

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



Harris, M; Rhodes, T (2018) "It's Not Much of a Life": The Benefits and Ethics of Using Life History Methods With People Who Inject Drugs in Qualitative Harm Reduction Research. *Qualitative health research*. p. 1049732318764393. ISSN 1049-7323 DOI: <https://doi.org/10.1177/1049732318764393>

Downloaded from: <http://researchonline.lshtm.ac.uk/4647080/>

DOI: [10.1177/1049732318764393](https://doi.org/10.1177/1049732318764393)

Usage Guidelines

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

“It’s not much of a life”: the benefits and ethics of using life history methods with people who inject drugs in qualitative harm reduction research.

Magdalena Harris and Tim Rhodes, London School of Hygiene & Tropical Medicine

Qualitative Health Research, accepted for publication 16 February 2018.

Abstract

A life history approach enables study of how risk or health protection is shaped by critical transitions and turning points in a life trajectory and in the context of social environment and time. We employed visual and narrative life history methods with people who inject drugs to explore how hepatitis C protection was enabled and maintained over the life course. We overview our methodological approach, with a focus on the ethics in practice of using life history timelines and life grids with the 37 participants. The life grid evoked mixed emotions for participants: pleasure in receiving a personalised visual history and pain elicited by its contents. A minority managed this pain with additional heroin use. The methodological benefits of using life history methods and visual aids have been extensively reported. Crucial to consider are the ethical implications of this process, particularly for people who lack socially ascribed markers of a ‘successful life’.

Introduction

The use of life history methods, encompassing an exploration of the life from birth, is rare in contemporary research with people who use drugs. Seminal studies in the field focus on the life since drug use commencement, detailing the complex negotiations involved in maintaining a socially devalued career over time. Qualitative harm reduction research with people who use drugs generally focusses on the proximate relationships, events and understandings informing risks such as infectious disease transmission and overdose. While well placed to elucidate short-term influences, what is lost here is a picture of how risk practices and understandings are shaped by critical transitions and turning points in a life trajectory and in the context of social networks, environments, and time. We employed visual and narrative life history methods with people who inject drugs in London to explore how hepatitis C avoidance was enabled and maintained over the life course. Reflexive field and analytic memos documenting research processes sensitised us to the ethical implications of using life history methods with this population. Primary analyses, therefore, included attention to methodological process. In this article we overview the methods of the Staying Safe study, with a focus on how the co-constructed and graphically rendered life history impacted participants and informed our findings.

Research studies using life history methods with people who use drugs predominantly focus on the life since drug use commencement. Preble and Casey's (1969) ground-breaking depiction of agency and ingenuity amongst New York heroin users employed life history interviews to present drug use as a meaningful, albeit devalued, career. Career was a defining concept in this period of biographical drugs work, following Becker's seminal (1963) study which accentuated the 'work' and agency involved in maintaining a 'deviant' drug use career. Courtwright et al. (1989) conducted life history interviews during the late 1970s and early 1980s with older heroin users (ages 55 – 93), attending to the strategies they employed to reach their relatively advanced ages. In both studies, childhood

experiences and influences are rarely reported. Contemporary research, using life history methods with people who use drugs, has a similar temporal focus. Attention is to patterns of drug use, procurement, treatment, and cessation, as well as to related trajectories of criminality, income generation and incarceration (Barratt et al., 2016; Boeri, 2004; Hser et al., 2001; Murdoch, 1999; Wachsmuth et al., 2016). Exceptions include a study in which 208 women who used crack cocaine were asked about significant childhood events, in addition to their drug use trajectory (Daniulaityte, Carlson & Siegal, 2007). Timelines were constructed for 25 of these women, informed by secondary analyses focussing on 'extraordinarily disturbing events', 'usual stressful events' and periods of drug use.

To understand how protective practices are informed and enabled over time we were interested in exploring the whole life; participants were invited to talk about their upbringing and earliest memories through to the present day. To facilitate recall and deprioritise the (re)telling of a drug-use history (potentially a routine narrative for clients of drug treatment services) we co-constructed a hand drawn timeline with participants, spanning from birth to the date of the interview. This we translated into a computer generated 'life grid'; used with participants in a second interview to facilitate a focused exploration of the interrelationships informing viral risk and protection.

The structure and implementation of life history visual aids differ across studies, but share some common elements. Timelines generally refer to a single straight line along which biographically significant points are entered by the participant (Gramling & Carr, 2004) or researcher (Barratt et al., 2016; Boyd et al., 1998); points represented by written notations and, less frequently, pictures (Gramling & Carr, 2004). Life history calendars or life grids typically comprise a grid format, with key domains of interest listed vertically at the left margin, and time or age units horizontally along the

top. These can be limited to a precise timeframe (Day et al., 2004; Harris & Parisi, 2007), broad life periods (Wilson et al., 2007) or the entire life span (Yoshihama et al., 2005). We provide detail regarding our timeline and life grid construction in the methods section below, accompanied by an illustrative figure.

Visual aids, such as timelines, life grids, lifelines and life history calendars, are not new to health research with people who use drugs and other marginalised populations. They have aided exploration of: drug use trajectories (Adams & Henley, 1977; Barratt et al., 2016; Day et al., 2004); drug use cessation (Woodhouse, 1990); stressors relating to drug use (Boyd et al., 1998); parental substance use (Wilson et al., 2007); experiences of sadness (Gramling & Carr, 2004); intimate partner violence (Yoshihama et al., 2005) and welfare transitions (Harris & Parisi, 2007). Reported benefits of using visual life history methods include the facilitation of participant recall and data validity (Day et al., 2004; Freedman et al., 1988; Yoshihama et al., 2005); tension diffusion in relation to sensitive issues; enhanced interview transparency, rapport, and co-collaboration (Harris & Rhodes, 2012; Wilson et al., 2007). Despite the sensitive subjects explored in these studies, and the immediacy of viewing a life thus rendered, there is little published reflection on the challenges or ethics of employing these methods.

Definitions of and approaches to biographical methods differ depending on disciplinary and epistemological position. Orientations towards concepts such as truth, reality and accuracy inform desired outcomes and the methods employed – including the use and purpose attributed to visual aids. Although life history methodology is generally described in ‘post-positivist’ terms (Cary, 1999; Cole & Knowles, 2001), researchers concerned with obtaining as ‘accurate’ picture of a life or events as possible, may triangulate interview data with data from key informants, documentary evidence,

calendars or timelines to check for inconsistencies and get a clear picture of the 'facts' (Maddux & Desmond, 1975; Schechter & Francis, 2010). The timeline follow-back technique, for example, is regarded as a valid and reliable tool for measuring substance use over time; used in quantitative studies to mitigate recall bias (Day et al., 2004). Interpretive life history approaches are less concerned with the truth as such, than the facilitation of the person's subjective interpretation of their life (Plummer, 2001). A constructivist approach situates the life story as a contextually informed collaborative construction between interviewer and interviewee. Here the life story is a situated construction as opposed to a rendition of a truth or unmediated subjective viewpoint (Jarvinen, 2000; Hewitt, 2007). Our epistemological framework sits within a constructivist approach; the role of the researcher in the co-construction of the participants' life story is not side-lined.

