Development and feasibility evaluation of MyJourney: A self-guided
online intervention for people with unmet parenthood goals

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# Thesis Summary

**Background:** Parenthood is a central goal for most people. Fertility trends indicate an increase in the number of people experiencing unmet parenthood goals (UPG), defined as not having children or fewer children than desired. Facing a UPG can trigger loss and grief, potentially leading to a difficult adjustment process. Currently there is limited knowledge about what support for people with UPGs should comprise and there are no accessible evidence-based interventions to support this population.

**Aims:** This thesis' aim was to develop an accessible, research-informed, and evidence-based intervention to support people with UPGs, named MyJourney.

**Methods:** Various methodologies were used. A prospective mixed methods study to investigate the acceptability of an initial prototype of the intervention; a mixed methods online survey study to gain in-depth understanding of how childless by circumstance individuals adjust to their UPG and their support needs; a phased development process of MyJourney following MRC guidance to develop complex interventions; and a randomised controlled feasibility trial to determine whether MyJourney, and the study protocol, were feasible.

**Main results:** The main findings from the studies undertaken demonstrate there is demand for support across different pathways to a UPG (e.g., unsuccessful fertility treatment, childlessness by circumstance) and that its delivery as an online self-guided intervention is acceptable to people with UPGs. The phased development facilitated clarity regarding the active ingredients and design principles of MyJourney, to maximise its acceptability, and develop the final MyJourney prototype. Findings from the feasibility RCT indicate MyJourney is acceptable,

feasible to implement as an online self-guided tool, and demonstrated limited efficacy. Its development process can move forward to a full scale RCT to evaluate efficacy.

**Conclusion:** The work in this thesis contributed to the emergent research on UPGs and demonstrated it is possible to develop and deliver evidence-based support for people with UPGs.

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# Publications, presentations, and posters

**Publications**

Rowbottom B. and Gameiro S. (under review). Prospective mixed methods acceptability study of the first prototype of MyJourney: a psychological online self-help intervention for individuals with an unmet parenthood goal. PlosOne.

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Rowbottom B. (2021). Reinventing hope after unsuccessful treatment. Invited lecture in: 'Fertility of hope': a delicate balance for patients and providers. In the 37th Annual Meeting of the European Society for Human Reproduction and Embryology (ESHRE) (virtual). June 2021.

Rowbottom B. (2020). *MyJourney* to acceptance - when does it start? Economic and Social Research Council Festival of Social Science. November 2020.

**Posters**

Rowbottom B. and Gameiro S. (2021) "It felt as if it was written by somebody who really understood living a life without children": Research-informed online support for people with an unmet parenthood goal (UPG)". Poster presentation at Fertility 2021 (virtual).

Rowbottom B. and Gameiro S. (2020) Prospective acceptability study of a psychological online self-help intervention for individuals with an unmet parenthood goal (UPG). Poster presentation at the 36th Annual Meeting of the European Society of Human Reproduction and Embryology (ESHRE) (virtual). June 2020.

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# Glossary of abbreviations

**ACT:** Acceptance and Commitment Therapy

**APF:** Portuguese Fertility Association

**ART:** Assisted reproductive technology

**CCBT:** Contextual cognitive behavioural therapy

**CED-S:** Centre for Epidemiological Studies Depression scale

**ESHRE:** European Society for Human Reproduction and Embryology

**FNUK:** Fertility Network UK

**HFEA:** Human Fertility and Embryology Authority

**IVF:** In Vitro Fertilisation

**NICE:** National Institute of Clinical Excellence

**MRC:** Medical Research Council

**ONS:** Office of National Statistics

**PPI:** Patient and public involvement

**PBA:** Person based approach

**RCT:** Randomised controlled trial

**UPG:** Unmet parenthood goal

**WHO:** World Health Organization

# Chapter 1:Introduction and thesis outline

**Global increases in childlessness and declining total fertility rates**

Although most of the demographic literature does not report on whether increasing childlessness or declining fertility rates are involuntary, it is important to provide an overview of the patterns reported over the past several decades and the current trends to provide context for the present thesis. Demographers have drawn attention to a decline in total fertility rates, defined as "the average number of children each woman would deliver in her lifetime if the fertility rates by age observed in a given period remained constant" (Schmidt et al., 2012 p. 31), below replacement level in a majority of European countries (Frejka & Sobotka, 2008). This decline indicates that women are having fewer than two children. In addition to this, the prevalence of permanent childlessness has followed a U shaped trend over the past one hundred years, with the lowest levels reported in cohorts from the 1940 followed by an increase (Sobotka, 2017), with some European countries more recently reporting up to 20% of women remaining permanently childless (Kreyenfeld & Konietzka, 2017). The USA has recently reported declining levels of childlessness (Frejka, 2017), but it is unclear whether Europe will follow this trajectory. Younger cohorts are reporting increased levels of childlessness and postponement of childbearing. Some research suggests that it is unclear whether this will lead to temporary or permanent childlessness (Köppen et al., 2017), or fewer children in the future. However, other research indicates that this increasing prevalence of postponing childbearing (Berrington, 2004) is connected with increased risk of childlessness (Rybińska & Morgan, 2019) and smaller family sizes (Mac Dougall et al., 2012). The trends of increasing childlessness and declining fertility rates are occurring for numerous reasons, such as parenthood postponement, access to

contraceptives, and more women in education and work (Leridon, 2006; Mills et al., 2011). Furthermore, it is estimated that around 10% of people experience infertility (Boivin et al., 2007), defined as failure to achieve a pregnancy after 12 months of unprotective sexual intercourse (Zegers-Hochschild et al., 2017). It is currently unclear what impact the COVID-19 pandemic will have on the already declining fertility rates. Berrington et al. (2021) highlighted the complex and numerous factors that may influence fertility rates following the pandemic and attempted to predict the ongoing fertility trends in the UK, overall concluding that rates will decline further.

**Increasing numbers of people are faced with an unmet parenthood goal (UPG)**

Most people anticipate that they will have a child or children at some point in their life (Lampic et al., 2006; Martinez et al., 2006; Thornton & Young-DeMarco, 2001). Parenthood is considered an expected part of adult life (Riggs & Bartholomaeus, 2018) and societal beliefs likely shape these normative life transitions (Heckhausen et al., 2010).

Despite voluntary childlessness becoming more prevalent, data from European cohort studies indicate that on average only 3.2% of childless people are voluntarily childless (Miettinen et al., 2015) and although more people are having one child, having two children is still considered the norm and the ideal family size across Europe (Sobotka & Beaujouan, 2014; Thomson, 2015). In a large study by the Australian Institute of Family Studies, with over 3,000 participants, only up to 5% of childless participants said they definitely did not want children, and on average 60% of parents with one child said they definitely wished to have another (Weston et al., 2004). Furthermore, research on fertility intentions, desires and outcomes for a random sample of women in USA demonstrated that significantly more childless women wanted a child compared to those who did not (Shreffler et al., 2016). A

recent review has also indicated that men's desires to have a child or children were similar to women (Hammarberg et al., 2017). Similarly, a study with childless men in Eastern Europe reported that perceptions of childlessness are complex and change across the life course but for most participants, their childless status was undesired (Maříková, 2021).

Therefore, it can be argued that many people who are childless are likely to experience this involuntarily and many parents may still maintain the goal to have more children. Fundamentally, if the desired parenthood goal (whether that is one child or more) is not pursued or cannot be achieved (e.g., infertility), despite having a child wish, this can result in a UPG. Therefore, a UPG is defined as having not having the children one desired or having fewer children than desired.

**Potential pathways to UPGs**

To begin to build an understanding of the UPG experience, it is important to explore the reproductive and demographic literature to identify some of the potential pathways. Although most of this literature, particularly the demographic literature, does not identify the presence of a UPG, it can provide some insight into the factors that may lead to a UPG. For simplicity the next section will focus on two broad areas: infertility (plus other reasons people might seek fertility treatment) and circumstantial factors. However, it will be demonstrated that for some people, both areas together may lead to childlessness or fewer children.

*Infertility*

Global estimates indicate around 72 million couples experience infertility (Boivin et al., 2007) and of those who engage with assisted reproductive treatment (ART), around 20-30% of individuals will end treatment without a child (McLernon et al., 2016; Pinborg et al., 2009). It is reasonable to suggest that those who are diagnosed

as infertile, or define themselves as infertile, and who engage with fertility treatment

have a child wish (Greil et al., 2010). Therefore, if they are unable to achieve their

desired number of children with fertility treatment, it is likely they will have a UPG.

Notably, only around half of people diagnosed as infertile seek medically assisted

reproductive treatment and even less, up to 25%, will receive treatment (Boivin et

al., 2007). Furthermore, even if patients begin treatment there are several barriers

that mean they discontinue before achieving their desired parenthood goal, such as

the financial or psychological burden (Brandes et al., 2009; Gameiro et al., 2012).

The reproductive literature is dominated by participants who have engaged with

treatment as often recruitment occurs from fertility clinics (Greil & McQuillan,

2010). Therefore, understanding the presence of UPGs in those who may meet the

definition of infertility, but who don't engage with treatment, is less clear. Finally,

many people experience secondary infertility, defined as 'a woman unable to

establish a clinical pregnancy but who has previously been diagnosed with a clinical

pregnancy' (Zegers-Hochschild et al., 2017) and may be unable to achieve their

parenthood goal of one child or more.

**Engaging with fertility treatment for reasons beyond infertility.** Other

reasons that people may engage with ART include poor health or illness (Jacob et al.,

2003; White & McQuillan, 2006), medical conditions such as Turner Syndrome

(Morgan, 2007) or cystic fibrosis (Lissens et al., 1996), and people who identify as

LGBTQ+ who intend to have a biological child(ren). However, as noted above,

engagement with ART does not guarantee parenthood will be achieved. Although

live birth rates may be higher for people who engage with treatment for other

reasons, e.g., same-sex couples (Human Fertilisation and Embryology Authority

[HFEA], 2020) , they may face barriers to receiving fertility treatment in the first

instance. For example, female same-sex couples or single women in some areas of the UK usually need to self-fund 6-12 cycles (depending on location) of intra-uterine insemination prior to being offered funded in vitro fertilisation (IVF) from the National Health Service (HFEA, 2020), meaning cost may be a barrier to accessing treatment to meet their goal of biological parenthood.

### *Circumstantial factors*

The second area focusses on circumstantial factors that could lead to a UPG. This is an understudied area compared to infertility related factors and most of the data comes from demographic research which, as noted, often does not report on whether the people who remain childless or have fewer children have a UPG. However, there are several circumstantial factors that may contribute to increasing numbers of people experiencing UPGs and this section will focus on the most common, such as not wishing to pursue parenthood alone, socioeconomic factors, and parenthood postponement.

**Not wishing to pursue parenthood alone.** Across Europe, for people who are not able or are unwilling to pursue parenthood alone, not being able to find the right partner who also wishes to have a child or children, and maintaining this partnership are considered critical factors when addressing reasons for childlessness (Berrington, 2017; Köppen et al., 2017; Kreyenfeld & Konietzka, 2017; Rotkirch & Miettinen, 2017; Tanturri & Mencarini, 2008). Some argue that being single is the most frequently cited reason for childlessness (Connidis & McMullin, 1996). Changes in the dynamics of partnerships, such as fewer periods or shorter periods of cohabitation, have also been linked to increasing childlessness (Jalovaara & Fasang, 2017) and reduced family size (Qu et al., 2000). Although most studies do not report on the desired parenthood status of single childless individuals, a large survey study

in Australia, using national random samples of men and women between 20-39

years, did report that only up to 16% of single childless men and women between the

ages of 30-39 were definitely against having a child (Weston et al., 2004).

Furthermore, being single predicts childlessness in both men and women. Data from

the Netherlands Kinship Panel Study reported that women and men who have no

partner during their fertile years could be 7 times and 11.5 times more likely to

remain childless respectively (Keizer et al., 2008). Despite the advancement of ART

meaning women can pursue their desired parenthood goal alone and men can pursue

parenthood via surrogacy, the numbers of patients pursuing these options remain low

at around 3% and 0.4%. respectively, of all treatment cycles in the UK (HFEA,

2017).

     **Sociodemographic factors.** There is extensive demographic literature on the

role of socioeconomic factors when addressing childlessness. These factors consist

of occupational status, income, and education attainment, but it has been challenging

to disentangle causality. Therefore, socioeconomic status can be considered both a

reason for, and a consequence of, childlessness. Furthermore, there is a paucity of

reports on parents reporting fewer children related to socioeconomic factors. Unlike

remaining single, there appears to be gender differences in the relationship between

socioeconomic status when addressing childlessness. Overall, patterns of increased

education and childlessness are reported for women (Berrington, 2017; Mynarska et

al., 2015; Rybińska & Morgan, 2019). For example, for every extra level of

education (on a scale of 1 = did not complete elementary school to 10 =

postgraduate), the odds of a women remaining childless are 1.14 times higher

(Keizer et al., 2008), but this relationship is not seen in men (Berrington, 2017;

Keizer et al., 2008). A suggested explanation for this is that the increased time taken

to achieve higher academic achievements means that women may be more likely to be exposed to sub-fertility following childbearing postponement (Kreyenfeld & Konietzka, 2017). Furthermore, a study of Finnish men found that higher educated men were less likely to be childless and had more children overall when compared to men with lower education (Nisén et al., 2014). And finally, it has been reported that sustaining employment may increase the odds of a woman remaining childless by 31%, whereas continuous employment for men results in odds being lowered by 36% (Keizer et al., 2008). It has been reported that men with lower income may have less potential to become a partner and father (Fieder et al., 2011), whereas overall women with higher socioeconomic status are more likely to be childless (dos Santos Silva & Beral, 1997; Keizer et al., 2008). However, it has been reported that only 2% of women reporting a choice of career over parenting, often considered the reason for childlessness (Berrington, 2017). Although causality is difficult to determine, these differences may relate to the gendered approach to child rearing, where the female may be more likely to have to balance childcare and career responsibilities. It is important to note that many of the studies mentioned here do not report on whether childlessness, or number of children, was a choice, so it is not possible to infer the presence of UPGs.

**Parenthood postponement.** As highlighted previously, the pathways discussed here are complex and are likely to overlap. An example of this is the postponement of parenthood (Beaujouan, 2021; Mills et al., 2011). Over the past seventy years, a body of literature has focussed on a subgroup of this population, described as 'postponers' (Callan, 1984), with this postponement of childbearing first reported in cohorts born in the 1950s (Berrington, 2017). This group maintains the intention of having children but ultimately do not achieve biological parenthood

(Tonkin, 2010). Research suggests that many are simply unaware of the decline in fertility and therefore do not set out to have children at a reproductively suitable age (Heffner, 2004), meaning that time to live birth is longer (Lampic et al., 2006) or no live birth occurs. Other research suggests reasons for postponement include pursuing further education, particularly for women (Rybińska & Morgan, 2019; Te Velde & Pearson, 2002), and reaching the desired socioeconomic status, which may be accentuated by the economic turbulence caused by the COVID-19 pandemic (Berrington et al., 2021; Luppi et al., 2020). This was also reflected in research with childless men in Denmark and Sweden reporting on a desire to 'do things in the right order': receive an education, sustain a relationship, be employed and achieve their desired financial status before pursuing their parenthood goal (Hviid Malling et al., 2020). Therefore, it can be argued that initially circumstantial factors result in parenthood postponement and then the age-related decline in fertility means biological parenthood or their desired parenthood goal is never achieved. Arguably this is less of an issue for men as they can father children at older ages, in effect giving them more time to pursue higher education qualification or meet their desired socioeconomic status to have children. However, particularly for women, fertility treatment is unlikely to compensate for an age-related decline in fertility (Leridon, 2004). Primary infertility, defined as a woman who has never been diagnosed with a clinical pregnancy or a man who has never initiated a clinical pregnancy, and for either meeting the criteria of being classified as having infertility, is reportedly more prevalent than secondary infertility, arguably due to increasing rates of parenthood postponement (Chandra et al., 2013). Although most of the literature does primarily refer to childless individuals, postponement of childbearing may also lead to fewer children. The age of first birth is increasing (Mathews & Hamilton, 2009) and as

noted, for women, fecundability, defined as the probability to conceive each month, declines with age. Therefore, the conception of a second or third child may take longer or never occur (Billari et al., 2007; Mascarenhas et al., 2012). Mac Dougall et al. (2012) interviewed couples where the women had given birth to their first child over the age of 40 years with the assistance of IVF and found that participants reported that having fewer children than desired was a disadvantage of having a child at an older age, with two thirds having only one child. Interestingly, it may not only be the biological deadline that is barrier to people childbearing at older ages. Social deadlines are defined as perceiving that a behaviour can occur too early or, more relevant to this topic, too late, and across most European countries, the social deadline for having a child is considered to be 40 years old (Billari et al., 2011).

Overall, being infertile or seeking treatment for other reasons can lead to a UPG as fertility treatment is not always successful. Other barriers (e.g., psychological burden or cost) can also mean fertility treatment is not pursued and therefore desired parenthood goals are not reached. Circumstantial factors can also act as barriers to achieving one's desired parental goal as biological or social deadlines are reached before childbearing occurs.

**Psychosocial implications**

Overall, the research investigating the psychosocial implications of having a UPG indicate that this is a distressing and difficult experience. There are several theories that can provide insight into why having a UPG can lead to negative psychological consequences. For example, identity theory suggests that the identities one holds, e.g., parenthood, can influence wellbeing (Thoits, 1983, 1986), via a mediating role of meaning and purpose in life, and the absence of an identity or disruption to an identity can negatively impact psychological wellbeing (Thoits,

1991, 2012). Secondly, a review of research on childlessness and wellbeing from a life course perspective reported that the childless experience is also likely to be affected by several factors, including if it is desired or not, the social context, and the pathway to childlessness, and this should be taken into consideration when investigating the impact of childlessness on wellbeing (Umberson et al., 2010). McQuillan et al., (2012) integrated identity theory and life course theory and argued that childlessness concerns were related to identity disruption resulting from childlessness, mediated by the importance placed on parenthood and the perceived level of choice. For example, an individual who holds a strong belief about the importance of parenthood and who is unable to achieve this due to reasons they consider beyond their control, will experience more identity disruption than someone who does not place as high importance of parenthood or who feels that they have more choice or control. It is therefore reasonable to suggest that if an individual's intentions or desires for children are incongruent with the outcomes, i.e., they are involuntarily childless or have fewer children than desired, and they place a high importance on the parenthood identity, they may be more likely to experience distress and a difficult adjustment process. There is variability in the implications of having a UPG; gender, the social context, and the presence of a partner can shape this experience. The following section will describe the individual, relational, and social impact of having a UPG.

### *Individual impact*

At the individual adjustment level, research refers to periods of intense grief and poorer mental health and wellbeing that can persist over time.

**Intense and complex grief.** Consistently throughout the UPG literature, a sense of profound loss and prolonged grief appears central to the UPG experience,

across genders and regardless of the pathway (Gameiro & Finnigan, 2017; Hadley & Hanley, 2011; Koert & Daniluk, 2017; Tonkin, 2010; Volgsten et al., 2010). In-depth interviews with 10 women and 9 men after failed fertility treatment reported that the grief process can be hindered through a lack of realisation that they were grieving or, particularly for men, feeling that they needed to allow their partner to grieve first, leading to a prolonged grief process (Volgsten et al., 2010). Often individuals do not realise that they are grieving as there may be no external representation of the loss (Menning, 1980). Therefore, the loss can be perceived as invisible to others, and this appears particularly pertinent for people who did not try to conceive or attribute their UPG to circumstantial factors (Koert & Daniluk, 2017; Tonkin, 2010). They may also grieve the loss of the life they expected to life with children (Fieldsend & Smith, 2021). The grief process for UPGs has been related to complicated grief (Lechner et al., 2007), defined as experiencing intense grief symptoms for longer than expected (Prigerson et al., 2009). From interviews with involuntary childless women, interpretive phenomenological analysis reported that the grief is described as ambiguous and intangible, complicating the grieving process leading to symptoms consistent with prolonged grief disorder (Fieldsend & Smith, 2020). This is consistent within the reproductive literature providing guidance for support where the grief is described as an 'unfocused grieving of many losses' (Sewall & Burns, 2006, p. 420). Furthermore, research has also shown that individuals can experienced recurrent grief symptoms following unsuccessful treatment, for example when their peers become grandparents (Bell, 2013; Daniluk, 2001; Wirtberg et al., 2007). In sum, although grief is a normative response to loss, the grief associated with a UPG appears to be complex and difficult to process.

**Mental health and wellbeing.** There has been considerable research in the reproductive literature on the adjustment to UPGs after unsuccessful treatment. Measures of individual adjustment often focus on dimensions of mental health, e.g., the presence of depression and anxiety symptomology, and wellbeing, e.g., satisfaction with life and quality of life (Verhaak, Smeenk, Evers, et al., 2007). Therefore, the following section will focus on mental health, and hedonic and eudaimonic wellbeing. Mental health is defined by the presence or absence of mental illness or disorder (e.g., presence of depressive and anxious symptomology are thought to represent psychological distress (Veit & Ware, 1983)). Hedonic wellbeing is described as a subjective measure of pleasure, enjoyment and happiness, and eudaimonic wellbeing is considered a subjective measure of self-realisation, fulfilment, and meaning and purpose in life (Ryan & Deci, 2001).

*Overall, having a UPG is associated with poorer mental health and wellbeing.* Having a UPG is associated with poorer mental health and wellbeing. For example, a meta-analysis of the psychosocial implications of a UPG following unsuccessful treatment demonstrated that people experience mild to moderate impairments in mental health and wellbeing (Gameiro & Finnigan, 2017). Although this article did not include those who have not engaged with fertility treatment or who have a UPG for circumstantial reasons, other research indicates that it is a similarly distressing and difficult experience. For example, data from the Norwegian Life Course, Ageing and Generation Study indicated that both life satisfaction (measured with Satisfaction With Life Scale) and self-esteem (measured with Self-Esteem Scale) scores were significantly poorer for childless women when compared to mothers, although this finding was not replicated for men (Hansen et al., 2009). This study also reported on depression, using the Centre for Epidemiological Studies

Depression scale (CES-D), finding that parental status was not associated. However, despite this study exploring potential moderating factors, such as marital status, they did not distinguish between involuntary and voluntary childlessness. Research indicates that those who consider themselves involuntarily childless, as opposed to childless by choice or voluntarily childless, are more likely to report experiencing negative psychosocial implications. For example, voluntarily childless women demonstrated higher levels of hedonic wellbeing, measured with the Scales of Psychological Well-Being–Short Form, when compared to involuntary childless women (Jeffries & Konnert, 2002), indicating that the involuntary nature of the childlessness may be associated with poorer wellbeing. Another study that did not distinguish between voluntary and involuntary childlessness did find that childless men and those that did not live with their children had lower psychological wellbeing and mental health compared to men living with children, but that this association was moderated by being single (Dykstra & Keizer, 2009). European data, analysed with regression models, from the Survey of Health, Ageing and Retirement in Europe (SHARE) indicated that at the aggregate level (across 13 countries) childlessness predicted poorer mental health, measured with the presence of depressive mood. This finding was sustained at the regional level for Southern Europe only. Although in this study, childlessness was not found to predict quality of life (Gibney et al., 2017), again the voluntary or involuntary nature of the childlessness was not determined. A longitudinal study in Australia, using data from 10 waves of data from the Household, Income and Labour Dynamics in Australia study, reported that across the life course, the physical and mental health of childless women varied in comparison with mothers, which may explain some of the mixed findings in the literature. It was reported that childless women experienced poorer

mental health, social functioning and emotional related role limitations when compared to mothers during their reproductive years (age 25 to 44), but this was no longer true for women over the age of 65 (Graham, 2015).

   ***Intentions towards parenthood and sustaining a child wish can moderate individual adjustment.*** Intentions towards parenthood and sustaining a child wish appear to play a role in the adjustment process and presence of poorer mental health. For example, data from the National Survey of Families and Households, including a large sample (~2,200) of men, women, childless people, and parents, found that the process of letting go of one's intention to fulfil one's goal to have (more) children was associated with increased distress. Although women were also more likely to experience distress than men, indicating gender differences in adjustment, there was not a statistically significant difference between childless individuals and parents, suggesting they similarly experienced distress (White & McQuillan, 2006). Research that focused on anxiety used a nationally representative sample of women to investigate subfecundity, defined as impaired ability to have children in the demographic literature, and the presence of generalised anxiety disorder (GAD) symptomology (King, 2003). Results indicated that fecundity status, i.e., sterile or subfecund, was positively associated with anxiety for women who desired a child, but this relationship was not apparent for those who did not have this desire. It was also reported that seeking or engaging with treatment did not moderate these effects. Supporting this is a prospective cohort study of couples that lasted up to 5 years after their final treatment cycle. It was found that the childless women who reported that they were no longer trying to have a child and had turned their attention to new life goals reported lower levels of depression and anxiety compared to the childless women who continued to try and get pregnant (Verhaak, Smeenk, Evers, et al.,

2005), although overall the women's anxiety and depression scores returned to baseline levels at the last follow up. Finally, a cross sectional study reporting on mental health in women 11-17 years after fertility treatment reported that, although parenthood status has a moderating effect and there is a worse impact for those who are childless compared to parents, a sustained desire for a(nother) child was reported as a driver for poorer mental health, for both childless individuals and parents (Gameiro et al., 2014). However, these studies were cross-sectional so associations should be interpreted with caution and causality is difficult to ascertain. Despite this, overall, research suggests that relinquishing the parenthood goal is distressing and holding on to a child wish may be associated with poorer mental health and wellbeing.

Overall, people who had a UPG experience poorer mental health and wellbeing compared to controls or normative data, and this can persist over time. Although research with people with UPGs who did not engage with treatment or attribute their UPG to circumstantial factors has been carried out to a lesser extent, the literature indicates that they also experience poorer mental health and wellbeing. Holistic reports of individual adjustment allow a better insight into the complex impact of having a UPG.

### *Relational impact*
When exploring relational adjustment, attention focusses on the impact of this unmet goal on couples and how men and women respond through measures of satisfaction, conflict and support. The consequences of failed fertility treatment and remaining childless have been reported as worse for women than men (Petersen et al., 2015) and this may affect the overall adjustment of the couple as their perception of the experience may differ. Although, Keizer and Ivanova (2017) found that

childless men are more negatively affected than childless women if the couple

dynamic is poor. The couple dynamic was measured using self-reported health and

mental wellbeing, relationship satisfaction and relationship conflict, and support

from the partner. These findings highlight that there may be an interaction effect

from a partnership and marriage on how men and women adjust to involuntary

childlessness. Similarly, some research has suggested that marital status may play a

mediating role between childlessness and mental health and wellbeing (Gibney et al.,

2017; Koropeckyj-Cox & Call, 2007). It has been postulated that childless men have

reported being more satisfied with their life than fathers but that this is linked to

having a partner, with those who do not have a partner reporting lower health levels

(Keizer et al., 2009). This finding is consistent with earlier work by Akerlof's

(1998), which reported that general health is better for childless married men. It is

important to consider different aspects of relational satisfaction. Conflicting findings

have reported on whether experiencing a UPG can weaken or strengthen a

relationship. For example, 33-month longitudinal study with 38 childless couples

after unsuccessful fertility treatment reported that across the 3 time points, sexual

satisfaction declined significantly, which could be attributed to the effect of trying to

conceive over a long period and then undergoing fertility treatment, but no

significant changes were observed for martial satisfaction (Daniluk & Tench, 2007).

Some research suggests that childless couples may be more likely to separate, as the

presence of children is considered a protective factor in couples remaining together

(Kjaer et al., 2014; Martins et al., 2018) On the other hand, other research suggests

the experience of unsuccessful fertility treatment can strengthen a relationship,

resulting in fewer separations (Bryson et al., 2000; Sundby et al., 2007; Sydsjö et al.,

2011). It is important to note that many people with UPGs resulting from

circumstantial factors may not have a partner, and if the presence of a partner has a

protective role in adjustment to UPGs, their adjustment could be poorer than those

who have a partner.

*Social impact*

      When addressing social impact, the literature has reported on the social

isolation and stigma faced by those with a UPG and the role of social support and

social perceptions of normative roles of parenthood on individuals faced with this

challenge. Men reported poorer satisfaction with social support than population

norms (Lechner et al., 2007) and women isolate themselves from others with

children (Johansson & Berg, 2005). People who remain involuntary childless are

also likely to encounter social isolation from their networks as they are unable to

share parenthood experiences with their peers (McCarthy, 2008). Furthermore,

children are often the link to the community and enable connections to local

networks (Keizer et al., 2009). Childless individuals who live in pronatalist societies,

such as nations at- or above- replacement fertility, compared to those who live in less

pronatalist societies, report poorer life satisfaction and lower happiness than people

with children (Tanaka & Johnson, 2016). However, data was not collected on

involuntary and voluntary childless status and causality is not clear. Analysis on 30

interviews and 41 questionnaires from involuntarily childless women highlighted the

perceived stigma experienced, due to the related socially discreditable identity of

being childless, leading to a desire to control the information they shared with others

and avoid those who made them feel particularly uncomfortable (Miall, 1986). Other

research with Israeli women has shown that this stigma can be particularly

challenging when there no culturally acceptable alternative options to motherhood

(Remennick, 2000). Although these papers are more than 20 years old, more recent

publications demonstrate that stigma around involuntary childlessness is still present (Archetti, 2020; Bell, 2013; Stenström, 2020).

There is some evidence that social isolation can persist into old age. Elderly childless individuals have been reported to be more likely to live alone or in residential care homes when compared to elderly parents (Koropeckyj-Cox & Call, 2007) and are less likely to be able to name someone to give them support (Hogan & Eggebeen, 1995). The amount of social support received is reportedly less for older childless men and women when compared to parents, but the likelihood of receiving social support does not differ between these groups (Albertini & Kohli, 2017). Older childless individuals experiencing health issues may be more likely to spend time in a care home or use other formal support services if they do not have children to support them (Dykstra & Hagestad, 2007), which may place a financial burden on countries that offer national health support services. Therefore, research on the social consequences of UPGs indicate that this experience can be isolating and that this can continue into old age.

To summarise the UPG experience, having a UPG can have prolonged and multi-dimensional impact on people's lives. It not only affects their mental health and wellbeing, but other areas of functioning, including how one evaluates their life and perceives social support, leading to feelings of isolation and stigmatisation.

### Limitations in the UPG literature
It is important to note one of the main limitations in the UPG literature, is that the UPG research often focuses on the psychological experience following unsuccessful fertility treatment (Gameiro et al., 2016; Johansson et al., 2009; Johansson & Berg, 2005; Kuivasaari-Pirinen et al., 2014; Wischmann et al., 2012), with a paucity of research on individuals and couples who are childless and did not

engage with fertility treatment or due to circumstantial factors (Connidis &

McMullin, 1996; Hadley, 2019a; Hadley & Hanley, 2011; Tonkin, 2010). This will

be discussed in more detail in Chapter 3. The imbalance in the literature is likely to

be a result of accessibility challenges, as participants are often recruited from fertility

clinics (Greil & McQuillan, 2010), or that having a UPG because of circumstantial

factors could be considered a more recent occurrence. Additionally, findings on the

psychosocial implications of a UPG for those who have not engaged with fertility

treatment or who have a UPG for circumstantial reasons has produced mixed

findings. Reasons for this are likely to relate to reports of the childless experience

without distinguishing whether the childlessness is voluntary or involuntary, and

numerous different measures being used to evaluate the psychosocial implications

which makes comparisons difficult. It may also arise from a measurement or study

design issue, as infertility, and its associated treatment and outcomes, pregnancy and

live birth, are definitive. Therefore, psychological functioning is measured following

this, potentially repeated for each treatment cycle. Whereas people who do not

engage with treatment, or who attribute their UPG to circumstantial factors, may

only realise they have a UPG at the end of their reproductive window or experience a

gradual realisation that parenthood may not occur as this milestone approaches.

Therefore, it is challenging to determine the right time to measure the psychological

response. Furthermore, it is possible for someone to have a UPG but never pursue

their parenthood goal (Koert & Daniluk, 2017), so again the appropriate time to

evaluate the psychosocial implications is difficult. The menopause for childless

women presents an appropriate opportunity, as the prospect of remaining childless

may become definitive. Finally, another key limitation in the literature is the cross-

sectional design of most studies, meaning causality is difficult to determine and associations are challenging to interpret.

**Supporting people with UPGs**

Given that having a UPG can have a prolonged and multi-dimensional impact on mental health, wellbeing, and other areas of functioning, it is reasonable to suggest that the development of psychosocial support is warranted. Descriptive research has aimed to characterise the psychosocial adjustment process and a systematic review of qualitative data of people with UPGs after unsuccessful treatment reported on the mechanisms through which people adjust to their UPG (Gameiro & Finnigan, 2017). From this review, the Three Task Model of Adjustment (3TM) was proposed. This model suggested that engagement with three mechanisms may promote mental health and wellbeing. These were meaning making, acceptance, and the pursuit of new life goals. The 3TM also outlines protective factors for adjustment to a UPG including social support, lower importance of parenthood, and a sense that all treatment options had been explored and exhausted (Gameiro & Finnigan, 2017). This model was evaluated in a heterogenous sample of people with UPGs who did and did not engage with fertility treatment and indicated that the model was invariant across different pathways to a UPG (Appendix A). Therefore, the 3TM is chosen as the theoretical model underpinning the intervention developed in the present thesis because it was developed from research on successful adjustment of people with a UPG and there is no other model specific to this experience. The three tasks will be described in detail below, including related psychological theories and the mechanisms through which these tasks may promote adjustment.

*Meaning Making*

The UPG experience is an uncontrollable and unpredictable life event (or non-event) that can prompt individuals to ask, 'Why me?' and bring about a desire to find some meaning in their experience. Women faced with UPGs have reported experiencing a loss of purpose or meaning in life (McCarthy, 2008), saying that ''My life is meaningless without children, this has dominated my life" (Wirtberg et al., 2007, p. 601). Furthermore, couples with UPGs after unsuccessful treatment report questioning their own beliefs and values about marriage and family (Daniluk, 2001). Women may question what it means to be a woman (without being a mother) (Johansson & Berg, 2005). Childless people with UPGs may also question the meaning of their identity, experiencing an 'identity shock' (Matthews & Matthews, 1986), particularly if parenthood is considered a central identity.

When focussing on the literature on UPGs, meaning making strategies include meaning-focused coping, for example positive reappraisal coping or benefit finding. Specific examples of meaning making in the UPG literature include a prospective study evaluating cognitive coping strategies and depressive symptoms in definitively childless people across two assessment moments spanning two years. It was reported that while self-blame and rumination were positively associated with poorer depressive symptoms, positive reappraisal coping had an inverse significant association (Kraaij et al., 2008). This suggests that blaming oneself and remaining stuck with thoughts about involuntary childlessness may be risk factors for poorer adjustment, whereas being able to find positives in their childlessness may promote adjustment. Another cross-sectional study of 83 definitively childless people, self-reported on coping strategies and positive and negative affect. Cognitive coping, for example positive reappraisal coping, was positively associated with positive affect

(Kraaij et al., 2009). A longitudinal study focusing on coping in response to

infertility, in particular dyadic coping over 5 years of unsuccessful treatment,

reported that meaning-based coping (e.g., finding the positives, feeling that they had

positively grown as a person) was related to decreased personal distress for women

and decreased martial distress for women and also their partner (Peterson et al.,

2009). Although it was not clear how many participants were still engaged in

pursuing their parenthood goal at the 5-year point, making it difficult to generalise

these findings to those who were no longer pursuing their parenthood goal.

However, this study provided some insight into the individual and dyadic benefits of

cognitive coping, and specifically meaning-based coping, for those experiencing

unsuccessful fertility treatment.

Meaning making is understood to be a common, and even universal, response

to stressful life events (Davis et al., 2000; Park, 2010; Updegraff et al., 2008). A

proposed meaning making model suggests that the process of meaning making is

triggered when people experience distress from a stressful event or experience that is

incongruent with their global meaning (i.e., beliefs, goals, and subjective feelings of

the world around them). Meaning making is the attempt to minimise the distress and

facilitate adjustment by reducing the discrepancy between appraised meaning of an

event or experience and their global meaning (Park, 2010; Park & Folkman, 1997).

Importantly, it is argued that meaning made as a result of meaning making should

lead to adjustment (Park & Folkman, 1997). Meaning making coping can include

positive reappraisal, re-ordering priorities, adaptive goal processes, and infusing

ordinary events with positive meaning (Folkman, 1997, 2008). Meaning made can be

measured as a feeling of having made sense of something, acceptance,

comprehension of why something happened, a sense of personal growth, a changed

identity, reappraisal of the meaning of the event or experience, altered global beliefs

or goals, or a restored sense of meaning in life (Park, 2010). Meaning-focused

coping is thought to represent the presence of accommodative coping (Carver &

Connor-Smith, 2010), in which the individual adjusts their own perspectives via

cognitive reappraisal or re-prioritising values (Brandtstädter & Renner, 1990).

Meaning-focused coping is considered particularly useful for adjustment to

unpredictable and uncontrollable stressful life events (Folkman, 2008). Meaning may

also need to be sought when one's identity has been disrupted or a desired identity is

not achieved (Thoits, 1983, 1986, 1991, 2012).

Meaning making has been operationalised and measured in different ways,

which is likely to have led to mixed findings in the adjustment literature. The

importance of considering who and under what circumstances, particular meaning

making strategies are useful, has been highlighted (Park, 2010). Therefore, in the

3TM meaning making is defined as adaptive cognitive processing of the UPG

experience to bring clarity and meaning to one's new identity and life without their

desired child(ren). The 3TM postulates that when faced with a UPG, individuals

engage in meaning making to re-evaluate their life values and re-evaluate their

personal values and question social constructs and their own beliefs about family and

parenthood, to promote adjustment (Gameiro & Finnigan, 2017).

### *Acceptance*

As mentioned, when discussing individual adjustment to a UPG, people

experience grief as an intense and central part of their adjustment process.

Furthermore, the findings from the UPG literature that demonstrate people

experience grief for a prolonged period or that they experience repeated grief

episodes, suggests a lack of acceptance or tolerance of the loss(es) associated with

the UPG. This assertion is supported by research that indicates people with UPGs reported engaging in avoidance coping or behaviours, such as avoiding people or places with children (Throsby, 2001). Furthermore, individuals may not even realise that they are grieving as there may be no external representation of the loss (Menning, 1980). The grief process for UPGs has been described as disenfranchised (Tonkin, 2010), where the grief appears to be unvalidated or recognised by society (Doka, 1989). In some instances, support has been withheld due to the lack of understanding of the loss experience associated with involuntary childlessness (Turnbull et al., 2016).

In the UPG literature, although most research is qualitative, there is consensus that acceptance appears to promote adjustment. For example, during in-depth interviews between 6 months and 3 years after unsuccessful treatment, 13 of 14 participants, who were childless or did not have a biological child, reported that acceptance of their childlessness helped them experience spiritual growth (Lee et al., 2009). In-depth interviews with 15 women and 13 couples, including childless individuals and parents who had engaged with fertility treatment, demonstrated that questioning the social expectations of parenthood helped with acceptance and that no longer engaging with avoidance behaviours regarding being around children represented acceptance to them (Throsby, 2001). Finally, research on adjustment for infertile couples and women reported that acceptance was related to building a sense of hope towards the future (Daniluk, 2001) and a sense of personal strength (McCarthy, 2008). Acceptance appears to be a necessary component to the adjustment process, but it is challenging. A recent online survey of 176 childless by circumstance women showed around 30% of the women described a sense of gradual acceptance of their involuntary childlessness (Chauhan et al., 2020) and research

with involuntary childless men also describes acceptance as a complex process

(Hadley, 2019a). A sense that one has tried everything (i.e., engaged with fertility

treatment) can facilitate this acceptance process (Bell, 2013), but overall people are

likely to need support to build their acceptance (Daniluk, 2001; Lechner et al., 2007).

When faced with the challenge of acceptance, many people engage in avoidance

coping.

This is consistent with theoretical conceptualisations of grief as although

grief is a normal response to loss, grief models can provide some insight into why

people with UPGs may face difficulties moving through their grief. The dual process

model of grief suggests that those who can oscillate between loss-orientated (e.g.,

experiencing the difficult emotions and thoughts) and restoration-orientated (e.g.,

engaging with the changes resulting from the loss) processes may adjust better to

their grief (Stroebe & Schut, 1999, 2010). Furthermore, the cognitive-behavioural

framework of grief suggests that when individuals are unable to integrate loss into

their autobiographical knowledge and engage in avoidance behaviours, grief

symptoms can persist and reoccur (Boelen et al., 2006). This is also consistent with

theoretical conceptualisations of acceptance where active acceptance, defined as a

willingness to actively acknowledge and experience the difficult emotions and

experiences in connection with difficult life events or loss can facilitate adjustment

(Ciarrochi et al., 2013; Davis et al., 2016; Nakamura & Orth, 2005). Developing

acceptance is thought to reduce distress by minimising the struggle with negative

emotions or feelings (Block-Lerner et al., 2009), as opposed to experiential

avoidance, where one avoids situations or emotions by trying to alter their form or

frequency (Hayes et al., 1996). This has been associated with increased distress

(Feldner et al., 2003), prolonged and problematic grief (Boelen et al., 2010), and

other psychopathology (Hayes et al., 1996). The avoidance coping can also be related to stress and coping theory. For example, stress and coping research on infertility indicates that individuals who engage in avoidance coping strategies in response to loss are likely to experience poorer adjustment (Berghuis & Stanton, 2002). Acceptance strategies appear particularly important in response to uncontrollable stressors, such as UPGs, as it is considered a form of accommodative coping (Nakamura & Orth, 2005; Zimmer-Gembeck & Skinner, 2010). Acceptance is often reported as an outcome, but more recently has been considered an ongoing process of willingness to experience difficult private events (e.g., thoughts, emotions) (Davis et al., 2016).

Definitions of acceptance vary across the literature (Block-Lerner et al., 2009; Nakamura & Orth, 2005), but in the 3TM, acceptance is defined as the emotional processing of difficult emotions to build tolerance and a willingness to experience them, without trying to change or suppress them. As the UPG experience can represent several losses, the 3TM proposes that people build experiential acceptance of the difficult emotions related to these losses which promotes adjustment (Gameiro & Finnigan, 2017).

### Pursuit of new goals

When people realise that their desired parenthood goal is no longer attainable, some report engaging with other meaningful goals to help them adjust to their UPG, even if they are initially just used as a distraction (Boden, 2007). However, this can be challenging as disengagement from the parenthood goal requires active effort (McCarthy, 2008; Wirtberg et al., 2007). It has been argued that those who anticipate their blocked parenthood goal, for example because of postponement of childbearing, may find it more difficult to relinquish the goal as

there may be a perceived component of responsibility and regret (Anderson, 2003; da Silva et al., 2016). Furthermore, an unrealistic hope for a child(ren) could influence the ability to relinquish a parenthood goal (Boden, 2007).

The UPG literature has demonstrated the benefits of goal disengagement and pursuit of other goals. Heckhausen, Wrosch and Fleeson (2001) conducted two studies, the first used positive and negative affect (Positive and Negative Affect Scale – PANAS) as a measure of subjective wellbeing when investigating goal engagement and disengagement. It was reported that women who had passed the biological deadline of being able to have a child (i.e., menopause) but still recalled a high number of baby-relevant sentences (a measure of goal engagement), reported increased negative affect. However, high recall of other goals (a measure of goal disengagement) and positive affect appeared to be related. In the second study, it was reported that strategies involved in goal engagement of a blocked goal had a disadvantageous effect on mental health (measured using the CES-D) (Heckhausen et al., 2001). A meta-analysis of parental blockage, through the lens of self-regulation theory, indicated that re-engagement with other meaningful goals was associated with improved wellbeing, operationalised as positive mood (da Silva et al., 2016). However, it was highlighted that self-regulation theories are often considered at the individual level and therefore may not apply to many with a UPG, as this is often experienced in a dyad.

This is consistent with theoretical conceptualisations of new goal pursuit because goals are considered 'mental representation of desired states…as cornerstones of developmental regulation' (Haase et al., 2013, p. 965) and the pursuit of goals across the lifespan are thought to play a role in wellbeing and personal development (Brunstein et al., 1999). It is suggested that adaptive self-regulation will

occur when individuals disengage with a blocked goal and reengage with other(s), and findings have shown that this is associated with reports of high subjective wellbeing (Wrosch et al., 2007; Wrosch, Scheier, Carver, et al., 2003). As cited in a recent review (da Silva et al., 2016), there are three key developmental regulation theories: the Dual-Process Model of Assimilative and Accommodative Coping (Brandtstädter & Rothermund, 2002), the Model of Selection, Optimization and Compensation (Freund & Baltes, 2000), and the Motivational Theory of Life-Span Development (Heckhausen et al., 2010). It has been argued that these theories relate to three key processes – goal engagement (to continue to try an attain the goal), goal disengagement (to let go of the goal), and meta regulation (or optimisation) (to evaluate goals in the context of opportunities and initiate engagement or disengagement accordingly) (Haase et al., 2013). Goal engagement entails further commitment and effort towards the pursued goal, whereas goal disengagement involves the removal of that commitment and effort (da Silva et al., 2016).

The 3TM defines pursuit of new goals as engagement with other goals that helped individuals feel that they were moving on from their UPG, while providing a sense of fulfilment. The 3TM suggests that individuals who can pursue other meaningful goals may experience better adjustment (Gameiro & Finnigan, 2017).

**Developing support for people with UPGS**

Currently there is no freely available evidence-based intervention support for people with UPGs. To the author's knowledge, only one has been reported on for definitively childless women but is does not currently appear available for public use (Kraaij et al., 2016). Despite the promising results of this study, the intervention only focused on changing how people think about their UPG (cognitive coping) and the only outcome assessed was depression. Furthermore, this intervention lacked

inclusivity (only focused on infertile childless women). Counselling interventions could, but have not, been evaluated and are often embedded within the private and public fertility health care sector. They are therefore less accessible for people with a UPG due to unfavourable circumstances. Uptake of effective mental-health support may be hindered by the stigma associated with accessing mental-health services (Rüsch et al., 2005) and poor professional awareness of how a UPG affects mental-health (Gameiro et al., 2016). Several patient-led organisations offer support for UPGs (e.g., The Dovecote, Gateway Women) but efficacy has not been evaluated, as is the case with many online and app-based support (Larsen et al., 2019). Those who engage with fertility treatment often perceive very little or no support from their fertility clinics (Daniluk & Tench, 2007; Gameiro & Finnigan, 2017; Gameiro et al., 2016; Koert & Daniluk, 2017) or report barriers to receiving support, such as cost (Payne et al., 2019b). Research has demonstrated that considerable effort has been put into supporting people while they are undergoing treatment, with more than 30 evidence-based interventions being accessible to patients (Frederiksen et al., 2015), but less attention has been paid to support them adjusting in the aftermath of unsuccessful treatment. This is despite evidence showing that support needs at this stage completely differ from the treatment period (Verhaak, Smeenk, Van Minnen, et al., 2005). To counteract this support gap, National and International Guidelines (e.g., European Society for Human Reproduction and Embryology [ESHRE] Gameiro et al., 2015; HFEA, 2019; National Institute for Health and Care Excellence [NICE], 2017) recently outlined a need to tailor psychosocial support for individuals after unsuccessful treatment.

It is challenging to quantify the need for support as so many people with UPGs do not engage with fertility treatment, and subsequently are missing from the

reproductive literature (Greil, Slauson-Blevins, et al., 2016). Therefore, a similar call

for support for people with UPGs due to circumstantial factors has not yet been

made. Only more recently have researchers become more interested in the non-

clinical population of people with UPGs and men remain under researched. Despite

these limitations in the literature, the intervention developed and reported on in the

present thesis aims to support people with UPGs, regardless of their pathway. This

decision is supported by the study reported in Appendix A.

When looking to produce an intervention, best practice guidance suggest

that interventions should be developed using the best available evidence and

appropriate theory (Craig et al., 2008). Interventions that are evidenced based have

been evaluated for efficacy or effectiveness and developed based on research and

expertise. Specifically, the development of an evidence-based intervention should

aim to answer the question of whether the chosen mechanisms of change, and how

they are targeted in an intervention, consistently lead to change in the outcomes of

interest (Michie & Abraham, 2004). Therefore, it is important to clearly outline the

therapeutic goals, therapeutic frameworks, and development process of the

intervention developed within this thesis. This not only allows for evaluation but also

for other researchers to provide support or develop interventions for the same target

population. The development of the intervention is presented in detail in Chapter 4

but will be outlined below.

***Therapeutic goals of the intervention***
An intervention for people with UPGs should be based on the 3TM. As

mentioned, this model has been developed specifically for this experience and is

consistent with other theories of stress and coping and grief in response to

uncontrollable stressors. The therapeutic goal of the intervention should be to target

the three tasks: meaning making, acceptance, and the pursuit of new goals. It is

important to note that these three tasks are interdependent and engagement with one

can facilitate engagement with the others. For example, building tolerance of the

thoughts and emotions associated with grief can help bring clarity to the things that

bring meaning to one's life (i.e., the things that are important to them), which can

then be used to define meaningful goals away from parenthood. Ultimately leading

to building a fulfilling life without the children they wished for. Recently, there has

been a shift towards the promotion of mental wellness or mental wellbeing, which

can be measured with assessments of positive psychological functioning

(Manderscheid et al., 2010). It is widely recognised now that one cannot just focus

on mental health (i.e., the presence or absence of mental illness or disorder), but that

a more holistic approach to mental wellbeing (i.e., the presence or absence (or low

levels) of mental illness and levels of wellbeing or flourishing) should be promoted.

This is known as the complete state model of mental health (Iasiello et al., 2018;

Keyes, 2005). The three tasks in the 3TM are expected to have a holistic impact on

mental health and wellbeing. Finally, although the 3TM is based on the adjustment

experience after unsuccessful treatment, it was evaluated with people who did not

undertake fertility treatment or experienced circumstantial factors to determine its

validity in these populations (Appendix A; Chapter 3).

***Targeting the therapeutic goals in the intervention***
        The content for the intervention must be developed specifically for people

with UPGs (i.e., tailored and sensitive language) and contain psycho-educational

elements to support people to normalise their experience and validate it (Gameiro &

Finnigan, 2017). Content for the therapeutic activities must target the proposed

mechanisms of change. Contextual cognitive behavioural therapy (CCBT) has been

chosen as the underlying therapeutic framework for MyJourney, specifically

Acceptance and Commitment Therapy (ACT). CCBT aims to alter the influence an

experience has on a person's thoughts, emotions and feelings, rather than change the

content of them (Hayes et al., 2013). Across the literature, ACT has a proven record

of being efficacious across a range of outcomes (Thompson et al., 2021), and is

considered transdiagnostic meaning it can be applied to both clinical and sub-clinical

populations (Davis et al., 2016; Kashdan & Rottenberg, 2010). In particular, third

wave therapies, such as ACT, are considered appropriate for people following

unsuccessful treatment (Cunha et al., 2016; Peterson & Eifert, 2011) as this type of

therapy focuses on emotional regulation to an uncontrollable stressor. It has also

been suggested that ACT is a suitable framework for approaching difficult grief

processes (Davis et al., 2016). Furthermore, ACT was appraised to complement the

3TM as the central tasks of the 3TM include acceptance and pursuit of fulfilling

goals, which are key components of ACT. Research has also shown that ACT can be

delivered successfully via self-guided and online interventions (Brown et al., 2016;

French et al., 2017; Kelson et al., 2019). Meaning making is challenging to

contextualise and subsequently it is difficult to determine the best strategies to

trigger these processes. This intervention therefore aimed to introduce the target

population to multiple strategies to facilitate meaning making, offering flexibility.

Positive reappraisal coping was included because research shows that positive

reappraisal coping can promote adjustment as a meaning making strategy,

particularly in relation to definitive childlessness and infertility (Kraaij et al., 2009;

Kraaij et al., 2008), and value clarification was introduced as a part of the ACT

model (Hayes & Smith, 2005) as another technique to facilitate meaning making.

Positive reappraisal coping does not traditionally sit within the CCBT theoretical

framework as it is consistent within cognitive behavioural therapy (CBT) techniques.

Although there are key differences between CBT and ACT, it is argued that

combining the techniques together can be beneficial and cater to individual coping

preferences (Hallis et al., 2016). Additionally, some research suggests that

acceptance-based therapies and reappraisal coping may facilitate one another (Kivity

et al., 2016) and that mindfulness aspects of CCBT may also play a key role in

positive reappraisal coping (Garland et al., 2009), overall supporting integration of

therapeutic strategies. Integration of ACT and CBT has been successfully

implemented in other interventions for depression (Hallis et al., 2016) and anxiety

(Carrier & Côté, 2010), although these studies were small and lacked control groups.

It is suggested that eclecticism, drawing techniques together from different

therapeutic frameworks, is used frequently by therapists in practice (Cook et al.,

2010). Overall, the evidence, although limited, does not suggest the integration could

be problematic.

***Development of the intervention***

Interventions should be developed systematically and using the best available

evidence (Craig et al., 2008; Skivington et al., 2021). As noted, the evidence

reviewed indicates the 3TM is generally consistent with theories of adjustment to

stressful life events and loss, with the added benefit of being tailored to the UPG

experience. The main implication of adopting the 3TM is to simultaneously target

three mechanism of change – meaning making, acceptance, and pursuit of new goals.

The Medical Research Council (MRC) highlights the added complexity of

developing interventions that target more than one mechanism of change and

recommend that the best approach is to be highly theory based, to ensure the causal

logic underlying the intervention is clear, and applying a phased approach to

development, with high focus on piloting the intervention using mixed methods

approaches to collect feedback to iteratively improve it (Craig et al., 2008;

Skivington et al., 2021). A logic model can present this underlying causal logic

diagrammatically (Kellogg Foundation, 2004). Therefore, this was the approach

taken in the present thesis and is presented in detail in Chapter 4.

**Thesis outline and research questions**

Figure 1.1 presents the chronological outline of the present thesis and

following section describes the aims and research objectives for the present thesis.

