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Informing HIV Social Care Service Design through Participatory Zine Making

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ABSTRACT *Visual communication materials relating to HIV have long included activist, community-based design practices such as zine making. Arguably, a need for new graphic materials has arisen in the wake of medical advancement, to accurately reflect contemporaneous experiences of living with HIV. As HIV discourse pursues ‘future-oriented’ narratives (Namiba et al. 2016) in order to move past cyclical descriptions of HIV stigma, it is crucial to generate new materials from which to draw upon. This is especially true for underrepresented groups, such as women living with HIV, for whom there is little historical visual documentation.*

We utilised participatory design methods to investigate how a group of women living with HIV in the UK conceptualised and visually expressed their experiences of peer support services through zine making. Weekly workshops were conducted over five weeks with nine members of a peer support group in the North East of England, hosted by a local charity. The workshops were facilitated by two staff members of the charity and led by a designer-researcher (the first author). Using a method informed by Wizinsky’s translational model of design research (2019) and the participatory empirical graphic design approach of Bennett et al (2006), the workshops resulted in the production of a 24-page zine, and themes associated with strengths gained through peer support.

We make two contributions to Design4Health. Firstly, we illustrate the experiences of the “time” theme using language, visual metaphors, and narrative structures. Secondly, from a methodological perspective, we explore the role of the designer-researcher at various stages to inform our understanding of meaningful participant involvement. We present zine making as a novel visual participatory method, informing service design through community-based means.

Keywords: HIV, women, participatory research, service design, zines

Introduction

Visual communications relating to HIV/AIDS have historically included activist, community-based design practices, such as zine making. Zines are self-published documents, usually with a limited print run, where the maker(s) control the content, production process(es), and distribution of the publication. In the 1980s, zine making was adopted by some living with HIV/AIDS as a means for self-expression, community building, and information exchange between those who felt unrepresented, ignored, or hidden from mainstream representation or activism (Long, 2000).

In recent years, the zine format has been appropriated as a means for academic HIV research dissemination for underrepresented groups. Examples such as the *'The Criminalization of HIV in Canada: Experiences of People Living with HIV'* zine, which facilitated self-publishing of academic research reports (McClelland 2019), utilise zines to provide a *medium* for HIV information dissemination and advocacy rather than a participatory method. Considering zine-making as a *participatory method* requires a definition of "participation" that includes how contributors become meaningfully involved.

The importance of critical engagement with participatory visual methods (PVMs) was raised by Switzer (2018), pointing to a lack of clarity between PVMs and their methodological foundations. Switzer highlights that *"participatory initiatives can often put the burden of responsibility back onto individuals and communities and take attention away from the importance of larger state responses to inequity,"* arguing that greater criticality should be applied to the power relationships connected to choosing and using PVMs (2018, 199). Boydell et al. (2012) explicated ethical challenges within arts-based health research (ABHR) specifically, outlining a need for further methodological development.

Meaningful involvement of participants (MIPA) has been advocated for within HIV discourse, promoting participatory research approaches and pursuing 'future-oriented' narratives to move past cyclical descriptions of HIV stigma (Nambia et al. 2016). Design-led interdisciplinary collaborations in participatory HIV research have led to insight about PVMs and design methodologies through the collaboration of expertise, referred to by Wizinsky (2019) as a translational model of design research. Equally, the necessity to coordinate multiple diverse stakeholders, often inherent within HIV design research, has led to new transnational design methods, such as Bennett and colleagues' use of an empirical approach to graphic design (2006, 184). These works highlight the generative and editorial efficacy of using PVMs within HIV-specific visual communication research and have contributed methodological insight through their practices and analyses.

Informed by these works and critical PVM/ ABHR discourse, we designed a series of zine-making workshops, resulting in a zine to be used within the hosting organisation's initial meetings with potential clients. Our inquiry focused on (1) how experiences are conceptualised, and what language, visual metaphors, and narrative structures were expressed; and (2) in methodological terms, how much influence participants desired from a professional designer at various stages of the zine design and production process.

