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“Either stay grieving, or deal with it”: the psychological impact of involuntary childlessness for women living in midlife

Running title: Involuntary childlessness and women in midlife

Megumi Fieldsend*, and Jonathan A. Smith

Department of Psychological Sciences, Birkbeck, University of London, Malet Street,
London WC1E 7HX, UK

*Correspondence address, E-mail: megfieldsend@gmail.com

Abstract

Study question: What is it like for women to be involuntarily childless in midlife?

Summary answer: Involuntarily childless women may be suffering from prolonged grief due to its ambiguous and intangible nature; however, they are also striving to find ways of dealing with their internal pain in order to live with their loss.

What is known already: Many studies examining issues around human reproduction have tended to place childlessness in the realm of medicalised infertility and report generalised mental issues, such as depression and psychological distress, existing among women undergoing fertility treatments. Few studies, however, have focused on the individual with regard to the experiential significance of involuntary childlessness and living beyond the phase of trying for a baby.

Study design, size, duration: A phenomenologically oriented person-centred qualitative design was used. In-depth semi-structured interviews were conducted with 12 White British women, who identified themselves as involuntarily childless, recruited via three leading childless support networks in the UK.

Participants/materials, setting, methods: In order to retain an idiographic commitment to the detailed account of a person's experience, a homogeneous and purposive sampling was used applying the following criteria: women aged between 45 and 55, in long-term heterosexual relationships with no adopted children, step-children, or children of a partner from a previous marriage or relationship, and no longer trying to have a child. Considering the homogeneity of ethnic background, and wishing to respect cultural differences, this study focused on White British women living in the UK. Of the 12, one woman was found to not meet the criteria, and therefore, the experiential data of 11 interviews were used for the study and analysed using interpretative phenomenological analysis (IPA).

Main results and the role of chance: Two higher order levels of themes that illustrate intrapersonal features were identified: the intrapersonal consequences of loss, and confronting internal pain. The former explicated the depth of internal pain while the latter revealed ways in which the participants deal with it in their everyday lives. The important finding here is that both themes are co-existing internal features and dynamically experienced by the participants as they live with the absence of much-hoped-for-children.

Limitations, reasons for caution: Given the homogenous sampling and the small number of participants, which is consistent with IPA, we want to be cautious in generalising our study findings.

Wider implications of the findings: This study offers the view that there might be potential mental health issues surrounding involuntary childlessness that are currently overlooked. Particularly because the loss of hope cannot be pathologised, and the grief is ambiguous and intangible, it might make people's grieving process more complicated. An ongoing sense of uncertainty also may persist in that involuntarily childless people may develop symptoms similar to those diagnosed with Prolonged Grief Disorder (PGD). The overall findings elucidate the need for clinicians, counsellors and health professionals to be aware of the possible association with PGD, and promote long-term support and care in helping to maintain psychological well-being for people dealing with involuntary childlessness. Furthermore, this research points to an educational application for younger people by offering information beyond an explanation of infertility and fertility treatment, helping to understand the lived experience of involuntary childlessness.

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Introduction

The development of ARTs has given women having problems conceiving hope, with possible alternative routes towards motherhood. With the advancement of ARTs, a growing number of studies using questionnaires and scale-based measures have been conducted with a focus on infertility and fertility treatments (Greil, 1997). Many of these studies have assessed mental health issues in women with reproductive problems and those who underwent ARTs, and have reported high levels of depression, anxiety, and psychological distress (Demyttenaere *et al.*, 1991; Schwerdtfeger and Shreffler, 2009; Prasad *et al.*, 2017). The emotional distress accompanying fertility treatments has been found to be a strong reason for childless couples to take the decision to end their attempts to conceive (Gameiro *et al.*, 2012).

Infertility may be understood as a temporal life event (Sundby *et al.*, 2007) and childlessness can be studied in relation to failed fertility treatments (McCarthy, 2008; van Balen and Trimbos-Kemper, 1995). However, there are also reports in the existing literature of enduring and prolonged desire or regret (van Balen and Trimbos-Kemper, 1995; Koropecjy-Cox, 2002; Jeffries and Konnert, 2002), long-term mental health issues, such as persistent anxiety, depression and stress (Cousineau and Domar, 2007; McQuillan *et al.*, 2003), and profound grief (Kirkman, 2003) caused by the absence of children. Given the mixed results found in existing research, some researchers have attempted to identify the sources of distress which infertile women face.

In a population-based (United States) longitudinal study, Greil *et al.* (2011) examined whether the distress infertile women experience was caused by the infertility itself (inability to conceive/without a live birth experience) or was due to their undergoing infertility treatment. The authors used the National Survey of Fertility Barriers and collected data through telephone interviews at two time-points (three years in between). Data from 266 infertile American women who completed interviews and reported the condition of their infertility at both time points were used. Based on the participants' infertility treatment experiences and live birth experiences, they were divided into eight groups, which included a group of 44 infertile women who had not had treatment nor had a live birth subsequent to infertility. The authors conducted a series of one-way ANOVAs and a post hoc test to assess whether there were significant differences between the groups. They further conducted a 2 x 8 mixed ANOVA to examine the interaction between time and treatment on fertility-specific distress. The results did not clearly show whether fertility-specific distress was a consequence of infertility or infertility treatment. However, their study did find a higher level of distress in groups of women who had infertility treatment over those of who had not. Over the three years, while fertility-specific distress was found to have decreased in the group of 44 infertile women (no treatment, no live birth), it increased in the groups of women who experienced infertility treatments, not only those who did not have a child but also those who experienced a live birth. The highest increase was found in a group of 19 women who reported having treatments at both time points but had not experienced a live birth. The authors point out both the importance of considering ways to reduce stress levels caused by infertility treatment, and the impact that "not having a desired child" (Greil *et al.*, p. 93) has on infertile women.

