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Publication details:

Sexual Health

v. 19

Chapter No. 5

Medium: Print

pp. 448 - 455

1448-5028 (ISSN); 1449-8987 (ISSN)

Publication Date:

2022

Publisher DOI:

<https://doi.org/10.1071/sh22052>





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Patient-centred approaches to providing care at HIV diagnosis: perspectives from healthcare and peer-support workers

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Handling Editor:

Jami Leichter

Received: 1 April 2022
Accepted: 21 June 2022
Published: 22 July 2022

Cite this:

Wells N *et al.* (2022)
Sexual Health
doi:[10.1071/SH22052](https://doi.org/10.1071/SH22052)

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ABSTRACT

Background. Early uptake of HIV treatment among those newly diagnosed with HIV can improve individual health and prevent onward transmission. Patient-centred care is considered an important aspect in health care, the management of HIV, and can improve uptake of and adherence to HIV treatments. **Methods.** Semi-structured interviews were conducted with sexual health clinicians (n , 10) and HIV support workers (n , 4) to understand how they approached HIV diagnosis delivery and care immediately thereafter. **Results.** Our thematic analysis identified three themes: (1) centring patient needs at diagnosis; (2) assessing patients' readiness to begin treatment; and (3) referrals to psychosocial support services. Our findings highlight centring patients was an important aspect of how participants delivered HIV diagnoses. By taking this approach, clinicians were best able to consider patient readiness to initiate treatment and referrals to social support services. **Conclusions.** Given HIV diagnoses are increasingly occurring in generalist health services, our findings offer an important opportunity to learn from the experiences of specialist sexual health clinicians and HIV support workers.

Keywords: clinician perspectives, HIV, HIV diagnosis, patient-centred care, peer support, sexual health, treatment initiation, qualitative.

Introduction

Early uptake of HIV treatment among those newly diagnosed with HIV is a key aspect of Australia's strategy to reduce new HIV diagnoses.¹ Effective treatments have transformed the medical needs of people living with HIV (PLHIV),² can reduce HIV to undetectable levels, and render HIV sexually non-transmissible.^{3–5} Current Australian HIV guidelines recommend beginning antiretroviral therapy either immediately after diagnosis or as soon as possible thereafter.^{1,6} However, these guidelines may not always coincide with an individual's readiness to commence treatment. Some attention has been given to the role of health professionals in the ongoing management of HIV-related care,^{2,7–9} and positive experiences with healthcare providers can improve treatment adherence and retention in care.^{10,11} To date, however, little research has explored the perspectives of healthcare providers in the context of delivery of HIV diagnoses.

The concept of patient-centred care emerged in the mid-20th century^{12,13} and has since become an important aspect of medical education¹⁴ and health care delivery.^{14–16} Despite no universal definition, patient-centred care can be characterised as care that considers the unique circumstances of patients beyond simply treating specific medical conditions.^{17,18} Patient-centred care takes a holistic approach to health care delivery and accounts for economic, cultural, psychosocial, and familial contexts as also affecting health outcomes.^{18,19} Aspects of patient-centred approaches include: understanding medical conditions from the patient's perspective;^{20,21} shared decision making between patients and healthcare providers;^{15,22–24} clear and open communication;²² respecting patient autonomy;²⁴ and the development of an ongoing relationship between patients and

healthcare providers.^{20,23} These are all central to the delivery of high-quality health care and patient satisfaction.^{22,25} Rather than merely acquiescing to patients' wants or demands,²⁰ however, patient-centredness requires an ongoing negotiation between healthcare providers and patients.^{21,23} It is important for health professionals to balance patient autonomy with their own expertise to offer patients the best health outcomes.²⁶ By understanding patients' perspectives and unique circumstances, healthcare providers are more appropriately positioned to work with patients and arrive at shared health decisions.

