Chapter 1: The good, the bad and the ugly: How do people living with HIV experience care in the health system?

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Chapter overview

What it is like to live with HIV in the global north has changed dramatically over the last two decades. There have been significant developments in the treatment and prevention of HIV, and the healthcare landscape continues to evolve. This chapter intends to highlight some of the impact of such changes on people living with HIV, who are accessing healthcare in the United Kingdom (UK). Initiating conversations with the contributors to this chapter commenced by asking them to recount part of their story using healthcare services that was particularly poignant, memorable or important to them – what stands out to you? was the question. The good, the bad and the ugly encounters with health and social care came forth in response.

Through sharing and discussing some of their helpful and hindering experiences of health services, HIV or otherwise, what could be seen as some of the common psychological challenges associated with living with HIV were also illuminated.

This chapter aims to bring attention to the lived experience of people living with HIV and the care they receive; to consider what works– and what does not. The contributors to this chapter have all helped to achieve this aim. Other first-hand accounts of healthcare experiences, published elsewhere have also been drawn upon.

Reflection boxes have been included throughout the chapter and are an invitation to explore and consider any experiences you may have of proving care for people living with HIV. Perhaps you work in a HIV service. If you do not work in HIV services specifically, it is possible that you might be in a position of working with someone living with the diagnosis. How does the content of this chapter apply to you in the context that you work?

Firstly,
Jesse *reminds us that 'everyone living with HIV has a completely different story and a very different approach in how they see and think of their HIV status'.* The collection of perspectives here offers an insight into some of the experiences, but not all. That is to say that the issues raised are not exhaustive or necessarily representative of everyone's perspective. Similarly, as the readers of this chapter you too will bring a range of unique experiences personal to you.

Reflection box 1: Capturing initials thoughts and feelings

Before you continue reading, consider the following:

What comes to mind for you upon reading the title and introduction to this chapter?
What might you be expecting to read about as you move through the content?

Make a note of what you consider could be the good, the bad and the ugly of experiences of healthcare for people living with HIV.

At the time of diagnosis

Consistent across the conversations with the contributors to this chapters was the support required at the time of diagnosis. Irrespective of time since diagnosis, age, sexuality and gender the overwhelming response to diagnosis has been reported in the literature (Walker, 2019), and speaking to Bella there was an acute sense of the shock and distress that was felt upon being diagnosed:

> *When I got diagnosed with HIV in March 2008, I was totally devastated and felt that my whole world had been blown apart. Bella*

A HIV diagnosis can be sudden and unexpected. In Bella's case the sensation of her world, as she knew it, having been 'blown apart' evokes an image of destruction. For Jack, a participant in a study by Flowers, Davis, Larkin, Church, & Marriott (2016) feelings of worthlessness and loss were apparent:

> *'Close friends, family, anybody, even new people that I'd meet; I just felt that I couldn't, I suppose I felt quite, quite worthless because I didn't have the, [sighs] I felt like I'd lost something, I just found everything so tiring, I didn't have anything to give, I didn't feel that I had anything worthwhile to kind of contribute, I don't know, I was just kind of like shell shocked I suppose'* (p. 1382)

Jack's sigh is almost audible as you read his account. When a HIV diagnosis is sudden and unexpected; and can be experienced as traumatic. Shock, numbness and distress are commonly cited as initial responses. A 20-year-old participant in a qualitative research study investigating experiences of motherhood recalled the time they were diagnosed with HIV very clearly:

> *'It was a big shock, and things got kinda blurry. I just remember going into my mother's bedroom and going to bed. I stayed there for like 2 to 3 days. I was diagnosed in my formative years; you're not really the same person after diagnosis.'* (in Sanders, 2008, p. 4).

Similarly, Judith comments on the defining moment she was diagnosed:

> *'I got my positive result and life has never been the same since'.*

Reflection box 2: Response to being diagnosed

The excerpts above provide an insight into the major impact a HIV diagnosis had on them.

Why might have the people quotes here responded in the way they did, about being diagnosed with HIV?

A dramatic change was felt by the Bella, Judith and the participant from the study by Walker (2019). Making sense of diagnosis seems, for some, to be via the separation of their lives into the temporal categories of before and after the event. There is a sense of *who I was*, then *what happened*, and *who I am now*. A key theme developed in the analysis of the experience of receiving a diagnosis of HIV was 'unwelcome and problematic changes in identity' (Flowers, Davis, Larkin, Church, & Marriott, 2011, p. 138). This was experienced as an identity crisis for some, in which parts of the self were considered to have died and a mourning process for the lost aspects of identity commenced. The everyday experience of living with HIV can encompass a series of unfolding stresses for the individual, including starting treatment, managing side effects, sharing HIV status with others and anticipating and/or experiencing HIV-related stigma. Together these can call into question the coherence of one's life and personhood, and can cumulatively constitute a traumatic stressor (Hefferon, Grealy & Mutrie, 2009). James Meeks and Emma Jones in chapter 4 explore the impact that HIV has on mental health.

Whilst the current HIV treatment context consists of very *effective treatments* that enable people, predominantly those diagnosed early in the course of the infection, to live a long and healthy life, diagnosis and starting treatment can nonetheless be experienced as a life-transforming event. This is not to be underestimated. People living with HIV have reported that the way in which HIV results were given to them made the testing process more difficult, upsetting, or disturbing (Hult Maurer &

Moskowitz, 2009). For one participant in a qualitative research study, the diagnosis was experienced as being made in a ‘scripted’ and impersonal’ fashion:

> *‘I was surprised there wasn’t much conversation ... the person who did it just handed me couple of brochures about places where I could go’* (Hult Maurer & Moskowitz, 2009, p. 186)

It could be said that individuals may struggle to comprehend the meaning of a positive test result when they are first diagnosed. In the same study, one participant said:

> *‘…from that point on, I couldn’t hear anything. I mean, they try to talk to you, they try to counsel you, they try to tell you everything’s okay. I don’t know what they said. I don’t remember. I just remember sitting there going, “Uhh ... uh, uh, yeah ...” just my mind was just shut down* (Hult Maurer & Moskowitz, 2009, p.187)

Sarah Rutter and Sam Warner explore the psychological effects of trauma further in chapter 6.

