

NHIVNA Best Practice

Rules of engagement for 'hard-to-reach' patients living with HIV: a guide for nurses

Pauline Jelliman MSc, BA, RGN

Former Clinical Lead HIV and TB Community Services, Liverpool, UK

Background

In this best practice guidance we will examine the importance of meaningful engagement between people living with HIV and health care, clarify the terms 'hard to reach', 'meaningful engagement' and examine why some individuals struggle to engage in care. The guidance section will suggest ways to overcome highlighted issues.

Guidelines provide the backdrop to guide us in our practice to deliver safe, effective, patient-centred care. However, access to such rich evidence-based resources could be futile if services cannot engage with patients in the first instance. This can be frustrating for nurses and inequitable for patients in an era of such monumental advances in HIV treatment and care.

A diagnosis of HIV can hinder engagement with services as a stand-alone issue, or as a component of other health and social problems rendering a minority hard to reach. This situation can lead to poorer health outcomes for people with HIV and potential onward transmission for sexual partners. The purpose of this document is, therefore, to enhance already excellent HIV services in the UK by providing additional guidance on how nurses can engage with those deemed hard-to-reach. This will not only contribute to further exceeding UNAIDS targets [1] but help to address unmet needs for those who require maximum support.

Keywords

HIV, patient engagement, hard to reach, met need

Aim

This guidance aims to:

- clarify the terms 'hard to reach' and 'patient engagement' generally and in the context of HIV;
- review reasons why there are barriers to engagement between health services and people living with HIV; and
- identify components of a best practice model to guide nurses working in HIV, general nurses and other healthcare professionals on how to engage with hard-to-reach individuals and groups.

Evidence

Defining 'hard to reach'

There appears to be a lack of consensus about the meaning of the term 'hard to reach' [2] also described as a contested and ambiguous term commonly used within the spheres of social care and health [3]. A literature search found similar terms used were vulnerable, transient, marginalised, refusers, hidden, underserved, disadvantaged and special or forgotten populations [2]. Within the literature, hard-to-reach groups have been identified as sex workers, drug users, people living with HIV and people from lesbian, gay, bisexual, transgender and intersex communities [4,5]. Additionally, other groups to which the description, hard-to-reach, applies include prisoners, asylum seekers, refugees, black and minority ethnic communities (BAME), children and young people, disabled people, older people [6] and traveller families [7]. Factors affecting engagement with the hard-to-reach are identified as attitude of staff; service flexibility; working in partnership with other organisations; and empowering users' involvement [2].

Defining patient engagement

There are many definitions of patient engagement, but all share an underlying theme: facilitation and strengthening of the role of those using services as co-producers of health, and healthcare policy and practice [8]. Meaningful patient engagement is recognised as an integral part of health care and a critical component of safe people-centred services, and engaged patients are better able to make informed decisions about their care and better use the resources available to them [9]. However, patients and everything that is individual to them impact on and influence how they engage with health and social care.

Difficulties in care engagement

Reasons why some patients do not engage in their care have been identified within patients' characteristics, such as demographics and health literacy, severity of illness or health conditions; knowledge and attitudes of healthcare professionals, the ability of the healthcare professional to respond to the challenges of required

behaviour change; and the healthcare setting e.g. primary or secondary care [9]. A patient's perception of their role and status as subordinate to clinicians has been identified as key in hindering patient engagement. For example, a fear of being labelled 'difficult' results in a passive role [10]. Other issues experienced by those deemed hard-to-reach affecting engagement may include: language barriers, lack of family support, unrealistic expectations, lack of education, uncertain legal status (which may prevent employment or benefits), few positive role models, unrecognised or non-existent qualifications, low literacy and numeracy ability or financial difficulties [11].

People living with HIV deemed hard-to-reach and care engagement

There are many reasons why some people living with HIV are hard to reach and engage with, some of which we will discuss here.

Stigma may render people as hard to reach owing to the fact that they are perceived as being somehow different [2].

