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“Support for the Supporters”: A Qualitative Study of the use of WhatsApp by and for Mentor Mothers with HIV in the UK

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“Support for the Supporters”: A Qualitative Study of the use of WhatsApp by and for Mentor Mothers with HIV in the UK

Third-sector organizations, an important support for people living with HIV, increasingly use digital technology to improve service efficiency and reach. However, there is limited empirical evidence on this use by women living with HIV. The 4M Network (4MNet) is a peer-run UK-wide network of trained Mentor Mothers (MMs) living with HIV; it uses the WhatsApp platform as its primary digital communication tool. We report on a qualitative study about 4MNet MMs’ experiences of using WhatsApp, to inform the design of future digital support services. Seven telephone interviews were conducted with five MMs and two project management team (PMT) members in February 2019. Interviews were analyzed using Interpretive Phenomenological Analysis (IPA). WhatsApp was found to have several key features that provided both positive and negative use considerations. WhatsApp eased communication among MMs and supported participation in group activities despite differing schedules and geographic locations. Challenges encountered with WhatsApp included: financial restrictions to data storage and continual access; self-confidence using technology; and security and privacy concerns. Peer-led digital communication is found to be acceptable and effective for women living with HIV. Understanding barriers and valued features of existing digital platforms increasingly used among potentially marginalized groups is vital for informing inclusive innovation.

Keywords: women; peer support; digital; ICT; WhatsApp

Background

Women make up over half of the total adult population living with HIV globally (UN Women, 2016). Of the 93,385 people in the UK living with HIV and receiving care in 2017, 28,877 were women (National AIDS Trust [NAT], 2018). This is an increase from a decade ago, which is attributed to effective treatment for HIV prolonging life and ongoing new diagnoses. In 2018, 87% of people living with HIV in the UK were estimated to have an undetectable viral load, meaning HIV could not be transmitted (Public Health England [PHE], 2018). Despite this,

experiencing stigma is common for women living with the condition (Amin, 2015; StigmaSurveyUK, 2016). Previous research has shown the value of peer support for addressing internalized stigma for and enhancing self-esteem amongst women living with HIV (French, Thorne, Byrne, Cortina-Borja, & Tookey, 2017; Peters et al., 2017; Baek et al., 2007; Richter et al., 2014).

Peer-support is defined as support provided by individuals with shared lived experience(s) to those being supported. Peer support methods include group meetings and support networks, and are proven to be successful interventions for enhancing self-esteem in the UK (Positively UK, 2017). Social support can be informational (e.g. advice), instrumental (e.g. providing transport), and/or emotional (e.g. providing empathy) (Cohen, Gottlieb, Underwood, 2000; Huh, Liu, Neogi, Inkpen, Pratt, 2014). Such support has been shown to improve both the experience of individual service users and their journeys within medical care (Positively UK, 2017). Peer support has been broadly effective as an initiative led by, with, and for those living with stigmatized long-term conditions, such as mental health diagnoses (Repper & Carter, 2011) and Type-2 Diabetes (Wingate, Graffy, Holman, Simmons, 2017; Johansson, Keller, Sönnichsen, Weitgasser, 2017), and has been shown to lower overall costs of medical provision (Wingate et al., 2017; Positively UK, 2017; Johansson et al., 2017).

Currently, HIV-related peer support in the UK is championed and provided by non-profit organizations, such as Positively UK (2017). These services aim to support medical pathways through involvement at local HIV clinics, and link those living with HIV to social services, such as housing or employment support. Peer support is explicitly recommended as a quality of care indicator by the British HIV Association (British HIV Association [BHIVA], 2018), including for management of HIV during pregnancy (BHIVA, 2019). However, peer support services are rarely offered within

HIV clinics, making them increasingly rare in the face of austerity, with many HIV non-profits closing or reducing services (NAT, 2016).