**Figure 1.1**

**Thesis outline**
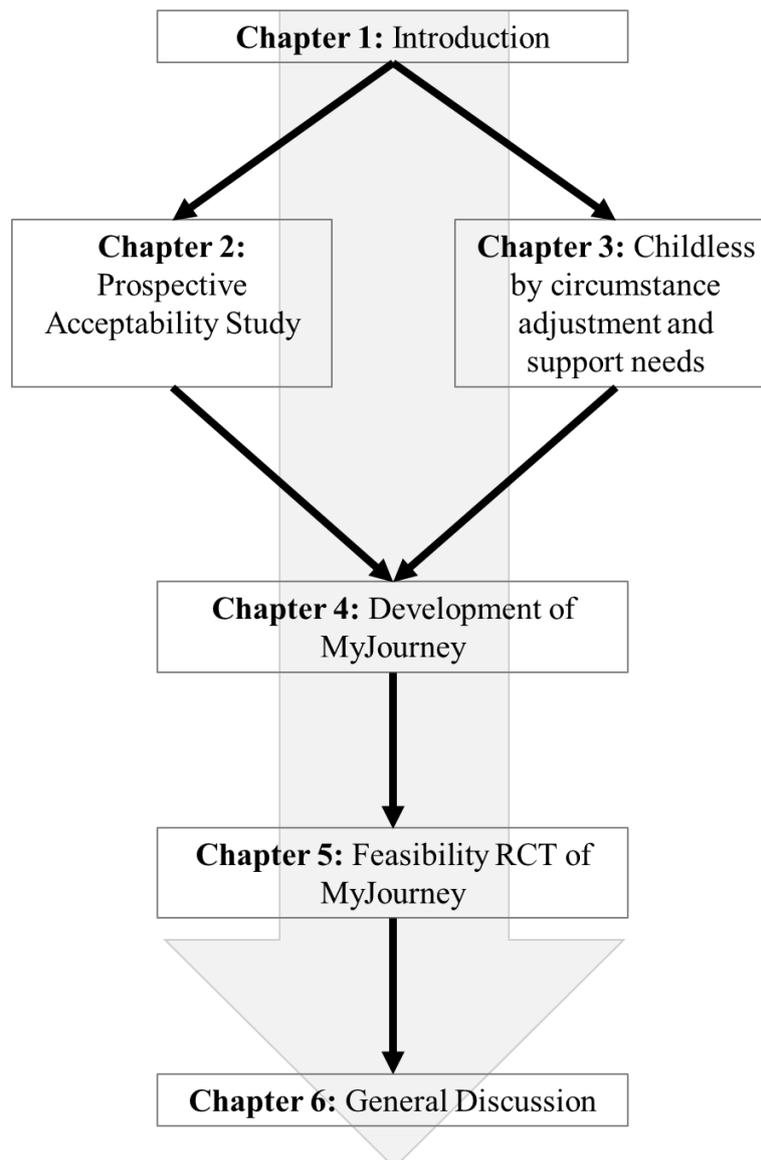


Chapters 2 and 3 were key activities in the early development and delivery of

the intervention. Following these studies, most of the development of the

intervention content and design was completed to produce the final prototype, and therefore they will be presented prior in a chronological order in the thesis and presented within the MRC phases in Chapter 4. The name of the intervention emerged through the development process, therefore it is referred to as 'the intervention' up until Chapter 4, where it is then described as 'MyJourney' for the remainder of the thesis. This was done to demonstrate that the name was chosen based on the data collected during this research project.

***Overall research aim and objectives for the present thesis***

The overall aim of this thesis was to apply the 3TM as the theoretical model underpinning the phased development and co-production of a psychosocial intervention for people with UPGs.

The objectives underlying the overall aim of the present thesis are:

1. Determine the acceptability of an early prototype of an online self-guided intervention (that become known as MyJourney) for people with UPGs (Chapter 2)

2. Determine whether the 3TM can be applied to childless people who consider they have a UPG due to circumstantial factors and report on this population's support needs (Chapter 3)

3. Present a detailed report on the development of a prototype of the MyJourney to be put forward for feasibility evaluation, which followed the MRC framework. (Chapter 4)

4. Determine the feasibility of MyJourney and its study protocol to move forward for evaluation in a full scale RCT (Chapter 5).

## Chapter 2: Prospective mixed methods acceptability study of the first intervention prototype

## Introduction

As noted in Chapter 1, current fertility trends show people are increasingly delaying their parenthood goals and that this is coupled with increasing childlessness (Kreyenfeld & Konietzka, 2017) and having fewer children than desired (Schmidt et al., 2012). Consequently, more people reach the end of their reproductive life with a UPG. To reiterate from Chapter 1, this is defined as people not having the children they desired or fewer children than desired. This can result from an inability to conceive spontaneously, when not overcome with fertility treatment, or from unfavourable circumstances, such as not wishing to pursue parenthood without a partner or having a partner that does not wish to have children (Graham et al., 2013), or postponing parenthood (Berrington, 2004). Regardless of the reason, many people refer to the strong emotional pain that comes with the inability to fulfil their parenthood goals and to the distress associated with the need to let go of such goals (White & McQuillan, 2006). The COVID-19 pandemic is thought to be accentuating these trends, for instance by stopping or delaying access to fertility treatment (Boivin et al., 2020) or decreasing or delaying childbearing due to delays in marriage, higher divorce rates and lower in-person dating opportunities (Ibarra et al., 2020). People with a UPG experience intense and protracted feelings of grief, loss, and distress, which reflect in lower self-reported mental-health and wellbeing (Gameiro & Finnigan, 2017; Keizer et al., 2009; Koert & Daniluk, 2017; Wirtberg et al., 2007).

In response to the lack of evidence-based support for people with a UPG, regardless of how this came to be (e.g., fertility problems, unfavourable circumstances), the first research-informed widely and freely accessible online

intervention to promote psychological adaptation to a UPG was developed[1].

Although online support can have limitations, such as lack of in-person contact, one of its main benefits is accessibility: it can be used anonymously by anyone, when and where convenient (Bennett & Glasgow, 2009), which is likely to become the new reality resulting from COVID-19 (Figueroa & Aguilera, 2020). Online interventions have been shown to be effective for those facing a breadth of health conditions and losses, e.g., infertility (Cousineau et al., 2008; Hämmerli et al., 2010), miscarriage (Kersting et al., 2011) and bereavement (Dominick et al., 2010).

An initial intervention prototype was developed following the MRC guidance for the development of complex interventions (Craig et al., 2008), and a detailed description of the intervention development process is presented in Chapter 4. Briefly, the first objective in the development process was to identify the evidence base with a meta-synthesis of all quantitative and qualitative research focusing on long-term adjustment to a UPG in the aftermath of failed fertility treatment, resulting in the 3TM (Gameiro & Finnigan., 2017). This model hypothesises that those who find meaning in their UPG and integrate it in their life narrative, who develop willingness to tolerate the negative emotions caused by their UPG, and who are able to explore and pursue alternative life goals, will adjust better. The second objective in the development process identifies and develops the theory by empirically testing the theoretical model (3TM). A third objective is to model the key components of the intervention using the evidence and theory developed from the previous two objectives. This consists of the developing and refining a logic model and conducting formative evaluation activities. The study described in this chapter forms

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[1] The first prototype of the intervention was created by Dr Sofia Gameiro and Dr Ana Galhardo, with the author of this thesis providing feedback for refinement prior to the invention being launched as part of the study described in this chapter.

one of those formative evaluations. Logic models can be used to graphically depict an intervention, highlighting the causal pathways through which the intervention is expected to promote the outcomes (Kellogg, 2004), in this case adjustment to a UPG, and are particularly useful for complex interventions. The logic model can then be refined following exploration of the needs of the target population. The first logic model informing the prototype presented in this chapter is shown in Figure 2.1.

As noted earlier, the therapeutic activities of the prototype are based on CCBT, more specifically, ACT (Hayes & Smith, 2005) and a number of RCTs have demonstrated ACT's efficacy (Thompson et al., 2021). ACT is based on six core principles directed at promoting acceptance of one's life and helping individuals clarifying their values and pursuing goals consistent with such values (Hayes & Smith, 2005). Applying these principles to the specifics of adjustment to UPGs, the intervention invites users to engage with a total of eight activities. Three directed at facilitating meaning-making, including cognitive restructuring via reframing (Harris & Hayes, 2019) and positive reappraisal, and value clarification (Hayes & Smith, 2005). Two activities directed at facilitating acceptance by prompting self-compassion (Neff & Tirch, 2013) and reduction in experiential avoidance (Harris & Hayes, 2019). Two activities focus on supporting individuals to develop and commit to new value-congruent goals (Harris & Hayes, 2019; Hayes & Smith, 2005). The final activity syntheses the therapeutic skills covered and encourages maintenance of positive change. The definitions and rationales for the therapeutic targets and mechanisms of change for each activity are also described in detail in Chapter 4, Table 4.3. Participant engagement with these activities is expected to trigger meaning making, acceptance and pursuit of new goals (outputs), leading to improved

mental-health and well-being (outcomes), ultimately decreasing the duration of this

adjustment process.

     For interventions to have a real impact on people's adjustment people need to

be willing to use them. The Medical Research Council's (MRC) guidance on

complex intervention development (Craig et al., 2008), recommends acceptability

testing should happen during the intervention design stage and before feasibility and

efficacy testing. This facilitates progressive refinement of the intervention (Craig et

al., 2008) to ensure the delivery and content are acceptable. Acceptability testing

should be based on qualitative methods that better capture perceptions and needs of

the target population, enabling insight into their experience and meaning of engaging

with the intervention (Bowen et al., 2009; Hammarberg et al., 2016) and allowing for

early identification of perceived barriers to use (Donkin & Glozier, 2012). In

particular, think aloud interviews can facilitate an understanding of users' initial

impressions and bring attention to aspects that the researchers may not have

considered (Van den Haak et al., 2007).

**Figure 2.1**

*Logic model of the first prototype of the intervention*
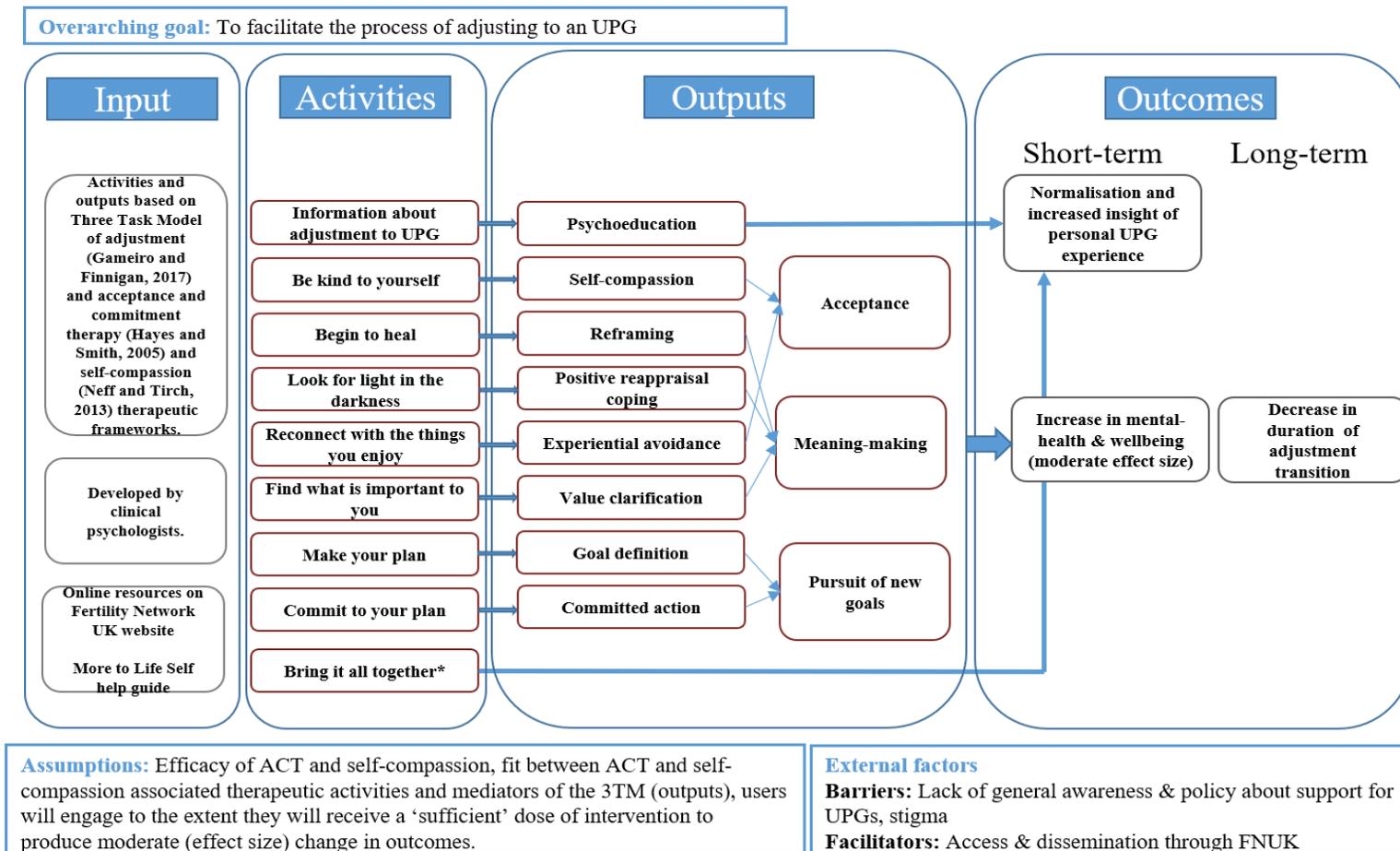


*Note.* Thicker arrows demonstrate the output that each activity aims to target, and the thin arrows indicate the mechanism that these outputs aim to facilitate. *Synthesis activity to encourage users to reflect back on their progress.

Quantitative data can also be collected to allow for data triangulation (O'Cathain et al., 2010) to validate the findings. Despite acceptability being a key component of intervention development and evaluation, there is no consensus about what acceptability entails (Eldridge et al., 2016; Sekhon et al., 2017). Within the psychology literature (Eckert & Hintze, 2000; Finn & Sladeczek, 2001; Nastasi & Truscott, 2000), acceptability has been operationalised as "judgments by persons, clients, and others of whether treatment procedures are appropriate, fair, and reasonable for the problem or client." (Kazdin, 1977, p. 493). These include judgements about whether the intervention is necessary (i.e., social significance: is it necessary to improve the mental-health and well-being of people with UPGs?) and adequate (i.e., social appropriateness: are users willing to use it?), and whether its effects are valued by users (i.e., social importance: do users perceive benefits from using it?) (Carter & Wheeler, 2019; Wolf, 1978). Such operationalization is consistent with definitions of acceptability adopted within the field of intervention research (Bowen et al., 2009).

This prospective mixed methods acceptability study, a key formative evaluation activity in the intervention development process, aimed to assess if individuals with a UPG were willing to use the first prototype of the intervention (i.e., social appropriateness) and how satisfied they were with its perceived outcome(s) (i.e., social importance). Social significance was not assessed as this has already been demonstrated (Gameiro & Finnigan, 2017) and integrated into policy guidelines (e.g., HFEA, NICE). Acceptability was assessed via participants' first reaction to the intervention, as this is expected to influence their future engagement with it, and their perceptions of it after being given the opportunity to fully engage with its contents and activities over a recommended period of eight weeks. Results

inform the design of the subsequent prototypes of the intervention to put forward for

feasibility and efficacy testing.

## Methods and Materials

**Design**

This was a prospective mixed methods study with two assessment moments:

when individuals were first exposed to the intervention (T1) and eight weeks later,

after individuals had been given the opportunity to engage with the full contents and

activities (T2). Qualitative data was collected via semi-structured interviews or

online surveys and quantitative data was collected via online surveys at T1 and T2.

**Participants**

Ethical approval was obtained from the University Ethics Committee

(EC.19.02.12.5576). The study was advertised via the MoreToLife campaign

(Fertility Network UK) social media and in other support websites for childless

individuals and parents that may have a UPG (e.g., HealthUnlocked Forum, The

Dovecote, Childless by Circumstance Facebook group). The researcher attended

relevant events (e.g., Fertility Fest) to raise awareness of the study and provide

information to prospective participants. Prospective participants were provided with

an information sheet and consent form (Appendix B). Inclusion criteria were: having

UPG(s); not currently pursuing these goals (e.g., not doing fertility treatment); and

being able to access the online intervention at least on a weekly basis. Participants

were offered a £50 Amazon voucher for their participation in this study.

**Intervention**

The intervention is described below using the TIDieR checklist (Hoffmann et

al., 2014). The first intervention prototype was made available on the MoretoLife

section of Fertility Network UK's website (largest UK infertility association),

dedicated to support involuntary childless people. It was named 'The MoreToLife

Self-Help Guide' due to its location on the website. As noted earlier, the 3TM is the

underlying theoretical framework and CCBT is the therapeutic framework for the

activities. When accessing the intervention, users were presented with materials

including information about what most people in their situation experience and in-

depth explanations of the three tasks from the 3TM (meaning making, acceptance,

and pursuit of new goals). Finally, users were invited to engage with eight

therapeutic activities (see the intervention logic model in Figure 2.1), available in

PDF format. Each activity consisted of a brief rationale of the therapeutic technique

it referred to, an explanation of how it applied to the user's situation, questions for

users to reflect on, and tasks for them to engage with in that moment or during their

daily life. For example, the self-compassion activity "Be kind to yourself" asked

users to write a letter to themselves from the perspective of a loving and

compassionate friend and to reflect on the words and sentiments they had written.

The intervention was delivered entirely online and designed to be used individually.

A tracker offering the recommended order of activities and a suggestion of one

activity per week was provided, but users were free to engage with the activities in

whichever order and whatever pace they wished.

**Procedures**

Eligible participants who provided consent were first interviewed (T1) via

Skype or Zoom at a time that was convenient for them.  They were then invited to

use the intervention over eight weeks. A weekly reminder email was sent to each

participant thanking them for their continued participation and inviting them to

engage with the next activity (available via a clickable link and attached PDF). A

follow-up interview (T2) (via Skype or Zoom) was arranged two months after the

initial interview to gather retrospective feedback on the intervention, after which a

debrief form was sent. Recruitment ended when no new themes emerged, and it was

considered that data saturation had occurred (Guest et al., 2006).

In the first interview (T1) participants were asked to access the intervention

and 'think aloud' (state out loud what they were thinking) as they navigated through

the intervention materials and activities at their own will, in the virtual presence of

the researcher. The think aloud protocol was used because it captures the

participants' initial judgements of the intervention in an open and natural way,

allowing participants to focus on the aspects they find more important (Boren &

Ramey, 2000). Once participants were satisfied that they had seen enough of the

intervention, they were asked a series of semi-structured questions adapted from

Gresham and Lopez's (1996) assessing social appropriateness (9 questions, e.g., Do

you find the Self-Help Guide easy or difficult to use and why?) and social

importance (5 questions, e.g., What are the main benefits you would expect

(T1)/experienced (T2) from using this Self-Help Guide?). Participants were also

prompted for additional suggestions or comments. At the eight-week follow-up

interview (T2), participants were asked to report if they read and engaged with each

of the eight activities, to describe their experience of using the intervention and were

asked the same questions (with variation in tense) from T1 interview.

At both assessment moments, participants completed surveys online straight

after their interviews. These asked them five questions with a five-point or six-point

Likert response scales, 1 (*strongly disagree)* to 6 *(strongly agree*) and 1 (*not at all)*

to 5 *(extremely)*, via an online survey. Three questions were adapted from the

abbreviated acceptability rating profile (Tarnowski and Simonian 1992), measuring

social appropriateness (e.g., Overall, I like the Self-Help Guide) and social

importance (e.g., Overall, the Self-Help Guide seems helpful), and two from

Lancastle and Boivin's (2008) acceptability questionnaire, measuring social

appropriateness (e.g., How suitable do you think the Self-Help Guide is for people

with an unmet child wish?). The T2 assessment included one additional question on

social importance (i.e., satisfaction with the outcomes of using the intervention) and

questions targeting engagement with all activities, i.e., whether they read and

completed each activity, and whether they considered each activity to be useful and

challenging via a five-point Likert scale, 1 (*strongly disagree)* to 5 (*strongly agree).*

**Data analysis**

All interviews were audio recorded and transcribed verbatim. Field notes

taken at the time of the interviews clarified which aspects of the intervention

participants were accessing at each moment. All transcripts were imported to QSR

International's NVivo 12 software.

A recurrent cross-sectional analysis was conducted (Grossoehme & Lipstein,

2016). This approach is appropriate when the research question focuses on the

perspectives of participants at two distinct time points, in this case whether

participants' first impressions of the intervention changed once they fully engaged

with it. According to this approach, thematic analysis was applied to code the data

collected at each time point separately, and then synthesising and highlights change

across time in emergent themes and their endorsement. Following the six phases of

thematic analysis (Braun & Clarke, 2006; Braun et al., 2019), first, the coders (B.R.

and S.G.) familiarised themselves with the data by reading through the transcripts

several times. Then they inductively generated codes that described a piece of

information present in the data. This exercise was descriptive with the least possible

inference made to minimise researcher bias. Codes were then grouped into themes

that captured a recurrent idea or topic present in the set of data (Vaismoradi et al., 2016). Themes were developed from analogous data, but attention was also given to divergent data if it was strongly endorsed by the participant(s). The first three transcripts (first and follow-up interviews) were independently coded by both B.R. and S.G. Afterwards the coding was compared for similarities and differences. Where differences arose, these were discussed until agreement was reached regarding the final coding to ensure analytic rigour, including prevention of selectivity of data. After this calibration exercise, the B.R. coded all transcripts. B.R. and S.G. continued to meet multiple times for peer debriefing and to actively reflect and discuss, review, and name the themes emerging from the data. Themes were also reviewed several times by checking them against extracts of data, in essence quality checking. This iterative process originated subsequent versions of thematic maps, whose last version was transferred into table format, one for each assessment moment (see Appendix C). After these analyses were completed, the meta-synthesis step focused on identifying differences and similarities between the T1 and T2 data and their endorsement (Grossoehme & Lipstein, 2016).

The data analysis was presented as a narrative summary accompanied by a thematic map, summary of observed changes across time, and illustrative verbatim quotations. Within illustrative quotations the use of (…) indicated part of the quotation was not presented because it was not relevant, whereas […] indicated additional text was added for clarity (i.e., readability, comprehensibility). Grammatical errors were corrected. Individual participant number was indicated with P.

Quantitative data from the survey responses were imported into IBM SPSS Statistics for Windows Version 25. Descriptive statistics were reported on

participants' evaluation of the intervention at T1 and T2 and of each activity. Once

this was done, these themes were also triangulated with the quantitative data

collected, by tabulating the qualitative themes against the survey response data, to

evaluate the degree of convergence between data sets (O'Cathain et al., 2010).

Farmer, Robinson and Eyles' (2006) convergence coding scheme (i.e., agreement,

partial agreement, silence, dissonance) was used to define the degree of convergence.

# Results

## Sample characteristics

A final sample of twelve women (but no men) agreed to take part in the study

between April and October 2019 (see participant flow chart Figure 2.2). One

participant did not complete the T2 assessment due to work commitments.

Demographic details are included in Table 2.1.

## Interviews and survey responses

Interviews ranged from 31 to 110 minutes (average was 71 and 46 minutes at

T1 and T2, respectively). Ten participants answered at least half on the online survey

questions and eight answered all.

## Engagement with activities

All participants read all the activities and two thirds completed them.

Engagement declined as participants moved through the activities with all

participants completing Activity One (self-compassion) and eight participants (67%)

completing Activity Eight (synthesis activity). Four participants chose not to

complete three activities (Activity Three: positive reappraisal coping, Activity Four:

experiential avoidance, Activity Seven: committed action towards goals). Reasons

given were: unclear instructions; not practical to do so; and activity was too

demanding.

**Themes**

   The coding process resulted in the generation of nine main themes that were

grouped into three higher order themes according to whether they referred to: the

intervention meets the users' needs, working through the UPG experience, and the

intervention is appropriate (Figure 2.3). Consistency of the themes across the two

time points are reported in Table 2.2.

**Figure 2.2**

*Participant flow chart*
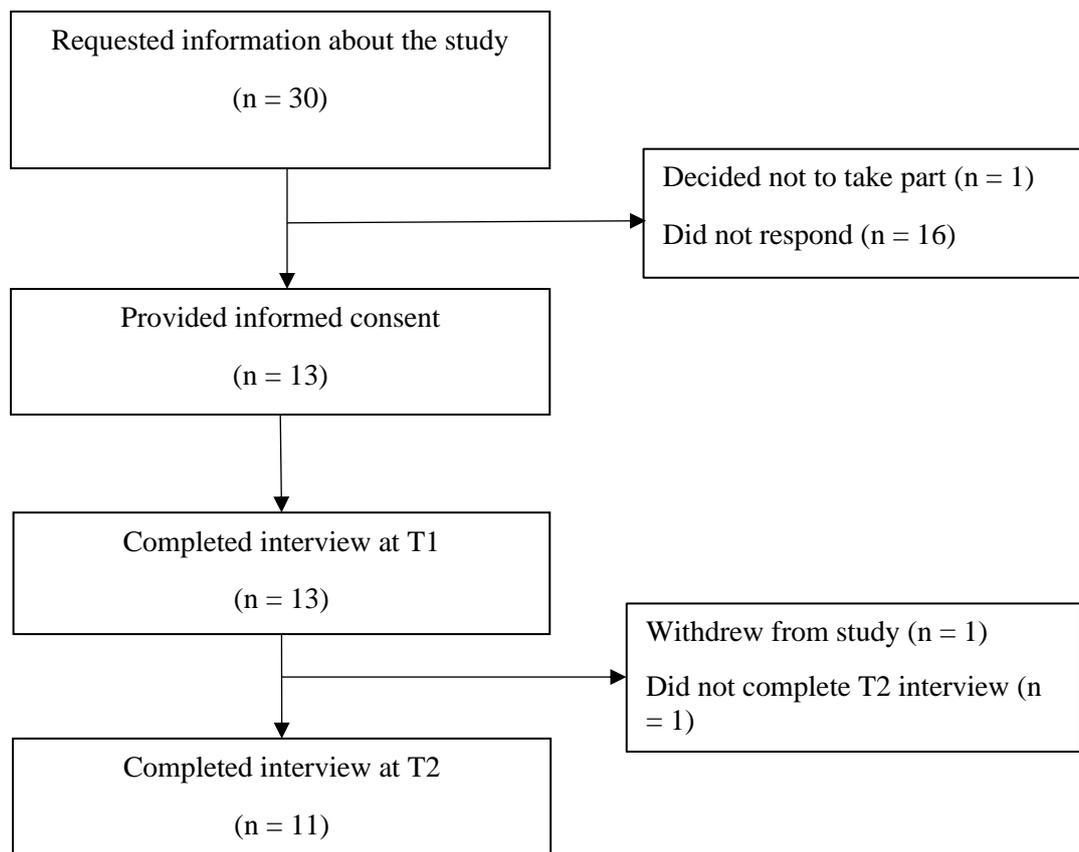
**Table 2.1**

*Participant demographic details*

| ID | Gender | Age | Relationship Status | Education | Employment | Actively conceived in past? | Engaged in fertility treatment? | How long since finished treatment? (months) | Able to conceive spontaneously? | If no, why? |
|---|---|---|---|---|---|---|---|---|---|---|
| **P1** | F | 45 | Married | Undergraduate degree | Employed | Yes | Yes | 36 | No | Unexplained infertility |
| **P2** | F | 49 | Married | Undergraduate degree | Employed | Yes | No | N/A | Yes | Childless by circumstance* |
| **P3** | F | 36 | Married | No degree | Employed | Yes | Yes | 16 | No | Male and female infertility |
| **P4** | F | ^ | Married | Postgraduate degree | Employed | Yes | Yes | 1 | Yes | History of recurrent miscarriage |
| **P5** | F | ^ | Married | No degree | Employed | Yes | Yes | 42 | No | Female infertility |
| **P6** | F | 42 | Married | Postgraduate degree | Employed | Yes | Yes | ^ | No | Male and female infertility |
| **P7** | F | 40 | Married | Postgraduate degree | Employed | Yes | Yes | 36 | No | Unexplained infertility |
| **P8** | F | 43 | Married | Postgraduate degree | Employed | Yes | Yes | 96 | No | Male infertility |
| **P9** | F | 37 | Married | No degree | Employed | Yes | Yes | 24 | No | Male infertility |
| **P10** | F | 52 | Married | Postgraduate degree | Unemployed | No | No | NA | No | Female infertility |
| **P11** | F | 44 | Married | Postgraduate degree | Employed | Yes | Yes | ^ | No | Male and female infertility |
| **P12** | F | 41 | Married | No degree | Employed | Yes | Yes | 18 | No | Female infertility |

*Note.* Childless by circumstance described as not meeting right partner until after fertile years. ^ Did not provide an answer N/A   Not applicable

**Figure 2.3**

*Thematic Map: meta-themes identified across assessment moments (T1 and T2)*
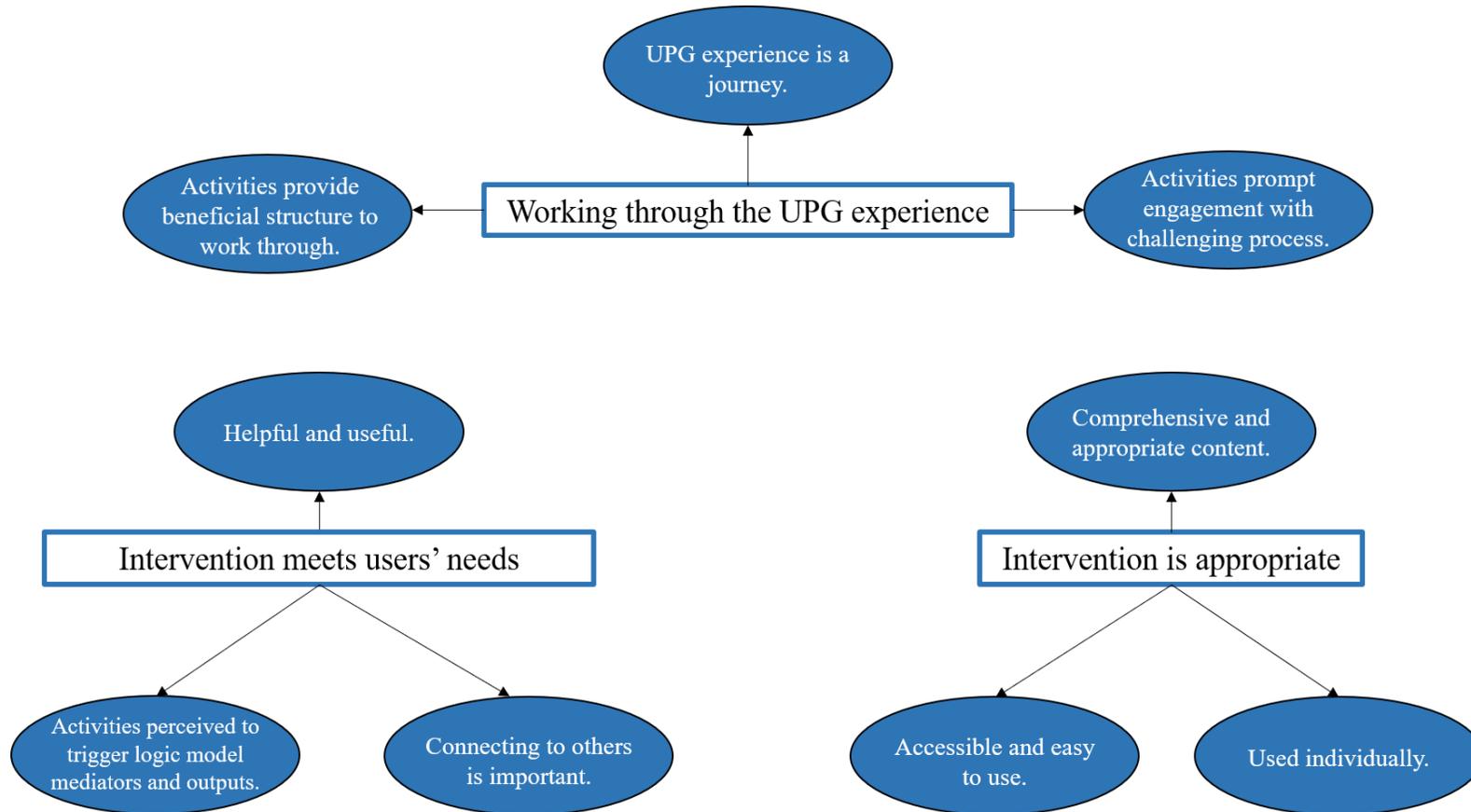


*Note.* UPG = unmet parenthood goal.

**Table 2.2**

*Observed change in views of the intervention from the moment users first accessed it (T1) to after using it for eight weeks (T2)*

| Theme | Observed change |
| --- | --- |
| **Intervention meets the needs of users** | |
| *Helpful and useful* | Perceptions of helpfulness and usefulness were maintained across T1 and T2. At both T1 and T2 participants did not feel the intervention would be useful for their male partners (if they had one). |
| *Activities perceived to trigger logic model mediators and outputs* | At T1, overall participants were positive about the activities, appearing willing to engage with them, but unable to say whether the activities would trigger the logic model mechanisms of change. At T2, most participants were able to describe ways the activities had triggered the logic model mechanisms of change. |
| *Connecting to others is important* | At T1, most participants alluded to the UPG experience being isolating and some anticipated the intervention would help them feel less alone. At T2, participants reflected that the intervention could be used to help them connect with others, e.g., using it within a group. |
| **Working through the UPG experience** | |
| *Prompts engagement with a challenging process* | At T1, almost all participants anticipated that engagement with the intervention would be a challenge, feeling concerned with facing emotional pain. However, at T2, two thirds did not report any negative effect and the third that did, described their negative emotions as part of the change process. |
| *The UPG experience is a journey* | At T1, all participants referred to the UPG experience as being a journey. At both T1 and T2, most participants highlighted that where one was on that journey was important regarding engagement with the intervention, generally indicating that engaging earlier in the journey would be better. |
| *Activities provided a beneficial structure to work through* | At T1, a majority recognised that the structure of the intervention could facilitate working through their experience and moving forward. At T2, half referred to this structure as a main benefit and around half wanted more content (e.g., contact to help with anger) to be added into the structure. |
| **Intervention is appropriate** | |
| *Ease of use and accessibility* | Participants perspectives on the accessibility of the intervention were more negative at T2 compared to T1, most notably around using it on a mobile device. However, most participants maintained a positive view on the appearance of the intervention but did note that there was a lot of text. |
| *Comprehensive and appropriate* | Perceptions of comprehensiveness, sensitive and appropriate language, and relatability were maintained across T1 and T2. Nonetheless, at both T1 and T2 a minority noted some wording that was complex and not inclusive. |
| *Used individually* | At T1 all but one participant anticipated using the intervention individually and reported they had done so at T2. At T1, half planned to set time aside to use it the intervention and at T2 two thirds reported they did set this time aside. |

*Note.* UPG = unmet parenthood goal.

*Intervention meets users' needs*

**Helpful and useful.** Participants were almost entirely positive about the usefulness and helpfulness of this intervention across T1 and T2. For instance, a third felt the intervention was useful to work through feelings: "it may be what someone needs to finally break through a cycle of sadness and give themselves permission to be sad and then also permission to move forward" (P6). At T2, nine participants expressed the intervention was useful because it looked at all aspects of the experience, guiding a person through them: "I think, actually thinking, and writing and recording, in quite structured worksheets, there's not lots of space, it kind of guides you through, I think that's really useful." (P8). Seven participants also described the intervention as helpful, for example to gain a better understanding of oneself: "[the intervention] is really good because it helps you get an understanding about yourself and then takes you on a journey through" (P9). At T1, some participants expressing a sense of the intervention being useful to those who were ready to overcome their experience: "I'm actively seeking out help to get me through it [the experience] then this is just perfect for me…" (P10). In the end (T2), all participants were able to describe ways in which engaging with the intervention had been beneficial, such as finding fulfilment in other ways: "having something that starts you thinking about an alternative life to something you've really longed for, for quite a long time, is good in itself" (P8), and gain new skills: "it gives me skills that I'm able to take away and practically use and repurpose again" (P10). Comments from some participants suggest a positive impact of the intervention on their mental health: "now I feel much better. Yea, I feel, I feel quite different after doing it [the intervention] …" (P5); "With nearly all of them [activities] I felt better…" (P10). Only one participant commented that the intervention required work to make certain aspects more helpful. After using the intervention (T2), just under half of the

participants reported that the intervention would not be appealing or useful for their partners. Consistently, only one participant engaged their male partner when using the intervention.

**Activities perceived to trigger the logic model mediators and outputs**. During the initial interview (T1) not all participants accessed all the activities, but in general, the initial feedback was positive: "…this is all really good stuff…" (P5); "…I mean the stuff in here is really interesting…" (P8). At T2, all the participants provided specific feedback for the activities. Overall, it appears that the mechanisms of change (from the logic model) that the activities aimed to facilitate were triggered, for example, the self-compassion activity enabled one participant to see herself as her own friend: "it's been lovely to be kind to yourself, to be your own friend" (P3); the positive reappraisal exercise enabled another to think about their life in a more positive way: "that exercise really made me realise that the life I have…it's a different life…[but] it opens up opportunities for us" (P10); and the committing to goals activity facilitated one participant to keep on track with the things that were important to them: "…so each week I can see how I am doing but it's keeping me on track with what I wanted to do instead of me forgetting or just thinking oh never mind…" (P5).

**Connecting to others is important.** During the initial assessment moment (T1), seven participants talked about feeling isolated at some point during their UPG experience and five anticipated using the intervention to feel less alone: "I think it's a good support, overall, to know that you're not alone." (P7), and a majority of participants alluded that connecting to others is important. Just under half of the participants talked about online support being a part of realising that others feel the same. At T2 around half the participants felt that it could be beneficial to use this

intervention with others, either in a group setting or with a partner: "there is an opportunity for some kind of working through this with others who are going through it…somehow, that would be helpful…" (P4).

***Working through the experience***

**Activities prompt engagement with challenging process.** Initially (T1), all but two participants, anticipated using the intervention would be challenging, in that they may feel upset or experience emotional pain: "I think some of the stuff in them [the activities] is a bit triggering" (P8), or that some activities might be difficult: "you kind of feel that they are quite tough questions, yea, and they might need to be more step by step umm through the psychology of it all" (P11). At T2, three participants felt more warnings of how using the intervention could be challenging were needed. This challenge was not seen as a negative by some: "I don't think it's necessarily a negative, because you're kind of having, you need to deal with it as well" (P7) and even part of the process: "before you get to the bit of what you can do to feel better, isn't it. You have to get to that horrible point…" (P5). After engaging with the intervention (T2), a third of participants described any (negative) emotions experienced as unsurprising and part of the process and two thirds did not report any negative effect.

**UPG experience is a journey.** All participants referred to a journey at T1, three quarters applying this metaphor to their UPG experience: "we've had a ten-year journey" (P3), and over half applying it in the context of using the intervention: "…the journey that you would want somebody to follow through this guide" (P9). All but one participant referred to the use of the intervention being dependent on where one was in their journey at T1, a view maintained by most participants at T2. Participants had different views about when in their journey people should use the

intervention, but overall, they seemed to concur that it should be completed early in the journey, even if it proved somewhat challenging: "if I'd done it when I got my diagnosis, so you know, it might have been a bit more difficult…but… I felt like, you know, actually, you know, having this at the beginning, would have probably been very helpful." (P8).

**Activities provide a beneficial structure to work through.** All but one participant noted the intervention provided structured support. At the outset (T1), a majority felt it offered a structure to work through and move forward: "help people through that journey and help them progress into a better place and so self-realise how they can get there so [the intervention is] it's a tool to help them" (P9). Half of the participants thought this structure was one of the main benefits of the intervention at T2. Nonetheless, two participants suggested removing two activities they did not consider useful. Around half of the participants also suggested additional content, such as help with anger.

Although the structure of the intervention was recognised, some participants expressed difficulties navigating through it on the website at T1: "I found that a little bit difficult to work through and know which bit I should be going to next and how that all flows together…" (P9). Some participants made suggestions about website navigation tool bars to make this structure easier to follow.

At T2, two thirds of participants felt the weekly schedule was a good feature and over half said that the reminder emails were useful. Three participants felt the weekly schedule was too quick, asking too much of the user in a short space of time: "I think you are asking a person to get to a certain point too quick" (P11) and one felt it was too slow. Only one participant was able to engage with one activity per week

and they felt rushed: "I felt at times I was rushing the questions to get them done that week." (P12). The remaining participants completed two activities or more some weeks and none other weeks but were happy to use the intervention in this way: "Doing two together, it didn't feel like it was too much work to do it." (P8).

### *Intervention is appropriate*
**Accessible and easy to use.** In general, participants felt the free online self-help format of the intervention was accessible: "it's nice also because it's online, you see with counselling and things, it's nice that there is another person but you have to pay for it or it ends….whereas this you can revisit…"(P5), and easy to use: "I'm not the most technical of people so yea it was fine umm, easy to use" (P12). At T2, some participants thought the intervention would not be easy to use on a phone: "I would have really struggled to do it on my phone" (P8) and were frustrated that they were not able to edit the activities online: "I couldn't seem to do any of the activities online, I had to print out the questions…so that was a bit annoying but nothing major" (P2). A minority of participants suggested that the intervention could be made available in a single PDF booklet for people who enjoy writing or using pen and paper.

Participants' feedback at both assessment moments (T1 and T2) indicated they liked the appearance of the intervention, as it provided space to write answers and described what needed to be done in a clear way: "it is very easy to use, umm, it is informative around what the purpose of an exercise was" (P9). However, some participants felt there was a lot of writing in some sections: "…the sheets are a bit wordy…they are a bit harder to kind of engage with…" (P1). The initial positive feedback reduced once participants had used the intervention and this seemed to be related to the worksheets being quite formal and 'work' or 'school' like: "I'm not

sure exactly what you would put in, but it does look like something you would get in a training thing at work" (P11). Although participants said they didn't expect to see lots of pictures, in general they suggested that the appearance of the activities could be more inviting.

**Comprehensive and appropriate content.** Almost all participants thought the intervention was comprehensive across T1 and T2: "there is a lot of thought here you know, it's a wee self-help guide but it is actually quite [like] a thorough book that you could buy off the shops…" (P11). Furthermore, a majority felt, at T1 and T2, that the language was overall appropriate and sensitive: "It was very sensitively put, you know, and it was, if I remember correctly, using 'we' instead of 'you…" (P4). However, around a third of participants felt that some complex language made aspects of the intervention hard to understand: "there's a bit too much psychological jargon that a lot of people might not understand or feel umm uncomfortable with" (P11). Additionally, less than half the participants felt strongly that some phrases that referred to individuals who already had children but still experienced a UPG should not be used, highlighting one phrase in particular as problematic: "that issue about umm '*strong unfulfilled desire to have'*, and then in brackets *'more children'*, I struggle with that [wording]" (P10).

All participants reported being able to relate to aspects of the intervention when they read it for the first time at T1: "yea everything I read on there just makes me think I could have written it…" (P12), and over half reiterated this at T2, who felt it offered tailored support: "it felt as if it was written by somebody who really understood, umm, living a life without children when you wanted children" (P10). They also expressed satisfaction with the fact that the intervention acknowledged the

pain of experiencing a UPG and that using the intervention to move through it could be challenging.

**Used individually.** All but one participant anticipated, and did, use the intervention individually. One participant used the intervention verbally with her husband: "I talked through it all with my husband, again because I am more of a talker than a writer" (P9). Five participants thought they might involve their partner: "speak to him later, later on in the day about what I've done today and what does he think or any views that he has on it" (P12), but ultimately only two participants actually talked to others about their engagement with the intervention at T2: "I did talk to friends about how I was feeling after I did activities, and how they were quite helpful, you know, but not really about them [the activities]" (P5).

Around half the participants planned to set time aside to complete the activities and almost two thirds of the participants did this (e.g., a lunch break). The remaining participants described difficulties fitting in the weekly activities, especially with busy work schedules: "There wasn't a set time that I completed them [the activities] and it depended upon what I had to do each week." (P7). A couple of participants described completing activities when they felt ready to: "some of them I didn't feel ready on that day so I printed the form out…and I would build myself up gently to do it." (P3).

At T1 a vast majority of participants predicted that they would printing the activities or writing in a notebook and a minority anticipated using their computer only. In the end (T2), more than half printed the activities, one participant used a notebook only, two participants accessed the intervention on their phone and two used their computer.

**Online Survey Data**

*Social appropriateness*

Results shown in Figure 2.4 show that at T1 the vast majority of participants liked, were willing to use and were confident to recommend the intervention to someone else experiencing an UPG. Overall, this positive appraisal increased at T2. No participants thought that the intervention was not at all suitable at either assessment moment.

*Social Importance*

At both assessment moments, all participants agreed to some degree that the intervention was helpful, but ratings increased by 15% at T2, with 50% of participants being extremely satisfied.

**Appraisal of activities.** As shown in Figure 2.5, all participants reported that Activity One and Activity Eight were useful, and more than half of participants considered the remaining activities as useful to some extent. Participants reported that Activity Two and Activity Seven were the most challenging and Activity Eight the least, but all activities were reported as challenging to some extent.

**Triangulation**

Triangulation of the qualitative and quantitative data demonstrated a high degree of agreement regarding the theme '*Intervention is appropriate*' and moderate agreement regarding '*Intervention meets users' needs*' and '*Working thorough the UPG experience*'. Moderate agreement was mostly due to the fact that pre-set quantitative questions did not cover some of the emerging subthemes in qualitative analysis, resulting in silence (Farmer et al., 2006), defined as one data set covering a theme or example and the other data set being silent on the theme or example (see Appendix D for detailed results).

**Figure 2.4**

*Participants' ratings of measures of social appropriateness and social importance*
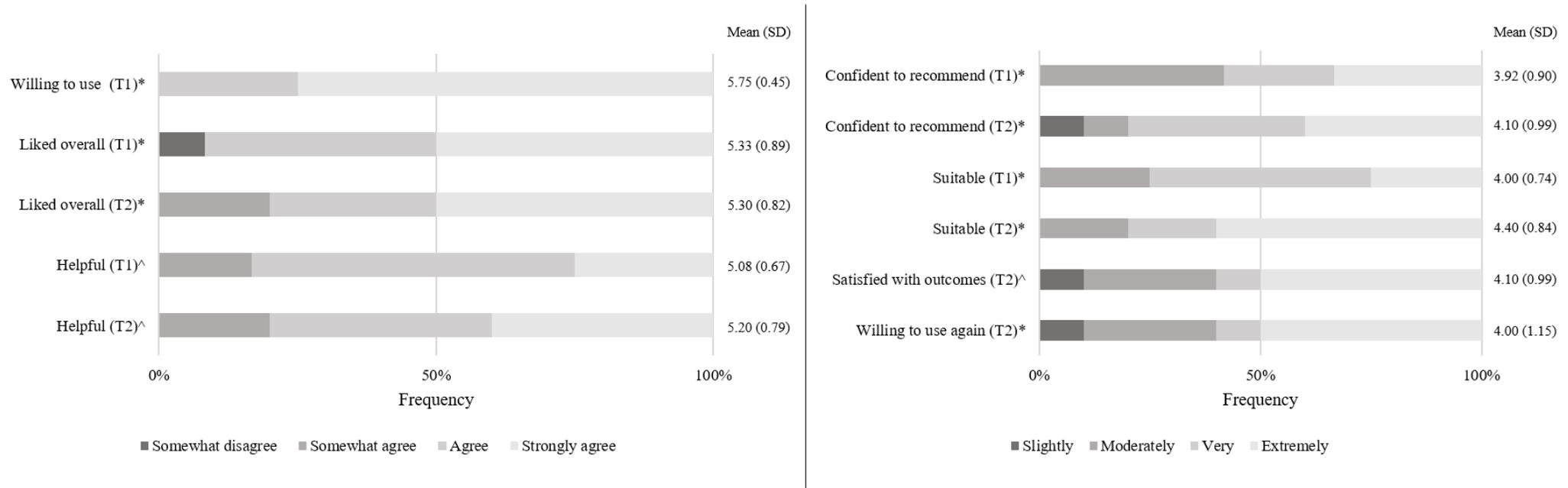


*Note.* * = measure of social appropriateness, ^ = measure of social importance. Likert scales of *strongly disagree* (1) to *strongly agree* (6) (left) or *not at all* (1) to *extremely* (5) (right). The *strongly disagree* (1) and *disagree* (2) categories were not selected by any participants and so were excluded from legend (right graph). This was also the case for *not at all* (1), which was also excluded from legend (left graph).

**Figure 2.5**

*Participants' ratings of perceived usefulness and challenge of activities (social importance)*
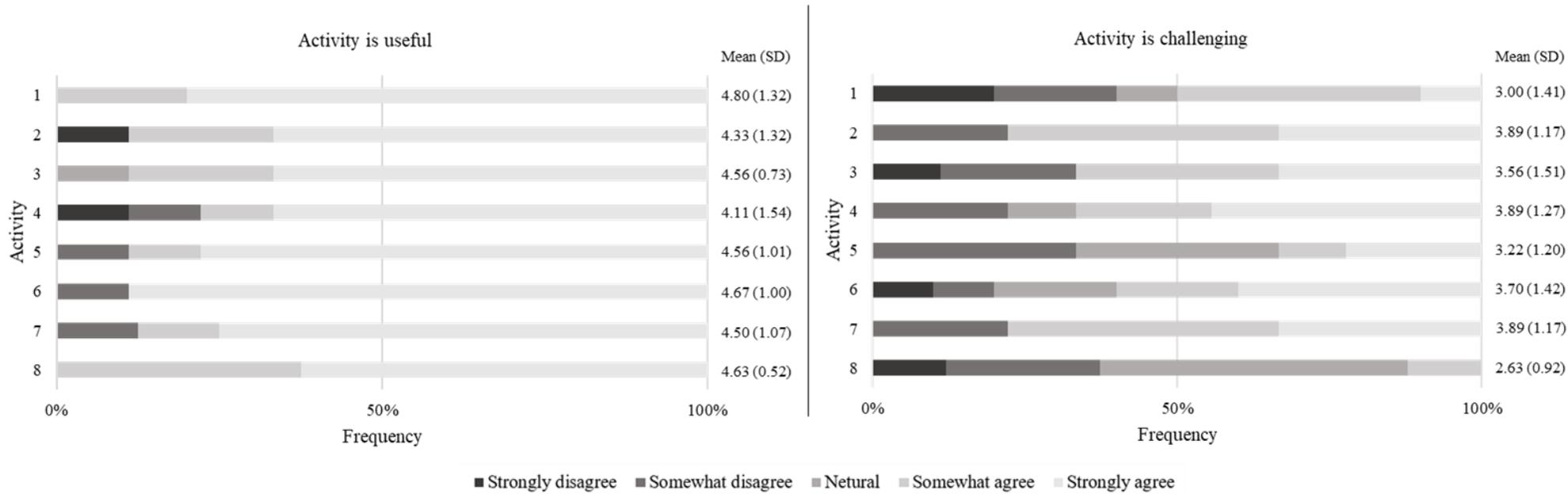


*Note.* Likert scales of *strongly disagree* (1) to *strongly agree* (5).

# Discussion

**Overview of findings**

The first intervention prototype, based on the 3TM of adjustment to UPGs, is perceived as acceptable and useful. In the views of participants, it meets their support needs by providing adequate tools and skills (e.g., reframing thoughts), produces desired psychological benefits (e.g., finding fulfilment), and facilitates engagement with the challenging process of adjusting to a UPG. Furthermore, it is considered accessible, easy to use, comprehensive, and overall sensitive to their experience. High quantitative ratings on social appropriateness and social importance corroborate overall acceptability of the prototype. Nonetheless, participants found three activities somewhat challenging and identified aspects for improvement, particularly design, interactivity, navigation, and some language. Findings indicate that the intervention's development can proceed, integrating participants' feedback, followed by feasibility and efficacy testing.

All participants felt the intervention was useful and helpful, often attributing this to the structure which facilitated them to develop new perspectives on their lives. Survey responses also indicating that once participants had fully engaged with the intervention, they were more likely to recommend it and to considered it more suitable. The logic model presented in Figure 2.1 shows expected outputs include reframing, self-compassion, reducing experiential avoidance, and goal definition and pursuit. Between them, participants reported experiencing all these effects, providing some confidence that the intervention activates the hypothesized mechanisms of change. However, only future quantitative mediation analysis will provide definitive evidence on this, including if the dose of exposure is sufficient to trigger moderate increases in mental-health and well-being.

Participants valued the intervention being online and accessible to use when they wanted, alone and at home, but many noted that the UPG experience is isolating, suggesting connectivity would be a useful aspect of support. Despite this, all but one participant used the intervention alone. Although other research has indicated preference for a romantic partner or close friend as a peer counsellor for web-based self-help psychological interventions (Bernecker et al., 2017), infertility coping literature demonstrates that men often present themselves as strong and stoic, rather than open to share their experiences with their partners (Peterson et al., 2006; Throsby & Gill, 2004). This may explain why nearly all the women used this intervention alone. However, social support, in particular from family members, is a key component in adjustment to uncontrollable stressors (Lechner et al., 2007; Valentiner et al., 1994) such as a UPG. Participants also referred to using the intervention as part of an online community and research shows these can offer support (Hinton et al., 2010; Malik & Coulson, 2008), and help build coping skills and self-esteem (Malik & Coulson, 2013). Focusing on developing skills that facilitate communication about a UPG with close people (family, friends) may facilitate social connectivity and integration of the loss in one's life.

Although social importance ratings were high overall (e.g., usefulness of each activity), they were not at the maximum, indicating an area for improvement. This was reflected in a majority reporting that it was emotionally challenging to some extent to engage each activity, and three participants describing experiencing negative effect. In particular, three activities were rated with lower usefulness and higher challenge (Activity Two – reframing, Activity Four - experiential avoidance, and Activity Seven – committed action). This could indicate an unwanted adverse effect of triggering momentary distress that should be monitored in future evaluation.

Nonetheless, some participants acknowledged that experiencing unwanted emotions or emotional pain is part of the process of change, particularly earlier on in the UPG experience, and were unconcerned. However, perceptions of the intervention being challenging or triggering negative emotions can act as barrier to engagement. ACT literature refers to an unwillingness to tolerate the discomfort that engaging with ACT brings (Harris, 2013; Hayes & Smith, 2005), which appears similar to the concerns expressed here. These data suggest that specific strategies should be provided early in the intervention to encourage users to develop willingness to experience uncomfortable or difficult emotions and clarify that this is part of the change process. To cultivate willingness, Harris (2013) suggests focusing on acceptance skills, for example, and cognitive defusion, which 'attempt(s) to change the way one relates to thoughts by creating contexts in which their unhelpful functions are diminished' (Hayes et al., 2006, p. 8). These skills could help users manage the uncomfortable emotions they may experience.

The experience of pursuing and then adjusting to a UPG is perceived as a personal journey, in which participants recognize different stages and paces in the process of moving towards adjustment. Though this is not a desired nor easy journey, it is necessary, and referring to it as 'my' or 'our' rather than 'this' journey seemed to empower participants, giving them a sense of control and ownership. In this context, participants considered the intervention facilitated engagement with this adjustment process and provided structure to help them navigate through, implicitly suggesting the intervention could shorten the adjustment period or make it less daunting. The journey metaphor has been used in fertility treatment literature (Hinton & Miller, 2013; Wilson & Leese, 2013) and is consistent with the temporal nature of adjustment to loss, demonstrating participants' awareness of this issue.