Patient-centred care is considered important in managing HIV,^{6,8,9,27} particularly in relation to decisions and practices around HIV treatment.²⁸ Patient-centredness is also associated with retention in HIV care and treatment adherence,^{7,29} particularly for newly diagnosed PLHIV.¹¹ Perazzo *et al.* argue that when delivering HIV diagnoses, it is necessary for clinicians to address patients' concerns and (mis-)understandings about HIV, assess what emotional supports are needed, and consider patients' readiness to begin treatment.³⁰ Previous research has explored patient-centred approaches to the ongoing management of HIV.^{7-9,11,29} However, little research has explored how it is deployed by clinicians in the context of diagnosis itself. Therefore, the aim of this analysis is to describe the nature of interactions between healthcare providers and patients at the time of HIV diagnosis, and the extent to which patient-centredness features in this context. In this paper, we describe: how service providers assess and respond to the needs of individual patients and population groups; how clinicians discuss treatment initiation; how health professionals balance the provision of medical and social support; and the kind of referral pathways that are provided to connect patients to psychosocial support services. This paper provides new insights into clinician perspectives on HIV diagnosis delivery to inform approaches to treatment discussions and referral pathways to HIV support services.

Materials and methods

Study setting

Analysis for this paper is drawn from an ongoing, qualitative cohort study of PLHIV exploring linkages to and retention in HIV specialist care and peer-based support among recently diagnosed PLHIV. The larger study explores the experiences of adjusting to an HIV diagnosis among recently diagnosed PLHIV and the accounts of delivering HIV care among healthcare workers and community-based HIV support workers.

Eligibility and recruitment

To be eligible, participants must have had experience in providing HIV care shortly or immediately after diagnosis. Potential participants were identified through convenience

sampling methods. Participants were contacted via telephone or email by a member of the research team and invited to be interviewed. As we were seeking individuals with experience in delivering HIV diagnoses and care, this recruitment strategy was considered most appropriate for the study design.

Data collection

Semi-structured interviews were conducted face-to-face, via telephone or through video conferencing by members of the research team. An initial interview schedule was developed based on previous learnings^{31,32} and stakeholder consultations. Interviews ranged approximately 30–60 min in length and were conducted between June 2019 and February 2020. Clinicians were asked about their strategies for delivering HIV diagnoses, their observations of how patients responded to a positive diagnosis, how they accounted for differences between individual responses to diagnosis, what referrals they provided to support services, and how they approached the subject of treatment initiation. Peer-support workers were asked about the kinds of support they offered, what support they believed patients needed, how they received patient referrals, and their relationships with clinic-based services. Interviews were audio recorded, transcribed by a professional transcription service, and de-identified. Our analysis in this paper focuses primarily on the clinical diagnosis itself. Interviews with community-based support workers provide a perspective of HIV-care outside the clinical encounter.

Analysis

Interview transcripts were entered into NVivo software ver. 12 and thematically analysed.^{33,34} The coding process began with a close reading of each transcript by SP and NW. An initial coding framework was developed by SP based on two interviews. SP and NW then met to discuss the complexities within the initial coding framework and the interview content. Subsequent analysis was conducted by NW and the codebook revised as additional transcripts were coded. Reliability was ensured through meetings among the broader research team to review the analysis process and discuss findings as they arose.

Ethical approval

All authors approved the article for submission. All procedures involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethics approval was provided by the UNSW Human Research Ethics Committee (HC161712).

Results

Ten clinicians and four community-based HIV support workers participated in this study. Clinicians had delivered at least two HIV diagnoses in the year preceding their interview, with most having several years' experience delivering diagnoses in high caseload settings. Support workers each had more than 2 years' experience working with PLHIV. Participants worked in settings that included private and public health clinics, sexual health centres, and community-based HIV organisations in major urban centres across five Australian jurisdictions: New South Wales (*n*, 6), Queensland (*n*, 3), Victoria (*n*, 2), South Australia (*n*, 2), and Tasmania (*n*, 1). No demographic characteristics were collected. Patient-centred care was not a prescribed topic in interviews but was instead identified in participants' accounts of delivering HIV diagnoses. This theoretical lens was subsequently applied to the analysis and writing of results.

