

Facilitating and supporting HIV+ parenthood: lessons for developing the advocate role of voluntary HIV support services workers. *Journal of Sexual & Reproductive HealthCare*.

Abstract

Objective

Increasingly as people living with HIV (PLWHIV) aim to become parents, they engage with HIV voluntary services for support through either fertility or adoption services. Yet, little is known about the role of HIV support services workers in facilitating access to fertility treatment or child adoption. The purpose of this study was to explore the role of HIV support workers based in HIV voluntary organisations who have a key role helping PLWHIV in navigating relevant fertility and adoption processes.

Methods

This was an exploratory qualitative study which involved interviewing six HIV support workers, from across the UK. Interviews were conducted using face to face interviews, recorded and transcribed.

Results

Findings revealed that HIV services support workers provide practical support in advocating service provision, and emotional and social support along the journey. They also face challenges in their role from health care professionals including information sharing and gatekeeping.

Conclusion

The role of HIV support workers is important in facilitating access to resources and complex systems. HIV support workers should be recognised and as they are often a trusted professional to address stigma, discrimination and barriers to services. The study contributes to research seeking to understand the emerging needs and support requirements for people living with HIV seeking fertility and adoption. Further work in this area is warranted.

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Introduction

National Health Service (NHS) England's national service specification for HIV specialised services identifies HIV support services provided by third sector and other voluntary organisations as an important element for care pathways and clinical guidelines for people living with HIV (PLWHIV) [1]. Support services delivered through voluntary organisations reflect the ideals of person-centred planning and holistic provision of services to health and social care provisions. In voluntary agencies, HIV specialist health and social care workers deliver support services including information, psychological support, advocacy, sign-posting, and social and family planning support. The National AIDS Trust posits that HIV support services are common to a majority of PLWHIV [2]. This means that support services offered by the voluntary sector are invaluable and continuously complement care provided by specialist primary care and social services departments, along with family planning, contributing to best outcomes in the health and well-being of PLWHIV [3].

In 2015, an estimated 101,200 people lived with HIV in the United Kingdom (UK). This equated to 1.6 per 1,000 people above the age of 15 years. Of these, 96% were on antiretroviral therapies [4]. These figures mean that those ready to have children or to expand their families may seek fertility treatment or child adoption [5]. Fertility treatment can be expensive, reducing the possibilities of access for some [6], although limited government funding for fertility treatment may mean that some PLWHIV may seek financial assistance and guidance from HIV voluntary services [7]. In terms of adoption assessments, they present procedural challenges. PLWHIV who have accessed child adoption services report concerns about adoption workers being reluctant to

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assess them, citing stigma and discrimination [5,8,9,10]. Additional voluntary support to access these services may be necessary to help navigate fertility or adoption services.

In voluntary sectors, HIV support workers offer parenting advice, support with sexual relationships, family planning, 1–1 and peer group support. UK stigma research [11] reports a substantial level of access to HIV voluntary support services among PLWHIV. About 79% of PLWHIV reportedly seek support from HIV voluntary sectors. In some countries, HIV workers provide antenatal and postnatal support, HIV testing and surveillance activities [12,13,14,15] bridging access between otherwise inaccessible community resources and specialist services [13]. Without this ‘bridge’, inadequate support for PLWHIV may result in unplanned pregnancy, lack of reproductive health support and increased perceptions of stigma [14,15].

In the UK, PLWHIV seeking reproductive support have unmet needs. There is a gap in supporting the fertility needs of PLWHIV. The British HIV Association [16] highlights areas of urgent support for PLWHIV in the UK, including pre-conception counselling, parenting decisions and choices, contraception, risk, and discrimination by fertility services. Without good links between those delivering fertility treatment and adoption services, it is unlikely that PLWHIV will have equal access. There is a gap in research regarding support around fertility options or adoption. This study examines the role of HIV support workers in voluntary organisations and their input around fertility treatment and adoption.