While they agreed that the intervention could be most useful earlier on the journey, they also referred to individual variability in people's readiness to embark on the journey, which could influence acceptability of the intervention and pace of progression through it. According to Hendricks and Boroditsky (2016) the journey metaphor can indicate a form of reappraisal coping, by allowing a person "to change the way we feel about something by changing the way we think about it" (p. 1164). Ludden et al., (2014) used the journey metaphor to successfully motivate users' engagement as this can "contribute to adherence in the long run by creating meaning and fostering engagement" (Ludden et al., 2015, p. 9). Overall, these data suggest integrating the journey metaphor in the intervention can facilitate a sense of appropriateness and familiarity for users, as well as communication about the structure and pacing of the intervention. Future research should focus on acceptability according to the users' stage of journey and whether this intervention itself could increase a sense of readiness to start the journey.

Finally, the social appropriateness ratings for this intervention were high, with reported perceptions that it was easy to use, comprehensive, inclusive, and appropriate. All participants used the intervention and most completed all activities, itself an indication of acceptability. However, it is important to note that adherence to internet-based self-help interventions in the 'real world' can be poor (Christensen et al., 2009; Eysenbach, 2005; Fleming et al., 2018). The high acceptability reported here might have been a product of the study context, as participants knew they were expected to talk about their experiences of engaging with the intervention. Future testing of the intervention needs to better emulate 'real world' use of self-help interventions (e.g., no researcher-participant contact). Though acceptability of the content is encouraging, design and interaction limitations should be addressed. More

than half completed the activities in hard copy, with some frustrated that they were

unable to edit the activities or felt it was not accessible on a phone. Developing a

more interactive format, such as a web app, could aid in delivering it dynamically,

enabling users to engage at their convenience as most reported difficulties with

fitting the activities into schedules. This has been in demonstrated in a randomised

controlled trial comparing smartphone versus PC delivery of an internet-based

cognitive-behavioural treatment, showing those with the smartphone could integrate

it into a routine (Stolz et al., 2018).

**Strengths and limitations**

   This study was well placed in the intervention's development process,

allowing for improvements to be informed by users. Its prospective and mixed

methods design enabled a nuanced account of participant perspectives (Hammarberg

et al., 2016), with the quantitative data further enabling corroboration of findings.

There was a low attrition rate, only one participant did not complete the follow up

interview. This is contrary to the literature often reporting high attrition rates for

eHealth intervention studies (Eysenbach, 2005). It is possible that this further

endorses the acceptability of the intervention and the requirement from individuals

with an UPG for support, although it could also be a consequence of the in-person

interview research design where participants may find it difficult to say no to

engaging with the intervention.  In addition, personal contact with a researcher in

studies on smartphone interventions has been shown to reduce attrition rates

(Linardon & Fuller-Tyszkiewicz, 2020), as is monetary incentive (Linardon &

Fuller-Tyszkiewicz, 2020), which was also provided. Another strength was the think

aloud protocol, offering a naturalistic perspective of user engagement and allowed

participants to express what they found important. However, although participants

were asked to be as honest as possible, that the interviewer was part of the

development team may have influenced their appraisal.

Finally, the study had a small homogeneous sample of self-selected childless,

married, infertile women. There were no perspectives of people with children (but

who desire more) or men, and only one described themselves as childless by

circumstance, limiting the generalisability of these findings. The lack of

representation of these groups is consistent with their absence in other research

(Greene & Biddlecom, 2000; Tonkin, 2014). Participants were also self-selected, so

if someone found this type of intervention unacceptable, they would have not taken

part in the study. Owing to the small sample size, it was not possible to analyse

inferential statistics and so a more in-depth evaluation of the change across time has

not been conducted.

**Implications**

In sum, findings indicate a future version of the intervention should

incorporate the journey metaphor, include activities to increase social connectivity

(new outputs in logic model), and the order of activities should be revised to start by

promoting acceptance (willingness). Adopting a web based responsive design,

improving user-interface, and addressing inclusivity issues should increase perceived

appropriateness. Findings also have implications for the testing of the upgraded

intervention: testing should emulate 'real word' use of the intervention, evaluate any

potential short-term aversive effects and how these are associated with acceptability,

and proceed to quantitative testing of the logic model. More generally, findings show

that people with a UPG are receptive to online support that helps them developed

perspective of where they are in their journey and offer a map and associated skills

to navigate through it.

This study shows an early prototype of a psychological intervention based on the 3TM, is acceptable and useful, successfully meeting the needs of women with a UPG. Despite being a challenging experience for some, all women engaged with the intervention, commending its well-structured guidance. Results overall support the logic model underlying the intervention with only minor revisions needed (Appendix E). Further development of the intervention can now be carried out from these findings.

# Chapter 3: Childless by circumstance adjustment and support needs

## Introduction

In the previous chapter the early prototype of the intervention was evaluated for acceptability. Almost all the participants in the study were infertile childless women, and as noted in Chapter 1, the reproductive literature often focuses on people who have engaged with fertility treatment. However, people find themselves definitively childless for numerous reasons, and often resulting from a combination of factors, with research suggesting that over 95% of childless individuals perceive this to be involuntary (Miettinen et al., 2015). It is becoming increasingly clear that many people experience UPGs because of circumstantial barriers and more research is now needed to better understand this experience. Therefore, this chapter aims to validate the 3TM in a sample of circumstantially childless people and gather data on their support needs and preferences.

The terminology for childless by circumstance people varies across the literature. In some contexts, the term represents individuals whose childlessness arises from social reasons, as opposed to medically-related inability to conceive (Cannold, 2004; Tonkin, 2010). In others, the term includes the above social factors in addition to biological or infertility reasons (Chauhan et al., 2020; Connidis & McMullin, 1996). It is often considered the opposing term to 'childless by choice' (Cannold, 2004); broadly, 'childless by circumstance' terminology is synonymous with involuntary childlessness. In this chapter, childless by circumstance people are defined as individuals who identify themselves as permanently childless and attribute their childlessness to unfavourable circumstances, e.g., not having a partner.

As noted in Chapter 1, there are several circumstantial barriers that lead people to consider themselves childless by circumstance, with the most cited ones being partnership, education, employment (Mynarska et al., 2015), and parenthood postponement (Berrington, 2004; Mills et al., 2011). Gender differences are apparent for some of these factors. For example, additional levels of education and sustained employment are predictors of childlessness for women, but not for men (Berrington, 2017; Keizer et al., 2008) and it is possible this is due to the experience of sub-fertility following postponement of childbearing (Kreyenfeld & Konietzka, 2017). Conversely, remaining single predicts childlessness in both men and women (Berrington, 2017; Connidis & McMullin, 1996; Rotkirch & Miettinen, 2017). As a result of these factors, people may postpone parenthood and this plays an important role in people ultimately remaining childless (Beaujouan, 2021; Mills et al., 2011). This impacts both men and women as, although women have a definitive biological reproductive window, men are also impacted by this if their partner is older. Furthermore, the increasing understanding that it may not only be the biological barriers, but also social barriers - where there is a perception that society would consider a certain age too old to have a child (Billari et al., 2011). Although research on predictors of childlessness does not often differentiate between involuntary and voluntary childlessness, there are often several reasons that contribute to circumstantial childlessness and there are gender differences regarding education and employment as predictors of childlessness.

Lack of awareness about the relevance of investigating the negative psychosocial impact of undesired childlessness has been reflected in population representative studies on childlessness. Data where self-perceptions of childlessness are not taken into consideration have contributed to mixed findings about how

parental status or childlessness is associated with mental-health and wellbeing. For example, data from the Survey of Health, Ageing and Retirement in Europe (SHARE) reported that childlessness was not associated with psychological wellbeing once controlled for socio-economic factors (Gibney et al., 2017), but whether the childlessness was involuntary was not determined. Data from the National Longitudinal Study of Youth 1979 indicated involuntary childlessness was not associated with psychological distress (Maximova & Quesnel-Vallée, 2009). However, it was noted that across the two time points many participants revised their intentions, with only quarter indicating voluntary childlessness at the first wave, increasing to three quarters of participants by the second wave. This change of intention across time may be why no association with childlessness and distress was found as people were able to reduce the incongruence between their intentions and outcomes. This is supported by other research that indicates people revise downwards their number of desired children over time (Berrington, 2004; Liefbroer, 2009). A longitudinal study in Australia using 10 waves of data from the Household, Income and Labour Dynamics in Australia study reported that across the life course, the physical and mental health of childless women varied in comparison to mothers. They reported that childless women experienced poorer mental health, social functioning and emotional related role limitations when compared to mothers during their reproductive years (age 25 to 44) but this was no longer true for women over the age of 65 (Graham, 2015). However, perceptions of whether the childlessness was involuntary were not captured, and it was not possible to determine causality. Other research indicates childlessness may be associated with poorer eudaimonic wellbeing, indicated through data from the Norwegian Life Course, Ageing and Generation (NorLAG) study suggesting that childless women report lower life

satisfaction and self-esteem than mothers (Hansen et al., 2009). In sum, although no definitive conclusions can be drawn as these large cohort studies were not designed to evaluate involuntary childlessness and psychosocial implications, their findings do suggest that there is some evidence to warrant further investigation of the psychosocial implications of involuntary childlessness.

In addition to self-perceptions of childlessness, as non-parenthood is often considered a non-normative life transition, the social context and perceived social support may play a role in subsequent psychosocial implications. For example, childless people are more likely to experience perceived stigma (Bulcroft & Teachman, 2004; Miall, 1986), impacting their mental health, with this burden being higher in pronatalist societies (Donkor & Sandall, 2007; Gold, 2013; Slade et al., 2007). In some countries consequences can include violence (Stellar et al., 2016). In addition to perceived stigma, childless individuals often report poorer social support. An exploratory cross-sectional study based in Australia reported that women who reported being circumstantially childless (defined as not having children as a result of circumstances such as no partner) had significantly lower social support scores than women who were childless for other reasons (undecided, future childed (i.e., intend to have biological or social children in the future), voluntary childless or involuntary (defined as unable to achieve a viable pregnancy)) (Turnbull et al., 2016). Furthermore, research on men and women indicates that childlessness is associated with a sense of 'being an outsider' (Hadley & Hanley, 2011; Letherby, 2012), or 'socially invisible', and experiencing loneliness (Pinquart, 2003), in particular in older ages (Albertini & Mencarini, 2014; Dykstra & Hagestad, 2007). It is important to note the associations between childlessness and social support and relationships are complex and may be mediated by marital status and gender

(Pinquart, 2003), and the availability of extended family and friends (Deindl &

Brandt, 2017). However, the social context, in addition to the perception of whether

the childlessness is involuntary, should be taken into consideration when researching

this population.

Individuals who experience involuntary childlessness are likely to undergo an

adjustment process, triggered by the loss of an identity, e.g., parent, and/or the loss

of the goal, e.g., parenthood. Research often focuses on theories that facilitate

understanding of the causes of childlessness and some have approached the

adjustment process, but primarily following unsuccessful fertility treatment (Daniluk

& Tench, 2007; Gameiro & Finnigan, 2017; Kraaij et al., 2009; Sabatelli et al., 1988;

Verhaak, Smeenk, Evers, et al., 2007). Individuals who experience childlessness

because of unsuccessful treatment reportedly undergo an adjustment process that

includes working through and integrating their grief, making meaning from their

experience and eventually engaging with other fulfilling goals. This process was

proposed as the Three Task Model of Adjustment (3TM), where the three tasks are:

acceptance, meaning making, and the pursuit of other meaningful goals (Gameiro &

Finnigan, 2017). There is consensus that certain factors are protective for adjustment,

e.g., social support (Daniluk & Tench, 2007) and the passage of time (Gameiro et al.,

2016; Kuivasaari-Pirinen et al., 2014), and others are not, e.g., avoidance coping

(Daniluk & Tench, 2007) or the absence of accessible meaningful alternative goals

away from parenthood (Kraaij et al., 2009). As this research focuses on involuntary

childlessness after infertility, it is not clear how emergent knowledge about this

adjustment process is applicable to those who find themselves circumstantially

childless. However, research focused on the childless by circumstance experience

has provided evidence of similarities. For example, McQuillan et al., (2012) found

that individuals who considered themselves childless as a result of situational

barriers reported similar importance of parenthood scores to individuals who

reported biomedical barriers. Research focusing on why loss of motherhood matters

in circumstantial childlessness indicates that women experience feelings of loss and

grief, (Tonkin, 2010), which are also experienced following unsuccessful treatment

(Daniluk, 2001; Volgsten et al., 2010). Furthermore, Koert and Daniluk (2017)

found that women who had delayed childbearing until they were subsequently

permanently childless experienced feelings of grief and loss. Hadley and Hanley

(2011) also reported this sense of loss amongst involuntary childless men. More

recently an online survey study indicated circumstantially childless women undergo

gradual acceptance of their childlessness (Chauhan et al., 2020).

Research with infertile participants suggests that they engage in meaning

making processes such as positive reappraisal coping when faced with definitive

childlessness (Kraaij et al., 2008; Lechner et al., 2007). Whether circumstantially

childless people also engage in a meaning making process and what strategies are

used remains unclear. However, interpretive phenomenological analysis of

permanently childless women after delayed childbearing indicated that women

experience a need to make sense of their childlessness, engaging in cognitive coping

by reflecting on their intentions and reconciling with themselves that they had make

the best decisions they could, based on their values and beliefs (Koert & Daniluk,

2017).

Adjustment research suggests that engagement with other meaningful goals is

an important factor in adjustment to life stressors (Kraaij et al., 2009). There may be

differences between the infertility and circumstantial childless populations within

this aspect of the adjustment process. For those who remain childless via infertility,

and engage with fertility treatment, the pursuit of other goals can be difficult as it involves active effort to move away from their pursuit of parenthood (McCarthy, 2008; Wirtberg et al., 2007). Arguably, this may be easier for the circumstantial childless population as predictors of the circumstantial childlessness experience include exploring further education or sustaining a career, therefore it may not require much active effort to continue pursing these alternative goals away from parenthood, therefore facilitating adjustment. Furthermore, individuals who are childless by circumstance may not have sought to actively try to conceive and this may make relinquishment of this goal easier. Some research suggests that individuals who did anticipate having children are able to voluntarily relinquish this goal through adapting to the lifestyle they build for themselves without children (Buhr & Huinink, 2017).

Given that the psychosocial implications of involuntary childlessness have been outlined and that individuals undergo a challenging adjustment process, which may be influenced by the social context, it would be reasonable to suggest that this population may seek support. Research has shown consistently that beneficial social relationships and social support can have a positive influence on adjustment. Individuals who have undergone fertility treatment benefit from social support (Rockliff et al., 2014). Sharing their experience within trusted social relationships can foster that support (Johansson & Berg, 2005) and long-term adjustment to unsuccessful treatment may be buffered by the presence of social support (Gameiro & Finnigan, 2017). However, due to the associated stigma, an appraisal of whether social networks are supportive in relation to the childlessness may be important for the childless by circumstance population before they choose to disclose this information, both formally (e.g., a certified therapist) and informally (e.g., peer

support). Furthermore, research also suggests that the pathway to childlessness may more profoundly influence social consequences than the status itself (Kohli & Albertini, 2009) and so the heterogeneity of the experience may be reflected in the perception of available social networks and support. Research shows that people turn to online communities to share their experiences of childlessness, usually anonymously, however these are often centred around the infertility experience or those trying to conceive (Malik & Coulson, 2013; Stenström, 2020). In sum, the perceived availability of supportive social relationships may play an important role in the adjustment process for childless by circumstance individuals.

Overall, the data supports the notion that adjustment to involuntary childlessness unfolds as proposed by the 3TM. Evidence suggests that this model is applicable to those who describe themselves as childless by circumstance, though this needs to be empirically tested. Furthermore, there may be nuances in how this population engages with the three tasks of acceptance, meaning making, and pursuit of new goals. For example, without the definitive end point often experienced when one must make a decision to stop fertility treatment, the grief and subsequent acceptance process, or the process of making meaning of their experience, may take longer for childless by circumstance individuals. However, childless by circumstance individuals may find it easier to engage with other meaningful goals as they are more likely to already have fulfilling goals, such as pursuit of further education. An in-depth understanding of such nuances will contribute to inform the development of the intervention presented in this thesis, so that it better meets the needs of this particular population.

Finally, research also suggests that an objective indicator of adjustment is a self-reported relinquishment of the goal of parenthood, this being associated with

better mental health and wellbeing (Daniluk, 2001; Gameiro et al., 2014; Verhaak, Smeenk, Evers, et al., 2007; Verhaak, Smeenk, Nahuis, et al., 2007). Research demonstrates that the number of individuals sustaining this child-wish will diminish over time (Gameiro et al., 2014; Verhaak, Smeenk, Nahuis, et al., 2007; Wischmann et al., 2012). Given that the consequences to involuntary childlessness resulting from infertility and circumstances are similar in other areas (Koert & Daniluk, 2017), it seems reasonable to suggest that circumstantially childless individuals may also sustain a child-wish, and that this may either act as a barrier to adjustment or may be considered an output of unsuccessful adjustment. Therefore, this study will also consider whether childless by circumstance individuals sustain a child wish and the role this may play in their adjustment process.

The aim of this cross-sectional mixed methods study was to empirically test the validity of the 3TM to explain the adjustment process of people who are childless by circumstance and evaluate support needs. The specific hypotheses of this study were (1) the empirical model will demonstrate validity using predefined criteria, (2) qualitative data will indicate whether participants describe a similar adjustment process to those who were unsuccessful after fertility treatment, (3) people who are childless by circumstance who sustain a child wish may experience adjustment difficulties, and (4) participants will report a demand for both informal and formal psychosocial support. The mixed-methods design was adopted because quantitative analysis enables the first empirical testing of the 3TM for this population and qualitative analysis facilitates understanding of nuances of the childless by circumstance experience. Results will indicate whether the 3TM is applicable to the childless by circumstance experience and will inform future development of the intervention to ensure it is suitable for this population.

## Methods and Materials

**Design**

The study consisted of a mixed-methods online survey built using Qualtrics

software (Copyright 2020; Qualtrics, Provo, UT).

**Participants**

This study was approved by Cardiff University's School of Psychological

Ethics Committee (EC.20.04.14.6010). The survey was advertised on social media,

including Twitter and Facebook. Specific support groups for childless individuals

were contacted directly and the survey was shared with permission. Google

advertisements were also distributed, and the Prolific recruitment platform was used.

To complete the survey, participants were required to click the link in the online

advertisements. Participants were then presented with the information sheet and

informed consent form (Appendix F). They were also informed they could be

entered into a prize draw to win one of four £30 amazon vouchers on completion of

the survey.  Participants who complete the survey via the Prolific recruitment

platform completed an initial eligibility survey (using the eligibility question about

whether they are childless by circumstance in the survey content below, they will

have already been filtered for age), and those who were eligible were invited to

complete the full survey. Participants who complete the survey in this way received

payment for both surveys they completed (eligibility and full survey) and were not

entered into the prize draw.

Eligibility criteria were being childless by circumstance, defined as

identifying as permanently childless, presumed fertile during childbearing years, and

childlessness due to unfavourable circumstances (e.g., not having a partner or didn't

find the right partner), and being aged 35 or over. This minimum age has been used

in other studies (Tonkin, 2014) and was set as fertility declines sharply around this

age (for women) and people are likely to be aware that they may be approaching a

point where they would be unable to conceive a child. Other research has included

people who define themselves childless by circumstance even when they are infertile

and engage with fertility treatment (Chauhan et al., 2020; Connidis & McMullin,

1996) and people are increasingly engaging with fertility treatment at older ages

($\geq$35) (Ben Messaoud et al., 2020), potentially following parenthood postponement

(Beaujouan, 2021), therefore people who considered their infertility as resulting from

an unfavourable circumstance were also included in this study.  The term 'childless

by circumstance' was chosen as this term is used colloquially and facilitates

inclusion of individuals who self-identify with this, and the survey was open for all

genders. On completion of the survey, participants were provided with a debrief

form.

**Materials**

The online survey included socio-demographic questions, questions about

participants' pathway to childless by circumstance, their childless experience (these

data will be reported elsewhere), and current child-wish. Existing psychological

questionnaires were used to measure the 3TM predictors, mediators and target

outcomes. A final set of questions assessed participants' need for formal and

informal support and perceived impact of the COVID-19 pandemic.

***Sociodemographic questions***

Participants were asked to provide their age (in years), gender (0 = female, 1

= male), country of residence, relationship status (0 = single (including divorced or

widowed), 1= in a relationship), education level (0=no University education, 1 =

University education) and employment status (0 = not employed: unemployed,

student, retired, 1 = employed part or full time).

*Pathway to childlessness*

Participants were asked the question 'Please explain how you have become childless by circumstance?', and answers to this question were coded to extract different categories of the reasons (e.g., single/did not find the right partner, economic reasons, medical (not including infertility), partner did not want children). If more than one reason was given, the first reason was chosen as this was considered the most salient to the participant. Individuals were dummy coded into those who cited fertility problems and/or treatment (1) and those who did not (0) so that this could be controlled for during analysis.

*Sustaining a child-wish*

Participants were asked whether they sustained a child wish (0 = no, 1 = yes).

*Predictors, mediators and outcomes of the 3TM*

In addition to age and gender, importance of parenthood and social relationships were considered as predictors, due to their relevance in adjustment to a blocked parenthood goal, as outlined in the introduction.

**Importance of parenthood.** Participants were asked how they rated the importance of parenthood on a scale of 1 (*not at all important)* to 5 (*very important*).

**Social relationships.** This was assessed with a four-item scale developed by the researchers and based on other papers that specifically investigated childless by circumstance (Hadley, 2019b; Tonkin, 2010). The first two questions focus on availability of supportive social relationships and the last two focus on feelings about their social relationships. In house development of questions was chosen as the researchers wanted a brief questionnaire that specifically asked participants their perspective of how they related to others around them in relation to their childlessness, and as there is a paucity of research on the childless by circumstance experience, it was felt that there was not a validated questionnaire that captured this.

The four questions were: My friends and family understand my feelings about my childlessness; I can talk to my friends and family about my childlessness; I feel isolated because of my childlessness; I feel I am treated differently because I am childless. Participants were asked to respond to each statement on a scale of 1 (*never)* to 5 (*always)*. Negatively scored items were reversed and scores were then summed, with the total score varying between four and 20, with higher values indicating higher perception of available and supportive social relationships.

**Meaning Making.** Positive reframing is considered a meaning-making coping strategy associated with better adjustment to definitive childlessness (Kraaij et al., 2009; Lechner et al., 2007), This was evaluated with the brief COPE inventory subscale (Carver, 1997), which assesses positive reframing with four items (e.g., 'I try to see it in a different light, to make it seem more positive'). The item scores ranged from 1 *(I haven't been doing this at all*) to 4 (*I've been doing this a lot*) and a total summed score ranging from four to 16 was calculated, with higher scores indicating more positive reframing.

**Acceptance.** This was assessed with the acceptance subscale of the SCREENIVF Questionnaire (Verhaak et al., 2010). This subscale assesses acceptance with six items (e.g., 'I have learned to accept my fertility problems'). The items were adapted to assess acceptance towards childlessness e.g., 'I can deal with the consequences of being childless', instead of '…my fertility problems'. The response scale varied from 1 (*do not agree*) to 4 (*strongly agree*) and a total summed score ranging from six to 24 was calculated, with higher scores indicating higher acceptance.

**Pursuit of new goals.** This was assessed with the re-engagement subscale of the Goal Disengagement and Reengagement Scale (Wrosch, Scheier, Miller, et al., 2003). The scale assesses the ability to identify new life goals (two items, e.g. 'I have convinced myself that I have other meaningful goals to pursue.'), to commit to new goals (two items, e.g. 'I have put effort toward other meaningful goals.') and to start an active pursuit of new goals (two items, e.g. 'I have sought after other meaningful goals.'). Participants were asked to answer on a five-point scale from 1 (*strongly disagree*) to 5 (*strongly agree*). The total sum score ranged between six and 30, with higher scores indicating greater engagement in other meaningful life goals.

**Mental health.** This was assessed with the Mental Health Inventory (MHI-5) (Berwick et al., 1991), a five-item scale that assesses mental health by asking participants how they have been feeling during the previous four weeks ( e.g., Have you been a happy person?) on a six point scale from 1 (*none of the time*) to 6 (*all of the time*). Negatively scored items were reversed and items were then summed and linearly transformed to produce a total score ranging from zero to 100, with higher scores indicating better mental health. A suggested cut off score for MHI-5 is 76, with scores equal or below this indicating the presence of common mental disorder (Kelly et al., 2008)

**Wellbeing.** Wellbeing was differentiated between hedonic (subjective experiences of pleasure and enjoyment) and eudaimonic (subjective experience of meaning and purpose in life) wellbeing.

*Hedonic wellbeing.* This was assessed with the World Health Organisation Wellbeing Index (WHO-5 (;Topp et al., 2015). Participants were asked to rate how well each of five items (e.g., 'I have felt calm and relaxed') applied to them over the

past two weeks on a scale from 0 (*none of the time*) to 5 (*all of the time*). All items were summed, and the total score was linearly transformed to vary from zero to 100, with higher scores indicating better hedonic wellbeing. General population mean scores for WHO-5 are estimated at 70 (Bech et al., 2003), scores $\leq 50$ indicating reduced wellbeing (Topp et al., 2015).

*Eudaimonic wellbeing.* This was assessed with the Flourishing Scale (FS) (Diener et al., 2010). This brief eight-item scale assesses subjective success in areas such as purpose and self-esteem (e.g., 'I lead a purposeful and meaningful life'). Participants were asked to indicate how much they agree with each statement on a scale of 1 (*strongly disagree*) to 7 (s*trongly agree*). All scores were summed and varied between eight to 56, where higher scores indicated higher eudaimonic wellbeing. General population mean scores for English speaking adults have been estimated at 43.8 (SD= 8.4) (Hone et al., 2014).

### *Support needs*

Participants were asked four questions about their support needs which were generated by the researcher. Two questions asked whether participants felt they needed professional/formal (e.g., certified therapist or counsellor) or informal support (e.g., peer support, online forums, self-help) and to explain this in detail. One question asked whether participants would use an online support app to manage the social and psychological implications of being childless by circumstance and one question asked what content or features participants would expect to see in such an online support app.

### *Perceived impact of COVID-19*

This survey was launched at the beginning of the COVID-19 pandemic response in the UK (national lockdown) and therefore two questions were added one

week after the survey launched to assess how the COVID-19 pandemic was affecting

the participants wellbeing and their experience of being childless by circumstance.

Both questions had a response scale of 1 (*very negatively affected*) to 5 (*very*

*positively affected*). One open question also invited participants to write any further

comments about the pandemic in relationship to their childless by circumstance

status.

**Data analysis**
       Descriptive statistics (frequencies, percentages, means and standard

deviations) were used to describe the sample socio-demographic characteristics. Chi

squared tests were conducted to evaluate any differences in characteristics of

participants who started and completed the survey fully or not.

       To test the 3TM model a path analysis was conducted with maximum

likelihood estimation using IBM SPSS AMOS v23 structural equation modelling

software. The predictor variables (IVs) in the model were age, gender, importance of

parenthood and social relationships. The mediators were meaning making (positive

reframing), acceptance and pursuit of new goals, and the dependent variables (DVs)

or outcomes were mental-health and hedonic and eudaimonic wellbeing. Causal

arrows were drawn from all predictors to all mediators and from all mediators to all

outcomes. The residuals of all mediators were covaried (because it was hypothesised

these would be associated) and of all outcomes (because they all measure

psychosocial adjustment). To consider if socio-demographic variables (age, gender,

in relationship, education, employment) and reported fertility problems and/or

fertility treatment should be controlled for, their correlations with outcomes were

inspected. In addition, gender and social relationships were covaried as gender

differences have been reported in the literature (Peterson et al., 2006). Finally,

arrows were drawn between social relationships and all outcomes due to the

extensive literature on the direct (i.e., not via hypothesized mediators) protective

value of social relationships to psychosocial adjustment. The model was then tested

in a series of steps. In Model One, all associations between covariates identified in

the bivariate correlations and outcomes were included. Upon inspection of the

estimates of this model, non-significant associations between covariates and

outcomes were removed, which was Model Two. To examine the models' goodness

of fit the chi-squared ($\chi^2$), the Bentler comparative fit index (CFI), and the Steiger–

Lind root mean square error of approximation (RMSEA, corrects for model

complexity) were considered. A model is considered to have very good fit if the chi-

squared ($\chi^2$) statistic is non-significant, the CFI is greater than 0.95 and the RMSEA

is below 0.06 (Hu & Bentler, 1998). A good fit is established if the chi squared

statistic is non-significant ($\chi^2$), the CFI is greater than 0.90 and the RMSEA is below

0.08 (Bentler, 1990; Hooper et al., 2007). Only statistically significant standardised

path coefficients ($p < .05$) were reported. Values less than .10 indicate small effects,

values around .30 medium effects, and values $\geq .50$ large effects (Cohen, 1988). The

validity of the final model within the context of the COVID-19 pandemic was tested

using two invariance models, one with the two COVID variables as predictors and

one with them as covariates.

To investigate participants perceptions of their adjustment process, in

particular in relation to the three tasks, thematic analysis was carried on textual data

from the online survey, according to the six steps outlined by Braun and Clarke

(2006). This first involved familiarisation with the data by reading through the

survey responses several times. Then inductive generation of codes that described a

piece of information present in the data. To minimise researcher bias, this exercise

was descriptive to ensure the least possible inference. Codes were then grouped into themes that captured a recurrent idea or topic present in the set of data (Vaismoradi et al., 2016). Themes were developed from analogous data, but attention was also given to divergent data if it was strongly endorsed by the participant(s). Themes were reviewed by checking them against extracts of data and then the themes were defined and named. During this process, B.R. and S.G. came together repeatedly for peer debriefing, reflection and to discuss and review the codes. The analysis was presented in a summary with illustrative verbatim quotes presented in a table. Quotes are accompanied by participant number (P), gender (M or F) and age (in years).

To investigate if sustaining a child wish was associated with differences in adjustment processes and outcomes, multivariate analysis of variance was conducted twice (one for 3TM mediators and one for adjustment outcomes).

Finally, to investigate needs for psychosocial support, descriptive statistics (frequencies) were used to describe participants engagement with or perceived need for informal and formal support. Thematic analysis was also conducted on the textual responses.

## Results

### Sample characteristics

Two hundred and eighty-one individuals accessed the survey and 149 (53%) were included in the final analysis. See the participant flowchart (Figure 3.1) for reasons of non-inclusion.

The sample characteristics are presented in Table 3.1. The average age of the survey completers was about 46 ($SD = 7.42$) years of age, and 29 participants (19.5%) were men. Around half were in a relationship and a majority had a

university education and were employed full or part-time. The majority were from

the UK and still had a child wish. The three most cited reasons for being childless by

circumstance were being single or not finding the right partner (68, 47.6%), a partner

not wishing to have children (19, 13.3%), and medical reasons (not including

infertility; 19, 13.3%).

**Figure 3.1**

*Participant flowchart*
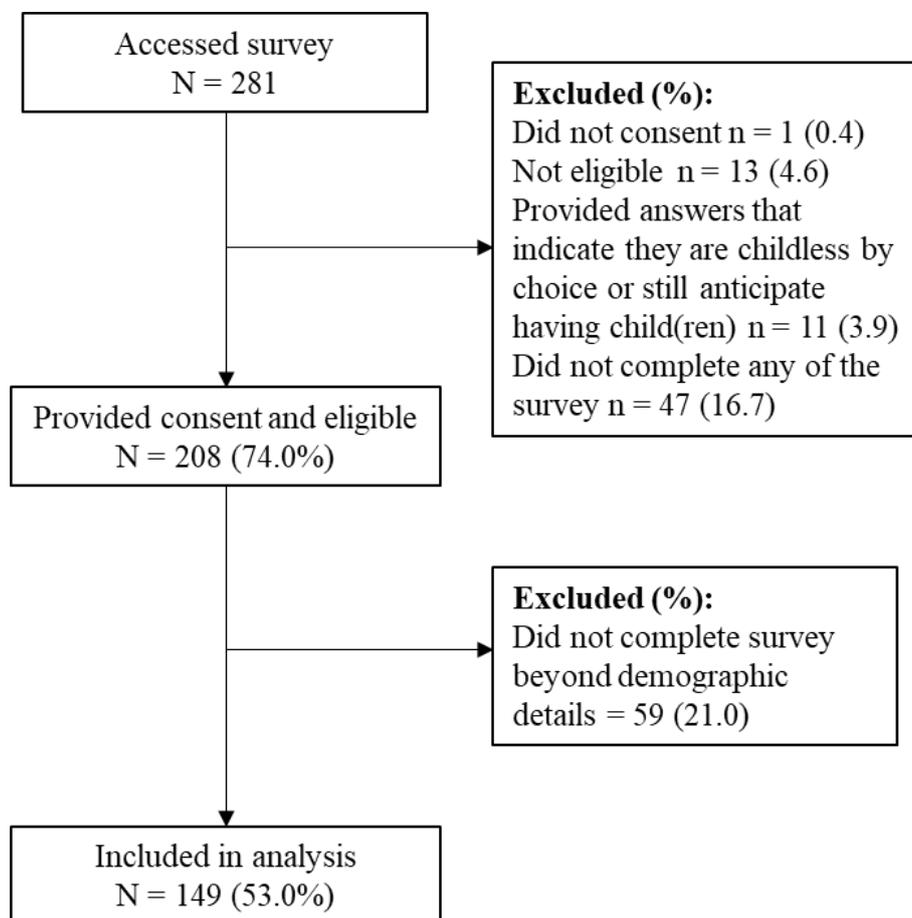
**Table 3.1**

*Summary of sociodemographic details of participants and differences between survey completers and non-completers*

| Variable | Survey completers | | Survey non-completers | | $t(192)^a / \chi^{2a}$ | $p$ |
|---|---|---|---|---|---|---|
| | $n = 147$ | | $n = 47$ | | | |
| | M | SD | M | SD | | |
| **Age [range = 35-68]** | 45.95 | 7.42 | 46.85 | 7.09 | -0.73 [-3.33, 1.53] | .466 |
| | $n = 149$ | | $n = 42$ | | $t(190)^a$ | $p$ |
| **Importance of parenthood** | 3.45 | 1.23 | 3.72 | 1.14 | -.1.30 [-0.69, 0.14] | .198 |
| | $N = 149$ | | $N = 49$ | | | |
| | n | % | n | % | | |
| *Gender* | | | | | | |
| **Female** | 120 | 80.5 | 45 | 91.8 | 3.39 | .078 |
| *Relationship status* | | | | | | |
| **Relationship** | 76 | 51.0 | 30 | 61.2 | 1.55 | .460 |
| *Education* | | | | | | |
| **Degree (including UG and PG degree)** | 121 | 81.2 | 43 | 87.8 | 1.11 | .292 |
| *Employment* | | | | | | |
| **Employed (part time/ full time)** | 119 | 79.9 | 39 | 79.6 | 0.00 | .967 |
| *Country* | | | | | | |
| **United Kingdom** | 92 | 63.0 | 31 | 64.6 | 2.66 | .448 |
| **Rest of Europe** | 31 | 21.2 | 6 | 12.5 | | |
| **USA and Canada** | 16 | 11.0 | 7 | 14.6 | | |
| **Rest of World** | 7 | 4.8 | 4 | 8.3 | | |
| *Sustained child wish* | | | | | | |
| **Yes** | 85 | 60.7 | 26 | 61.9 | 0.02 | .890 |
| *Reasons for childlessness* | | | | | | |
| **Single or not found the right partner** | 68 | 47.6 | 1 | 25.0 | 8.35 | .302 |
| **Partner did not want children** | 19 | 13.3 | 0 | 0.0 | | |

| Variable | Survey completers | | Survey non-completers | | $t(192)^a$ / $\chi^{2a}$ | $p$ |
|---|---|---|---|---|---|---|
| **Medical (not including infertility)** | 19 | 13.3 | 2 | 50.0 | | |
| **Fertility problems and/or treatment** | 14 | 9.8 | 0 | 0.0 | | |
| **Economic reasons** | 9 | 6.3 | 0 | 0.0 | | |
| **Gay or lesbian** | 3 | 2.1 | 0 | 0.0 | | |
| **Difficult upbringing (including parents' divorce)** | 4 | 2.8 | 0 | 0.0 | | |
| **Other (including informally caring for parents)** | 7 | 4.9 | 1 | 25.0 | | |

*Note.* $M$ = Mean, $SD$ = Standard Deviation UG = Undergraduate, PG = Postgraduate. Rest of world = Australia, New Zealand, Mexico and South Africa. [a]Tests for a

difference between completers and non-completers, and were estimated using chi squared test or t tests, [Confidence intervals].

Table 3.1 also presents the descriptive statistics for the study variables for

participants who did or did not complete the survey (excluded from analysis). No

association was found between completing the survey and age, gender, being in a

relationship, having a university education, being employed, country of residence,

sustaining a child wish, or reasons for childlessness.

**Testing of the Three Task Model of Adjustment**

Table 3.2 presents means and standard deviations, internal consistency

coefficients, and bivariate correlations among the variables of the 3TM. It can be

observed that all the scales used had internal consistency (Cronbach's alpha) $\geq$ .84.

Participants reported average scores on social relationships, and above the average

response values scores on meaning making, acceptance, and pursuit of new goals.

Participants' psychosocial adjustment outcome scores for mental health, hedonic and

eudaimonic wellbeing were lower on average compared to normative or validation

data. Eighty five percent and 53% of participants in this study scored below the cut-

off score (MHI-5 $\leq$ 76) that indicates the presence of mental health disorders and

below the cut-off score (WHO=5 $\leq$ 50) that indicates reduced wellbeing,

respectively.

Overall, as shown in Table 3.2, there were weak to moderate

associations between the predictors, psychological tasks, and adjustment outcomes.

There were strong correlations between adjustment outcomes, with the strongest

association being between mental health and hedonic wellbeing, $r = .776, p < .001$.

Fit indices for the three models tested are presented in Table 3.3. Inspection

of the model fit parameters show that the three models tested present good fit to the

data, with Model Three (presented in Figure 3.2) presenting the best fit scores across

all parameters.

**Table 3.2**

*Means and standard deviations, internal consistency and correlations among the Three Task Model of Adjustment (3TM) variables tested (Max*

*N=149)*

| Variables | n | M (SD) | Normative Scores | α | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **1. Age** | 147 | 45.95 (7.42) | - | - | -.004 | -.005 | -.044 | .133 | -.007 | -.011 | .196* | .064 | .142 | .038 | .064 |
| **2. Gender**[a] | 143 | - | - | - | - | -313*** | .261** | .274** | .120 | .096 | .174* | .098 | -.002 | .0589 | .057 |
| **3. Importance parenthood** | 149 | 3.45 (1.23) | - | - | | - | -.334*** | -.437*** | -.274*** | -.089 | -.285*** | -.257** | -.026 | .036 | -.214* |
| **4. Social Relationships** | 144 | 10.70 (4.51) | - | .856 | | | - | .445*** | .474*** | .354*** | .477*** | .540*** | .479*** | .106 | .289** |
| **5. Acceptance** | 149 | 16.18 (5.32) | - | .951 | | | | - | .489*** | .423*** | .459*** | .439*** | .362*** | .124 | .277** |
| **6. Meaning Making** | 146 | 10.85 (3.49) | - | .836 | | | | | - | .487*** | .299*** | .340*** | .367*** | -.046 | .112 |
| **7. Pursuit of new goals** | 148 | 21.70 (5.19) | - | .922 | | | | | | - | .460*** | .468*** | .480*** | .201* | .273** |
| **8. Mental Health** | 148 | 54.57 (19.96) | 80.0 (16.0)[b] | .874 | | | | | | | - | .776*** | .625*** | .242** | .315** |
| **9. Hedonic WB** | 148 | 45.94 (21.51) | 68.7 (19.0)[c] | .906 | | | | | | | | - | .673*** | .238* | .321*** |
| **10. Eudaimonic WB** | 147 | 40.03 (8.64) | 43.8 (8.4)[d] | .863 | | | | | | | | | - | .168 | .233* |
| **11. COVID WB** | 114 | 2.32 (0.82) | - | - | | | | | | | | | | - | .447*** |
| **12. COVID CbyC** | 117 | 2.57 (0.91) | - | - | | | | | | | | | | | - |

*Note.* * $p < .05$, ** $p < .01$ ***$p < .001$, M = Mean, SD=standard deviation, α = Cronbach's alpha, WB = wellbeing, CbyC = Childless by Circumstance experience. [a]Point-biserial correlations presented for gender (0=female, 1=male), [b](Hoeymans et al., 2004), [c](Bech et al., 2003), [d](Hone et al., 2014).

**Figure 3.2**

*Path Model Testing the Three Task Model of Adjustment (3TM) to unmet parenthood goals (Model Three)*
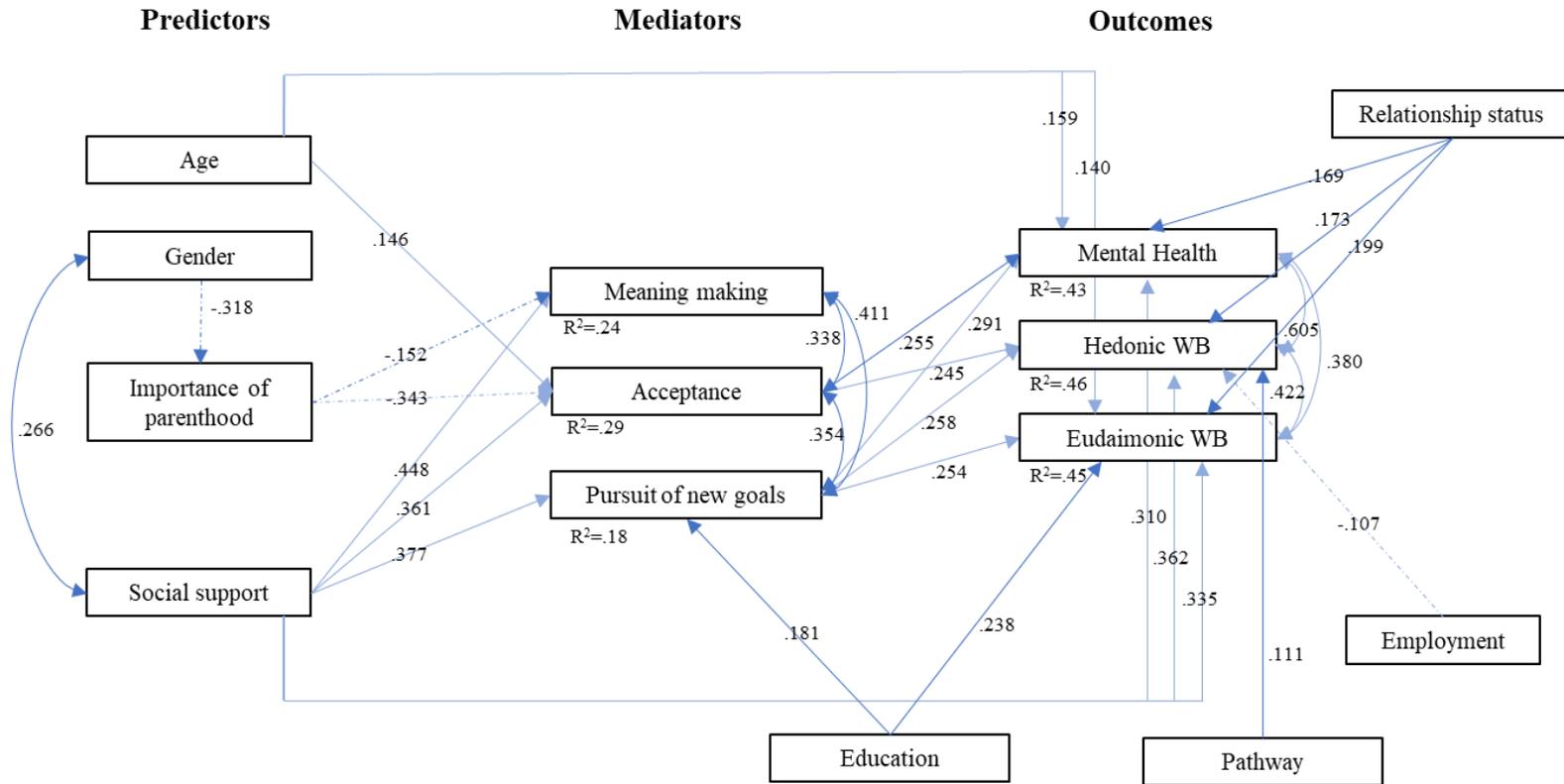


*Note.* Model fit was X²(53) = 88.522, p = .002, CFI = 0.938, RMSEA = .067 90%CI [.041, .091]. Controlling for socioeconomic varaibles that correlated with at least one outcome. Continuous and dashed unidirectional arrows represent positive and negative regression weights, respectively. Continuous bidirectional arrows represent positive correlations. Only statistically significant paths shown in figure. WB = Wellbeing.

**Table 3.3**

*Fit indices for all models*

| 3TM validity criteria | Model 1 | Model 2 | Model 3 |
|---|---|---|---|
| $\chi^2$ **is non-significant** | $\chi^2(48) = 87.808{***}$ | $\chi^2(50) = 92.405{***}$ | $\chi^2(50) = 88.522{**}$ |
| **CFI > 0.90** | **CFI = 0.930** | **CFI = 0.926** | **CFI = 0.938** |
| **RMSEA<0.08, 90%LCI<0.05 & 90%HCI<0.08** | **RMSEA = .075 90%CI [.049, .099]** | **RMSEA = .076 90%CI [.051, .100]** | **RMSEA = .067 90%CI [.041, .091]** |

*Note.* $\chi^2$: chi-squared statistic, CFI: Bentler comparative fit index, RMSEA: Steiger–Lind root mean square error of approximation, CI: confidence interval, LCI: lower value of confidence interval, HCI, higher value of confidence interval, $*p < .05$, $**p < .01$, $***p < .001$. Bold means criteria were met.

The fit indices for the initial model (Model One: all associations between covariates identified in the bivariate correlations and outcomes included) were tested (see Appendix G for figure). An inspection of the estimates revealed that the relationship between age and hedonic wellbeing and employment and eudaimonic wellbeing were not significant and these regression paths were removed from the model. Upon inspection of the estimates of the second model (Model Two), it was shown than gender had non-significant associations with all 3TM mediators but did have a significant association with importance of parenthood (see Appendix G for figure). Due to literature highlighting gender differences in parenthood importance (Newton et al., 1999; Stöbel-Richter et al., 2005) and differential associations with wellbeing (Moura-Ramos et al., 2012), a third model (Model Three) was tested, where gender was considered to predict (instead of being associated with) importance of parenthood, which in turn predicted the three tasks, as considered in the 3TM. Sensitivity analysis indicated that the COVID-19 pandemic did not affect the model in this sample (Appendix H).

Overall, age was positively associated with acceptance, mental health, and

eudaimonic wellbeing. Whereas importance of parenthood was negatively associated

with acceptance and meaning making. Social support was positively associated with

all 3TM mediators. The strengths of associations were small to medium. Meaning

making was not significantly associated with any of the adjustment outcomes.

Acceptance was positively associated with mental health and hedonic wellbeing, and

pursuit of new goals was positively associated with all adjustment outcomes. The

strength of associations between 3TM mediators and adjustment outcomes were

medium. The covariances between the 3TM mediators and the adjustment outcomes

were positive and strong. The final model (Model Three) explained 43% of the total

variance in mental health, 46% in hedonic wellbeing, and 45% in eudaimonic

wellbeing.

**Participants experiences of the 3TM mediators**

Ninety-eight participants (65.8%) provided answers for at least one of the

open response questions about the 3TM mediators. Thematic analysis revealed 6

themes (Table 3.4; in text Q refers to quote reference in Table) and mapping of the

themes onto the 3TM is presented in Figure 3.3.

***Gradual but non-linear process to acceptance, where pain may always remain, and
a minority of participants demonstrated an insight into where they felt they were in
the adjustment process***

Around a third of participants referred to adjustment as a gradual process that

occurred over time (Q1) and that eventually it felt easier to manage (Q2). Around a

fifth of participant responses also highlighted that this was not a linear process and

that difficult emotions could come and go (Q3). Participants attributed these

fluctuations to triggering moments (Q4) and that at times moving through their

experience was a constant struggle (Q5). A minority provided responses that

indicated they were able to place themselves within this linear adjustment process,

**Table 3.4**

*Themes and quotes demonstrating participants experiences of the 3TM mediators*

| Theme | Quote reference | Example quotes |
|---|---|---|
| *Gradual but non-linear process to acceptance, where pain may always remain, and a minority of participants demonstrated an insight into where they felt they were in the adjustment process.* | Q1 | "Time heals to an extent and I recognise that I can and do 'get round/accept' childlessness because it is an immovable fact for me." (P123, F, 58) |
| | Q2 | "I no longer feel the acute sadness at not being a mother. I can very easily be around people with children without experiencing hurt or pain or feeling 'I will never have this'" (P111, F, 39) |
| | Q3 | "I feel that the path to recovery and acceptance is not linear, from time to time something will come along and swipe you in the face with childlessness but I'm learning not to dwell on those moments." (P20, F, 48) |
| | Q4 | "There are triggers every day which can floor me out of the blue and set me back in my journey." (P106, F, 41) |
| | Q5 | "it is a daily challenge that I work towards acceptance of my childlessness but it often feels like two steps forward three steps back and the sense of failure I get from this is overwhelming" (P185, F, 44). |
| | Q6 | "I accepted long ago that I would be childless" (P73, M, 42) |
| | Q7 | "I feel that I have accepted it most of the time, with little wobbles in between." (P85, F, 37) |
| | Q8 | "I feel that one day I will be able to accept and cope well with my childlessness, but it's too early in my journey at the moment, and I'm still finding it very tough." (P133, F, 48) |
| | Q9 | "I can fill my life with other things so I'm not just sitting depressed and hoping. Those things though are very different to what they would be if I was a mother and that is a constant psychological reminder that I am different. This is why I think I'll never really accept it" (P75, F, 63) |
| *Participants engaged in cognitive coping strategies to facilitate adjustment, but some were more beneficial than others.* | Q10 | "I tend to focus on the positives of my situation and the good things that have emerged, some of which would likely not have been possible if I'd had children" (P6, F, 37) |
| | Q11 | "I find that trying to see the positive can sometimes diminish the acknowledgement of the pain and loss, so I try not to do that so much." (P5, F, 40) |

| Theme | Quote reference | Example quotes |
|---|---|---|
| | Q12 | "I find it very difficult to look for something good in what is happening as I don't see anything good in my inability to have children." (P185, F, 44) |
| | Q13 | "I need to grieve the losses and process my trauma before I can step into a life where my childlessness is not the main focus of my identity and existence" (P5, F, 40) |
| | Q14 | "What is much more helpful is getting in touch with the pain and allowing myself to feel that which can be hard sometimes because we cover it up with daily life" (P109, F, 52) |
| | Q15 | "When I get distressed about being childless I have to tell myself that it's not my fault, and to try and look at from an alternative viewpoint of its something that has happened to me not because of something that I did or didn't do." (P185, F, 44). |
| | Q16 | "When I feel in distress about my childlessness, I try to support the feelings through self-compassion." (P132, F, 42) |
| | Q17 | "I cope with my childlessness by trying to avoid setting[s] where I am reminded of my loss and difference, which works well enough but can narrow my life opportunities sometimes." (P141, F, 42) |
| | Q18 | "I guess I accept it [childlessness] because I have to." (P22, F, 51) |
| | Q19 | "I can cope with being childless as there is no real choice but it doesn't make it any easier." (P92, F, 60) |
| | Q20 | "I cope with it because I have no choice short term but the ability to do this wears thinner as time goes on" (P119, F, 44) |
| *Participants were able to allude to some of the benefits of their experience, including a sense of personal growth.* | Q21 | "I've realised who understands and cares about me and reach out to them when I need to" (P64, F, 44) |
| | Q22 | "For example, going back to university at 37 - I doubt that I would have done that had I had children." (P85, F, 37) |
| | Q23 | "my experience has meant I have had to be resilient. I have had to be strong and keep going despite the adversity of leading a life that I never envisaged or would have chosen for myself" (P76, F, 38) |
| | Q24 | "I feel coming to terms with involuntary childlessness is as equally a transformational experience as becoming a parent." (P66, F, 48) |
| | Q25 | "I have to believe that this will make me a stronger and better person because something has to be worth the pain!" (P130, F, 37) |
| *Some societal contexts (e.g. pronatalist), lack of social support,* | Q26 | "I can have accepted being childless BUT society and the workplace make it ALMOST IMPOSSIBLE to cope with because we live in a pronatalist society which shames childless people, especially women" (P101, F, 50) |

| Theme | Quote reference | Example quotes |
|---|---|---|
| *and avoidance can make the adjustment process more difficult.* | Q27 | "I still don't feel like I fully have a place to share the grief." (P97, F, 37) |
| | Q28 | "I think one of the main issues I have is that we are ignored in society. We are unseen and unheard but each childless women has an unique story that should not be silenced." (P60, F, 39) |
| *Alternative goals are meaningful and provide sense of fulfilment.* | Q29 | "I have developed my creative side, I sew, do pottery and upcycle things" (P92, F, 60) |
| | Q30 | "we are in the planning stage of a trip of a lifetime to New Zealand" (P152, F, 40) |
| | Q31 | "I've established a new career, which is something I'd always dreamed of - but thought impossible." (P6, F, 37) |
| | Q32 | "My career is very important to me. I work in the charity sector…I believe the job I'm doing contributes to creating a better world and I am at peace with myself because of this." (P7, M, 58) |
| | Q33 | "I have been hosting a local meetup group to give me a sense of purpose and helping others to connect" (P141, F, 42) |
| | Q34 | "Supporting women in tech and diversity in the workplace" (P131, F, 42) |
| *Seeking other goals requires support and can be difficult and for a minority alternative goals will never replace the desire for children or be as fulfilling.* | Q35 | "I really struggle with this one. I don't have a plan B." (P103, F, 38) |
| | Q36 | "I seem to go up and down when it comes to other goals. I have difficulty sticking to pursuing other goals." (P104, F, 60) |
| | Q37 | "I believe the counselling I am receiving will also help me find my way in life." (P126, F, 51) |
| | Q38 | "I have been thinking a lot recently about changing careers/doing something more meaningful but this is hard mental work. I just feel quite weary about the whole thing." (P187, F, 47) |
| | Q39 | "I have some things I would like to do but know that I need to be able to talk to people about my childlessness without shame if I am to build friendships" (P146, F, 49) |
| | Q40 | "There is nothing that compares to being a parent so no point in looking for alternatives. It's not like trying to find a different pair of shoes." (P3, F, 47) |
| | Q41 | "I currently still feel that my life is pointless without children. I have tried to look for other goals but none seem to have the same value." (P88, F, 47) |
| | Q42 | "I have other goals but they still feel second best and that attaining them will never give me what being a mother and part of mainstream society would have." (P75, F, 63) |

*Note.* Q = quote number; P = participant; F = Female; M = Male; age is provided in years).

