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Recognising resilience factors among people living with HIV seeking to adopt

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Abstract

This article discusses the challenges faced by people living with HIV in the adoption process, looking especially at resilience factors. Resilience is framed in the context of HIV-related infertility that motivates people living with HIV to apply for adoption. The article draws on psychological definitions of resilience and presents four factors that promote and sustain it: individual strengths, good health management, social network and wider recognition in society. This is illustrated by a case study. The study emphasises that ‘the prospective adoptive child’ should always be at the centre of any assessments and encourages social workers to consider sensitive and inclusive practice when assessing prospective adopters living with HIV.

Keywords

HIV, adoption, resilience

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[H1] Introduction

A small number of researchers have begun to examine social work practice with regard to people living with HIV who wish to adopt children (Cane, 2017; Cane, Vydellingum and Knibb, 2018; Underhill, et al., 2016). In the UK, this author (Cane,2017) explored how this particular group perceived the quality of inter-professional collaboration between adoption assessors and their specialist HIV clinicians or voluntary workers. They reported concerns in terms of inadequate collaborative working between social workers, HIV health consultants and HIV support workers. Cane also identified that perceived discrimination in the adoption system overall, as experienced by people living with HIV, contributed to their increased sense of vulnerability when pursuing adoption. This vulnerability was associated with the kind of stigma and discrimination that increases a sense of social disadvantage in applicants.

Later, Cane and colleagues (2018) explored the lived experiences of a number of people living with HIV who had pursued the adoption process. Although some participants described positive experiences with social workers, they were in the minority. Most reported a lack of information, inadequate support, stigma and discrimination, cultural insensitivity and disempowerment. Nonetheless, implicitly, the findings suggested that they were able in certain circumstances to find strategies for coping with both challenging infertility experiences and intrusive adoption processes. While these are

small-scale studies and generalisations have to be limited, the relationship between HIV and adoption is under researched in the UK and it is hoped that the studies will prompt practitioners to begin thinking about the sensitivities around HIV.

There are no specific figures showing how many people living with HIV are entering the adoption system in the UK. However, the choice to adopt often presents vulnerabilities and challenges, such as fear of discrimination, rejection and anxiety (Gerrand, 2012). In Ontario, Underhill and colleagues (2016) examined the structural barriers and facilitators affecting adoptions by people living with HIV by assessing the perceptions of independent social work practitioners and private and public adoption agencies on their eligibility to adopt. Of 77 participants, 64% reported that HIV was not a criterion to exclude them from adoption whereas 4% would not consider HIV and 9% reported applying certain restrictions associated with an HIV+ serostatus; the other 23% did not know if there were any restrictions associated with HIV. The findings suggested that adoption agencies would consider assessing prospective adoptive parents with HIV, although discrimination might exist. In the UK, anecdotally, it is known that local authorities and adoption agencies are assessing and approving people living with HIV who are deemed suitable to adopt and as noted in Cane and colleagues (2018). Cane's small scale studies suggest that those with HIV who have sought to adopt have encountered discrimination and stigma, and often these were repeated experiences. It is important, therefore, to think about this group in the broader context of recruiting sufficient numbers of prospective adopters, as those who are competent might be able to meet the complex needs of children who would benefit from adoption.

[H1] HIV-related infertility as adversity

This article considers the concept of ‘adversity’ in respect of people living with HIV seeking to adopt as a specific experience within a series of traumatic life events associated with a HIV diagnosis and the stressful disturbances arising from this. It also explores the circumstances linked to a life with HIV as well as HIV-related infertility (voluntary or involuntary) and challenges experienced when seeking reproductive treatment. It explains how these factors, combined with intersectional encounters, can limit positive life experiences for people living with HIV and affect their quality of life. The complexity and unique adversarial situations associated with HIV make it difficult for some of those affected to develop resilience compared with people experiencing other health problems (Nightingale, Sher and Hansen, 2010)

[H1] Resilience in the context of HIV-related infertility

Resilience has been associated with ‘elasticity’ and a response that involves ‘bouncing back,’ rebounding, leaping forward or basic human resourcefulness (Bonanno, Romero and Klein, 2015). Various psychological or psychiatric perspectives frame resilience as a personality attribute or a positive and dynamic process involving positive adaptation to adversity, threats, traumatic events, risk or stress (Olsson, et al., 2015; Rutter, 2012).