Methods

This study utilised a qualitative, exploratory design to investigate the research question: How do HIV services support workers see their role in supporting PLWHIV accessing fertility treatment

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and child adoption services? An interpretative phenomenological approach (IPA) was selected to explore how voluntary services support workers perceive, experience, and interpret their role of support for PLWHIV [18].

Recruitment and participants

The study was promoted through HIV magazines and forums such as the Positive Nation magazine, internal bulletins published by charitable trusts, as well as word of mouth, and as part of a larger study looking at experiences of people with HIV seeking fertility treatment and adoption. Convenience sampling was used to recruit six HIV support workers from HIV charitable organisations in Greater London. All participants had experience of exploring fertility options with PLWHIV, advocating fertility or adoption, with some facilitating access to both services for either sero-concordant or sero-discordant couples.

Data collection and analysis

Data was collected through face-to-face interviews at participants' office base. All interviews were conducted by one interviewer- the researcher (who also conducted the analysis). An interview guide was used with semi-structured questionnaires and open and closed questions. Interviews lasted 40 minutes to one hour; were audio-recorded with consent; transcribed verbatim; read multiple times to generate familiarisation, making conceptual and linguistic comments. Using the IPA framework, the researcher concentrated on in-depth and delicate stories [19] and a staged analytical process was applied [20]. Emerging themes were extracted, then clustered. Superordinate and sub-themes were developed, and a cross-case analysis was conducted. Some participants were revisited to validate their accounts. Although studying a small sample, this enabled focusing on subtle articulations within the data [21].

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Ethical consideration

Ethical approval for the study was received from the University of Surrey. Anonymity was strictly maintained to protect the organisations that participated in the study. It was pre-agreed that the HIV support workers would seek and receive consent from their service users to tell their stories as part of this study.

Results

All participants who were approached agreed to contribute to the study (see Table 1). Of the six participants, five were female and one was male, they had all worked with HIV support services for at least three years.

Table 1: Description of support service workers and nature of support provided

Interviewee	Experience (years)	Type of Support Service	Nature of Support
Tenby*	3	Fertility options	HIV prevention, information, guidance. Empowerment, discrimination, advocacy, language facilitation.
Manisha*	5	Fertility treatment	Information, guidance, addressing fear of discrimination.
Sasha*	7	Fertility/adoption options	Confidence issues, psychological issues, disease management, moral/emotional issues, discrimination, advocacy, advice.
Benitta*	4	Fertility	Childhood/psychological issues, advocacy, HIV prevention, stigma.
Pamela*	3	Fertility/adoption options	Disclosure, counselling, discrimination, empowerment, advocacy, information, guidance.
Joel* (male)	3	Fertility treatment	Disclosure, counselling, discrimination, empowerment, advocacy, information, guidance.

*Pseudonyms

Findings from the research were organised around three main themes generated in the analysis: the role of the HIV support worker, under this theme seven sub-themes were identified; the

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challenges faced with supporting PLWHIV contained two subthemes, and calling for education, knowledge and non-discriminatory services with two subthemes. Table 2 provides a summary of these themes and subthemes.

Table 2: A summary of themes and subthemes identified

Themes	Subthemes
The role of HIV support workers	The preventative role The emotional support The facilitating disclosure role The navigator The identifying alternatives role The advocate role The non-judgemental role
Challenges around supporting PLWHIV	Challenges and barriers in the HIV support worker's role Challenges presented by PLWHIV
Calling for education, knowledge and non-discriminatory services	Training of GPs and Professionals Anti-discriminatory statements

The role of HIV support workers

During the interviews, it emerged that the support workers not only saw themselves as service ‘co-ordinators’ but also as having different roles depending on the needs of the individual service user.