Noelly’s account of her experience shines a different light on what it is like to be diagnosed with HIV. A found poem has been constructed from Noelly’s interview transcript. Please see Gabriel, Lee and Taylor (2018) and Amos (2019) for discussion on the process of creating found poetry.

Reflection box 3: A found poem by Noelly
‘What really stands out’

What really stands out is going for my HIV test
not in a bad way
just that I remember
I was really scared

took me a long time before I went
I remember walking in
I was on my own
lining up and getting into the room where the nurse had to take my blood
clearly it said on the sheet HIV
I could see the nurse looking at me
I don't know whether it was
I would say pity
I could see she felt for me
I was there
you know, really worried
and everything you know
I remember that memory very well
just going all the way up to the hospital
the journey was very long and sitting there all by myself
that kind of stands out for me

Reflective questions:
What is your response to this poem?
Do any of the words, phrases, sections stand out to you?
Note down any immediate thoughts, feelings or bodily sensations.

It is worth noting here the words that Noelly uses: '*not in a bad way'* she says, when recalling the time of her diagnosis. She remembers it but she seems keen to state that her recollection is not because it was felt exclusively as damaging. Perhaps there is an assumption that the person receiving the diagnosis will respond negatively. Could this by why the nurse working with An looked at her with '*pity*'? The power of diagnosis in transforming self and relationships highlights it to be as Jutel (2009) deems 'a powerful social tool' (p.289). There is no doubt that some people experience significant distress in response to being diagnosed. However, it seems it could be harmful if healthcare professionals assume that this will be the case. Giving a HIV positive test result requires time and skill to provide the emotional support that the experiences shared here suggest are needed. Rayment, Asboe and Sullivan (2014) report that in an ideal circumstance a confirmed positive test result would be delivered face to face by the team or clinician who conducted the test, and that this would take place in a confidential environment with clear language being used. Watson, Namiba and Lynn (2019) draw attention to the power of language and provide a useful overview of the preferred language of HIV. Table 1 summarises three rules that the authors encourage practitioners to observe.

Rule 1: Positive words	***Rule 2 Person-first language***	***Rule 3: Avoid the language of war***
Focus on using positive words such as 'promoting health' (two positive words) rather than 'ending disease' (two negative words).	*It is important to use language that puts people first. Using language that puts people first acknowledges people living with HIV as fellow human beings.*	*Describing HIV in militaristic ways such as immune cells as soldiers fighting HIV, or ending HIV as elimination, killing or the scourge of AIDS or using these words may lead people to think those living with HIV have to 'fought' or 'eliminated'.*

Table 1: Reference : The language of HIV: a guide for nurses by Watson, Namiba and Lynn, *HIV Nursing,* 2019; 19(2).

Historically, disclosure has been the termed used to describe the process of telling someone about their HIV status. If you look at the definition of disclosure it is often referred to as the action of making new or secret information known (Watson, Namiba and Lynn 2019). In many definitions of disclosure, the word secret often appears, which brings with its implications of confession, revelation and biblical connotations.

The term disclosure is loaded with legal and negative terminology and reinforces self-stigma and the underlying belief that the person living with HIV is doing something wrong. Therefore we encourage people to use words like telling or sharing to reduce stigma and to reduce the implications that something is being hidden.

When referring to a person avoid using the word infectious as the word 'infectious' can be associated with wards like, dirty or tainted and can imply that someone is contaminated. Using more neutral words such as ‘acquire’ or ‘transmit’ say the same thing but carry different feelings foe people (Watson, Namiba and Lynn 2019).

The use of stigmatising language unfortunately still exists both in the media and in published academic articles. Challenging others on their use of inaccurate terminology can possibly evoke feelings of anxiety. Not challenging the use of inaccurate language can perpetuate stigma and discrimination (Leahy, 2018). Chapter 5 delves further into the navigation of difficult conversations that can occur within HIV care.

It may seem reasonable to think that following diagnosis, therapeutic intervention such as counselling or psychological therapy would be an appropriate next step. For some people this may well be what they want and need. However, the psychological processing of a HIV diagnosis can take time and not everyone perceives the benefit of talking therapy at such an early stage. For example, Neil did not:

> *I was diagnosed and was still coming to terms with my diagnosis of HIV. I felt unready really to go deep with any talking and turned down further sessions at that point. Neil*

How someone responds to their HIV diagnosis will depend on many contributing factors including access to support, knowledge, previous experience of trauma and other psychosocial factors (Pence, 2012). The range of mental, emotional, physical and behavioural reactions associated with a trauma response (see chapter 6) are considered part of a normal reaction and for a lot of people, these thoughts, feelings and behaviours reduce naturally as they psychologically adjust to living with HIV. To offer psychological intervention at this point has the potential to pathologise that process. Ensuring that the medical implications of the diagnosis are understood might be the primary focus for a healthcare professional involved in HIV testing and diagnosis. Regardless, for the overwhelming majority of people, this process of adjustment is most successful when they feel listened to and heard by those supporting them.

Reflection Box 4: Checking-in

Engaging with the lived experiences of being diagnosed is one way in which to improve the process in which a HIV positive test result is given (Schrooten, et al., 2001).

In what way might your engagement with the experiences shared so far in the chapter support you in your professional role?

How might you understand your response and apply it in your practice context?

What skills might be considered useful in supporting someone at the time of diagnosis?

Feeling heard

Hardavella, Aamli-Gaagnat, and Frille (2017) acknowledge that:

> Bad news may be broken in a nonempathetic way, messages may be given to the nurses over the patient's head while interrupting the consultation, difficult words may be used that the patient does not understand, and the patient may feel excluded from conversations with almost no concern showed for their feelings and emotions. Often, what is everyday routine clinical data to the healthcare practitioner may be completely unfamiliar to the patient, giving the impression that the clinician is cold and unsympathetic to the individual's emotions as they try to come to terms with the diagnosis and its implications. (p.131).