Theme 1: responding to individual patients' circumstances

Participants described a broad spectrum of patient reactions to receiving a positive diagnosis. While some patients were shocked and distressed, others were more pragmatic and, in some instances, even expected a positive result. Participants therefore felt it necessary to be flexible in their approach to the care and support they offered. Participants frequently explained that the pathway diagnoses followed was guided by patient reactions to a positive result:

If it is positive, conveying that result [and] giving them a period of time to respond to that. Allowing them to respond rather than going on and launching into some information, because many people respond differently. Some people get upset, some people cry, some people say: 'look, tell me what that means [and] tell me what I need to do about it' ... Giving them time to formulate their response, whatever it might be, and then responding to that. (Service Provider [SP]02, physician)

Given each diagnosis was unique, allowing patients time to respond was emphasised as enabling clinicians to consider the types of care and support patients might need. This was felt to be important as each diagnosis was unique. As another participant stated:

I will then just give them some time and let them take it in ... That varies completely between people: whether they want to get stuck in straight away into talking about [their diagnosis], or whether they need a bit of time and some thoughts and emotions to get through without saying anything. (SP04, physician)

The various reactions observed by participants highlights the complexity of matching patient needs with appropriate follow-up care. As described here, being attentive to patient reactions enabled this participant to provide the kind of support they felt most appropriate and tailor the consultation to meet this.

While participants referred to patients' reactions as individualised, their accounts also provided insight into the ways they categorised patients according to certain criteria. This categorisation was drawn on as a heuristic to respond to patients' reactions and subsequent needs. For example, familiarity with HIV, which was often attributed to gay male communities, was believed by some participants to make the diagnosis easier to accept:

Some people process the diagnosis extremely well and in a short timeframe. You generally find those people [are] gay, white men ... so they have good knowledge and awareness about HIV. (SP10, peer-support worker)

Given that in Australia HIV has disproportionately affected gay, bisexual, and other men who have sex with men (GBMSM), participants commonly characterised Australian-born GBMSM, who were also involved in gay communities, as having greater awareness of HIV and as being more likely to have HIV-positive men in their social networks. This led to a perception among some participants of needing to spend less time educating GBMSM on aspects of HIV care, treatments, and undetectable viral load. This often led to a more patient-led approach to treatment initiation, with some participants prescribing treatment on the day of diagnosis if requested by a patient. In contrast, participants frequently reported taking a more clinician-led approach for those with lower HIV awareness. One participant, with extensive experience working with Indigenous populations, stated:

[For newly diagnosed] Indigenous folk, it varies. We have to really play it by ear. There are some folk who don't know anything at all, others who do have some knowledge. But it's often the issues around housing. It's food security. It's [social services]. It's getting a phone. So we involve social work more than we've done before ... to get people to understand what's going on and the importance of going onto treatment [and] staying on it. (SP01, doctor)

Reflecting patient-centred approaches to care, this participant described HIV care as encompassing more than simply treating the virus, but also addressing other factors that might influence the health of individuals more broadly. This was reflected by another participant who stated:

Different patients do receive different levels of care, but I suppose that's about making things equitable ... There are obviously people who appropriately receive less-intense

follow-up. It might be detrimental for them to have to come into clinic five times. They might not need it. It might disrupt their work life. It might disrupt their homelife. If it's not necessary, then why would we offer it? (SP04, physician)

This participant highlighted that while high engagement with clinical care might be appropriate for some, that same level of care might negatively impact others. It was therefore important for participants to balance the level of care they provided. Centring the needs of patients, allowing them to respond to the diagnosis, and considering their broader social environment enabled participants to judge the most appropriate forms of HIV-care.