More recently, Patel *et al.* (2018) looked at studies on infertile patients undergoing fertility treatments and their infertility specific distress (ISD). The authors defined ISD as "the degree

of emotional strain associated with failure to conceive or experience childbirth” (p. 320). In their review different conceptual frameworks used to study ISD were identified, including individual identity approaches to investigate the impact infertility can have on the development of self and identity, and phase/stage theories to examine psychological distress and adaptation processes which consider pre-treatment through post-treatment. Further, the authors pointed out that the application of grief and bereavement approaches to loss experiences caused by infertility may also be experienced by women during the time of their menstrual period as cyclical grief. The desire for a child, as well as the failed outcome of fertility treatments, influences those unable to have children of their own in different ways. Although the authors drew upon papers which looked at distress in relation to patients’ clinical outcomes, they also indicated ways in which research into ISD can develop our understanding of the complexities surrounding infertility.

With an experiential focus on infertility, Harris and Daniluk’s (2010) paper explored the experiences of 10 infertile women who successfully conceived through ART but who then experienced pregnancy loss. Their study employed a phenomenological perspective and identified nine emergent themes. One referred to the ‘sense of profound loss and grief’, described as the participants’ sense of despair and sadness, while another, the ‘ongoing reminder of their loss’, pointed to the lasting effects of the loss. Their paper points to the importance of understanding the grief involuntarily childless people go through, because “chronic sorrow” (p.718) may make their grieving process more complicated.

Having children and becoming a parent is a natural progression in the lives of most people in midlife: it is a milestone in adult development where people find personal meaning through parental roles (Marcia, 2002; Newton and Stewart, 2010), such as developing and

establishing care and responsibilities for their children (Erikson, 1959/1980; McAdams, 2001). Involuntary childlessness, therefore, impacts on both men and women, and possibly across their entire lives.

Given the diverse issues that exist for people living without the children they hoped for, further research on human reproduction needs to consider involuntary childlessness as part of the complex human developmental processes. Research which investigates personal reproductive experiences as a dynamic continuity (Atchey, 1989) and from life-span perspectives (Baltes, 1987) can provide insights into the nature of human reproduction.

Methodologically, Greil *et al.* (2010) express their concern over the prevalence of quantitative methods and “clinical emphases” (p. 140) in existing studies. Quantitative research is valuable when the focus is an examination of levels of depression childless women have in comparison with mothers. However, it can undervalue childless individuals’ accounts ascribed to depression caused by infertility. While the authors acknowledge overall methodological developments, they also emphasise the necessity for quantitative and qualitative integrations in infertility research.

There has been, however, a gradual increase in qualitative research on involuntary childlessness, including phenomenologically oriented studies. For example, Johansson and Berg (2005) examined the *life-world* of eight childless women (aged between 34 and 41), all of whom ended their IVF treatments two years prior to being interviewed. Their study identified “life-grief” (p. 60) as the core structure of involuntary childlessness. Daniluck (1996) looked at 37 infertile women (aged between 25 and 44, mean age = 36) seeking fertility treatments, and pointed out that infertility is a long-lasting adaptation process rather

than a single life event. McCarthy (2008) investigated the lived experience of 22 infertile women (aged between 33 and 48, mean age = 39.9) with an average of 3.9 years post-failed-treatment. The findings pointed to the core feature of the women's experiences as "living an existential paradox" (p. 321). These studies show insightful features pertaining to involuntary childlessness that cannot be gained through scale-based standardised measures.

There is indeed a vital need for further research into involuntary childlessness, placing it in the area of human reproductive studies. There is also a need to apply an approach that takes a participant-centred experiential perspective, one which focuses on what involuntarily childless individuals experience as they live and "allows for an in-depth attention to the participants' subjective experiences and helps to generate an understanding of some of the complex issues that [may] arise" (Stuart-Smith *et al.*, 2012, p. 2074).

It is also true to say that men's experiences of fertility treatments and/or accounts towards non-fatherhood are under-represented, and the need for research on men in this regard is evident (Fisher and Hammarberg, 2012; Hadley, 2018; Hadley and Hanley, 2011). However, given that there is little research specifically focusing on childless women living beyond the phase of trying for a baby, and not limited to those who underwent fertility treatment, this research set out to look into the psychological impact and the experiential meanings of the absence of children on involuntarily childless women in midlife. The research was guided by the exploratory question: what is it like for women to be involuntarily childless in midlife? In this paper, we focus on intrapersonal features, and wish to illustrate the experiences of the participants as they face and deal with the challenges of involuntary childlessness.

