

# Co-creating poetry for communicating individuals' emotional experience of living with HIV

Caroline Claisse<sup>1</sup>, Bakita Kasadha, Abigail Durrant<sup>1</sup>

<sup>1</sup> Northumbria University, UK

<sup>2</sup> Terrence Higgins Trust, UK

## ABSTRACT

*We report on three 'co-creation workshops' that aimed to qualitatively understand self-care practices for living well with HIV. Taking a participatory, arts-based approach, the research team formed a partnership of designers, peer researchers and experts in the lived experience of HIV. 17 adults living with HIV participated in the workshops in total, engaging in creative making activities and responding to questions about self-expression, self-care practices, receiving care, and the role of healthcare professionals in this care. This co-creative work resulted in three visual poems that are intended to inform the person-centred design of supportive care management services. Our innovative analytic method draws on Found Poetry and Visual Inquiry, to make sense of material artefacts that participants created to represent their experiences and the group discussion that took place. Creative responses to the data, formed by participants and by the researchers (a communication designer, a peer researcher who is a poet, and an interaction designer with expertise in social psychology), captured idiographic understandings of lived experiences. The poems communicate the psychosocial dynamics within self-care practices, plus the challenges of sharing such practices with healthcare professionals. Our contribution is two-fold. First, we offer new qualitative insights into the practice of self-care for living and ageing with HIV, a health context remaining underexplored at Design4Health. Such insights are transferable to wider discourses on supporting the management of long-term conditions. Second, we offer reflection on the efficacy of our co-creative methods to deliver findings about complex experiences through a medium that retains emotional resonance*

*in its expression. We consider the transferability of our methodological insight for utilising Poetic Inquiry in research.*

Keywords: Co-creation; Poetic Inquiry; Self-care; HIV; Long-term Condition

## Introduction

Through effective treatment, the Human Immunodeficiency Virus (HIV) has been transformed into a long-term condition with normal life expectancy for the majority of UK-based people receiving treatment (May et al. 2014). The focus of HIV care has consequently shifted towards maximising quality of life for people as they age (Lazarus et al. 2016), supporting self-management and self-reporting about living with the condition to HIV clinicians (NAT 2016). There is a growing interest in using self-care strategies for supporting whole-person care to live well with HIV (Schnall et al. 2018), going beyond viral suppression to understand experiences of daily life and routines.

In this paper, we report on three 'co-creation workshops' that were conducted in 2019 to qualitatively understand self-care practices for living well with HIV; the workshops formed the first phase of a 30-month research programme to design supportive digital services. Grounded in Phenomenology, and taking a participatory approach, the workshops served to explore how individuals living with HIV engage in and make sense of their own care. We also aimed to 'co-define' key research questions and terminology to inform the research programme going forwards. 17 adults living with HIV participated in the workshops in total (11 women, 6 men); they engaged in creative making activities and responded to questions about self-expression, self-care, receiving care, and the role of healthcare professionals in care. Outputs from these sessions were analysed using Poetic Inquiry combined with Visual Inquiry (Butler-Kisber 2010; Margolis and Pauwels 2011). This co-creative work resulted in three visual poems that are intended to inform the person-centred design of supportive care management services.

Herein, we present the three individual poems and describe how co-creative practice has enabled us to develop understandings about the practice of self-care for living and ageing well with a long-term condition like HIV – a health context remaining underexplored in the Design4Health community. We further endeavour to demonstrate the potential value of the outputs from our co-creative methods for communicating these empirical understandings.

## Methods

### *Co-creation workshops to understand and define HIV self-care practices*

The workshops were organised in partnership with two partnering HIV organisations: Blue Sky Trust ([www.blueskytrust.org](http://www.blueskytrust.org)) and Terrence Higgins Trust (THT) ([www.tht.org.uk](http://www.tht.org.uk)), to ensure that the provided settings for participants were private and safe. Two workshops took place in Northern England and one in Southern England, over a 2-month period. The two-hour workshops were facilitated by this paper's authors, representing multi-disciplinary expertise; the lead author is a communication designer and researcher; the second is a peer researcher who is also a poet; and the third is an interaction designer and researcher with expertise in social psychology. To clarify, a peer researcher practices research skills whilst sharing similar lived-experiences with participants (Ibáñez-Carrasco et al. 2019).