Digitally-mediated peer support has been shown to be acceptable to those living with HIV (Laurence et al., 2019; Senn et al., 2017) and other potentially stigmatized conditions, such as mental illness (Naqshbandi et al., 2016; O'Leary, Schueller, Wobbrock, Pratt, 2018). The utilization of digital technologies for peer support, in addition to in-person services, allows service users to choose options for support that meet their needs and preferences (Positively UK, 2017). Previous work exploring HIV peer support has demonstrated the need for digital peer support services to adapt to individual requirements (Simoni, Kutner, & Horvath, 2015; Singh, Gibbs, Estcourt, Sonnenberg, & Blandford, 2017), which may change over time and use (Laurence et al., 2019; Senn et al., 2017). Information Communication Technologies (ICTs) are well suited to address such requirements via customizable features. Within the HIV sector, existing, publicly-available ICTs such as WhatsApp are utilized for service support provision; it offers customizable features such as levels of notification for messages received. It has been suggested that such platforms could be more effective than bespoke tools (such as apps) by “integrating interventions within existing online social environments” (Warner, Maestre, Gibbs, Chung, & Blandford, 2019, p.1); utilizing ‘ordinary’ communication channels that work to normalize communications around HIV. However, the use of such channels in community-led peer support service delivery remains under-explored (Taggart, Grewe, Conserve, Gliwa, Isler, 2015).

This is especially true when considering women living with HIV, a group who are underrepresented in both HIV research (Sophia Forum, 2018) and the Human-computer Interaction (HCI) field (Natarajan & Parikh, 2013; Tufts et al., 2014).

Previous work has shown that effective digital health interventions must be guided by

user needs, rather than financial considerations (Williams, 2012; McColl, Rideout, Parmar, Abba-Aji, 2014); therefore, it is crucial to first consider the context of actual use in order to design acceptable digital tools or services in the future.

Materials and Methods

We conducted a series of telephone interviews (n=7) with members of the 4M Network (4MNet), a peer-run UK-wide network of trained Mentor Mothers (MM) living with HIV, to identify benefits and constraints to their use of the WhatsApp platform. 4MNet uses WhatsApp as a communication tool, providing informational, emotional, and practical support to members. Herein we present insights consolidated with research participants and stakeholders from Salamander Trust (the 4MNet Project host) to support the meaningful involvement of women living with HIV within research (Namiba et al., 2016; Kumar, Gruskin, Khosla, Narasimhan, 2015). This study explored 4MNet Mentor Mothers' experiences of using WhatsApp, to inform the design and implementation of future digital support services.

Methodology

Our approach to the interview study is phenomenological in orientation, placing analytic focus on understanding the lived experiences of the individual women who took part, and how they make sense of their digital platform use (Lyons & Coyle, 2007). Interpretative Phenomenological Analysis (IPA) is concerned with embodied and situated meaning-making, by people living in the world with each other, and in this way, is both “a singular but also pluralist endeavor” (Smith, Flowers, Larkin, 2009, p.12).

IPA differs from other qualitative analytic approaches because it is an idiographic approach to inquiry, rooted in the pursuit to understand individual

experiences of phenomena. Sample sizes are typically small (minimum of one participant) and representative of “a fairly homogeneous sample...for whom the research question will be meaningful” (Smith, Flowers, Larkin, 2009, p.49). This approach is well suited to the subject matter of our inquiry, as we investigate experience within a specific context with limited membership and access.

Another distinct feature of IPA is its application of purposeful sampling, in contrast to qualitative analytic approaches that use theoretical sampling such as Grounded Theory. In this way, analytic methods guided by IPA do not intend to exhaust emergent themes, but rather illuminate specific, situated experiences of phenomena. We do not intend for our findings reported in this paper to be illustrative of all experience, for example of women living with HIV, or of WhatsApp users, and thus be generalizable, but rather to present insight into the experiences of members of 4MNet that may be used to inform future research, policy, and services (Brocki & Wearden, 2014).

Methods & Recruitment

IPA informed the design of an interview study, which was led by the first and second authors with input from the eighth author. The first author conducted seven interviews with five group members and two project management team members in February 2019 over telephone or Skype. Participants were recruited via convenience sampling by a peer researcher within the group to ensure group and individual privacy, and were remunerated with a £10 shopping voucher for their time. Calls were recorded using a call recorder app for Skype and/or a telephone audio recorder with informed consent.