Reflexivity, a continual and critical taking stock of the research process and the researcher's impact on this process, sensitises to the dilemmas of ethics in practice. Here, following Guillemin and Gillam (2004) we distinguish ethics in practice or 'everyday' ethics from procedural or regulatory ethics, as instantiated in formal guidelines and institutional requirements. Procedural ethics is, of necessity, underpinned by broad universal principles. Research ethics in practice, while informed by these principles, is shaped by context and must be responsive to it. Everyday ethical dilemmas – however small and often unanticipated – characterise qualitative health research (Morse, 2007). Through building rapport, eliciting memory, co-creating a story, we risk harm – even when our participants are not obviously vulnerable or the research focus sensitive. For those who are structurally disempowered, the risks are more acute, and revisiting the life as lived can be painful.

The Study

Staying Safe is an international collaborative project with separate studies taking place in the United States, Australia, England, Russia, Spain, and Canada. Sam Friedman of the New York study team

(Friedman et al., 2008) devised the project concept. The methods employed in each country differ according to the backgrounds of the researchers and site-specific requirements, yet all operate according to the same positive deviance framework, as described below. This article pertains to the standalone London study. Ethical approval was received from the London School of Hygiene and Tropical Medicine Ethics Committee [5597] and the Camden & Islington Community Research Ethics Committee [10/H0722/20]. Participants provided written informed consent, pseudonyms are used in this and other project publications.

The aim of the Staying Safe research was to explore hepatitis C avoidance in contexts of high risk. We sought to learn from the experts (Mateu-Gelabert et al., 2010) – people who have been injecting for the long term and remain hepatitis C free. This focus on protective, rather than risky, practices and conditions is typical of a ‘positive deviance’ framework, which derives from research addressing relative child health in environments of high malnutrition (Lapping et al., 2002). People who inject drugs (PWID) who remain hepatitis C free in environments of high transmission risk and children who remain relatively healthy in environments of widespread malnutrition, deviate from the norm. For example, hepatitis C prevalence among London PWID who have injected for between eight and 15 years was 67% at the time of study commencement, twice the odds of infection among those who have injected for less than eight years (Hope, 2008). People who have injected for the long term and avoided hepatitis C were, in our schema, the ‘cases’ while people with a comparable injecting history who are hepatitis C antibody positive were the ‘controls’. Here, the protective individual, social and environmental factors associated with viral avoidance are of interest. A positive deviance framework operates from an affirming strengths-based approach rather than one focused on deficit and risk (Friedman et al., 2008) and invites exploration of indirect social conditional factors, not proximal to risk. In this way, positive deviance and life history methods are mutually supportive.

London-based findings pertaining to the central study aim have been widely reported. We found that social practices not directly or proximally linked to hepatitis C, such as social relations of methadone diversion, stigma avoidance, drug use preparedness and venous care, might nonetheless have hepatitis C prevention effects (Harris, Treloar & Maher, 2012; Harris & Rhodes 2013a; 2013b; McGowen et al., 2013). This article is the first to explore how the life history methods employed informed these findings and the everyday ethical dilemmas encountered in this process. Reflexive practice, in the form of extensive field notes taken after each interview, informed primary analysis. While referencing overarching study findings, we focus here on methodological process – with particular attention to the use of life history visual aids with people who inject drugs.

Sampling and recruitment

Recruitment was facilitated by service providers at two low threshold community opiate substitution therapy (OST) prescribing services in South East and North London and through a community member field worker who accessed drug user networks in South London. Participants were required to have injected for at least eight years and within the last thirty days, also to be willing to participate in two interviews and be tested for hepatitis C. An eight-year injecting history, chosen in line with the positive deviance approach outlined above, was modified to six-years once interviews began. This allowed inclusion of data from one participant who, we discovered once the interview began, had over-estimated his injecting trajectory. Hepatitis C negative participants and women were purposively sampled for; the latter due to their underrepresentation in much harm reduction research. Hepatitis C status was ascertained, with participant permission, through a nurse who conducted blood borne virus testing at each service. If status was unknown or recent test results not available, a hepatitis C test was booked with the service nurse for between the first and second interviews. Thirty-eight participants were recruited, 22 hepatitis C antibody negative and 15

hepatitis C antibody positive. One participant dropped out of the study and did not undertake a hepatitis C test, therefore was excluded from analysis.

Data generation

In-depth interviews were conducted between April 2010 and March 2012, with timelines and life grids concurrently generated to aid and supplement the interview process. Participants were interviewed two to three times; each interview lasted approximately 90 minutes and occurred two to three months apart. Most interviews took place in a quiet private room at the recruiting service; three participants were interviewed at their homes and two in a small, relatively deserted, park. All interviews were audio recorded with participants consent. The first interview concentrated on the participants' life history, assisted by a hand drawn timeline. Participants were informed that the timeline, alongside the interview transcript, would be used to create a computer-generated life-grid which would be brought to the second interview. Three participants, interviewed by TR, did not co-construct a timeline in situ as part of a life history narrative approach. Here, the life-grid was generated post-interview on the basis of transcribed narrative. MH created all life-grids. Three participants were interviewed a third time, when there were specific areas the research team wished to follow up. Two participants attended one interview only. One was excluded from analysis as his hepatitis C status was unknown, while the other was included as he was tested and provided rich and detailed data on all domains of interest in his first interview. Interviews included for analysis totalled 76: six conducted by TR, 70 by MH. Detailed field notes, generated after each interview, included impressions of structuring themes also comment on spoken and visual cues not captured by the audio-recording such as interview context, participant affect and researcher/participant interactions. These field notes often segued into analytic memos, and acted to inform both life grid and coding frame structures (Phillippi & Lauderdale, 2017).

Use of visual aids

All but three first interviews commenced with MH laying out two blank A3 pages on a flat surface such as a table or a park bench. These were angled so she and the participant could see and access the pages. MH drew a rough line lengthwise across both pages, with the year of the participant's birth at the start and the year of the interview at the end. The participant was then prompted to "tell me about your life, starting wherever you want, in any way you want". As they talked, MH made notations along the timeline, asking for date clarification where necessary. Many participants started with their birth, and followed a roughly chronological trajectory, while others started with significant memories and moved back and forth in time as the line was filled in. Participants often gestured at or touched the timeline when speaking about a specific time-period, or the relationship of one period to another. MH, in making notations along the line, kept in check a balance between ascertaining dates with participants and letting their narrative flow. Where required she asked directive questions, such as 'can you tell me more about your childhood', 'what happened then', in relation to gaps in the timeline and the impact of specific events on the participant.