According to Emlet and colleagues (2010), resilience and the absence of it make a difference in how people living with HIV succumb to the diagnosis and adjust their lifestyle. In addition, the longer people live with HIV, the greater their resilience (Emlet, 2016). The process involves motivation and positive individual strengths, as well as interpersonal and external systems that promote adaptation and bouncing back after adversity. It also entails positive development and healthy psychological growth (Masten, 2011). It may be that people living with HIV adjust to their circumstances by

way of building hope, engaging in better regulation of emotion and optimism in order to cope with the traumatic life experiences that threaten maintaining an equilibrium. Thus, those who are able to mobilise their internal and external resilience factors may be able to reduce negative experiences in their journey of seeking adoption (whether or not they are successful). With an increased desire for people living with HIV to adopt, mobilising adoption may become a unique experience that involves a process of demonstrating one's parenting capability, individual strengths and good health management.

[H1] Individual strengths

Some people living with HIV have personality attributes that enable a high ability to develop resilience regardless of the adversities they encounter or may have experienced. They may exhibit traits such as emotional strength or stability, diligence, post-traumatic growth and an ability to appreciate new possibilities, building resilience and positive adaptation (de Araújo, et al., 2017). Studies have identified that speaking openly about a seropositive HIV status is linked to tenacity and greater psychological protection (de Araújo, et al., 2017; De Santis, et al., 2013; Zea, et al., 2005).

Bailey, Ellis-Caird and Croft (2017) examined the resilience of women who endured repeated treatment after unsuccessful fertility treatment and established that infertility as an adverse life experience may result in individuals identifying their resilient qualities, helping them to overcome distress and gain a sense of optimism and hope. Other studies refer to personal attributes that enable individuals not to become embittered or hardened when living with a chronic condition. Such openness and acceptance of infertility and the drive to seek to adopt may reflect a source of strength

that facilitates dealing with adversity through continuous efforts to achieve parenthood (Cal, et al., 2015; Rooney and Domar, 2018). It is argued that people living with HIV approaching adoption services uphold resilient qualities reported in the above studies. Often, they have worked hard to invest in support or helping services and coping strategies, which enables them to respond well to future life challenges (Cane, 2018), although this does not necessarily mean that every person with HIV seeking to adopt is resilient enough to do so.

Studies have indicated that some women may withdraw from services when faced with the increased emotional costs associated with seeking parenthood. While some cannot reconcile with childlessness and ambiguous loss (Freedgood, 2013), due to doubt, helplessness and further vulnerability, others can reconnect with services. This allows them to rebuild their resources and pursue parenting. People living with HIV tend to return to specialist support services where they receive group, peer support or specialist reproductive counselling or advocacy services, demonstrating that they can endure challenging and complex systems with optimism (Cane, et al., 2018). It is expected that by the time they approach adoption services, they are optimistic and positive about the assessment process and its intrusive nature.

As with women, some HIV+ men experience repeated sperm wash procedures because the technique itself may impair sperm motility and reduce its quality (Zafer, et al., 2016). Arya and Dibb (2016) recognised the psychological impact of infertility among infertile men, including stigma, social isolation and shame. Others identified the impact on their sense of identity, self-esteem and self-concept (Greil, McQuillan and Slauson-Blevins, 2011). Individual strengths have been associated with how some individuals

