 participants felt that accepting home help could lead to confidentiality breaches. Participants in Petchey et al.'s (2000) study were concerned about information management in General Practice medicine, and the impact that divulged information would have on their lives, particularly in relation to locally provided services.

Overall, the existing literature indicates that nurses' attitudes about HIV/AIDS patients vary from acceptance to prejudices against patients who have the virus. In relation to the most preferred location of care, most HIV/AIDS patients prefer being cared for in a specialist unit as opposed to a general unit. Finally, studies demonstrate that fear of breaches in confidentiality by health workers are common among people with HIV/AIDS.

### THE STUDY

#### Methodology

The data set presented here is related to one of the thematic findings of the study which initially set out to explore nursing care experiences of people with HIV/AIDS. Because participants contributed useful information about their relations with other patients that was likely to inform nursing decisions, the narrower focus solely on nursing care was broadened slightly and re-framed as 'hospitalisation experiences'. Criteria for entry to the study were that participants would be HIV positive with experience of being inpatients in an Irish hospital since diagnosis.

A sample size of ten was sought, and the logistics of selection were as follows: A letter and a poster outlining the study were mailed to eight agencies and hospitals who provided services to people with HIV/AIDS. The key people at these hospitals and agencies were asked to explain the study's aims to service users. Individuals who were interested in taking part in the study were given the researcher's telephone number to enable them to make contact. The poster was used as a reference for interested participants. After having obtained further details and a guarantee of anonymity, the first ten to approach the researcher agreed to participate. The sample was comprised of 3 women and 7 men. The age range was 29-50 years.

In-depth interviews were conducted during April and May 1998 at a time when all participants were out-patients. While an open style was adopted, a topic guide was used, and interviews were audiotaped. Included on the topic guide were issues relating to patients' positive and negative experiences of nursing care, their perceptions of their care vis-à-vis other patients, their satisfaction with information received, and demographic

details. These broad issues were deemed the most useful in addressing the research aim. As the interviews progressed, concepts became more refined. The term 'nursing care' was used in its normal discourse and participants were asked to explore their experiences of it. A working definition of 'nursing care' was not imposed, thus allowing participants to identify what they felt nursing practice to be. This facilitated the construction of nursing care as framed by patients, which could contribute to the debate about what constitutes nursing practice.

Data were analysed using a qualitative content analysis, whereby patterns were first identified, and data then scrutinised for variations and exceptions to these patterns. An attempt to explain what was going on in data was then sought, without imposing existing explanatory frameworks on data. Where established theoretical insights were used to illuminate aspects of data, the fit between theory and data was not forced.

#### The concept of stigma

Stigma is a broad and multidimensional concept, the essence of which centres on the issue of deviance. A stigmatised person possesses an attribute that makes him or her different from others in the 'normal' category and, therefore, less desirable; the person becomes tainted, discounted, and discredited (Goffman, 1963). Alonzo and Reynolds (1995) state that people with HIV are stigmatised because their illness is associated with deviant behaviour, is perceived as the responsibility of the individual, is viewed as

contagious and a threat to the community, and is linked with an 'undesirable and anaesthetic form of death' (p. 305).

While much has been written in recent years on the topic of stigma associated with a range of chronic conditions (see Kelly & Field, 1996) none has surpassed Goffman's writings, now over thirty years old, in theorising on the subject. Even more recent attempts by scholars to focus on bodily aspects of identity have been accused of rehashing much of Goffman's works (among others) (Williams, 1996). While there was no attempt made to 'force' the data into any particular theoretical framework, the analysis that follows draws heavily on Goffman's works, the significance of which became clear after data had been collected.

# Conceptual themes arising from data

HIV positive patients' experiences of stigma during hospitalisation, with special references to interactions with nurses, have been conceptualised under four themes, namely, participants' perceptions of nurses attitudes to their HIV status, the stratification of stigma, participants' preferences for segregated care, and the significance of confidentiality in relation to their care.

Participants' perceptions of nurses' attitudes to their HIV status

Participants in this study gave very rich descriptions of experiencing stigmatising attitudes from nurses, some of which they believed to be rooted in existing prejudices associated with the lifestyle or risk behaviours of those who are HIV positive. People with HIV who were infected sexually, or through sharing needles were particularly vulnerable to 'victim-blaming' (Green, 1995).