The stage in-between interviews involved a hepatitis C antibody test for the participant, if they had not recently been tested with a verified result and, for MH, the development of the hand-drawn life line into a colour life grid using TimelineMaker Professional software (see figure below). Initial analysis of field notes and transcripts informed broad domains structuring the life grid. These comprised: family, accommodation, education, relationships, drug use, income generation, justice system, health, and harm reduction. A different colour was used to represent each domain with events grouped vertically by domain and horizontally by time. A key at the bottom of the page identified the domains, not all present for each participant. The key difference between this process

and that identified by other research using life grids (Day et al., 2004; Harris and Parisi, 2007), is that domains were not predetermined and did not lead the interview questions. Ours was a two-step process whereby a timeline and qualitative interview informed the life-grid. These varied in complexity, dependent on the data provided. Figure 1 illustrates a simple life-grid constructed from a cross-section of participant data, in order to preserve anonymity.

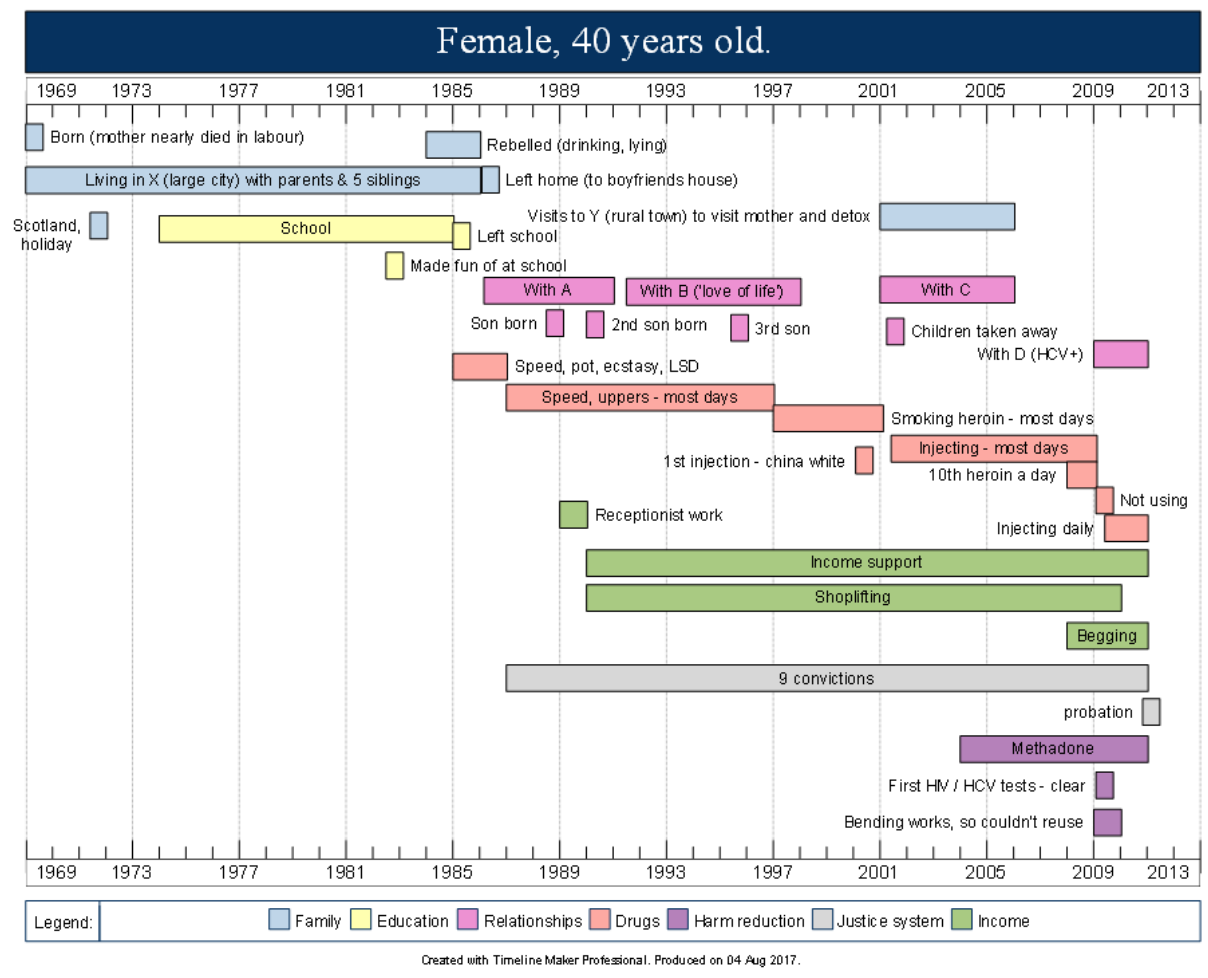


Figure 1. Example life-grid

Participants were provided two copies (A4 and A3) of their life-grid at the start of the second interview; their reflections generated the opening conversation. This interview, aided by the life-grid, explored interrelationships between specific contexts, relationships, events, and practices, with

a greater focus on injecting related practices and attitudes towards blood-borne viruses than the first interview.

Analysis

We conducted a thematic analysis of field-notes and interview transcripts, comprising the steps of data familiarisation; first and second level coding; categorisation and theme development (Saldana, 2016). These analytic steps are, of necessity, recursive – folding back on themselves rather than following a simple linear progression. Analysis continued alongside data generation, with new interviews and insights necessitating changes to early analytic frames. All analytic decisions were documented in a code-book alongside analytic memos and reflections. Data familiarisation was aided through field notes and narrative summaries of each interview, the latter created as transcripts became available. After the first interview, MH conducted an initial analysis of the participant's hand-drawn timeline, narrative transcript summary and relevant field notes to develop their life grid. Domains structuring the life grid, derived from this analysis, were kept purposefully broad in order to reduce variation in life grid structure across participants, thus aiding comparability at the later stage of theme development. MH and TR held regular analytic meetings, with a final coding frame informed by data familiarisation (field-notes, narrative summaries) and exploratory open (line-by-line) coding conducted on a sample of the interviews. Textual data, field notes and transcripts, were coded according to this frame in NVIVO 8 by MH. Focused codes were grouped by MH and TR to develop concept driven categories and then, with reference to the life grids, themes with transferable harm reduction utility (see Harris & Rhodes, 2012; Harris & Rhodes, 2013a; 2013b; McGowan et al., 2013). Field notes and transcript data pertaining to methodological process inform analysis presented in this article.