The preventative role

One of the main responsibilities identified was that of ‘safeguarder’ through their risk prevention and support role:

With some clients, you have to remind them that there are still risks attached to having condomless sex even when their viral load is stable. They will think you no longer have to use condoms. [Sasha]

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Such support sometimes begins prior to PLWHIV considering fertility treatment or adoption services. It involves educating PLWHIV on the understanding that parenthood is an option:

They often think they cannot have babies and that this is not an option for them. We discuss what options are available for them and how to access different services to help them. If they need to have babies it is about making sure that they are provided a lot of information and support. We empower them to get this arranged through their consultants. [Tenby]

The emotional support

Participants reported that they also play an active role assisting PLWHIV in dealing with various emotions and building confidence, that extends beyond the task involved with advocating for services:

We speak about pregnancy and confidence-building and we facilitate peer support [Manisha].

In addition to confidence-building, they provide mental preparation for disease management and advise on fertility needs challenges. To address HIV discrimination and stigma, one HIV support worker explained that preparing for parenthood required PLWHIV to go through mental preparation to access services

Sometimes HIV affects fertility. PLWHIV struggle with accepting that. When they have to look at other ways to have children, they have to be prepared mentally to be able to go through it. [Sasha]

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HIV support workers supporting PLWHIV described a holistic awareness of their service users, best-placing them to address the needs of those who use their services and navigate a path towards accessing fertility treatment. Sometimes, this included exploring historical life experiences to address fertility desires. One support worker reported an account that related to a person living with HIV who had grown up with HIV and a genetic illness that affected his childhood development:

He said that, all these things that he went through when he was a child, when he was a teenager, were just very difficult. ... He said, it is fine now but I don't want to pass them on to my children. [Benitta]

The facilitating disclosure role

Most participants described providing emotional support, which required counselling skills, listening, and actively supporting service users. For many of the support workers, self-disclosure was necessary to reassure others:

I disclose a little bit about my own experiences with HIV and the discrimination I faced ... I was open about it, I speak at conferences about it. So why not disclose to help and reassure others. [Pamela]

For other support workers, peer support experiences were valuable for encouraging disclosure and demonstrating the potential outcome of these processes:

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Sometimes, we invite women who have had their children and have already gone through the process to tell them that it is possible. It may also be talking to a man who thought he didn't think that he would be able to have a child. [Manisha]

While the HIV support workers' role included advocating and supporting PLWHIV through a fertility or adoption service, they reported taking an active role in navigating complicated procedures.

The navigator

Knowledge of organisational policies was deemed essential through gathering information, reading and understanding guidelines and policies on fertility treatment and adoption services. HIV support workers believed this to be helpful for service users:

Actually, the letters that we had written, we cited them and we said that, look according to your policies and procedures this is what you are meant to be practising. You cited this, we believe that this is in line with your procedures and guidelines. We quoted sections in their policies, that kind of thing. [Pamela]

The identifying alternatives role

HIV support workers engage in a process of supporting PLWHIV through the challenges of applying for fertility funding or making adoption applications and assessments. This involved

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accessing the right provider and pathway by collaborating with service users and providers. One respondent reported:

It was simply not easy to be accepted by adoption agencies we approached here. In the end she decided to adopt a child with HIV from her own country. [Pamela]

Another respondent spoke of linking or connecting service users to a provider who best suited their long-term needs:

If they were conceiving naturally it is a 50/50 per cent chance [that they will be HIV+ or haemophiliac] and accept that this is the case. But this is not the case given that they are already going through this artificial process and that it is only this one extra step added to help them access the treatment they need... [Benitta]

The advocate role

The identifying alternative role links with the advocate role. Advocating service provision in regard to fertility treatment is a long process that begins with accessing the right provider and ensuring that the service user is accessing the right people in that service:

We got the details of their own primary care trust in their own borough, with names of who we can approach and the names of one other person whom he was given. Someone said to him, if you need to do this, you need to approach this person ... We need to approach that person but we are not sure how [he] relates to all this but we will approach him anyway.