anticipate loss and discrimination, as this might have become an expected part of a life with HIV (Earnshaw, et al., 2015). The capacity for HIV+ men approaching adoption services to forge networks of support, utilising proactive reflection, internal coping resources, harmless coping mechanisms, self-efficacy and sufficient social support, and redefining a masculinity-identity narrative, have been identified as aspects of strength that help men with fertility problems adapt to adversity (Crawshaw, 2013). These factors, as well as adequate intrapersonal relationships and high-stress tolerance, have also been linked to good quality of life, all of which contributes to a high resilience level (Herrmann, et al., 2011). From these perspectives, the argument is that, once HIV+ men have carefully redefined their masculinity narrative in a way that is acceptable to them and others, they should be able to focus on problem-solving coping mechanisms that help them feel confident and positive about their responses to future crisis.

The case study below provides an example of a sero-concordant couple that successfully adopted two children. It illustrates the pair's experiences of adversity linked to health problems and infertility and their resilience factors.

[H1] Case study: Shanice and Maloney

Shanice (female, HIV-, 37 years) and Maloney (male, haemophilic, HIV+, 43 years) were a sero-concordant heterosexual couple who had gone through 10 repeated cycles of unsuccessful in vitro-fertilisation (IVF) treatments and later adopted two children.

[H2] Maloney's health

Maloney contracted HIV through blood transfusion in the 1980s while undergoing haemophilia treatment. Living with haemophilia and HIV meant that he had to adhere to high-intensity treatment regimens as he was growing up and in early adulthood. Maloney's psychosocial functioning, personal and professional life were not always

stable. He received strengths-based psychological support that helped him to overcome life challenges and to grow from his experiences. He learned to accept his health and lifestyle, developed coping skills, motivation and resilience, and managing his cognitive functioning, behaviour and emotional reactions. This equipped him to cope well with the stressors he faced in his life. He considers himself ‘tough’ and positive.

[H2] Fertility treatment

Due to Maloney’s HIV+ serostatus and the need to avoid horizontal and vertical transmission, the couple sought assisted reproductive treatment with the hope of having biological children. He went through sperm/seminal washing (a procedure that removes spermatozoa from seminal fluid) before IVF to reduce the risk of transmission. Maloney and Shanice utilised the maximum limit of three cycles of free IVF treatment under the National Health Service (NHS); thenceforth, they turned to their savings to privately fund seven treatments. Their journey through fertility treatment was fraught with challenges, including making several grievances to the NHS and seeking compensation towards Maloney’s health as he contracted haemophilia through blood infusion. Other challenges included inaccessible treatment centres specialising in HIV (long-distance travel to access treatment), exhaustion, lengthy absences from work, stigma, anxiety, emotional distress, worry and stress linked to the intrusive nature of fertility treatment. Financial problems added to these difficulties, as well as the disappointment and helplessness over unsuccessful treatment results. The couple saw the inability to conceive in this way as a loss of biological childbearing capability, although this was mitigated by knowing that they could adopt.

[H2] Dealing with infertility grief

Shanice and Maloney accessed counselling for help with their emotional experiences and to buffer the impact of the distressing fertility journey. They saw this crisis as a joint problem and worked through it as a couple and redefined their identities. They knew they had exhausted everything possible to produce biological children and were open, optimistic and flexible about adoption as a potential option to achieve parenthood.

[H2] A break before adoption

Shanice and Maloney knew they needed time to deal with their grief before commencing the adoption process. While they were worried about the urgency of age,

they were cautious about rushing an adoption application. They took two years to prepare emotionally for taking on adoptive children. They were familiar with the adoption process and this being an accepted alternative to biological parenting in the family, there were no concerns about stigma. The couple maintained their social relationships and support networks to sustain their positive emotional capacities.