Participants commented on the judgmental speech pattern of nurses, as one respondent describes:

Tony: Some of them used to give out to us; 'We haven't got time for you, there's more sicker people than you'...It was because I was a criminal and a drug-user.

Clearly, Tony was surmising what nurses were thinking here, and while Tony's subjective experiences are valid, Goffman (1963) has noted how stigmatised individuals may readily read unintended meanings into people's actions. Indeed Jane, in the next example, was conscious of this tendency:

I'm very conscious of the fact that most of us might be over sensitive ...we might be looking for that. I think it's doubly so when there's a drug connection...because anyone who is a drug-user is dirt, and that's how a lot of us would feel.

However, there were a number of other accounts where nurses were reported to have been extremely candid about their perceptions that the disease was self-inflicted if acquired through intravenous drug use:

Tony: I don't think she [the nurse] liked drug addicts. She was very abrupt with me. I used to say 'I'm in pain'. She used to say 'Well that's what you get for using drugs'. . . It was terrible when I look back now. Even if I said something, it all depended on who the nurse was on the day. They'd say 'Well listen, this is your fault'...The main thing is all this branding the patient. Most of them, when they get sick, they get afraid and they don't want to be a nuisance because some of them feel it's self-inflicted on them, what they did, because of the virus.

Kate: Even to this day, you'd get some [nurses] that would say, 'Well you knew the virus was out, so long ago, and why are you still using', not to me, but to other people that I knew. It's like a slap on the hand... I think the nurses nowadays should be more caring with people that have the virus. We didn't ask for it, even though we had problems, like drug addicts. We didn't ask for that plague. They were no wiser than we were. We don't want to be knocked.

Not all participants were critical of nurses' attitudes to HIV positive patients. One participant did not feel nurses blamed him for his illness:

Frank: I don't think nurses hold... well I hope not... as I said, the staff in one hospital, they come across as, 'Don't blame yourself', you know like that. Trying to lift your spirits, as if to say 'Don't be blaming yourself for what happened, we all make mistakes'. It's like being strung out on gear; is like someone being strung out on coffee or strung out on tea. So there is support...

Frank described how the nurses' non-judgmental behaviour promoted a supportive environment:

There was one particular male nurse that worked there and he was very good to the patients that were HIV, like he'd make a cup of tea or something like that.

Tony, who was quoted earlier criticising nurses' judgmental attitudes described more egalitarian treatment he received at another hospital:

...treat them as a normal patient and that's the way I felt, like a normal patient.

The importance of being treated equally with other patients was also elucidated by Jane:

When you're going in you do feel very vulnerable and you're waiting to be judged or to be criticised. So the nurses are in a prime position to make them feel at ease...judgement from all over the place, when you're in hospital and you're sick, you're even more vulnerable so it can really make a difference, psychologically, if a nurse treats you...I hate the word 'normal'...but as you would any other patient.

The last three examples are interesting insofar as Frank praised nurses for being 'good to the patients that were HIV', while Tony's and Jane's praise is rooted in persons living with HIV being treated as 'normal', or it seems, being nursed just like other patients.

The stratification of stigma

Goffman (1963) has noted how stigma can be stratified, that is, stigmatised people within the same broad category can display a separation from one another. This seemed to occur in this study based on the means by which study participants had contracted the disease, with particularly clear divisions among 'the gays' and 'the drug abusers.' Although the stigma associated with HIV/AIDS is pervasive, findings here suggest that individuals with the disease do not necessarily experience the same degree of stigma. There is evidence in the data that participants believed that the stratum to which they belonged impacted on the quality of the nursing care each group received:

Tony: I have nothing against gays, but they were getting treated first and out of the way.

Frank: ...you know it's the ah...a lot...between drug abusers and ah, between gays that go over to the hospital, I think those that are gay seem to get more attention than those that are drug abusers.

14

A third participant, who was not a drug user, described the difficulties he experienced when there were drug users in the same ward:

Mike: ...she [nurse] said 'Mike, you're too quiet', you know, because people from the IV community tend to be a bit more vocal on the ward. That can be a bit overpowering from time to time. And the way I look at that is they have as much right to be there as me. But when you're listening to that, when it becomes very intense and you're sick, it can be very overpowering.