'HIV remains a stigmatised and under-recognised condition that disproportionately affects already vulnerable populations. Gay and bisexual men, transgender woman, black African men and women, and people who use drugs continue to be disproportionately represented among people living with HIV.' [12].

HIV-related stigma and discrimination can negatively impact quality of life, and a patient survey demonstrated that stigma and discrimination also existed within healthcare settings. Issues included concerns about being treated differently, avoidance of health care when they needed it, a small proportion felt that they were refused health care and delayed treatment or medical procedure. Additionally, the survey indicated issues of an individual's inability to share their HIV status with anyone other than healthcare professionals and needing help with this issue [13].

The prevalence of mental health problems among people living with HIV is substantially higher than in the general population [14,15,16], and remains the most common comorbidity in HIV [17], indicating an increase in chronic depressive and anxiety disorders, a decrease in organic brain disorders and acute mental health syndromes. The impact of antiretroviral therapy (ART) side effects and recreational drug use is also discussed in the latter study [17].

Mental health issues may be responsible for loneliness and isolation, which is an emerging issue for people living with HIV and has been identified as the greatest unmet need [18].

Why is initial and continued care engagement so important in hard-to-reach people living with HIV?

The importance of engaging with hard-to-reach individuals is to ensure equity of access to the advances in HIV treatment and care over the past 30 years [19].

Furthermore, clinical outcomes for people living with HIV in the UK today are amongst the best in the world, aligning with an elite group of countries in prematurely surpassing the UNAIDS targets [1]. In addition to implementation of effective combination prevention, expansion of testing and early ART treatment the commitment and relentless work of HIV specialist services and public health has been astounding and is commended by both professionals, organisations and patients [13].

However, one could argue that this may not have been achieved quite so successfully without meaningful engagement on many levels between patients and HIV services. The cruciality of initiating and maintaining engagement is multifaceted. Firstly, continued engagement with HIV care services undeniably achieves best clinical outcomes including survival, and additionally enables supported access to other health and social care services. Reduced mortality and morbidity are directly associated with higher levels of engagement in care at all stages of HIV infection [20]. Secondly, by controlling and suppressing HIV viral load. The risk of HIV transmission in serodifferent couples via condomless sex when HIV viral load is suppressed, is effectively zero [21]. These findings underpin both the benefits of early testing and treatment for HIV and the global message of the U=U (undetectable equals untransmittable) campaign [22]. Finally, there is a cost implication which is relevant in the current financially-pressured NHS. Patients without the skills to manage their health care incur costs up to 21% higher than patients who are highly engaged in their care [23].

Guidance

Nurses are well placed to engage with the hard-to-reach to facilitate treatment, care and support allowing people with HIV to live well. Figure 1 presents factors that contribute to rendering a person hard to reach. The surrounding four sections highlight suggestions for clinicians and multidisciplinary team to keep those who are hard to reach in care and iterate the importance of location and advocacy in achieving the same.

Closing words

HIV nurses work closely with people with HIV, and are sometimes the only professionals involved in care especially in community roles. The NHIVNA Best Practice guidance documents should dovetail together as an effective resource for nurses.

I will conclude this document with a couple of relevant quotes to provoke some critical thinking about the concepts of 'hard-to reach' and patient engagement, and I hope readers have found this document useful.

'No one is hard to reach, just more expensive to reach. It is important to put more effort and creativity in reaching these groups.' Paul Vittles [11]

'Patient engagement is critical to shaping the way forward. It has the potential to save lives through safety and quality improvements informed by patient experience.' [9]