Hosting workshop sessions in two UK regions enabled us to encourage socio-cultural diversity across geographical locations. Participants were ethnically diverse, with age ranging between 24 and 68 and had different sexualities (e.g. heterosexual, bisexual, pansexual). Overall, we involved more women - a group that is historically less visible in HIV research (THT & Sophia Forum 2018). The workshops also provided an opportunity for older participants to voice their experience of ageing with HIV - important as the UK is witnessing the first wave of long-term diagnosed people (pre-1996) who are growing older with the condition (THT 2017). All participants were receiving clinical care and most lived with other long-term conditions such as diabetes, chronic pain and depression. People with HIV are at increased risk of developing comorbidities, which greatly impacts their quality of life (Frontline AIDS 2018).



Figure 1: Ice-breaker activity package given to each participant (left).  
Two brooches created by one participant (right).

The workshop featured creative and 'hands-on' activities, intended to help participants communicate their experiences through verbal, non-verbal and embodied means. We designed a set of material resources for these activities, to scaffold self-reflection and self-expression.

The workshop method had a three-part structure:

- Part 1 was an ice-breaker activity inviting participants to create artefacts (i.e. brooch, badge, fridge magnet or keyring) to express aspects of who they are (i.e. Self-Identity) (Figure 1).
- Part 2 invited discussion about practicing self-care and self-management of HIV in daily life. In pairs, participants were first invited to discuss what the term 'self-care' meant to them whilst thinking about the care they provide to themselves and receive from others (Figure 2). Individually, they were then prompted to complete a mapping exercise, to draw their 'Circles of Care' (Tulunan 2004) (i.e. networks of care visualised as overlapping circles).
- Part 3 prompted participants to think about the types of information that people with HIV may find valuable to share during a routine clinical consultation, and to highlight the information that they did not currently have the opportunity to share with clinicians.

After each activity, participants shared what they felt comfortable with.



Figure 2: Two participants working together in Part 2 of the workshop.

In practice, we found that the dialogical and generative nature of the three-part method enabled participants to collectively contribute to a conversation, and provided an opportunity for peer-education whilst we learned from them. Overall, the sessions were well received, as described by one participant:

'Very enjoyable. It was fun to be creative and the process of making things helped us to bond with other participants. The creative tasks really helped

manage the discussions and allowed everyone to play a part – they also helped to keep people on topic, avoid over-sharing or focusing on negative experiences.'

Making and sharing the artefacts with the group prompted participants to take turns to talk about the personal values that they held, what they felt was important for their wellbeing (e.g. mindfulness and the emotional growth since diagnosis). The activities also prompted discussion about the medical context of living with HIV, and showed different experiences based on individuals' locations and particular needs, as highlighted in feedback: 'Everyone is an individual and this approach enabled us to be individuals and express our respective views.'

Each workshop was audio-recorded; material outputs were photographed. We devised a method for analysing the data through which our experience-centred, participatory and generative orientation was sustained.

### *Analysis and synthesis through co-creative practice*

Poetry is a language that presents 'a window into the heart of human experience' (McCullis in Miller 2018 p383). Researchers in the social sciences have increasingly recognised the value of using Poetic Inquiry (Butler-Kisber 2010; Sjollema et al. 2017) for analysing and representing qualitative data generated from interviews. Poetic Inquiry is part of Creative Analytic Practice (Richardson 1994), and is recognised for providing researchers with means to acknowledge the embodied and emotional dimensions of their research:

'Poetry has forever had the power to attract humankind because of its ability to convey poignancy, musicality, rhythm, mystery and ambiguity. It appeals to our senses and opens up our hearts and ears to different ways of seeing and knowing (Butler-Kisber 2010, p82).'