In the extract below, in the course of a discussion on nurses' attitudes to people with HIV, Jane elucidates the subtle messages she received:

Jane: There is still a little tendency, and it can come across, comments you know, that if someone is using drugs it's their own fault. That wouldn't be stated but it would be 'Oh you poor thing, you got it from sexual contact, ah God that's different'.

A strong feature of data was the high degree of stigma compared to other groups that drug-users reported, and which they claimed was related to their lifestyles.

Preference for segregated care

Several participants, for various reasons, stated a preference for being nursed on a specialist ward rather than a general ward. Such a preference may be explained through Goffman's (1963, p. 31) construction of two types of people sympathetic to the stigmatised individual, the 'own' and the 'wise'. The 'own' are described as those who share the same stigma and the 'wise' as those who come from working in establishments which cater to the wants or actions of those with a particular stigma. When stigmatised individuals are among their own, Goffman contends, they can organise their life. Goffman has noted how the immediate presence of 'normals', that is those without the stigmatising characteristic, is likely to reinforce the extent to which individuals perceive themselves as falling below a particular standard. In a specialist unit, while HIV positive patients may still have to deal with tensions among individuals on the basis of how the disease was contracted, at least they do not have to confront other patients without the disease whose presence may intensify their sense of difference.

The preference for segregated care is clearly articulated by Jane below:

Jane: I had been taken to my local hospital by ambulance, you know the way you have to be taken to the nearest hospital. If it happened again I would just go straight to the specialist hospital...

In one case, at least, the predilection for separation was based on the fact that social contacts with others with HIV were facilitated and patients would be among people they knew rather than among strangers:

Mary: I'd prefer to be on a ward where everyone was HIV... Yes, yes, because there were young ones that you knew. Whenever I'm in there I know somebody.

Kate also describes the social cohesion that specialist wards might foster:

Kate: ...they should make the wards out for HIV only, and not have other medical patients in there. If they're treating HIV they should leave the ward for the people with HIV, so we can get on with our own little ward and we don't have to mix with other people and at least you have that little bit of privacy. We're all in the one boat and if people want to talk about it they can relate to someone, it's helpful...you could say what medication you're on, and the people are going through what you're after going through and you could give them a bit of advice.

In the case of an individual who has been recently diagnosed as HIV positive, it is probable that others who have been diagnosed longer can help him/her cope. What Kate described (above) was close to Goffman's (1963) description of a 'welcome . . . to the club' (p. 50) which can instruct newly stigmatised persons how to manage physically and psychologically. A study by Lewis (1999) also found evidence of social networking by HIV positive gay with others who were living with HIV in an effort to overcome stigma and isolation associated with the disease.

Significance of confidentiality in relation to care

While confidentiality is important in all realms of nursing practice, nowhere is it perhaps as critical as in areas where the individual receiving care carries a high degree of stigma and is sharing the care space with others who do not possess the stigmatising attribute. Goffman's (1963) distinction between stigmatised persons that are 'discreditable' and 'discredited', is useful in understanding the significance of confidentiality in the care of those with HIV/AIDS. In the case of the 'discreditable' individual, the person's stigma is neither known to observers (other patients) nor perceivable by them, and the management of information is central. A discreditable person can 'pass' as 'normal' (Goffman, 1963, p. 58) and clearly most participants in this study hoped to do this in presenting themselves to other patients. For the 'discredited' individual, the stigmatised person assumes that his or her differentness is immediately perceptible, and therefore the management of tension in Where information is not handled tactfully and social encounters is central. confidentially by the staff in question, the stigmatised person can move from being 'discreditable' to being 'discredited', creating a great deal of tension for him or her in encounters with other patients.

A number of participants referred to issues of confidentiality when discussing the quality of the nursing care they received. Findings from this study suggest that sometimes confidentiality may be breached intentionally or unintentionally, and threaten or actually push a person's identity into the category of discredited:

Jane: ...sometimes I think nurses are very kind and very serious, but there are patients on either side of the bed, just to be aware... Well I'm thinking of two instances in particular

where I started to talk very quietly and then the two nurses got louder and louder and the patient next to me was awake and I had to say 'Shush'..... And I'm very confident about talking about it, but I know that some people get very, very put off... It's very important if they're commenting on stuff. That its not done within earshot, saying things to them in front of others or within earshot of others...