In this case study account, we present zine-making as a participatory visual method to inform the design of future-orientated HIV social care services. Additionally, we offer new empirical insights on

how women living with HIV conceptualise and visually communicate the tacit value of peer support services. We then contribute a critically informed participatory visual method for conducting arts-based health research.

Study Design

A workshop series was devised to run across weekly peer support group meetings for women living with HIV (see Figure 1). Nine women were recruited to participate via the hosting organisation, Blue Sky Trust [BST], and two staff members supported workshop activities.

The topic of ‘strengths developed through peer support services’ was chosen through conversations with BST for two reasons: (1) this topic had been raised within peer group activities running at that time; and (2) ‘strengths’ would support a ‘future-focused’ dialogue and avoid raising trauma among participants.

The study protocol was discussed with staff prior to commencement. Ethical approval was granted by Northumbria University, and informed consent granted by participants. Workshops were scheduled within existing sessions and communication materials simplified, to prevent unintentional disclosure. Participants were remunerated with a £10 voucher and copy of the zine.

Study Procedure

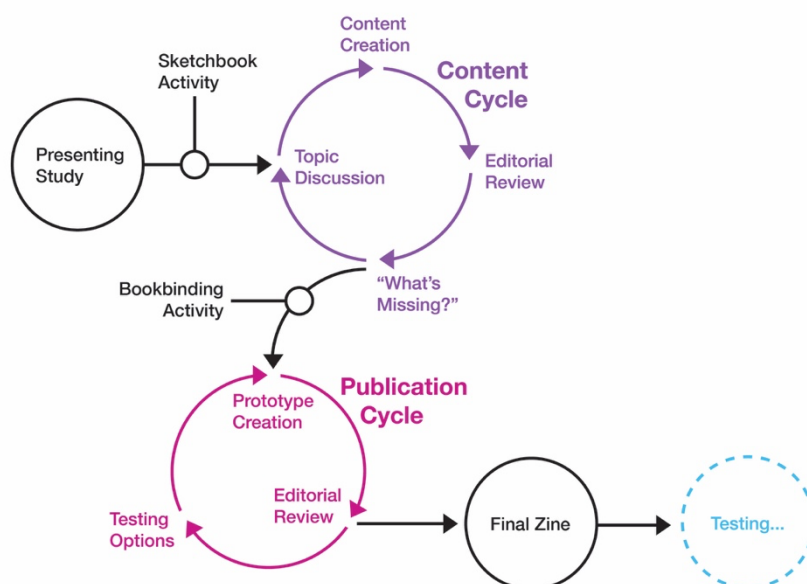


Figure 1: Zine-Making Process

Prior to workshops, an informal presentation on the aims, structure, and ethical consent processes was given. Those consenting to participate were given a small sketchbook, with a prompt to reflect on what ‘strengths’ they had developed through their peer support journey, and a zine introducing

zine making. The series consisted of five workshops, with informal post-workshop visits for production updates. Workshop tasks covered the basic workflow of zine production: topic discussion; creating content; deciding an editorial order and layout; and producing the zine. These tasks were divided into two iterative cycles: content production and publication production.

To create content, participants were given blank page templates with three design prompts on which to create zine pages (see Figure 2). Several media options were given to participants for creating zine pages, including printing personal photos, drawing, painting, and writing; however, collage-making was predominantly chosen.