Materials and methods

Study design

Interpretative phenomenological analysis (IPA) (Smith *et al.*, 2009), which is a well-established participant-centred qualitative approach, was used to examine the participants' lived experience of involuntary childlessness. The present study was designed by the two authors, and a total of 12 participants were recruited via three leading childless support networks in the UK between early February 2015 and mid-May 2015. Three active support networks were chosen with the aim of reaching out to as many potential participants as possible, but also to avoid any possible bias that might have existed had a single support community been used. The recruit information sheet was distributed via the following three sources: the first was an e-newsletter written by Lesley Pyne, which supports childless women; the second source was Gateway Women, an online community for childless people organised by Jody Day, who also allowed us to place posts on her private UK Facebook group; and the third source came via Kate Brian, a journalist and editor of the Journal of Fertility Counselling, and our recruitment advertisement was also put on her own home page, Fertility Matters. She also posted it on the web page More to Life (an involuntary childless support group which comes under the umbrella of the Infertility Network UK), where she acts as the London representative. This combination of sources resulted in a snowball effect, helping in the overall recruitment process.

In order to investigate detailed accounts of women's personal experiences in the shared context of childlessness, homogeneous and purposive sampling was applied using the following criteria: women (i) aged between 45 and 55 who wanted to have their own biological children but were no longer trying to have a child; (ii) in long-term heterosexual relationships with no adopted children, step-children, or children of a partner from a previous marriage/relationship; and (iii) White British women resident in the UK and not engaged in

any therapy or counselling, nor under fertility treatment. Of the 12 women recruited, one was found to not meet the criteria and was, therefore, excluded from the study.

All participants showed a willingness to participate in the study and signed a consent form before taking part. Pseudonyms were used throughout to ensure confidentiality and the protection of each participant's identity, and ethical approval was granted by Birkbeck, University of London.

Participants

All of the participants identified themselves as involuntarily childless at the time of recruitment and following initial data collection the following characteristics were further identified: of the 11, five (Maggie, Kelly, Renee, Heather, and Clare) were married, three (Penny, Alana, and Emily) were co-habiting, and three were divorced and either living with a new partner (Susie) or had re-married (Lucy and Denise); the age range was from 45 to 54 with a mean age of 50; nine had had some form of fertility treatment and/or experienced miscarriage; and two of the women (Clare and Emily) had not pursued ARTs, nor had had instances of miscarriage. Finally, the number of years since the participants had stopped trying for a baby varied from between one and two (Kelly, Heather, and Lucy) to more than ten years (Maggie, Renee, and Clare) (see Supplementary Table SI for the 11 participants' characteristics).

Data collection

As suggested by Smith (1995), semi-structured interviews were conducted to explore as flexibly as possible areas that mattered to each participant without questions being fixed in a particular order or interviews being overly controlled. To aid the interview process, opening

questions asked about general daily activities, before moving on to current life and the future, concluding with questions that focused on the past. All the participants clearly understood that the interview would involve talking about their experiences of involuntary childlessness, and it was felt that because talking about the past would involve a lot of personal reflection, participants would feel more comfortable doing so once a rapport and trust had been established. However, as the researchers were careful to allow the interview to unfold gently, questions which asked directly about childlessness were excluded. In practice, all of the women talked about their childlessness before any prompting became necessary. Had that not been the case, one question had been prepared to help with this (see Supplementary Data for the interview schedule).

The interviews were carried out by the first author, and of the 11, five took place at Birkbeck, University of London, and four at the participants' homes. The remaining two were Susie, whose interview took place in a private room at her office, and Heather, at a rented therapy/counselling room close to her home. All participants completed the interviews, which lasted between 52 and 95 minutes. The interviews were audio-recorded and transcribed verbatim for analysis.

Analysis

The analytical process was subjected to IPA (Smith *et al.*, 2009), in that a detailed case-by-case idiographic analysis was prioritised, and then patterns were explored across the cases. IPA is inductive rather than theory driven and values individuals' experiences on their own terms. The explorative nature of IPA also allows the researcher to engage actively, through a process of double hermeneutic, in interpreting the elements of which the person being interviewed is trying to make sense.

The aim of the case analysis was to identify themes that were particular to each individual and after completing all the cases, and considering the convergences and divergences of the themes identified through each analysis, this was continued to develop higher order levels of themes that represented the wholeness of involuntary childlessness experienced by the 11 women. The analysis was led by the first author, and each step of the analytical process was checked and audited by the second author.

In order to present an illustration of the depth and complexities that emerged through the analysis, this paper specifically focuses on themes that highlight intrapersonal loss and gain: The intrapersonal consequences of loss, and confronting internal pain.

Results

In this section, key themes are presented with illustrative extracts from the participants' interviews. Although all the key themes are supported by quotes from more than half of the participants, meeting acceptable sampling criteria suggested by Smith (2011), not all the extracts are included in this paper due to space limitations. In the extracts, [] indicates editorial elision of material deemed unnecessary by the authors, three dots ... indicates a short pause, and use of *italics* indicates emphasised words.

The intrapersonal consequences of loss

Living with embodied pain and ongoing grief

The loss of the hope to have children, for most of the participants, remains as grief, with complex emotions living deep inside for years after trying for a baby. Nine out of the eleven participants experienced different types of medical interventions, including IVF. The

diminishing hope of having one's own children through the use of ARTs is devastating, because generally people have high expectations of success when using such methods to conceive. In particular, three participants (Heather, Kelly, and Lucy) who all stopped trying for a baby only one to two years before the time of the interviews showed a strong sense of loss. This may not be surprising as their experiences were quite recent. However, their accounts amplify the grief associated with failed IVF and how it has impacted on them emotionally and mentally.