Neil recalls his engagement with psychological services in which he felt dismissed:

> *‘I did feel at the time that the psychologist had seen it all before and was more concerned to tell me that I wasn’t going mad and get me off his books, although that might have been my impression at the time. It made me feel that other people were more important than me as they were in greater difficulty.*’

Medical doctors in practice report a lack of training in clinical empathy (Buckman Tulsky, & Rodin, 2011). However, there is a substantial literature to support the claim that doctor -patient relationships strengthen as a result of the detection of emotional cues and expression of empathy by doctors to the patients they work with (Flickinger, Saha, Roter, Korthuis, Sharp et al, 2016) please see chapter 5 and 6 for the importance of relationships and communication. What results is a feeling of being heard, supported and accepted. In turn this can have a major impact on subsequent retention in care. Hardavella, Aamli-Gaagnat, and Frille (2017) go on to provide some top tips for dealing with challenging situations within the patient-doctor dyad that may be found useful. Chapter 5, Stormy waters difficult conversations in HIV care explored these tips further.

It has already been highlighted that the way people are given a HIV diagnosis can greatly impact the individual’s experience, as well as their decision-making in relation to treatment down the line. These are findings well documented in the literature (Evans, et al, 2016), and is why Martin Buber’s work provides a valuable framework in which to consider how to communicate with the people you work with. The discomfort felt by some healthcare providers in disclosing positive test results, or in some cases even offering a patient a HIV test have been brought to light (Mitchell, Bushby, & Chauhan, 2011; Connors et al, 2012). It is worth saying here, that the effect of delayed diagnosis can result in avoidable loss of life (May et al, 2011) and late diagnosis of HIV remains an important clinical and public health issue in the UK (Chadwick & Freedman, 2019). A national audit of late diagnosis highlighted that a third of individuals diagnosed with advanced HIV had earlier missed opportunities for diagnosis documented (Byrne, Curtis, Sullivan, et al., 2016). It was identified that most of these missed opportunities were due to clinicians not offering an HIV test, as opposed to patients declining to have one.

The emotional requirements for professionals involved in provider-initiated HIV testing and diagnosis can be experienced as stressful. Feeling inexperienced in giving a HIV diagnosis, not knowing how patients will respond and managing the ethical dilemmas related to disclosure were all cited as factors contributing to the emotional work required, in addition to organisational contexts in which nurses and midwives felt over-worked and under-supported (Evans, et al , 2016). What is going on for someone internally has an impact on the way in which they relate to others (please see chapter 2, 5, 6)

People waiting to receive their HIV test results have noticed when healthcare professionals were upset, nervous or crying when communicating the diagnosis. One person said:

> *‘When he came back, he was crying. He told me that, ‘‘I’m sorry, you tested positive.’’ ... And, he’s crying, I’m like, ‘‘Okay, I need to calm myself down,’cause I gotta take care of him!’* (Hult Maurer & Moskowitz, 2009, p. 186)

This points to the importance of supervision for professionals involved in managing complex issues such as testing and diagnosing (Horwood, Voce, Vermaak, Rollins & Qazi, 2010).

In response to the poem created from Noelly’s narrative perhaps you have considered what constitutes a helpful encounter with a healthcare professional, for someone living with HIV. Particular attitudinal qualities may come to mind. When asked about experiences of a particularly good interaction with services, and what made it so, these were some of the responses from contributors:

> *She [sexual health advisor] talks to me like a human being and has even cried with me. (Bella)*
>
> *‘this other doctor in the same clinic was just so nice , so friendly, so patient and understanding...they [doctor] took the time and listened...it was the first time since my diagnosis that I felt I had some control of my own care...that I was able to choose what I was able to do. I almost cried as it felt that someone was actually listening to me. There is something about being listened to and understood and having some autonomy in your own care…being treated like a human being who’s quality of life matters (Jesse)*
>
> *what made it helpful was she [psychiatrist] understood how I was feeling and she did not talk much but she listened to me (Kya)*

> *‘Being able to talk freely without it turning into a tick box exercise...someone who would just listen and not necessarily give you answers as sometimes you just need to talk’ (Mason)*

Reflection box 5: What helps?

What do you notice Jesse, Kya and Mason are talking about in relation to helpful experiences they have had in healthcare?

What does the word autonomy mean to you?

Empathy, authenticity and honesty

People have different ways of interacting with others so the expectation that there are set of prescribed responses to be adhered to is certainly not what is advocated. However, not feeling heard can leave an individual feeling misunderstood, unaccepted and unsupported by others, and as a result might be less likely to foster self-acceptance (Gillon, 2009). Empathy is distinctive from sympathy, with the latter perhaps defined as *feeling sorry for someone*. Empathy is the attempt to *understand how it feels for another person. Imagining what it would be like to stand in their shoes; feel how they feel and see the world through their eyes.*

Reflection box 6: What is empathy?

Carl Rogers (1975), in his development of the person-centred therapeutic approach reflected on empathy as both ‘an unappreciated way of being’ and ‘possibly the most potent and certainly one of the most potent factors in bringing about change and learning’ (p. 3). Empathy could be said to refer to the process of seeking to understand the world of another person - as they experience it, or what could be described as the internal frame of reference of another.

Can you recall a time when you experienced empathy from someone else?

What happened?

How did you know it was empathy?

Note down your responses to these questions

Empathy requires authenticity; another quality that was prized by the contributors to this chapter.