Tony: ...One man came in and I heard the nurses telling him that I was a drug addict and to be careful of his possessions. And I'll never forget it. He had a briefcase. He rang his sister, and my girlfriend went out into the hall and she heard him saying, 'There is a guy on the ward and he is a drug addict, and I want you to come up and take my briefcase'...

Red stickers had been placed on patients' medical and nursing notes to alert health care workers that the patient had an infectious disease. These red stickers had been identified by the four participants, quoted below, as a breach of confidentiality:

Jane: I believe the red dots on the charts are for all the infectious diseases, but I know that was something a lot of us were very uncomfortable about. You know, the way people ask what are the red dots for. And a lot of women believe they are the only ones with the red dots... some their families don't even know, and that's a real big one. You have families coming in, that's why you worry the red dots on their chart and what they're going to say and that kind of thing.

Mike: I found confidentiality was a big thing, I found confidentiality was broken...The big thing that I had about the hospital was the big red sticker on the chart. That goes with the territory, God I hate red.

Frank: The way the elderly men knew, or their visitors knew, that we would be HIV, would be by a little red mark that would be on your chart and that would be at the end of your bed.

Kate: ...That I think is discriminating. That is like saying 'Kate Bloggs, big red dot, she has the virus'.

The extent to which nurses had jurisdiction over the placement of red stickers on case notes is unclear, but it is most likely to have been an institutional decision rather than restricted to a nursing one.

Another participant describes the shame and humiliation she felt when she lost her anonymity.

Kate: When I had, gave birth to Ann, it was a shock birth. She came so fast, they could not have noticed a big red circle on my chart, that's to say that I was HIV, and I was in the admission room... but she [nurse] did not look at my chart and she had a cut. I'll never forget this, never forget it and of course she mingled with my blood, my waters and then she discovered I was HIV. Well I needn't tell you, it went around the hospital like wild fire, like wild fire...and I was the talk of the hospital, because they knew there was a woman in there with HIV who gave birth in the admission room and 'now the nurse is infected'. I was never able to show my face because I was in the ward with the women and then I was taken back out and then in a ward on my own, so it was obvious they knew it was me. It was very, very degrading.

As in the other examples, Kate's status had moved rapidly from discreditable to discredited, and created a great deal of distress for her in the process.

#### **Discussion**

The foregoing qualitative data have explored the experiences of HIV positive hospital inpatients regarding their interactions with nursing staff and, to a lesser extent, with each other. These data support existing study findings pertaining to the judgmental attitudes of nurses towards people with HIV/AIDS, especially regarding the means by which the patient contracted the disease and the extent to which nurses' believed this to be selfinflicted (Armstrong-Esther & Hewitt 1990; Breault & Polifroni, 1992; Eliason, 1993; Kelly et al., 1988; McCann & Sharkey, 1998; Melby et al.,1992). The preference for segregated care also supports findings from existing research (Beedham & Wilson-Barnett, 1993; Schietinger & Daniels, 1996; van Servellen et al, 1991). However, data from the present study suggest that segregated units for those with HIV/AIDS are not likely to be unproblematic locations for patients because of the way in which stigma is stratified by virtue of how individuals contracted the disease. Although segregated units may ensure that patients do not have to confront 'normals' (that is, other patients without the disease), they are unlikely to overcome fissures between different groups of patients, most notable gay people and drug users. Indeed, without being burdened by concerns with presenting themselves to 'normals', tension between these two group may in fact intensify. Moreover, unless nurses working in segregated units can overcome prejudice towards some people with HIV/AIDS, most notably drug users, degrees of stigma and differentials in the quality of care are likely to result.

Findings here also suggest that disquiet expressed in other studies by people with HIV/AIDS about confidentiality concerning their disease (Armes & Higginson, 1999; Beedham & Wilson-Barnett, 1995; Moneyham et al., 1996; Ong, et al., 1993; Petchey et al., 2000; Schietinger & Daniels, 1996) may not be unfounded. Whatever control nurses may or may not have regarding institutional policies to label patients' case notes with stickers, there is clear evidence that nurses were careless when handling patients' information. Indirect references to patients may be as damaging to patient confidentiality as more direct ones, where pieces of information may be linked together by observers and collectively identify the patient in question. For example, 'a woman . . . with HIV who gave birth in the admission room' is highly revealing, even if the person is not overtly named, if admission-room deliveries are rare, leading the patient to (probably correctly) assume that 'it was obvious they [other patients] knew it was me'. For nurses to merely refrain from directly naming a patient and his or her disease to others beyond the immediate therapeutic situation would appear to be insufficient to the preservation of confidentiality. Vigilance in handling information that may reveal identities is also demanded.