The main attributes in this couple's inner strength were feelings of hope, persistence, adaptability and openness to learn from traumatic life events. Experience of life challenges and stressors helped them to gain new strength as they prepared to take control of the adoption journey. Shanice and Maloney were resourceful, adaptable, proactive and had a clear vision for their future as parents. Maloney, as an individual, had reconstructed his identity in the context of his dual health as influenced by his individual social context and later as a couple. Together, they possessed a strong sense of self-esteem, as individuals and as a couple, and had problem-solving skills that enabled them to respond positively to Maloney's health challenges and their experiences of treatment. They knew that the adoption assessment would have to evaluate their capacity to parent and provide stability, as well as their resilience and ability to respond appropriately to children with a history of trauma who were likely to sometimes present difficult and unpredictable behaviours.

It could be argued that their inner strength and ability to deal with adversity and construct new meaning to their lives mean that people living with HIV ultimately develop resilience. According to the infertility resilience model (Ridenour, Yorgason and Peterson, 2009), resilience for those going through adoption can be the result of an association between individual capabilities, external factors, joint interactions and perceptions of those seeking parenthood. Those assessing people living with HIV should consider these dimensions to help understand how those approaching the adoption service view their social context, capabilities, self-resources and constructs that enable them to thrive when confronted with adversity.

[H1] Good health management

Researchers have noted good health management as an important factor in the resilience of people living with HIV but have not linked the topic to adoption. For example, Emlet

(2016) and Harris and colleagues (2018) have shown that resilience, adherence to medication, self-care and illness management can contribute to a longer life with HIV. Others have suggested that when those affected are able to deal with challenges around adherence and management of health, they cope better with the various commitments in their treatment regimens (De Santis, et al., 2013; Woollett, et al., 2016).

Advances in HIV treatment have notably improved survival, quality of life, reduction in mortality and other HIV-related illnesses. Thus, many people living with HIV on treatment have good medication adherence with an established routine for medication intake. Others may have an undetectable viral load and are not on treatment, while still others have simple and unnoticeable treatment plans. In any of these cases, it is possible to maintain a high quality of life, cognitive function, good physical health, engagement in social activities and a desire to have children (Wanyenze, 2013; World Health Organization, 2013). However, there might be diverse reasons that affect people living with HIV's ability to maintain good health, and this may result in a number of psychological or social vulnerabilities (Furniss, et al., 2014). In terms of adoption, this could be disqualifying, as one may be deemed medically or otherwise unfit to become an adoptive parent.

Emler (2017) suggested that when people living with HIV take a holistic approach to managing health this in itself increases resilience. It would be expected that those coming to the adoption system are effective at mastering their illness (Emler, 2017). Some have a flexible and 'pragmatic acceptance' where they are comfortable with their circumstances and health journey (Woollett, et al., 2016). Those who are seeking to adopt children have often identified a priority towards good health management and

also invested in social capital (Nanfuka, et al., 2018). Many are already clear of barriers that affect their adherence to treatment and have addressed these issues to avoid relapse. As a result, they have taken charge of future life choices due to a sense of control over challenging aspects of vulnerabilities that are HIV-related (Rueda, et al., 2012).

[H1] Support networks

Featherstone, Gupta and Mills (2018) identified that it is good practice to engage with and understand the sources of support and networks available to adoptive parents during assessments. On the other hand, Cane and colleagues (2018) highlighted the important role of HIV charitable organisations in providing resources and support for those affected seeking to adopt. Additionally, Hill and colleagues (2007) assert that parents involved with social services appreciate receptive, flexible, non-oppressive and non-stigmatising services that value the expertise of individuals. In their work, therefore, social workers can acknowledge existing support networks in the lives of people living with HIV. Social workers can also offer constructive help, enabling them to build a supportive working partnership and recognise them for their strengths, resourcefulness and resilience (Department for Education Schools and Families, 2008).

Social networks are an important ecological phenomenon that interconnects with resilience among those living with HIV (de Araújo, et al., 2017; Bonanno, Klein and Kelin 2015; Woollett, et al., 2016; Li, et al., 2015). Transactional relationships between the individual seeking to adopt, their social networks and the community resources available to them can promote the evolving and developmental process of resilience (Ridenour, Yorgason and Peterson, 2009). Social networks provide a forum for emotional support that reduces psychological problems such as stress. Sometimes,

though, positive sources of support that are well intended can also contribute to strain if individuals experience high levels of interference, which may affect the experience of those seeking parenthood (Ridenour, Yorgason and Peterson, 2009).