Participant characteristics

The study sample comprised 37 hepatitis C antibody negative (n=22) and positive (n=15) PWID, of whom ten (27%) were women. Participants ranged in age from 23 to 57 (average 40) with an injecting history of six – 33 years (average 20). Thirty-three participants had injected drugs in the past month, four identified smoking as their current main mode of administration. Heroin was the primary drug used by 25 participants, with 12 using a crack and heroin mix. Most participants (28) were white British. All participants were unemployed at the time of the interview and the majority resided in council (public housing) flats (25, 68%) with eight living in hostels (21%), two living with their mother and two street homeless. Thirty-five (94%) participants were on an OST program, their duration on OST ranging from less than 18 months (n=5) to over 15 years (n=4).

Methodological findings

Eliciting retrospective data and compiling this in a timeline format posed challenges for the researchers and participants. Some participants expressed reservations about their recall ability and, occasionally, provided conflicting data regarding dates, locations, and contexts of events. This was challenging for us to unravel and map out in a linear format, yet the process allowed for anomalies to be explored and worked through in the second interview. To some extent, these issues are unremarkable and to be expected. Of note, however, were participants' reactions to the life history process; in particular, the use of visual aids. We frame our findings in relation to these reactions, closing with reflections on the ethical implications of using life history methods with people who use drugs and other marginalised populations.

Emotions in tension: pleasure and pain

We commenced the second interview by providing participants with a copy of their life grid and asking them to reflect on it. Initial responses demonstrated a tension of emotions; a play of pleasure

– at receiving a personal rendition of one’s life – and pain – when viewing its contents. Comments such as: “I think it’s brilliant” (Ros), “Yeah, I like that. That’s pretty good.” (Alice), could be quickly followed by expressions of regret and loss: “it’s ugly ... just the misery all over it” (Dan). Seeing one’s life mapped out graphically in this format was confronting for many – bringing home a felt paucity of experience. As Andy says, “for a life, it doesn’t really seem that much”. Andy’s comment reflects both the inability of the grid to capture the life as lived: “everything is very cold when you read it like this”, and the dominance of drug use in many of the participants stories – reflected visually in the spatial allocation of the grid: “if that’s to do with drugs its accurate, and it would be even badder if there was more space taken up by drugs really”. Kyle captures this mix of emotions when he describes his life-grid as both “perfect” and “shocking”. Elaborating on the latter, he states: “Just how much drugs I was using and that, I lost my job, things went downhill for me”.

These tensions, but also the productive aspect of the process, are illustrated by Giles when he sees his life-grid for the first time:

Right. Family, my god, family is very small on that, they’re the most important things aren’t they and, oh, it’s very small and fragmented and just horrible ... Very nice, very well done.

Of note, is Giles’ emphasis on the lack of family presence in his life-grid. He describes our depiction as “absolutely true”, yet as representing loss: “it’s things that I’m often thinking about. I think it [family] is the thing that you usually dream about at night”. There is a tension in Giles’ narrative between the ‘horror’ of the grids contents and his pleasure at our care in developing it “very nice, well done”. For the purposes of our study, the grid is productive – eliciting sustained reflection from Giles on the role of family, class, and upbringing in informing his attitude to risk:

I grew up in a council estate. We were quite poor ... you’ve got less to live for ... [my mother] obviously didn’t have a lot of chance bringing up four kids ... She didn’t have a lot of time to

sit down, cuddle, and do these sort of things ... And I think that really plays a part doesn't it. You know, that positive reinforcement of how nice a human being you are, I think it's really important ... We [peers] all knew, you know that this [sharing needles] is dangerous ... this [HIV] could happen to you, but so what. What's worth living for anyway?

For Giles, family – or the lack of it – was the first thing that stood out for him in the grid and a subject he continued to talk about at length. In this narrative – encompassing class, poverty, his father's heavy alcohol use, and his mothers' difficulties in raising four children – Giles made explicit connections between his and his peers backgrounds and their attitudes to risk: (“you've got less to live for”), connections which may not have arisen in a risk event orientated interview format or without the use of visual methods. The shock of depiction elicited reflection. As Giles said, “I'd never thought of it in that way”.

Loss of time

The timeline was experienced as confronting for some in that it foregrounded issues relegated to the back of their minds, as well as graphically inscribed the passing of time, which – as lived – can be experienced as truncated or fleeting. For example, some participants expressed surprise at how long they had been using illicit drugs and/or had been on OST. While they were aware of this passage of time (reporting drug use and OST commencement dates in the first interview) the graphic mapping of these years in relation to their lifespan may have never been directly experienced:

It [timeline] just says, boom, that's my life, look what you've done with it, it's drugs, drugs, drugs and headaches. (Joseph)

It [the timeline] is strange ... Cause I never, I don't know, I never thought about, about this.

And now I just see what I've been doing all this time [sighs]. (Marco)

The initial viewing of the life grid led some participants to reflect on their life in less than positive terms: “I’ve wasted it” (Rick), “I haven’t done anything, I’ve done nothing with it really” (Joseph), “Don’t look very fruitful, does it?” (Ethan), “[It is] quite depressing ... not done much with my life, just all revolved around drugs really” (Dan). Many of these sentiments can be seen to reflect cultural attributions of value, where illicit drug use per se is denigrated as a ‘waste of a life’. Some participants explicitly worked against this narrative. Ros was unequivocally positive about the grid saying: “I’m surprised I’ve lived this long” and Basil, who had been injecting heroin for more than 20 years, stated:

I haven’t wasted my life, no, no ... I haven’t done much lately, but I’ve done loads of things that no one else has done, you know what I mean, your average bod in the street.

Of therapeutic value?

Despite the confrontational aspects of the life grid and the foregrounding of illicit and stigmatised practices such as injecting and selling drugs, most participants expressed pleasure at receiving this personal memento, with a number stating that they were going to show it to others. We asked participants about their plans for the grid. Responses provided insight into social networks and trusted others:

I’m going to show them to my missus and my mum and that. I reckon they’re good, I reckon they’re good, it shows you your life up to today init? (Kyle)

This comment precipitated a conversation about the relationship Kyle had with his mother – who turned out to be an important source of support, also influencing his protective strategies around financial preparedness: “my mum’s brilliant with money, she’s pucker with money. [I picked that up] from her ... yeah, keep it close with my mum”. Andy, who lived in a hostel, said of the process:

It's been fun, I especially like these [the life-grids], they're good. The staff will love these back at the house.