**Figure 3.3**

*Mapping qualitative themes onto the 3TM*
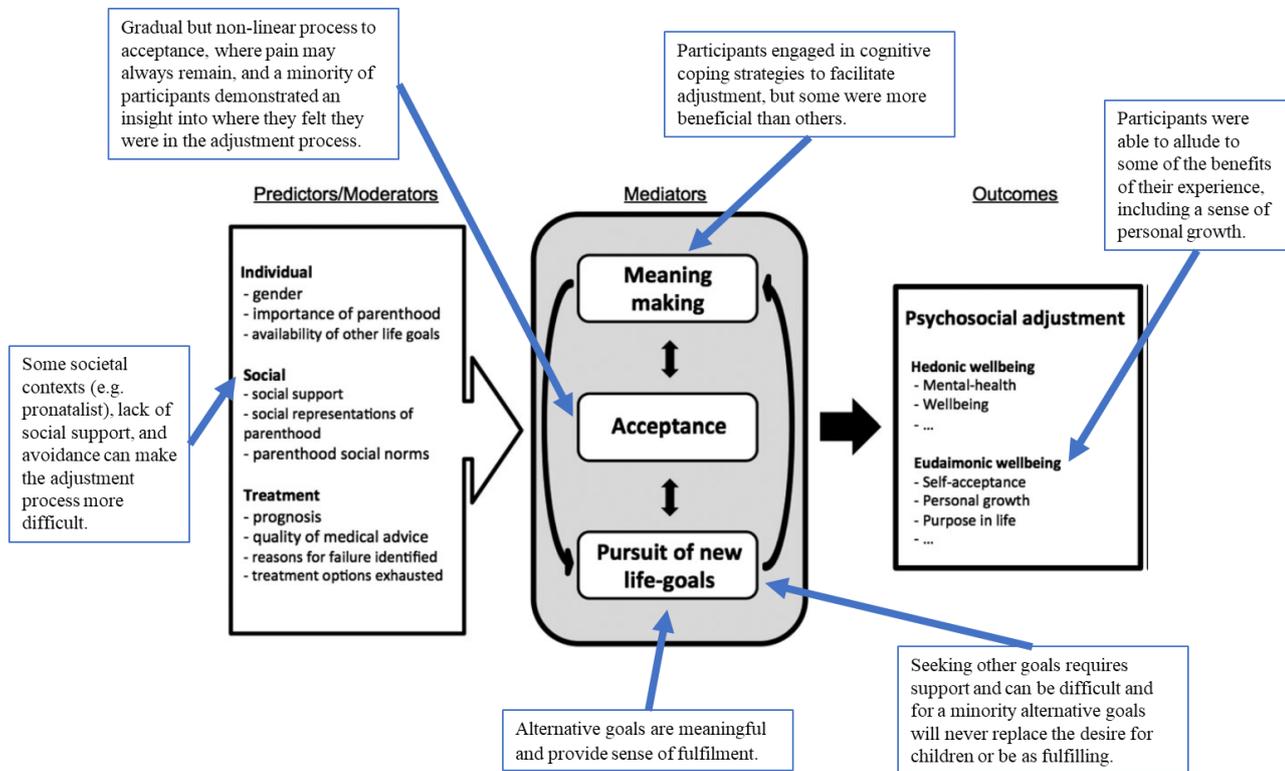


*Note.* Blue arrows and blue text boxes represent themes from current study mapped onto the 3TM.

for example some participants felt that they had reached full acceptance (Q6) and others felt they had accepted but experienced occasional challenges (Q7). Some participants felt that they would reach acceptance at some point, but that it was currently too early in the process (Q8). Finally, some participants thought they would never reach a point of acceptance (Q9).

***Participants engaged in cognitive coping strategies to facilitate adjustment, but some strategies were more beneficial than others***

Participants provided examples of cognitive coping strategies that they had used. For example, over a third of participants' responses indicated that they had engaged in positive reappraisal coping by trying to find the positives in their experience (Q10). However, a small minority of participants indicated that looking for positives in their experience was not acceptable to them (Q11), or that it was not possible for them to see any positives (Q12). Around half the participants reported awareness and willingness to both grieve the losses (Q13) and face the difficult emotions associated with the experience (Q14) to help them adjust. A minority tried to look at their experience with a different perspective (Q15) or engage in self-compassion (Q16). Some participants indicated that they engaged with avoidance coping, but that this did limit the opportunities in their life (Q17). Just under a fifth of participants portrayed coping or accepting as something they did not have much control over or choice about (Q18 and Q19) and others indicated that keeping this up became difficult over time (Q20).

***Participants were able to allude to some of the benefits of their experience, including a sense of personal growth***

A minority of participants were able to provide specific examples of the benefits they experienced because of their experience, such as learning who was a supportive friend (Q21) or being able to return to further education (Q22). Others saw the experience as something to learn from or that they had more opportunity to travel in the absence of children. Just under a fifth of participants referred to ways in which they had a sense of personal growth because of their childlessness, for example they felt they had become stronger and more resilient (Q23) and that it was even a transformational experience (Q24). Participants also felt they could become a better person because of the challenge they had faced (Q25).

***Some societal contexts (e.g., pronatalist) and a lack of social support can make the adjustment process more difficult***

A minority of participants noted that the societal beliefs and norms that they lived in, namely pronatalist societies, made reaching acceptance more challenging (Q26). Participants reported not feeling comfortable to be open about their grief (Q27) and that when this was experienced, it fostered a sense of being ignored or silenced (Q28).

***Alternative goals are meaningful and provide sense of fulfilment***

A majority of participants were able to provide examples of alternative goals that brought them a sense of meaning or purpose. Many of these goals involved activities participants enjoyed, such as being creative (Q29), learning new languages or travelling (Q30). Around a fifth of participants had turned to their careers for fulfilment, for example, starting a new career (Q31) or working in the third sector (Q32). Just under a fifth reported that they supported and advocated for other childless people (Q33) or others in need (Q34). Finally, a minority of participants reported they had also pursued further education as an alternative goal.

***Seeking other goals requires support and can be difficult and, for a minority, alternative goals will never replace the desire for children or be as fulfilling***

Around a third of participants reported difficulties in seeking alternative goals to parenthood. Some reported that it was difficult to either think of other goals (Q35) or remain committed to other goals (Q36). A small minority of participants referred to engaging with support when responding the questions about their goals (Q37). Other participants wanted to pursue other meaningful goals, and perhaps had even thought of some, but taking the steps towards pursuing the goal(s) was hard work (Q38). One participant noted that they needed to work through some of their difficulties before engaging in new goals, for example the ability to talk about their childlessness (Q39). A minority of participants referred to alternative goals never

being able to replace a desire for children or provide the same fulfilment. For

example, one participant indicated that they could not see the benefit in seeking

alternative goals (Q40). Others noted that even when alternative goals are pursued,

they could not ever be as fulfilling as parenthood (Q41) or facilitate a sense of being

part of mainstream society (Q42).

**Differences in the 3TM mediators and psychosocial adjustment in participants sustaining and not sustaining a child-wish.**

Mean differences on the 3TM mediators and adjustment outcomes for those

who did or did not sustain a child-wish are presented in Table 3.5. Multivariate

analysis of variance showed significant group differences on the 3TM mediators

according to whether participants sustained a child wish or not (controlling for

gender) ($F$ (3, 129) = 14.13, $p < .001$; Wilk's $\Lambda$ = 0.76, partial eta squared, $\eta^2_p$ =

.24). Follow-up univariate results indicate that participants who sustained a child

wish had a lower acceptance and meaning making than participants who no longer

sustained a child-wish. No significant differences were observed for pursuit of new

goals.

Multivariate analysis of variance showed significant group differences on the

adjustment outcomes according to whether participants sustained a child-wish or not

(controlling for age, gender, relationship status, education, employment, experienced

fertility problems and/or treatment) ($F$ (3, 123) = 3.41, $p < .05$; Wilk's $\Lambda$ = 0.92,

partial eta squared, $\eta^2_p$ = .08). Follow-up univariate results showed that participants

who sustained a child wish reported lower mental health and hedonic wellbeing. No

significant differences were observed for eudaimonic wellbeing.

**Table 3.5**

*Mean differences (and standard deviations) on the 3TM mediators and adjustment*

*outcomes for participants who did and did not sustain a child-wish*

| | Sustained a child-wish | | | | | |
|---|---|---|---|---|---|---|
| | Yes (*n* = 80) | | No (*n* = 54) | | | |
| | *M* | *SD* | *M* | *SD* | *F* (1,131) | $\eta^2_p$ |
| **3TM mediators** | | | | | | |
| *Acceptance*[a] | 14.61 | 5.12 | 19.21 | 4.36 | 34.96*** | .21 |
| *Meaning Making*[a] | 9.98 | 3.24 | 12.25 | 3.32 | 16.82*** | .11 |
| *Pursuit of New Goals*[a] | 21.45 | 4.77 | 22.44 | 5.29 | 1.46 | .01 |
| **Adjustment Outcomes** | (*n* = 79) | | (*n* = 54) | | *F* (1, 125) | $\eta^2_p$ |
| *Mental Health*[b] | 50.70 | 19.96 | 60.89 | 18.10 | 8.12** | .06 |
| *Hedonic Wellbeing*[b] | 41.43 | 21.04 | 51.26 | 20.89 | 9.15** | .07 |
| *Eudaimonic Wellbeing*[b] | 39.17 | 8.08 | 41.31 | 9.53 | 2.57 | .02 |

*Note.* \*$p$ < .05, \*\*$p$ < .01 \*\*\*$p$ < .001, *M* = mean, *SD* = standard deviation. [a] Controlled for Gender [b]

Controlled for age, gender, relationship status, education, employment, experienced fertility problems

and/or treatment. *F* ratio = follow up univariate analysis of variance; $\eta^2_p$ = partial eta squared.

## Self-reported support needs: professional and informal support and use of an online app

### Formal support

Fifty-seven participants (40.4%) reported feeling they would need to or had

already engaged with professional or formal support (e.g., mental health

professional) for their childlessness, and a similar number (59 participants, 41.8%)

said they did not feel they needed this support. Eight participants (5.7%) noted they

had engaged with therapy for other issues (e.g., alcohol, spousal bereavement etc)

and referred to talking about their childlessness during these sessions. Seventeen

participants (12.1%) provided text responses that indicated they were unsure or that

they would only seek this type of support on certain conditions, for example, seven

participants (5.0%) who were unsure felt that professional support should only be

provided from someone who had knowledge or insight of the psychosocial

implications of childlessness or had experienced it themselves.

*Informal support*

Eighty-nine participants (62.2%) reported that they felt they needed informal support, for example the opportunity to talk or share their experience with others in a similar situation on online forums, whereas only 38 participants (26.6%) did not feel they would engage with this. Sixteen participants (11.2%) indicated they were unsure about using this support, citing reasons such as some online forums having negative environments, or being only for people with fertility issues.

*Use of an online app*

Nearly half the participants (68, 48.9%) who answered the question about using an online app to manage the psychological and social implications of being childless by circumstance said they would use this type of support. However, 55 participants (39.6%) said they would not use an online app for support, citing reasons such as it may lack options for connection to others, or not wanting pre-programmed responses. The remaining participants (11.5%) were unsure about using an app.

*Online app content*

Thirty-two participants (21.4%) provided a textual response with suggestions for content for an online app. The majority of responses indicated that participants would like an online support app to provide them with a way to connect to others who are in a similar situation. This could be either directly via online interaction: 'if we could chat if we wanted to that would be lovely' (P181, M, 56); or learning about others' experiences and how they overcame challenges; 'Examples of women (past and present) who have survived childlessness by circumstance and are thriving' (P103, F, 38). It was noted that this should be vetted and moderated, and preferably lead by other involuntarily childless people; 'properly moderated, membership vetted in some way…I'd want it to be run by other childless-not-by choice / childless-by-circumstance people' (P66, F, 48). Only one participant mentioned anonymity.

A majority of participants indicated that they would like an online support to provide mental health support, practical advice and resources about childlessness. Regarding mental health support, they felt that inclusion of positive, motivational quotes would be helpful; 'I think affirmations, positive quotes' (P77, F, 47), and support with the grief experienced; 'Support on grief as that is the most misunderstood part of childlessness' (P20, F, 48). Around a quarter of responses suggested that practical advice and information would be useful, for example, advice for organising support groups; 'Help with organizing local support groups at churches or elsewhere within the community' (P103, F, 38), or advice supporting oneself in later life; 'tips for planning to support yourself in retirement (without adult children)' (P186, F, 39). Within this support and advice, participants particularly wanted to see content that would help them manage difficult or triggering situations; 'Constructive support i.e., how to manage certain situations' (P80, F, 47), and could even offer support during one of those situations; 'it could be used in moments of difficulty and triggering situations' (P132, F, 42), 'something that can make you feel less alone when you are at a social gathering and someone says something upsetting/tactless?' (P92, F, 60). Over a third of participants felt that the inclusion of resources about childlessness would be beneficial, including information about health issues; 'health implications of never having children, especially for women' (P186, F, 39), and more generally signposting to resources such as books, podcasts.

Around a third of textual responses referred to the heterogeneity of the childless by circumstance population and referenced to separate sections within the app for either different pathways: 'I just think it [should]…be welcoming to all and then special information for each group' (P187, F, 47); or different stages of the

journey; 'acknowledgement that we're all at different stages of our journey so different areas in the app' (P66, F, 48).

**Childless experience during COVID pandemic**
Fifty-four (36%) participants provided textual response to the questions asking for further comments about the COVID-19 pandemic. Of these responses, around a third referred to feeling frustrated with the emphasis of families with children in the media and assumptions about the childless experience; "nasty comments on social media about how easy childless people are having it during the pandemic" (P66, F, 48). Around a quarter of responses indicated that the pandemic had exacerbated feelings of loneliness, isolation and lack of purpose; "The 'lack of purpose' and loneliness feels even more acute in a lock down scenario." (P76, F, 38). Finally, just over a quarter of responses indicated that some participants experienced some positives because of the pandemic, such as having more time to reflect and engage in grief work; "I've had more time to reflect and do my grief work" (P100, F, 38).

## Discussion

**Overall findings**
        Results indicate that the individuals who consider themselves childless by circumstance struggle to adjust and a majority consider that they would need support to move through this process. Childless by circumstance individuals describe a similar adjustment process to those that experience unsuccessful treatment. They report that adjustment occurs progressively over time, with some participants demonstrating insight into where they were in that process and some reporting a sense of personal growth resulting from progression through that process. Important protective factors play a role in this adjustment process, such as a supportive and culturally favourable social context, the passage of time, and disengaging from the

parenthood goal (lower importance of parenthood, not sustaining a child-wish).

Overall, the findings suggest that support interventions for infertile individuals and

those who consider themselves childless by circumstance can be similar.

Quantitative data showed that the participants in this study may be facing

adjustment difficulties related to their childlessness, indicated by poorer mental

health and wellbeing scores when compared to normative data. Qualitative responses

corroborate this with participants reporting the difficulties they have faced, such as

feeling that adjusting to their childlessness is a daily struggle and that the pain

resulting from this may never disappear. A majority felt that informal support (e.g.,

via online forums etc) was needed, however there was more variability for the need

to seek formal support (e.g., a mental health professional). Firstly, this indicates that

those who consider themselves childless by circumstance are willing to seek support

in response to difficulties faced in adjusting to their childlessness, and secondly this

suggests that informal support may be preferred to formal support or perhaps that

this is easier to access. Barriers to formal support may be stigma of engaging with

mental health support (Rüsch et al., 2005) and the often-associated cost. Participants

also noted that if they chose to engage with mental health professionals, they should

have a comprehensive understanding on the implications of being childless to

provide the most effective support. Around half of participants indicated willingness

to engage with online support indicating that support could successfully be delivered

via self-help informal online support. Due to the cross-sectional nature of this study,

it is possible that individuals who have not faced difficulties in adjusting or have

already adjusted are underrepresented in this survey as the findings here contrast the

results of longitudinal studies carried out with childless individuals, such as

Maximova & Quesnel-Vallée's (2009) and Graham's (2015) studies, where it was

reported that overall childless people are able to successfully adjust over time But as stated earlier, these studies often do not determine whether the childlessness is involuntary or report that childless intentions had changed over time.

Although the 3TM was developed from meta-synthesis of literature for infertile individuals who had unmet parenthood goals as a result of unsuccessful fertility treatment, the empirical model from these data showed a good fit to the theoretical model, providing new evidence that the 3TM could also be applied to individuals who consider themselves childless by circumstance. Childless by circumstance individuals appear to be able to easily find other meaningful goals, engage in cognitive coping, have an awareness of the need to be in contact with uncomfortable emotions. The quantitative data also demonstrates that those who try to reach acceptance of their situation and pursue other meaningful goals may have better mental health and wellbeing. However, meaning making, operationalised as positive reappraisal coping, did not predict adjustment outcomes, although qualitative data indicates that around a third did engage in this type of coping. Some research proposes that meaning making is formed from two distinct processes: making sense and finding benefit (Davis et al., 1998) and it is suggested that adjustment occurs from first making sense, and then finding benefit (Janoff-Bulman & Frantz, 1997). It is possible that the participants in this study may still be in the 'sense making' phase of meaning making. Alternatively, other research with breast cancer patients considers benefit finding as the 'identification of benefit from adversity' (p487) and positive reappraisal coping as the extent to which individuals 'intentionally use benefit-related information as a coping strategy' (p487-88), and found that those who engage in benefit finding only, and do not translate this into positive reappraisal coping, did not see improvements in well-being (Sears et al.,

2003). Textual responses suggest that participants in this study were able to identify

some benefits, but it is possible they were not utilising this benefit-related

information to cope with their childlessness. It is also possible that this study sample

engaged in other meaning making strategies that were not measured here. The

qualitative data responses did show that a small minority of participants found

positive reappraisal coping as unacceptable, supporting the argument that other

strategies may be more beneficial. Consistently, the pursuit of new goals is

associated with all three measures of adjustment outcomes highlighting that this has

an important role in helping individuals move forward in the adjustment process, and

this was supported by the qualitative data which demonstrated that a majority of

participants were engaging in other meaningful goals and participants were able to

articulate how these were bringing fulfilment to their lives.  In summary, these

findings suggest that the 3TM provides a theoretical understanding of the adjustment

experience that childless by circumstance individuals undergo, but that additional

measures of meaning making should be considered in future work.

Participants indicated that adjustment occurred over time but that this process

was not linear, and pain may remain. This reflects similar experiences that have also

been described for those following unsuccessful treatment (Daniluk, 2001; Wirtberg

et al., 2007). This non-linear process highlights the challenging process of

adjustment. Reminders of their undesired childlessness and triggers of difficult

emotions can occur at any time and over prolonged periods as normative milestones

are met by their peers, for example becoming parents and then grandparents. This is

similar to the findings reported by Koert and Daniluk (2017) who also found that

processing the loss required repeated and ongoing work. The cognitive behavioural

model of complicated grief suggests that when there is poor integration of the loss

into autobiographical knowledge or avoidance, that grief symptoms can reoccur

(Boelen et al., 2006). This suggests that the avoidance coping some participants

alluded to in their text responses is likely to be a barrier to adjustment. Despite this

challenging process, some participants reported a sense of personal growth

suggesting that post traumatic growth (PTG), a positive change resulting from a

challenging life event, (Tedeschi & Calhoun, 2004) may be possible as a result of the

experience of being involuntarily childless. Other research has demonstrated PTG

may occur following infertility (Paul et al., 2010) and bereavement (Calhoun et al.,

2010). In sum, adjustment process to being childless by circumstance is a

challenging and ongoing one, exacerbated by repeated triggers as one is unable to

meet normative milestones.

The findings of this study suggest that several factors shape the experience of

being childless by circumstance. For example, socially favourable contexts play a

protective role in the adjustment process for childless by circumstance individuals.

The presence of supportive relationships facilitates engagement with the three tasks

in the 3TM, individuals perhaps prefer to seek support informally, and online self-

help support is expected to facilitate connection with others. Other research has also

noted the benefits of sufficient social support for infertile childless individuals by

reducing the associated distress (Lechner et al., 2007), and even offsetting ineffective

coping styles (Verhaak, Smeenk, Evers, et al., 2005). However, if social support is

perceived as unsatisfactory by individuals who experience unsuccessful fertility

treatment, this may lead to negative consequences, such as increased distress and

avoidance coping (Daniluk, 2001; Mindes et al., 2003). This was also reflected in

some participant responses in this study who noted reasons why they might avoid

informal support, for example some online forums keep a person focussed on the

negatives or there can be a perceived hierarchy of the different experiences which results in less support, e.g., perception that online support is only for individuals who experience infertility. Furthermore, the context of a pronatalist society can result in a perceived lack of social support, stigma, and loneliness. As social identity seems significantly affected by the childless by circumstance experience (Miall, 1986), social identity theories can offer an explanation of the sense of 'us' (non-parents) and 'them' (parents) (Tajfel et al., 1979). Qualitative data from this study alluded to a sense of being marginalised and suggests this context is a barrier to them being able to move forward in their adjustment, and the COVID-19 pandemic had exacerbated this for some participants.

Other protective factors that shape the childless by circumstance experience include attributing a lower importance to parenthood and not sustaining a child-wish. According to the model, those who attributed a higher importance to parenthood were less likely to engage in the acceptance and meaning making tasks. However, the model also suggested that attributing higher importance of parenthood did not appear to hinder engagement with other goals. This may be linked with the higher socioeconomic status of these participants, for example a majority were employed and had a degree, and therefore may not consider their parenthood goals as considerably more important than other life goals. Other research has shown that individuals with lower socio-economic status may place a higher importance of parenthood (Moura-Ramos et al., 2012). Nearly two thirds of participants reported that they had sustained a child-wish demonstrating that childless by circumstance individuals do sustain this wish in a similar way to individuals who experience childlessness through infertility. The data suggests that those who did hold onto their child-wish appeared to find it harder to move towards acceptance, engage in positive

reappraisal coping, and had poorer mental health and hedonic wellbeing. This is

consistent with other literature that suggests infertile childless women who sustain a

child-wish are nearly three times more likely to develop clinically significant mental

health disorders than those who no longer hold on to this wish (Gameiro et al., 2014)

and experience more adjustment difficulties (Kraaij et al., 2008; Verhaak, Smeenk,

Evers, et al., 2007; Verhaak, Smeenk, Nahuis, et al., 2007). However, sustaining a

child-wish did not seem to be barrier to pursuing other goals for this population, nor

did it seem to be associated with eudaimonic wellbeing. It appears that these

participants were able to engage in other goals that brought them fulfilment, despite

holding on to their wish for children. Literature focussing on adjustment of

individuals who have a sustained child-wish following unsuccessful treatment may

provide insight into where the participants of this study are in the adjustment

process. For example, research suggests that around 3-5 years after end of treatment

around 40% (of infertile women) still have a child wish (Verhaak, Smeenk, Nahuis,

et al., 2007), then 10 years later approximately 25% (Wischmann et al., 2012), and

then 11-17 years later this falls to around 6% (Gameiro et al., 2014). Applying this to

our study sample suggests that these participants are either in the early stages of

adjustment or, without the definitive cut off point such as ending treatment,

relinquishing this child wish may take longer for childless by circumstance

individuals. The suggestion that this relinquishment takes longer, and is challenging,

is supported by most participants indicating that they would seek support and half

reporting they would use an online app for support. If these participants are early in

their adjustment process, it is possible that sustaining a child-wish could hinder the

adjustment process. However, the cross-sectional nature of this study makes it

difficult to make any definitive conclusions. The majority of participants sustaining a

child-wish may simply reflect the characteristics of the participants who chose to take part in this study as individuals who have found it particularly difficult to adjust to their childlessness and relinquish their child-wish. In sum, a socially favourable context that is also not parenthood centric, a lower importance placed on parenthood and the ability to relinquish a child-wish, are likely to shape the childless by circumstance experience.

The findings from this study provide evidence that a support intervention should be developed individuals who consider themselves childless by circumstance. The participants suggest that content should include practical advice; expectation management that the adjustment process may always be ongoing and repeated cognitive work may be required to manage difficult emotions; more interactive elements to facilitate connection with others, e.g., via online forums or chat; and additional resources, such as blogs, literature and research. In addition, participants alluded to the difficulties of living within pronatalist societies and strategies to manage these difficulties should made explicit in support provided. Acceptance strategies such as cognitive defusion (Masuda et al., 2010; Masuda et al., 2004), may be useful when dealing with a societal context that is beyond one's control. Recognition of the diversity of experiences that may lead to a UPG was also considered as important and this could be supported by providing examples of different experiences of others with UPGs, highlighting this diversity and promoting inclusivity. Those who considered that they will never be able to accept their childlessness may be reluctant to engage with online self-help. However, some research suggests that online self-help programs may promote help seeking behaviour (Kauer et al., 2014; Taylor-Rodgers & Batterham, 2014), suggesting that an online self-help intervention, could still be beneficial.

**Strengths and limitations**

The strength of this study is the mixed methods approach. Quantitative analysis has provided evidence for a theoretical understanding of the childless by circumstance adjustment process and this was triangulated with qualitative data, enabling the researcher to support and contextualise the findings by providing a nuanced understanding of the complexities of the experience. That the participants were invited if they self-identified with being childless by circumstance is also a strength as it led to a diverse sample, providing insight the different perceptions or pathways leading to circumstantial childlessness. This highlights the challenge of trying to use distinct labels such as 'childless by circumstance'. Just under 10% of participants experienced fertility problems/and or treatment indicating that people may attribute circumstances that have postponed their parenthood goals as the main reasons for their childlessness which subsequently led to experiencing infertility. However, it is difficult to know this for certain. There is also novel evidence that childless by circumstance individuals want and do seek support to help them overcome the challenges faced as a result of their childlessness. It is well known that male participation in fertility and childless research is often lacking (Greene & Biddlecom, 2000; Harrison, 2012), but this study has a comparatively high proportion of men, ensuring heterogeneity of the study sample and enabling the researchers to investigate the predictive role of gender on the importance of parenthood and the association between gender and social support in the final model. Gender also had significant correlations with one mediator (acceptance) and one outcome (mental health), indicating that women experience worse mental health and acceptance compared to men. Although, there is mixed research on whether there are gender differences in adjustment to UPGs (Maximova & Quesnel-Vallée, 2009; White & McQuillan, 2006), overall, it is considered that women experience worse adjustment

to men (Ying et al., 2015). Therefore, further work on adjustment to UPGs should continue to ensure a high proportion of male participation in studies and consider analysis exploring gender differences. However, this study was cross-sectional and therefore causality is difficult to distinguish. The social relationships scale used in this study was not a validated scale and although the reliability was very good, it is not clear what exactly was measured. Future work should use a validated scale to gain understanding about which aspects of social support play the most importance role. The sample size was small, and this should be taken into consideration when interpreting results. Attrition rates were just under 50% which is consistent with other online surveys, but better financial incentives (Göritz, 2006) or particular attention to the initial information presented in the survey (Hoerger, 2010) should be considered in future studies to minimise attrition rates. All participants were self-selected and therefore might bias the findings towards individuals who has experienced the most difficulties adjusting their childlessness and who are more likely to seek support. Although the use of online recruitment platforms has become more prevalent, some concerns have been highlighted about the lack of naivety (e.g., participants are familiar with questionnaires) (Chandler et al., 2015) and motivation (i.e., to earn money) of participants. However, Prolific was developed specifically for researchers (Palan & Schitter, 2018) and a previous study has noted that the data quality from Prolific is high, assessed via measures of attention, naivety, and dishonesty, and provides access to a diverse population, when compared to other platforms such as MTurk (Peer et al., 2017). Around a third of participants in this study were recruited via Prolific and it is possible, that these participants were not seeking support for their UPG and could have captured people who met the inclusion criteria but having a UPG may not have been so central to their life or identity.

Therefore, it would have been useful to conduct analysis to see whether those who were likely to be seeking help (recruited from social media) differed on measures of psychological adjustment from those who were not. Finally, analysis of the qualitative questions asking more in-depth questions about the childless by circumstance experience were not included in this chapter.

**Implications**

As with previous research with infertile patients (Chapter 2), the participants of this study expressed wish for support to address social issues and further expansion of this could be to develop a more in depth understanding of the specific aspects of social relationships and support that help to address the social challenges faced by childless by circumstance individuals. Future work should also focus on forming a better understanding of how this population may engage with meaning-based coping. This can then be incorporated into the content development of the online support app. For childless by circumstance individuals who do engage with formal support, the findings of this study should be considered by mental health professionals. The empirical evidence for a theoretical framework of adjustment presented may help provide insight into which therapeutic techniques would be most beneficial (e.g., acceptance-based therapy). Additionally, it has highlighted factors that shape the childless by circumstance experience, such as the social context or sustaining a child-wish, which should also be considered when supporting clients.

## Chapter 4: Development of the intervention: MyJourney

## Introduction

The following chapter will describe, in detail, the development process of the intervention – from theory to the development of an intervention to put forward for feasibility testing. The previous two chapters (2 and 3) formed key activities in the early development process and will be referred to here.

As noted in the previous chapters, and to reiterate, undesired childlessness and the number of people having fewer children than desired has been increasing in the UK and across Europe (Miettinen et al., 2015) and the COVID-19 pandemic is likely to have accentuated this trend (Ibarra et al., 2020; Smith et al., 2020; Trombetta et al., 2021). The majority of people faced with a UPG undergo a challenging and prolonged adjustment process and may benefit from support to move through this process. Research has demonstrated that considerable effort has been put in to supporting people while they are undergoing treatment (Frederiksen et al., 2015), but less attention has been paid to supporting them adjusting in the aftermath of unsuccessful treatment. Despite evidence showing that support needs at this stage completely differ from the treatment period (Verhaak, Smeenk, Van Minnen, et al., 2005), only one support intervention has been evaluated (Kraaij et al., 2016). More specifically, the evidence suggests that effective support should not focus on promoting stress management or other coping skills specific to overcome treatment challenges, but on helping people to integrate the loss into their lives (acceptance), find meaning from their past experience and current situation (meaning making), and pursue other meaningful life goals (pursuit of new life goals), which should lead to better mental-health and wellbeing (Gameiro & Finnigan, 2017)

(Appendix A). While there is a paucity of research on those who face a UPG due to reasons other than infertility, for instance unfavourable circumstance or other health problems, it can be argued that they also have a need for and seek out support (Chapter 3). Although peer-based support is available online and in person (pre-COVID) (e.g., Gateway Women, The Dovecote, MoreToLife Health Unlocked Forum), and anecdotally people report experiencing benefit, this support has not been empirically evaluated for its effectiveness or unintended consequences.

Online delivery of psychosocial support has been increasing and further emphasis been placed on the development of web-based support (WHO, 2020). Online self-guided interventions, for instance web-based apps, are easy to implement widely, allowing accessible, anonymous access at a time and place that suits individuals and without waiting lists. They also bypass possible stigma by indicating to individuals that other people are seeking support (Donkin & Glozier, 2012), which may validate self-perceptions of support need and motivate engagement. They are well suited for sub fertile individuals, who value online information (Tuil et al., 2006) and feel more comfortable with online interactions than face-to-face (Malik & Coulson, 2008). Individuals who consider themselves childless by circumstance also seek out online support (Chapter 3). Therefore, a self-guided internet-based intervention, named MyJourney, was developed. MyJourney is easily accessible and meets the needs of, and is acceptable to, individuals with a UPG, addressing the gap in evidence-based support for this population.

Within the intervention literature there is considerable focus on the evaluation, and often the development and formative evaluation phases are not as well reported (Michie & Abraham, 2008; Wight et al., 2016). Development guidance highlights the benefits of planning and developing an intervention carefully: the

intervention is more likely to be implemented, it is more likely to be acceptable, and resources are not wasted in full scale evaluation of an intervention that may not be effective (Craig et al., 2008). Several frameworks for intervention development are available, and in the UK the Medical Research Council's (MRC) framework for complex interventions (Craig et al., 2008) has been widely adopted. Consistent with other frameworks, it recommends a phased approach to intervention development, beginning with an evidence or theory-based understanding of the problem; modelling of how it can be addressed, which should be closely linked to the production and refinement of the intervention prototypes; followed by feasibility pilot testing of the intervention; and after, full efficacy evaluation, for example via a randomised controlled trial. MyJourney was developed following the phases of the MRC framework, of the which the development phase includes 3 elements: identifying the evidence base; identifying and developing the theory; and modelling processes and outcomes, which will be reported in this chapter. Following the development phases is a feasibility and piloting phase, which will be reported on Chapter 5. Early MRC guidance suggested the phases of the MRC framework occur in a stepwise manner (Campbell et al., 2000). However, more recently and in practice, developing an understanding of the problem, developing the intervention, and its evaluation can occur simultaneously and in a cyclical manner, facilitating an iterative process of intervention optimisation (Campbell et al., 2000; Campbell et al., 2007; Skivington et al., 2021).

The first key objective in the development of complex interventions is to identify the evidence-base, which consists of developing an understanding of what is known about similar interventions and how they have been evaluated (Craig et al., 2008). The second is to identify and develop theory, which facilitates intervention

development based on an understanding of the processes of change (i.e., mediators

or outputs) necessary for the desired outcomes to occur. Once the evidence and

theory-base have been established, the third objective is to model the components of

the intervention. Logic models are a useful tool to any intervention development

project, by graphically demonstrating the proposed causal logic (Kellogg

Foundation, 2004). In particular, this is useful when an intervention is complex with

a number of interacting components (Craig et al., 2008).

There is consensus that investigating the needs of potential users from their

perspective is a key part of modelling processes and outcomes (Baker et al., 2014;

van Gemert-Pijnen et al., 2011). Given the paucity of evidence-based interventions

for individuals with a UPG, understanding the needs of this population from their

perspective was critically important to identify the outcomes MyJourney should

target. Therefore, to compliment the theory-based approach to intervention

development, patient and public involvement (PPI) was incorporated in the

development phases of MyJourney. In addition to PPI, it is also recommended that a

person based approach (PBA) is adopted (Muller et al., 2019; Yardley, Morrison, et

al., 2015), whereby potential users are not only asked for their views on practical use

of the intervention, but also about the intervention content and what might act as

facilitators or barriers to use, via the use of qualitative and mixed-methods designs

(Campbell et al., 2000). Involvement of potential users is extremely beneficial

identifying the intervention processes and designing and producing their underlying

therapeutic activities, even more for online self-guided interventions, as this will

facilitate an understanding about how users might engage with the intervention and

how its delivery can be optimised (Yardley, Morrison, et al., 2015). Think aloud

interviews can offer insight into users' initial impressions of early intervention

prototypes, enable the researcher to understand how the intervention might be used

(Van den Haak et al., 2007), and highlight the aspects that are most important to

users. Findings from these interviews can assist refinement of the intervention and

once these refinements are made, further feedback should be collected. The PBA

also contributes to the generation of intervention guiding principles to promote

acceptability of and engagement with the intervention (Yardley, Morrison, et al.,

2015). The guiding principles reflect in the design or layout and user-interface of the

intervention (Yardley, Ainsworth, et al., 2015).

The aim of this development phase was to co-produce a free and easily

accessible self-guided, internet-based psychosocial intervention that meets the needs

of and is acceptable to individuals with a UPG. Therefore, this chapter provides a

detailed description of the development phase of MyJourney, including identifying

the evidence base, identifying and developing the theory, and modelling processes

and outcomes. These are reported in line with GUIDED recommendations (Duncan

et al., 2020): associated checklist presented in Appendix I). As a result of this phased

development process, it is expected that MyJourney will be used by people with a

UPG and to prove feasible and efficacious in forthcoming evaluation studies.

## Methods and Materials

### Core intervention development team[2] and timelines

The development phase includes three elements: I. identifying the evidence base,

II. identifying and developing the theory, and III. modelling processes and outcomes.

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[2] This chapter reports on the full development process of MyJourney, but the author was not involved in the first element of the development phase (identifying the evidence base). The author was the lead or co-lead on all other phases.

Table 4.1 presents a chronological description of each of MyJourney's development

activity. The team consisted of two clinical psychologists with expertise in fertility

care (S.G. and A.G.) and a doctoral researcher (B.R.). The first prototype of the

intervention was produced between September - November 2018. PPI involvement,

directed at informing intervention design, occurred between March 2019 – October

2019 and in September 2020. Prototype refinement occurred between April 2020 –

November 2020, when the MyJourney feasibility trial was launched.

**I. Identifying the evidence base**

Systematic mixed-methods review of studies reporting on psychosocial

adjustment after unsuccessful fertility treatment published between 1978 and

December 2015 in 5 electronic databases. This mixed-methods review was

conducted by Gameiro and Finnigan (2017) and aimed to investigate how patients

adjust after failed fertility treatment, and to determine the components of an

explanatory model of adjustment that could form the basis of future theory-led

interventions. Quantitative studies had to include group mean comparisons on

psychological adjustment (wellbeing, mental health) between patients who had a

failed treatment and a control group (successful treatment, with children after

treatment). Two meta-analyses were performed on the group's mean difference in

mental-health and wellbeing with a random effect model, with Hedge's g as the

primary outcome (.20, .50, .80 indicated small, moderate, and large effect sizes).

Quality of the studies was also reported on. Qualitative studies had to focus on

experiences of psychosocial adjustment after failed treatment. A three-stage thematic

analysis was conducted on results reported in the primary qualitative studies

included, producing first order descriptive and second-order interpretative themes.

**Table 4.1**

*MyJourney development process: chronologic description of each development activity, including their names, time frame, goals, main findings and outputs*

| Activity | Time frame | Goal | Main findings | Outputs |
|---|---|---|---|---|
| **I. Identifying the evidence base** | | | | |
| **Systematic mixed-methods review** | October 2014-February 2017 | To quantify the impact of undergoing unsuccessful fertility treatment and identify a theoretical model that can inform theory-led interventions to promote adjustment to UPGs | Undergoing unsuccessful fertility treatment is associated to moderate to large impairments in mental-health and wellbeing.<br><br>After unsuccessful fertility treatment, people who are willing to experience the difficult emotions, thoughts and experiences associated with their UPG (acceptance), who try to make-sense of past efforts to have children and re-evaluate their life values (meaning-making), and who define and pursue new fulfilling goals (pursuit of new life goals) report being able to progressively adjust to their UPG. | Three task model of adjustment to unmet parenthood goals (3TM), which predicts that acceptance, meaning making and pursuit of new life goals are associated with positive adjustment to an UPG. |
| **II. Identifying and developing theory** | | | | |
| **Identification and empirical testing of the theoretical model underlying MyJourney: the 3TM.** | a) November 2017-March 2018<br><br>b) April 2020-September 2020 | To test the validity of the 3TM in two populations: a) People who self-identify as having a UPG b) People who self-identified as childless due to unfavourable circumstances | a) findings indicate the 3TM can be applied to people who self-identify has having a UPG, regardless of the pathway that led to this. b) findings indicate the 3TM can be applied to people who self-identify as having a UPG as a result of unfavourable circumstances, but additional targeting of social issues/support is needed. | Empirical evidence in support of applying the 3TM model to inform the development of MyJourney. However, social aspects may not be sufficiently supported by only targeting the three tasks. |
| **III. Modelling processes and outcomes** | | | | |

| Activity | Time frame | Goal | Main findings | Outputs |
|---|---|---|---|---|
| **Development of MyJourney's logic model** | November 2018-November 2020 | To graphically depict the causal logic underlying MyJourney | MyJourney should integrate a total of 10 therapeutic activities. Three activities – 'Be kind to yourself', 'Travel at a safe distance' and 'Step out of your comfort zone' - are expected to promote users' acceptance of their UPG; two activities – 'Set your direction of travel' and 'Illuminate your journey' - will support users in making meaning of their situation; and two activities – 'Plan your route' and 'Stay on route' - in the pursuit of new goals. Three additional activities are expected to validate the UPG experience and provide rationale for MyJourney, support connection to others (and acceptance), and promote maintenance of skills gained. By engaging with these 10 therapeutic activities, users will progressively adjust to their UPG, which should reflect in better hedonic and eudaimonic wellbeing, mental-health and post-traumatic growth. | Three iterative versions of the MyJourney's logic model were developed. The final logic model version (MyJourney v1) is presented in Figure 1. |
| **Formative evaluation activity 1 - Prospective qualitative acceptability study** | March 2019-October 2019 | To evaluate the acceptability of the 1st MyJourney prototype (MoreToLife Self-Help Guide) | The 1st MyJourney prototype was acceptable to users, but several improvements can be made to maximise acceptance. There is value in integrating the feedback received to continuing to develop MyJourney into a new prototype. | Compilation of a list of content and features of MyJourney which were valued and considered appropriate, as well as of a list of recommendations for improvements. |
| **Formative evaluation activity 2 - Consultation exercise** | September 2020 | To evaluate the acceptability of the 2nd MyJourney prototype (MyJourney v0) | Feedback on the 2nd MyJourney prototype (MyJourney v0) indicated it was perceived as comprehensive and flexible. Minor suggestions for improvement informed the final version of MyJourney v1. | Compilation of a list of content and features of MyJourney which were commended (Appendix L), as well as of a list of recommendations for improvements (Table 3). |
| **Development of guiding principles** | November 2018-November 2020 | To define guiding principles to inform development the design | To promote user engagement with MyJourney, a design and user interface that reflected inclusivity, | Six guiding principles described in Table 4 |

| Activity | Time frame | Goal | Main findings | Outputs |
|---|---|---|---|---|
| | | and user interface of MyJourney, to promote user engagement | empathy, and sensitivity to the UPG experience were important factors to facilitate engagement. | |
| **Therapeutic and technical development** | November 2018- November 2020 | To design and produce the MyJourney intervention | It is possible to iteratively design and produce a self-guided, interactive online intervention to support people adjusting to UPGs. | Three prototypes were produced: 1st: MoreToLife Self-Help Guide 2nd: MyJourney v0 3rd: MyJourney v1 – described in Table 5 |

A systematic review of existing psychosocial interventions for a UPG or adjustment after failed fertility treatment was not conducted because a rapid literature search only identified one intervention (Kraaij et al., 2016) already known by the team.

## II. Identifying and developing the theory

### *Identification and empirical testing of the theoretical model underlying MyJourney*

To investigate if  the theoretical model underlying MyJourney, the Three Task Model of Adjustment to Unmet Parenthood Goals (3TM), was applicable to explain the adjustment process of anyone with a UPG, it was tested in two populations: a) individuals who self-identified as having a UPG and not undergoing fertility treatment, regardless of parental status (childless, with children) and of the pathway leading to their UPG (infertility with treatment, infertility without treatment, and unfavourable circumstances) (Study One); b) individuals, aged 35 or older, who self-identified as childless due to unfavourable circumstances (e.g., lacked the right partner) (Study Two). Two independent survey-based cross-sectional studies were conducted. Each study was advertised online, via social media, charities, and Facebook and Google ads, and participants were offered the chance to win a small financial incentive for participation. In both studies participants were asked to complete an online survey assessing background and parenthood/fertility or childless profile (i.e., risk and protective moderating factors). Well-validated questionnaires (except where otherwise specified) were used to measure the psychological constructs hypothesized to underlie psychosocial adjustment to a UPG (i.e., three mediators: acceptance, meaning making, and pursuit of new goals) and psychosocial adjustment (outcomes: hedonic and eudaimonic wellbeing, and mental health). Empirical testing of the theory was conducted using path analysis with maximum likelihood estimation using IBM SPSS AMOS v23 structural equation

modelling software. In the second study only, to obtain an in-depth understanding of adjustment to being childless by circumstance, thematic analysis was conducted on textual responses of participants' perceptions of how they adjusted to their experience. Finally, to investigate these participants' needs for psychosocial support, descriptive statistics were used to describe their engagement with informal and formal support.

## III. Modelling processes and outcomes

### *Logic model development*

Informed by results from the previous research steps, a logic model was developed to graphically depict the causal logic underlying the MyJourney intervention, in particular the causal link between activities, mediators (outputs), and outcomes. This logic model was progressively refined throughout the development phases, in conjunction with the refinement of the intervention itself, informed by feedback from users collected in the formative evaluation activities described below.

### *Formative Evaluation Activities*

**Prospective qualitative acceptability study.** This was conducted in 2019 to evaluate the acceptability of the first intervention prototype of MyJourney. Participants, who considered themselves to have a UPG, were individually interviewed twice: immediately after they were first presented to the intervention (T1); and after they had an opportunity to engage with the content over eight weeks (T2). The interviews assessed participants' perceptions of how important (e.g., perceived benefits of using the intervention) and appropriate (e.g., willingness to use intervention) the intervention was. Interviews were carried out online and audio recorded. At T1, participants were asked to 'think aloud' to the researcher as they engaged with the intervention for the first time, a semi-structured interview then took

place. The interview was repeated at T2. Interviews were transcribed verbatim, and a recurrent cross-sectional analysis was conducted using thematic analysis.

**Consultation exercise.** This was conducted in September 2020. An advisory committee was formed to evaluate the second MyJourney prototype. The interdisciplinary committee consisted of users, reproductive health practitioners and research collaborators, marketing experts and fertility charities from the UK, USA, Netherlands, and Portugal (See Table 4.2). B.R. conducted and S.G. attended the English sessions and S.G. and A.G. conducted the Portuguese sessions. Members of the committee were presented with MyJourney and brief information on the intervention rationale (see Appendix J), after which they provided feedback via an online individual or group Zoom session. Feedback from the Portuguese sessions was translated to English by S.G. and A.G. and all feedback from the sessions was thoroughly examined to extract all recommendations for refinement or improvement, which were collated in a table. The core development team discussed the feasibility of implementing each of the recommendations. If it was deemed feasible within the timeframe defined for the start of the MyJourney feasibility trial, the change was implemented and incorporated in the current prototype of MyJourney (v1).

### *Development of Guiding Principles*

Guiding principles can be used to promote engagement and facilitate the development of a design that is suitable for target users (Yardley, Ainsworth, et al., 2015). This was done in group discussions between the core development team, a marketing expert, and the MyJourney design technical team. These discussions were informed by the results from other research activities (i.e., feedback from the acceptability study and consultation exercise) and literature on the delivery of self-guided online interventions.

**Table 4.2**

*Consultation exercise advisory committee members*

| Profession or patient role | Country | Individual or Group Session |
|---|---|---|
| Potential user | UK | Individual |
| Clinical Psychologist | USA | Group 1 |
| Professor of Health Psychology | UK | Group 1 |
| Consultant Assisted Reproduction | UK | Individual |
| Potential user (also a FNUK Volunteer) | UK | Individual |
| Professor of Medical Sociology | UK | Individual |
| Director of Human Fertilisation and Embryology Authority (UK) | UK | Group 2 |
| Associate Professor and Clinical Psychologist | Netherlands | Group 2 |
| Chair of British Infertility Counselling Association and Counsellor | UK | Group 2 |
| Potential user and organiser of childless support network | UK | Group 3 |
| Potential user and organiser of childless support network | UK | Group 3 |
| Chief Executive of leading UK Fertility Charity | UK | Individual |
| Associate Professor (Marketing) | UK | Individual |
| Associate Professor in Assisted Reproduction and Consultant | Portugal | Individual |
| Associate Professor in Assisted Reproduction and Embryologist | Portugal | Individual |
| Potential user | Portugal | Individual |
| Clinical and Health Psychologist in Reproductive Medicine | Portugal | Individual |
| Clinical Psychologist and Assistant Professor in Reproductive Health | Portugal | Individual |
| Clinical Psychologist and Post -Doctoral Fellow Health Psychology (experience in developing online apps) | Portugal | Individual |
| Nurse working a Public Fertility Centre | Portugal | Individual |

The persuasive system design (PSD) model (Oinas-Kukkonen & Harjumaa, 2009) suggests that features of digital design can influence adherence with interventions (Kelders et al., 2012), therefore design principles from this model were also used to develop guiding principles and inform the design and delivery of MyJourney.

***Therapeutic and technical development***

The intervention activities were mostly based on the Acceptance and Commitment Therapy (ACT) therapeutic framework (Hayes et al., 2006). This framework was judged adequate because of its sound evidence-base and because it aligns with the MyJourney theoretical model of adjustment to a UPG (the 3TM), as ACT aims to: promote a willingness to experience unpleasant or uncomfortable thoughts and emotions as part of the human experience (similar to acceptance);

clarify core values (valued life directions) for areas of life that are most important and encourage one to live congruently with those values (one aspect of meaning making); and facilitate committed action to value-based goals (essential to pursuit of new goals). However, if deemed necessary to trigger the hypothesized mechanisms of change, other therapeutic frameworks were used, such as self-compassion (Neff & Tirch, 2013) and mindfulness (Grossman et al., 2004). Despite being based on general therapeutic frameworks, all MyJourney activities were tailored to its target population. To cater for different usage preferences, multiple modes of delivery were combined: psychoeducation, audio mindfulness and compassion meditations, and interactive exercises.

Once the first MyJourney prototype was developed, a cyclical process of formative evaluation (as described above) and refinement occurred, encompassing both therapeutic and technical development and extending over a total period of 12 months, culminating in the production of the third prototype (MyJourney v1) submitted for feasibility evaluation.

## Results

### I. Identifying the evidence base

***Systematic mixed methods review***
Nine quantitative (9052 individuals from eight countries) and nine qualitative (267 individuals from six countries) studies were included. Two of the quantitative studies (22%) had high quality ratings, seven were moderate (78%), and none had low ratings. Three of the qualitative studies (27%) had high quality ratings, eight were moderate (73%), and none had low ratings. Six quantitative studies (67%) reported on mental-health and seven (78%) on wellbeing. Results from the meta-analysis show that individuals in the unsuccessful treatment group experienced

poorer mental health (g = -0.450, p = .002, 95% CI [-0.734, -0.267]; I2=85%, $p <$ 0.001) and wellbeing (g = -0.319, $p$ <0.001, 95%CI [-0.439 -0.198], I2=45%, $p =$ 0.001) than the control group. Meta-synthesis of qualitative data (33 first-order themes, grouped into six second-order themes) showed participants perceived their individual, relational and social adjustment improves over time, while experiencing fewer support needs, resulting from efforts to 1) accept their situation (i.e., a willingness to experience difficult emotions and experiences), 2) make meaning of it (i.e., making sense of past efforts and re-evaluating life values), and 3) pursue new life goals, i.e., finding other fulfilling goals and 'moving on' from their experience (e.g., caring for others, travelling).

These mixed-methods findings were operationalized in the proposal of the Three Task Model of Adjustment to Unmet Parenthood Goals (3TM). This model proposes a comprehensive framework of the therapeutic mechanisms that promote adjustment to a UPG and underlies the development of MyJourney. Discrepancies in the findings indicated that the qualitative data suggested a more positive perspective of adjustment over time in comparison with the quantitative data. Reasons for caution relate to few studies being included as this is an emergent topic and only five (25%) being rated as high-quality. Furthermore, the qualitative synthesis was based on published data that already had a degree of interpretation.

## II. Identifying and developing the theory

### Identification and empirical testing of the theoretical model underlying MyJourney

**Study One.** The 3TM was identified and empirically tested in a final sample of 420 individuals who self-identified as having an unmet parenthood goal (full report in Appendix A). The average age was 35 years old ($SD$ = 8.57) and only two

(0.5%) participants were men. The majority were in a relationship (91%), had a university education (63%), and were employed (75%). The empirical test of the 3TM showed a good fit to the theoretical model ($\chi^2(24) = 28.147$, $p = .253$, CFI = 0.997, RMSEA = .021 90%CI [.000, .047]). The model explained 41%, 43% and 35% of variance in mental-health, hedonic and eudaimonic wellbeing, respectively. Positive reframing was associated with better eudaimonic wellbeing ($\beta = .198$), acceptance with mental health ($\beta=.148$) and hedonic wellbeing ($\beta =.244$), and pursuit of new goals with better mental-health and hedonic and eudaimonic wellbeing ($\beta = .273, .223, .410$). The model was also found to be invariant across participants who did or did not do fertility treatment. However, those with fertility or health problems who did engage in fertility treatment were more likely to have stopped trying to conceive (N = 109, 63.0%, $p < .001$) and were older ($M = 38.91$, $SD = 8.12$, $p < .001$, partial eta squared, $\eta^2_p = .153$). People with fertility or other health problems who completed treatment reported better mental health ($p < .05$, $\eta^2_p = .020$) and eudaimonic wellbeing ($p < .05$, $\eta^2_p = .029$) than those who did not do treatment.

**Study Two.** The 3TM was identified and empirically tested in a final sample of 149 individuals who self-reported as childless by circumstance. The detailed results of this study can be found in Chapter 3. The average age was 46 years old and 29 (20%) were men. Around half (51%) were in a relationship and a majority had a university education (81%) and were employed (80%). The empirical data had a good model fit to the theoretical model proposed ($\chi^2(53) = 88.522$, $p = .002$, CFI = 0.938, RMSEA = .067 [.041, .091]). The model explained 43%, 46% and 45% of variance in mental-health, hedonic and eudaimonic wellbeing, respectively. Acceptance had positive associations with mental health and hedonic wellbeing ($\beta = .255, .245$), and the pursuit of new life goals had positive associations with all

psychological outcomes (mental health, $\beta = .291$, and hedonic, $\beta = .258$, and eudaimonic wellbeing, $\beta = .254$). However, meaning making (measured as positive reframing) was not significantly associated with any of the outcomes. Multivariate analysis of variance also indicated that participants who sustained a child wish had lower acceptance and meaning making scores that those who did not sustain this wish ($F (1, 131) = 34.96$, $p < .001$; partial eta squared, $\eta^2_p = .21$; $F (1, 131) = 16.82$, $p < .001$; partial eta squared, $\eta^2_p = .11$ respectively). Results also showed that participants who sustained a child wish reported lower mental health ($F (1, 125) = 8.12$, $p < .01$; partial eta squared, $\eta^2_p = .06$) and hedonic wellbeing ($F (1, 125) = 9.15$, $p < .01$; partial eta squared, $\eta^2_p = .07$). Thematic analysis revealed six themes: Gradual but non-linear process to acceptance, where pain may always remain, and a minority of participants demonstrated an insight into where they felt they were in the adjustment process; Participants engaged in cognitive coping strategies to facilitate adjustment, but some were more beneficial than others; Participants were able to allude to some of the benefits of their experience, including a sense of personal growth; Some societal contexts (e.g., pronatalist) and a lack of social support can make the adjustment process more difficult; Alternative goals are meaningful and provide a sense of fulfilment; Seeking other goals requires support and can be difficult and, for a minority, alternative goals will never replace the desire for children or be as fulfilling. These themes highlighted that individuals who are childless by circumstance experience adjustment difficulties and appear to engage with the three tasks outlined in the 3TM. Descriptive statistics showed that participants were willing to seek formal (57, 39.3%) and informal (89, 64.0%) support to help them move through their adjustment process. Furthermore, of the

participants who answered the question about using an online app for support, 68

participants (48.9%) said they would use this type of support.