# Limitations of the study

There are two main limitations to the study presented here. The first is the relatively small

sample size, and the second is the negative way in which nursing care is presented in this

data set. The limitations of the small sample size are to some extent countermanded by

the rich data gleaned from participants. Although qualitative data are notoriously uneven

in quality, the self-selection of participants for the study ensured consistently prolific data

that enabled themes and social processes to be identified with a remarkable degree of

consistency. In relation to the second issue - the negative portrayal of nursing - the focus

on stigma as an analytical concept in this article lent itself to concentrating mainly on

poor nursing practices, but on balance, handling data in this manner allowed a degree of

depth to be obtained. However, it is acknowledged here that there were very positive

aspects of nursing expressed by participants and these will be reported on elsewhere.

Conclusion

The preceding data on HIV positive patients' experiences of stigma during hospitalisation

and particularly in nurse-patient interactions has elucidated the complex nature of stigma

and how it permeates patients' experiences in a number of ways. These findings challenge

all nurses working with persons living with HIV/AIDS to become more self-aware of

their practices to maximise the quality of care provided to all, regardless of whether that

care is given in a specialist or a general unit.

Word count: 5,465 words

23

# References

All, A.C., & Sullivan, L. (1997). The effects of an HIV/AIDS educational programme on the anxiety level of nursing students. *Journal of Advanced Nursing*, *26*, 798-803.

Alonzo, A.A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303-315.

Armes, P.J., & Higginson, I.J. (1999). What constitutes high-quality HIV/AIDS palliative care? *Journal of Palliative Care*, 15(4), 5-12.

Armstrong-Esther, C., & Hewitt, W.E. (1990). The effect of education on nurses' perception of AIDS. *Journal of Advanced Nursing*, *15*, 638-651.

Beedham, H., & Wilson-Barnett, J. (1993). Evaluation of services for people with HIV/AIDS in an inner-city health authority: perspectives of key service providers. *Journal of Advanced Nursing*, 18, 69-79.

Beedham, H., & Wilson-Barnett, J. (1995). HIV and AIDS care: consumers' views on needs and services. *Journal of Advanced Nursing*, 22, 677-686.

Breault, A.J., & Polifroni, E.C. (1992). Caring for people with AIDS: nurses' attitudes and feelings. *Journal of Advanced Nursing*, *17*, 21-27.

Carney, J.S., Werth, J.L., & Martin, J.S. (1999). The impact of an HIV/AIDS training course for baccalaureate nursing students. *Journal of Nursing Education*, 38(1), 39-41.

Carroll, J. (1993). Attitudes of professionals to drug abusers. *British Journal of Nursing*, 2(14), 705-711.

Cederfjall, C., & Wredling, R. (1999). The expressed needs of a group of HIV-infected men subsequent to hospital care. *Journal of the Association of Nurses in AIDS Care*, 10, 66-74.

Cole, F.L., & Slocumb, E.M. (1993). Nurses' attitudes toward patients with AIDS. *Journal of Advanced Nursing*, 18, 1112-1117. Dimick, L.A., Levinson, R.M., Manteuffel, B.A., & Donnellan, M. (1996). Nurse practitioner's reactions to persons with HIV/AIDS: the role of patient contact and education. *Journal of the American Academy of Nurse Practitioners*, 8(9), 419-426.

Dols, C. L., & Bradley-Magnuson, L. D. (1996). Those who have will, those who haven't won't: caring for HIV-positive patients. *The Journal of Continuing Education in Nursing* 27(2), 80-84.

Eliason, M. J. (1993). AIDS-related stigma and homophobia: implications for nursing education. *Nurse Educator*, 18(6), 27-30.

Eliason, M. J. (1998). Research briefs: Correlates of prejudice in nursing students. *Journal of Nursing Education*, *37*, 27-29.

Erlen, J. A., Riley, T.A., & Sereika, S.M. (1999). Psychometric properties of the Index of Homophobia Scale in registered nurses. *Journal of Nursing Measurement*, 7(2), 117-33.