De Araújo (2015) identified that people living with HIV who openly disclose their seropositive status tend to have larger social support networks, acting as ‘psychological protection’ and a resource for coping with adversities, which ultimately increases their resilience. Supportive friends, families and support groups may encourage them to share their experiences, emotions or challenges and seek a range of assistance (Latkin, et al., 2013). For example, family support and social networks, including spiritual and religious groups, can be helpful resources for health management and sometimes influence decisions about parenting (Lefebvre, et al., 2018; Mishra, et al., 2017).

[H1] Wider recognition in society

How people living with HIV are seen or recognised in the wider society will have an impact on how they cope with the adoption process and any challenges that this process may bring. Alex Honneth (2007) provided a critical theorist perspective on spheres of recognition, suggesting that denial of recognition affects human flourishing and contributes to feelings of self-worthlessness (Rossitter, 2014). In the context of adoption, if people living with HIV seeking to adopt see themselves as prospective adoptive parents, are recognised more widely and have their abilities acknowledged, their sense of identity is validated, which further promotes their self-confidence and social esteem.

Cane and colleagues (2018) observed that some people living with HIV who had applied for adoption had respectable jobs, a good social standing and positive self-esteem; and they recognised their rights to adopt children. Scott and Kindred (2013) found that, as well as seeking to become a parent, they were often influenced by the altruistic or community-focused benefits. Recognition and engagement with communities enable positive psychological states for people living with HIV, as well as resiliency and the development of self-esteem. However, one of the challenges for their pursuing adoption is that their recognition relies on others who hold a position of power. Sometimes, this creates a sense of struggle for recognition in order to assert autonomy (Rossiter, 2014). As recognition is dependent on inter-subjective relationships, it is important to understand how those living with HIV may have experiences of injustice. Social workers in the adoption system can provide rectification of equality, rights and care but adoption structures are still very much power related. They rely on individual resources, financial means and a person's ability to prove they are competent in their parenting – what I call 'parenting competence capital' where applicants have to prove that they are suitable adoptive parents, whether or not they have any experience of parenting.

Parenting competence is a resource that should be assessed in order to determine one's ability to adopt (Lind and Lindgren, 2017). Like others, people living with HIV are required to go through assessment processes to prove 'parenting competence capital'. This is important in demonstrating that the applicant is efficient in delivering unique and diverse adoption-related tasks, including those around reparative parenting (The Donaldson Adoption Institute, 2013).

[H1] First, the child is paramount

The most important person in an adoption assessment is the child and their right to a family and stability. People living with HIV have the right to apply and be considered for an assessment and any evaluation should include open-mindedness from the assessor towards the process, including the emphasis given to the health information of applicants when looking into their suitability to adopt. However, this should not override the needs of the child for permanence with a 'suitable and safe' family or carer. This is the underpinning principle guiding adoption in the UK Children Act 1989 and the Adoption and Children Act 2002.

[H1] Social work approaches when considering people living with HIV for adoption

Social work values provide a moral grounding for social workers to practise ethically and sensitively. Therapeutic engagement with service users offers a chance to promote and foster resilience. In adoption, social workers have an opportunity to identify the strengths of those accessing the adoption system. Ellis (2011) interviewed adoptive parents and reported the importance of social workers acting as a 'sounding board' through empathy and positive attitudes. Assessment dialogues that explore what social workers expect of prospective adopters can be helpful if they are sensitive, relationship based and non-confrontational (Featherstone, Gupta and Mills, 2018; Ruch, et al., 2010). This involves understanding the challenges faced by people living with HIV, be they contextual or bio-ecological factors, and including and appreciating the resilience and psychological growth arising from those (Bronfenbrenner, 2005).