Theme 2: considering patients' circumstances when initiating treatment

Participants commonly discussed balancing the needs of individual patients with broader public health obligations to ensure treatment options were discussed in early consultations. Like the diagnosis itself, participants commonly explained that they considered their public health obligations in relation to patients' needs and responses. One participant described gaining a sense of patients' attitudes toward treatment in early consultations, stating, 'treatment should be entering the conversation, as in I will actively bring that up. 'Have you heard [or] thought [about treatment]? What do you think about treatment?' (SP03, physician). Considering treatment a necessary component of early HIV care, this participant approached treatment discussions by first understanding patients' perspectives of HIV treatments. They went on to describe considering patients' 'emotional and social state, and whether they understand this is going to be a lifelong treatment and they need to take it every day.' By taking this approach, this participant was better positioned to assess the kinds of information most appropriate for patients and, coupled with their own medical expertise, provide what they perceived as the most appropriate care.

Treatment initiation was also influenced by individual patient circumstances. For those with high HIV awareness, for example, some participants would initiate treatment on the day of diagnosis if requested by patients. For patients with complex health needs, such as mental health concerns, problematic drug and/or alcohol use, or those experiencing homelessness, initiating treatment was more considered:

The only situation in which I could think that you might defer [treatment] would be if someone ... is homeless, has psychological health issues, has [an] intellectual impairment. Just to ensure that you can get all the framework around them so that they can be as successful as possible the first time around. (SP02, physician)

Psychosocial needs such as those described above can negatively impact treatment adherence³⁵ and retention in care.^{36,37} Participants therefore felt it important to work with patients to address broader concerns beyond simply treating HIV. This was echoed by another participant, who stated:

People who've got obstacles to getting started on treatment will probably have much closer multidisciplinary engagement ... people with unstable housing and people with mental-health needs are much more complex in terms of safe delivery of care and they require a much more carefully processed, team approach. And so I'd be much less likely to start people in those circumstances on treatment straight away until there's been some good assessment by nursing and psychology or social work about ... their strengths and vulnerabilities. (SP11, physician)

As described here, treatment initiation extended beyond simply prescribing medication and also included working with patients and other support services to enable newly diagnosed PLHIV to actively manage their diagnosis. While deferring treatment could be considered a form of gatekeeping by clinicians, it was part of a more holistic approach to care that extended beyond solely managing HIV. As described above, it was important to not only address patients' vulnerabilities, but also capitalise on their strengths. Although more clinician-led, such approaches were felt important to enable those with complex health needs to have greater control over their health.

Theme 3: the importance of referrals to psychosocial support services

Despite effective treatment rendering HIV a chronic condition,³⁸ participants recognised the emotional difficulties of receiving a positive HIV diagnosis owing to its history, association with deviancy, permanency, and persistent stigma.³⁰ As such, participants also recognised the importance of providing non-medical support as part of a diagnosis:

Number one is social support. I think the most essential thing, if nothing else, is to ensure that the patient returns because if they don't return, there's nothing else that you can do with them. (SP03, physician)

Although participants believed that HIV could be managed medically, they also recognised significant social challenges such as anticipated stigma, social isolation, and challenges navigating sexual and romantic relationships. While this participant's comment highlights social support as a necessary aspect of retaining patients in ongoing medical care, it also considers social support as important for patients' overall wellbeing beyond the clinic.

Some participants highlighted a need to balance their role as medical professionals with the appropriate kinds of emotional support they had the capacity to provide and the importance of a multidisciplinary health team to assist individuals adjusting to an HIV-positive diagnosis. Some participants acknowledged their own lack of expertise in delivering more formalised counselling support to the extent that they felt uncomfortable and ill-equipped to provide that kind of support:

I'm not any expert in giving emotional support. I will ask patients if there's anything I can do for them ... but that's why I work in a multidisciplinary team with counsellors and psychologists, because I don't really have those skills. (SP06, nurse)

Allied health, mainly in the form of counselling, and community-based peer-support services were identified as important sites through which newly diagnosed individuals could receive support. Participants commonly worked in dedicated sexual health centres and often had in-house counselling and psychological support services available. Given this proximity, it was common for participants to refer patients to these services, occasionally even walking the patient to the counsellor.