Reasons for caution for both these studies include their cross-sectional

design, meaning causality is difficult to determine, and participants being self-

selected and therefore possible bias in the findings towards individuals who have

experienced the most difficulties adjusting their UPG and who are more likely to

seek support.

## III. Modelling processes and outcomes

### *Logic Model*

Several logic model versions were iteratively developed for MyJourney

(Chapter 2: Figure 2.1; Appendix E and K). The final logic model is presented in

Figure 4.1, which integrates all reviews done in response to feedback received during

the formative evaluations. All the logic models included four components: 1. Input –

the inputs required to produce MyJourney; 2. Activities – the specific therapeutic

activities of MyJourney, which were developed to trigger the hypothesized

mechanisms of change; 3. Outputs – the hypothesized mechanisms of change

(mediators); 4. Outcomes – the desired outcomes of MyJourney. The logic model

also presents the set of assumptions about the therapeutic frameworks chosen to

underlie MyJourney and users' engagement with it generated from the literature and

expert opinion, as well as factors that may impact on implementation, including

anticipated barriers and facilitators.

**Figure 4.1**

*Logic Model of MyJourney (v1)*



| Input | Activities: Steps and Routines | Outputs | | Outcomes |
|---|---|---|---|---|
| | **Step 1: Your starting point** *Routine*: Stop and be present[m] | Validation of experience and intervention rationale | | |
| | **Step 2: Be kind to yourself** *Routines*: Loving kindness[m] / Self-compassionate postcard[j] | Self-compassion | Acceptance | **Primary:** Hedonic wellbeing |
| Activities based on Three Task Model of adjustment (Gameiro and Finnigan, 2017) and acceptance and commitment therapy (Hayes and Smith, 2005) and self-compassion (Neff and Tirch, 2013) therapeutic frameworks. | **Step 3: Travel at a safe distance** *Routines*: Watching thoughts[m] / Weight of your luggage[j] / I am having the thought that[p] | Cognitive defusion | | |
| | **Step 4: Set your direction of travel** *Routines*: Act values[p] / Think values[j] / Talk values[o] | Value clarification | Meaning Making | **Secondary:** Eudaimonic wellbeing |
| | **Step 5: Illuminate your journey** *Routines*: Feeling the positives[m] / Good daily vibes[p] | Positive reappraisal | | |
| | **Step 6: Plan your route** *Routines*: Fit new habits in your routine[p] / Enlist help[o] / Future steps[j] | Goal definition | Pursuit of other meaningful goals | Mental – health |
| | **Step 7: Step out of your comfort zone** *Routines*: Stop and breathe in difficult situations[m] / Acceptance aids[p] | Experiential avoidance | | Post-traumatic growth |
| | **Step 8: Connect to others** *Routines*: Reacting to insensitive comments[o] / Giving and taking meditation[m] / The wall of insensitive comments[p] | Connectiveness skills | Connection to others | |
| | **Step 9: Stay on route** *Routines*: Keep going[p] / Facing a dead end[j] / Stay committed[p] | Committed action towards goals | | |
| | **Step 10: Looking ahead** *Routines*: Remember your ABC[j] / Self-compassion break[m] / Looking ahead kit[j] | Promote maintenance | | |

*Assumptions:* Efficacy of ACT and self-compassion, fit between ACT and self-compassion associated therapeutic activities and mediators of the 3TM (outputs), users will engage to the extent they will receive a 'sufficient' dose of intervention to produce moderate (effect size) change in outcomes.

*External factors*
**Barriers:** Lack of general awareness & policy about support for UPGs, stigma. **Facilitators:** easily accessible, no training required, no cost to users.

*Note.* [m]=Mindfulness meditation (audio), [j]= journaling, [p]= practicing new skills, [o]= can be completed with someone else.

The inputs were the 3TM as the underlying theoretical model and the expertise of clinical psychologists. MyJourney consists of a total of ten activities (Table 4.3 for rationale). Most activities were designed to trigger one specific mechanism of change (mediator), but one activity (Step Eight: Connect to others) triggers both acceptance and connection to others. The activities designed to trigger acceptance were based on principles of self-compassion, cognitive defusion, experiential avoidance, and social connectiveness. Those designed to trigger meaning making were based on values clarification and positive reappraisal coping. Finally, those designed to trigger pursuit of new goals were based in goal definition and committed action. Based on results from empirical testing of the 3TM, it was hypothesised that increases in acceptance will result in improvements in hedonic wellbeing and mental health, increases in meaning making efforts will result in improvements in eudaimonic wellbeing, and increased engagement with other meaningful goals will result in improvements in mental health, hedonic and eudaimonic wellbeing. Engagement with all tasks was hypothesised to promote a sense of personal growth, considered within eudaimonic wellbeing in the 3TM, and operationalised as post-traumatic growth in the logic model. In sum, based on the magnitude of effects found in the quantitative and qualitative meta-synthesis, it was expected that exposure to all MyJourney activities will emulate the full adjustment process to a UPG (as portrayed by people who underwent it), which should result in moderate to large increases in outcomes.

**Table 4.3**

*Therapeutic targets and mechanisms of change (mediators) for each Step in MyJourney*

| Step | Therapeutic Target | Mediator | Definition and Rationale |
|---|---|---|---|
| ***1. Your starting point*** | Validation of experience and rationale for intervention | | *Definition:* Validate the UPG experience and present rationale for support overall. Promote insight into how one feels etc at start of engagement with support.<br><br>*Rationale:* Experience and grief often reported as 'invisible' to others (Kirkman, 2003; Koert & Daniluk, 2017; Tonkin, 2010) and people with UPGs may not realise they are experiencing grief or want to avoid that grief (Fieldsend & Smith, 2020), therefore validation of the experience is important (Gameiro & Finnigan, 2017). |
| ***2. Be kind to yourself*** | Self-compassion | Acceptance | *Definition:* Self-compassion consists of three components: self-kindness, common humanity, and mindfulness, which aim to promote a positive view towards one's self and experiences (Neff, 2003).<br><br>*Rationale:* Empirically, self-compassion is positively associated with acceptance (Neff & Tirch, 2013; Neff et al., 2005). Acceptance is a key mechanism of adjustment to a UPG (Gameiro and Finnigan, 2017). For example, many people blame themselves for their UPG and therefore developing self-compassion could be beneficial. Self-compassion is considered an adaptive coping strategy that can facilitate acceptance of stressful situations (Allen & Leary, 2010). People who report being more self-compassionate engage in less experiential avoidance (Costa & Pinto-Gouveia, 2013). |
| ***3. Travel at a safe distance*** | Cognitive defusion | Acceptance | *Definition:* Cognitive defusion describes one's ability to distance themselves of their internal experiences, observing them as psychological states or events rather than literal representations of reality (Forman et al., 2012; Masuda et al., 2004).<br><br>*Rationale:* Cognitive defusion can minimise the emotional discomfort of negative thoughts or emotions (Masuda et al., 2010; Masuda et al., 2004). Non-clinical sample exposed to a pro-defusion experimental condition reported increased willingness and reduced discomfort of negative self-statements (Healy et al., 2008), i.e., facilitated acceptance. Acceptance is a key mechanism of adjustment to a UPG (Gameiro and Finnigan, 2017). |

| Step | Therapeutic Target | Mediator | Definition and Rationale |
|---|---|---|---|
| *4. Set your direction of travel* | Value clarification | Meaning Making | *Definition:* Values are principles through which one feels a sense of meaning and purpose in life and clarification of these values facilitates one to identify and then define what is most important to them (Harris & Hayes, 2019).<br><br>*Rationale:* It is considered that many people make meaning from stressful life events by being able to clarify their values or priorities in life (Park, 2010; Park & Folkman, 1997). Values based interventions have demonstrated desired effects on numerous outcomes (Rahal & Gon, 2020). Considering one's values associated with parenthood is a key mechanism of adjustment to a UPG (Gameiro and Finnigan, 2017). |
| *5. Illuminate your journey* | Positive reappraisal coping | Meaning Making | *Definition:* Positive reappraisal coping is described as cognitive efforts to re-evaluate a situation or experience in a positive way to change the meaning, and is a form of meaning-based coping (Folkman, 1997, 2008; Lazarus & Folkman, 1984; Park, 2010).<br><br>*Rationale:* Positive reappraisal is thought to lead to a sense of meaning when faced with a stressful life event (Garland et al., 2015; Lazarus & Folkman, 1984). Positive reappraisal coping has been reported as a useful coping strategy in the face of uncontrollable stressful life events, including a UPG (Kraaij et al., 2009; Kraaij et al., 2008; Ockhuijsen et al., 2014b). |
| *6. Plan your route* | Goal definition | Pursuit of other goals | *Definition:* Defining achievable goals (short, medium, and long-term) based on one's underlying values (Hayes et al., 2006).<br><br>*Rationale:* Both the focus of goals and the motivation behind them (e.g. values) can influence well-being (Sheldon et al., 2004). Pursuing other meaningful goals away from parenthood is an important mechanism of successful adjustment to a UPG (Gameiro and Finnigan, 2017). |
| *7. Step out of your comfort zone* | Experiential avoidance | Acceptance | *Definition:* Experiential avoidance is considered the opposite to acceptance and is the unwillingness to experience emotions, thoughts, feelings etc and is reflected in a person taking steps to change the form or frequency of these private experiences (Hayes et al., 2006; Hayes et al., 1996).<br><br>*Rationale:* Experiential avoidance, when it is costly or life altering, is correlated with poorer mental health and wellbeing and other measures of psychopathology (Hayes et al., 2004; Kashdan et al., 2006; Tull et al., 2004). Minimising experiential avoidance can increase the willingness to engage with negative or uncomfortable thoughts or emotions, thereby promoting acceptance. Building acceptance of difficult thoughts or emotions can lead to living a more fulfilling life (eudaimonic wellbeing) (Davis et al., 2016) and acceptance is a key mechanism of adjustment to a UPG (Gameiro and Finnigan, 2017). |
| *8. Connect to others* | Connectiveness skills | Connection to others | *Definition:* Perceptions of positive or meaningful social relationships with or support from others (Eisenberger & Cole, 2012; Wilkinson et al., 2019). |

| Step | Therapeutic Target | Mediator | Definition and Rationale |
|---|---|---|---|
| | | Acceptance | *Rationale:* Social connection appears in Maslow's Hierarchy of Needs (Abraham, 1954) and is one of the 3 basic human needs focused on within self-determination theory (Deci & Ryan, 2013). Social connection plays a role in both preventing and attenuating poorer mental health (Cruwys et al., 2013). Social connection can be disrupted after major life changes (Wilkinson et al., 2019), and therefore support to promote connection is important. Social support is a protective factor for adjustment to a UPG (Gameiro and Finnigan, 2017). Promoting social connection is also considered to promote acceptance as the perception of social support may minimising the need to engage with experiential avoidance. |
| *9. Stay on route* | Committed action towards goals | Pursuit of new goals | *Definition:* Committed action is defined as mindful, valued and effective action (Harris & Hayes, 2019). <br><br> *Rationale:* It is easier to stay committed to goals that are consistent with values and can promote long term improvements in wellbeing, and intentional action may be a bigger predictor of happiness (subjective wellbeing) than own set point (see paper) or circumstances (Lyubomirsky et al., 2005). Pursuing other meaningful goals away from parenthood is an important mechanism of successful adjustment to a UPG (Gameiro and Finnigan, 2017). |
| *10. Looking ahead* | Promote maintenance | | *Definition:* Promotion of insight into how one feels after engagement with the support and promotion of maintenance of skills developed. <br><br> *Rationale:* National Institute of Mental Health and Psychosocial Intervention Development Workgroup suggest psychosocial interventions should contain maintenance strategies to prevent recurrence of past problems/difficulties (Hollon et al., 2002). The adjustment process to a UPG is characterised by recurrent experiences of grief and loss, sometimes triggered by other peers meeting normative milestones (Gameiro and Finnigan, 2017), and therefore maintenance strategies could be used to support recurrence of adjustment difficulties. |

*Formative Evaluation Activities*

**Prospective qualitative acceptability study.** The detailed findings of the acceptability study can be found in Chapter 2. The analysis resulted in nine main themes organised under three higher order themes: intervention meets users' needs; working through the UPG experience; and the intervention is appropriate. Themes 'under intervention meets users' needs' showed all participants felt the intervention was useful and helpful, and most participants were able to describe how the activities had triggered the mechanisms of change in the logic model, with participants describing feeling better after engaging with it. Participants thought that connecting with others is important and that the intervention should support this. Themes under 'working through the UPG experience' highlighted that participants saw their experience of adjusting to a UPG as a journey that the intervention can facilitate. Around two thirds of participants initially felt concerned that engaging with the intervention might be challenging. However, a majority experienced no negative effect, with three participants reporting they felt upset at times. A majority noted it provided a structure to organise and clarify thoughts, whilst providing guidance to move through their loss. Themes under 'the intervention is appropriate' reflected participants considered the intervention acceptable due to being easy to use, comprehensive and appropriate. Nearly all participants used the intervention individually, with one using it verbally with their partner. Just under half engaged with it digitally, the rest printed out the activities. Barriers to appropriateness included limited digital access, poor interactivity, and unclear navigation. A minority of participants felt some sections were difficult to understand and some language was not always appropriate. The findings confirm the value of continuing the development of MyJourney by integrating participants' feedback and progressing to feasibility testing. This study only included a small homogenous sample of childless

married women presenting with infertility diagnosis and therefore may not represent

the views people who have children and wish to have more, those who consider

themselves childless by circumstance, and of men.

        **Consultation exercise.** The feedback from the advisory committee about

MyJourney was overall very positive. Specifically, the committee noted the

comprehensive nature of the support, commended the flexible nature of delivery

(e.g., users could engage at times that suited them), and that overall, this support

would be useful for those seeking support. Additionally, committee members who

represented potential users reported that they would recommend MyJourney to

someone else as it felt relatable and met the challenges one faces while going

through their own journey. Overall, suggestions for minor amendments were

provided, which are presented in Appendix L, with those deemed feasible and

integrated in the final version of MyJourney being presented below in Table 4.4.

**Table 4.4**

*Feedback from advisory committee and the changes that were implemented*

| Feedback | How the change was applied |
|---|---|
| *Accessibility* | |
| **Text too long in places** | Use of more bullet points and break up sections of text |
| **Language too complex** | Review all content and simplify language further |
| **Sequence of steps is not clear enough** | Addition of numbers against each step to show sequence |
| **Suggestion to include examples where users are asked to write down a response** | Include hints at the bottom of each text box with examples or further explanation of what users are being asked to write about |
| *Data protection/Security/Confidence in support* | |
| **Concerns about entering personal information/data** | Ensure terms of data protection and collection are explicit |
| **Suggestion to include information about the team who created MyJourney** | Addition of content on landing page with image and short bio of each person |
| *Inclusivity* | |
| **Request for inclusive support recommendations** | Ensure support page contains diverse support recommendations |
| **Queried if support was developed for men** | Make text clearer on language page that content is available for any gender |

| Feedback | How the change was applied |
|---|---|
| **Queries about how to support individuals who are not sure if they are ready to engage with support** | Addition of 'Not ready yet' page that outlines how a person can address this feeling and if not ready, to set a reminder to come back and engage with support at a later date |
| *User interaction* | |
| **Suggestion that users will want to receive feedback about their wellbeing score** | Provide tailored feedback (based on gender and country of residence norms (Topp et al., 2015)) for users, each time they complete wellbeing questionnaire |
| **Queries about the requirement for mandatory test responses to allow progression to the next step** | Remove mandatory text responses and replace with a prompt to remind users to write down their answers in order to get the most out of the support |
| **Suggestion to ensure examples provided are not too prescriptive** | Reviewed all examples to ensure they were supportive but not prescriptive |
| **Suggestion to make it clear about what happens when all ten steps are completed** | Include a pop up box at end of each step (including final step) to highlight what to do next |
| *Design* | |
| **Some icons are not appropriate (road signs)** | Replaced any road sign icons |
| **Suggestions to display which step users are on as they move through each page of the same step** | Title of step visible at the top of each page so users are reminded what step they are working on |
| *Specific content* | |
| **Step 3 – include content that encourages users not to judge or evaluate their own thoughts** | Included content that advises users think about whether they can just describe and not judge thoughts: 'Can I describe, not judge?' |
| **Step 4 – suggestion to amend the word 'domain' as too harsh** | Changed word life 'domain' to life 'area' to make language softer |
| **Step 7 – suggestion of more support for this step** | Included text at end to highlight benefits of not engaging in experiential avoidance and also recognition that this can be difficult |
| **Step 8 – suggestion to change title and reformat delivery of content to make it easier to read and ensure content reflects different cultures** | Changed title to reflect content more, split the content into three pages to make it easier to read, and updated responses to insensitive comments to reflect cultures where confrontation would not be appropriate |
| **Step 10 – suggestion to amend content to focus on tolerance of emotions rather than whether they have changed over the engagement of intervention** | Content was revised to encourage users to think about whether their tolerance of difficult emotions had changed while using the intervention and also to offer reassurance if no changes were perceived. |
| **Backpack – Looking Ahead Kit – suggestion to make it clear this can be used in advance of a difficult situation and normalising experiencing difficult situations** | Content revised to provide clear indication of when this section of the support can be used and reassurance that experiencing difficulty does not mean weakness |
| *Reminders* | |
| **Suggestion that any reminders are empowering** | Developed content of reminders to ensure that they were empowering and encouraging |

## *Guiding Principles*

**Development of guiding principles.** Table 4.5 presents the guiding

principles developed to inform MyJourney, particularly aiming to ensure it was

appropriate for the intended users and promoted engagement. Design principles were

also used from the PSD model (Oinas-Kukkonen & Harjumaa, 2009) to promote

engagement and are outlined in the table. For example, the primary task category

supports user's engagement with the intervention; dialogue support category

provides a degree of system feedback; system credibility support category outlines

principles to build an intervention that is credible; and the social support category

aims to motivate users to engage with the intervention via social leverage.

**Table 4.5**

*Guiding principles for MyJourney*

| Guiding principles – MyJourney should… | Key intervention features |
|---|---|
| *reflect empathy towards the experience of people with a UPG* | Use of positive, non-judgemental, simple, and empathic language. Provision of content to reassure users who are concerned about engaging in a challenging process of adjustment. |
| *inspire users to move forward through the adjustment process* | Tailoring of intervention by answers to previous steps being used in subsequent steps (e.g., users provide their own values, and these are presented in a subsequent step when users are asked to think of goals associated with their values). Principles from the PSD model – 'normative influence' (social support) (i.e., inclusion of quotes from others who have shared a similar experience to both normalise the experience and provide inspiration) and 'tailoring' (primary task) (i.e., users receive feedback on their wellbeing score). |
| *be inclusive to anyone who has a UPG* | Careful use of language to account for the heterogeneity of the experience and to ensure inclusivity of gender, parenthood status, ethnicity, etc. Not for profit intervention ensuring cost is not a barrier to use. |
| *promote user autonomy* | Allow users to engage with steps in the intervention at their own pace, but the sequence of steps is fixed so that users work through the intervention in a logical manner, which is informed by the logic model. Examples provided to prompt users to enter their own answers, or a set of options are provided, e.g., specific set of life domains provided (Step 4) from which users can build their own values and subsequent goals. Principles from the PSD model - 'reminders' (dialogue support) (i.e., email reminders were sent to users to complete a Step or start a new Step). |
| *promote user competence* | Provision of clear, structured support, with optional additional resources for those who wish to engage with them. Each therapeutic activity broken down into shorter sections (with step-by-step guidance) to enable users to engage on a smaller screen (e.g., smartphone) so that it can be engaged with at convenient moments. Encouragement of small goal setting and small changes to behaviour/engagement with thoughts to promote confidence. Principles from the PSD model – 'tunnelling' (primary task) (i.e., guiding the users through a series of Steps). |
| *promote trust in and credibility of the intervention* | Present a professional and consistent intervention design. Content that explains user data will be kept securely and in line with GDPR regulations. Intervention developed to meet the field guidelines (ESHRE, HFEA, NICE) that recognise that this support is needed. Principles from the PSD model – 'trustworthiness' and 'expertise' (system credibility) (i.e., providing information that the intervention was evidence-based and developed by experts). |

*Therapeutic and technical development*

**Development and refinement of intervention contents and delivery.** Table 4.6 presents the intervention contents and delivery, in accordance to the TIDieR checklist (Hoffmann et al., 2014) and Figure 4.2 presents screen shots of MyJourney. The first prototype of the intervention (The MoreToLife Self-Help Guide) is presented in Chapter 2. This initial prototype underwent considerable changes following formative feedback from the acceptability study. The most substantial changes included: (1) each activity presented as a Step and was rewritten to follow the same structure – an aim, a rationale, and the main exercise(s) which were split across multiple pages to make it easier to read on smaller devices; (2) the title and contents of each activity were amended to portray a sense of a journey and the sequence of Steps was re-evaluated; (3) the language was simplified and revised to minimise the anticipated challenges of engaging with the intervention and to increase inclusivity; (4) the delivery was transformed from static webpages to an interactive web-based design built around a journey metaphor, including mindfulness and compassion meditation audio files. In addition to this, the entire content was translated from English to Portuguese by an expert native speaker (including the mindfulness and compassion meditation audio recordings). This version (MyJourney v0) was then presented to the advisory committee for the consultation exercise and less substantial changes were then made, as summarised in Table 4.3, leading to the final version (MyJourney v1) put forward for feasibility testing.

**Table 4.6**

*Description of MyJourney (v1) as put forward for feasibility testing, according for TIDieR checklist (Hoffmann et al., 2014)*

| TIDieR Items | Description |
|---|---|
| *Brief Name:* | |
| **Provide the name or a phrase that describes the intervention** | MyJourney |
| *Why:* | |
| **Describe any rationale, theory, or goal of the elements essential to the intervention** | The 3TM (Gameiro & Finnigan, 2017) informed the hypothesised mechanisms of the change targeted by the intervention. Contextual Cognitive Behavioural Therapy (CCBT), in particular Acceptance and Commitment Therapy (ACT) (Hayes et al., 2006) was chosen as the therapeutic framework for the activities of the intervention expected to trigger the mechanisms of change, focussing on a person's relationships with their thoughts, emotions and behaviours (Hayes & Hofmann, 2017). |
| *What:* | |
| **Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (such as online appendix, URL)** | All materials for MyJourney were developed to be used independently by users at their own time and pace, and are provided within an online web app which can be accessed at www.myjourney.pt. This link provides access to the landing page which includes information about who MyJourney is for, what participants can expect and the benefits of engaging with MyJourney. To use MyJourney, participants must create an account and complete sociodemographic details, following this they can access the main content. |
| **Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities** | MyJourney is structured in two main sections: the Map and the Backpack. The Map is organized into ten ordered Steps, which correspond to the ten therapeutic activities of the MyJourney logic model. Therefore, each Step is a structured therapeutic activity designed to trigger a specific theorized mechanism of change (See Figure 1). Each Step has up to three additional optional therapeutic resources called Routines. These are unlocked with the completion of the Step and added to the Backpack area. These Routines are designed to encourage participants to sustain engagement with the Step therapeutic activity. Overall, each Step and its associated Routines can make use of different models of delivery (psychoeducation, audio mindfulness mediations, journaling, and interactive exercises) to engage users. |

| TIDieR Items | Description |
|---|---|
| | On completion of the last Step, participants get access to a Looking Ahead section, designed to prevent relapse by encouraging users to recognise the appropriate therapeutic skills to use in specific stressful or challenging situations they may face. |
| | At the start of each Step, users complete a wellbeing assessment (WHO-5, Life Satisfaction and Happiness scales) which provides them with their score from the WHO-5 in comparison to normative values and additional information to be able to interpret it. If users score below 50 repeated times or below 28 at any time (Topp et al., 2015), this triggers a message to users that recommends they seek additional support, e.g., an accredited mental health professional. A list of support contacts is also provided as this intervention is delivered without in-person support. |
| *Who provided:* | |
| **For each category of intervention provider (such as psychologist, nursing assistant), describe their expertise, background, and any specific training given** | N/A |
| *How:* | |
| **Describe the modes of delivery (such as face to face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group** | Web-based app designed to be used individually |
| *Where:* | |
| **Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features** | Users can engage with MyJourney wherever is most convenient for them and using their preferred device (e.g., tablet, smartphone, laptop). |
| *When and how much:* | |
| **Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity, or dose** | Participants are recommended to engage with one Step per week, implying that total time recommended for the intervention is 10 weeks. However, users are free to progress at their pace. Each Step takes approximately five minutes to read but each participant has the flexibility to answer (write down or reflect on) the questions or concepts introduced, or practice an associated skill, for as long as they wish. Completing the Step unlocks its Routines, as well as the next Step. There is no recommend time for users to spend on the Routines, and they can engage with the same Step and Routine repeated times. |
| *Tailoring:* | |
| **If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how** | The intervention is personalised to users. Users receive personalised feedback about their wellbeing scores. The MyJourney steps present users with questions for them to reflect on their personal circumstances and some of the data imputed is displayed in future Steps, so that users can continue reflecting on particular aspects of their situation. For instance, in Step 4 users are |

| TIDieR Items | Description |
|---|---|
| | asked to reflect and write down values and these are fed back on Step 6, so that users can define concrete goals that will help them pursue those values. On Step 9 users are then presented with the goals they defined and asked to consider ways they can commit to these goals. Overall, it is expected that this organization will provide a sense of personalisation or tailoring. |
| **Modifications:** | |
| **If the intervention was modified during the course of the study, describe the changes (what, why, when, and how)** | N/A |
| *How well:* | |
| **Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them** | N/A |
| **Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned** | N/A |

**Figure 4.2**

*Screen shots of MyJourney*
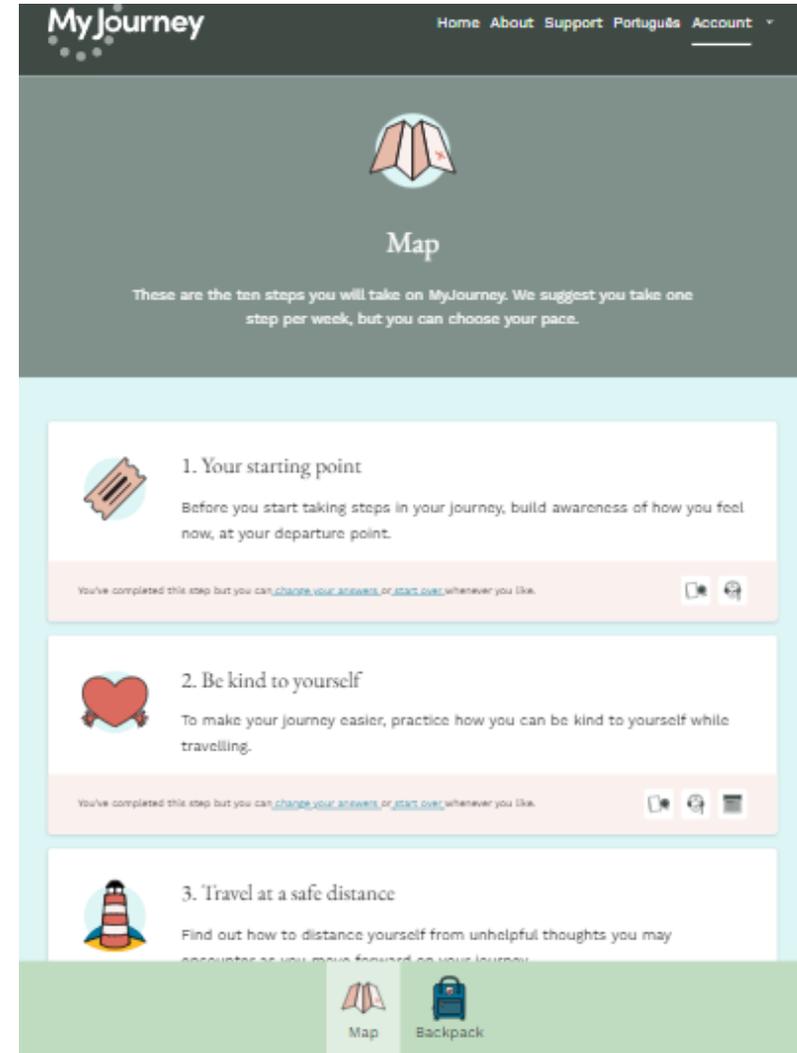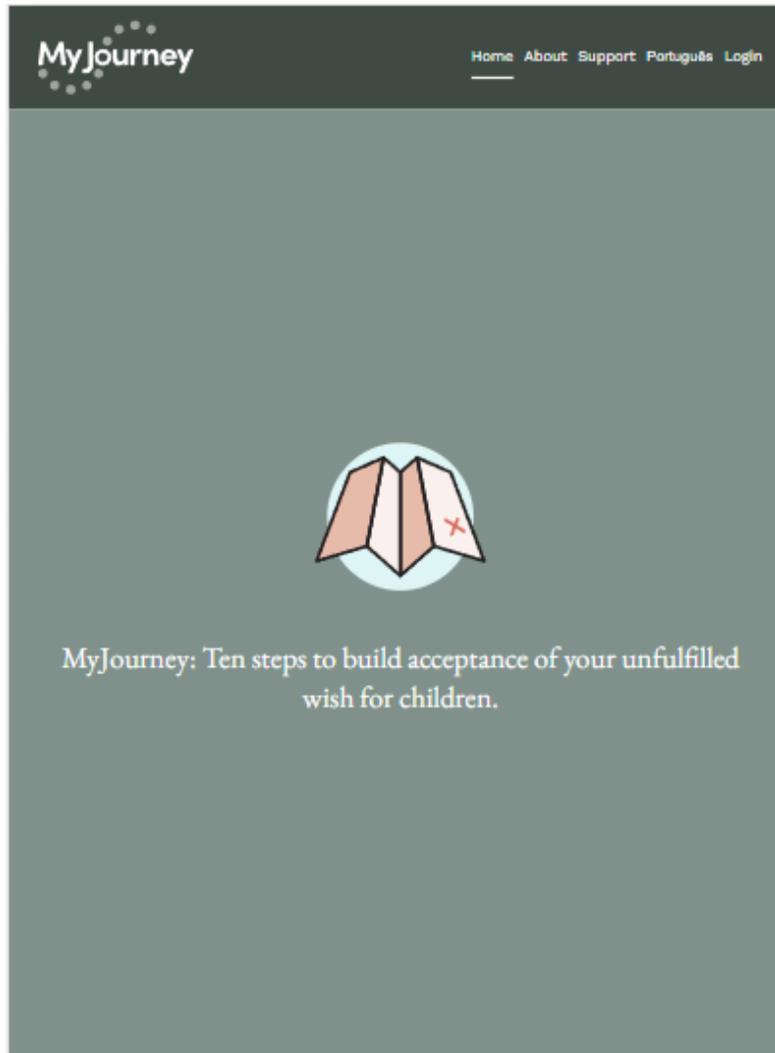
**Map > 1. Your starting point**
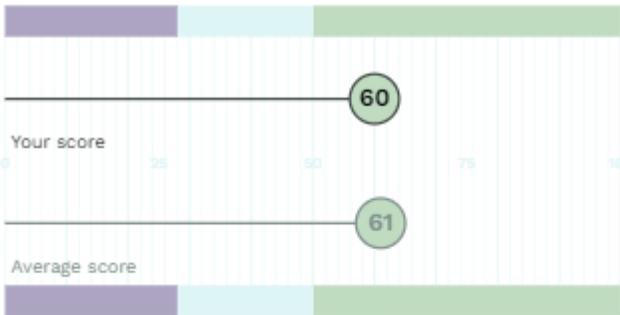


60

Your score

0          25          50          75          100

61

Average score

## Understanding your wellbeing score

Your wellbeing score reflects how well you feel now and it can vary from 0 (worst wellbeing possible) to 100 (best wellbeing possible). Usually women living in the UK score 61.

**Your wellbeing score is 60.**
Scores higher than 50 indicate that the person seems able to cope, regardless of how rocky their journey might have been so far. However, if you feel concerned about your wellbeing, please do not hesitate to seek specialised support here .

Scores between 28 and 50 indicate that the person is struggling and may find it hard to cope without additional support. If you feel this applies to you, or if you scored lower than 50 repeated times, we recommend you seek specialised support. You can find useful contacts here .

Scores lower than 28 indicate that the person is really struggling and finding it hard to cope. We recommend everyone who scores lower than 28 to seek specialised support.

Map     Backpack

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## 2. Be kind to yourself

To make your journey easier, practice how you can be kind to yourself while travelling.

**Map > 2. Be kind to yourself**

Self-compassion involves treating yourself the way you would treat a dear friend who is struggling and facing a tough time. This may seem difficult but following the steps outlined below will give a better idea of what we are talking about.

**How self-compassionate are you normally?**

5 - Extremely

4 - Very much

3 - A moderate amount

2 - A little

1 - Not at all

Try to think back to a time when a close friend felt really bad about themselves. How did you try to comfort your friend? Think also about what you typically do and say when you are trying to comfort people around you. How do you address them, what words and tone of voice do you use?

Describe how you usually act when you are trying to comfort someone. Do you speak differently, for example use certain words or tone of voice? Write these here.

Map     Backpack

## Discussion

**Main findings**

Results from this chapter show it is possible to develop a theory-led and acceptable psychosocial intervention that aims to promote positive adjustment to UPGs. MyJourney is based on the 3TM, which was informed by a systematic review of all evidence on how people adjust to unsuccessful fertility treatment and proved applicable in heterogeneous samples who self-identified has having a UPG or who self-identified as childless due to unfavourable circumstances. The inclusion of formative evaluation exercises and definition of guiding principles allowed for the progressive refinement of MyJourney to maximise its acceptability and inclusivity. Overall, this phased, iterative approach resulted in the production of a self-guided, internet-based intervention that is considered to meet the needs of, and is acceptable to, intended users and health professionals who could recommend MyJourney to their clients. The evidence collected through this development process supports the idea that it is feasible to deliver MyJourney. However, this, including limited efficacy (Bowen et al., 2009), must now be evaluated in a feasibility RCT.

MyJourney is based on a comprehensive model of adjustment to UPGs. This model, informed by an exhaustive review, proposes the mechanisms through which people adjust to their UPG. Despite this model being developed from the experience of unsuccessful treatment, the validation work indicated overall that the model could also be applied to those who did not do treatment or consider themselves to have a UPG due to circumstantial reasons. The implication of this is that MyJourney could be considered useful support for anyone with a UPG, regardless of the factors that led to this. However, there were some inconsistencies in the findings about how meaning making may facilitate adjustment. More specifically, the findings suggest

that other meaning making strategies, beyond positive reappraisal coping, may need

to be contemplated. As the systematic review that informed the 3TM referred to

participants engaging in re-evaluation of their values, particularly around

parenthood, it was considered that therapeutic activities targeting values clarification

could also be beneficial. The ACT framework considers the clarification of values as

representative of a way to create meaning in life (Hayes et al., 2012). A recent

systematic review, that reported specifically on the values-based aspects of ACT

interventions, indicated that values-based interventions demonstrate efficacy for

numerous outcomes including depression and anxiety across clinical and non-clinical

samples (Rahal & Gon, 2020). But, as noted by another qualitative study with ACT

experts investigating the values process within ACT, it is difficult to draw out and

measure values processes separately from the broader aim of ACT to promote

psychological flexibility (Barney et al., 2019), therefore the systematic review

should be interpreted with caution. As the development process of MyJourney

continues, further work is needed to better understand the most beneficial meaning-

making strategies for individuals with a UPG.

    The only other online self-help intervention developed for people with UPGs

used cognitive behavioural therapy (CBT) techniques and the findings indicated that

depression scores (the only outcome) were improved in the intervention group

compared to the waitlist control group (Kraaij et al., 2016). ACT, instead of CBT,

was chosen to provide the therapeutic framework for MyJourney because this

framework appears to integrate well with the 3TM, but only quantitative mediation

analysis will provide evidence that the three tasks are being targeted by the

intervention. Several systematic reviews indicate that online or internet based and

self-guided ACT-based interventions for mental health, such as depression and

anxiety, and wellbeing outcomes, such as quality of life, offer promising findings of

the efficacy/effectiveness (Brown et al., 2016; Cavanagh et al., 2014; French et al.,

2017; Thompson et al., 2021). The feedback throughout the development process for

MyJourney has indicated that ACT-based activities are considered suitable for online

self-guided delivery and appear to address the needs of people with UPGs.

Therefore, at this stage in development there is confidence that ACT lends itself to

this intervention as MyJourney targets multiple mechanisms of change and has taken

a more holistic approach towards adjustment. What was not possible to clarify yet

was the minimum dose of engagement with MyJourney that is sufficient to instigate

clinically relevant change, which should be determined in future work.

One of the most important findings of this chapter is that the phased development

of MyJourney has resulted in an intervention that is, overall, considered acceptable

by users and reproductive health professionals. Although the first prototype of

MyJourney was considered acceptable, engaging in the phased development has

allowed for significant changes to be made to the intervention to strengthen

acceptability. For example, the introduction of an interactive web-based design and

the simplification and segmenting of the written content into more easily read

sections. Lack of acceptability of interventions can hinder engagement and

implementation, meaning that the benefits of the intervention are never determined

as the required dose to instigate change is not met, and as such acceptability is

considered an essential requirement for the effectiveness of an intervention (Sekhon

et al., 2017). This has been further evidenced by the increasing references to

acceptability in each of updated versions of the guidance (between 2000 and 2015)

from the MRC for complex interventions (Sekhon et al., 2017). Therefore, the

strengthened acceptability through the development process of MyJourney

demonstrates the value in engaging in this type of intervention development to ensure the best chance at evaluating efficacy. In addition to the overall acceptability, the features that reflect the guiding principles were positively evaluated in the consultation exercise, suggesting that these principles meet their objectives. For example, advisory committee members noted that MyJourney was flexible, which reflects the guiding principle outlining that MyJourney should promote user autonomy. In addition, the committee members who represented potential users felt they would recommend MyJourney to someone else, which indicates the guiding principle to promote trust in and credibility of the intervention was successful. However, the acceptability of newer features of the intervention remains to be evaluated in more depth for acceptability, for example the audio mindfulness meditations. Although other research has demonstrated promising results that this has been successfully delivered in other self-guided interventions (Cavanagh et al., 2014; Taylor et al., 2021), this was not included until the final prototype. Therefore, future work should ensure that acceptability of newer features continues to be evaluated.

It was clear from the formative activities that there is individual variability in readiness to engage and the pace at which people will engage with MyJourney. This is consistent with theoretical models of change, e.g., the Transtheoretical Model of Change (Prochaska & Velicer, 1997). In this model, it is not always clear how long one might remain in one stage and people who are in the contemplation stage may be likely to relapse if they are presented with support aimed at someone in the action stage (Krebs et al., 2018). Furthermore, it has been argued that interventions tailored to the stage of change are critical for a successful outcome (Prochaska & Norcross, 2001). Future research should clarify how this readiness is associated with

acceptability and efficacy so that MyJourney can be better tailored for those it can help the most and/or it can be improved to facilitate engagement, as those approaching this support are likely to be at different stages. In particular, the formative evaluation exercises indicated that the perceived challenge of engaging with this type of support may be related to one's stage of change and that this may influence engagement. Although the researchers have attempted to address the feedback suggesting there is an overall perceived challenge of engaging with the intervention, it is not known whether this is sufficient to help people engage with MyJourney earlier in their adjustment process. The perceived emotional challenge could be considered an unintentional harm of the intervention and should continue to the monitored as development progresses. Investigating this further will not only inform the future work on MyJourney but will also be helpful for other researchers who wish to develop support for people with UPGs.

The findings so far suggest that that delivery of MyJourney as a self-guided, internet-based intervention is feasible, however this can only be determined in a RCT feasibility trial. For example, feedback from users during the development process has shown that users are willing to progress through steps at their own pace. However, participants who provided feedback were either given a set time frame to engage with the intervention (e.g., 8 weeks in the prospective acceptability study) and knew they would be asked for feedback following this, or the researchers directly presented MyJourney to those evaluating it. This means the findings reported are unlikely to represent high ecological validity. Although it will not be possible to replicate real-life use, it is important that during feasibility testing MyJourney is used with minimal contact with the researchers and that users are encouraged to engage with it in a way that suits them best. This can facilitate data

being gathered on how this type of intervention will be engaged and adhered to.

More specific features also need to be evaluated for feasibility including the option

for users to enter responses to questions, use slider scales to enter their wellbeing

data, and receive feedback on their wellbeing scores.

**Strengths and limitations**

The development of MyJourney followed a phased approach that closely

followed the MRC guidance (Craig et al., 2008). Furthermore, the iterative

development was responsive to stakeholders' feedback, resulting in the production of

three different prototypes. Another strength is the close link between theory and

operationalisation of intervention, which will also translate into a better ability to

evaluate efficacy in the future, via high conceptual clarity in the assessment of

mediators and outcomes. However, the theoretical model is based on the UPG

experience following unsuccessful treatment only. Despite this, validation studies

indicate that the theoretical model could be applied to those who did not engage with

treatment or attribute their UPG to circumstantial factors. A systematic review of

other interventions was not possible to inform the initial phases, however the

development team have in-depth knowledge of the field. The choice of therapeutic

techniques was not evidence based (i.e., no systematic reviews of interventions to

promote acceptance, meaning making, pursuit of new goals) to identify active

components. Instead, the choice was made based on perceived conceptual fit with the

3TM. But evidence is reassuring about the adequacy of the therapeutic techniques

chosen. Finally, resource and time constraints meant that PPI with several people

was not always possible at each stage, for example during the planning phase of the

intervention. However, it is recognised that it is challenging to implement PPI at

every stage of development (Yardley, Morrison, et al., 2015).

**Implications**

The detailed description provided in this chapter will enable others, for example other researchers or mental health support practitioners (e.g., within primary care and fertility pathways), to create similar interventions using similar processes, which is needed given the scarcity of evidence-based support for UPGs. The findings from this chapter suggest that a theory and research informed acceptable intervention that meets the needs of the intended users has been developed. MyJourney addresses the current gap in evidence-based support for individuals with a UPG. The development of MyJourney will continue to follow MRC guidance and move into the exploratory phase, in which the feasibility of both the intervention and study protocol to assess it will be evaluated. This phase will also allow for limited efficacy testing of MyJourney, so that the hypothesis that engagement will result in better wellbeing and mental health can begin to be examined. Once feasibility has been established, efficacy of MyJourney can be evaluated in a full-scale RCT. However, these initial findings already suggest that MyJourney could become an important tool for the provision of support to individuals with a UPG.

# Chapter 5: Randomised controlled feasibility trial of MyJourney

## Introduction

The previous chapter described the development of MyJourney in detail and the following chapter will now describe the feasibility evaluation of the latest prototype of the intervention and study protocol used to evaluate it.

In response to a recognised demand and multiple calls for support from guidelines and regulatory bodies (e.g., ESHRE, HFEA, NICE), the MRC framework for developing complex interventions (Craig et al., 2008) was adopted to develop MyJourney, a self-guided intervention to support individuals with a UPG (See Chapter 4). MyJourney is theoretically informed by the Three Task Model of Adjustment (3TM) (Gameiro & Finnigan, 2017) and applies contextual cognitive behavioural therapy (CCBT), in particular the Acceptance and Commitment Therapy (ACT) framework (Hayes et al., 2006). In brief, MyJourney is a web-app designed to guide users through 10 therapeutic activities that are hypothesized to promote the development of skills to build acceptance of ones' UPG, find meaning in their current situation, and move on towards other meaningful goals in life, ultimately leading to improvements in hedonic wellbeing (primary outcome), as well as eudaimonic wellbeing, mental health, and post traumatic growth (see MyJourney's logic model in Figure 4.1, Chapter 4). Although the MRC phased approach, including patient and public involvement (PPI), has been undertaken in the development of MyJourney, uncertainties remain, with the overarching research question being whether MyJourney and the study protocol used to evaluate it are feasible to be implemented in a full scale randomized controlled trial (RCT) to determine efficacy.

As previously noted, to the author's knowledge only one intervention tailored to UPGs (i.e., undesired definitive childlessness) has been developed and evaluated. While results suggest self-guided interventions for UPGs can be feasibly implemented and evaluated (Kraaij et al., 2016), MyJourney has many novel aspects that warrant feasibility testing. Specifically, it aims to be inclusive of anyone with a UPG regardless of how this came to be, it is entirely self-guided, and it requests a long (10-week) engagement period from users. Furthermore, it was designed to be freely available to people with UPGs, so it was important to ascertain if people would independently access and use it (i.e., with no user-researcher or user-clinician contact). Therefore, in this chapter, Bowen et al's (2009) feasibility outcomes were operationalised to evaluate MyJourney via a feasibility RCT with an embedded qualitative process evaluation.

Uptake, usage, and sustained adherence with online self-guided interventions can be influenced by numerous factors, traversing different feasibility outcomes. Adherence is defined as to the extent the participant engages with the content of the intervention (Eysenbach, 2005). Within trials, complete adherence to smartphone interventions reportedly ranges between 34-64% of participants, with usage declining over time (Linardon & Fuller-Tyszkiewicz, 2020). Reasons cited for low uptake or adherence, include poor usability (e.g., difficult to use), lack of user centric design (e.g., does not meet the needs of intended users), and concerns about privacy (Torous et al., 2018). Elsewhere higher estimates of complete adherence to online interventions within RCTs have been reported, between 50-70% for depression and around 50-90% for anxiety disorders (Christensen et al., 2009). However, uptake and adherence with entirely self-guided interventions, with no researcher or clinician input, are likely to be at the lower end of these percentages (Eysenbach, 2005). It is

unknown to what degree the phased approach to intervention development made MyJourney resilient to these issues and therefore empirically evaluating acceptability and demand is crucial. Although acceptability had been established with an earlier prototype, significant changes were implemented to address feedback for improvements to warrant a re-evaluation of the resulting final version. Additionally, as MyJourney was accessible to anyone interested in using it, profiling study participants (e.g., socio-demographic background, fertility history) can provide insight into the typical user of MyJourney and, more generally, of online support for UPGs. In particular, research suggests that when people are first faced with their UPG, intense grief (Gameiro & Finnigan, 2017) or, paradoxically, lack of insight about grief (Turnbull et al., 2016), can make them less receptive to support. Other research has demonstrated that users' receptivity to support (i.e., whether they are help seeking or not) may also be an important factor when considering engagement with interventions and subsequently evaluating efficacy (Krafft et al., 2019). Exploratory work gaining insight about how acceptability and demand vary according to participants' stage of their UPG journey can help clarify on when people feel ready to engage with support.

Online interventions offer promising features that can overcome barriers to access support, such as no requirement to travel, low or no cost, and flexibility to engage whenever and wherever suitable. Furthermore, persuasive systems strategies can be used to promote adherence, such as primary task support (e.g., tunnelling – using the intervention to guide the user through a process), dialogue support (e.g., reminders to engage with the intervention), and system credibility support (e.g., intervention incorporates demonstrates knowledge and expertise of the problem) (Oinas-Kukkonen & Harjumaa, 2009). However, despite using these strategies,

online and webapp interventions are technically complex to implement and, in particular for self-guided interventions, participants can choose to discontinue use easily if barriers arise (Eysenbach, 2005). Therefore, it was also important to ascertain whether MyJourney can be fully delivered as an online self-guided tool (implementation) and if there are factors constraining its implementation (practicalities). MyJourney is bilingual (English and Portuguese) and, even though its logic model was informed by research evidence involving people from multiple countries and its development included consultation with English and Portuguese speaking potential users, documenting acceptability and demand differences between participants who engaged with it in English and Portuguese will inform on the success of its adaptation (Barrera & Castro, 2006).

Finally, a recent systematic review of psychosocial care and stress management apps found that only 2% had evidence of feasibility or efficacy (Lau et al., 2020). To ensure users can make informed decisions about whether to use MyJourney, limited efficacy was evaluated, i.e., whether engagement with MyJourney promoted positive adjustment to UPGs. Kraaij et al. (2016), showed that a cognitive behavioural intervention aimed at promoting cognitive coping and goal adjustment in women with undesired definitive childless improved depressive symptoms within a month. Given the overlap with MyJourney's mechanisms of change (meaning-making, pursuit of new goals), it was expected that MyJourney would also produce benefits. However, to fully capture adjustment experiences as reported by those who undergo this adjustment process, and therefore as hypothesized by the 3TM (Gameiro & Finnigan, 2017), adjustment was operationalised in a holistic way. This considers not only how people feel (hedonic wellbeing, mental health) but also their perceptions of self-realization in life and

personal growth due to facing their UPG (eudaimonic wellbeing, post-traumatic

growth).

In addition, the study procedures designed to evaluate MyJourney required

appraisal to ensure these were acceptable to participants and that meaningful data

was collected, fundamentally answering the question of whether this study could be

carried out (Gadke et al., 2021; National Institute for Health Research, 2012). Again,

this evaluation was operationalised using Bowen et al's feasibility outcomes (2009).

Specifically, this trial aimed to determine whether the recruitment target would be

reached within the proposed timeframe and the rate of attrition, defined as

participants not completing all trial assessment moments (Eysenbach, 2005)

(demand). A meta-analysis of smartphone interventions reported that attrition rates

are 24.1% for short term follow up ($\leq$ eight weeks) and 35.5% for long term follow

up (> eight weeks) (Linardon & Fuller-Tyszkiewicz, 2020). This trial also aimed to

determine whether participants would consider the randomisation and assessments as

acceptable (acceptability); any reported issues that were raised regarding

implementation of MyJourney and how these were addressed by research team

(implementation); time taken to complete assessment moments and time taken to

administer the trial (practicalities); and finally, whether they would be any

differences in dissemination, recruitment and retention between participants who

engaged in English and Portuguese (adaptation).

In sum, the main objective of this trial was to gather data on uncertainties

about the feasibility of MyJourney. These included 1) what is the typical MyJourney

user profile and whether participants would independently access and engage with

MyJourney in a similar way to other online support tools, and whether this was

influenced by the stage of their UPG journey (demand); 2) whether participants

positively evaluate MyJourney (acceptability), and whether this was influenced by the stage of their UPG journey; 3) whether participants engaged with the intervention as intended, whether the proposed ten-week engagement period was considered appropriate (implementation), and whether there were barriers to or facilitators of engagement (practicalities); 4) whether there were engagement variations between participants using MyJourney in Portuguese and English (adaptation); and 5) whether MyJourney demonstrated promise of limited efficacy by reporting on effect sizes for primary and secondary outcomes. A second goal was to gather data on uncertainties about the feasibility of the study protocol used to evaluate MyJourney. The trial included a qualitative process evaluation to develop a more in-depth understanding of the implementation of MyJourney, how engagement with it may trigger change, and whether there are any external factors that may influence delivery (e.g., the device MyJourney was accessed on) or engagement (e.g., personal or work commitments) (Moore et al., 2015).

The hypotheses of this feasibility trial were operationalized in terms of predefined progression criteria for each feasibility outcome, which also informed whether work could continue to a full scale efficacy RCT (Avery et al., 2017). It is hypothesised that MyJourney, and its study protocol, would prove feasible overall. Results from this chapter, reported according to the CONSORT guidelines for feasibility and pilot trials (Eldridge et al., 2016) (Appendix M for checklist), will inform modifications to be done in MyJourney and in the study protocol to test efficacy via RCT. Results can also be informative for the implementation of other interventions tailored to UPGs and infertility care more generally, in particular self-guided and online care.

# Methods and Materials

**Design**

      This was a two arm, parallel-group, non-blinded feasibility online trial with 1:1 randomised allocation to the intervention group (immediate access to MyJourney) or waitlist control group (receive access to MyJourney after 10 weeks), including an embedded qualitative process evaluation. There were three assessment moments: one at baseline (pre-exposure to intervention, T1) and one 10-weeks after baseline (post exposure to intervention, T2), followed by a 1-hour semi-structured individual interview for process evaluation participants only, and one at 6-months after baseline (for intervention participants only; post exposure to intervention, T3). Only the first two assessment moments, T1 and T2, will be reported in this chapter (third assessment moment data collection and analysis were not intended to be included in this thesis submission). Ethical approval was obtained from the School Research Ethics Committee, School of Psychology, Cardiff University (E.C..20.10.13.6082). The trial was registered at Clinical-Trials.gov (NCT04850482).

**Participants**

*Recruitment*

      The recruitment phase took place between November 2020 – March 2021. A Facebook page and Twitter account with information about the intervention and trial were created for MyJourney. These were disseminated by fertility charities (e.g., Fertility Network UK, Portuguese Fertility Association, etc.,), advocates and support groups, via their website, social media, blogs, or newsletters. The trial was also disseminated via the Prolific recruitment platform. The Facebook and Twitter adverts included a link directing participants to MyJourney's landing page

(containing information about MyJourney, the research behind it, contact details,

language options), where interested individuals could register for the trial, by reading

the participant information sheet and completing the consent form (Appendix N).

Consenting participants had the option to be entered into a prize draw to win one of

ten £20 Amazon vouchers at each assessment moment and participants who took part

in the process evaluation were also offered a £15 Love to Shop voucher. Participants

who took part in the trial via the Prolific platform were not entered into the prize

draw as they received payment via the platform.

### *Eligibility criteria*

Inclusion criteria were being an adult (>18 years), able to give consent, self-

identifying as having an unfulfilled wish for children, able to access and use

MyJourney (have an internet connection, suitable device and have an active email

address), understanding English or Portuguese, and able to fill in online

questionnaires. MyJourney is a self-help tool, and it is not a substitute for

professional support. It is possible that MyJourney is not the most adequate support

for distressed individuals. This is explained to participants in the terms of use of

MyJourney. Therefore, the exclusion criteria were having been diagnosed with a

mental-health disorder within the last two years (to be conservative), currently

receiving therapy for a clinically diagnosed mental-health problem (individual or

group therapy) or being unable to use MyJourney due to other health problems (e.g.,

vision impairments), all self-reported. This was to limit any confounding factors that

could diminish the impact of the intervention by decreasing the ability to be able to

engage with MyJourney.

**Intervention**

   The intervention was described using the Template for Intervention

Description and Replication (TIDieR) (Hoffmann et al., 2014) and is presented in

Table 4.6 (Chapter 4).