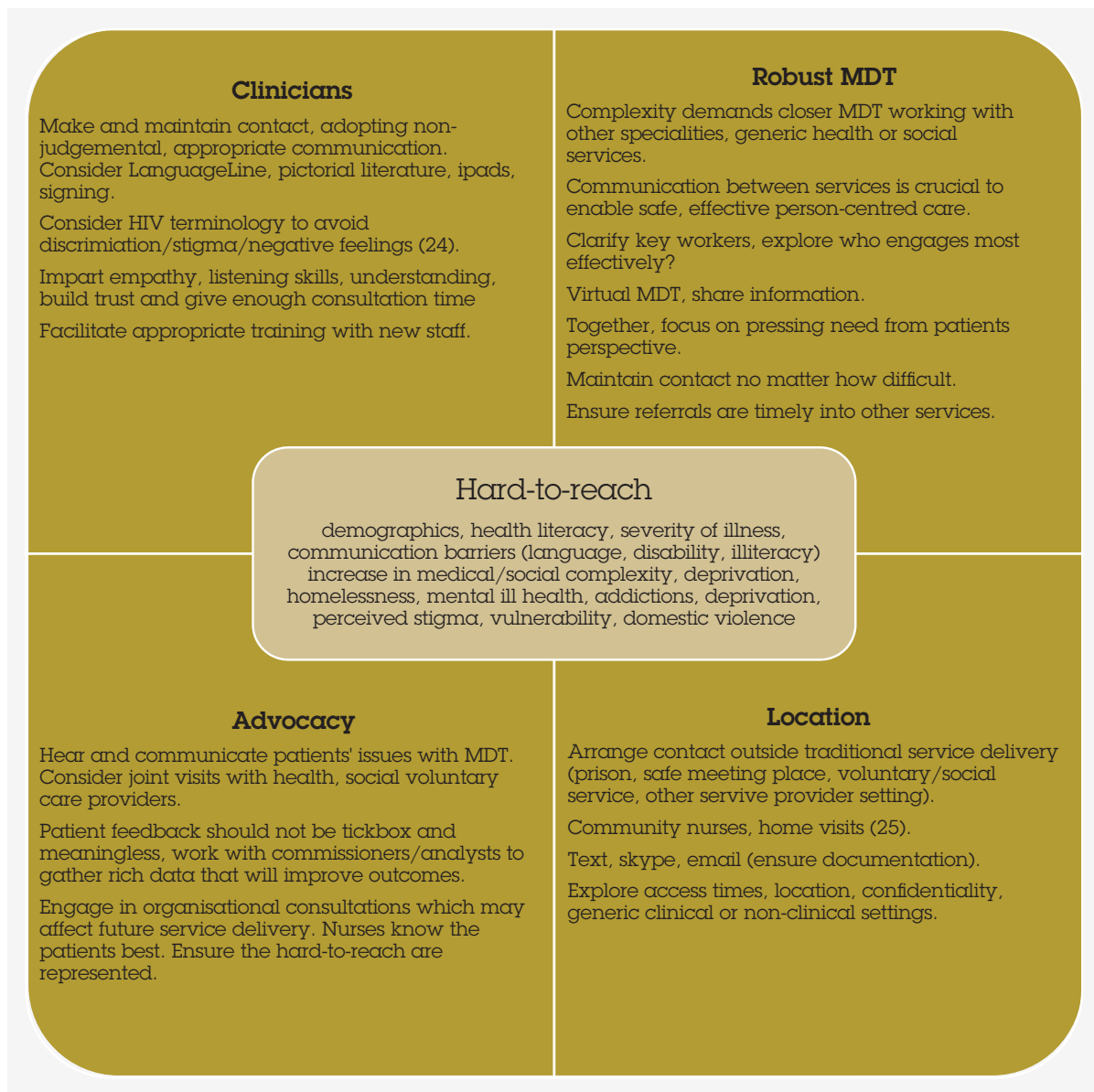


Figure 1: Hard-to-reach contributory factors and suggestions for maintaining individuals in care. MDT: multidisciplinary team

Achieving meaningful patient engagement, especially amongst those who struggle to engage will contribute to keeping them safe:

'One of the most remarkable features of patient safety movement is the lack of attention paid to the patient's perspective.' [26].

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Conflicts of interest

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Correspondence: Pauline Jelliman
 pjelliman@blueyonder.co.uk