Heather revealed her emotional devastation:

That was a disaster. An absolute disaster. [] erm...they...they all died, all the eggs died. [] because they'd all died, they [IVF clinic] phoned me up and they said they'd all died. All the eggs had died so, it wasn't gonna be possible.

The repeated use of the words 'all died' vividly captures her perceived sense of loss. For Heather, 'the eggs' are not medical or clinical terms for fertility. She saw them as personated lives. Unsuccessful IVF for Heather, therefore, possibly remains traumatic.

Kelly described her profound feelings towards the deaths:

...the third time, I was pregnant but then, erm...when we went to have the scan, it was really sad, because that...erm...the little embryo, the fetus had *died*...

Here, her hidden sense of the loss appears with sensitive shifts through her words. For example, she says 'pregnant', but did not say 'miscarried' when expressing her loss. Instead,

she uses ‘the little embryo’, ‘the fetus’ and ‘had died...’. Her sense towards the personified ‘little embryo’ appears, and it is for Kelly a fragile *little person* or *little baby* who ‘died’.

Lucy talked about the psychological impact that the failed IVF had had on her:

Directly after...my second failed IVF attempt. I just had a bit of counselling...
because it...it did really psychologically affect me...[] that was such a big thing
for me.

Grief over the loss can encompass psychological strain that, in this case for Lucy, is perceived as ‘a big thing’. Failed IVF, therefore, can be experienced as a loss of the imagined child who was felt and desired.

Penny, who experienced three pregnancies that all ended in miscarriage, spoke about her grief:

one of the things that throws me is it feels like the path that...that we’re on, is entirely unpredictable. So I keep the grief pop...jumps out at me...at different times...[] I know it sounds kind of a bit crazy, but that’s what behind me, thousands and thousands and thousands and thousands of successful human reproduction. []...and I suddenly thought and it stops with me.

Penny’s grief over her miscarriages appears as physically felt pain that ‘pop...jumps out’ at her. Her sense of loss due to childlessness is explicitly presented against the repeated use of ‘thousands’ of successes, directing us to feel her sense of sadness and guilt over the self who

failed to be part of and contribute to this ‘human reproduction’. Penny’s account powerfully captures her embodied grief over the pain and sadness.

Emily, who did not pursue ARTs, nor did she experience a miscarriage, described her sense of ongoing loss:

there’s always a moment when...I...I may have spent whole evening or the whole day joining in and played with the kids...and...you know, I’ve just been part of the...of the...erm...goings on. And then, at some point there is a moment when I realise or whether or when it sort of hits me, and then it’s hard.

Everyday life for these participants is living with unavoidable triggers for pain and sadness, which seems to be overwhelming. Participants also portray the loss as personified: an embodied manifestation of loss. Grief over non-death loss of involuntary childlessness may stay internally at a deep level.

Multifaceted effects of childlessness

Most of the participants have a sense of worry and fear and the long-term effects of their suffering.

Penny talked about new worries she never used to have, worries about her partner, for example, who ‘could technically go and find a younger woman who is still fertile’:

it’s like...[tearful] it feels like an onion...and every time I...think...I’ve worked out one set of fears, I then just discover a whole another set of fears.

Here, the metaphor 'like an onion' illustrates the layers of fear and endless worry that Penny experiences.

Heather revealed her concerns towards the future:

it's...it's always on my mind to be honest. You know, you...you...you know you're gonna *die, never having* experienced having a baby, or feeling what it's like, looks [like]...and what it feels like to have a baby...erm...that is not gonna happen to you...*ever*...that's it. You get your one life.

What is striking here is Heather's sense of her own death. She clearly feels no more hope can be expected, as she acknowledges the need to terminate her dream – 'that's it'. At the same time, her fear appears with a sense of mortality. There is a sense of reduced life, since having a child gives an extension to one's own life; for Heather, death without experiencing and creating a new life results in her own life being incomplete. This is captured in the final sentence, 'you get your one life'. This short statement further points to a life regret. For Heather, therefore, the fear of death without her having generated her second life is 'always on my [her] mind' triggering existential concerns.

Several of the women talked explicitly about the long-term effects of their internal pain.

Denise, who tried for adoption after several unsuccessful attempts of IVF, reflected on her experience:

I was suffering from anxiety and depression. And I was on antidepressants and stuff. I

thought I'm not really that stable...[little laugh]...not that I would...do something to...but, I just thought I don't really want them [social workers] to go through all this thing and say...and say that I'm not suitable cos I'm suffering from depression which...was really...is a consequence of everything that I went through.

In order to alleviate the emotional suffering caused by the failed IVF, she tried to adopt with a hope of finding fulfilment. However, because the emotional impact was so acute, she could not go through all the procedures necessary for adoption. The quote above, mixed as it is with past and present tenses, suggests that her mind floats back and forth between the past and the present, showing her state of uncertainty, and the long-term effects of her suffering.