> *An: I think clarity is really important...its about having a grown up conversation, be honest with people and do not make assumptions that people will not understand, you need to be honest with them'.*

An expresses the need for clarity. This could refer to the provision of clear and accurate information that is imparted to people living with HIV that could support them in their treatment decisions. It could also refer to a 'way of being' with people that is characterised by honesty, authenticity and genuineness. A human connection is what is important. A way of relating that is characterised by reciprocity and mutuality; communicating person to person. This is what philosopher, Martin Buber (1988), described as the difference between I-It and I- thou methods of relating in his work to understand the nature of dialogue. In the I-It relationship, the person relates to the person in a functional manner, like the way one might relate to an object. In contrast, the I-thou relationship is typified as a two-way relationship, between persons all of whom are actively engaged with each other in a shared effort to enter into an authentic relationship. In establishing and maintaining a human connection to the person you are working with you are someone 'with' the person as opposed to someone doing something 'to' them. Given the descriptions provided by Bella, Jesse, Kya and Mason what transpires to be the most helpful experience at the time of diagnosis is someone who can tune in to the emotion/s being felt by the individual who has been diagnosed. Noelly put it succinctly when she explained that it is not what the healthcare professional feels like that matters but what the person living with HIV feels like: *'What is more important for people living with HIV is how they deal with living with the virus'.* HIV care is for life and so the importance of good care to maintain quality ongoing relationships is paramount. Good care requires time and the ability to apply a patient centred approach, in which communicating empathy both verbally and non-verbally is central. HIV-related stigma is an important aspect to consider when thinking about the nature and quality of the working relationships as it is well known that this is a persistent issue for the HIV population (see chapter 8).

HIV-related Stigma

Stigma in society

The most stressful problems reported by people living with HIV/AIDS are related to navigating challenging social situations including discrimination, stigma, confidentiality, and sharing HIV status (Pakenham & Rinaldis, 2002). It affects the quality of life and mental health of people living with HIV and is also related to disengagement from HIV care and treatment (Varni, Miller, McCuin, & Solomon, 2012; Donovan & Durey, 2016). So, what is stigma, and why is the impact of HIV-related stigma so significant? Perhaps the words stereotypes, prejudice and discrimination come to mind. Respectively, these could be said to be the cognitive, affective and behavioural manifestations of stigma. Erving Goffman defined stigma, in his seminal work, as 'an attribute that is deeply discrediting' (1963, p.3). Associated with a deviation from a constructed ideal or expectation, stigmatising attitudes can evoke feelings of fear and revulsion towards stigmatised groups, and in the context of HIV, can sometimes result in the ‘unfair and unjust treatment of an individual based on his or her real or perceived HIV status’’ (UNAIDS, 2003), known as discrimination. Stigma could be said to challenge one’s humanity and contribute to an exercise of power (Dovido, Major & Crocker, 2000).

Reflection box 7: Reflecting on your personal experience

You are invited to think about a time in your life when you felt isolated or rejected for being seen to be different from others or when you saw other people treated this way

What happened? How did it feel? What impact did it have on you?

Since Goffman’s work stigma has continued to be studied within social psychology (Bruce & Phelan, 2001). Research has sought to understand the mechanism in which categories are constructed and linked to stereotyped beliefs (Link & Phelan, 2001), as well as the extent to which stigma generates and perpetuates health inequities (Hatzenbuehler, Phelan, & Link, 2013). Stigma continues to be significantly problematic for people living with HIV today. The following reaction to HIV diagnosis from a male pinpoints some of what the stereotyped, group-based beliefs can be about people living with HIV:

> ‘*this only happens to promiscuous sluts having BB [bareback] chem sex every weekend … I felt dirty, infected, unclean and scared of the future and what people, friends and family would think of me’* (in Walker, 2019, p.102)

The evidence suggests that stigma is created and sustained by social structures as well as interpersonal processes (Hatzenbuehler & Link, 2014). The consistent message across the corpus of data is the negative impact stigma has on the lives of those people identified as possessing an attribute (real or perceived) that is linked to a negative social identity (Crocker, Major, & Steele, 1998). The majority of respondents who participated in a study on contemporary experiences of HIV diagnosis in the UK (Walker, 2019) articulated how, in their view, the social dimensions of HIV is what separates it from other long-term health conditions. Participants suggested that other long-term health conditions generated more sympathy as they were not associated with shame or stigma in the same way as HIV is possibly as it is related to sex, drugs and a legacy of when death was almost certain. A participant diagnosed within 6 months of taking part in the study reported:

> *'I knew little about HIV when I was diagnosed. I thought someone had just told me I had 5 years to live. Now I know it is a manageable long-term condition, you can have babies and you suppress the virus to UD [undetectable] levels. The only problem is the stigma attached to it. Had I been diagnosed with some other illness I would have told my mom and close family members. I would have told my now ex-boyfriend'* (in Walker, 2019, p. 106)

This extract from Walker (2019) illustrates the power of stigma in silencing people, and unfortunately the act of concealment and 'keeping secrets' can exacerbate feelings of shame. Which in turn lead to people feeling ashamed and then increases stigma.

Reflection box 8: HIV-related stigma

There are considered to be different ways in which HIV-related stigma can manifest.

Earnshaw and Chaudoir (2009) highlight the following in their framework:

Enacted stigma: *Actual experience of stigma and discrimination based on HIV status*

Anticipated stigma*: also known as felt or perceived stigma, relating to the expectation of being stigmatised by others because of HIV status*

Internalised stigma: *self-directed stigma in which negative assumptions about what it means to be living with HIV are accepted by the person living with HIV.*

Some of the ways that HIV-related stigma might negatively affect the well-being and/or healthcare of persons living with HIV have already been raised.

Can you think of any other effects of HIV-related stigma on people living with HIV?

Telling others about their HIV status may seem a frightening experience for someone living with HIV who anticipates they may be judged negatively or treated unfairly as a result. It is not uncommon for people living with HIV to feel reluctant to share their status with the medical professionals they have support from:

> ‘*I know a lots of women and men who are still not able to tell their HIV status to their GP because they have fear*.’ (Noelly)

A fear of stigma and confidentiality breaches can silence individuals. Perhaps this is not surprising. Afterall, HIV-related stigma is a reality. If someone expects to be stigmatised, and potentially discriminated against in their interactions with others then avoiding circumstances in which this may occur seems an understandable response. This notion becomes increasingly concerning when it is considered that HIV-related stigma extends to healthcare settings too.