Goffman, E. (1963). *Stigma: notes on the management of a spoiled identity*. Englewood Cliffs, N.J.: Prentice-Hall.

Green, G. (1995). Attitudes towards people with HIV: are they as stigmatizing as people with HIV perceive them to be? *Social Science and Medicine*, 41(4), 557-568.

Hayter, M. (1999). Burnout and AIDS care-related factors in HIV clinical nurse specialists in the North of England. *Journal of Advanced Nursing*, 29(4), 984-93).

Kelly, J. A., Saint Lawrence, J. S., Hood, H. V., Smith, S., & Cook, D. J. (1988). Nurses' attitudes toward AIDS. *The Journal of Continuing Education in Nursing*, 19(2), 78-83.

Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health and Illness*, 18(2), 241-257.

Kemppainen, J. K., Dubbert, P. M., & Williams, P. (1996). Effects of group discussion and guided patient care experience on nurses' attitudes towards care of patients with AIDS. *Journal of Advanced Nursing*, 24, 296-302.

Kermode, M. (1995). Patients' experiences of nursing interventions during hospitalisation with an AIDS-defining illness. *Australian Journal of Advanced Nursing*, *12*(3), 20-30.

Lewis, A. (1988). *Nursing Care of the Person with AIDS/ARC*, Rockville, MD: Aspen Publications.

Lewis, J. (1999). Status passages: the experience of HIV-positive gay men. *Journal of Homosexuality*, 37(3), 87-115.

McCann, T. V. & Sharkey, R. J. (1998). Educational intervention with international nurses and changes in knowledge, attitudes and willingness to provide care to patients with HIV/AIDS. *Journal of Advanced Nursing*, 27, 267-273.

Melby, V., Boore, J. R. P., & Murray, M. (1992). Acquired immunodeficiency syndrome: knowledge and attitudes of nurses in Northern Ireland. *Journal of Advanced Nursing*, *17*, 1068-1077.

Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L. & Guillory, J. (1996). Experiences of disclosure in women infected with HIV. *Health Care for Women International*, 17(3), 209-221.

Ong, E.L.C., Clarke, K.W., Dunbar, E.M., & Mandal, B. K. (1993). Health care of people with HIV. *AIDS Patient Care*, 7(2), 98-101.

Petchey, R., Farnsworth, B., & Williams, J. (2000). 'The last resort would be to go to the GP.' Understanding the perceptions and use of general practitioner services among people with HIV/AIDS. *Social Science and Medicine*, 50(2), 233-245.

Pratt, R. (1995). HIV and AIDS: A strategy for nursing care 2nd ed. London: Edward Arnold.

Preston, D. B., Forti, E. M., Kassab, C., & Koch, P. B. (2000). Personal and social determinants of rural nurses' willingness to care for persons with AIDS. *Research in Nursing and Health*, 23(1), 68-78.

Schietinger, H., & Daniels, E. M. (1996). What nurses need to know: The consumer perspective. *Nursing Clinics of North America*, *31*(1), 137-152.

Schlub, S. M., & Martsolf, D. S. (1999). Orthodox Christian beliefs and homophobia in baccalaureate nursing students. *Nursing Forum*, *34* (2), 15-22.

Siminoff, L. A., Erlen, J.A., & Sereika, S. (1998) Do nurses avoid AIDS patients? Avoidance behaviours and the quality of care of hospitalised AIDS patients. *AIDS Care*– *Psychological and Socio-Medical Aspects of AIDS/HIV, 10*(2), 147-163.

van Servellen, G., Lewis, C. E., Leake, B., & Schweitzer, S. O. (1991). Patient satisfaction on AIDS and oncology special care units and integrated units: a pilot study. *Journal of the Association of Nurses in AIDS Care*, 2(3), 29-39.

van Wissen, K., & Siebers, R.W.L. (1993). Nurses' attitudes and concerns pertaining to HIV and AIDS. *Journal of Advanced Nursing*, *18*, 912-917.

Williams, S.J. (1996). Medical sociology, chronic illness and the body: a rejoinder to Michael Kelly and David Field. *Sociology of Health and Illness*, 18(5), 699-709.

Young, E.W. (1988). Nurses' attitudes toward homosexuality: analysis of change in AIDS workshops. *The Journal of Continuing Education in Nursing*, 19(1), 9-12.