By using Poetic Inquiry, we aimed to generate new dialogical understandings of experiences that appreciated how individuals make sense of the world (Sjollema et al. 2017). Poetic Inquiry can encourage reflective practice (Butler-Kisber 2010; Sjollema et al. 2017) and address power relationships; final poems may intertwine both the participants' and the researcher's voices (Glesne in Butler-Kisber 2010). We aimed to foreground emotional experience and emerging empirical themes whilst ensuring that individual participant voices were not dissipated through the analysts' collective voice (Butler-Kisber 2010; Sjollema et al. 2017).

### *Analytic method*

Our analytic practice engaged with a dataset of: (anonymised) transcripts of audio recordings of the workshops, plus photos of the artefacts made by participants. We appropriated an existing method (Sjollema et al. 2017) whereby Thematic Analysis is combined with Poetic Inquiry to interpret and disseminate insights from transcripts. We combined two types of Poetic Inquiry in conjunction with visual-based methods (Butler-Kisber 2010) to devise a method involving two steps. First, we used Generated Poetry to create collective poems that addressed our research questions. Second, we used Found Poetry to produce a set of individual poems; these conveyed three participants' (one from each workshop) particular experiences of practicing self-care. Within the limits of this paper, we explicate the second step in our method. We give an overview of our process before sharing our insights and reflection.

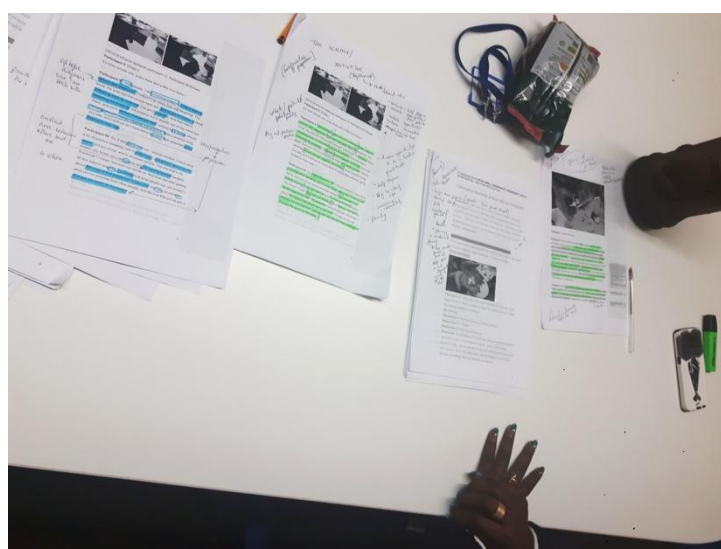


Figure 3: Preparing the data for the Found Poetry engagement.

### *Found Poetry to convey participants' unique journey*

**Gearing in by collating data:** Each transcript of a workshop included photographs of each artefact created by each participant, in the timecode in the workshop where it was presented.

**Immersing ourselves through coding:** Guided by our impetus to address our research questions, we utilised Deductive Thematic Analysis (Braun and Clarke 2006) to code the transcripts; using the commenting tool in Microsoft Word, we attended to how participants talked about their journey. This resulted in a set of themes that illuminated experiences and definitions of HIV self-management and self-care.

**Enhancing coding through Poetic Inquiry:** This process allowed us to capture verbal and non-verbal cues, including pauses and speed of speech, and the metaphors, imagery and repeated utterances. Individually, we also commented on our recalled feelings in facilitating the workshops, highlighting emotive moments, which we found relevant.

**Preparing data for Found Poetry:** We shared the annotated transcripts between us and selected three participants, one from each workshop; these represented diverse profiles and experiences. For each, we focussed on all their captured utterances and expressions. At this stage, we selected extracts that conveyed the emerging theme of a sense of self and self-growth (Figure 3).