While Andy had spoken in somewhat disparaging terms about the hostel system, particularly the hostel where he was currently living, this statement indicated that he had developed an element of trust and camaraderie with the staff there. Colin and Alice said they planned to show the life grid to their drug and alcohol case managers, with Alice planning to give her trusted keyworker a copy. This was poignant, as when trying to contact Alice for a third interview, her keyworker rang to let the research team know that she had unexpectedly died – a 32-year-old mother of three; homeless, charismatic, and resourceful.

Other participants said they would show the timelines to a friend and/or their sexual partner, with the majority stating that they would keep them to reflect on personally. For some this was expressed in terms of therapeutic value. When asked if he would show anyone the life grid Dan said:

No, it's just for me really, just to look back, like in a couple of years or whatever, to see how far, if I've gone backwards or forwards really, to see how my life is in a couple of years compared to how it's been the last 37 years or whatever, see if I can make change in my life.

Max referred to the timeline process as "good therapy" and Rebecca said she would keep the grid as a reminder of "where I don't want to go back to". The narrative life history interview process also appeared to be therapeutic for some:

It's good talking about this. Yeah. Remember me, remember me. I have to do something. I have to be strong. All my life, from the age of 17 it was always drugs, drugs, drugs ... I am missing lots of things, and now my son and my family. (Marco)

"Remember me". This can be seen as a call to reclaim the self, to reclaim aspects of life experienced as subsumed by drugs, such as family. Dan expressed that it was "nice to talk ... because I don't have

no one to really talk to, and it doesn't, how can I put it, it don't happen often for me". For Simon, this experience was also rare: "I've never really sat down and spoke to anyone, I haven't ... I've never really spoken openly to no one myself". He framed this in terms of a lack of trust in his drug and alcohol service providers, a common refrain amongst participants. We can see here how interaction with the, relatively trusted, interviewer contributes to a narrative co-construction, but also how the potential recipients —the ghosts in the room— might influence the construction of the story told (Harris, 2015; Riessman, 2008).

Refusing the life-grid: pragmatics and pain

Four participants chose not to take the life-grids. For Sandra, this was pragmatic. Her son who lived with her had been in recent trouble with the police and she was worried about the timeline falling into the wrong hands:

I'd rather not take it, I'd just rather not have it in the house ... [the] address isn't safe from the police and I wouldn't want them to get hold of something like that, because they're not nice about it basically.

For Tom, this also stemmed from a pragmatic reflection about what he felt he could handle in his daily life. The life history interview had brought up more issues for him than expected, and by leaving the life-grid behind it was easier to 'keep the lid on':

There are certain issues that if I was ever gonna resolve them I would have done by now, and in an ideal world, maybe I should resolve everything, but I'm not going to help myself, maybe put the lid back on, if you know what I mean.

The two other participants, who chose not to take their grid, reacted more forcefully. Keith refused to look at the life-grid, stating: "I can't look at it, it does my nut in ... I can't keep it because it does my nut in, I can't". Rueben's reaction was explosive:

Fucking hell what, look at that, what a fucking life eh? [*How do you mean?*] What do you mean, how do I mean? Look, well come on, my dad having an affair and then I'm looking at all the bad points, I suppose I'm looking at the bad points aren't I? And well there ain't no good points on there. Dad having an affair, mum died, they moved, I went into a hostel, you know you're drinking, smoking pot and then heroin and that and now I'm fucking in another hostel again. I don't like looking at that, that's horrible.

Of note here, is how the reactions of Rueben and Keith regarding their ownership of the life-grid, or desire to keep it, appears shaped by the dynamics of the data generation approach. In both cases, and in contrast to the approach generally taken, their life histories were co-produced through interview without the aid of a visual time-line. Toward the end of their second interview, the life-grid, which was produced from transcribed interview data, was introduced. This approach differed then, in that the visual timeline was not used as a framing device for the production of life history narrative at the outset, and neither was it co-constructed as part of the interview process. These participants might, therefore, have been less prepared when presented with their storyline graphically rendered than the other participants. With the life-grid not framing interview talk from the outset, there was not only a shorter timeframe to discuss and work through resulting emotions in the second interview but less emphasis given to account-giving around the production of the life-grid itself. Furthermore, with the life-grid element of the life history having been constructed 'outside' of the moment of the first interview, there is less sense of ownership over the life-grid produced.

Coping with distress: ethical implications

The life history interview and the timeline process, as indicated, generated a range of emotions among participants. While each interviewer did their best to ascertain that participants were not in any distress at the close of the interviews, through attention to affect, body language and question responses, it became evident that unwelcome feelings could surface later. Three participants spoke of using heroin due to the first interview, all who were trying to cut down. In Rick and Rebecca's accounts heroin helped them to cope with unpleasant memories brought up by the life history process:

When I saw you back in, what November? Yeah. I used that day. When I find I have to talk about shit, I just use. *But then I didn't use till about last month* or something. (Rick)

To be honest, when I left, I went and used. ... Yeah, I did, I felt really crap, I think going over everything ... *it wasn't your fault* 'cos I was still sort of dabbling then anyway, but, you know ... I felt like shit, so I went and used. (Rebecca)

For Giles, it was talking about drug use and injecting practices that triggered his use. As he says:

Like I hadn't used in so often and eh, talking to you and I started doing it again, you know, like *I'm not blaming you for it* but it's just you get it into your head don't you that it's a nice way to have a hit you know.

Indications of our impact on participants drug use are of concern. As if anticipating this, participants use phrases (italicised above) which act to soften or mitigate attributions of researcher responsibility: 'it wasn't your fault'; 'I'm not blaming you for it'. Here a mutual ethic of care is implied – with a protective impetus extended from participant to researcher as much as the other way around (cf. Harris, 2015). These modes of accounting also operate to position and affirm the participants agency and autonomy in their drug use practices – “but then I didn't use till about last month” – countering a marginalising impetus associated with notions of 'vulnerability' and

'vulnerable populations'. As Gustafson and Brunger articulate, regarding ethical protocols for work with a disability community, vulnerability can read "broken; not capable; people in need of protection" (2014:999). In the narratives above, vulnerability is simultaneously acknowledged and refuted; accounts reveal pain yet promise resilience.

Of the total sample of 38 participants, only two did not attend their second interview. The first, excluded from analysis, was cycling in and out of the criminal justice system and fell out of contact. The second, whose data we included, postponed his second interview twice, finally texting the lead researcher to say:

I feel really uncomfortable about doing it [the second interview] it took me quite a while to get over the last one. Why don't you just write whatever you think and keep the money? Be better for me as I am very depressed right now and another session will just start it up again. Sorry. (Adam)

Here, Adam can also be seen to display an ethic of care – both to himself (refraining from a second interview) and the researcher, enjoining her to write what she likes and 'keep the money'. In his first interview Adam, spoke of a history of depression for which he was receiving ongoing and long-term counselling. Despite this support, it is of concern that our interview triggered a depressive episode for Adam and a desire to self-medicate for three other participants. While these numbers are small, it is important not to discount them; as discussed below there is a need to envisage how we can better protect the interests and safety of participants involved in life history research.