Clare, who did not have fertility treatment, but like Denise did experience an unsuccessful adoption, recalled her emotional journey:

when I was 34, I decided we, I wanted children. [] For me, it's been a...a *huge*...grief journey, [] 36 I was getting worried, 38 I was desperate, I thought it's never gonna happen. 40 I had an early menopause, so I *knew* it was never gonna happen...erm, so...it was probably from 34 to 44, it was 10 years of...angst...

The lost opportunity to have children brings emotional struggles in different ways. This sense of 'angst' is accompanied by hidden anxieties and a long journey of grief.

Losing life purpose

Chronic worry and fear induce anxiety. In a similar way, the long journey of grief most participants have appears to generate complex internal struggles that they ascribe to their own life.

For some participants living a life without children is clearly apparent through a sense of loss of meaning. Penny remarked:

Sometimes when I'm down, I do think... 'Oh my life is meaningless...I'm not looking after...a baby...I'm not directly bringing up a child...so what is my worth and value'.

The absence of children affects Penny's entire life. Her contemplation on this is reflected in the following expressions: 'I'm not looking after' and 'meaningless'. These expressions signify 'directly bringing up', suggesting that 'care' for her own desired children would have given her life greater meaning. Penny has not got this. She lost her 'worth and value' in life. This loss is depicted in 'when I'm down', which further suggests the possibility of a prolonged depressive state.

Maggie recounted her struggle:

I was struggling, really. I was lost. I didn't really know what I wanted to do. What to do with my life.

Her reflection here suggests that the emotional impact of childlessness prohibits the finding of fulfilment in her life. She 'was lost' and meaninglessness took over her life.

A lack of evidence for positive outcomes of being involuntarily childless often results in a sense of hopelessness. Renee expressed the devastating feeling she had because she couldn't find a childless role model:

Who do you...you know...who's found a life...from that...that you can actually put there and say, 'OK, they've been through this, they've struggled with it, but now they are having a great life'. I want that. And there seem to be *absolutely nothing*.

As with all the other participants, Renee feels the absence of her own children in her life is an unwanted outcome. Having a life with children for Renee was envisioned as having 'a great life', and that was lost. Here Renee demonstrates her sense of an endless search for positives on childlessness. She 'still' desperately 'want(s)' to find positives that a childless life can bring. However, through the words 'absolutely nothing,' her strong sense of hopelessness appears.

Confronting internal pain

Although all the participants showed a deep-seated sense of loss, each also revealed their own way of challenging their inner turmoil.

Re-evaluation of self

The participants spoke of long held feelings of internal struggle, and their personal reflections emerged as a form of self-evaluation. Penny reflected on herself as she tried to reveal her understanding of who she 'really' is:

the problem was is at the time, I couldn't admit to myself that I was...I was one of

them [women who haven't been able to have children] [] And it was only...a couple of years later that I went...actually...I really am...[laughs] I didn't wanna own it, but it's me...[laughs]

Her comment that 'the problem was is' is revealing. She describes herself in the past—'was'—as she was unable to have children, but also in the present—'is'—to suggest that she still has the problem of accepting who she is. However, by self-categorisation, that is viewing herself in a group ('I was one of them') that she did not want to belong to, her perception of herself has shifted. She has started to acknowledge herself in the context of childlessness, and further, to initiate having responsibility towards a ('didn't wanna own') childless self.

Most of the participants acknowledged their limitations with regard to having their own children, although difficulties appear amongst participants in finding ways to accept limitations and to modify their internal suffering.

Two of the participants indicated avoidance as their approach. Maggie, who expressed several times during the interview that she enjoys her life—'positive, very happy, and fulfilled...'—commented on her way of dealing with concerns about the future:

when we get older, I know having done quite a lot for my...both my parents and Ken's parents still...his Mum...we...you do wonder who's gonna do that for us, actually. But I'm not gonna think about it now, because I'll think about that later, because it'll...what's the point in worrying about it.

Maggie's care of her own and her husband's parents reflects back to the self as a concern for the future. However, the strategy she uses here is to delay finding a solution to that concern. She prioritises what matters to her in her life at present. Maggie uses avoidance as a way to deal with her feelings of uncertainty.

Heather also expressed a sense of avoidance, but towards 'change':

I...to be honest, I don't really like change. And I'll try and avoid 'change' wherever possible to be honest with you.

Making changes is generally a way to achieve adjustment, however, it can also have negative outcomes. Heather appears to be concerned about the latter, and avoiding change is perhaps her way of dealing with her life.

Finding ways to move on

Dealing with emotional difficulties is a multifaceted process. While dealing with their internal conflicts, the participants have become conscious of their own situations and needs, and are taking actions that matter to them: they are making meaningful choices on their own terms. As Clare emphasised:

I think it's been a choice, *definitely*. I'd like to emphasise the choice [Int: choice] that you can either stay, grieving this is what I want, woe is me...or...[] deal with it, and get on with it and find something else.

Clare's strong determination to move on appears in this extract. For her, modifying her sense of loss by 'finding something else' is a choice, which seems to help her regain self-control; she chooses not to 'stay grieving' but to move on. This also suggests that finding 'something else' is a conscious decision which enables her to have an aim to live for, giving her life a new meaning.

Emily spoke about the importance of taking responsibility for her choices when she said 'whichever choices you make or whatever cards you are dealt, we always have to make the most of it'; Maggie is finding her core values by putting 'the past behind' her and working out who she is; and Alana is 'wanting to move into' something that has a value for her, and chooses to create 'children's book illustrations'. The choices they have made are, therefore, manifestations of changes in their lives.