Stigma in healthcare

In accordance with the Equality Act 2010 people living with HIV are entitled to fair access and equitable care. However, experiences of HIV-related stigma exist beyond personal relationships, and are also experienced in interactions with medical and mental health service providers (Elford, Ibrahim, Bukutu, & Anderson, 2008).

Reflection box 9: HIV-related stigma in healthcare

Earlier in the chapter, an empathic way of being with others was raised as a central ingredient to helpful encounters with professionals. Stigma could be said to be the expression of bias and can therefore block/impede/get in the way of empathising with someone.

Consider the following:

What assumptions might a healthcare professional make about someone who has been diagnosed with HIV?

In what ways might a healthcare professional discriminate against someone living with HIV?

Here are some examples of how HIV-related stigma can manifest in a health care setting:

When Jordan first went for a HIV test, he was asked by the doctor why he was requesting it and what profession he was in. When Jordan responded he was told by the doctor – 'You can't be a police officer if you are a homosexual, and it will have to be reported to the police that you have been for an HIV test'.

Judith was delayed dental treatment for a year after visiting the practice to enquire about a problem with her gums. Judith attended for several appointments however was refused treatment, being directed to back to her GP time and time again.

Can you put yourself in their position and imagine how this must have felt?

A number of studies have reported on the acts of discrimination experienced in healthcare environments towards people living with HIV. These have been enacted in numerous ways, including breaches of confidentiality, humiliating practices by health care professionals (for example 'double gloving'), and refusal of treatment as demonstrated in Judith's story. In fact, the Positive Voices Survey (2017) found that one in 9 (11%) people living with HIV in the UK have been denied healthcare or delayed a treatment due to their HIV status. Displays of negative attitudes, or prejudice occur, as shown in Jordan's case; drawing attention to how HIV-related stigma is often experienced intersectionally alongside other attributes that may also generate marginalisation, including a person's gender, ethnicity, social class (Boucher,. et al 2019).

Jordan went on to share how his fear of stigma and discrimination impacted on his decision to engage with care. When he moved to a different area, he highlighted his preference to remain registered with his current GP practice - as it was more 'personable'. He reflected on the 'fear of having to tell people at another practice about his diagnosis' and the thought that crossed his mind: '*If I am ill, I'd rather just be ill than go there'*. A further finding from the Positive Voices Survey (2017) highlighted that 18% of people living with HIV had avoided healthcare when they needed it because of fear of being treated differently to other patients.

Jesse recalled experiences of having his confidentiality breached in a healthcare setting. His experience visiting his GP is shared here first of all:

> *‘I went in for a random thing…I can’t remember what and my folder was on the front desk…and it had HIV on the front of it in red marker pen…it was on the front desk where everyone checks in for everyone to see … you could see my name on it… it made me feel so violated...so... I was to you know be treated differently …that made me feel awful.’*

The use of a red marker pen stands out here. For some, the colour red has long been associated with danger. It attracts attentions and can signify threat. Jesse’s use of the word violation suggests a traumatic experience in which a boundary was crossed.

A question emanating from discussions with people living with HIV was *‘what is it with dentists?*’. Recall Judith’s experience of seeking dental treatment and being denied, described earlier in this section. Jesse also described his experience of registering with his local dental practice once they became aware of his HIV status:

> *‘When we handed her back the forms but her tone very much changed …we are quite a busy dental surgery… funny appointments are quite difficult for us…you would have to call on the day to see if we could fit you in at the beginning or at the end…which we knew what that was code for..’*

Reflection box 10: Making sense of T’s experience

Jesse describes how it felt for him to see his folder on the front desk marked in red pen with the letters HIV.

How might you feel if you saw sensitive information about you on display?

Jesse described the communication he received from the dental receptionist as 'code'.

What do you think Jesse is describing here?
What is the message being implied?

In Jesse's interaction with the dental receptionist it is suggested, though not directly expressed, that his appointment will need to be scheduled either side of routine appointments. There is no scientific reason why Jesse's appointment should be scheduled in this way. Implicit messages such as this are harmful and such practices are unlawful and clinically unnecessary. Advancements in HIV treatment mean that HIV will not be transmitted by people who are virally suppressed Undetectable= Untransmittable (U=U), therefore appointments throughout the day should be made available to all. Thankfully, a fruitful dialogue appears to be taking place within the discipline of dentistry, in which stigmatising experiences of people living with HIV in this context, are being illuminated, including the challenges faced with registering with dental practices and being refused treatment (Levett, Slide, & Mallick, 2009). Methods to tackle this issue are also at the forefront, particularly in the context of staff training (Okala et al, 2018). For example, the BDJ Team, which is a peer-reviewed online magazine, supported by the British Dental Association, recently published an article outlining the key facts that primary care dental teams need to know about blood borne viruses (Lala, Harwood, Simon, Lee, & Jones, 2018). There is a need to raise culturally sensitive awareness and develop educational tools to address stigma. Okala et al., (2018) emphasise that training should focus on the ways to support patients after sharing of their HIV status. The authors suggest it should include training on:

> ‘ensuring confidentiality, using non-discriminatory language, booking appointments at any time of day, having up-to-date knowledge of current antiretroviral therapy, treatment outcomes for people living with HIV and comorbidities likely to affect patients who have been living with HIV for a number of years and who have been on long-term antiretroviral therapy’ (p. 150).

It could be safe to say that the recommendations made by Okala et al., (2018) are relevant to the training of healthcare teams working in HIV services or otherwise. The psychological impact of shame stigma and HIV are discussed in more depth in chapter 8.

Healing suffering

As has already been indicated earlier in the chapter, receiving a diagnosis of HIV or any other chronic disease is often characterised by negative psychological outcomes such as helplessness, guilt, anxiety and depression (Richardson et al, 2001). In addition, trauma responses have been increasingly recognised as an important factor associated with HIV diagnosis (LeGrand, et al, 2015). Kevin and Jane’s stories are presented here to provide an insight into the impact of such a response.