Participants represented a range of demographics, and data were collected regarding age and region of residence within the UK. The mean age of participants was

49.7 years, with the majority (80%) reporting their ethnicity as Black African. Other characteristics are presented in Table 1.

[Table 1 near here]

Analysis

In order to conduct research that aligns with best practices in the HIV sector (Kumar et al., 2015; Namiba et al., 2016), we involved participants in multiple stages of the analysis, which we will explain below. Through these participatory engagements, we supported the meaningful involvement of participants in the analysis, while also not placing an undue burden of work on them, in line with the 2017 Consolidated guidelines on the sexual and reproductive health and rights of women living with HIV (World Health Organization [WHO], 2017).

Following data collection, individual transcripts were manually coded and analyzed by the first and second author using IPA (Smith et al., 2009). This was a two-step ('double-hermeneutic') process, first coding how participants made sense of the interview, where possible reflecting their actual words; and, second, coding how we researchers interpreted this participant sense-making to address our research questions. Codes were then grouped into themes and refined through further collective analytic sessions involving authors 1, 2, 3, 4 and 8, and subsequently authors 1, 6 and 8. This multi-stage analytic process allowed us (authors) to reflexively engage with codes at multiple time points, both individually and collectively. Collective analytic sessions allowed for discrepancies to be addressed, discussed, and resolved, utilizing IPA's double-hermeneutic stages (Smith et al., 2009), to provide guidance on how codes had been informed, and subsequently how an author's interpretation of that code developed.

As IPA is concerned with how the experiences of researchers impact upon data interpretation, we provide a brief overview of authors' backgrounds. Authorial

contribution to this study is comprised of several individuals representing a broad range of experience within this topic, including academics with expertise in HIV and technology design, an HIV physician specializing in women's health, experienced HIV peer researchers and experts in HIV research and HIV support services. Additionally, two of the authors were also participants within the study itself as project management team members of 4MNet. The interdisciplinary experience represented through these contributions allowed for rich and multifaceted discussion; and the inclusion of 4MNet members and study participants within these stages supported (1) the goal of IPA for individual experience to be represented through the analytic process; and (2) methodological alignment with guidance on the meaningful engagement of women living with HIV within research (WHO, 2017).

Ethics

Ethical approval was granted from the University Ethics Review Committee of the affiliated institution (REF 9885). Informed consent, participant privacy, and guarding against participant harm and unintentional disclosure of HIV status was paramount (Maestre et al., 2018). These were considered and realized in additional considerations for MMs' engagement, including ensuring all communications contained no reference to living with HIV, and working closely with the service providers and the fifth author, an HIV physician with expertise in conducting qualitative research with women living with HIV.

Results

Insights reveal Mentor Mothers (MMs) to be technology users for whom the use of ICTs, such as WhatsApp and text messaging (SMS), is an established component of peer support service engagement. We found existing ICTs to offer their users both

benefits and constraints; and fear of confidentiality loss was found to affect how participants communicated via ICT platforms and platform choice. In the following, we present how key features of the platform included both positive and negative considerations of use, as well as specific benefits and constraints voiced by the MMs about the use of WhatsApp for peer support.

Benefits of WhatsApp Use

The decision to use WhatsApp was made together by the peer group, as it presented a moderated platform that would allow involvement that suited a broad range of schedules and availabilities. As Participant 1 [P1] described: “I don’t get time to go to support groups, I don’t have time to follow up more; I don’t read blogs or emails much, so at least [the WhatsApp group] is keeping me in the loop some.”

Involvement with the digitally-mediated peer support inherently reduced feelings of isolation. The benefit of this community existing digitally was expressed by Participant 5 [P5], a member of the peer support network who was geographically distant from the majority of members: “[My favorite aspect of the WhatsApp network is] being connected to other women from all over the country, ... it just helps me to know that there are other people that I can speak to, if I need to.”