**Drafting individual poems:** We selected previously coded utterances that we felt would 'breathe life into the poem' (Butler-Kisber 2010) whilst conveying the themes. The peer-researcher drafted poems, developing compositions that used participants' original words and phrasing, but slightly altering the order in which they were spoken.

**Forming a visual responding to the poems:** A further creative step was to respond to the poem using Visual Inquiry (Butler-Kisber 2010; Yuen 2016). A visual response led by the communication designer interpreted metaphors and evocative feelings portrayed by the poems. Visual Inquiry enabled a creative engagement with text and with the non-verbal utterances that had been noted and reflected on previously. Within the scope of this paper, we do not report on the outcomes of this step; we focus on the content of poems presented in Figures 4-6.

**Sharing and disseminating the poems:** The poems were created in collaboration with our participants. We shared draft versions with them and invited their creative response and feedback. This informed the finalisation of each poem and its visual presentation, for future dissemination.

## Discussion and Concluding Thoughts

### *Qualitative insights*

We suggest herein that the three poems, 'To persevere' (participant 1, P1), 'The teacher' (P2) and 'Becoming the advocate' (P3), work to communicate qualitative insights about individuals' sense making on practices of self-care for living and ageing with HIV. Arguably, each poem incorporates key phenomenological themes, as presented in in Figures 4-6 (themes are indicated on the right).

*To persevere* represents the challenges of living with comorbidities, which, in the case of P1, is more challenging than living with HIV (Figure 4, theme highlighted in blue). The poem also conveys the role of the HIV community in empowering P1 to self-manage and practice self-care. *The teacher* highlights the central importance of connecting with others and sharing experiences as a source of self-empowerment and to help with getting support that is needed (Figure 5, theme highlighted in green). Self-care is described in terms of self-responsibility and agency, starting with oneself (e.g. 'Unlock it,

then you start getting all this support'). *Becoming the advocate* captures a sense of a personal journey over time shared by participants; the poem emphasises how emotional growth and self-reflection enabled P3 to build his resilience in the face of adversity, and to grow confident about his HIV status (Figure 6, theme highlighted in orange). Below we present the three poems. The annotations highlight key themes.

### To persevere

not hmm give  
give together two faces

Challenging stigma, being myself

No!

I want just one

as I am

going through every, every  
every obstacle

Developing resilience

– obstacles

I will be me

I have

An ongoing journey, long-term  
diagnosed

28 years of HIV

Self-care is very hard for me

things are good with me, with my HIV

Self-care is too hard for me

Comorbidities, reaffirming that HIV  
(with access to treatment) is a  
manageable chronic condition

my diabetes

Sometimes I go down

it influences my – my blood sugar

going on hypos

*No come up, you can't go down*

I must take care of me

I am lucky I think and I am happy

Feeling of gratitude

I have so much strength around me

Peer-support, being empowered  
by others

from YOU ALL

Today is a good day to care of me

Self-care involves self-responsability  
for looking after oneself

I go on

as I believe I am



Figure 4: 'To persevere' (P1) emphasises the challenge of living with comorbidities (blue text).

The teacher	
<p>The myth can fall aside          The world has not ended          I'm moving forward          unlocking potential          that won't go away from me          the potential other people have got          un          lock          it          something to put into practice</p>	<p>Challenging stigma and poor          mental health related to diagnosis.          An ongoing journey</p>
<p>Shingles  <i>We need to – we need to test for HIV</i>          immediate support there were the doctors          unlock it          then you start getting all this support you see!          Every week I'm doing goal setting          planning for my health          ahead of time          Every Monday, every Thursday          they cook hot meals here          serve hot meals          free to every service user          they pack you food          unbelievable!</p>	<p>Living with commorbidities</p> <p>Self-care starts with yourself          Self-responsability</p> <p>Vulnerability, possible latent message          of poverty, support required</p>
<p>Self-stigma they call it          I heard situations where families deject when they hear          my immediate support was my family          number one!          Continue self-stigmatising myself          I would not have got it          the support that people come to give you!          They're fully supportive</p>	<p>Being grateful</p>
<p>Go and get out          unlocking the positivity          anything you want to add there?          love there          unlock it          support          what you've unlocked from other people          changes the world, for the better</p>	<p>Peer-support, supporting others is          empowering</p>

Figure 5: 'The teacher' (P2) emphasises peer support and connection to others (green text).