Kevin’s story:

Kevin was 18 when he received his HIV diagnosis. He contracted HIV from his first sexual partner who was older than him and was unaware of her own HIV status until Kevin was diagnosed.

Kevin was a self-confessed bad boy, who liked taking risk and had experimented with drugs which led him to being involved in a local gang. For years Kevin struggled with the being in the gang and was very fearful that the other members of the gang would find out his HIV status. Due to this fear of people finding out about his status Kevin refused to take medication.

As Kevin's immune system began to decline he started to lose weight and was eventually admitted on to the ward very unwell with pneumonia.

A subjective sense of loss of control is commonly associated with a trauma response. In Kevin's story so far there is a sense of the build of fear he experienced; his anxiety about those around him becoming aware of his HIV status and what that might mean for him. The shame that Kevin experienced led him to conceal his status to such an extent that he felt too fearful of taking the necessary medication to support his immune system. Perhaps by not taking up antiretroviral treatment Kevin was attempting to regain a sense of control over what he felt he had lost since being diagnosed. Inevitably, his refusal to take medication had significant consequences for his physical health. It could be argued that this constituted a further loss of control; over his body as he became increasingly unwell.

Jane's story

Jane was diagnosed HIV positive after a long period of unexplained illness, she had been admitted to a variety of different hospitals and been exposed to numerous tests, biopsies and procedures. This had led to mistrust between Jane and the medical team as Jane felt that the team were not looking after her properly as she continued to deteriorate. Eventually Jane was offered a HIV test. She recalled that the team at the time felt that this was an unlikely diagnosis as she was young (23) and white British. Looking back on this Jane felt that the doctors attempts to *reassure her were not medical in origin and more moralistic. At the time of her HIV diagnosis her immune system was low and she had multiple HIV related opportunistic infections.*

Once Jane received her diagnosis she was transferred to a specialist unit for inpatient care. During her admission Jane become very withdrawn and felt very anxious about her diagnosis. She reported feeling a sense of loss of the future that she had hoped for. The nursing team and psychologist engaged with Jane to explore the distress that she was feeling.

Janoff- Bulman (1992) conceptualises the psychological impact of trauma as emanating from the shattering of fundamental assumptions a person has about the world and about the self. The assumption that the world is kind and that the self is good and capable can shift. As a result of trauma, the world can suddenly be perceived as unsafe and scary, and the self unable to cope or perhaps even to blame. As Jane reflects, the loss she felt for her imagined future led her to withdraw from support.

Awareness of trauma responses to HIV diagnosis is becoming increasingly more important when providing psychological support for people living with HIV. Feelings of fear, guilt, shame, anxiety and low mood can exist in the everyday life of living with HIV. Kya states that *'a good service in my experience is where a consultant or a healthcare specialist recognises the need for a patient to be referred onto psychological or psychiatric services'.* Increasing understanding of the relationship between physical and mental health can ensure that individual need is recognised and appropriate referrals made (Naylor, 2016). In chapter 6, Sarah Rutter and Sam Warner explore the relationship between trauma and physical and mental health.

Let's see how Kevin and Jane's stories develop.

Kevin’s story continued…

During his admission to hospital he discussed his concerns with the specialist nurse. As the therapeutic relationship developed it gave Kevin the opportunity to explore his diagnosis and his hopes for the future. During this time Kevin began to re think his diagnosis and stated that he felt that his HIV diagnosis had given him the opportunity to re-evaluate what was important to him. This resulted in Kevin agreeing to take antiretroviral therapy.

Kevin reported that he had never felt happier contributing to society in such a positive way. During his clinic visit Kevin was very candid and stated that he felt that his diagnosis had changed his life in a positive way and had he not had the opportunity to rethink his life as a result of his diagnosis, then he would have ended up in prison or dead.

Despite being happy in his work life Kevin expressed a desire to have a committed relationship and to one day become a father. Kevin felt that due to his HIV diagnosis that neither were possible. To help Kevin explore these issues further he was referred for Clinical Psychology.

Two years after his hospital admission and support from the specialist nurse and clinical psychologist Kevin was delighted to announce that him and his partner were expecting their first child.

Jane’s story continued..

Jane mentioned that she had always wanted to become a nurse and was at the start of her nurse training when she became unwell. Jane felt devastated and worried that because of her diagnosis she would not be able to complete her nursing course.

As Jane became physically better, she decided that she was going to use her desire to become a nurse to help with her recovery and decided to set this as a goal. Jane wanted to restart her nurse training within one year of diagnosis.

Jane responded well to treatment and her immune system recovered well. Jane was still very anxious about her HIV diagnosis and the stigma that she had received prior to being transferred to the specialist unit, Jane engaged in a series of sessions with the HIV clinical psychologist and specialist nurse with regards to the issues that she was experiencing. This was mainly around her desire to become pregnant and end the current relationship that she was in. Jane felt a sense of conflict and was concerned that she would never have the future she had hoped for.

One year after diagnosis Jane recommenced her studies at the university, at first, she found this challenging she managed to complete her course and graduated with a first -class honours degree. After Jane had qualified as a nurse she felt a strong passion and motivation to 'give something back'. For Jane, this meant that she was going to use her training and qualifications to work with people living with HIV to improve standards of care. Over a period of time Jane became a very passionate HIV activist and would attend clinic appointments with stories about her work; always protecting confidentiality when she did so.

Four years after her initial diagnosis Jane attended clinic and she informed the team that she was pregnant. She had finally managed to leave her old partner and fell in love with a man whom she had met via a friend.

Reflection box 11: Healing suffering

What is different about these sections of Kevin and Jane's' story?

What has shifted for Kevin and Jane, and how might you make sense of this?