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The consultant said you need to speak to XXX if you need to take this further so we are going to try and speak to her as well. [Sasha]

So, he basically asked us to help him with the process of advocating gender selection while they are going through IVF ... He desperately needed to ensure that haemophilia is prevented from the child they will have. [Benitta]

The non-judgemental role

HIV support workers noted that PLWHIV were selective in accessing support to address their needs due to the perceptions that mainstream services lack empathy and understanding around HIV.

She said that they [social workers] do not understand HIV. They would rather come to a service like ours because we have the specialist knowledge and they think we better understand what they are going through. Besides, they fear to be judged and prejudiced. [Manisha]

Fear of accessing services is linked with lack of confidence in asking about the impact of their illness on fertility treatment or adopting, given previous experiences of stigma and discrimination. An example of a service user's perception of previously experienced discrimination was reported as a barrier to access adoption services independently:

I spoke to a lady who wanted to foster and she already has a child. She said when she disclosed her status to the social workers, they told her that they did not think she was

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suitable to foster. She said she asked about adoption and [they] told her she was unlikely to be considered also. She said they told her it was not because of her HIV status but she said she did not believe that. She feels discriminated against. She is still thinking of adopting but she does not feel confident to try again without our support. [Tenby]

Thus, at times, HIV disclosure was reported as a risk associated with possible discrimination or social exclusion that required the assistance of HIV support workers:

Disclosing is a risk. There are service users here who do not disclose their HIV to their GPs. They will only talk to their HIV consultant and keep their GP separate. They say that, why do I need to tell my GP if I am only going to use the medication that the consultant prescribes. It is about who they tell and it is something we work on because if they do not disclose to social workers, this may go against them. [Tenby]

Challenges around supporting PLWHIV

Challenges and barriers in the HIV support worker's role

Often, HIV support workers felt that fertility doctors dismissed the request to consider fertility treatment funding. They perceived that doctors 'passed the buck' to another professional, such as financial managers, without providing sufficient details of where and how to make such contact, and that, while service users struggled to navigate through fertility treatment channels, they too encountered similar difficulties, feeling undermined and ignored due to the lack of reciprocal communication:

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The doctors just ignored this ... just not taking it seriously. The doctors were just focusing on the fertility aspect of it and not appreciating other health issues that he was bringing to the table. He [the service user] reported to me that, they were kind of saying, what is this and why are you showing us this letter from XXX [HIV co-ordinator]. [Sasha]

After the first consultation meeting, I had accompanied this couple to explore their options again with a written letter. They [the service user] said that the consultant did not even look at the letter that we had crafted together, he did not even consider it. [Benitta]

Rarely did this stop HIV support workers from continuing to advocate on behalf of their service users. When doctors failed to acknowledge letters from HIV support workers, further letters were sent though not always with success:

One letter was to the consultant who was very dismissive; who I am sure, did not even look at it. He said why are you telling me this kind of thing? The second letter was to the funding officer and we are waiting a response from them. So those were two letters and no positive responses. [Tenby]

It was clear that those advocating for services needed to receive formal communication and feedback from fertility providers, especially after they had written supporting letters. This lack of communication was a barrier to effective collaboration with other professionals.

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Information-sharing was seen by support workers as one-sided, lacking consideration from other healthcare professionals that more complete information might benefit the service users. This issue was exaggerated by fears of breaching bureaucratic rules and NHS procedure – both of which were complex.

If, with its challenges, the NHS believes in the work we do and works with us, then together, we would make it easier for PLWHIV who want to have children. [Pamela]

A barrier to achieving a holistic perspective on the service user's needs is acknowledging their right to privacy and confidentiality around their health issues:

It is not interactive ... I am getting snippets that XXX said you have to self-fund or that XXX has said call XXX. As an advocate, I am trying to put pieces together, it makes it difficult ... Through second hand communication, I'm trying to understand their response to what I am saying effectively. That's quite challenging. [Benitta]

HIV support workers perceived that PLWHIV eventually felt frustrated when HIV organisations struggled to make an impact, given the systemic barriers, often because of the lack of communication discussed above. It is not surprising, therefore, that HIV support workers spoke of a desire to improve collaboration among those providing services for PLWHIV:

It will help our clients if more direct communication is possible. That will allow us, no matter what the response is, it would allow us to move the case forward. [Pamela].