## Becoming the advocate

Coming from the blue self-reflection	Mental health, double entendre: participant is a former navy and refers to his mental well-being
Coming from the blue self-discovery	
Coming from the blue cost two people their jobs	Stigma, highlighting the loss of opportunity and connection due to stigma
I didn't know who I was	
Coming from the blue Obviously the treatment wasn't available straight away Big one for me is being listened to I need a treatment discussion it was really rushed slowly starts to deteriorate long-term side effect I go every six months a consultant that just doesn't trust my judgment! I'm trying not to get my activist hat on but...	Reaching out for support  Being vulnerable
Coming from the blue my affinity to the sea Spiritual connection with the elements A very spiritual journey Massive fifteen year journey	Personal journey, emotional growth
He's been an absolute constant my fluffy he's been an absolute constant he is always there	Companionship provides emotional support
I am back at work Coming from the blue getting myself brought off my antidepressants I love what I do	Maintaining good mental health
I disclosed on my application my interview even disclosed to my line manager Don't have to this is me part of my life it's nothing to be ashamed of if I can change things from the inside I will	Challenging stigma, sense of pride, growing confidence

Figure 6: 'Becoming the advocate' (P3) emphasises the personal journey and importance of self-reflection (orange text).

## *Practising co-creative analysis: closing reflections*

Reflecting on our co-creative inquiry, we highlight herein how we attended to each other's positionality, subjectivity and expertise in visual design, creative writing, and social psychology, respectively. We built on previous work (Miller 2018; Sjollema et al. 2017) to acknowledge the importance of trusting our intuition and empathetic engagement as practitioners: we were emotionally engaged to form creative responses; we took interpretative steps in dialogue and creative exchanges; we took turns to engage with the data, and considered each other's perspectives. We (i.e. the three researchers) were involved throughout all stages: from devising the workshops, to their delivery and analysis. Moreover, as a peer researcher, the poet is living with HIV, which helped us build relationships of trust with the participants, and facilitated dialogue.

Reflecting on our emotions when engaging with the data and acknowledging how they shape interpretation was critical for negotiating ethical tensions in this work. We developed awareness of how our relationships with the data encouraged reflective practice between us (Schon 1983). Externalising our feelings helped us retain a closeness to the data and individual participant voices.

Finally, we recognise that 'knowledge claims are conditioned and partial' (Lichterman 2017), meaning that we are 'knowledge co-creators' with the participants. We engaged in 'ethical crafting' (Sjollema et al. 2017), nurturing a dialogue with them. Looking forwards, we identify the value of co-creative analytic practice for design-led research, to communicate and disseminate research findings in a way that retains the original voice of the idiographic account, and places emphasis on emotional experience and how this is made sense of in dialogue and remains open to interpretation. In closing we highlight the potential of alternative platforms for disseminating poems as empirical outcomes, and considerations around their performative reading to particular audiences. We encourage other Design4Health practitioners to appropriate Poetic Inquiry for capturing the complexity of lived experience, in ways that acknowledge how participant-researcher-subjectivities are illuminated in co-creative research practice.

## Acknowledgements

We thank our partners Blue Sky Trust and Terrence Higgins Trust, and the research participants for their invaluable contributions. We also thank Kiersten Hay for her advice. This work is funded by EPSRC, grant number EP/R033900/1.