**Procedures**

   Participants who clicked the button to take part in the trial were presented

with the information sheet and informed consent. Participants who fit inclusion

criteria and consented were allocated a random Study ID and invited to complete the

online (Qualtrics survey, Copyright 2021, Qualtrics, Provo, UT) baseline assessment

(T1), after which they were randomly assigned to the intervention or waitlist control

groups. Ten weeks after completion of the baseline (T1) assessment, all participants

were invited by email to complete a follow-up assessment (T2). Upon completion of

this assessment (T2), participants in the waitlist control group were debriefed and

given access to MyJourney. Participants in the intervention group were invited by

email to complete a final 6-months follow-up assessment (T3), after which they were

debriefed. Reminder emails and SMS were sent four, seven and ten-days after email

invitations to register an account with MyJourney and complete assessment

questionnaires. If participants did not complete questionnaires after all reminders,

they were sent a short questionnaire to determine their reasons for dropping out and

provided with a debrief form.

   Between February and March 2021, approximately two weeks after being

invited to complete the follow-up assessment (T2), participants were sent an email

inviting them to take part in a short semi-structured individual interview for the

process evaluation. Informed consent was obtained from participants who agreed to

take part and online interviews using Zoom were arranged at a time convenient for

the participant.

MyJourney automatically stored data on registration details (e.g., gender,

country of residence, language), number of visits, duration of visits overall and per

Step/Routine, Steps started and completed, number of times Steps were completed

(i.e., repeated), rating of Steps (usefulness, challenge), and any answers entered by

participants within the Steps (i.e., if they were prompted to write a response).

**Feasibility Outcomes**

***Intervention***

The feasibility outcomes for MyJourney, according to Bowen's (2009)

guidance on feasibility trials are outlined in Table 5.1. As suggested by Avery et al.

(2017), a traffic light system has also been implemented for progression criteria -

green: proceed; amber: proceed with amendments; red: do not proceed to main trial

(Table 5.1).

**Table 5.1**

*Feasibility outcomes and progression criteria for the intervention*

| Outcome | Description | Progression Criteria |
|---------|-------------|----------------------|
| *Demand.* **The extent that MyJourney is likely to be used.** | Number of participants who registered, set up account, and started and completed Steps 1 to 10<br>Time spent overall, total number of visits, time spent on Steps and Routines, and number of times these were visited. | Green: >50% in the intervention group register and start using the intervention (completed Step 1) |
| | | Amber: 10-50% in the intervention group register and start using the intervention (completed Step 1) |
| | | Red: <10% in the intervention group register and start using the intervention (completed Step 1) |
| *Acceptability.* **The extent that MyJourney is judged as** | Quantitative ratings of MyJourney regarding: successful in supporting people with UPGs, user-friendly interface, visually appealing, easy to | Green: For all intervention group participants the average rating for is >4 (somewhat agree/very) for all acceptability variables. |

| Outcome | Description | Progression Criteria |
|---------|-------------|----------------------|
| **acceptable, e.g., suitable or attractive, by participants.** | understand, inclusive, trusted content, wellbeing feedback useful and Step assessment useful. | Amber: For all intervention group participants the average rating is >3 (neither agree nor disagree/a moderate amount) for all acceptability variables. |
| | | Red: For all intervention group participants the average rating is 1 (strongly disagree/not at all) for all acceptability variables. |
| | Nr who recommend to others and intend to keep using | Green: >50% of intervention group participants would recommend to others and intend to keep using |
| | | Amber: 10-50% of intervention group participants would recommend to others and intend to keep using |
| | | Red: <10% of intervention group participants would recommend to others and intend to keep using |
| | Quantitative ratings of Steps regarding usefulness and challenging | Green: For all intervention group participants the average rating for all steps is >4 (very much) for usefulness and <2 (a little) for challenging. |
| | | Amber: For all intervention group participants the average rating for most steps is >3 (moderately) for usefulness and <3 (moderately) for challenging. |
| | | Red: For all intervention group participants the average rating for all steps is >1 (not at all) for usefulness and <5 (extremely) for challenging. |
| *Implementation.* **The extent that MyJourney can be delivered as planned.** | Issues/problems reported during the trial Responses to open-ended questions about technical issues and appropriateness of 10-week recommended engagement | No criteria set. |
| *Practicalities.* **The extent that participants can engage with MyJourney.** | Nr who used intervention as intended, who received a sufficient dose (defined as completing up to Step 6 meaning they completed at least 1 Step associated with each of the 3TM mediators) and who received less than a sufficient dose (did not complete up to Step 6) Time taken to complete Steps 1 to 10 and time taken to complete Steps 1 to 6 (sufficient dose) | Green: > 50% intervention group participants receive sufficient dose within 10-week timeframe |
| | | Amber: 10-50% intervention group participants receive sufficient dose within 10-week timeframe |
| | | Red: < 10% intervention group participants receive sufficient dose within 10-week timeframe |
| *Adaptation.* **The extent that MyJourney usage varies in different populations.** | Differences in number of participants engaging with intervention in Portuguese and English who registered, set up account, started, received a sufficient dose and completed all 10 Steps Differences between participants engaging with intervention in Portuguese and English in time spent overall and total number of visits | No criteria set. |

| Outcome | Description | Progression Criteria |
|---------|-------------|----------------------|
| *Limited efficacy.* **The extent that MyJourney shows promise of being successful in influencing outcomes.** | Modified intention-to-treat (all participants randomized) and per protocol (only participants who received a sufficient dose) analyses on outcomes and mediators<br><br>Difference in proportion of participants who experienced clinically significant change in hedonic wellbeing (i.e., increase of ≥10 points) in the intervention and waitlist control group for mIIT and PP analysis | No criteria set. |

*Study protocol*

Feasibility outcomes for the study protocol included: participation and

attrition rates; reasons for non-participation/withdrawal (demand); proportion who

completed T1 and T2 questionnaires (acceptability); reported issues relating to

procedures (implementation); time taken to complete questionnaires and process

evaluation interviews and researcher's time to administer the study (practicalities);

and finally, participation and attrition rates according to language of engagement

(adaptation). Progression criteria are presented in Table 5.2.

**Table 5.2**

*Feasibility outcomes and progression criteria for the study protocol*

| Outcome | Progression Criteria |
|---------|---------------------|
| **Demand** | Green: >50% of participants who demonstrated an interest in the trial are eligible.<br>Green: >50% of eligible participants are recruited.<br>Green: <20% lost to follow up |
| | Amber: 30-50% of participants who demonstrated an interest in the trial are eligible.<br>Amber: 30-50% of eligible participants are recruited<br>Amber: 20%-80% lost to follow up |
| | Red: <20% of participants who demonstrated an interest in the trial are eligible.<br>Red: <20% of eligible participants are recruited<br>Red: >80% lost to follow up |
| **Acceptability** | Green: >70% participants complete both assessment moment questionnaires (number completed / number invited at each assessment moment) |
| | Amber: 30-70% participants complete both assessment moment questionnaires (number completed / number invited at each assessment moment) |
| | Red: <30% participants complete both assessment moment questionnaires (number completed / number invited at each assessment moment) |
| **Implementation** | No criteria set. |
| **Practicalities** | No criteria set. |
| **Adaptation** | No criteria set. |

*Process evaluation*

The feasibility of the intervention and study protocol for an efficacy RCT

was operationalised in terms of participants' perceptions and expressed comments.

**Materials**

Table 5.3 outlines the materials and questionnaires presented to participants

at the T1 and T2 assessment moments and for which group.

**Table 5.3**

*Materials and questionnaires presented to participants at each assessment moment*

| Variable | Measure / Scale | Description | T1 | T2 |
|---|---|---|---|---|
| **Socio-demographics** | Researcher developed questions | Participants were asked to provide their age (in years), gender (0 = female, 1 = male), country of residence, relationship status (0 = single (including divorced or widowed), 1 = in a relationship), education level (0=no University education, 1 = University education) and employment status (0 = not employed: unemployed, student, retired, 1 = employed part or full time). English speaking participants were also asked to provide their ethnicity. This was not asked to Portuguese participants as the National Statistics Institute in Portugal does not include questions about ethnicity in the census and therefore it was not considered appropriate to define categories of ethnicity for these participants. | ✓ INT<br>✓ WL | |
| **UPG journey status** | Researcher developed questions | To capture participants' status regarding their unfulfilled wish for children, they were asked their parental status (0 = no children, 1 = children (including stepchildren), whether they sustained a child wish (i.e., Do you still have a child wish? 0 = no, 1 = yes), whether they had engaged in fertility treatment in the past (0 = no, yes = 1). Participants were also asked about where they considered themselves in their UPG journey (i.e., What best describes your journey status?) using the Stages of Change Model (Prochaska et al., 1993) with 6 options reflecting five stages of change (i.e., precontemplation: not trying to accept; contemplation: not trying to accept but thinking of trying; preparation: just started trying to accept; action: trying for less than 6 months; maintenance: trying to accept for more than 6 months) and an 'Other' option, in which patients could specify their situation in an open-ended response. Based on these, participants were categorised as 1) not trying to accept (precontemplation/contemplation), 2) trying to accept for less than 6 months (preparation, action), 3) trying to accept for more than 6 months (maintenance) and 4) accepted (termination), 5) Other/don't know. | ✓ INT<br>✓ WL | |
| **Engagement with other support** | Researcher developed questions | Participants were asked three questions about their engagement with formal support in the past (e.g., from a certified therapist or counsellor, either in | ✓ INT | ✓ INT |

| Variable | Measure / Scale | Description | T1 | T2 |
|---|---|---|---|---|
| | | individual or group format), informal support in the past (e.g., peer group support, online support, self-help books), and whether they were currently engaged with informal support. At T2, participants were asked whether they had since engaged in formal or informal support during the trial. | ✓ WL | ✓ WL |
| **Recruitment** | Researcher developed questions | Participants were asked how they found out about the trial and were provided with 11 options including Facebook, Fertility Network UK (FNUK), and Portuguese Fertility Association (APF). Participants could provide any other options not already provided by writing in the free text response box. | ✓ INT ✓ WL | |
| | | **Mediator (outputs) and Outcome (outcomes) variables** | | |
| **MEDIATORS (outputs)** | | | | |
| *Meaning Making* | *Positive reappraisal:* Brief COPE inventory subscale (Carver, 1997). | This subscale assesses positive reframing with 4 items (e.g., 'I try to see it in a different light, to make it seem more positive'). The item scores ranged from 1 (*I haven't been doing this at all)* to 4 (*I've been doing this a lot)* and a total summed score ranging from 4 to 16 was calculated, with higher scores indicating more positive reframing. In this sample the Cronbach's alpha was .852 at T1 and .870 at T2. | ✓ INT ✓ WL | ✓ INT ✓ WL |
| | *Valued action:* Motivation and activation subscale of the Comprehensive Assessment of Acceptance and Commitment Therapy processes scale (CompACT) (Francis et al., 2016). | This subscale assesses valued action with 8 items (e.g., I make choices based on what is important to me, even if it is stressful). Item scores ranged from 0 (*Strongly disagree)* to 6 (*Strongly agree).* Negatively scored items were reversed and items then summed to produce a total score ranging from 0 to 48, with higher scores indicating greater valued action. In this sample the Cronbach's alpha was .900 at T1 and .917 at T2. | ✓ INT ✓ WL | ✓ INT ✓ WL |
| *Acceptance* | *Acceptance:* Acceptance subscale of the SCREENIVF Questionnaire (Verhaak et al., 2010). | This subscale assesses acceptance with 6 items (e.g., 'I have learned to accept my fertility problems'). The items were adapted to assess acceptance towards an unfulfilled wish for children e.g., 'I can deal with the consequences of having an unfulfilled wish for children', instead of '…my fertility problems'. The response scale varied from 1 (d*o not agree)* to 4 (*strongly agree)* and a total summed score ranging from 6 to 24 was calculated, with higher scores indicating higher acceptance. In this sample the Cronbach's alpha was .937 at T1 and .948 at T2. | ✓ INT ✓ WL | ✓ INT ✓ WL |
| | *Self-Compassion:* Self-Compassion Scale - Short | This scale assesses one's compassion towards themselves with 12 items (e.g., When I'm going through a very hard time, I give myself the caring and tenderness I need). The response scale ranged from 1 (*never)* to 5 | ✓ INT ✓ WL | ✓ INT ✓ WL |

| Variable | Measure / Scale | Description | T1 | T2 |
|---|---|---|---|---|
| | Form (SCS-SF) (Raes et al., 2011). | (*Always*). Negatively scored items were reversed and items then summed to produce a total score ranging from 12 to 60, with higher scores indicating higher self-compassion. In this sample the Cronbach's alpha was .871 at T1 and .887 at T2. | | |
| | *Openness to experience:* Openness to experience (acceptance and defusion) subscale of the CompACT scale (Francis et al., 2016). | This subscale assesses acceptance and defusion with 10 items (e.g., I can take thoughts and feelings as they come, without attempting to control or avoid them). The response scale varied from 0 (*strongly disagree)* to 6 (*strongly agree)*. Negatively scored items were reversed and items then summed to produce a total score ranging from 0 to 48, with higher scores indicating greater openness to experience. In this sample the Cronbach's alpha was .793 at T1 and .841 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| ***Pursuit of new goals*** | *Goal re-engagement:* Re-engagement subscale of the Goal Disengagement and Reengagement Scale (Wrosch, Scheier, Miller, et al., 2003). | The scale assesses the ability to identify new life goals (two items, e.g. 'I have convinced myself that I have other meaningful goals to pursue.'), to commit to new goals (two items, e.g. 'I have put effort toward other meaningful goals.') and to start an active pursuit of new goals (two items, e.g. 'I have sought after other meaningful goals.'). Participants were asked to answer on a five-point scale from 1 (*strongly disagree)* to 5 (*strongly agree)*. The total sum score ranged between 6 and 30, with higher scores indicating greater engagement in other meaningful life goals. In this sample the Cronbach's alpha was .914 at T1 and .927 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| | *Committed action:* Committed Action Questionnaire (CAQ-8) (McCracken et al., 2015) | This scale assesses commitment to goals with 8 items (e.g., I can remain committed to my goals even when there are times that I fail to reach them). The item scores varied between 0 (*never true)* to 6 (*always true)*. Negatively scored items were reversed and items then summed to produce a total score ranging from 0 to 48, with higher scores indicating greater committed action. In this sample the Cronbach's alpha was .861 at T1 and .875 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |

| Variable | Measure / Scale | Description | T1 | T2 |
|---|---|---|---|---|
| *Social connection* | *Social connection:* Social concern subscale of the Fertility Problem Inventory (FPI) (Newton et al., 1999). | This subscale assesses sensitivity to comments from others and feelings of social isolation with 10 items (e.g., I find it hard to spend time with friends who have young children). The item scores ranged from 1 (*strongly disagree)* to 6 (*strongly agree)*. The item scores were reversed (except the ones that were already negatively scored) and items then summed to produce a total score ranging from 6 to 60, with higher scores indicating higher social connection. In this sample the Cronbach's alpha was .888 at T1 and .869 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| **OUTCOMES** | | | | |
| *Primary: Hedonic Wellbeing* | World Health Organisation Wellbeing Index (WHO-5 (;Topp et al., 2015) | Participants were asked to rate how well each of five items (e.g., 'I have felt calm and relaxed') applied to them over the past two weeks on a scale from 0 (*none of the time)* to 5 (*all of the time)*. All items were summed, and the total score was linearly transformed to vary from 0 to 100, with higher scores indicating better hedonic wellbeing. General population mean scores for WHO-5 are estimated at 70 (Bech et al., 2003), scores ≤ 50 indicating reduced wellbeing (Topp et al., 2015). In this sample the Cronbach's alpha was .883 at T1 and .888 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| *Secondary: Eudaimonic Wellbeing* | *Life is worthwhile*: Office of National Statistics (ONS) single item eudaimonic wellbeing scale from the Annual Population Survey (Office for National, 2012) | *Life is worthwhile.* 'Overall, to what extent do you feel the things you do in your life are worthwhile?' The scale ranged from 0 to 10, with higher scores indicating better eudaimonic wellbeing. The average score from the Annual population Survey 2012 was 7.7 (Hicks et al., 2013). | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| | *Satisfaction with life*: Single item satisfaction with life scale (Ahrendt et al., 2017) | *Satisfaction with life.* 'All things considered, how satisfied are you with your life as a whole these days?' The scale ranged from 1 (completely dissatisfied) to 10 (completely satisfied), with higher scores indicating higher satisfaction with life. The average score in Europe is reported as 70.0-7.1 (Ahrendt et al., 2017). | | |
| | | *Happiness.* 'Taking all things together on a scale of 1 to 10, how happy would you say you are?' The scale ranged from 1 (very unhappy) to 10 | | |

| Variable | Measure / Scale | Description | T1 | T2 |
|---|---|---|---|---|
| | *Happiness*: Single item happiness scale (Ahrendt et al., 2017) | (very happy), with higher scores indicating greater happiness. The average score in Europe is reported as 7.4-7.5 (Ahrendt et al., 2017). | | |
| *Secondary: Mental Health* | Mental Health Inventory (MHI-5) (Berwick et al., 1991). | This 5-item scale assesses mental health by asking participants how they have been feeling during the previous four weeks (e.g., Have you been a happy person?) on a six-point scale from 1 (*none of the time*) to 6 (*all of the time*). Negatively scored items were reversed and items were then summed and linearly transformed to produce a total score ranging from 0 to 100, with higher scores indicating better mental health. A suggested cut off score for MHI-5 is 76, with scores equal or below this indicating the presence of common mental disorder (Kelly et al., 2008). In this sample the Cronbach's alpha was .833 at T1 and .898 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| *Secondary: Post traumatic Growth* | Post Traumatic Growth Inventory – Short Form (PTGI-SF)(Cann et al., 2010). | This assesses the degree to which a person grows as a result of a difficult life experience or event with 10 items (e.g., I changed my priorities about what is important in life). The introduction to the questionnaire was adapted to ask participants to answer the items in relation to their unfulfilled wish for children. The item scores varied between 0 (*I did not experience this change as a result of my unfulfilled wish for children*) to 5 (*I experienced this change to a very great degree as a result of my unfulfilled wish for children*). The total sum score ranged between 0 and 50, with higher scores indicating a greater degree of post traumatic growth. Normative scores and threshold scores for the presence of growth have not yet been reported. In this sample the Cronbach's alpha was .881 at T1 and .916 at T2. | ✓ INT<br>✓ WL | ✓ INT<br>✓ WL |
| **Perceived impact of COVID-19 pandemic** | Researcher developed questions | Invitations to complete the second assessment began during the third national lockdown (UK) and therefore two questions were added to assess how the COVID-19 pandemic was affecting the participants wellbeing and their experience of having an unfulfilled wish for children. Both questions had a response scale of 1 (*very negatively affected*) to 5 (*very positively affected*). One open question also invited participants to write any further comments about the pandemic that related to their experience of having an unfulfilled wish for children. | | ✓ INT<br>✓ WL |

| | | | |
|---|---|---|---|
| **Evaluation of study protocol** | Researcher developed questions | All participants were asked whether they had any comments about the trial itself (e.g., how they were recruited, thoughts about the assessment moments). | ✓ INT<br>✓ WL |
| **Evaluation of intervention** | Researcher developed questions | Seventeen questions about the intervention were also presented to the intervention group only. Ten of these questions asked participants to rate the intervention (e.g., whether they thought it was user friendly or visually appealing) with ratings ranging from 1 (*strongly disagree)* to 5 (*strongly agree)* or 1 (n*ot at all)* to 5 (e*xtremely),* or provide yes or no responses (e.g., whether they would recommend the intervention to someone else, 0 = no, 1 = yes). The remaining 7 questions asked participants to provide free text responses about their experience of using the intervention (e.g., whether they experienced any technical issues). Intervention participants were also asked for any other comments about the intervention. Intervention participants who engaged with the intervention were asked to rate to what extent they found each Step's useful or challenging with ratings from 1 (n*ot at all)* to 5 (e*xtremely)*. | ✓ INT |

**Process evaluation**

The script for the process evaluation semi-structured interviews was informed by Bowen et al's (2009) feasibility criteria and included 16 questions covering the intervention's acceptability (5 questions, e.g., Were there any aspects of MyJourney you particularly enjoyed or found particularly helpful?), demand (2 questions, e.g., What were your expectations about MyJourney?), implementation and practicality (3 questions, e.g., What mode of technology did you engage with MyJourney on?), as well as the trial procedures (6 questions, e.g., How demanding did you find the trial?). Participants were prompted for additional suggestions or comments.

**Sample Size**

Participation and retention rates of other online infertility interventions (Cousineau et al., 2008; Hämmerli et al., 2010; Kersting et al., 2011; Van Dongen et al., 2016) indicated around 60% of interested people would be eligible, consent and complete the baseline questionnaire (T1), from these 80% would register to MyJourney, and from these 70% would complete the follow-up (T2) questionnaire, suggesting a participation and retention rate of 60% and 34%, respectively. Recruiting 152 participants, a participation rate of 60% to within a 95% confidence interval of +/-8% and completion rate of 34% to within a 95% confidence interval of +/-7% could be estimated and a final sample of 50 (25 per group) could be obtained. The latter represented enough power to detect moderate-to-large effect-size differences in limited efficacy testing ($F = .25$, $\alpha = .05$, power $=.90$) (Mayr et al., 2007).

**Randomisation**

Randomisation occurred after participants completed the consent form and baseline assessment (T1). Participants were stratified into an English-speaking group

(EN) and a Portuguese-speaking group (PT) (indicated by their choice of language to complete the questionnaire) and then both groups were randomised in a 1:1 ratio via the randomiser feature in the Qualtrics software (e.g., EN Intervention, EN Waitlist Control, PT Intervention, PT Waitlist Control). Participants were informed which group they had been allocated to upon completion of the baseline assessment (T1) and the researchers were also aware of the randomisation result.

**Data analysis**

Quantitative data was analysed using into IBM SPSS Statistics for Windows Version 25. A two-sided $p$ value was considered statistically significant if it was lower than .05. Continuous variables were presented with means ($M$) and standard deviations ($SD$) and categorical variables with absolute numbers and frequencies. Extreme outliers (i.e., data points greater or less than 3 x interquartile range outside of the upper and lower hinge of the boxplot respectively) were excluded from the analyses.

To describe the sample, between group comparisons (intervention and waitlist control groups and 10-week follow up assessment (T2) completers and non-completers) were performed using independent samples $t$-tests (continuous variables) or chi-squared tests (categorical or dichotomous variables).

Data for demand, practicality, acceptability, and adaptation (intervention and study protocol) were reported with descriptive statistics ($M$, $SD$, frequencies). As not all intervention group participants engaged with the intervention, data related to the intervention collected from the online questionnaire at T2 were presented for 1) all intervention group participants, and 2) only those who used the intervention. These data were also presented per journey status.

Data for limited efficacy were reported for modified intention to treat (mITT) (i.e., all participants who completed T1 and T2) and per protocol (PP) (i.e., only for participants who received sufficient dose). The PP analysis will indicate potential efficacy of the intervention and mITT analysis more closely represents use of the intervention in real-life. Mean and standard error were presented for all mediators and outcomes. Limited efficacy was analysed via two-way mixed ANOVAs and MANOVAs (for eudaimonic wellbeing) with Group (waitlist control, intervention) as the between-subject factor and Time (baseline T1, 10-week follow-up T2) as the within-subject factor. Effect sizes (partial eta squared, $\eta_p^2$) were reported [small = .01, medium = .06, and large = .14 (Cohen, 1988)]. Finally, statistical significance of the difference in proportion of participants who experienced clinically significant change in hedonic wellbeing (i.e., increase of $\geq 10$ points) (Topp et al., 2015) in the intervention and waitlist control group for mIIT and PP analyses was tested with a Chi-square test.

Process evaluation interviews were audio recorded and transcribed verbatim. Survey data for factors that influenced implementation of the intervention and study protocol were of a qualitative nature and were inductively analysed. Reasons for non-participation were reported for each assessment moment and were inductively categorised against Bowens' feasibility outcomes. Qualitative data from these survey free text responses and interviews were analysed, according to the six steps outlined by Braun and Clarke (2006; 2019) for thematic analysis, using QSR International's NVivo 12 Software. This first involved familiarisation with the data by reading through the free text survey responses or transcripts several times. Then, inductive generation of codes that described a piece of information present in the data was completed. This exercise was descriptive with minimum inferences made to

minimise researcher bias. Codes were then organised according to Bowen's (2009)

feasibility criteria. Themes were developed from analogous data, but attention was

also given to divergent data if it was strongly endorsed by the participant(s). ED and

BR performed the analysis on the interview data and BR performed analysis on the

free text survey response data. BR, SG, and ED came together repeatedly for peer

debriefing, reflection and to discuss and review the codes. Quotes are accompanied

by participant number (P), gender (M or F), age (in years), and language (EN or PT).

## Results

**Sample characteristics**

Four hundred and forty individuals accessed the baseline survey but 25 did

not meet the inclusion criteria and 12 represented duplicate access of questionnaire

by the same person (identified by email address). Of the 403 remaining, 235 (58.3%)

completed the baseline and were randomised into the intervention and waitlist

control groups, and 16 (4.0%) participants withdrew at this point, so 219 (54.3%)

were included in analysis. One hundred and twenty-eight (31.8%) filled follow-up

(T2) questionnaire. Figure 5.1 presents the participant flowchart.

Table 5.4 presents the sample characteristics. The average age of participants

was 39 years old and around one in ten were men. The majority had a white ethnic

background, were in a relationship, had a university education, and were employed.

MyJourney was accessed from 25 different countries, but most participants were

from the UK and Portugal. Only 14% of participants had children, most still

sustained a child wish and were trying or thinking of trying to accept their unfulfilled

wish for children, with around half having engaged with support in the past and a

minority being currently engaged with informal support. Table 5.4 presents the

sociodemographic details for participants in the intervention and waitlist control group, and at T1 there were no significant differences between these two groups.

At T2, participants reported on average that the COVID-19 pandemic had negatively affected their wellbeing ($M$ = 2.36, $SD$ = 1.02) and their experience of having a UPG ($M$ = 2.52, $SD$ = 0.96). There was no difference between intervention and waitlist control groups for either variable (wellbeing: $t(127)$ = .196, $p$ = .845; experience of having a UPG: $t(127)$ = -.450, $p$ = .653).

Comparisons of sociodemographic details of those who completed or did not complete the 10-week follow up (T2) are reported in Appendix O. Overall, no significant differences were observed. The exceptions were that participants who completed the follow up assessment (T2) were more likely to be younger, reside in Europe (excluding UK and Portugal), and to have been recruited via Prolific.

*Process evaluation participants*
Ten participants were recruited for the qualitative process evaluation, five (50.0%) from the intervention group (2 English, 3 Portuguese) and 5 (50.0%) from the waitlist control group (all English). The average age of these participants was 42 ($SD$ = 5.56) years old. All were female, a majority (80.0%) were in a relationship, all but one had a university education (90.0%), and two thirds were employed (60.0%). None of these participants had children, and all but one sustained a child wish (90.0%). Most (7, 70.0%) had been trying to accept their unfulfilled wish for children for more than 6 months, 2 (20.0%) within 6 months, and one (10.0%) was not trying to accept.

**Figure 5.1**

*Participant flow chart (following CONSORT, 2010; Moher et al., 2012)*
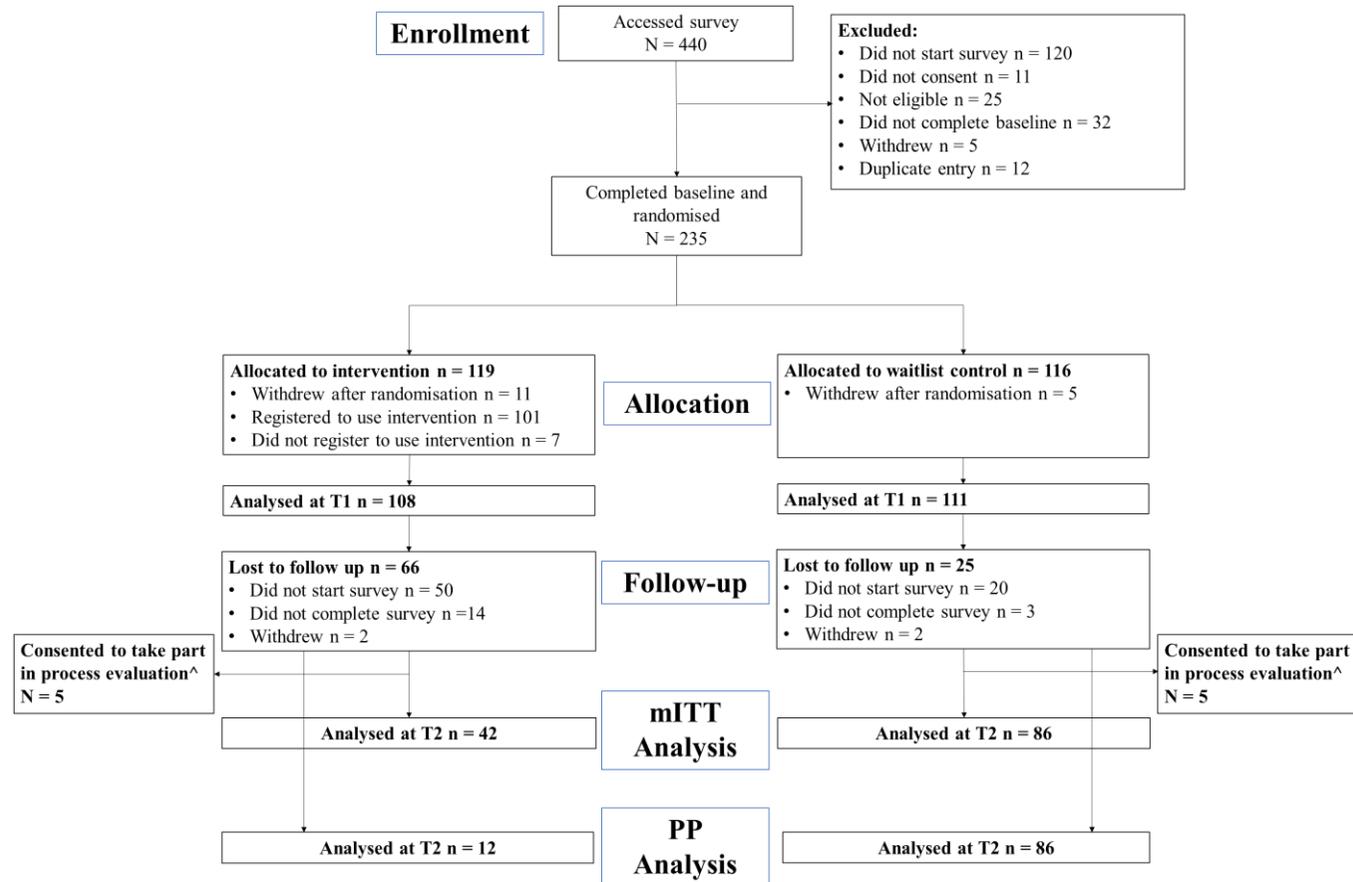


*Note.* ^All participants who completed the baseline questionnaire (T1) between November 2020 and February 2021 were invited to take part in the process evaluation. mITT = modified intention to treat, PP = per protocol.

**Table 5.4**

*Summary of sample characteristics of participants who completed baseline and differences between intervention and waitlist control group*

| Variable | Baseline N = 219 | | Intervention N = 108 | | Waitlist Control N = 111 | | t(215)ᵃ [CI] | p |
|---|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | M | SD | | |
| Age, years [range 18-72] | 39.15 | 9.53 | 39.28 | 10.05 | 39.01 | 9.05 | 0.20 [-2.30, 2.82] | .84 |
| | n | % | n | % | n | % | χ²ᵃ | p |
| Female | 192 | 87.7 | 92 | 85.2 | 100 | 90.1 | 1.29 | .52 |
| In relationship | 175 | 79.9 | 83 | 76.9 | 92 | 82.9 | 1.24 | .27 |
| University education | 169 | 77.2 | 86 | 79.6 | 83 | 74.8 | 0.73 | .39 |
| Employed part/full time | 182 | 83.1 | 92 | 85.2 | 90 | 81.1 | 3.10 | .21 |
| White ^ (n = 148) | 136 | 91.9 | 64 | 90.1 | 72 | 93.5 | 0.56 | .45 |
| Country | | | | | | | 3.64 | .46 |
| *United Kingdom* | 88 | 40.2 | 42 | 38.9 | 46 | 41.4 | | |
| *Portugal* | 68 | 31.1 | 35 | 32.7 | 33 | 29.7 | | |
| *Rest of Europe* | 41 | 18.7 | 17 | 15.7 | 24 | 21.6 | | |
| *USA* | 11 | 5.0 | 8 | 7.5 | 3 | 2.7 | | |
| *Rest of World* | 10 | 4.6 | 5 | 4.7 | 5 | 4.5 | | |
| Sustained child wish | 184 | 84.0 | 90 | 83.3 | 94 | 84.7 | 0.07 | .79 |
| With children | 31 | 14.2 | 14 | 13.0 | 17 | 15.3 | 0.25 | .8 |
| Engaged in fertility treatment | 133 | 60.7 | 60 | 55.6 | 73 | 65.8 | 2.39 | .12 |
| UPG journey status | | | | | | | 1.49 | .83 |
| *Not trying to accept* | 54 | 24.7 | 27 | 25.0 | 27 | 24.3 | | |
| *Just started or trying to accept for less than 6 months* | 68 | 31.1 | 34 | 31.5 | 34 | 30.6 | | |
| *Trying to accept for more than 6 months* | 80 | 36.5 | 39 | 36.1 | 41 | 36.9 | | |
| *Accepted* | 6 | 2.7 | 4 | 3.7 | 2 | 1.8 | | |
| *Other / Don't know* | 11 | 5.0 | 4 | 3.7 | 7 | 6.3 | | |
| Engaged with support in the past | 176 | 80.4 | 90 | 83.3 | 86 | 77.5 | 1.19 | .28 |
| Currently engaged with informal support | 50 | 22.8 | 25 | 23.1 | 25 | 22.5 | 0.01 | .91 |

*Note.* M = Mean, SD = Standard Deviation, CI = confidence intervals. ᵃTests for a difference between intervention and waitlist control group, and were estimated using Pearson chi squared test or independent *t* tests. ^Ethnicity question not presented to Portuguese participants.

**Feasibility Outcomes**

*Intervention*

  **Demand.** Of the 108 intervention participants who were provided with the link to register with MyJourney, 101 (84.9%) registered and 91 (76.5%) completed their account set up, with 87 (80.6%) agreeing to receive reminders. Seventy-one (65.7%) participants started using MyJourney (i.e., engaged with the Steps), with 51 (47.2%) participants completed at least one Step (Figure 5.2). On average, participants used the intervention for 10 hours ($SD = 18.08$, range: 0.04–79.37) and accessed it 8 times ($SD = 5.38$) (Figure 5.2). Although participants revisited the Steps on average 2.5 times, overall, they only completed each step once (Figure 5.3). To the open-ended question asking participants why they may not have completed all steps, twenty-one (19.4%) participants responded stating they forgot to use the intervention or had other commitments (e.g., work) (9, 42.9%) ("I didn't get involved due to lack of time and forgetfulness"; P247, F, 38, PT); not being able to register with the intervention (8, 38.1%), they would have engaged more if MyJourney had been a mobile app ("I think if I had the app as an icon on my phone, I would have engaged with it more as I would see it often."; P323, F, 37, EN); the intervention triggered negative emotions, or they needed more time to deal with those emotions (4, 19.0%) ("I started, but every time I wanted to enter - I felt sad and had unpleasant thoughts"; P264, F, 27, EN).

**Figure 5.2**

*Percentage of intervention participants who completed the Steps for all participants and per journey status*
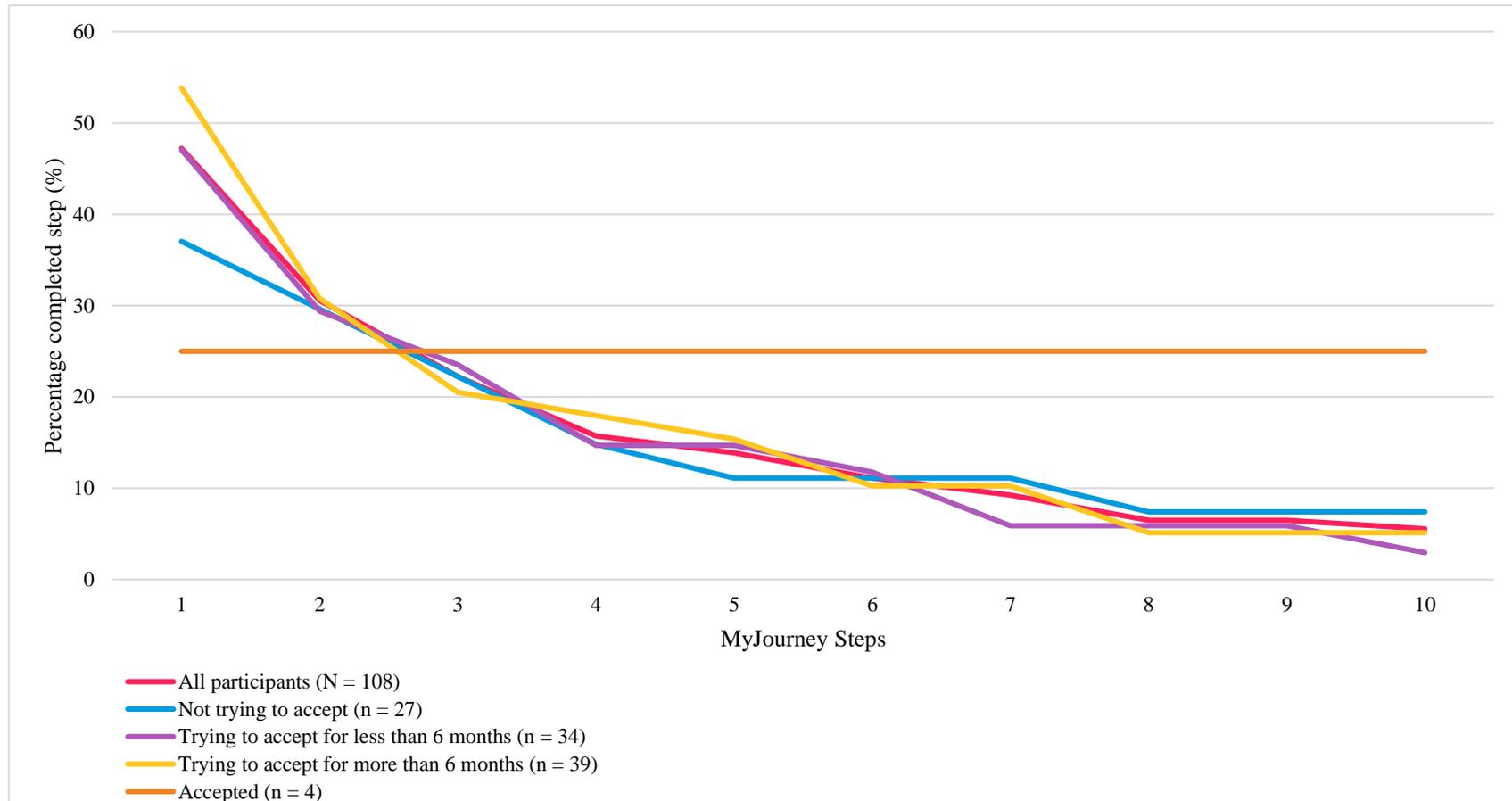
**Figure 5.3**

*Average hours per Step and number of times participants accessed Steps*
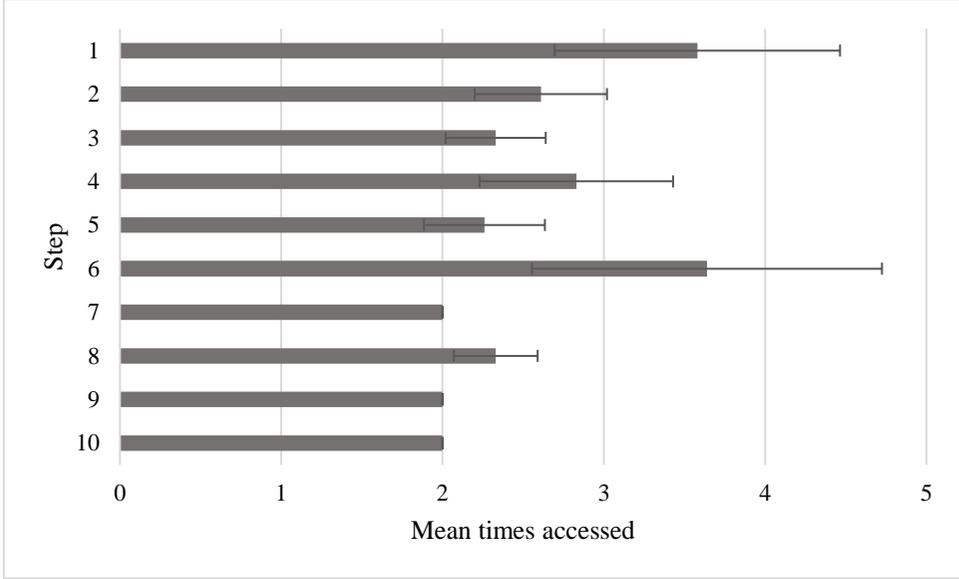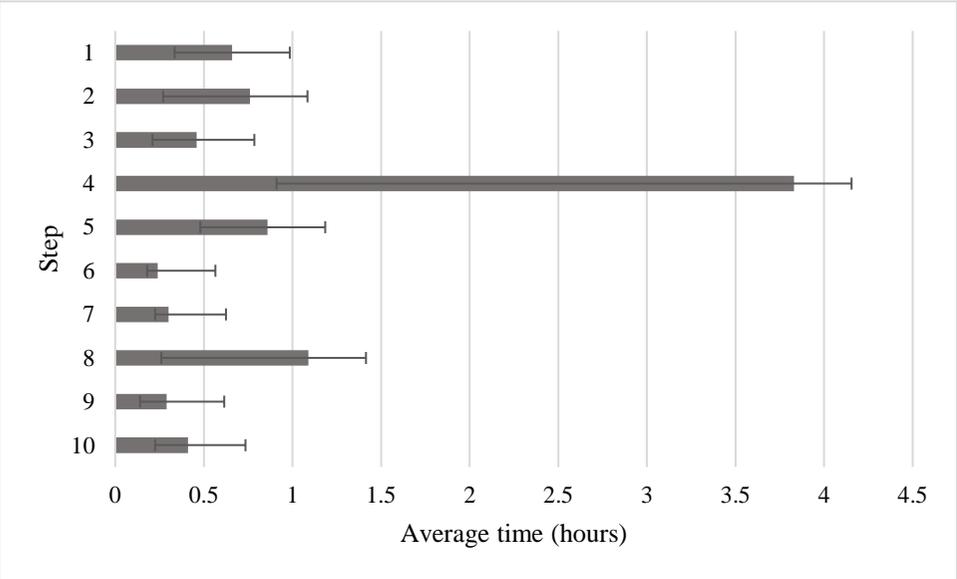
All routines were accessed apart from '*Remember your ABC*' (Step 10). Figure 5.4 presents the average time and frequency participants accessed the Routines. On average, participants accessed routines for 1.4 minutes (*SD* = 1.6, range: 0.10–0.90) and accessed 0.23 routines (*SD* = 1.5, range: 0–22). Routines were revisited on average 1.3 times (*SD* = 0.48) (Figure 5.4). Only five (4.6%) participants selected at least one routine as being a favourite. Mindfulness audio files were accessed on average 1.5 times (*SD* = 0.86), with '*Watching thoughts*' being accessed by the most participants and '*Self-compassionate break*' the least.

**Acceptability.** Figures 5.5 and 5.6 present acceptability ratings of the intervention. Overall, for all participants, most of the acceptability ratings were around 4 (very or somewhat agree), ranging from 2.79 (*SD* = 1.36) (successful at supporting people with an unfulfilled wish for children) to 4.07 (*SD* = 0.84) (user friendly interface). Overall, the majority of participants would recommend MyJourney to someone else in a similar situation and the majority intended to keep using it, as this was consistent across all stages of the journey apart from 'accepted', however this was only one participant (Figure 5.6).

Figures 5.7 and 5.8 present participants' average ratings of usefulness and challenges for the Steps. Overall, for all participants, the ratings of usefulness were moderate, with Step 10 '*Looking Ahead'* having the highest rating (*M* = 4.17, *SD* = 0.98). Across all stages of the journey, most participants rated the Step between moderately and very useful. Descriptives suggest those who were not trying to accept their UPG reported higher average usefulness ratings for the majority of Steps. Overall, participants' ratings for whether the Step was challenging were moderate, with Step 6 'Plan your route' presenting the greatest challenge (*M* = 3.42,

**Figure 5.4**

*Average number of minutes and times accessed for Routines*
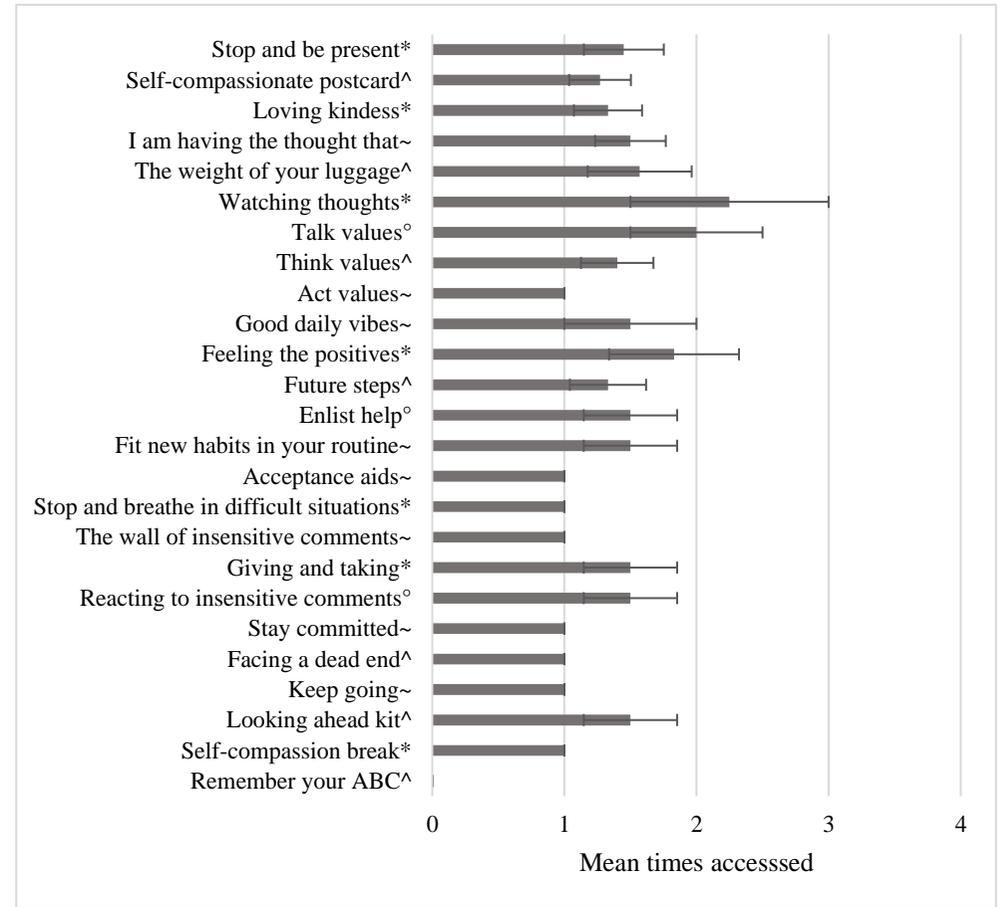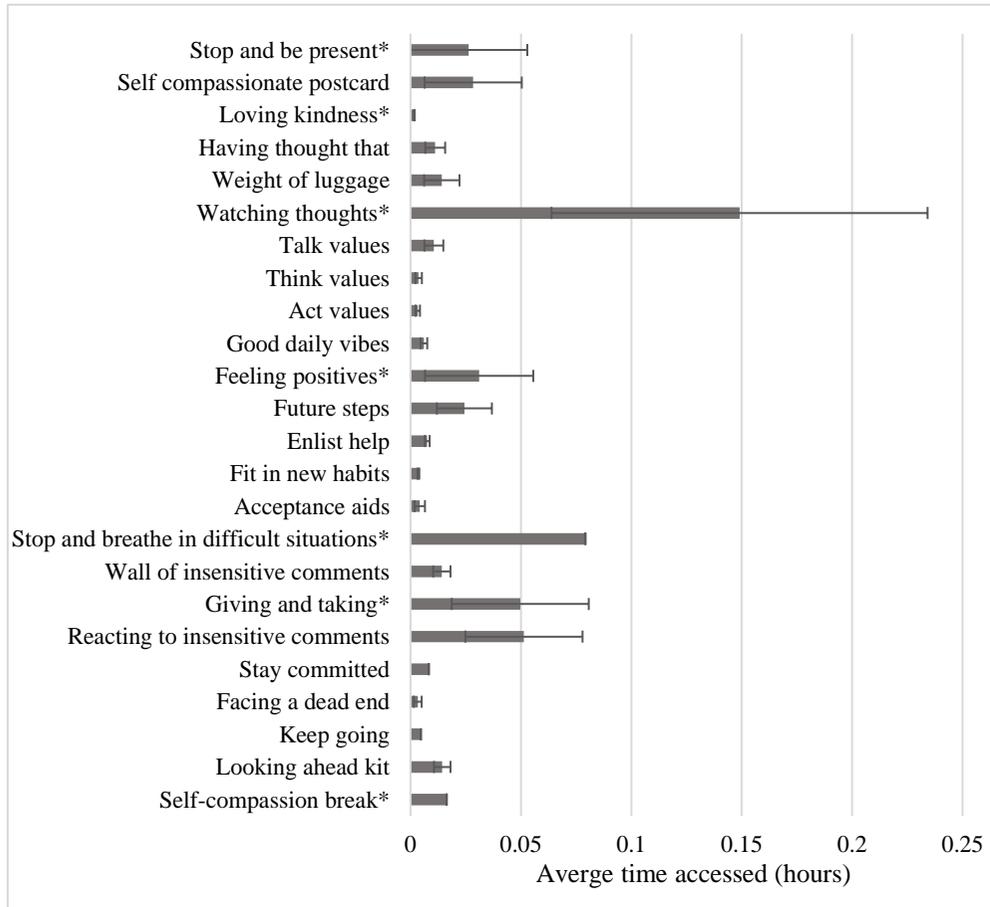


*Note.* * = Mindfulness meditation (audio), ^ = journaling, ~ = practicing new skills, ° = can be completed with someone else. Error bars = standard deviation.

**Figure 5.5**

*Acceptability ratings of the intervention at T2 for all participants and per journey*

*status*
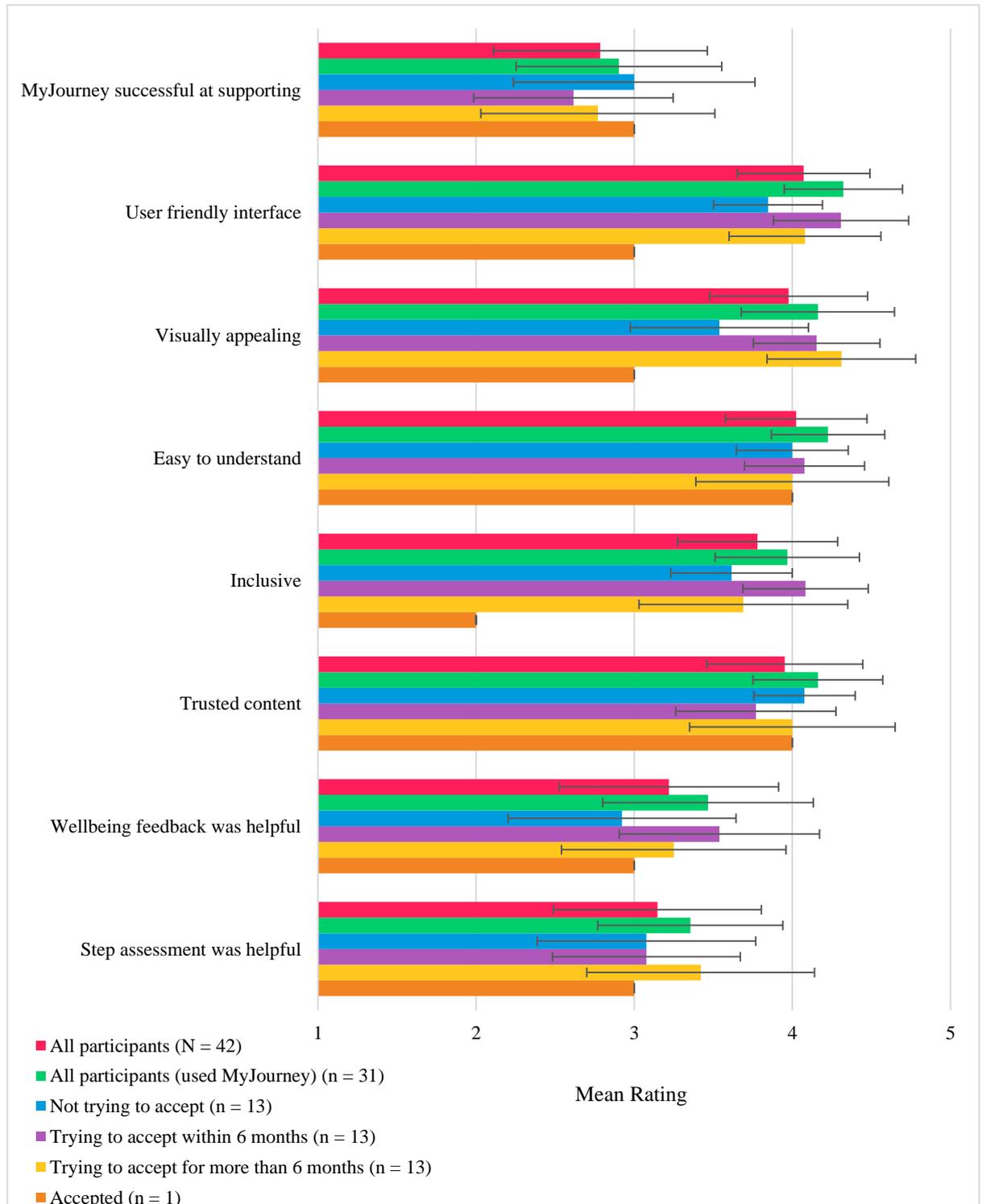


*Note.* Error bars = Standard deviation. N = maximum number of participants who provided a rating, n

= maximum number of participants who provided a rating for each group.