Establishing connection between those who share experiences was perceived as a key benefit of peer support service use. Participants appreciated the ability of digital messaging platforms to provide a platform for interaction despite geographical and scheduling limitations. Within the group, conversations were moderated by rules created together by members, supporting a friendly, professional community, as [P1] voiced.

There [are] a lot of boundaries. When we set up the group we [made] group rules... so there were a few guidelines. So yeah, we are friends, but it's a more professionally minded group. When we're in that network, in that WhatsApp group, it's strictly work related so it's more in a colleague mind-set. At the same time, we are friends when we wish to be outside of that. [P1]

These 'boundaries' allowed members to feel that their participation was effective and meaningful. Participant 2 [P2] explained that, while she may get multiple messages daily from other professional or personal WhatsApp groups, she would always check any notifications about 4MNet messages, as "if there's something then it's going to be worthwhile." These messages often included positive emotional support instances when the group would 'rally around' members going through difficult times or share achievements.

Participants commented on several instances of ICT supporting positive experiences with peer support services. [P2] described how the community gathered within WhatsApp provided a positive, supportive environment.

I view myself as more supported. And I think that's because I would have viewed myself as supportive before, but I think being part of this group, it means that I'm – because I think I was not someone to reach out for support. So – and it, it doesn't feel like you're reaching out for support, it's just that you're sharing and then you'll receive support. [P2]

By communicating to peers on WhatsApp, [P2] received support without needing to ask for it explicitly. This allowed her to sidestep reservations about asking for help, and enabled her to engage with peers more fully. The ease of communicating and supportive response associated to this interaction resulted in a positive experience.

Key Features of WhatsApp

The analysis produced three key digital features, voiced in participant accounts, which supported the decision to use WhatsApp as the primary means for the group to engage with each other: *Accessibility*, the low barriers to access in using WhatsApp; *Adaptation*, the potential for the platform's usage to change based on an individual's need at a given time without affecting the group overall; and *Customization*, the ability of each user to have control over how the application operated on their own device [see Table 2]. These key features presented both negative and positive considerations in actual use.

[Table 2 near here]

Constraints to Use

In addition to benefits, participants identified several constraints to using ICTs like WhatsApp for engagement, despite the group decision to use a digital platform. Main concerns with use were voiced as: financial costs to users; self-confidence issues using technology; security and privacy concerns.

1. Financial Costs

Participants highlighted how Internet-enabled digital tools and services place the cost of access, use and data storage on the individual, through both hardware maintenance and Internet access costs, as illustrated here by Participant 3 [P3] talking about using a digital service for peer support.

With the limitations of data and things like that on the phone, you can't have many messages on your phone, taking up all your space...because we use our personal phones. [4MNet] is not providing us to put all this extra information... in your phone. [P3]

While all participants owned mobile phones and computers, many found ICT use to involve a financial burden, especially in relation to the cost of data or call plans, and digital storage. In considering her financial stability over the years, [P2] ruminated on how her past financial experiences in relation to digital connectivity may be the present reality for other women living with HIV: “Fortunately, at the moment, I'm in the position where I can pay for my contract...but, like, five years ago that would have been a real issue.”

These instances show how divisions can be created around who is able to afford access and sustain use of digital services. This raises considerations about the potential for service providers to subsidize costs for their users.

2. Self-confidence using technology

Some participants expressed a lack of confidence in their own abilities to use ICT platforms, as well as fear and distrust of technology. One participant, Participant 4 [P4], chose not to use the 4MNet WhatsApp group, as it was seen as a task that would demand additional time, and was instead updated on major group actions via SMS from PMTs. In analysis, we reflected how, as the cohort of people living with HIV ages, digital skills and self-efficacy in using digital tools and services could become a greater barrier to access. [P4] raised this as an issue of self-confidence:

I'm not confident in... and I'm scared of doing something wrong, that... I've, maybe wiped something. ... I definitely feel like if I had more confidence around certain applications, it would help me a lot [laughs]. It's like if you don't have much confidence around something, It's hard to... make the most of it, basically. [P4]

These voiced feelings prompt consideration for how digital skills training could be better integrated into digital service provision, especially for older users.