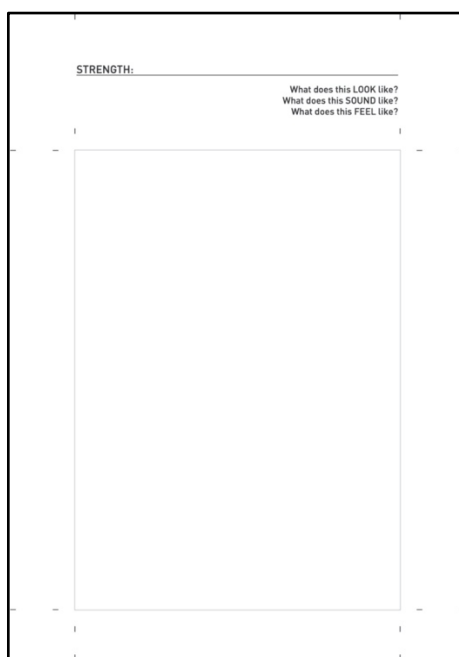


Figure 2: Zine Page Template

Collage-making provides a generative method in which “the creator seeks the fragments and glues them together to express a feeling or sense of an experience or phenomena rather than a particular idea” (Butler-Kisber 2010, 104); and facilitates reflection as “the joining of disparate fragments can produce associations and connections that bring unconscious thoughts to the surface” (ibid., 105). In this way, collage-making supported our research goals of exploring the *experiences* of women living with HIV, and supported discussion and reflection on how the metaphors and narratives were explained and expressed.

Once initial pages were created, an editorial workshop was conducted. Each participant presented their pages to the group before the group agreed on an editorial ordering of pages, layout design, and identified gaps to fill. Cyclical content creation and editorial stages then continued until a final version was agreed upon.

Analysis

An audio recording of the content editorial session was transcribed, anonymised, then used in conjunction with author field notes and visuals made by participants. In a visual analytic process

informed by interpretive phenomenology (Smith, Flowers, and Larkin 2009) and visual anthropology (Collier 2004), materials were contextually clustered and coded to illuminate themes conveying interpretations of intended meanings of the generated images, metaphors, and narratives.

Research Insights

We investigated how women living with HIV in the UK visually expressed their experiences of peer support services through zine making. Here we present selected pages from the final zine and describe “Time”, one of the themes identified, and key methodological insights.

The theme of time was represented through different media: clock faces (image), time (metaphor), and change (narrative). Two participants used clock faces in their page designs (Figure 3 and 4).



Figure 3: Pages by [P1]



Figure 4: Pages by [P2]

In presenting their collages, both participants explained that the clock was a metaphor, representing the concept of time passing, and expressed the significance of this in their lives. For P1, this related to her late diagnosis of HIV and initial prognosis of only two weeks remaining to live:

P1: And that [pointing to watch face] is time. I have a thing about time. [pause] I collect watches now. I'm obsessed with time. I think it's because they only gave me two weeks to live, and... it's just... [Staff: precious?] Yeah in my head now, about time... Yeah—I have to do [participants: certain things], yeah on the go, on the wheel all the time now; I can't stop, [P3: like a hamster] I can't stop; yeah. If I sit—if I sit down, I lose time... time is very important to me.

Time was something to be valued, and utilised to its maximum potential. As living with HIV had meant an extreme personal reflection on the time available, P1 expressed time as an obsession; something important that should not be wasted. While P2 also highly valued time, strength was identified and represented by having patience:

P2: Time for me is so... a big word, 'time', time... losing time; smart time; no time, to do the things... more time, to go... to go to that place, with the other[s]; n—no timetables. And... the... quiet-ful-ness that we have, in this place [peer support group]. We need quiet. We need quiet moments. In our busy lives... being patient. Is a gift. Yes it is. And very hard to obtain. To be a patient person. [Pause] You must waaait, a looooot of time for this, for that, for anything... [pause] to know how patient, how patient [you] will be. Like waiting in a hospital... like waiting for the time [to] pass or, any reason or... That's it; all about patience and time.

Unlike P1 wanting to be “*on the wheel*”, P2 found patience with time brought peace and strength to her experience of living with HIV. Patience was a difficult skill to master and particularly important in settings one could not control, such as waiting in a hospital. P2 expressed that “*quiet moments*”, peaceful moments away from everyday bustle, were a respite of value and importance that the service provider facilitated.

While both expressions of time present interesting implications for service design, the construction of a shared narrative around time presented another concept for consideration: temporality. While the metaphor of time differed in both P1 and P2's works, through conversations about time participants discussed how time related to a larger narrative of temporality in their lives; as stated by P1, “*time rules our lives*”. When considering how time ‘ruled’ their lives, P1 raised the added value of the time spent within the peer support group as a time to heal, building on P2's valued “*quiet moments*”—enjoyment of the present time with the group:

P2: Take advantage, the time that is near us now; this moment. So good.