Whilst the negative psychological impact related to HIV seropositive status is well documented, there is growing empirical evidence to substantiate the profound and positive change that people living with HIV can experience following their diagnosis. This has come to be known as posttraumatic growth, or experiences of benefit finding (Tennen & Affleck, 1998), or thriving (O' Leary & Ickovics, 1994). Such experiences appear to occur amongst people who share the common factor of a struggle with adversity following a traumatic experience. Subsequently, the individual is propelled 'to a higher level of functioning than which existed prior to the event' (Linley & Joseph, 2004, p.11). A systematic review of qualitative research (Amos, 2015) explored the experiences of posttraumatic growth among 203 people living with HIV across eight research studies. It supported what has been identified as being the central domains in which positive transformations in beliefs and behaviour are manifested when experiencing posttraumatic growth including: (i) improved relations with others; (ii) identification of new possibilities for one's life; (iii) increased perception of personal strength; (iv) spiritual growth; and (v) enhanced appreciation of life (Tedeschi & Calhoun, 1996, 2004).

Kevin and Jane's stories highlight the complexities involved in receiving a HIV diagnosis and the positive outcomes that can occur. A re-evaluation of life goals, and a motivation to live in accordance with what was deemed most meaningful to Kevin propelled him towards living a value-guided life. Jane's story illuminated how she managed to stay focused on her goals as a way of adjusting to her HIV diagnosis. She appeared to recognise her potential for acquiring knowledge and caring for others, and this was realised in her decision to train to be a nurse.

Reflection Box 12: Promoting growth

Think about a time you have had a challenging experience.

Were there any positives that came from what was a difficult situation ?

Within your professional role how could you support Kevin and Jane?

What are the implications for practice considering Kevin and Jane's story?

With the recognition of both traumatic stress and traumatic growth responses to HIV diagnosis, the attempt to untangle the relationship between these two concepts has become a focus (Bluvstein et al., 2013; Schuettler & Boals, 2011). Practitioners working in HIV services may benefit from increased awareness of the potential for posttraumatic growth to occur among the individuals they work with. Furthermore, the facilitation of growth may be considered as a clinical intervention different from interventions designed to alleviate distress. Healthcare professionals may wish to consider how they can support people living with HIV to 'find their own vehicles of change' (Woodward & Joseph, 2003, p.281). A strengths-based approach, that recognises and emphasis people's personal strengths and capabilities, rather than their limitations is advocated. In addition, acknowledging an individual's resilience where appropriate; drawing attention to how that person has survived and surpassed difficulties in their lives can help to instil hope. The participants in Woodward and Joseph's study reported 'experiences of an awakening, validating, nurturing, liberating and mastery nature' (p. 275) were important in bringing about positive change. Healthcare professionals may like to reflect on how such experiences may be facilitated. In the final section, the framework of care, in which all that has been discussed so far occurs, is explored.

An inter-professional approach: working together towards meaningful change

Early access to treatment reduces susceptibility to opportunistic infection associated with AIDS and increases life expectancy (Sherr et al., 2010). In order to maintain this, a consistent and continuous delivery mode of health, treatment and social care, that is in line with clinical treatment guidelines (British HIV Association, 2018) is required. Working in isolation does not work, whilst interprofessional working enables preventative care (BHIVA, 2018). Crowley (2013) discusses how the restructuring of the National Health Service in the UK has led to a significant decrease in third sector services available to people living with HIV, such as voluntary and community organisations and charities. In addition, the funding cuts imposed on local authorities has resulted in the removal of HIV provision in some places altogether (Dalton, 2016). This, as Dalton (2016) labels it, culminates in a 'postcode lottery' when it comes to the provision of HIV support services. Research completed by the National AIDS Trust (2016) reported that service users want to be supported by HIV specialist provision and that being part of a community was vital for psychological and physical wellbeing. The contributors to this chapter were generally of the view that continuity of care was of the utmost value to them.

Roland has experienced both the one- stop shop service offered by his clinic when he was diagnosed in 2006 and the current fragmented offer. He comments:

> *'It's like moving from being chauffeur driven in a Bentley to being put behind the steering wheel of a juggernaut, never having driven one before. I feel like I am now the one having to do all the steering work, chasing up appointments and referrals, being the messenger between clinic, GP and other specialists, sometimes transmitting messages that I have no understanding of. Before I felt safe and secure in the knowledge that someone was actually in control of my care. Now, it seems that I have to be in control. But I am not qualified or*

> *competent enough to assume that control and indeed it is not the position I want to be in. Of course, I want to be fully participant in the management of my condition, but I don't want to be the one leading on it'.*

This seems to emphasise the importance of supported empowerment via the joining up of healthcare services working together to create a secure framework. This makes sense given how physical and mental health are interchangeable entwined (refer to chapter 3). Bella reflects on how interdisciplinary working significantly benefits services users, using her local support centre as an example: *'We have an amazing working relationship with our clinic and I think that this combination works. They have the medical side and we have the holistic side and the two combined work'.* Unfortunately, this model of healthcare management has come to be an exception.

Kya's experience in primary care brought to her attention that *'the practitioner had little or no knowledge about some of the issues facing a person living long-term with HIV'.* Fragmentation in HIV care can result in people feeling batted back and forth between their GP and their HIV consultant. What can result, is people feeling like they have been missed; a part of a bigger system of care however not treated as an individual with individual needs. This experience can act as a trigger for people with complex histories that include abuse and neglect (please refer to chapter 6). For example, Neil and Jesse shared how experiences of being ignored and dismissed had significant repercussions for their mental health:

> *'I have recently had to go back to my old HIV medication as a result of an interaction with my antidepressants. I think that this could have been picked up before as it sent my mental health and depression in to a tail-spin...' (Neil)*

> *'I was put on to Atripla which has efavirenz in it which is a medication that caused me a great number of horrible side effects. I had insomnia, migraines, visual and auditory hallucinations. I had anxiety attacks which went on for the best part of nine months. I had spoken to my doctor about it a couple of times but he kept saying but you are doing fine your viral load and CD4 count are doing well just keep at it' (Jesse)*

Jesse's extract highlights that the HCP was only focusing on the physical aspects of his care and did not consider the wider impact that these side effects were having on Jesse's life.