3. Security and privacy concerns

Several participants raised concerns around digital trust, safety, and security, and the potential negative outcomes of using digital platforms to engage with peers, despite the fact that the WhatsApp group operates privately and is moderated by managing members using communally drafted rules. [P3] and [P2] raised concerns about *disclosing* personal information via digital platforms, and conveyed a sense of lacking control over knowing what's happening to it once this information is shared.

Does our information go anywhere beyond us without us knowing? [P3]

If I'm mentoring, there is, you know, I would always ask... if you're comfortable with, you know, even, because on some thi[ngs]- like on WhatsApp, there's my [profile] picture...I'm not famous or anything, but even then, someone [other than the mentee] could see that picture and then think, "Oh, well, I've seen that [in relation to HIV]" you have to be quite careful with someone who really doesn't want to disclose their status, what you're sharing, and what links other people might make. [P2]

Such perspectives highlight the importance of facilitating individual control over the sharing of personal information, in order for users to feel empowered in their

mediated communications. The implications of confidentiality concerns on digital technology use should also be taken into consideration, as concerns about the potential for both intentional or unintentional *de-contextualization* of digital communications and the re-purposing of captured or *disclosed* content were common. While these concerns could scale to larger, more general concerns about the personal control of information online, we identify additional considerations revealed within the context of sharing HIV-related communications with others digitally.

Discussion

Peer support for HIV in the UK is managed largely by non-profit and peer-led community organizations, resulting in limited resources with which to design, support, and maintain digital resources. Simply put, bespoke communication platforms are largely unfeasible for many providers of HIV peer support services, and service designers should take this into consideration when creating and evaluating new tools and services for peer support. Peer support providers are successfully utilizing existing ICTs due to these restrictions.

Utilizing existing ICT platforms for HIV peer support is cost-effective.

However, designers of digital services must demonstrate that their choice of platform maintains effective privacy considerations to ensure the intended users' control over data through informed consent. This is to ensure that platform-level data gathering, such as targeted adverts or contact recommendations, does not negatively impact individuals' self-management of sensitive communications.

Additionally, it is important that communications involving HIV are supported by facilitating users' individual control over their personal information privacy and security, both in connection with commercial entities (e.g. apps) and with others receiving communications. Rather than using explicit privacy actions, such as

anonymous profiles, our participants reportedly managed control and context through the content of interactions and the selection/ customization of ICT platform(s) through which group members engaged each with other. Previous work has addressed the potential risks associated with HIV-related ICT communication through the design of advanced privacy features within bespoke digital interventions (e.g. Laurence et al., 2019; Pendergrass, Hieftje, Duncan, Arora, & Fiellin, 2018). However, the separation of these bespoke interventions from existing, ‘ordinary’ ICT communication platforms raises a major issue in actual use: the familiarity of communication within existing ICT platforms encourages HIV peer support communications as ‘ordinary’ communication. Increasing openness around HIV-related communications and individual control within existing ICTs has been previously reported on by Warner et al. (2018) in relation to explicit HIV status fields in the online geosocial hookup app ‘Grindr’. However, our findings suggest that the use of existing ICTs for peer support similarly allow users to assert individualized control over communications, free from the platform itself denoting the communication as ‘unordinary’. This distinction of being ‘ordinary’ confronts negative perceptions of HIV communications as something to be hidden by reinforcing that they are no different from any other on the platform, assisting in the goal of peer support for women living with HIV to address internalized stigma and enhance self-esteem through the sharing of experience to be an ‘ordinary’ action.

The barriers of financial and educational costs, as well as digital literacy limitations, are widely acknowledged within HCI research as digital divides (Nielsen, Rohman, Lopes, 2018). The use of existing ICTs for peer support raises specific concerns around two key division factors: financial costs of mobile connectivity and storage, and the provision of digital literacy education for service users.