**Figure 5.6**

*Acceptability ratings (Yes) of the intervention at T2 for all participants and per journey status*
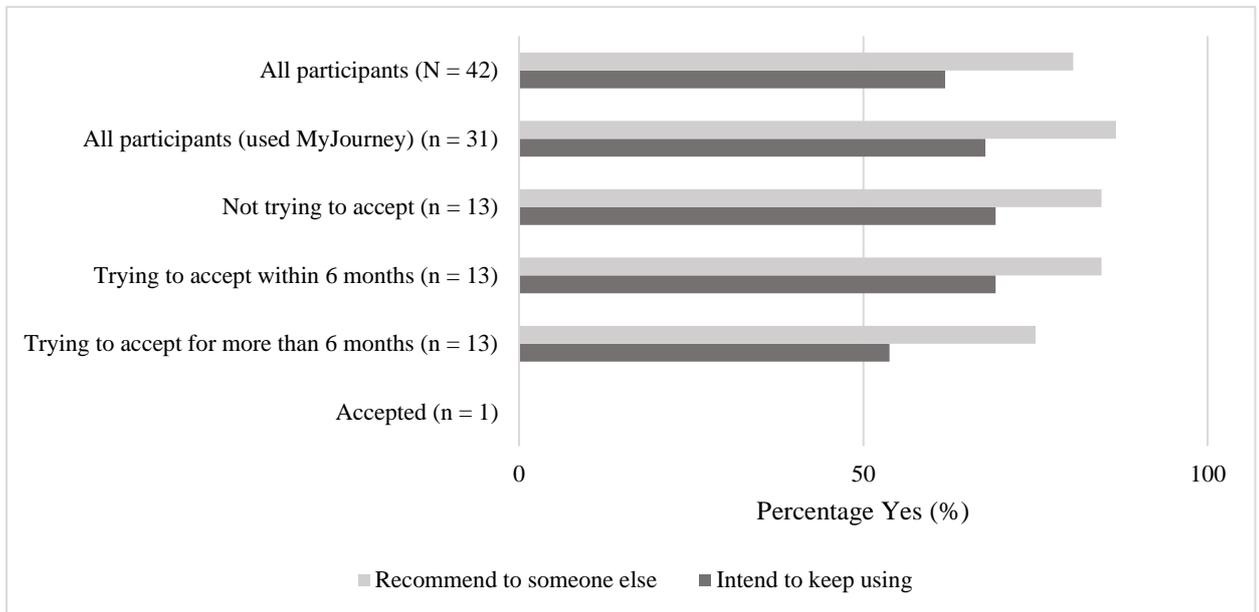


*Note.* N = maximum number of participants who provided a rating, n = maximum number of

participants who provided a rating for each group.

**Figure 5.7**

*Participants' average ratings of perceived usefulness of Steps*
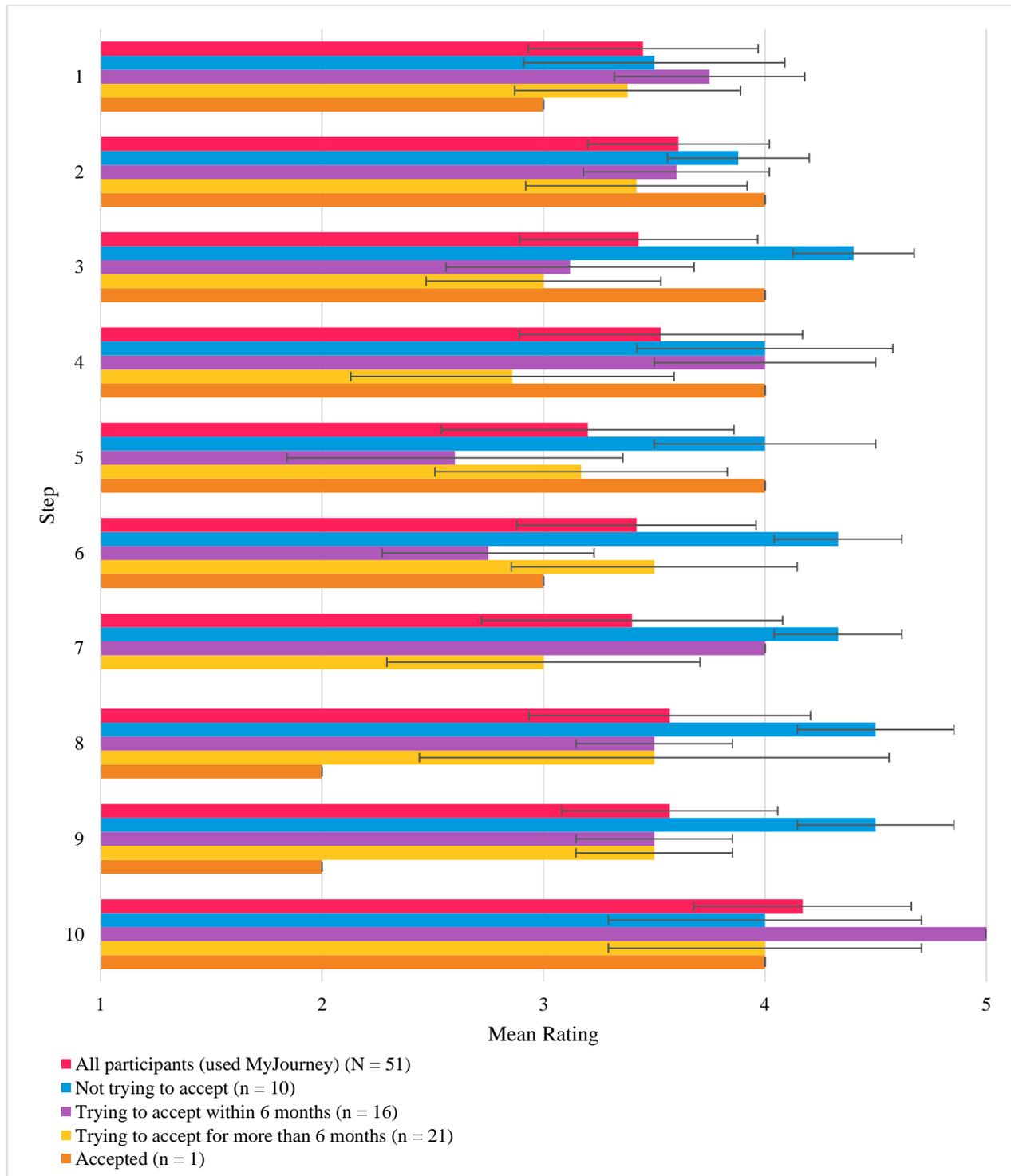


*Note.* Data from all participants who completed the Step and rated it are included in this figure. N = maximum number of participants who provided a rating, n = maximum number of participants who provided a rating for each group. Error bars = standard deviation.

**Figure 5.8**

*Participants' average ratings of perceived challenge of Steps*
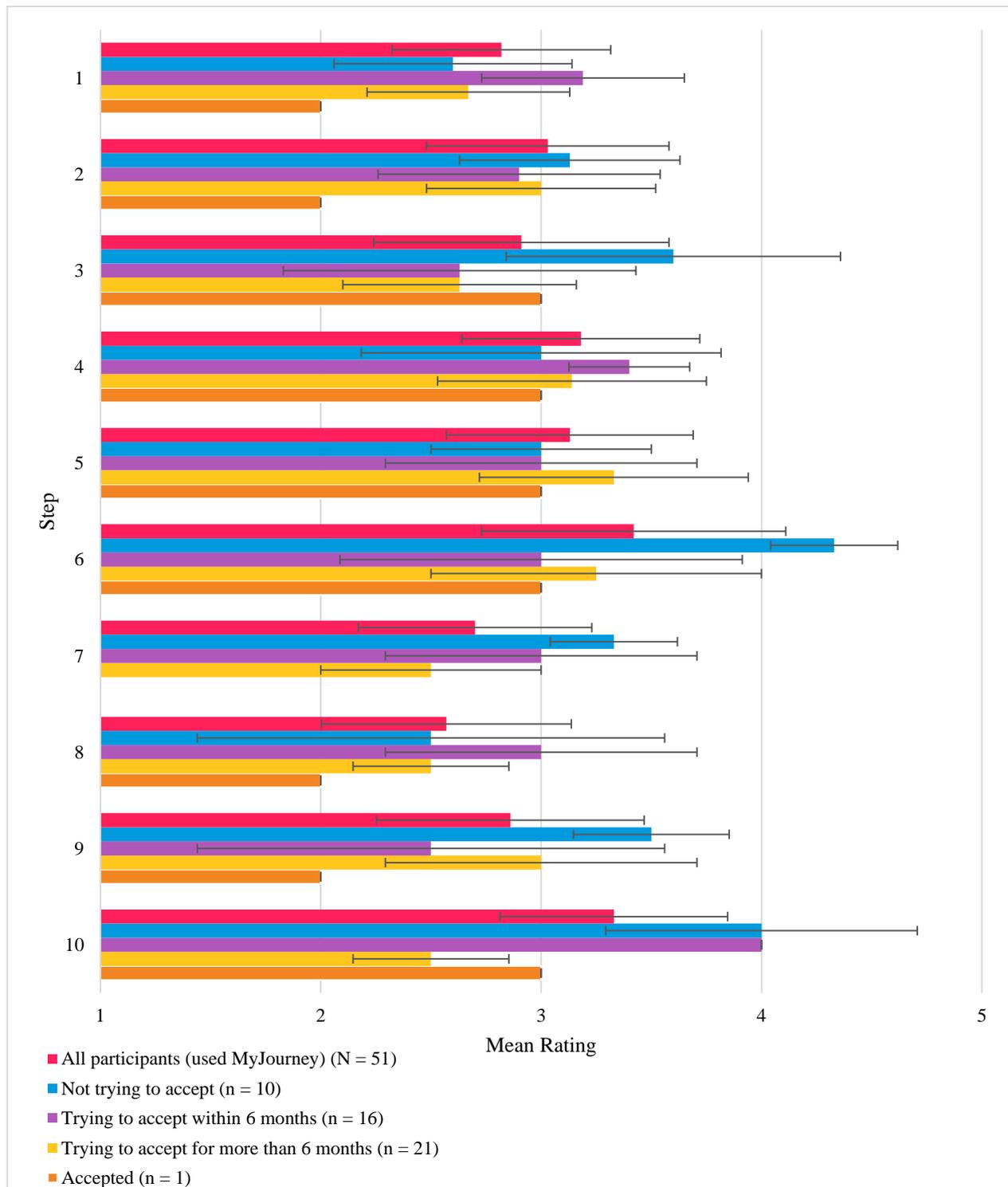


*Note.* Data from all participants who completed the Step and rated it are included in this figure.

N = maximum number of participants who provided a rating, n = maximum number of participants

who provided a rating for each group. Error bars = standard deviation.

*SD* = 1.38). Those who were not trying to accept their UPG reported higher

challenge ratings on average for the majority of Steps.

Thirty-three (78.6%) participants who completed the follow-up

assessment (T2) provided free text responses indicating their views on acceptability

(i.e., what they liked most, liked least). Overall, the most favourable features of the

intervention were the structured and supportive content (10, 30.3%) ("Relatively

short, simple, self-directed steps"; P456, F, 39, EN, "it was designed and written

from a place of understanding"; P275, F, 42, EN); the ease and flexibility of use (8,

24.2%) ("the fact that I could advance the various levels at my own pace also pleased

me"; P260, M, 30, PT); and the general helpfulness (4, 12.1%) ("It is a helpful

program for people who may not be willing or able to see a therapist"; P457, F, 50,

EN). The most cited least favourable aspects related to the reminders (e.g., wanted

more or less of them; 4, 12.1%) ("Text reminders would have helped me refocus";

P298, F, 50, EN); and wanting access to additional support (2, 6.1%) ("an option of

booking an appointment with someone for support if needed"; P323, F, 37, EN),

with 10 (30.3%) participants reporting there was nothing they disliked ("I can't

answer, I wasn't displeased with anything."; P451, F, 39, PT).

**Implementation.** Thirty-one (73.8%) participants provided a comment on

whether they experienced technical issues. A majority (23, 74.2%) did not

experience issues, 3 (9.7%) experienced issues registering, 3 (9.7%) felt the login

process was not accessible, and 2 (6.5%) reported other issues (i.e., missing content

or data not being saved). Twenty-five participants (59.5%) commented on the 10-

week recommended engagement period. Twelve participants (48.0%) felt it was the

right amount of time ("Yes, one step a week was good - not too daunting but enough

to keep me focused. Any more would have been too much."; P275, F, 42, EN), 7

(28.0%) felt that it was too short ("In my specific case, I think they should extend this time, as these are very personal issues, and acceptance of them will take time."; P324, F, 44, PT), 5 (20.0%) felt there should be unlimited time to engage to suit individual profiles ("[…] we heal differently and we also learn differently."; P449, F, 32, EN), and 1 (4.0%) thought it was too long.

**Practicalities.** From participants who were given access to MyJourney, 6 (5.6%) participants completed all 10 Steps, 12 (11.1%) received the sufficient dose six Steps). The average time taken by participants who completed all ten Steps was 12.4 hours ($SD = 16.66$, range: 2.21–37.30) and by those who completed six Steps (sufficient dose) was 15.6 hours ($SD = 18.15$, range: 1.53-53.25).

**Adaptation.** Seventy-nine (78.2%) participants registered with MyJourney in English and 22 (21.8%) in Portuguese. Of the participants who engaged in English, 50 (63%) started the first Step, 9 (11.3%) received the sufficient dose and 5 (6.3%) completed all ten Steps. Of the participants who engaged in Portuguese, 21 (95.5%) started the first Step, 3 (13.6%) received the sufficient dose and 1 (4.5%) completed all ten Steps. Portuguese speaking participants were significantly more likely to start the first Step compared to English speaking participants ($\chi^2 (1) = 8.53$, $p = .004$), but there was not a statistically significant difference between English and Portuguese participants who received sufficient dose or completed all ten Steps ($\chi^2 (1) = 0.08$, p $= .774$ and $\chi^2 (1) = 0.10$, $p = .754$, respectively). There was not a statistically significant difference for the time spent using MyJourney or number of visits for English (Time spent (hours): $M = 10.07$, $SD = 17.57$; number of visits: $M = 12.44$, $SD = 20.27$) and Portuguese (Time spent (hours): $M = 10.08$, $SD = 20.04$; number of visits: $M = 9.25$, $SD = 5.15$) participants; $t(79) = -0.004$, $p = .997$ and $t(79) = 0.69$, $p = .490$, respectively.

**Limited efficacy.** Descriptive statistics for the study outcomes and

mediators for the intervention and waitlist control groups at baseline (T1) and

follow-up (T2) in the mITT and PP analysis are presented in Tables 5.5 and 5.6. *F*

ratios and effect-sizes are presented as a function of Group (waitlist control,

intervention) and Time (baseline T1, 10-week follow-up T2) for the mixed ANOVAs

and MANOVAs.

*Primary outcome.* Figure 5.9 presents the means and standard errors in

hedonic wellbeing for the intervention and waitlist control groups across assessment

times. In the mITT, the mixed ANOVA for hedonic wellbeing showed significant

interactions of Time by Group. Simple effects test showed a large increase in

hedonic wellbeing in the intervention group from baseline (T1) to the 10-months

follow-up (T2), while no change was observed in the control group. Seventeen

(40.5%) and 15 (17.4%) participants in the intervention and waitlist control groups,

respectively, reported a clinically significant improvement in hedonic wellbeing

from baseline (T1) to the 10-months follow-up (T2). The difference in proportions

was statistically significant ($\chi^2$ (1) = 7.99, $p$ =.005).

For the PP analysis, the mixed ANOVA for hedonic wellbeing showed a

significant interaction of Time by Group. Simple effects test showed a large increase

in hedonic wellbeing in the intervention group from baseline (T1) to the 10-months

follow-up (T2), while no change was observed in the control group. Six (50%) and

15 (17.4%) participants in the intervention and waitlist control groups, respectively,

reported a clinically significant improvement in hedonic wellbeing. The difference in

proportions was statistically significant ($\chi^2$ (1) = 6.63, $p$ =.010).

**Table 5.5**

*Descriptive statistics for outcome and mediator variables at baseline (T1) and 10-week follow up (T2) and F ratios and effect-sizes for the two-way mixed ANOVAs and MANOVAs testing limited efficacy for the study outcomes and mediators, presented as a function of Group (Intervention, Waitlist control) and Time (baseline T1, 10-week follow-up T2) (mITT) (N = 128)*

| Variables | Intervention | | Waitlist Control | | $F$ statistic, $\eta_p^2$ | | |
| | N = 42 | | N = 86 | | Time main effect | Group main effect | Time x Group interaction |
| | M (SE) | | M (SE) | | | | |
| | T1 | T2 | T1 | T2 | | | |
| OUTCOMES | | | | | | | |
| **Hedonic WB** | 49.40 (3.13) | 58.70 (3.01) | 43.95 (2.14) | 44.00 (2.05) | $F(1, 124) = 7.58^{**}$ T1<T2 $\eta_p^2 = .058$ | $F(1, 124) = 9.27^{**}$ C<I $\eta_p^2 = .070$ | $F(1, 124) = 7.43^{**}$, $\eta_p^2 = .057$ C: T1=T2, $\eta_p^2 = .000$ I: T1<T2, $\eta_p^2 = .156$ |
| **Eudaimonic WB** | | | | | $F(1, 120) = 3.48^{*}$, T1<T2 $\eta_p^2 = .080$ | $F(1, 120) = 2.13$, $\eta_p^2 = .050$ | $F(1, 120) = 1.02$ $\eta_p^2 = .025$ |
| *Life is worthwhile* | 6.38 (0.38) | 7.05 (0.37) | 5.61 (0.26) | 5.75 (0.25) | $F(1, 122) = 5.86^{*}$, T1<T2 $\eta_p^2 = .046$ | | |
| *Satisfaction with life* | 6.05 (0.31) | 6.74 (0.33) | 5.66 (0.21) | 5.91 (0.22) | $F(1, 122) = 8.08^{**}$, T1<T2 $\eta_p^2 = .062$ | | |
| *Happiness* | 6.05 (0.30) | 6.64 (0.32) | 5.56 (0.20) | 5.88 (0.22) | $F(1, 122) = 8.78^{**}$, T1<T2 $\eta_p^2 = .067$ | | |

| Variables | Intervention | | Waitlist Control | | $F$ statistic, $\eta_p^2$ | | |
|---|---|---|---|---|---|---|---|
| | $N = 42$ | | $N = 86$ | | Time main effect | Group main effect | Time x Group interaction |
| | $M$ ($SE$) | | $M$ ($SE$) | | | | |
| **Mental Health** | 57.70 (2.85) | 59.80 (3.09) | 51.91 (1.94) | 54.70 (2.11) | $F$ (1, 124) = 2.15, $\eta_p^2$ = .017 | $F$ (1, 124) = 2.92, $\eta_p^2$ = .023 | $F$ (1, 124) = 0.04, $\eta_p^2$ = .000 |
| **Post traumatic growth** | 23.15 (1.70) | 27.49 (1.75) | 21.64 (1.15) | 22.34 (1.19) | **$F$ (1, 122) = 6.95\*\*, T1<T2 $\eta_p^2$ = .054** | $F$ (1, 122) = 3.25, $\eta_p^2$ = .026 | $F$ (1, 122) = 3.60, $\eta_p^2$ = .029 |
| **MEDIATORS** | | | | | | | |
| **Acceptance** | | | | | | | |
| *Acceptance* | 13.37 (0.78) | 15.90 (0.78) | 12.66 (0.53) | 13.01 (0.53) | **$F$ (1, 124) = 18.73\*\*\*, T1<T2 $\eta_p^2$ = .131** | **$F$ (1, 124) = 4.17\*, C<I $\eta_p^2$ = .033** | **$F$ (1, 124) = 10.77\*\*, $\eta_p^2$ = .080** <br> **C: T1=T2, $\eta_p^2$ = .011** <br> **I: T1<T2, $\eta_p^2$ = .311** |
| *Self-compassion* | 33.70 (1.06) | 35.45 (1.06) | 30.28 (0.72) | 30.09 (0.72) | $F$ (1, 124) = 2.80, $\eta_p^2$ = .022 | **$F$ (1, 124) = 13.51\*\*\* C<I $\eta_p^2$ = .098** | **$F$ (1, 124) = 4.28\*, $\eta_p^2$ = .033** <br> **C: T1=T2, $\eta_p^2$ = .002** <br> **I: T1<T2, $\eta_p^2$ = .089** |
| *Openness to experience* | 28.63 (1.59) | 29.85 (1.63) | 25.65 (1.09) | 24.94 (1.11) | $F$ (1, 124) = 0.11, $\eta_p^2$ = .001 | **$F$ (1, 124) = 4.82\*, C<I $\eta_p^2$ = .037** | $F$ (1, 124) = 1.59, $\eta_p^2$ = .013 |
| **Meaning Making** | | | | | | | |
| *Positive reframing* | 11.18 (0.54) | 11.59 (0.55) | 10.39 (0.36) | 10.66 (0.37) | $F$ (1, 123) = 1.84, $\eta_p^2$ = .015 | $F$ (1, 123) = 2.01, $\eta_p^2$ = .016 | $F$ (1, 123) = 0.08, $\eta_p^2$ = .001 |
| *Value Clarification* | 36.74 (1.30) | 36.15 (1.32) | 34.07 (0.88) | 35.07 (0.89) | $F$ (1, 123) = 0.13, $\eta_p^2$ = .001 | $F$ (1, 123) = 1.63, $\eta_p^2$ = .013 | $F$ (1, 123) = 1.92, $\eta_p^2$ = .015 |
| **Pursuit of other goals** | | | | | | | |
| *Goal re-engagement* | 22.00 (0.86) | 22.92 (0.86) | 19.71 (0.57) | 20.64 (0.57) | **$F$ (1, 122) = 4.73\*, T1<T2 $\eta_p^2$ = .037** | **$F$ (1, 122) = 5.91\*, C<I $\eta_p^2$ = .046** | $F$ (1, 122) = 0.00, $\eta_p^2$ = .000 |

| Variables | Intervention | | Waitlist Control | | F statistic, $\eta_p^2$ | | |
|---|---|---|---|---|---|---|---|
| | N = 42 | | N = 86 | | Time main effect | Group main effect | Time x Group interaction |
| | M (SE) | | M (SE) | | | | |
| *Committed action* | 30.58 (1.18) | 29.21 (1.26) | 27.55 (0.79) | 27.53 (0.84) | $F(1, 122) = 1.63$, $\eta_p^2 =.013$ | $F(1, 122) = 2.99$, $\eta_p^2 =.024$ | $F(1, 122) = 1.57$, $\eta_p^2 =.013$ |
| Social connection | | | | | | | |
| *Social connection* | 32.74 (1.89) | 35.50 (1.77) | 32.01 (1.25) | 32.90 (1.18) | **$F(1, 122) = 5.82*$, T1>T2 $\eta_p^2 =.046$** | $F(1, 122) = 0.65$, $\eta_p^2 =.005$ | $F(1, 122) = 1.55$, $\eta_p^2 =.013$ |

*Note.* $*p < .05$, $**p < .01$ $***p < .001$, $F$ = F-ratio, $\eta_p^2$ = partial eta square.

**Table 5.6**

*Descriptive statistics for outcome and mediator variables at baseline (T1) and follow up (T2) and F ratios and effect-sizes for the two-way mixed ANOVAs and MANOVAs testing limited efficacy for the study outcomes and mediators, presented as a function of Group (Intervention, Waitlist control) and Time (baseline T1, 10-week follow-up T2) (PP) (N = 98)*

| Variables | Intervention | | Waitlist Control | | F statistic, $\eta_p^2$ | | |
|---|---|---|---|---|---|---|---|
| | N = 12 | | N = 86 | | Time main effect | Group main effect | Time x Group interaction |
| | M (SE) | | M (SE) | | | | |
| | T1 | T2 | T1 | T2 | | | |
| OUTCOMES | | | | | | | |
| Hedonic WB | 48.00 (5.67) | 63.33 (5.50) | 43.95 (2.12) | 44.00 (2.05) | *$F(1, 96) = 8.74**$* T1<T2 $\eta_p^2 = .083$ | *$F(1, 96) = 4.75*$* C<I $\eta_p^2 = .047$ | *$F(1, 96) = 8.63**$* $\eta_p^2 = .082$ C: T1=T2 $\eta_p^2 = .000$ I: T1<T2 $\eta_p^2 = .284$ |

| Variables | Intervention | | Waitlist Control | | $F$ statistic, $\eta_p^2$ | | |
|---|---|---|---|---|---|---|---|
| | $N = 12$ | | $N = 86$ | | Time main effect | Group main effect | Time x Group interaction |
| | $M$ (SE) | | $M$ (SE) | | | | |
| **Eudaimonic WB** | | | | | $F (1, 93) = 6.05^{**}$ T1<T2 $\eta_p^2 = .163$ | $F (1, 93) = 1.00\ \eta_p^2 = .031$ | $F (1, 93) = 3.00^*\ \eta_p^2 = .088$ C: T1=T2 $\eta_p^2 = .048$ I: T1<T2 $\eta_p^2 = .647$ |
| *Life is worthwhile* | 6.00 (0.70) | 7.17 (0.67) | 5.61 (0.26) | 5.75 (0.25) | $F (1, 95) = 6.24^*$ T1<T2 $\eta_p^2 = .063$ | | $F (1, 95) = 3.95^*\ \eta_p^2 = .040$ C: T1=T2 $\eta_p^2 = .012$ I: T1<T2 $\eta_p^2 = .160$ |
| *Satisfaction with life* | 5.25 (0.57) | 6.92 (0.59) | 5.66 (0.22) | 5.91 (0.22) | $F (1, 95) = 12.77^{**}$ T1<T2 $\eta_p^2 = .118$ | | $F (1, 95) = 7.03^{**}\ \eta_p^2 = .069$ C: T1=T2 $\eta_p^2 = .021$ I: T1<T2 $\eta_p^2 = .427$ |
| *Happiness* | 5.25 (0.54) | 6.92 (0.58) | 5.56 (0.20) | 5.88 (0.22) | $F (1, 95) = 17.32^{***}$ T1<T2 $\eta_p^2 = .154$ | | $F (1, 95) = 8.0^{**}\ \eta_p^2 = .078$ C: T1=T2 $\eta_p^2 = .051$ I: T1<T2 $\eta_p^2 = .370$ |
| **Mental Health** | 57.33 (5.28) | 65.33 (5.62) | 51.91 (1.97) | 54.70 (2.10) | $F (1, 96) = 3.92\ \eta_p^2 = .039$ | $F (1, 96) = 2.44\ \eta_p^2 = .025$ | $F (1, 96) = 0.91\ \eta_p^2 = .009$ |
| **Post traumatic growth** | 24.18 (3.21) | 29.64 (3.36) | 21.64 (1.15) | 22.34 (1.21) | $F (1, 94) = 3.78\ \eta_p^2 = .039$ | $F (1, 96) = 2.50\ \eta_p^2 = .026$ | $F (1, 94) = 2.25\ \eta_p^2 = .023$ |
| **MEDIATORS** | | | | | | | |
| **Acceptance** | | | | | | | |
| *Acceptance* | 13.00 (1.44) | 17.58 (1.46) | 12.66 (0.54) | 13.01 (0.55) | $F (1, 96) = 22.35^{***}$ T1<T2 $\eta_p^2 = .189$ | $F (1, 96) = 2.83,\ \eta_p^2 = .029$ | $F (1, 96) = 16.47^{***}\ \eta_p^2 = .146$ C: T1=T2 $\eta_p^2 = .011$ I: T1<T2 $\eta_p^2 = .602$ |
| *Self-compassion* | 33.50 (1.93) | 38.33 (1.93) | 30.28 (0.72) | 30.09 (0.72) | $F (1, 96) = 11.14^{***}$ T1<T2 $\eta_p^2 = .104$ | $F (1, 96) = 8.78^{**}$ C<I $\eta_p^2 = .084$ | $F (1, 96) = 12.99^{***}\ \eta_p^2 = .119$ C: T1=T2 $\eta_p^2 = .002$ |

| Variables | Intervention $N = 12$ $M$ (SE) | | Waitlist Control $N = 86$ $M$ (SE) | | $F$ statistic, $\eta_p^2$ | | |
|---|---|---|---|---|---|---|---|
| | | | | | Time main effect | Group main effect | Time x Group interaction |
| | | | | | | | **I: T1<T2 $\eta_p^2$ = .525** |
| *Openness to experience* | 32.75 (3.07) | 36.25 (3.01) | 25.65 (1.15) | 24.94 (1.12) | $F$ (1, 96) = 1.18 $\eta_p^2$ = .012 | **$F$ (1, 96) = 9.52\*\*** **C<I $\eta_p^2$ = .090** | $F$ (1, 96) = 2.68 $\eta_p^2$ = .027 |
| **Meaning Making** | | | | | | | |
| *Positive reframing* | 12.09 (1.01) | 13.18 (1.02) | 10.39 (0.36) | 10.66 (0.37) | $F$ (1, 95) = 2.79 $\eta_p^2$ = .028 | **$F$ (1, 95) = 4.45\*** **C<I $\eta_p^2$ = .045** | $F$ (1, 95) = 1.02 $\eta_p^2$ = .011 |
| *Value Clarification* | 40.73 (2.56) | 41.45 (2.47) | 34.07 (0.92) | 35.07 (0.88) | $F$ (1, 95) = 0.71 $\eta_p^2$ = .007 | **$F$ (1, 95) = 7.00\*\*** **C<I $\eta_p^2$ = .069** | $F$ (1, 95) = 0.02 $\eta_p^2$ = .000 |
| **Pursuit of other goals** | | | | | | | |
| *Goal re-engagement* | 22.00 (1.70) | 24.73 (1.61) | 19.71 (0.61) | 20.64 (0.58) | **$F$ (1, 95) = 6.57\*\*** **T1<T2 $\eta_p^2$ = .065** | **$F$ (1, 95) = 3.94\*** **C<I $\eta_p^2$ = .040** | $F$ (1, 95) = 1.59 $\eta_p^2$ = .016 |
| *Committed action* | 35.36 (2.25) | 34.27 (2.43) | 27.55 (0.80) | 27.53 (0.87) | $F$ (1, 95) = 0.37 $\eta_p^2$ = .004 | **$F$ (1, 95) = 9.90\*\*** **C<I $\eta_p^2$ = .094** | $F$ (1, 95) = 0.36 $\eta_p^2$ = .004 |
| *Social connection* | | | | | | | |
| *Social connection* | 30.46 (3.57) | 37.46 (3.44) | 32.01 (1.28) | 32.90 (1.23) | **$F$ (1, 95) = 9.53\*\*** **T1>T2 $\eta_p^2$ = .091** | $F$ (1, 95) = 0.18 $\eta_p^2$ = .002 | **$F$ (1, 95) = 5.74\* $\eta_p^2$ = .057** **C: T1=T2 $\eta_p^2$ = .014** **I: T1>T2 $\eta_p^2$ = .304** |

*Note.* \*$p < .05$, \*\*$p < .01$ \*\*\*$p < .001$, $F$ = F-ratio, $\eta_p^2$ = partial eta square.

***Secondary outcomes.*** In the mITT analysis, the MANOVA for eudaimonic wellbeing, subsequent ANOVAs for its three measures, and the ANOVA for post traumatic growth showed significant main effects of Time, indicating that, regardless of group, participants reported a moderate increase in eudaimonic wellbeing and post traumatic growth from baseline (T1) to the 10-week follow-up (T2). No significant effects were observed in the mixed ANOVA investigating limited efficacy on mental health or PTG.

**Figure 5.9**

*Estimated marginal means at T1 and T2 for intervention and waitlist control groups for primary outcome (hedonic wellbeing) for mITT and PP*

Modified intention to treat analysis

Per protocol analysis
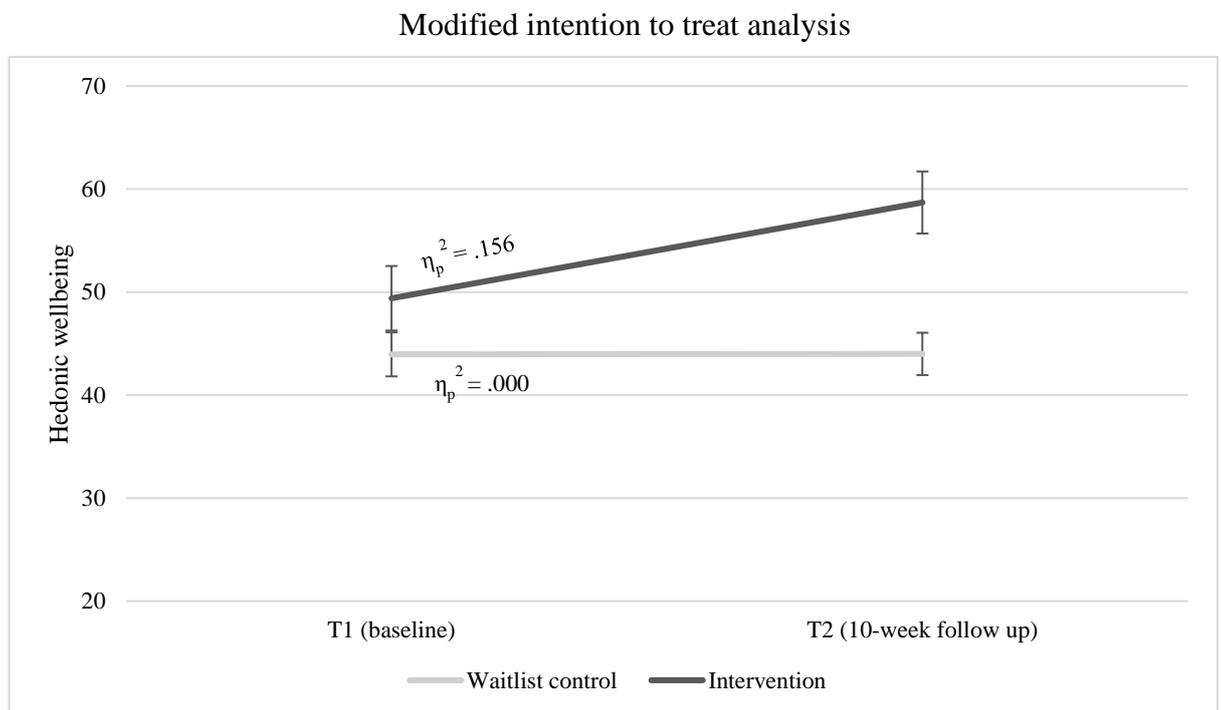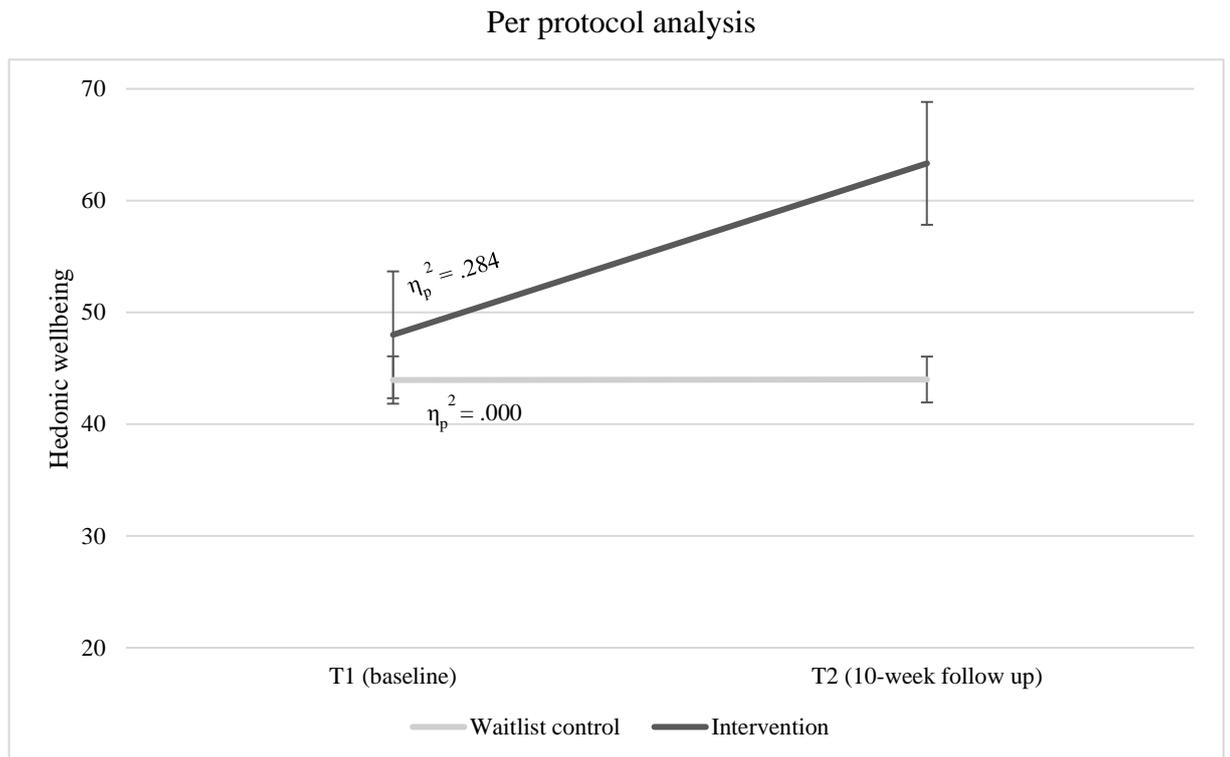


*Note.* $\eta_p^2$ = partial eta square. Error bars = standard error.

In the PP analysis, the mixed MANOVA for eudaimonic wellbeing and subsequent ANOVA for life is worthwhile showed a significant main effect of Time, indicating that, regardless of group, participants reported a moderate increase in their perceptions that their lives were worthwhile from baseline (T1) to the 10-week follow-up (T2). For satisfaction with life and happiness, the main effect of Time was qualified by a significant interaction of Time by Group. Simple effects tests showed large increases in satisfaction with life and happiness from baseline (T1) to the 10-week follow-up (T2) in the intervention group. The control group showed no change in satisfaction with life and a moderate increase in happiness. No significant effects were observed in the mixed ANOVA investigating limited efficacy on mental health or PTG.

*Mediators.* For the mITT analysis, the mixed ANOVAs for acceptance and self-compassion showed significant interactions of Time by Group. Simple effects

showed for both variables that there was a moderate to large increase across time in the intervention group while the waitlist control remained stable. Goal re-engagement and social connection showed significant main effects of Time, indicating that, regardless of group, participants reported a moderate increase from baseline (T1) to the 10-week follow-up (T2). Finally, a significant main effect of Group was observed in openness to experience (acceptance), and goal re-engagement. In all instances, the waitlist control scores were, on average, lower than the intervention group scores.

For the PP analysis, the mixed ANOVAs showed significant interactions of Time by Group for acceptance, self-compassion, and social connection. Simple effects for all showed a large increase across time was observed in the intervention group while the waitlist control remained stable. Goal re-engagement showed main effects of Time indicating that, regardless of group, participants reported a moderate increase from baseline (T1) to the 10-week follow-up (T2). Finally, a significant main effect of Group was observed for openness to experience (acceptance), positive reframing, value clarification, goal re-engagement, and committed action. For all of these, the average scores of the waitlist control group were lower than the intervention group.

### *Study protocol*

**Demand.** Participation and retention (T2) rates were 58.3% and 31.7%, respectively. Twelve (5.5%) participants provided reasons for non-participation/withdrawal, which were related to different feasibility outcomes: 5 (41.7%) were related to acceptability (e.g., dissatisfaction with language), 3 (25.0%)

were related to implementation (e.g., unable to register with MyJourney); 4 (33.3%)

related to practicalities (e.g., lack of time).

**Acceptability.** Fifty-four percent and 58.4% of participants completed the T1

and T2 questionnaires, respectively. Participants allocated to the waitlist control

group were more likely to complete the T2 assessments than participants who were

allocated to the intervention group (77.5% vs 38.9%, $\chi2$ (1) = 15.54 $p < .000$).

Participants were asked one open ended question about their thoughts of the

study protocol in the follow-up questionnaire (T2). Seventy-seven (60.2%)

participants provided a response. Forty-eight (62.3%) of these responses referred to

participants' satisfaction with taking part in the trial. Overall, the majority (37,

77.1%) considered the study protocol to be acceptable, examples included: "It was a

nice survey with very specific questions." (P353, F, 23, EN), and "The

questionnaires are simple and understandable." (P324, F, 44, PT). Ten participants

(20.8%) indicated that the assessments (T1 and T2) were not acceptable, for

example: "Oh my goodness it feels way too long!  Hard work to keep going." (P412,

F, 56, EN). The remaining participant's views on acceptability were neutral (1,

0.8%).

**Implementation.** Over the 8-month period of the trial, 19 (8.1%) participants

sent email queries. Thirteen (67%) concerned access or technical issues with the

intervention, 2 (11%) expressed a wish to withdraw from the trial, 2 (11%) expressed

dissatisfaction with language used in questionnaires, and 2 (11%) were related to

errors in the emails sent from the trial (e.g., intervention registration link missing on

email).

**Practicalities.** On average participants took 22 (*SD* = 11.97) and 23 minutes (*SD* = 20.67) to complete the baseline (T1) and follow-up questionnaires (T2), respectively. Process evaluation interviews ranged from 9.56 to 52.20 minutes (*M*= 24.42, *SD* = 9.49). It took on average 44 minutes (*SD* = 19.72, range: 15-240) a day for researchers to administrate the trial over a period of 8 months. All participants who started but did not complete the baseline assessment (T1) (32, 7.3%) were sent up to three reminders and of these, six (18.8%) participants ultimately did complete the baseline assessment (T1). At the follow-up assessment (T2), 128 (58.4%) participants were sent one reminder, 104 (47.5%) sent two, and 97 (44.3%) sent all three reminders if they did not complete it. Of these, 44 (20.1%) completed the follow-up assessment.

**Adaptation.** Participation rates for English participants and Portuguese participants were 59.0% and 46.7%, respectively ($\chi^2$ (1) = 5.73, *p* =.017), and retention rates were 35.8% and 25.0% at T2, respectively ($\chi^2$ (1) = 7.23, *p* =.007). Most PT participants were recruited via APF (32, 45.1%) whereas most EN participants were recruited from Facebook (30, 20.3%).

**Process evaluation**

The meta-themes and subthemes generated from the process evaluation data are presented in Table 5.7 and Appendix P.

*Intervention*

Overall, the process evaluation data corroborated the quantitative data, providing support for the demand for and acceptability of MyJourney. Furthermore, the qualitative data provided context for the quantitative results. For example, the demand for MyJourney was attributed to the particuarly challenging process of adjusting to a UPG and that most were already members of peer support groups.

Acceptability was credited to the supportive nature of MyJourney but around half had suggestions for improvements, which is consistent with the quantitative data indicating acceptability ratings were slightly above average. The quantitative data provides limited insight into the participants' views on the mindfulness meditations, but most participants who took part in the process evaluation felt they were a positive feature.

These data also indicated that engagement with MyJourney was multidetermined (implementation), providing insight to the varied engagement. Some indicated that they valued the flexibility of engaging whenever they wanted and this was reflected in participants taking longer than one week to complete each Step. Most felt that the decision to engage with MyJourney would be influenced by the stage of grief, with suggestions that engagement might be most beneficial earlier in the adjustment journey. Overall, it was practical to engage with (practicalities), for example because it was always available to access and online.

### *Study protocol*

Overall, the process evaluation data supports the quantitative data to suggest that the study protocol were considered both practical and appropriate. Specifically, participants felt the right questions were asked in the questionnaires, although only a minority understood why the randomisation was important.

**Table 5.7**

*Meta-themes from process evaluation*

| Meta themes | Themes and their description | Example Quotes |
|---|---|---|
| **INTERVENTION** | | |
| ***MyJourney is acceptable, meeting a perceived demand for support*** | *Support is needed and sought out.* Endorsement for the demand for MyJourney, in that participants described the challenges faced by having an unfulfilled wish for children and that around half had already tried alternative methods of support. Most were members of peer support groups. | "I was just isolated with it, there was no one else going through it, there was no one else to talk to…my mental health really suffered, really really suffered at that time" (IT2, 52, EN)<br><br>'I did CBT um a couple of years ago, just to really help me overcome somethings' (WL1, 43, EN)<br><br>"I am a member of a support group and I do regularly meet support group and talk about those sorts of things" (IT5, 39, PT) |
| | *MyJourney satisfies need for support.* A majority felt MyJourney satisfied their need for support and were glad that research on UPGs was being carried out. | "you very quickly get support, it does feel very supportive, even though it's very individual" (WL2, 42, EN)<br><br>"I think the reason I wanted to get involved was because it's like, oh my god wow, somebody is helping, somebody is even acknowledging that this is a really difficult thing" (IT2, 52, EN) |
| | *MyJourney is acceptable.* Overall, MyJourney was considered acceptable, with most reporting that mindfulness meditations were a positive feature, but half of participants did have suggestions for improvement | "I think the meditation part is awesome. It is very important for whom who practice, for whom has never practised, to who is not familiar with it… I found it very good" (IT4, 37, PT)<br><br>"there could possibly be some more work on the um on making it more customer friendly in a certain sense" (WL5, 48, EN) |
| | *MyJourney appears to target expected outcomes.* A majority felt that MyJourney appeared to achieve the expected outcomes. | "teach yourself to sort of let go of some of it and its ok to leave some of those bits of luggage behind that are maybe not as relevant now or as important as they were or would have been earlier on in the journey…so that one was useful" (IT1, 44, EN)<br><br>"I suppose it's that journey bit, but it's that sort of moving, moving you forward and giving you those strategies and those supports to be able to do that" (WL2, 42, EN) |
| ***Flexible engagement with MyJourney was valued and practical,*** | *MyJourney is flexible.* All participants valued the flexibility to engage with MyJourney as and when | "working through it at your own pace, and your own time, at your own pace is hugely beneficial" (WL2, 42, EN) |

| Meta themes | Themes and their description | Example Quotes |
|---|---|---|
| *but this engagement was multidetermined* | they wanted. Most reported not engaging with one Step per week. | "Even though it was on my own, with time, it took me some months… I found it very good" (IT4, 37, PT) |
| | *MyJourney is practical.* A majority felt engagement with MyJourney was practical, but a minority referred to less practical aspects such as needing to use MyJourney on a larger screen. | "This is one of the best parts, being always available" (IT4, 37, PT)<br><br>"So I think an online intervention tool is really useful" (IT1, 44, EN)<br><br>"I engaged with it on my phone, which was a regret...in hindsight I wouldn't have put it on my phone, I would have yeah, used it on a larger screen device" (IT3, 39, PT) |
| | *Engagement is multidetermined.* Engagement was influenced by many factors, e.g., by stage of journey, barriers e.g., work commitments or reminders going into the spam folder, and a desire to take one's time. | "maybe it is geared for people who are, yeah at the earlier stages, haven't quite, you know are sort of still flip flopping from one stage of grief to the other" (IT1, 44, EN)<br><br>"it went about 2 weeks and I hadn't logged in, I just forgot, busy with work and life and things" (WL3, 38, EN)<br><br>"perhaps had the ones that had gone into spam, arrived, I'd perhaps, perhaps might of engaged a little bit more" (IT4, 37, PT)<br><br>"I'm thinking maybe I'll give myself more than a week to do each step just to make sure I'm covering everything in the backpack" (WL1, 43, EN) |
| **STUDY PROTOCOL** | | |
| ***The trial study protocol are appropriate and practical.*** | *Study protocol are acceptable and appropriate.* Overall, all participants felt the study protocol were appropriate and a majority felt they weren't too demanding. | "I thought the questionnaires were good, they asked the right kind of questions in the right way you know they were nicely asked and the wording was nice" (WL3, 38, EN)<br><br>"Not demanding at all. It was not mandatory to complete all the parts; we could go back, amend, move forward." (IT4, 37, PT) |
| | *Study design was understood by some.* A minority reported understanding why randomisation was important. | "I knew I had a like, 50/50 chance of one or the other, and I thought yeah I'll participate irrespective of which group I get randomised into" (IT1, 44, EN) |

*Note.* IT = intervention group, WL = waitlist control group, age in years also provided, EN = interview conducted in English, PT = interview conducted in Portuguese.

**Progression Criteria**

The progression criteria met in this feasibility trial are presented in Appendix Q. All criteria either met the criteria to proceed (green) or proceed with amendments (amber). Three (33.3%) met the proceed (green) criteria indicating that more than half participants would recommend to others and intend to keep using, that more than half of participants who demonstrated an interest were eligible, and more than half of these were recruited. The remaining 6 (66.7%) met the proceed with amendments (amber criteria) indicating that between 10-50% of participants started using MyJourney, most ratings for acceptability variables were >3 (neither agree nor disagree/a moderate amount), most usefulness and challenge ratings of the MyJourney steps were moderate (>3 and <3, respectively), between 10-50% of participants completed sufficient dose within the 10-week recommend engagement period, between 20-80% of participants were lost to follow-up, and between 30-70% of participants completed the questionnaires at T1 and T2.

**Harms**

No harms or unintended effects of the intervention were reported.

## Discussion

**Main findings**

This randomised controlled feasibility trial has demonstrated that MyJourney, a self-guided online intervention, and its evaluation, are feasible. The findings of this trial demonstrate that there is demand for MyJourney, it is acceptable to its intended users, and implementation is feasible for Portuguese and English participants across different stages of the adjustment journey. Engagement is practical to a certain extent, however initiating the first Step and sustaining progression through the Steps is challenging and can be hindered by several factors, including lack of time and

technical issues. MyJourney has demonstrated promise of efficacy for the primary outcome (hedonic wellbeing) and a secondary outcome measure (eudaimonic wellbeing), with clinically relevant improvements in hedonic wellbeing observed in half of the intervention participants. Reported changes appear consistent with the Logic Model and underlying 3TM. Overall, the study protocol to evaluate MyJourney is feasible, but there was considerable attrition in the intervention group which could be linked with declining engagement with the intervention. As progression criteria was met (green or amber) overall (Appendix Q), development should continue to efficacy evaluation without significant changes to the Logic Model or content, but some minor adjustments to the intervention (e.g., address technical issues associated with registering) and the study protocol (e.g., changing random allocation from 1:1 to 2:1) should be considered.

Findings from this feasibility trial indicate that there is demand for MyJourney and that it meets this demand. Overall, demand appears to come from white, well-educated, and employed childless women at all stages of the adjustment journey who have not accepted their UPG, and around half had already actively sought out support previously. However, the participant sample might be biased by the recruitment strategies, particularly regarding people who are seeking support as many recruitment avenues were associated with offerings of peer support or similar, e.g., via social media of fertility support charities or childless advocates. Furthermore, the average scores for mental health and wellbeing in the participant sample were lower than normative data suggesting that people with UPGs with poorer mental health and wellbeing may be more likely to seek support and may need to use MyJourney. The process evaluation data supports the assertion that there is demand for MyJourney and that it satisfies a need for support. The only other

known intervention for people with UPGs did not report on demand (Kraaij et al., 2016), so it is challenging to compare these findings with other literature. However, this trial provides confidence that should other support be developed, there is likely to be demand for it.

Overall, the findings suggest MyJourney is generally acceptable for intended users. Most of the positive feedback was related to the design and easy to understand content. Perceived acceptability was average and somewhat at odds with the high intention to continue using and recommend others, this could simply reflect that the participants did not find some aspects as acceptable as others. Alternatively, it could be that ratings associated with whether MyJourney was successful at supporting people with UPGs and receiving the wellbeing feedback before each Step is likely to be related to the limited usage for most participants, as these are more difficult to rate from first impressions. As a majority intend to continue using, it is possible that their acceptability ratings may increase as they engage more with MyJourney. Overall, all Steps were rated as moderately useful and ratings of challenge were low to moderate, apart from Step 6 (Plan your route) and Step 10 (Looking ahead). This indicates that there is a potential perceived benefit of engaging with support and that this may outweigh the inherent challenge the adjustment process poses to these participants, but it may still influence perceptions of acceptability. However, it is important to note that usefulness and challenging ratings were only provided if participants engaged with and completed a Step and therefore the later Steps had low numbers of ratings as usage decreased. Exploratory findings across the different stages of adjustment journey imply that MyJourney is acceptable to all users irrespective of the stage, with those in the early stages experiencing more challenge but perceiving more benefit. This may suggest a more significant reframing process,

which may be reflected in more time needed to take action, which is consistent with the stages of change model (Prochaska & Norcross, 2001). This may also suggest that infertility professionals signposting patients to MyJourney at the point fertility treatment is likely to end could be useful. Acceptability of intervention is considered a key indicator of potential success and effectiveness (Sekhon et al., 2017). MyJourney has already demonstrated acceptability throughout the development process and feedback from this trial continues to reflect this.

Findings show that sustained progression through the MyJourney Steps proved challenging for most and indicated that MyJourney users may need to time to work through each Step and to transition to the next. A majority said they would continue using MyJourney though, indicating that they simply did not complete within the 10-week trial timeframe as opposed to disengagement. Participants' views seem to endorse than the minimum time needed to complete MyJourney is 10 weeks and that more time will be needed for some. This usage pattern may reflect the protracted nature of the adjustment process MyJourney targets. Naturally, it seems to occur around a 2-year period (Daniluk, 2001). MyJourney invited participants to explore the main issues central to adjustment within a 10-week timeframe, therefore it is unsurprising that progress may be slow and continue for much longer, which may explain why a majority intend to continue use. The exploratory work around different stages of the adjustment journey appear to indicate that, although group sizes were small, people at different stages of the UPG adjustment journey engaged at a similar pace. However, this may reflect that, although participants were advised they could engage at their own pace, it was recommended to engage with one Step per week. The process evaluation data highlighted that usage was multidetermined and that often this was external factors, such as work or other commitments.

However, some technical issues were noted that may have influenced adherence, such as challenges registering or remembering login details. Sustained adherence in web-apps is reported as a challenge across the literature (Christensen et al., 2009; Kelders et al., 2012; Linardon & Fuller-Tyszkiewicz, 2020). Although MyJourney applied several persuasive technology principles, such as reduction (reducing complex behaviours into simple steps), tunnelling (delivery of content to guide users through a process), and reminders (provide reminders about using the intervention) (Kelders et al., 2012; Oinas-Kukkonen & Harjumaa, 2009), the number of participants receiving the sufficient dose (completing 6 Steps) or completely adhering (completing all 10 Steps) was poor compared to other trials of webapp and online interventions (Christensen et al., 2009; Linardon & Fuller-Tyszkiewicz, 2020). According to the persuasive systems design framework, MyJourney uses only one social support persuasive technology strategy, i.e., normative influence (e.g., with the use of quotes from others with UPGs). Although this is consistent with a systematic review of persuasive technology elements of web-based interventions, where social support was used least often (Kelders et al., 2012), social support strategies should continue to be explored. Other strategies to sustain engagement specific to the feedback received in the trial should also be investigated now to increase the number of users that receive the sufficient dose, for example outlining clearly how long each Step may take to complete so that users can schedule their time to use the intervention around their other life commitments.