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For consultants, as busy as they are, if they get a letter setting out some questions or enquiries about our client, it will be good if they respond directly rather than dismiss it or ignore it, that kind of thing, our role really, supports theirs. [Benitta]

While HIV support workers encouraged service users to access expert advice, appropriate health assessments, medical support and to discuss options to achieve parenthood with a health professional or social worker, they did not see themselves as having personal ‘expertise’ – despite being the key contact joining up the services:

I always tell them to speak to social workers directly about this so that they know the process. Adoption is complicated and it is better they hear more it from the experts; even if they ask their questions without making much disclosures about themselves to begin with. [Sasha, speaking about adoption]

We always encourage people to ask their consultants specific health questions. Some of them worry about asking question so we tell them: you don’t have to worry about telling the consultant that you don’t understand. This can be a long conversation and it will be hard for them, to do that if they are not coping well to do that. [Manisha, speaking about fertility treatment]

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Challenges presented by PLWHIV

Sometimes HIV support workers identified language barriers specific to the service user they were working with. Insufficient English language experience was ‘certainly a barrier for some of our families’ (Benitta) When services users presented as a couple, HIV support workers were not always sure they both had the same desire for parenthood. These issues can prevent a full understanding of experiences and needs. One HIV co-ordinator expressed an experience around this issue:

I speak directly to her husband, but I am sure she is very, very keen to have a child. [Tenby]

Another barrier can be a service user’s personal beliefs, which can hinder the HIV support worker’s efforts to move them forward:

Some of our clients are strongly religious. Those who are religious believe that, only fertility treatment should work. They do not consider adoption to be an option. I remember someone telling me that they will continue fasting and praying, hoping to achieve pregnancy even though they had failed to achieve pregnancy after exhausting all their fertility treatment cycles. [Joel]

Calling for education, knowledge and non-discriminatory services

Training of GPs and Professionals

HIV support workers expressed a need for additional training for GPs and professionals working with PLWHIV. This would ensure that adequate information about parenting choices for PLWHIV are available.

Back in the day, I spoke to women who worried about what would happen to their children should they die. The guilt that someone felt was too much because she felt criticised by professionals. But now, they [PLWHIV] feel they can adopt. I would like to see in the future, particularly GPs and maternity services, obtaining more knowledge and providing more information about how PLWHIV can access services that help them to achieve parenthood safely. Just because someone is HIV positive does not mean that they should not be allowed to receive the treatment they need for that or to adopt children. My experience with GPs is that they say someone is HIV positive and therefore should not have children. [Pamela]

Anti-discriminatory statements

Further, Tenby expressed the need for ‘a statement somewhere to say that they [PLWHIV] should not be discriminated from IVF. People feel discriminated before they even try’. Another HIV coordinator noted:

Because of fear of being refused services, some of our members will say, I am not going to go through the IVF route because I have been discriminated against. So, there should be a statement to enable them to access the services they need to have children whether it is adoption or IVF without fear of being discriminated by a different service. [Manisha]

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Discussion

Findings in this study highlight that HIV support workers undertake a variety of roles in terms of supporting PLWHIV to access fertility treatment or adoption. As with other studies, this paper argues that HIV support workers in voluntary settings can be key in supporting PLWHIV to access adoption and fertility services [17]. Their role responds to reproductive and parenting desires, yet ultimately supporting HIV prevention strategies. Fertility and adoption policies need to recognise and endorse this role as this would raise the profile of what they do, underlining their professionalism. As the role of HIV support workers is not well accepted by other professionals, especially in mainstream health and social work services, this places some challenges in their advocacy role. Only when their role is supported and strongly recognised in policies will healthcare workers engage positively and proactively with other professionals. Only then will service users, whose needs are often more complex than other patients seeking fertility treatment, be understood and supported holistically. In the findings, one HIV support worker called for official recognition of the 'right' of PLWHIV to access adoption and fertility services. Again, enshrining this 'right' in official policy could lift many of the perceived barriers to accessing services.