Referrals to clinical counselling and psychological services were the most common type of referrals to occur among participants. However, participants also recognised HIV peer-support as an important aspect of HIV-care. Describing the role of peer-support, one participant stated these services were:

Essential because [peers] give a different perspective [to] a medical, clinic-based environment. ... There is something about coming into a medical centre and, in a clinical, professional sense, that they're a patient. ... [HIV/AIDS] organisations are really important to give [patients] that social perspective and understanding that we really can't give. (SP03, physician)

This was reflected in a comment by a community-based HIV support worker who contrasted the kinds of support they offered with that of counselling and psychological services:

Many people actually come and say they've been through counselling: 'I just want to talk to someone who's got lived experience.' I've had that a few times and [that peer perspectives are] really good, and really helpful. 'What is it like to navigate [HIV] on an app? What is it like to disclose? ... How many people are going to reject me?' ... 'What is really going on out there?'. (SP07, peer-support worker)

Despite acknowledging peer-support services as important, however, referral pathways were generally more passive and

made less systematically. While some participants reported making direct contact with peer-support services on behalf of patients, it was more common for participants to simply mention these services and allow patients to make contact themselves. As one participant stated: 'I will always let people know that [HIV peer-support services] are a thing. I like to respect peoples' autonomy and their ability to decide for themselves' (SP02, physician). The approach of this participant to HIV peer support was one of informing patients as to their existence and, from there, allowing patients to decide whether to engage with those services. While this approach was justified as respecting patients' autonomy, it contrasted with referrals to clinical, in-house counselling which were more structured: 'At [sexual health clinic], our standard rule is that we will get someone to engage with a counsellor at the first visit, just as an introduction' (SP02, physician). Despite acknowledging patients often reported positive experiences of peer support services, however, referrals to these services were passive.

Discussion

Our findings highlight patient-centred care as an important aspect in how clinicians deliver HIV diagnoses and provide an opportunity to learn from how experienced clinicians deliver HIV diagnoses. When delivering HIV diagnoses, participants commonly reported allowing patients to process their diagnosis and respond in their own way. Consideration of both the clinical and psychosocial needs of patients was central to how participants approached delivering HIV diagnoses and care immediately thereafter. Participants did not explicitly state taking a patient-centred approach. However, their accounts of how diagnoses were given reflected aspects of patient-centred care such as considering patients' unique individual circumstances, shared decision making, and clear and open communication. Indeed, patient-centred approaches appeared to be an almost entrenched and taken-for-granted aspect of participants' diagnosis process. Centring the needs of individual patients was a strategy used by participants to consider the most appropriate forms of support and to retain patients in care.

Australian guidelines to managing HIV encourage treatment initiation as soon as possible after diagnosis.¹ As with delivering a diagnosis, participants were largely guided by patients' individual circumstances when discussing and initiating treatments with an aim of beginning treatment as soon as possible. For patients with high HIV awareness, often gay men, participants felt diagnoses could involve less intense, clinician-led engagement. With this group, participants often reported discussing and initiating treatment earlier and often at the request of patients. For those with less awareness, however, participants reported taking a more active role in the initial diagnosis process. Participants

commonly described that these patients were often unaware of HIV treatments and reported having to spend more time educating patients and at times encouraging patients to begin treatment. We argue that although these early interactions were largely clinician-led, they were still patient-centred, as they were based on an understanding of patient needs and aimed at empowering individuals, through education, to take a more active role in managing their health.