There are also different degrees in the cognitive processes that enable a positive transformation within the self. One, which nearly half of the participants involve themselves in, is that of positive self-affirmation. Lucy, for example, described this process:

now...erm...you know I...I look at what I've got and I think you know...you did that, you...it's...because of what you've done, that you've got to where you are, and...I feel yeah, just really content and happy and you know...[] Erm...so I see a very bright future...so, yeah, it's...it's looking very positive...

Lucy is taking responsibility for actions which allow her to 'see' her future. Her suppressed sense of self, caused by her childlessness, also seems to have shifted. She 'now' appears to have regained her sense of self and is able to reconstruct a way to move on.

Searching for new purpose

Given that the time since each participant stopped trying for a baby differs (one year to more than 10 years at the time of the interviews), all participants are working to deal with the consequences. One of the motivational forces for participants that becomes apparent is to redefine their direction.

Denise expressed the need for change and the idea of moving to begin a new life:

So the only goal I really have is I would like to...I don't wanna live here forever. I would like to live near the sea.

Alana is on her 'train' and starting her journey:

I...I...I don't want to fail again. The gardening didn't work, the children didn't work. And erm...this has...it has to work now [chosen vocation is to produce children's books] [] I'm not gonna get off...this...train. I'm going to stay on it until...until I succeed which is...is helpful... because it means there's no alternative. And I need...I think...psychologically I'm...I need it...I need a goal and a challenge.

Alana's metaphorical use of 'train', 'not gonna get off' and 'stay on' illustrate her willpower towards the journey she has taken. Her remark that 'there's no alternative' captures her sense of pursuit of this new departure.

Considering Alana's psychological needs to find a goal and a challenge to underpin her journey, she has started self-exploration to find her potential, and regaining a sense of challenge in her own life appears as a way of reconstructing personal meaning and helping her get on with her life.

Emily feels that the fundamental positives in herself are the same as when she was twenty-five, and interestingly Kelly echoed Emily's account:

er...part of me still thinks of...[long pause] when I was 25, [] I still feel enthusiasm and still have interests and still have energy and...[] I feel...I...I haven't lost my sense of wonder...you know. That...that feeling that I have...you know... (Emily)

So I feel that the same sense of adventure that I had when I was 25, and the same sort of curiosity for life and the same...erm...connections that I wanted to create...so I see, I fe...I feel...coming back is that same passion for life. (Kelly)

Reconnection with the old self seems to be a way of restoring a sense of self. While both Kelly and Emily regain positives through having the 'same sense of adventure'. Penny has just started searching for the positives that she once had. She said:

There was a wise...there is a wise part of me, deep inside before I went to this weird journey. It's like I need to find the wise part and build a new life that's...fun and creative and spontaneous...

Penny recalled what she was like ‘before’ this ‘weird journey’ started and she feels ‘there is’ still a wise part within her. So, regaining positives that remain ‘deep inside’ seems to provide her with a way of dealing with a life without children. Reconstructing her life, which is ‘fun and creative and spontaneous’ can give meaning to her existence.

Susie, by contrast, is restoring positives in her new self and can now ‘look’ at children:

I just didn’t know how I was gonna move on. [] It [childlessness] impacts on every aspect of your life and I thought...it was gonna be like that for the rest of our lives. And it’s not. It’s not. [] I don’t have to not look.

Her recent experience of physical contact with her nephew’s new baby allows Susie to realise that she does have the ability to reconnect and that she no longer has to hide from babies as she once did. As children are present in everyday life, there are now opportunities for her and her partner that she could not engage with before.

Discussion

All the participants, regardless of the differences in characteristics identified, reported their feelings and emotions over the course of their lives living without the children they hoped for. Consistent with most of the existing literature discussing mental issues regarding infertility (Demyttenaere *et al.*, 1991; Schwerdtfeger and Shreffler, 2009; Prasad *et al.*, 2017), depression and anxiety were the most common problems expressed by the women in this study. These were found not only in the women who experienced failed fertility treatment, but also in those, Clare and Emily, who did not pursue ARTs. Clare’s grief was accompanied by hidden anxiety, while Emily found that being in the company of children triggered pain

and sadness in everyday life. Everyday life becomes a reflection of what one has not got (Mälkki, 2012).

For the women who had failed IVF and/or miscarriages, the outcome was perceived in terms of the loss of the potential child, rather than as a failed medical intervention or clinical issue. One participant, Heather, felt a hidden sense of ‘disaster’ that appeared to point to the death of ‘all the eggs’, and another, Kelly, said ‘the little embryo, the fetus had died...’.

The persistence of sadness and embodied pain were experiences that developed as grief persisted (Cousineau and Domar, 2007; McQuillan *et al.*, 2003; Kirkman, 2003) and the participants’ infertility became a long-term and emotionally insecure experience. The findings in our study are consistent with Johansson and Berg’s (2005) illustration of ‘life-grief’ and the long-term adaptation process suggested by Daniluk (1996), and contrasts with the temporal life event found in the study by Sundby *et al.* (2007). Although the number of participants in our study was small, the inclusion of women who had not experienced fertility treatments offered an opportunity to explore the experiences of involuntary childlessness beyond the boundary of medical interventions on which much of the existing literature tends to focus.