There are currently no broadly recognized practices in place for financially supporting the continual access of digital HIV peer support services. While these tools and services are often hailed as being cheaper to produce, provide, and support, they also shift responsibility and cost of access and upkeep to the user without providing explicit financial aid. These costs should arguably be actively and centrally addressed in the design, implementation, and funding of UK services. This issue may be approached similarly to current best practices for in-person HIV peer support service provision, for which financial considerations, such as travel costs, are already standard practice.

Our findings offer transferable insights for the global HIV sector, highlighting the need for service designers to facilitate support for digital skills and literacy development; this should be considered as essential in affording digital support pathways. This may be addressed through better integration of existing learning frameworks (Chu, Huber, Mastel-Smith, Cesario, 2009; Hong & Cho, 2017) for supporting digital skills training and digital self-efficacy, both within digital-supported service provision and digital services themselves. While there are benefits of utilizing familiar platforms (Taggart et al., 2015), such as WhatsApp, to take advantage of existing knowledge of digital platforms, continual learning support should be offered to enable users to fully engage, and with informed consent. Furthermore, we believe that best practice guidance for digitally-mediated peer support should also be included within future standards of HIV peer support.

We present the first study of its kind that makes interdisciplinary contributions to both HCI and HIV literatures. Through this we consolidate important insights about the use of digital technology by women living with HIV in the UK, analyzed and presented with meaningful involvement of the study participants. Our sample does not reflect the experience of all women living with HIV in the UK, nor, as a

phenomenologically orientated study, does it intend to. We lack representation of young women, LGBTQ* participants, trans women, and women living in Northern Ireland or Wales among many other demographics, all of which require and deserve additional research focus in both HCI and HIV sectors. Important research priorities in this area include the social context of establishing trust and rules within digitally-supported or mediated HIV peer support; cultural differences in ICT use for HIV peer support; and processes for digital education and induction for digitally mediated peer support.

Conclusion

In closing, we contribute a case study informed by an IPA approach, in which we have strived to meaningfully engage women living with HIV in our research (WHO, 2017). We have found that peer-led digital communication is acceptable and effective for women living with HIV. Despite some concerns, WhatsApp enabled MMs to build a community and share knowledge. With increased digital platform use, understanding the barriers and valued features of these platforms among potentially marginalized groups, through working in partnership with them, is vital for enabling peer-led research interventions and informing the practice of responsible and inclusive design innovation.

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Participant [P#]	Age	Location within UK
P1	44	London
P2	52	South of England
P3	44	London
P4	57	London
P5	40	Scotland
P6	60	South of England
P7	51	London

Table 1: Participant demographic information

Digital Features	Negative Considerations	Positive Considerations
Accessibility	<ul style="list-style-type: none"> • User verification concerns around those added to WhatsApp • Potential for messages/content to be accidentally sent to other WhatsApp groups 	<ul style="list-style-type: none"> • No subscription/download cost • Pre-existing knowledge of the platform and how to use it • The app may already exist on user's phone • No login required
Adaptation	<ul style="list-style-type: none"> • Potential information overload from too much content • The work of the group is always present on a personal device, which may add stress due to feelings of constant involvement 	<ul style="list-style-type: none"> • Use style can change over time as needed, allowing for adaption to user interests and availability • Can use in different scenarios and locations (e.g. WiFi, data, on desktop) • Can support multiple content types (e.g. photos, URLs, emoji)
Customization	<ul style="list-style-type: none"> • Potential for missed interactions due to individual control settings (e.g. muting the conversation) • The group being a constant presence could make some not join the group, as it was seen as an additional task to be done (prefer personal, direct, and specific interactions) 	<ul style="list-style-type: none"> • Can mute (no updates received) • Can create a personal profile, with image and descriptive text (if desired, not required) • Can delete messages or group discussion without changing the shared group history; can easily be re-downloaded later • Ability to delete/re-download application without losing data useful for those sharing devices (e.g. with children)

Table 2: Digital key features of WhatsApp as a platform, and respective positive and negative considerations in use