The adoption process itself involves scrutinising health records and health assessments as part of the screening process. It is during these assessments that bias might emerge if collaboration with other professionals is not conducted carefully and thoroughly. Previous research documents frustrations that lead to vulnerabilities and barriers that may prevent successful adoption, as being linked to insufficient information-sharing and culturally insensitive practices (Dance and Farmer, 2014). For example, disclosure should inform medical and holistic adoption assessments tailored towards the best interests of the child. Adoption studies have not only identified vulnerabilities relating to disclosing physical health but also emotional or mental health challenges (Dance and Farmer, 2014; Ellis, 2011).

Evangelini and Wroe (2017) noted that disclosing health challenges directly or indirectly exposes people living with HIV to the risk of rejection and discrimination. When prospective adopters feel vulnerable during the assessment process, this leads to feeling anxious about the possibilities of discrimination following disclosure. Cane and colleagues (2018) found that people living with HIV who enter the process are prepared for confidential discussions to take place between professionals because failure to disclose might be seen as dishonesty, resulting in disqualification. Factors that might be linked to this include the ability to engage in self-reflection, unfolding developmental competences that strengthen resilience and embracing meaningful life experiences (Woollett, et al., 2016). High levels of resilience have been observed in people living with HIV who are self-reflective and talk about their health and serostatus (Evangelini and Wroe, 2017; Woollett, et al., 2016). By using sensitive approaches and great care, adoption social workers can ultimately facilitate self-reflection and

encourage them to access adoption in ways that are congruent to social work values without fear of stigma or discrimination (Featherstone, Gupta and Mills, 2018; Ungar, 2013).

HIV remains a highly confidential health issue that requires stringent structures around sharing information. Underhill and colleagues (2016) noted that those living with HIV who wish to adopt need to be prepared to disclose their HIV status. Disclosure shows openness and transparency, yet still only a small number are confident in disclosing their serostatus to professionals. Featherstone, Gupta and Mills (2018) stress that adoption social workers should be ethical and positioned in ethical approaches, illustrating the complexities of individual circumstances. Anti-discriminatory and anti-oppressive practice must start with recognising the complexities around power; power could potentially be regarded as a barrier preventing people living with HIV from accessing adoption (World Health Organisation, 2013).

When assessing people living with HIV, it might be helpful to apply specific emphasis on a personalised assessment, providing sensitive feedback and affording non-judgemental practices. This, in turn, will motivate this particular group of prospective adopters to see the adoption process as a collaborative endeavour that is empowering. Sometimes, they may not be seen as ready to adopt, but the process of assessment should allow social workers to support, educate and provide a therapeutic approach rather than one that could be deemed as discriminatory and oppressive and, therefore, damaging the resilience that people living with HIV have developed.

[H1] Summary and conclusion

Potential adopters living with HIV have already gone through various challenges and vulnerabilities before approaching the adoption system. This has been illustrated in the case study of Shanice and Maloney. At the point when they sought to adopt, they had accessed various interventions focused on enabling them to enjoy a good quality of life. Thus, they were able to present a portfolio less dominated by risk and vulnerabilities and which was in line with other prospective adopters (HIV-).

Unfortunately, people living with HIV continue to experience additional hurdles in the adoption system compared to barriers faced historically by, for example, single adopters and same-sex couples. Although prejudice and stigma may still exist towards lesbian, gay, bisexual and transgender people, HIV is lagging behind, since stigma and discrimination continues in social work due to lack of understanding and up-to-date awareness about HIV today compared with other factors. Yet, people living with HIV may be able to provide desired outcomes for adoptive children. The key is to make certain that assessments are carried out in a sensitive way, to understand the resilience processes and resources used by would-be adopters living with HIV and to ensure adherence to non-discriminatory and strength-based practice. These procedures will enable social workers to draw on the unique skills possessed by each individual, while maintaining the ‘best interests’ principles within the concept of adoption.

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