Discussion

A common feature of life history or life course research is a focus on transitions and trajectories, which in the field of drug use or addiction studies generally relates to traumatic events and patterns

of drug use, initiation, cessation, relapse, and incarceration (Harris & Parisi, 2007; Hser, Longshore, & Anglin, 2007). In taking a broader approach, we invited participants to map out their life from birth to the present day. All spoke of their drug use trajectories, but this was as an aspect of their story, not the entirety. Identities other than those related to drug use (such as son, mother, friend, employee, activist) featured strongly, eliciting narratives of how these informed drug use strategies and related protective practices (cf. Biernacki, 1986; Murdoch, 1999). Some participants spoke of traumatic events, such as sexual and physical abuse at various stages of the life course, death of loved ones and the loss of children. These recollections were unsolicited and arose, alongside narratives of the quotidian, mundane, and pleasurable, in the context of a non-threatening non-directive interview situation.

The methodological benefits of using life history visual aids have been extensively reported – from facilitating recall to rapport. These, and additional benefits, were experienced in the Staying Safe study, but require consideration alongside the challenges and tensions the process evoked for participants. Although we aimed to operate from an affirming strengths-based approach rather than one focused on deficit and risk, the lives as described were often devoid of socially ascribed markers of ‘success’ and – for many – seeing these rendered visually was confronting. In part, this is a deficit also of the methods employed. Timelines and life-grids constrain and flatten – imposing a straightforward one-dimensional and linear logic on the incoherencies, complexities, fragmentations and richness of the life as lived. Labels provided are pared down, life periods compartmentalised as ‘in prison’, ‘using heroin daily’ obliterate the vicissitudes of relationships, identity and experience during these times. For this reason, the timelines and life grids were conceptualised as methodological tools – as a means to developing a deeper discussion and exploration of inter-relationships rather than as a study output or primary focus of analysis.

The ethical implications of using life history methods with people who may lack socially ascribed markers of a 'successful life', are rarely reflected on in biographical research with people who inject drugs. This lacuna is concerning, given the socially marginalised and devalued status of many in this population. Although we did not conceptualise the life grids as a primary output – they did hold this function for participants. Thirty three of the 37 participants took them away, and for many the life grids might provide an enduring memory of the study. This is not necessarily detrimental – most expressed pleasure in being provided with a personal visual history, albeit tempered with some pain. For some, the pain in seeing their life thus rendered over-rode any pleasure and they left the life grid behind. Attention to the reasons people may not want to participate in life history methods, or find the process problematic, features in Lindqvist et al's (2015) critical examination of 'Dignity therapy', which uses biographical methods to alleviate existential distress in end of life care. One woman who chose not to take part expressed that her life was 'too full and complex' to be constrained by a simple linear narrative. Others expressed reluctance to talk about unresolved issues or to engage in a process which operated to highlight the disparity between their 'imperfect' life and "a culturally sanctioned view of a perfect life with a happy ending for all" (Lindqvist et al., 2015:45). Other studies (Bohlmeijer & Westerhof, 2011; Tromp, 2011) also indicate avoidance of research employing biographical approaches by a significant minority of older people, potentially for similar reasons to Lindqvist's participants. Recruiting at 'arms length' we have no record of those who may have chosen not to take part in the Staying Safe study, but ethics in practice demands response to the reactions of those confronted with a rendition of their 'imperfect life' in the research process.

Participants' reactions to the life-grid are informed by a variety of inter-related contexts: their living environment; sense of social cohesion and support; current relationship to drug use; identification with or ability to resist ascribed social norms; as well as interview process, context and expectations. We highlight three dimensions in how the process of data generation affects participants'

differential engagements with the life-grid as part of their life history interviews. The first concerns how the occasion of interview talk is *framed*. In all but three occasions, the first interview was specifically framed around the co-construction of a hand drawn timeline. At the start of their first interview, participants were told that this timeline would be translated into a computer generated colour life-grid which would shape the second interview. The life-grid then facilitated reflection and conversation during the second interview. The three exceptions employed a narrative approach to generating life history, without using a timeline to frame such talk. In these cases, the life-grid was generated post-interview, on the basis of transcribed interview data, and then presented to participants during their second interview. Participants' differing engagements and expectations with the life-grid flow from these differences in methodological approach, with those whose first interviews were not framed by the production of a visual timeline being less prepared for it during later interviews, and consequently voicing greater shock in how their lives were graphically presented.

A second related dimension is the differing extent to which the life-grid is *co-constituted* as part of the interview. Where the timeline is co-constituted, from the outset, between participant and researcher, there is greater mutual investment in the object of the life-grid as a product of the interaction. In this approach, the life-grid is made in the moment on the 'inside' rather than post interview on the 'outside', is something *worked on* as part of the objective of the interview, and is thus afforded a greater sense of personal value and ownership. Moreover, this practice of working-on the object of the timeline generates the time and space for reflection, as the story of the life unfolds, facilitating the navigation (and dissipation) of the flow of emotions affected by the starkness of graphical presentations of life.

Thirdly, different researchers may affect differing effects in the generation of interview talk, aside from how the timeline is constituted as an interview device. One important effect here is how the 'peer' status of the lead researcher may have affected a greater sense of mutuality in the co-constitution of timelines and life-grids, especially in generating a sense of production from the 'inside' rather than 'outside', with this indirectly affording a greater sense of personal value. With the life-grid potentiating a shock and sense of loss given its stark graphical portrayal of life, especially in a context where lives embroiled by drugs and addiction are often cast as unworthy and unsuccessful, the presence of a peer relation arguably softens the potential felt harms of the life-grid.

The ethical implications of data generation process, therefore, extend beyond procedural concerns with voluntariness and consent. Ethics in practice alert us to the importance of timing as well as transparency in the generation and deployment of visual methods. In our case, involving participants from the outset in the co-construction of their timeline enabled some transparency and control over the resulting life-grid, which when presented early in the second interview allowed time for reflection and processing. Ethics in practice can also problematize procedural processes for providing support. We had made assurances to ethical research committees that participants impacted by the life history process would receive appropriate referrals to counselling and support services at the recruitment agencies. We soon realised, however, that given the lack of trust displayed towards drug treatment service providers, our plans for follow-up referral were inappropriate. A lack of trust in authority figures, particularly those associated with the health care system, is endemic among marginalised and stigmatised communities such as PWID (Friedman et al., 2007; Ostertag et al., 2006). Ascertaining the best way to support research participants therefore requires ongoing dialogue – including with the affected populations. This may involve a variety of

approaches specific to individual needs, possibly involving the allocation and financing of a trained peer support person.