At its most severe, people can be left feeling entirely on their own. When Billy was asked what issues he faced with the healthcare support he received. *He said:*

> *'I don't have health care support, it doesn't exist, I just have my GP. I am my own doctor and it's ridiculous because sometimes what I have to go through, we want our own doctor, for prevention. More designed for our sort of things because the problems are still there, it's not like oh everybody take prep, HIV is gone, what about the ones who are left over, there is a lot. I got friends who lost benefit, people living in poverty and they don't understand, I didn't find help because things start to shut down, now many people have lost everything'.*

This quotation outlines how the lack of interdisciplinary working and specialist services can result in feeling like there is no support at all. Respectfully supporting the autonomy of people living with HIV in navigating their care decisions does not imply that they take on the role of care coordinator. As Neil reports*: 'a service should* *be joined up more and practitioners should talk to each other, GP, mental health team etc'.*

In a population in which one in three people accessing HIV are over the age of 50 (Public Health England, 2016) cross-disciplinary collaboration provides an effective healthcare management model that can be support all people living with HIV. Ageing with HIV is explored further in chapter 10.Services working in isolation can be particularly detrimental for those people living with one or more additional conditions co-occurring with HIV (for example HIV and diabetes). Earlier in this chapter, the experience of feeling heard was highlighted as being one of the most important factors in what is considered to be good care. The consequences of not listening are starkly illuminated in Mason's account:

'I was concerned that the HIV treatments were affecting my diabetes. In 2000 I had an incident where my diabetes nearly killed me and I still didn't feel heard…'

A national audit completed by Croston (2016) reported a lack of mental health support in many UK services providing HIV care. It was reported that 'There was no mental health professional member (psychologist, mental health nurse, liaison psychiatrist or social worker) in 21 (40%) teams' who participated in the study. In light of the current care context described here, it is perhaps not surprising that people living with HIV cite HIV support in the community as *'raising awareness and providing the psychological services that the hospital service can no longer provide' (Bella).* Despite the reduction in third sector HIV services, participation with community HIV services for people living with HIV is considered by many as very helpful to their needs.

M recalls the positive experience he had accessing community support services:

> *‘I felt better with the group of people living with HIV because I could open up, I had more to share’.*

As has been reiterated throughout the chapter so far– ‘one size does not fit all’. For example, whilst some may find peer support very effective, others may be less keen to engage in this mode of support provision. Once again, the importance of remaining patient-centred is restated.

Summary

Returning to the title of this chapter, how might the good, the bad and the ugly of experiences with HIV care be summarised.

Reflection box 13: What does HIV care look like today?

Having engaged with this chapter consider the following questions:

What is it that stands out to you?

How do you think about HIV care?

If you do not work within HIV care specifically, what would you be mindful of if you were to work with someone living with HIV?

The good (what works)

- Accessible services without restrictions
- Ways of relating– listening, seeking to understand from the perspective of the person living with HIV, communication of empathy
- Timely referrals that reflect the individuals needs
- Clear and thoughtful communication of diagnosis
- Supporting autonomy in treatment decision-making

- Training for healthcare staff that includes awareness of stigma, transmission routes and U=U.
- Peer-support

The bad (what does not work)

- Working in 'silos' – resulting in poor assessment and treatment of co-morbidities
- People living with HIV finding themselves in the role of coordinating care

The ugly (what is unacceptable)

- Stigmatising and discriminatory practice – use of stigmatising language, non-adherence to best practice guidelines
- Withdrawal from treatment

The lasting impact of a good interaction with health services is clear from Noelly's reflections on her experiences in maternity care, Jesse's experience in his HIV clinic and Kya's experience in an appointment with a psychiatrist:

> *'the midwife was just…I still remember her to this day …she was just incredible…she was… she was reassuring. I think for me for me she made my pregnancy journey much more bearable and much more pleasant that it could have been otherwise if I had not had her as a midwife.' (Noelly)*

> *'Once I was stable and on the medication and happy, they were happy for me to be seen by the nurses twice a year. It's more relaxed, more chatty, more friendly and it has just made the whole experience a lot quicker and friendly*

> *and less like I was dealing with a serious condition more that it was a regular friendly health check and I think that has made the whole thing a lot less onerous; a lot more easy to manage.' (Jesse)*
>
> *'The staff member I saw was like a light at the end of a tunnel that I never thought I would exit. After so many years of struggling, she was the first to confirm I was not imagining things and actually confirmed that the way i was feeling. She was very caring and put things into place before letting me go home. She liaised with my HIV consultant and my GP and suggested a treatment regime. What made it helpful was she understood how I was feeling and she did not talk much but she listened to me*.' (Kya)

The quality of the relationship with professionals is what stands out as being particularly important to people living with HIV accessing healthcare. At present, when someone is diagnosed with HIV this means they will be involved with HIV care services for life. This means in your role as someone (potentially) supporting someone living with HIV, in whatever capacity, you contribute vitally to that experience. In the chapters following, some of the issues raised here will be explored in more depth. You are invited to take the voices of the people presented in this chapter with you as you venture further into this book and consider in more detail how your practice can promote the health and wellbeing of people living with HIV.

Helpful resources

- British HIV Association (2018), Standards of care for people living with HIV in London, Retrieved from https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf

- British HIV Association and Medfash (2011). Standards for psychological support for adults living with HIV, Retrieved from https://www.bhiva.org/file/BbShtfyMFNKCz/Standards_for_psychological_support_for_adults_living_with_HIV.pdf

- Changing Perceptions: Talking about HIV and attitudes

- Kall (2018) Met and unmet health, welfare and social needs of people accessing HIV services: Findings from the Positive Voices 2017 Survey. Public Health England. Retrieved from http://regist2.virology-education.com/presentations/2018/3healthyliving/06_kall.pdf

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- Roland Chesters (2018) Ripples from the edge of life

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