The current investigation revealed the women’s deeper sense of ambiguity. A coexisting sense of the loss of an imagined child and having a prolonged desire for children resulted in uncertainty in their lives. Penny’s unresolved childlessness brings about an endless sense of fear over her future, while Renee describes her sense of hopelessness as she attempts to find positive meaning, but states, however, that she has ended up with ‘absolutely nothing’.

Most of the women in this study showed a degree of angst caused by the difficulty of “making sense out of what they are experiencing” (Boss, 2006, p74). Boss (1999) introduced the concept of “ambiguous loss”–“loss without closure” (p. 35). She explained this as an “unclear”, “traumatic”, and “uncanny loss” (Boss, 2010, p.138) with two noticeable features that people may experience: the “physical absence with psychological presence”; and the “physical presence with psychological absence” (Boss, 2006, p.7). In line with the former, the emotional struggles found in the participants in our study are illustrations of involuntarily childless women suffering from physically absent, but psychologically present ambiguous loss.

Living with unresolved emotional struggles, some of the women talked of their existential concerns. Heather expressed a sense of her own death without ‘having experienced having a baby’; Heather felt regret over her childless life, but her feeling of not creating a new life seems to have further generated a sense of developmental uncertainty that has become a source of existential fear.

In Erikson’s (1980) psychosocial stage model of human development, he describes midlife as a stage for individuals to develop generativity, in which generative individuals find meaning in caring for others instead of being self-centred. Although Erikson recognises that parenthood itself does not account for generativity, McAdams (2001) points out that it can still be seen as the salient generative expression in midlife. Penny’s account speaks particularly to the impact that involuntary childlessness can have on developing generative identity, as her sense of ‘meaningless’ is the result of her ‘not directly bringing up a child’.

The experiential evidence given by the participants indicates that there might be potential mental health issues surrounding involuntary childlessness that are currently overlooked. The loss the individuals experience is centred on the personified non-existent hoped-for children, and the grief they experience is, therefore, potentially in response to an ambiguous loss. Involuntarily childless individuals may not recognise in themselves the need to grieve for such an intangible loss. This in turn may trigger prolonged psychological distress, such as depression and existential anxiety, over the absence of children in their life.

Despite this, however, the shift in intrapersonal processes are also evident in this study. While all participants demonstrated deep-seated feelings of loss, each has started their journey towards finding ways of alleviating their internal struggles. An important part of this process is the re-evaluation of the self where internal struggles reflect on one's own belief of an "assumptive world" (Janoff-Bulman, 1992).

The assumptive world is an organized schema reflecting all that a person assumes to be true about the world and the self on the basis of previous experiences; it refers to the assumptions, or beliefs, that ground, secure and orient people, that give a sense of reality, meaning, or purpose to life. (Beder, 2005, p.258)

Acknowledgment of the loss of belief in a life with children seems to change perceptions of the self. This is characterised in Penny's remark, 'I didn't want to own it, but it's me'.

In contrast, however, instead of accepting emotional pain embedded within the loss of belief, others seem to employ avoidance. Maggie decided to 'think about' her worries 'later', and Heather 'avoid[s] changes'. These are their ways of dealing with their loss by focusing on

what they can engage in now (Kotter-Grühn *et al.*, 2009) rather than being concerned with the future.

Finding the ability to engage in something will bring happiness (Seligman *et al.*, 2005). However, more importantly is the ability to make choices that give those choices meaning (Frankl, 2004). Choosing what matters to each individual creates ways of regaining a sense of self. Clare said ‘either stay or get on with it [woe]’, and chose not to stay. Maggie decided to ‘put[] the past behind’, and started to try to get to her core values. These are conscious decisions that signify ways of moving forward. The ability to make a choice seems to provide further potential that influences one’s perception. Both Clare and Maggie tried to be “more uniquely individual” (Levinson *et al.*, 1978, p. 33), and their emotions appear to have been meaningfully transformed.

Frankl (2004) refers to the notion that “the perception of meaning” arises when one is “becoming aware of what can be done about a given situation” (p. 145). Nearly half of the women in this study describe ways of self-affirming, which appear to promote positive change. This is illustrated as a way of finding reasons and helping to understand emotional struggles attached to childlessness. Self-affirmation helps positively in regulating emotions. In Lucy’s case, this leads her to ‘look at what I’ve [she’s] got’ and take responsibility for her life. The loss of her dream is viewed rather meaningfully, giving her an opportunity to ‘see a very bright future’.

Searching for fulfilment is a motivational force which activates the process towards self-actualisation (Cohen and Cairns, 2012), but in order to be a fully functional self, one may also need to find ways of “fulfilling of the self” (Maslow, 1998, p. 9). In the current study,

the women are in a process of self-exploration. Alana's use of metaphor—'not gonna get off this train'—illustrates clearly her determination to find fulfilment; Emily and Kelly are restoring their 'sense of wonder' and 'adventure' by revisiting the time they were in their mid-twenties; Penny is searching to regain the 'wise part' that she once possessed in order to build a fun and creative life; and Susie reclaims her positive sense of self through finding the ability to face babies. Finding positives provides ways of relinquishing emotional strain while exploring a new self.