P1: Our healing time.

Within this utterance, the value of peer support services is remarked upon as something important in the care of these participants: a space and time to heal and enjoy. Beyond service provision, this foregrounds the importance of supportive services for retaining a temporal healing space and time in the participant's life.

Methodological Reflections

The desire for creative involvement from the designer-researcher varied through different elements of the zine, highlighting the need for flexibility. While participants wished for no visual changes to be made to their individual collages, small adjustments (e.g. colour correction) by the designer-researcher were permitted to improve legibility and print quality. Providing multiple examples of work-in-progress was also well received by participants, and supported the voicing of layout preferences and other design decisions by them in conversation with the designer-researcher.

By example, Figure 3 and 4 depict two-page spreads, with the left page showing a written phrase inside a coloured border, and the right a collage. These layouts were devised through conversations during an editorial session. Recommending a repeating element to visually link pages together, the designer-researcher presented various examples with colourful shapes and backgrounds. The participants unanimously chose the border, with P1 explaining “*[it] looks nice... makes the page stand out*”. The designer-researcher selected initial border colours, which were later approved by participants.

Overall, participants preferred to maintain control over the main zine content; and maintain some control (choice) over supporting visual elements (e.g. colours); and leave publication-related aspects (e.g. image print quality) to the designer-researcher.

Discussion

Through zine-making and subsequent publication, individual experiences were expressed through image and text. In making and presenting collaged pages, participants engaged in a reflexive creative practice, and group discussion provided further insight into their experiences and values. Through discussion and editorial work, participants and the designer-researcher developed a shared understanding of the use of visual metaphors, retaining multi-voicedness whilst building a shared narrative. Through the generative and collaborative activities of zine-making participants were provided with a means to express themselves both as individuals and as a collective.

As a participatory method, participants preferred varying levels of creative input from the designer-researcher. While creative and thematic elements were mainly directed by participants, areas that required publication expertise were delegated to the designer-researcher. Through iterative editorial conversations, participants could decide on the aspects they wanted to lead and direct the researcher to provide support in other areas. In this way, the designer-researcher supported project facilitation—‘clearing the path’ of technical issues and offering examples for unfamiliar aspects of production.

Additionally, through participatory publication design, participants were given editorial control over the presentation of the final output. This output became an active component in service delivery for new referrals to the organisation, providing a valued contribution to future users of the peer support group they are part of. Through the collaborative creation of this final output and its distribution, zine-making facilitated a PVM that supported *meaningful* participation, which provided validation that participants’ experiences and expressions were valued and worthy of an audience.

This co-creation of a useful resource for the peer support group connects this method to its historical intentions: supporting community-building and advocating the importance of marginalised experiences *by* the marginalised. Women living with HIV are an underrepresented demographic within HIV discourse, uniquely affected by issues such as late diagnosis. Communicating individual and shared insights into how these experiences are conceptualised can arguably aid the design of supportive services to meet unmet needs, and in itself become a supportive exercise for participants.

It is crucial to state however that these two elements are intertwined: in order for solicited expressions of marginalised experiences to be impactful, they must be purposefully heard. As Switzer states, “*issues [of PVMs] are not just aesthetic: they are ethical and political*” (2018, 201). While PVMs may be perceived as ‘fun’ means for engagement, they should only be enacted with ethical and political considerations. We have endeavoured to address these considerations with our novel method, through: (1) ongoing discussions of participatory work delegation with participants; and (2) establishing the intended purpose of the final output, as a resource for newly referred clients, prior to study commencement.

Conclusion

We report on a co-creative participatory zine-making method, applied within an existing peer support group for women living with HIV in the UK. We argue that our study presents a basis for zine-making to be considered as a critically informed participatory visual method. While the final zine from our study is currently being evaluated as an artefact within social service provision, the process of zine-making has facilitated MIPA, via practice and impactful application of the output. Zine-making should be further explored as a PVM within ABHR for research pursuing critical inquiry with marginalised populations and engaging with ethical and political considerations.

Acknowledgements

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