Although participants characterised HIV-management as medically straightforward, they recognised the significant emotional and social impact a positive diagnosis could have.^{39–41} Given this, participants often saw a need for support that extended beyond their own medical expertise and included forms of psychosocial support. Spaan *et al.* found that psychological interventions are positively associated with improved treatment uptake and adherence because they address factors such as depression, experiences of stigma, and social isolation.³⁵ Such psychological interventions include counselling, drug and alcohol support, and peer-support services. While participants in our study regularly reported referring patients to counselling and psychological services, they less often directly referred patients to community-based peer-support organisations. This reflects previous research by Murphy *et al.* who also reported less structured approaches to clinician referrals to HIV peer-support services.³² This narrow focus on clinically recognised services keeps HIV-care primarily within a clinical environment. Potentially lost in this is the possibility for newly diagnosed PLHIV to establish social connections and gain non-clinical perspectives from others with a similar lived experiences.⁴²

Peer-support can play an integral role in treatment adherence⁴³ and retention in care among PLHIV.^{38,44,45} Recently diagnosed PLHIV who access peer-support are also less likely to engage in practices that risk onward transmission of HIV,⁴³ be more active in clinical decision making³² and have improved quality of life.⁴⁶ Our findings suggest that peer-support services may be under-utilised in comparison to other services. While peer services offer PLHIV an important source of support,⁴⁷ organisations offering these services often operate with limited funding and resources. It is therefore crucial that community-based HIV organisations are appropriately resourced so they can continue support PLHIV, particularly those who are newly diagnosed.

Patient-centred approaches can ensure newly diagnosed PLHIV are connected to appropriate clinical and non-clinical services and provide insight into patient readiness to engage with such services. As recently diagnosed PLHIV may not always be ready to engage with peer support programs, it is important that referrals to these services occur at the point of diagnosis and form part of ongoing HIV care. While new HIV diagnoses in Australia have traditionally been concentrated in dedicated sexual health and high HIV caseload clinics, new diagnoses are

increasingly occurring in general practice and primary care setting⁴⁸ where awareness of HIV and support services may be limited. Clinicians therefore need resources to describe peer-based programs and to provide patients with referral pathways. However, such resources are currently lacking. The inclusion of information about, and formal referral to HIV peer support services could lead to a greater number of successful referrals and strengthen networks between community-based services. Given the positive impact these programs can have on newly diagnosed PLHIV,^{36,43} it is important that these are also considered as part of a more holistic, patient-centred approach to HIV care that extends beyond the clinic.

Limitations

The focus of our analysis is on the perspectives of diagnosing clinicians and peer-support workers. This reflects participants' perspectives and priorities in the diagnosis, which may differ from those of newly diagnosed PLHIV. Previous research has shown that what healthcare providers and patients consider appropriate healthcare can differ.⁴⁹ Future research exploring the experience of HIV diagnosis should explore specific instances from both provider and patient perspectives.

Conclusion

Patient-centred care can assist patients when receiving difficult health diagnoses and can improve treatment adherence and retention in care. We found that centring the needs of patients was a strategy participants used to judge the approach to diagnosis and guide ongoing care immediately thereafter. This incorporated both patient-led and provider-led strategies. Patients' awareness of HIV, reaction to a diagnosis, and the presence of other health concerns influenced treatment initiation and referrals to support services. Non-clinical support such as that offered by peer- and community-based organisations is an important part of patient-centred HIV care and can empower newly diagnosed patients to take a more active role in the management of HIV. Despite acknowledging the value of these programs, however, participants rarely made direct referrals to these services. Incorporating formal referrals to peer support as part of the diagnosis could aid patients in adjusting to a positive diagnosis.

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Data availability. Data for this analysis are not publicly available.

Conflicts of interest. Christopher Fairley is an Editor of *Sexual Health* but was blinded from the peer review process for this paper. The authors declare no other conflicts of interest.

Declaration of funding. This study received funding from the National Health and Medical Research Council (NHMRC) Australia, Gilead Sciences, and the health departments of the Australian Capital Territory, New South Wales, North Territory, Queensland, South Australia, Tasmania, Western Australia, and Victoria.

Acknowledgements. We thank all participants for the involvement in this study and partner organisations for their support, particularly those who assisted with recruitment and referral of participants. The authors also thank Anthony K J Smith and Mohamed Hammoud for comments on an earlier draft of this paper.

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