To conclude, this paper presents the dynamic intrapersonal processes of 11 women living without the children they hoped for. While existing studies highlight depression and anxiety as outcomes of being infertile, and mainly from clinical viewpoints, this study adds to our understanding of the depth of internal suffering that involuntarily childless women face. More importantly, although our research does not specifically focus on grief, it is a significant feature identified in the participants' accounts. The loss involuntarily childless individuals face is ambiguous and intangible in nature, "because of the lack of physical signs or something obvious to the casual observer" (Harris, 2020, p. 239). Grieving over such loss can be ongoing with a sense of uncertainty, and as pointed out by Boss *et al.* (2011), experienced as a form of "chronic sorrow" (p. 163). This study also sheds light on the shifting processes participants experience as they deal with their grief. These are both co-existing and inseparable intrapersonal features evidenced in this study.

Given the homogenous sampling and the small number of participants, which is consistent with IPA, we want to be cautious in generalising our findings. However, our study did not find a significant difference between (i) women who stopped trying for a baby recently or some time ago, and (ii) women who experienced ARTs and those who did not.

This explorative study illustrates “the complex” (Stuart-Smith *et al.*, 2012, p. 2074) intrapersonal features and further provides holistic insights into human reproductive experiences, namely, involuntary childlessness. The overall findings elucidate possible clinical implications as well as resources for counsellors, life-coaches, and health professionals in helping to maintain psychological well-being for people dealing with involuntary childlessness. While the loss that an involuntarily childless individual faces may be considered as a loss of hope, it is a loss similar to that people face with the death of a loved one. Although the loss of hope cannot be pathologised, involuntarily childless people experience ongoing grief (Schultz and Harris, 2011), which may result in Prolonged Grief Disorder (PGD) (a newly introduced category in the 11th edition of the International Classification of Diseases, see Killikelly and Maercker, 2018; Prigerson *et al.*, 2009). While one diagnostic criterion for PGD refers to the loss ‘of a significant other’, clinicians may need to be aware of the potential association involuntarily childless individuals have with PGD. Moreover, counsellors and health professionals’ long-term support and care, and the support offered by family counselling, meaning-centred and/or grief therapies (Dallos and Draper; 2015, Neimeyer, 2012; Vos, 2018; Vos *et al.*, 2019) may promote better resilience.

Future research exploring interpersonal features, as well as men’s lived experiences of involuntary childlessness, would be invaluable.

Author’s roles

M.F. was the main researcher and carried out the interviews. J.A.S. supervised the research project and was involved in the design of the study as well as overseeing the analysis of the data. Both authors contributed to the writing of the paper.

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Conflict of interest

The authors have no conflicts of interest to declare.

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Supplementary Table SI Characteristics of the 11 female participants.

Name Pseudonym	Age	Marital status	Recency * see Note	Medical interventions** / miscarriage	Residency
Maggie	53	Married	10+	Yes / -	London
Penny	45	Co-habiting	4-5	Yes / Yes	Surrey
Alana	45	Co-habiting	4-5	Yes / -	North Yorkshire
Kelly	46	Married	1-2	Yes / Yes	South West England
Renee	54	Married	10+	Yes / -	Cheshire
Susie	52	Divorced / living with new partner	4-5	Yes / Yes	North West England
Heather	52	Married	1-2	Yes / -	Scotland
Emily	50	Co-habiting	8-9	No / No	London
Lucy	45	Divorced / re-married	1-2	Yes / -	East Sussex
Clare	54	Married	10+	No / No	West Midland
Denise	50	Divorced / re-married	8-9	Yes / Yes	West Berkshire

Note. (*) Degree of recency = number of years since stopped trying for a baby
10+ = more than 10 years.

(**) Medical interventions include IVF, and also medications to avoid the occurrence of miscarriage.

(-) Indicates unknown/not being mentioned.

Supplementary Data Interview schedule.

I. Life at the moment (Practical things/activities in life now)

1. Could you tell me a bit about yourself?
Prompts: job, family, hobbies, interests
2. What sort of things do you usually do on weekends or when you have free time?
Prompts: How do you spend your free time?
Do you go out often on weekends? If so, with whom?
3. What things make you feel good about yourself?
Prompts: In what sort of situation do you find yourself feeling fulfilled?

II. Goals and Meaning of life

4. How do you feel about being your age (e.g. 50)?
Prompts: What is the best thing about being (e.g. 50)?
How about the worst thing about being (e.g. 50)?
Mentally/physically/emotionally/spiritually
5. Do you think of yourself as having goals that you are working towards?
If so, could you tell me about them?
Prompts: Do you see yourself working towards something?
6. When you think about your future, say in five years' time, what do you hope to be doing?
7. Could you tell me who the important people are in your life?
Prompts: Could you tell me why? In what ways?
Personally? Socially? Family?

III. The past

8. Could you tell me about the best thing that has ever happened in your life?
Prompts: Personally? Socially?
9. Could you tell me about the biggest change that has ever happened in your life?
Prompts: Personally? Socially?
Could you tell me about the biggest decision you've ever made?
10. Do you see yourself as being the same person as you were when you were 25?
Prompts: In what ways are you similar or different?

*** *If there is no reference to children, then I will bring it in as the last question.*

11. You said that you wanted to have children. How do you feel about it now?
12. Is there anything else that you feel we haven't covered, that you would like to tell me?