## References

- Braun, Virginia, and Victoria Clarke. 2006. 'Using thematic analysis in psychology.' *Qualitative research in psychology* 3 (2): 77-101.
- Butler-Kisber, L. 2010. *Qualitative inquiry: Thematic, narrative and arts-informed perspectives*. Sage Publications.
- Ibáñez-Carrasco, Francisco, James R. Watson, and James Tavares. 2019. 'Supporting peer researchers: recommendations from our lived experience/expertise in community-based research in Canada.' *Harm reduction journal* 16, (1): 1-5. <https://doi.org/10.1186/s12954-019-0322-6>
- Frontline AIDS. 2018. 'Quality of life for people living with HIV is as important as ever.' Accessed 01 March 2019 from <https://frontlineaids.org/quality-of-life-for-people-living-with-hiv-is-as-important-as-ever/>
- Lazarus, Jeffrey V., Kelly Safreed-Harmon, Simon E. Barton, Dominique Costagliola, Nikos Dedes, Julia del Amo Valero, Jose M. Gatell et al. 2016. 'Beyond viral suppression of HIV—the new quality of life frontier.' *BMC medicine* 14 (1): 94. <https://doi.org/10.1186/s12916-016-0640-4>
- Lichterhan, Paul. 2017. 'Interpretive reflexivity in ethnography.' *Ethnography* 18 (1): 35-45. <https://doi.org/10.1177/1466138115592418>
- Margolis, E., and Pauwels, L. 2011. *The SAGE Handbook of Visual Research Methods*. London: SAGE Publications.
- May, M. T., M. Gompels, V. Delpech, K. Porter, C. Orkin, S. Kegg, P. Hay, et al. 2014. 'Impact on life expectancy of HIV-1 positive individuals of CD4+ cell count and viral load response to antiretroviral therapy'. *AIDS*, 28 (8): 1193– 1202. <https://doi.org/10.1097/QAD.0000000000000243>
- Miller, Evonne. 2018. 'Breaking research boundaries: a poetic representation of life in an aged care facility.' *Qualitative Research in Psychology* 15 (2-3): 381-394. <https://doi.org/10.1080/14780887.2018.1430733>
- National AIDS Trust, NAT. 2016. 'HIV in the Future NHS, what next for people living with HIV in England (December 2016). Accessed 01 March 2019 from [https://www.nat.org.uk/sites/default/files/HIV\\_futureNHS\\_Dec16.pdf](https://www.nat.org.uk/sites/default/files/HIV_futureNHS_Dec16.pdf)
- Richardson, L. 2002. 'Poetic representations of interviews.' *Health Care for Women International* 31 (11): 981–96. <https://dx.doi.org/10.4135/9781412973588.n50>
- Schnall, Rebecca, Hwayoung Cho, Alexander Mangone, Adrienne Pichon, and Haomiao Jia. 2018. 'Mobile health technology for improving symptom management in low income persons living with HIV.' *AIDS and Behavior* 22 (10): 3373-3383. <https://doi.org/10.1007/s1046>
- Schon, D. 1983. *The Reflective Practitioner*. Basic Books.
- Sjollema, Sandra, and Felice Yuen. 2017. 'Evocative words and ethical crafting: Poetic representation in leisure research.' *Leisure Sciences* 39 (2): 109-125. <https://doi.org/10.1080/01490400.2016.1151845>

Terrence Higgins Trust, THT. 2017. 'Uncharted Territory: A report into the first generation growing older with HIV (January 2017).' Accessed 01 March 2019 from [https://www.tht.org.uk/sites/default/files/2018-03/uncharted\\_territory\\_final\\_low-res.pdf](https://www.tht.org.uk/sites/default/files/2018-03/uncharted_territory_final_low-res.pdf)

THT & Sophia Forum. 2018. 'Women and HIV: Invisible No Longer (January 2018).' Accessed 01 March 2019 from <https://www.tht.org.uk/sites/default/files/2018->

Tulusan, Indri. 2004. *Circles of Care: A new approach to healthcare based on social networks*. The Helen Hamlyn Research Centre, Interaction Design, Royal College of Art.

Yuen, Felice. 2016. 'Collage: An Arts-Based Method for Analysis, Representation, and Social Justice.' *Journal of Leisure Research* 48 (4): 338-346. <https://doi.org/10.18666/JLR-2016-V48-I4-6922>