The involvement of a peer as a field-worker during recruitment and the identification of the lead researcher as a former drug user may have enabled the relating of difficult stories around stigmatised topics. Indeed, some participants attributed therapeutic value to the process, according with other life history studies (Daniulaityte et al., 2007). An apposite question is – what then? A therapeutic context may ideally presuppose an ongoing relationship where issues and emotions can be worked through on a regular basis. This is not offered in the research process, and indeed – might be one of the reasons why participants felt able to talk at length about uncomfortable topics. The context was non-evaluative: the researchers were not linked to services where disclosures could be perceived as detrimental (OST prescribing, social services); the interviews were finite and study-specific. This may, however, have not have been an ideal situation for all, with some participants continuing to contact MH for support well after the study ceased.

Ethics in practice is necessarily situated – dependent on and responsive to context. It brings to the fore unanticipated issues – not accounted for in procedural ethical protocols or assurances. These irruptions are part of the delight of qualitative research – encounters and impacts will surprise and can demand creative responses. We learn from the doing and reflection on this. As expressed by Guillemin and Gillam (2004) critical reflexivity is a sensitising tool to ethics in practice, a resource to work with and through ‘ethically important moments’ – such as viewing ones ‘imperfect life’ flattened and graphically rendered. In making this point we also caution against blanket assumptions of vulnerability and ‘vulnerable populations’ as instantiated in procedural ethics. As demonstrated by Gustafson and Brunger (2014) such descriptions and associated procedural ethical protections

can act to infantilise or further disempower populations whose vulnerability is structurally determined. This is not a call to refrain from working with people who inject drugs in rendering their lives, but to think creatively about how to do so, with their involvement from the outset.

Acknowledgements

We thank the participants and recruiting organisations for their time. The study was funded by the ESRC [RES-062-23-1766].

Declaration of conflicting interests

The authors declare there is no conflict of interest.

References

- Adams, L. D., & Henley, J. R. (1977). Measuring Various Drug Use Dimensions with a Calendar Method. *Substance Use & Misuse*, 12(2-3), 423-427. doi:10.3109/10826087709027233
- Barratt, M. J., Lenton, S., Maddox, A., & Allen, M. (2016). 'What if you live on top of a bakery and you like cakes?'—Drug use and harm trajectories before, during and after the emergence of Silk Road. *International Journal of Drug Policy*, 35, 50-57.
<http://dx.doi.org/10.1016/j.drugpo.2016.04.006>
- Becker, H. (1963). *Outsiders: Studies in the Sociology of Deviance*. New York: The Free Press.
- Biernacki, P. (1986). *Pathways from heroin addiction: Recovery without treatment*. Philadelphia: Temple University Press.
- Boeri, M. W. (2004). "Hell, I'm An Addict, But I Ain't No Junkie": An Ethnographic Analysis of Aging Heroin Users. *Human Organization*, 63(2), 236.
<https://doi.org/10.17730/humo.63.2.p36eqah3w46pn8t2>
- Bohlmeijer, E., & Westerhof, G. (2011). Reminiscence interventions: Bringing narrative gerontology into practice. In G. Kenyon, E. Bohlmeijer, & W. L. Randall (Eds.), *Storying later life—Issues, investigations, and interventions in narrative gerontology* (pp. 273–289). New York: Oxford University Press
- Boyd, C. J., Hill, E., Holmes, C., & Purnell, R. (1998). Putting Drug Use in Context: Life-Lines of African American Women Who Smoke Crack. *Journal of Substance Abuse Treatment*, 15(3), 235-249.
[http://dx.doi.org/10.1016/S0740-5472\(97\)00195-5](http://dx.doi.org/10.1016/S0740-5472(97)00195-5)
- Cary, L. J. (1999). Unexpected Stories: Life History and the Limits of Representation. *Qualitative Inquiry*, 5(3), 411-427. doi: 10.1177/107780049900500307
- Cole, A. L., & Knowles, J. G. (Eds.). (2001). *Lives in Context: The Art of Life History Research*. Walnut Creek, CA.: AltaMira Press.

- Connors, M. (1995). The politics of marginalisation: The appropriation of AIDS prevention messages among injection drug users. *Culture, Medicine and Psychiatry*, 19, 425-452.
- Courtwright, D., Des Jarlais, D., & Joseph, H. (1989). *Addicts Who Survived: An Oral History of Narcotic Use in America, 1923-1965*. Knoxville: University of Tennessee Press.
- Daniulaityte, R., Carlson, R. G., & Siegal, H. A. (2007). "Heavy users," "controlled users," and "quitters" : Understanding patterns of crack use among women in a midwestern city. *Substance Use & Misuse* 42(1), 129-152. DOI: 10.1080/10826080601174678
- Day, C., Collins, L., Degenhardt, L., Thetford, C., & Maher, L. (2004). Reliability of heroin users reports of drug use behaviour using a 24 month timeline follow-back technique to assess the impact of the Australian heroin shortage. *Addiction Research and Theory*, 12(5), 433-443.
<https://doi.org/10.1080/16066350410001713231>
- Freedman, D., Arland, T., Camburn, D., Alwin, D., & Young-DeMarco, L. (1988). The Life History Calendar: A Technique for Collecting Retrospective Data. *Sociological Methodology*, 18, 37-68.
- Friedman, S. R., Mateu-Gelabert, P., Sandoval, M., Hagan, H., & Jarlais, D. C. D. (2008). Positive deviance control-case life history: A method to develop grounded hypotheses about successful long-term avoidance of infection. *BMC Public Health* 8(94).
<https://doi.org/10.1186/1471-2458-8-94>
- Friedman, S. R., Mateu-Gelabert, P., Curtis, R., Maslow, C., Bolyard, M., Sandoval, M., & Flom, P. L. (2007). Social Capital or Networks, Negotiations, and Norms? A Neighborhood Case Study. *American Journal of Preventive Medicine*, 32(6), S160-S170. doi:
<http://dx.doi.org/10.1016/j.amepre.2007.02.005>
- Gramling, L. F., & Carr, R. L. (2004). Lifelines: A Life History Methodology. *Nursing Research*, 53(3), 207-210.