Undertaking the role of HIV support worker effectively required them to share and receive information about their service users, presenting opportunities to connect with health or social work professionals [12]. This connecting role was achieved through writing advocacy letters or making referrals to relevant services. However, this study highlighted barriers around information-sharing. In other studies, health professionals can be gatekeepers of services and resources, limiting success in securing resources that promote achieving parenthood for PLWHIV [6,15]. This represented a major barrier to collaborative working that frustrated service users, and in many

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cases led to HIV support workers feeling unable to keep processes moving forward, thus calling for ongoing moral and emotional support for their service users. In 2017, it is hard to understand how we are still in this place. PLWHIV are not different to other service users who seek confidentiality, except that there are specific sensitivities around their health issues. It is possible to create user-friendly protocols for exchanging, storing, using, and destroying personal information in a way that everyone involved can be protected. With such mechanisms, the process can continue to move forward and provide a supportive service to users.

For a group who face many day-to-day challenges – given the secrecy and perceived discrimination around their health – it is important to have a trusted agent. HIV support workers identify problems around stigma, disclosure, psychological problems and discrimination and provide support in those areas. Yet, the findings indicate that they do not recognise their own ‘expertise’ in working with PLWHIV, specifically around health as well as fertility and adoption processes. Enshrining their role in official policy will deal with this, allowing them to be experts in their own rights. The service they represent also needs to raise more awareness of the key role they provide in the area of fertility treatment and adoption advocacy. This will extend their role within health and social work where PLWHIV struggle with access to adoption and fertility treatment. Thus, HIV support workers in voluntary settings will receive better recognition, especially from other healthcare professionals. We are already seeing a burden of delivery shifting from mainstream health and social care services to the voluntary sector.

The role of HIV support workers, in its multiple nature, involves addressing perceived discrimination that PLWHIV have reported to their support workers. Previous work by Chipawe

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Cane [5] highlighted the challenges faced by PLWHIV due to poor collaborative work in adoption services. Funders need to consider supporting studies in this area, especially as this role is intertwined with HIV prevention and the right to family life, good health, access to fertility treatment and adoption services [22, 23]. This is a small exploratory study which, nonetheless, has highlighted not only the importance of HIV support workers and the hindrance that a lack of communication and collaboration can cause, but also the needs of PLWHIV in having workers to advocate on their behalf.

Implications for practice

Establishing a collaborative protocol between HIV charitable organisations and service providers would be a start in addressing some of the identified challenges faced by HIV support workers, as identified by Chipawe Cane [5]. It will be important for those governing the structures of fertility treatment and adoption services to integrate interventions from HIV support workers in their care plans in order to render greater support for PLWHIV. In this era of budget constraints to mainstream services, forcing many to shift to the voluntary sector, it is important to value HIV support workers.

Study limitations

As this is a small exploratory study with six participants from six HIV charitable organisations, its findings are not generalisable, thus causing some limitations to the methodology [18,20]. Further research is needed to fully understand the role of HIV support workers in assisting PLWHIV to navigate fertility and adoption services. It will be highly informative for a much larger study looking into the support offered by the voluntary sector to PLWHIV seeking fertility and adoption.

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Qualitative and quantitative studies will provide a clearer perspective on the number of PLWHIV seeking support, from which organisations and their experiences.

Conclusion

Structural and organisational challenges contribute to the complexity surrounding access to fertility resources and adoption services negotiated by HIV support workers. More effective collaborative work between health, social services, and HIV charitable organisations is necessary to better support PLWHIV. This would, in turn, create greater opportunities for increased access to fertility treatment or adoption services.

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