- Guillemin, M. & Gillam, L. (2004). Ethics, Reflexivity, and “Ethically Important Moments” in Research. *Qualitative Inquiry*, 10(2):261-280. DOI: 10.1177/1077800403262360
- Gustafson, D. L. & Brunger, F. (2014) Ethics, “Vulnerability,” and Feminist Participatory Action Research With a Disability Community. *Qualitative Health Research*, 24(7): 997–1005. DOI:10.1177/1049732314538122
- Harris, D. A., & Parisi, D. M. (2007). Adapting Life History Calendars for Qualitative Research on Welfare Transitions. *Field Methods*, 19(1), 40-58. doi: 10.1177/1525822x06292707
- Harris, M. (2015). Three in the room: Disclosure, embodiment and vulnerability in qualitative research. *Qualitative Health Research*, 25(12):1689-1699. doi: 10.1177/1049732314566324
- Harris, M. & Rhodes, T. (2012). Venous access and care: Harnessing pragmatics in harm reduction for people who inject drugs. *Addiction*, 107, 1090–1096. doi: 10.1111/j.1360-0443.2011.03749.x
- Harris, M. & Rhodes, T. (2013a). Methadone diversion as a protective strategy: The harm reduction potential of ‘generous constraints’. *International Journal of Drug Policy*. 24(6): e43-e50. doi: 10.1016/j.drugpo.2012.10.003
- Harris, M. & Rhodes, T. (2013b). Injecting practices in sexual partnerships: Hepatitis C transmission potentials in a 'risk equivalence' framework. *Drug and Alcohol Dependence*. 132(3) 617-623. doi: 10.1016/j.drugalcdep.2013.04.012
- Harris, M., Treloar, C. & Maher, L. (2012). Staying safe from hepatitis C: Engaging with multiple priorities. *Qualitative Health Research*, 22(1), 31-42. doi: 10.1177/1049732311420579
- Hewitt, J. (2007). Ethical Components of Researcher–Researched Relationships in Qualitative Interviewing. *Qualitative Health Research*, 17(8): 1149-115. DOI: 10.1177/1049732307308305

- Hope, V. (2008) Personal Communication. Based upon analyses of the data collected as part of *Annual unlinked anonymous surveys of injecting drug users in England and Wales*, London: Health Protection Agency.
- Hser, Y.-I., Hoffman, V., Grella, C. E., & Anglin, M. D. (2001). A 33-Year Follow-up of Narcotics Addicts. *Arch Gen Psychiatry*, 58(5), 503-508. doi: 10.1001/archpsyc.58.5.503
- Hser, Y.-I., Longshore, D., & Anglin, M. D. (2007). The Life Course Perspective on Drug Use: A Conceptual Framework for Understanding Drug Use Trajectories. *Evaluation Review*, 31(6), 515-547. doi: 10.1177/0193841x07307316
- Jarvinen, M. (2000). The Biographical Illusion: Constructing Meaning in Qualitative Interviews *Qualitative Inquiry*, 6(3), 370-391.
- Lapping, K., Marsh, D. R., Rosenbaum, J., Swedberg, E., Sternin, J., Sternin, M., & Schroeder, D. G. (2002). The positive deviance approach: Challenges and opportunities for the future. *Food and Nutrition Bulletin*, 23(S4), 130-137.
- Lindqvist O., Threlkeld G., Street A. F. & Tishelman, C. (2015). Reflections on using biographical approaches in end-of-life care: dignity therapy as example. *Qualitative Health Research*, 25(1):40-50. doi: 10.1177/1049732314549476.
- Maddux, J. F., & Desmond, D. P. (1975). Reliability and validity of information from chronic heroin users. *Journal of Psychiatric Research*, 12(2), 87-95. doi: 10.1016/0022-3956(75)90012-6
- Mateu-Gelabert, P., Sandoval, M., Meylaks, P., Wendel, T., & Friedman, S. R. (2010). Strategies to avoid opiate withdrawal: Implications for HCV and HIV risks. *International Journal of Drug Policy*, 21(3), 179-185. doi: 10.1016/j.drugpo.2009.08.007
- McGowan C, Harris M, Rhodes T (2013). Hepatitis C Avoidance in Injection Drug Users: A Typology of Possible Protective Practices. *PLoS ONE* 8(10): e77038. doi:10.1371/journal.pone.0077038

- Morse, J.M. (2007). Ethics in action: ethical principles for doing qualitative health research. *Qualitative Health Research*, 17(8):1003-5. DOI: 10.1177/1049732307308197
- Murdoch, R. O. (1999). Working and "Drugging" in the City: Economics and Substance Use in a Sample of Working Addicts. *Substance Use & Misuse*, 34(14), 2115-2133.
doi:10.3109/10826089909039441
- Ostertag, S., Wright, B., Broadhead, R., & Altice, F. (2006). Trust and other characteristics associated with health care utilization by injection drug users. *Journal of Drug Issues*, 36(4), 953-974.
<https://doi.org/10.1177/002204260603600409>
- Phillippi, J. & Lauderdale, J. (2017). A Guide to Field Notes for Qualitative Research: Context and Conversation. *Qualitative Health Research*, Online First,
<https://doi.org/10.1177/1049732317697102>
- Plummer, K. (2001). *Documents of life 2: An invitation to a critical humanism*. London: Sage.
- Preble, E., & Casey, J. J. (1969). Taking care of business--the heroin user's life on the street. *International Journal of the Addictions*, 4, 1-24.
- Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. CA, USA: SAGE Publications
- Saldana, J. (2016). *The coding manual for qualitative researchers*. Third edition. Sage: London, Thousand Oaks, New Delhi, Singapore.
- Schechter, D., & Francis, C. (2010). A Life History Approach to Understanding Youth Time Preference. *Human Nature*, 21(2), 140-164. doi: 10.1007/s12110-010-9084-2
- Tromp, T. (2011). Older adults in search of new stories: Measuring the effects of life review on coherence and integration in autobiographical narratives. In G. Kenyon, E. Bohlmeijer, & W. L. Randall (Eds.), *Storying later life—Issues, investigations, and interventions in narrative gerontology* (pp. 252–272). New York: Oxford University Press.

Wachsmuth, W., Blonigen, D. M., Jacob, T., & Price, R. K. (2016). Course of drug use from early adulthood to mid-life among Vietnam-era veterans. *Journal of Substance Use, 21*(1), 57-64. doi: 10.3109/14659891.2014.950701

Wilson, S., Cunningham-Burley, S., Bancroft, A., Backett-Milburn, K., & Masters, H. (2007). Young people, biographical narratives and the life grid: young people's accounts of parental substance use. *Qualitative Research, 7*(1), 135-151. doi: 10.1177/1468794107071427

Woodhouse, L. D. (1990). An exploratory study of the use of life history methods to determine treatment needs for female substance abusers. *Response to the Victimization of Women & Children, 13*(3), 12-15.

Yoshihama, M., Gillespie, B., Hammock, A. C., Belli, R. F., & Tolman, R. M. (2005). Does the life history calendar method facilitate the recall of intimate partner violence? Comparison of two methods of data collection. *Social Work Research, 29*(3), 151-163.

<http://dx.doi.org/10.1093/swr/29.3.151>