A key finding is that overall MyJourney appears to be beneficial, producing medium to large effects on the primary outcome (hedonic wellbeing), secondary outcome (eudaimonic wellbeing), and some mediators (outputs). These benefits are observed for participants who did not receive a sufficient dose, but the changes are

particularly noticeable for those who did receive a sufficient dose (engaged to at

least Step 6). The larger effect sizes for the PP analysis compared to the mITT

supports the assertion that poor engagement can affect the benefits reported from

using an intervention, i.e., the efficacy (Donkin et al., 2011; Wright et al., 2019). The

changes reported in the intervention group across time are consistent with the Logic

Model and the 3TM, providing some confidence the mechanisms of change (outputs)

and outcomes are being targeted as expected. The increases in wellbeing appear to be

driven by increases in acceptance of one's UPG, which is anticipated as most of the

initial Steps in MyJourney target acceptance, and previous research has

demonstrated moderate correlations between acceptance and hedonic wellbeing

(Chapter 3; Appendix A). The lack of positive changes in the mediators (meaning

making and pursuit of new goals) and secondary outcomes may be related to the low

numbers that received a sufficient dose or completed all Steps as those who did

receive a sufficient dose appeared to report a more holistic change in the outcomes.

It could also be that MyJourney is less effective at triggering these mediators or

outcomes or that a sleeper effect is being observed where any benefits may only be

visible at a later assessment moment. Other research has indicated that the process of

meaning making, and cognitive processing involved in this, can take time (Park,

2010), so the resultant benefits might not have occurred yet. Additionally, the pursuit

of new goals may also appear later in the adjustment process once one has built more

acceptance of their UPG (Gameiro & Finnigan, 2017) supporting the idea that it

could be a sleeper effect for this output. It could also be that it was too soon to

observe changes in some of the secondary outcomes, for example other research has

indicated that time is required for the cognitive processing related to post traumatic

growth to occur (Sears et al., 2003; Tedeschi & Calhoun, 2004). However, the only

other evidence-based intervention developed for people with UPG's did report improvements in depression scores one month after engagement (Kraaij et al., 2016). In a future trial, efforts to increase adherence to MyJourney should provide some insight on this.

Overall, the study protocol was considered adequate and acceptable to the participants. There was a high recruitment rate, and more participants were recruited than expected in the predefined recruitment period. The completion rate for the questionnaires at each assessment moment was between 50-60%, and the questionnaires, in particular the length, were considered burdensome for a minority of participants. This trial was exploratory which was reflected in the longer questionnaires. Although consideration was given to the length of questionnaires and associated burden, it is possible that questionnaires in a future RCT could be refined and shortened. The overall attrition rate was slightly higher than the fertility specific intervention studies used to determine the sample size (Cousineau et al., 2008; Hämmerli et al., 2010; Kersting et al., 2011; Van Dongen et al., 2016), and similar studies of online self-guided interventions and web apps (Cavanagh et al., 2014; Kelson et al., 2019; Linardon & Fuller-Tyszkiewicz, 2020; Melville et al., 2010). There was higher attrition in the intervention group compared to the waitlist control group. Other RCTs in the reproductive literature do not appear to report this differential attrition between the intervention and control groups (Cousineau et al., 2008; Hämmerli et al., 2010; Kersting et al., 2011; Van Dongen et al., 2016). However, a systematic review of smartphone interventions for mental health indicates that differential attrition does occur, with statistically significantly higher attrition in the intervention groups compared to inactive controls (Linardon & Fuller-Tyszkiewicz, 2020). This is consistent with a systematic review and meta-analysis of

differential attrition in health change behaviour RCTs which also suggested that there is often higher attrition in the intervention group, but this did include trials with various control groups (e.g., waitlist, care as usual, alternative interventions) and interventions were not all self-guided online or smartphone (Crutzen et al., 2015). It was also hypothesised that participants in RCTs often know they have been allocated to the intervention group and therefore have high expectations, and if these are not met, participants may drop out. Often the reasons for differential attrition are not explored but developing an understanding of this can provide some insight into ways to minimise drop out (Eysenbach, 2005). Although participants were asked their reasons for dropout in this trial, there were very limited responses, and it is not possible to determine whether there was a higher attrition rate in the intervention group because MyJourney did not meet their expectations or that it has resulted in poor outcomes or even harm. Alternatively attrition in the intervention group could be related to participants not completing all Steps in MyJourney, as suggested by Eysenbach (2005), where attrition (loss to follow up) follows non-usage of the intervention and both are considered to reflect a loss of interest in the trial and intervention. However, as noted, it is possible that participants were just moving more slowly through the Steps and did not complete the Steps in the 10-week timeframe (Linardon & Fuller-Tyszkiewicz, 2020). It is possible that lower attrition rates in the waitlist control are attributed to the incentive of receiving access to MyJourney upon completion of the follow up assessment moment (T2), although all participants were clearly informed that they would receive access regardless of whether they completed the T2 questionnaire. However, it is not possible to say this definitively.

**Strengths and Limitations**

This feasibility trial had a pre-registered protocol with predefined progression criteria. The trial utilised the Bowen et al., (2009) feasibility outcomes which has facilitated a time- and cost-effective comprehensive evaluation of both the intervention and study protocol. The trial emulated real world use of an online intervention (i.e., no researcher contact) to maximise ecological validity. The trial protocol is generalisable to other studies that wish to evaluate online interventions in this way. Another strength was the evaluation of limited efficacy consisting of per-protocol analysis and modified intention-to-treat analysis, allowing for analysis of the intervention when it was used as intended and analysis of it in a way that may more accurately reflect real-life usage. This trial also had an embedded process evaluation which strengthened reliability of the findings.

A key limitation of this trial was that participants and the researchers were not blinded to allocation. A future trial should consider blinding the statistical analysis. The participants were also a homogeneous group of white, well-educated, employed, childless women. Less than 15% had children and only 1 in 10 were men which may be representative of those seeking support. Subgroups were not evaluated as this is not within the scope of feasibility evaluation and it remains unclear whether MyJourney is useful or acceptable to men, parents or ethnic and minority groups. Therefore, a future, better powered study, analysis can be considered to explore different potential moderators of the impact of MyJourney on outcomes, including gender, parental status, baseline outcome levels, UPG pathway. Sampling bias may have occurred from using similar recruitment strategies and broader dissemination should be addressed in a future trial. As noted previously, data from the Prolific recruitment platform is of high quality compared to other platforms (Peer et al., 2017) and Prolific has been designed for academic research (Palan & Schitter, 2018).

Although the researcher is confident that the participants recruited from Prolific met the eligibility criteria, subgroup analysis to investigate whether there were any differences between the participants recruited via Prolific and those recruited via social media or online support group was not possible due to lack of power and beyond the scope of feasibility evaluation. Another limitation is that only self-report questionnaires were used, which could have resulted in a bias towards favourable evaluations of MyJourney. However, the heterogeneity of the acceptability ratings indicates that participants were comfortable to provide positive and negative feedback. Since this trial has been conducted, the validity of the CompACT subscale that measures openness to experience (used in this trial to evaluate acceptance) in Portuguese has come under question for validity (Trindade et al., 2021), and therefore a different scale may need to be considered in a future trial. The per protocol analysis did not have sufficient power as the sample size for the per protocol intervention group was smaller than the sample size required to observe moderate to large effects, meaning the results could be unreliable, for example with overestimations of effect size. Although participants were asked for reasons for drop out, very limited information was provided, and therefore it was not possible to determine whether participants dropped for reasons related to the feasibility outcomes. Finally, there are still uncertainties about whether MyJourney targets all outcomes or mediators meaning full evaluation of the underlying Logic Model was not possible. However, the 6 month follow up data may provide some insight into this.

**Implications: Changes to intervention and protocol**

The findings indicate that overall, the intervention and study protocol are feasible for efficacy testing, meeting the progression criteria (See Appendix Q). No

changes are needed for the Logic Model or the content, but strategies to improve

adherence through the MyJourney Steps need to be explored. For example, the

registration and technical issues reported for the intervention should be addressed to

make logging in and remembering login details easier, e.g., provide instructions how

users can add a MyJourney icon to their phone, options to remained logged in on

chosen devices, and support to help users integrate MyJourney into their busy

schedules, by providing examples to support regular or routine use. In a future trial,

different types of reminders (e.g., SMS, more tailored content) could be used to

determine which is most efficient at maintaining engagement. Previous feedback has

indicated that users value interactive design, short blocks of text, and clear language,

and this should continue to be explored. Overall, the study protocol in this feasibility

trial could be conducted on a larger scale in a RCT to evaluate efficacy. However, to

address minor amendments to the study protocol, it is recommended that a 2:1

allocation (intervention: waitlist control) is deployed in a future RCT to ensure a

sufficient sample size for follow up assessment moments. A future RCT could

include an interim assessment of the outcomes and mediators at 6 weeks (to allow

for sufficient dose), rather than after 10 weeks to reduce attrition rates. Statistically

significant differences in participation and retention rates between English and

Portuguese participants indicate that more Portuguese recruitment avenues should be

explored for a future RCT.

**Overall implications**

The findings from this trial indicate that there is high demand for support for

people with UPGs and attention towards the development of support initiatives is

necessary. MyJourney is a promising resource and self-guided support seems

sufficient to improve wellbeing. This is the first support that has been developed for

people with UPGs, regardless of their pathway. Delivery of an online self-guided

intervention is acceptable but a better understanding of barriers to engagement and

risk factors for disengagement is needed so that users can receive the sufficient dose

to subsequently experience the most benefit. Clinics, charities, and mental health

practitioners can be confident that engagement with MyJourney is beneficial for the

people and patients they aim to support. Progression criteria were met meaning that a

full scale RCT can now be planned to evaluate MyJourney's efficacy.

# Chapter 6: General Discussion

Overall, this thesis has brought substantial advances to the emergent research on support for people with UPGs, meeting all the research objectives outlined in Chapter 1. This chapter will present an overview of the main findings and implications, discuss areas for future research, provide suggestions for the future avenues for MyJourney, and explore the overall strengths and limitations of the work reported in the thesis.

## Summary of main findings

The research in the present thesis has demonstrated that a self-guided online intervention, named MyJourney, is a promising support tool for people with UPGs. From the perspective of people with UPGs, delivery of support as a self-guided and online intervention is acceptable and people who consider themselves childless by circumstance are likely to engage with this type of support. Furthermore, people still find MyJourney useful even if they are not thinking about trying to adjust and therefore early awareness of, and even limited engagement with, MyJourney could produce benefits. This suggests that fertility clinics should be signposting patients to MyJourney as soon as conversations begin about treatment ending after being unsuccessful. Additionally, it has been argued that users may need a certain level of mental health or wellbeing for online self-help interventions to be effective (Trompetter et al., 2016). However, the participants in the feasibility trial (Chapter 5) generally had poorer mental health and wellbeing compared to normative values and benefit was still observed, particularly for the primary outcome of hedonic wellbeing. Further work can now build on the evidence-base for MyJourney via a larger RCT to evaluate efficacy. Importantly, MyJourney has been developed in such a way that it can offered to people with UPGs without the requirement for training,

meaning it is a cost-effective and time-efficient support tool. Therefore, this work

and resultant output is relevant for health-policy makers, fertility clinicians, fertility

counsellors, general mental health practitioners, charities, peer supporters, and the

general public with UPGs. Additionally, being a freely available web-app, using

MyJourney does not require referral from a fertility clinic nor primary care

practitioner. It can be easily accessed by people with UPGs who do not engage with

fertility treatment or who do not wish to engage with formal support.

**Key discussion points**

The main findings from the present thesis contribute to improving the

provision of support for people with UPGs, across different care pathways. They also

contribute to the evolving delivery of support, as digital tools take an increasingly

important role. Finally, the findings in this thesis contributed to the phased

development of a research-based support tool, including theory validation of the

3TM.

*Conceptualising support for UPGs as a responsibility in care pathways*

The research in this thesis has made major advances in the provision of

support for people with UPGs, contributing to an understanding of the demand for

support and the areas that supportive efforts should be focused. MyJourney meets

this demand, not only as an easily accessible support tool, but one that has

demonstrated benefit. Supportive efforts should concentrate on helping people with

UPGs build acceptance of their experience, develop a sense of meaning, and channel

their efforts into the pursuit of other meaningful goals away from parenthood. Social

support also plays an important role and facilitating this should also be included in

these supportive efforts.

The work in this thesis is particularly relevant for fertility care and offers a tool that can support patients who have been unsuccessful at the end of their fertility treatment journey. Considerable work has been carried out on the provision of support during fertility treatment because of the recognised psychological burden (Frederiksen et al., 2015). Now national and international guidelines call for evidenced-based support in the post-treatment phase for fertility patients (Gameiro et al., 2015; HFEA, 2019; NICE, 2017) as it is increasingly recognised that unsuccessful treatment can have a long-term negative impact (Gameiro & Finnigan, 2017). MyJourney and its development have not only contributed to this area of research, but the resultant output is a tool that fulfils the requirement of the national and international guidelines for clinics to provide evidence-based support to their patients. Often patients can feel abandoned by their clinics once treatment ends (Boden, 2007; Daniluk, 2001) and UK guidance suggests emotional support should be offered post-treatment (HFEA, 2019). Offering this support tool could both minimise this sense of abandonment from the patient perspective and, for UK clinics, fulfil clinic licence requirements set out by the Code of Practice.

There is currently limited provision of tailored support and limited awareness of the need for support from among primary care providers and generic mental health services for people with UPGs. But this thesis has made an important contribution demonstrating that people from various UPG pathways seek out and would use support. This is particularly apparent from the findings from the mixed-methods study in Chapter 3. Additionally, people who consider themselves childless by circumstance indicate a preference for informal support. Increasing numbers of people may experience UPGs because of circumstantial factors. As more people delay childbearing, more people will not be able to meet their parenthood goals

(Beaujouan, 2021). Therefore, attention should be given to how to raise awareness within primary care providers about the impact of having a UPG, for example what questions could be asked to ascertain that people could have a UPG and the impact it might be having, so that they can determine who might need to be signposted to MyJourney. This could subsequently lead to greater awareness about MyJourney and knowledge about who it can benefit. As this research gets published and further work is carried out, this should raise awareness of, and evidence of, the need for this support.

Attention also needs to be paid to how people with UPGs, who do not engage with fertility treatment and who do not seek formal support via primary care pathways, can find out about MyJourney. One suggestion is raising awareness of MyJourney and provide support to people with UPGs via the workplace. Research suggests that the workplace can be a particularly difficult environment to navigate, with some indicating a desire for the workplace to be a 'safe space' (Malik & Coulson, 2013) and highlighting issues with discrimination and exclusion (Graham et al., 2019; Turnbull et al., 2018). To the author's knowledge, in the UK there is only one organisation with a support group and support materials online specifically for involuntary childless employees, the Childless Support Network, at University of Bristol (https://bristol.ac.uk/inclusion/staff-networks/childless-staff-network/). Specific workplace policy for employees experiencing infertility is also recommended, although not yet widely applied (Payne et al., 2019a) and there does not appear to be a call for this for people with UPGs. However, organisations could support involuntary childless employees by signposting them to MyJourney in their equality, diversity, and inclusion support materials. This could not only promote a sense among employees that their employers are supportive of people UPGs, but also

increase awareness of the availability of this support tool to people who experience UPGs via various pathways.

Finally, the COVID-19 pandemic has demonstrated the importance of online accessible support (Moreno et al., 2020). The impact of COVID-19 on the long term prevalence of people experiencing UPGs will not be clear for some time, but initial reports suggest that childlessness and people having fewer children will continue to increase as a result of the pandemic (Berrington et al., 2021). Both fertility care and primary care have been under increasing strain during the pandemic, and it is possible that people have not received psychosocial support when they needed it. MyJourney can address this gap by offering easily accessible online support for people who are seeking it.

### *MyJourney sits within the world of digital support in fertility care*
The inclusion of digital support in fertility care in addition to usual care is increasingly prevalent. From timely support for patients through their IVF treatment cycle, including educational support and push notifications (Timmers et al., 2021) to psychosocial and psychoeducational support to minimise the distress associated with fertility treatment (Kruglova et al., 2021). Fertility patients are already seeking additional digital support (Brochu et al., 2019; Haagen et al., 2003) and reproductive literature indicates the people who experience infertility highly value online information (Jones et al., 2020). Notably, there is limited research reporting on availability of digital support tools for post treatment and MyJourney appears to be the first readily available theory led and research-based online support tool for patients post treatment. Due to the digital and accessible nature of MyJourney, it could be easily offered to patients who are reaching the end of their fertility treatment journey, by any clinic staff members. Furthermore, from a patient

perspective, digital support tools provided at zero cost are highly valued, particularly as many will have spent a considerable sum on fertility treatment (Robertson et al., 2021). Therefore, it is important that MyJourney remains free of charge to access for users. MyJourney could be an innovative tool that sits within the evolving provision of both digital support during fertility care and support post treatment.

### MyJourney has a strong evidence base resulting from and developed along a phased iterative process

Smartphone apps and web-based resources are often not evaluated, nor evidence-based (Lau et al., 2020). More specifically, smartphone or web-based support interventions for fertility patients are similarly rarely research- nor evidence-based (Meyers & Domar, 2021). A recent review undertaken to provide an overview of the current availability of digital support from app stores for fertility patients highlighted the importance of evaluating and validating the digital tools in fertility care as this sector now moves forward (Robertson et al., 2021). In this review, it was noted that digital support tools should utilise frameworks to deliver theory-led, evidence-based, and evaluated support interventions. Fertility care interventions need to respond to the latest good practice recommendations for intervention development, for example the MRC guidance, used in this thesis (Craig et al., 2008, Skivington et al., 2021). By following these guidelines, support interventions will be based on theory, follow a phased development process, and demonstrate benefit. MyJourney is an example of this, with a strong evidence base resulting from, and developed along, a phased iterative process and has already demonstrated benefit. Furthermore, the development process of MyJourney has been reported in detail in Chapter 4, and can be useful as a demonstration of intervention development for people with UPGs, following MRC guidance (Craig et al., 2008), for others in fertility care who aim to produce similar support tools.

***Contribution to theory validation of the 3TM***

The work in the present thesis has contributed to the theory validation of the

3TM, not only for people following unsuccessful treatment, but numerous pathways

to a UPG. As noted previously, this work has clarified where supportive efforts for

people with UPGs should be focused. It is evident that developing acceptance of the

difficult emotions associated with UPG experience is a central but challenging aspect

of adjustment and being able to seek alternative meaningful goals is a key factor in

the holistic adjustment process. It is also apparent that meaning making is likely to

be based on multiple cognitive strategies. Qualitative research indicates that

strategies such as downward comparisons, re-evaluation of beliefs around

parenthood, and questioning traditional views about marriage and family, could be

used (Gameiro & Finnigan, 2017) and should be explored. It is also clear that the

social context will moderate adjustment to a UPG and needs to be considered in

support resources because of its protective role in individual adjustment.

Furthermore, lack of social support may hinder engagement with the 3TM mediators.

There are likely to be nuances around the timing of the adjustment process across the

different pathways to UPGs, but the findings in this thesis indicate that supporting

this process early on will be beneficial.

Although delivery of self-guided online support has been demonstrated as

acceptable and feasible, some people may prefer or feel they need more than the

online provision of support, e.g., one to one-, or in-person support. However, it was

noted by some of the participants in the present thesis that mental health support

should be provided from practitioners with knowledge or insight of the psychosocial

implications of having a UPG. Therefore, the 3TM could be used as a theoretical

framework for mental health support practitioners to deliver support to clients with

UPGs, via fertility care or primary care pathways, or within private provisions of support. Examples of this could be framing sessions around the 3TM, focussing on building acceptance, exploring meaning making, and looking into meaningful goals away from parenthood. Additionally, they could refer them to MyJourney itself as an adjunct to the support they receive and use this as talking points in sessions. The 3TM could also be used as a framework for group therapy sessions, which could also facilitate social support through contact with other attendees. Research indicates that people with UPGs value connecting with others who have faced a similar experience (Malik & Coulson, 2013; Stenström, 2020). Therefore, use of the 3TM as theoretical framework for mental health practitioners could facilitate the delivery of empathetic and efficacious support in various ways.

**Avenues for continued research**

Although the main research objectives were met in the present thesis, some questions remain, and new questions have emerged. The following section focuses on two key areas that require further investigation.

***Determining the optimal point in the adjustment process to provide support***

One of the key areas of research that emerged while carrying out this work, particularly from Chapter 2, relates to the stages of change of the adjustment journey. It led to the question: when is the optimal time in the adjustment process to provide support and when might receptivity be highest? Longitudinal research indicates that the UPG experience is likely to lead to a protracted adjustment process due to the complex grieving process (Daniluk, 2001; Wirtberg et al., 2007). Other research suggests that the percentages of people with sustained child wish will diminish over time (Wischmann et al., 2012). This implies that supporting people early in the adjustment process would be beneficial, helping them to work through to challenges of adjustment, shortening the duration. This is consistent with the

findings from the present thesis that, although it may be challenging, engaging with support early on would be most beneficial. This suggests that providing access to support as soon as unsuccessful fertility treatment ends could be useful, however, patients may simply feel it is too soon to consider developing acceptance of their experience and move forward, which may reflect in limited receptivity of support. It may be even more challenging the pinpoint the optimal time for support for people with UPGs due to circumstantial factors. There could be a gradual realisation that they will not reach their parenthood goals, or they may not even pursue parenthood. Therefore, more work needs to be done to explore these issues. One way to explore this could be using the concept of cues to action from the Health Belief Model (Rosenstock, 1974; Skinner et al., 2015), where external or internal factors can trigger a change in behaviour. Exploration of triggers that may result in people with UPGs developing insight into a need for support and subsequently seeking that support could be useful. For example, for fertility patients this could be at the end of their fertility treatment journey. In other pathways, it could be social (e.g., perceived normative ages to have a child) or biological deadlines (e.g., menopause).

When specifically considering MyJourney, follow up research investigating the stages of change for people with UPGs should attempt to better understand the timeframe through which people move through stages. This was explored in the feasibility RCT (Chapter 5), however, the limited number of participants that received sufficient dose or completed all 10 Steps means that, although some insight was gained, questions remain. It appears that people use and rate MyJourney in similar ways across different stages of the journey, apart from those who feel they have reached a point of acceptance. However, there was some indication that those who are in the active stages of change are more able to explore different, and

possibly unfamiliar, coping techniques, whereas this is more challenging to those in the pre-contemplation/contemplation stages. As noted above, the UPG adjustment process may be lengthy, and therefore the transtheoretical stages of change model (Prochaska & Velicer, 1997) applied in this thesis may be too contracted to be applied to the UPG adjustment process. Research should also be done to determine whether the timeframe differs according to pathway. Future work should aim to conduct prospective in-depth qualitative research following people through the stage of adjustment to gain insight into the stages of adjustment, and the barriers and facilitators to initial and sustained engagement with support for UPGs at each stage. This may also provide some insight into how more targeted recruitment could be used for people earlier in their adjustment process to promote receptivity.

### *Meaning making as a strategy in the specific context of facing a UPG*
The research in the present thesis was not able to clearly report on how meaning making operates in the specific context of adjusting to a UPG. Positive reappraisal coping has been shown to be efficacious for anticipatory anxiety during fertility treatment (Ockhuijsen et al., 2014a) and cognitive coping, particularly positive reappraisal coping, has been reported as an effective strategy to promote adjustment and positive affect for definitively childless people (Kraaij et al., 2009; Kraaij et al., 2008; Lechner et al., 2007). But this was not found in the results of Chapter 3 in the present thesis. Meaning making is a dynamic process and should decrease over time as meaning is made (Park, 2010), which could be why the findings from the cross sectional study in Chapter 3 were inconclusive. In the feasibility RCT (Chapter 5), meaning making was operationalised as both positive reappraisal coping and values clarification. However, results from the feasibility RCT did not show improvements in either of these meaning making strategies for the intervention group. At this stage

it was difficult to determine whether this was because MyJourney did not facilitate this or whether lack of engagement meant that participants did not report the benefits. It is also possible that because positive reappraisal coping and values clarification arise from different theoretical frameworks, unexpected paradoxical effects may have occurred, whereby one strategy could counteract the other. Although previous research has indicated that intervention users like to have the flexibility of different techniques to choose from (Hallis et al., 2016), and that integration has been successfully implemented (Carrier & Côté, 2010; Hallis et al., 2016), there a paucity of research on interventions that combine CBT and ACT and further work is needed to better understand how these frameworks could be integrated for particular populations or outcomes. Therefore, it is still not clear whether these represent effective meaning making strategies in the context of UPGs.

The meaning making literature is emergent and has not been researched specifically for people with UPGs and so a more in-depth evaluation of meaning making and meaning made should be carried out. More specifically, it is currently unknown whether meaning making strategies may vary across the different pathways to UPGs and therefore, more strategies and measures of meaning making need to be explored. As meaning making is a dynamic process, longitudinal quantitative work now needs to be carried out develop understanding of the connection between meaning making, meaning made, and adjustment (Park, 2010; Updegraff et al., 2008) for people with UPGs. Recent work has endeavoured to evaluate the relationships between meaning making, meaning made, and distress and the role these play in adjustment to stressful life events with university students. The findings highlighted the complexities of this area of research but it was concluded that different meaning making strategies can have different influences on adjustment,

particularly in the sense of whether meaning was made (Lachnit et al., 2020). The next stage of research with people with UPGs should also include investigations of the experiences of those who try to make meaning but do not manage this or make meaning in a non-adaptive way (e.g., consider themselves a failure in all aspects of life, including having children), as this is a possible barrier to adjustment over never trying to find meaning. For example, some research suggests that ineffective meaning making can lead to more distress (Davis et al., 1998; Michael & Snyder, 2005; Park, 2010; Park & Baumeister, 2017). Prospective research with patients approaching the end of their treatment would be optimal, however this is likely to be challenging to conduct. It would also be particularly difficult to carry out prospective research on meaning making with people with UPGs who do not engage with treatment or experience circumstantial factors as it would be difficult to pinpoint the right time to explore this. A suggestion would be assessment moments for women pre and post menopause.

**Future avenues for MyJourney**

Alongside research avenues generated from the empirical work in this thesis**,** consideration should also be given to priority areas for expansion of MyJourney. After MyJourney has demonstrated efficacy in a large scale RCT, two suggested areas of expansion for MyJourney are further social support features or content and expansion to cater for a more culturally diverse target population.

*Facilitating or emulating social support via MyJourney*

Most of the content and therapeutic activities within MyJourney aim to target individual adjustment to UPGs. As the development phases progressed, additional content was added to support the social adjustment to a UPG. Primarily, content to facilitate social connection to others and suggestions for how users could engage some of the people around them as they worked through the Steps and Routines.

Consistently, through the research from the present thesis and particularly in the qualitative findings, features that promote social connection or support are reported as important to people with UPGs. Attention should be given to understand how social support can facilitate meaning making, acceptance, and pursuit of new goals, and whether this can be emulated in self-help interventions, at least to a certain extent.

Participants in the present thesis suggested features such as online forums or peer to peer support as important features in support. This is consistent with the UPG research where people report making use of online forums, valuing their anonymity, ease of access, and generally supportive exchanges (Malik & Coulson, 2013; Stenström, 2020). However, risks also need to be recognised, examples of disadvantages of online communities or forums include being time consuming, hearing about others negative experiences, concerns about privacy, and inappropriate or insensitive comments from others (Coulson et al., 2016; Malik & Coulson, 2010; Mo & Coulson, 2014). Furthermore, an important factor in the success of online forums is appropriate moderation (Smith-Merry et al., 2019). Although research on the role of online peer support is mixed, overall, there are promising findings, and MyJourney should continue to signpost to charities and supportive networks that offer online communities and peer support.

Persuasive design features have already been incorporated successfully in MyJourney, primarily focused on primary task support, and therefore persuasive design features that facilitate social support should also be explored. Examples include 'social facilitation' where users can see how many other users are logged on at the same time as them, or 'recognition' where users write a testimonial of their experience of completing all Steps (Kelders et al., 2012; Oinas-Kukkonen &

Harjumaa, 2009). Design principles focused on social support are not used as often

as other elements (Geuens et al., 2016; Kelders et al., 2012; McCall et al., 2021), but

some research has demonstrated the success of using these design principles. For

example, using social support features might improve adherence and combining

different elements may even influence effectiveness, but due to limited use of these

in the intervention literature more work is needed to confirm this (Kelders et al.,

2012; Wildeboer et al., 2016).

Social support plays a key role in the adjustment process to UPGs. Expansion

of MyJourney should explore further ways to emulate or facilitate social support

using design features and continue to signpost to provisions of online peer support

provided by charities and other supportive organisations.

***Developing MyJourney for a culturally diverse target population***
Although MyJourney was developed in English and Portuguese, recruitment

was open globally and participants engaged with the trial from 25 countries around

the world. Therefore, one future consideration for MyJourney is the development of

this support to reach a cross cultural global target population. MyJourney was well

received by those living in western countries, however it unknown how MyJourney

would be received in non-western cultures. Culture can be defined as 'the distinctive

customs, manners, values, religious behaviour, and other social and intellectual

aspects of society' (Hynie & Burns, 2006, p. 61). A study including data from 78

countries investigating the prevalence of women aged 44 to 48 who still desired a

child at the end of their reproductive window argued that in most countries up to

50% of women had not reached their desired parenthood goals (Casterline & Han,

2017). Global research has demonstrated that having a UPG, particularly involuntary

childlessness, can have a negative impact on psychosocial outcomes (Dyer et al.,

2005; Inhorn & Van Balen, 2002; Van Balen & Bos, 2009). It is likely that people

from ethnic minorities and certain religious groups, may experience a more

challenging experience from having a UPG, particularly if a childfree lifestyle is

considered unacceptable or multiple children are expected (Culley et al., 2006; Greil,

Schmidt, et al., 2016; Hynie & Burns, 2006) and where abuse, abandonment, and

social exclusion occurs (Dyer et al., 2002; Gerrits et al., 2017). Research suggests

that culturally sensitive support is needed (Gameiro et al., 2019; Kirubarajan et al.,

2021).

Exploration of non-Western research is now needed to better understand the

support needs across cultures and how this can be translated into content within

MyJourney. However, at this point it is reasonable to suggest that the delivery of

MyJourney (i.e., anonymous, easily accessible online) lends itself to other cultures

where it may be more difficult to seek and access support. To approach the

expansion of MyJourney, there are two key considerations when focusing on cultural

contexts. One being the potentially hostile societal context in which one experiences

a UPG and the other the internalisation of beliefs and attitudes that are prevalent in

these contexts which can make adjustment harder. For example, cultures where

women are unable to consider the possibility of life courses apart from motherhood

or goals away from parenthood (Remennick, 2000). Although it is not possible to

change the hostile social context, content that focuses on supporting the isolating and

stigmatising aspects of having a UPG could be particularly useful.

Currently, support contacts provided in MyJourney highlight support in the

UK and Portugal, with some more global support contacts, but this list will need to

be expanded to ensure it is inclusive of other countries and cultures. Considering the

internalisation of societal beliefs and expectations, a future prototype of MyJourney

could target this with meaning making strategies, supporting people to question these beliefs and consider their own. Considering a more diverse cultural target population (but also relevant to western cultures), exploring the role of religion and spirituality could be an interesting research avenue. The WHO recognises the important role of religion and spirituality in health (Dhar et al., 2013), and religion is often a defining feature of many cultures. Some research has indicated this can play a positive role via a process of meaning making following loss (McIntosh et al., 1993; Park, 2005) and infertility (Latifnejad Roudsari et al., 2014). Notably religion and adjustment is a complex topic to research (Wortmann & Park, 2008) and more work would need to be done to understand the role of religion in adjustment to UPGs.

Strategies to improve cultural appropriateness of interventions include peripheral strategies (e.g., titles that suggest the content is relevant to different cultures); evidential strategies (e.g., use data to indicate the prevalence of the shared experience for different cultural groups); linguistic strategies (e.g., translating the content into different languages); constitute-involving strategies (e.g., engage with members of the different cultural groups to gain a better understanding of the nuances of cultural characteristics); and sociocultural strategies (e.g., demonstrate understanding of the normative beliefs and values across different cultures) (Kreuter et al., 2003). Some of these strategies could be explored to develop MyJourney for a more culturally diverse population and mean it can be signposted as a support tool with a broader reach.

**Overall strengths and limitations**

One of the main strengths of this thesis is the use of different study designs and methodologies to meet the objectives presented in Chapter 1. Consistent with MRC guidance (Craig et al., 2008; Skivington et al., 2021), mixed methods

study designs were used to develop and evaluate MyJourney. Following this guidance has facilitated efficient use of time and resource leading to a valuable contribution to the evidence-based support provision for people with UPGs. Furthermore, in line with the most recent guidance from the MRC (Skivington et al., 2021) the research in this thesis has gone beyond looking at whether MyJourney is efficacious, maintaining focus on other aspects that can influence successful of an intervention, such as acceptability. The prospective acceptability study and exploratory feasibility work were particularly important as comparisons to, or lessons learnt from, other evidence-based support tools for people with UPGs was not possible. Finally, well-substantiated methodology was rigorously followed and reported, and several reporting guidelines were also utilised in this thesis (e.g., CONSORT, TIDieR, GUIDED), facilitating transparent reporting to allow for replication of the research or the intervention.

The research in the present thesis began in 2018 and was completed in 2021, meaning that some stages of the research were carried out within the context of the COVID-19 pandemic. However, the design and methodology of all the studies conducted meant they could be completed online and MyJourney itself was designed as an internet-based intervention. This meant that the research could continue to be carried out in a timely manner and in the way it was planned. Consideration of the how the pandemic may have been affecting the wellbeing of the participants was included in the mixed methods study (Chapter 3) and feasibility trial (Chapter 5) by asking whether they felt the pandemic had affected their wellbeing or their experience of having a UPG. Although findings overall indicated that the pandemic did not influence the results, it is not possible to say whether people with UPGs who were considerably affected by the pandemic chose not to take part in this research.

    The key methodological limitation was the lack of diversity across the

participants included in the studies in the present thesis. The aim of recruitment is to

achieve a heterogenous sample that is representative of the population of interest that

is satisfactorily sized to achieve sufficient power. Recruitment efforts were made to

recruit diverse samples of people with UPGs. In some respects, this was successful

as around 20% men were recruited in Chapter 3 (which is comparatively high for

reproductive literature). However, when looking more broadly across all three

empirical studies, most participants were white, well-educated, help-seeking,

childless women. As mentioned previously, the research underlying MyJourney, and

research carried out in this thesis, focused on samples from western, well-developed

countries and further work now needs to be carried out with more cross-cultural

samples. There may also be an over-representation of highly educated people in the

samples in this thesis (more than three quarters of participants in all studies had

postgraduate degree). Some research indicates that women with lower educational

status may place higher importance on parenthood (Moura-Ramos et al., 2012) and

therefore may find it more difficult to adjust to their UPG. A wider range of

educational statuses should be included in future research. In Chapter 1, it was noted

that LGBTQ+ individuals may experience UPGs, however there is a distinct paucity

of research on this. Although recruitment aimed to recruit diverse experiences of a

UPG, participants were not asked whether they identified as LGBTQ+. In Chapter 3,

when asked for reasons for childlessness only 2.1% identified that being LGBTQ+

was the reason. MyJourney is an inclusive intervention, therefore, future work

should capture whether participants identify as LGBTQ+ via the sociodemographic

questions to determine whether there is a demand for support within this population

and further work should explore the LGBTQ+ UPG experience. Additionally,

although it is difficult to make direct comparisons to similar studies in the reproductive literature, other studies in that include childless people and parents report up to 50% of participants as parents (Raque-Bogdan & Hoffman, 2015; Throsby, 2001). Furthermore, the empirical study of the 3TM with a heterogenous samples of people with UPGs reported in Chapter 4 (Study One) (see also Appendix A) included 48% participants with children. Therefore, 14% of participants parents in the feasibility trial (Chapter 5) could be considered a low number. Future work should endeavour to explore recruitment avenues to reach more parents with UPGs.

Despite the online delivery of the studies and the intervention being beneficial to allow the research to continue unhindered through the pandemic, online recruitment also inherently biased the sample to people with access to the internet. Although this did facilitate recruitment beyond only people who are accessing fertility treatment. Generally, it was a notable challenge to gain the trust of gatekeepers of charities, online support groups, or childless advocates to recruit via or share information about the research on their platforms. They required assurance that the research being carried out was empathetic and sensitive to the UPG experience so that their members or followers would not be upset. This reflects the research demonstrating that having a UPG is often a stigmatised and isolating experience and not well understood by those who have not experienced it. The Prolific recruitment platform was used to recruit participants in the studies in Chapter 3 and Chapter 5. The researcher is confident that the participants in both studies met the eligibility criteria, and it is likely that these participants may be interested in taking part in research in general and not necessarily seeking support specifically for their UPG or seeking to take part in specific research about UPGs, which may have increased the diversity of the sample. Nevertheless, further analysis was not conducted to determine this.

Research suggests that participants from Prolific are similar to, if not better than,

university subject pools that are widely used for research recruitment, in terms of

data quality and response rates (Peer et al., 2017). However, this research is limited,

and more work needs to be done to provide confidence in the use of recruitment

platforms.

Many people who took part in this research were already trying to seek or

already had sought support which may bias the findings towards the perceptions of

help seekers rather than a representation of all people with UPGs. Reproductive

literature suggests that women may face more difficulties adjusting (Ying et al.,

2015) and be more likely to seek support, such as social support (Peterson et al.,

2006), but increasingly the literature indicates men experience adjustment difficulties

and want support too (Hadley, 2019a, 2019b) and progressively more researchers are

reporting on childlessness in men, about their pathways to childlessness and

particularly noting that men are more likely to be childless than women

(Chudnovskaya & Ueda, 2021). Ensuring MyJourney is inclusive is an important

feature of this intervention and its development. Overall, small subgroups of men in

each study meant that inferential statistics were not possible. This may have

impacted on the findings by combining genders because, as noted above and in

Chapter 1, some literature suggests that men and women may adjust differently

(White & McQuillan, 2006). Different genders may also engage in different coping

strategies, as this is reported when looking at how men and women cope with

infertility treatment (Peterson et al., 2006; Ying et al., 2015). Furthermore, it remains

unclear whether there is demand for MyJourney amongst men or whether men would

engage with MyJourney differently to women. Future work should include targeted

recruitment of men and could explore the use of large national databases to access

men who are childless. This could ensure that a sufficient sample of men are recruited to facilitate analysis on the role of gender.

Finally, most of the participants who contributed to the formative evaluations (prospective acceptability study, Chapter 2, and consultation exercise, reported in Chapter 4) were infertile childless women and therefore future PPI activities during the development of MyJourney should endeavour to include men and people with UPGs from pathways beyond infertility and who already have children.

**Conclusions**

Increasing numbers of people are experiencing UPGs. This can trigger a difficult and prolonged adjustment process, associated with poorer mental health wellbeing. This thesis has made a significant contribution to the understanding of the supportive efforts that should be focused on to help people with the UPG adjustment process across different pathways.

As outlined by the 3TM, people with UPGs should be supported to integrate the UPG experience into their lives, engage in meaning making strategies to build a sense of meaning and purpose from their experience, and finally, be encouraged to focus their efforts into other meaningful goals away from parenthood. Social support also plays a key protective role and facilitating this should be considered within supportive efforts.

The 3TM was applied as the underlying theoretical model of MyJourney, a self-guided, online interactive intervention. There is undoubtedly demand for this type of support, across different UPG pathways, and delivery in this manner is acceptable and feasible. Limited efficacy evaluation indicates that people who engage with MyJourney experience benefit and a full-scale efficacy evaluation via an RCT should now be carried out to confirm and expand on the findings from this

thesis. Efforts should also be focussed on improving awareness of this support tool

so that it can be offered to people with UPGs via fertility and primary care pathways.

Charities and other support organisations can also signpost people who are seeking

support to MyJourney.

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# Appendices

## Appendix A: Promoting adjustment to unmet parenthood goals: A test of the Three Tasks Model of Adjustment to Unmet Parenthood Goals

**Title:** Promoting adjustment to unmet parenthood goals: A test of the Three Tasks Model of Adjustment to Unmet Parenthood Goals

**Running title:** Promoting adjustment to unmet parenthood goals

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# Abstract

**Study question:** Is the Three Tasks Model of Adjustment to Unmet Parenthood Goals (3TM), a theoretical model informed by a systematic literature review that explains how people adjust in the aftermath of unsuccessful fertility treatment, valid and generalizable to a heterogeneous population of people with unmet parenthood goals (UPGs)?

**Summary answer:** The 3TM main assumptions that people with UPGs adjust better if they are able to develop acceptance of their situation, construct positive meanings of it and pursue new life goals, proved valid and invariant in a heterogeneous population of people who self-identified has having a UPG, regardless of the pathway leading to it (i.e., fertility/health problems with and without treatment and unfavorable circumstances).

**What is known already:** The number of people with UPGs, defined as having no or fewer children than desired, is growing worldwide. UPGs trigger intense grief that lasts around 2 years and is associated with moderate to large impairments in mental-health and wellbeing. There is a scarcity of evidence-based support for people with UPGs and one reason may be the lack of evidence about what such support should entail. The 3TM was developed to address this gap but its validity has not been empirically tested. Furthermore, it was based on evidence about how people adjust in the aftermath of unsuccessful fertility treatment and it is unknown if it is generalizable to other groups of people with UPGs, for instance, who did not do fertility treatment or faced other unfavourable circumstances.

**Study design, size, duration:** Cross sectional English online survey study with convenience sampling and explanatory modelling. The survey was posted from November 2017 to March 2018. Eligibility criteria were being 18 or older, having a UPG (not having been able to conceive or having conceived fewer children than desired), not currently undergoing fertility treatment and being able to respond in English. In total 806 individuals accessed the survey, but 204 did not answer the inclusion criteria questions and 140 did not meet these. Therefore, 516 (60%) individuals were given access to the survey questions. From these, 96 (18.6%) were excluded because they did not fill any of the survey questionnaires, 7 (1.4%) because textual comments made it clear they had not yet decided about wanting to become parents, 3 (0.6%) withdrew their data, and 410 (79.4%) completed the survey.

**Participants/materials, setting, methods:** Survey questions assessed socio-demographic background and fertility history, including pathway to UPG (fertility/health problems with treatment, fertility/health problems without treatment, unfavourable circumstances). 3TM predictors assessed were age, having stopped trying to conceive, importance of parenthood (1-item question), parental status, and social support (SCREENIVF support subscale). Mediators were meaning making (brief-COPE positive reframing subscale), acceptance (SCREENIVF acceptance subscale) and pursuit of new goals (reengagement scale of the Goal Disengagement and Goal Reengagement Scale). Outcomes were mental health (MHI-5) and hedonic (WHO-5) and eudaimonic wellbeing (Questionnaire for Eudaimonic Wellbeing). To investigate group differences in the 3TM variables according to pathway to UPG we conducted $\chi^2$ tests and one-way ANOVAs. To test the 3TM model we conducted explanatory modelling (path analysis with maximum likelihood estimation) considering a set of a-priori defined validity criteria. Finally, to test if the 3TM is generalizable regardless of pathway to UPG, its structural invariance was tested across the three UPG groups.

**Main results and the role of chance:** Average age was 35. Only 2 participants (0.5%) were men, 91% were in a relationship, 63% had university education and 75% were employed. Fifty-two percent were childless and 48% had stopped trying. Regarding pathway to UPG, 42% had done fertility treatment to overcome their fertility/health problems, 41% had not done treatment and 17%

had a UPG due to unfavourable circumstances. Based on the WHO-5 cut-off scores, 62% of participants experienced poor wellbeing and 32% were clinically depressed. Testing of group differences showed people with fertility or other health problems who did treatment were older (p<.001, partial eta squared, $\eta^2_p$=.153) and more likely to have stopped trying to conceive (p<.001) than those who did not do treatment and those with unfavourable circumstance. People with fertility or other health problems who did treatment reported better mental health (p<.05, $\eta^2_p$=.020) and eudaimonic wellbeing (p<.05, $\eta^2_p$=.029) than those who did not do treatment. Model fit was $\chi^2(24) = 28.147$, p =.253, CFI = 0.997, RMSEA = .021 90%CI [.000, .047]. Meaning making was associated with eudaimonic wellbeing ($\beta$=.198), acceptance was associated with mental health ($\beta$=.148) and hedonic wellbeing ($\beta$=.244), and pursuit of new goals with mental health ($\beta$=.202), eudonic ($\beta$=.190) and eudaimonic wellbeing ($\beta$=.380). The difference in fit between constrained and unconstrained models was not statistically significant ($\chi^2_{dif}(62) = 62.632$, p = .454) and the CFI difference (.001) was lower than 0.01, indicating the model was invariant across participants with different pathways to UPG.

**Limitations, reasons for caution:** Convenience sampling from social-media and support groups affects results generalisability, in particular for men, as only two participated. Assessment of meaning-making was sound but not comprehensive enough to capture the main strategies used by this population. Results support the 3TM but definite causal conclusions need to be based on prospective or experimental research.

**Wider implications of the findings :** People who self-identify as having a UPG experience low wellbeing. The 3TM is a valid therapeutic framework to address UPGs, regardless of how these came to be, and can therefore be used to inform the development of evidence-based interventions. Tailored support to UPGs should prioritize pursuit of alternative goals to parenthood, acceptance of UPG and, to a lesser extent, creation of positive meaning related to this loss. Research-informed suggestion to achieve these therapeutic goals are provided.

**Study funding/competing interest(s):** Dr. Gameiro reports consultancy fees from Ferring Pharmaceuticals A/S, Access Fertility and SONA-Pharm LLC, grants from Merck Serono Ltd, and that she is co-developer of the web-app to support people with UPGs, www.myjourney.pt. Bethan Rowbottom holds a PhD scholarship funded by the School of Psychology, Cardiff University and is a co-developer of MyJourney.

**Trial registration number:** n/a.

**Key-words:** Unmet parenthood goals / therapeutic model / evidence-based psychosocial support / mental health / wellbeing

# Introduction

In the UK and other European countries around 1 in 5 women reach the age of 45 without having children (Office for National Statistics, 2012), with only 3.2% of these being voluntarily childless (Miettinen et al., 2015, Präg et al., 2017). Many people do fertility treatment to conceive but almost one in three people in the UK will finish without achieving (McLernon et al., 2016), representing around 16,000 women per year (Human Fertilisation and Embryology Authority, 2016). Even when people manage to conceive, many end up having fewer children than desired (Miettinen, Rotkirch, Szalma, Donno and Tanturri, 2015, Weston et al., 2004). Overall a growing number of people are ending their reproductive lives without realizing their parenthood goals, a trend only expected to accentuate (Schmidt et al., 2012), now also due to the impact of COVID-19 (Berrington et al., 2021). Having an unmet parenthood goal (UPG), defined as having no or fewer children than desired, triggers intense grief that lasts around 2 years, from which some individuals never fully recover. People who go through this loss after unsuccessful fertility treatment report moderately to largely impaired mental-health and wellbeing compared to those whose treatment is successful (Gameiro and Finnigan, 2017). While there is an abundance of support for people trying to have children, the scarcity of support resources for when such attempts fail is well-noted (Gameiro et al., 2015). One reason may be the lack of evidence about what tailored support should entail. To address this knowledge gap Gameiro and Finnigan (2017) systematically reviewed the literature on how infertile patients adjust to a UPG after unsuccessful treatment. Their findings informed the Three Tasks Model of Adjustment to Unmet Parenthood Goals (3TM), the first explanatory model of adjustment to a UPG, which provides the theoretical basis to develop tailored support. This paper reports on the first empirical test of the 3TM.

The 3TM predicts three psychological mechanisms underlie positive adjustment to a UPG: meaning making, acceptance and pursuit of new goals (Gameiro and Finnigan, 2017). People engage in meaning-making as a way to solve the cognitive dissonance between their goal of having children (and associated beliefs) and the new meanings the loss triggers (Park, 2010), for instance by trying to find positives in the loss (i.e., positive reframing; Folkman, 1997). Individuals will also try to develop acceptance, defined as an willingness to experience their UPG without avoidance or struggle (Williams and Lynn, 2010), for instance, as people develop acceptance they may feel more able to tolerate the pain associated with their UPG and to learn to live with it (Fieldsend and Smith, 2020). Finally, people will pursue alternative goals, which has consistently been shown to promote positive adjustment, even when the UPG is not totally relinquished (Mesquita da Silva et al., 2016). There is evidence to suggest that these three tasks are inter-dependent, in that engaging with one eases engagement with the others (Gameiro and Finnigan, 2017). The 3TM also considers risk and protective factors. Being older, childless, and having stopped trying to have (more) children are expected to be associated with a stronger perception of loss and efforts to adjust to it in terms of meaning-making, acceptance, and pursuit of new goals (Gameiro et al., 2014, Kotter-Grühn et al., 2009), while attributing higher importance to parenthood and lacking adequate support makes this process harder (Kirkman, 2003, McQuillan et al., 2012, Thoits, 1992).

The 3TM was developed based on evidence from infertile patients who finished unsuccessful fertility treatment, but this is not the only pathway leading to a UPG. Many people who do not undergo fertility treatment or experience unfavourable circumstances to having children (e.g., no partner, no financial means, not being able to conceive spontaneously) also report being faced with a UPG, describing a grief process similar to those who undergo unsuccessful treatment (Koert and Daniluk, 2017). However, it could be argued that their adjustment process can differ due to the specificities of their experience. For instance, as the grief experienced by those who did not do treatment or did not try to conceive can be less visible to others (Kirkman, 2003, Koert and Daniluk, 2017) or because these individuals may fear judgement of others for not having tried (everything) to conceive (Turnbull et al., 2016), they may be less able to activate social support as they experience a sense of ' being an outsider' (Hadley and Hanley, 2011, Letherby, 2016). Perceived lack of control over their fertility history may also make it harder for them to make-meaning and accept their situation (Wirtberg et al., 2007). While this suggests these groups may find it harder to engage in meaning-making, acceptance or pursuit of new goals, psychological research suggests they should experience the same benefit once they do engage in these tasks.

In this study we used online survey sampling and explanatory modelling (Shmueli, 2010) to test the 3TM on a heterogeneous group of people faced with a UPG. First, we tested the main assumptions of the model and identified risk and protective adjustment factors. Our main hypotheses were that meaning-making, acceptance and pursuit of new goals would be inter-correlated and positively associated with psychosocial adjustment. We operationalized psychosocial adjustment in a holistic way, considering mental health and wellbeing, the latter both in terms of how people feel (hedonic wellbeing) and the extent they are realising their human potential and feel fulfilled in life (eudaimonic wellbeing). We also expected age, being childless, having stopped trying to have (more) children and social support would be positively associated with meaning making, acceptance, and pursuit of new goals, while importance of parenthood would be negatively associated. After, to investigate if the 3TM is equally applicable regardless of people's pathway to their UPG, we tested its invariance in three groups: people who did unsuccessful treatment, people who did not do treatment and people who did not try to have (more) children due to unfavourable circumstances. Our hypothesis was that the 3TM model main assumptions would be invariant across groups. Results, reported according to the Checklist for Reporting Of Survey Studies (CROSS) (Sharma et al., 2021), will inform on the therapeutic targets of support initiatives, not only for people who undergo unsuccessful fertility treatment but for anyone faced with a UPG.

## Methods

### Procedures

Cardiff School of Psychology Ethics Committee approved the study (EC.17.11.14.5138). We run a cross-sectional online survey with convenience sampling,

from November 2017 to March 2018 using Qualtrics (Provo Utah, USA), to recruit a large heterogeneous sample of people who self-described as having a UPG. We estimated we needed 157 participants to detect moderate effects sizes in up to 15 predictors (G*Power, $\alpha=.05$, power=.90) (Mayr et al., 2007), 222 participants to differentiate a good (.06) from a bad (0.1) fit model using RMSEA (Kline, 2005, Preacher and Coffman, 2006), and 330 participants to achieve a minimum 5 ratio between sample size and number of parameters estimated (Kline, 2005).

The survey was reviewed by a team of psychology experts in reproductive medicine and patient advocates before being advertised via multiple social media outlets. We requested infertility charities (Fertility Network, Resolve, Fertility Matters Canada, NISIG Ireland and Fertility New Zealand) and forums (Fertility Friends, The Not Mom, Net Mums, Mums Net, Health Unlocked) to advertise the survey and we also advertised it on Facebook and Google. The survey advert invited people to fill a survey on adjusting to unmet parenthood goals and indicated they had the chance to win one of four £50 vouchers. Interested individuals clicked on the survey link, where they were presented with the information sheet and informed consent. Those who consented and fit the inclusion criteria of being adults (18 or older), self-describing as having a UPG (not having been able to conceive or having conceived fewer children than desired), not currently undergoing fertility treatment (as the psychological burden of undergoing treatment would be a confound) and being able to respond in English were directed to the survey questions. Those wanting to participate in the vouchers' draw had to leave their e-mail, which were stored separately from the data. A debrief was provided at the end.

**Participants**

The final sample included 410 individuals with a UPG. Eight hundred and sixty individuals accessed the survey, but 204 did not answer the inclusion criteria questions and 140 did not meet it. Therefore, only 516 (60%) individuals were given access to the survey questions. From these, ninety-six (18.6%) participants were excluded because they did not fill any of the survey questionnaires, seven (1.4%) because textual comments made it clear they had not yet decided about wanting to become parents, and three (0.6%) withdrew their data.

Sample characteristics are presented in Table 1. All but two participants were women, average age was 35, the majority were in a relationship, had university education, were employed and from the UK. Most participants could not conceive spontaneously and had tried in the past but around half were childless and around half had stopped trying. Regarding pathway to their UPG, 42% had done fertility treatment to overcome their medical of fertility problems, 41% had not done treatment and 17% had a UPG due to unfavourable circumstances.

**Materials**

The survey had 39 questions organized in 5 sections that assessed participants' socio-demographics, fertility history, mediators, outcomes of the 3TM, and support needs (not reported here).

*Socio-demographics.* We assessed participants' age (in years), gender (female, male/other), relationship status (single/divorced/separated /widower, in relationship), university education (no, yes), employment status (unemployed/student/retired/other, employed part/full-time) and country of residence (open text).

*Fertility history.* Participants reported their parental status (childless, with children), the number of children they had and the number they desired to have. Participants reported if they had tried to conceive (no, yes), if they could conceive spontaneously (no, yes), if they had done fertility treatment (no, yes), and if they had actively stopped trying to conceive (no, yes).

*Pathway to UPG.* Participants were also asked why they could not conceive spontaneously. Options were fertility problems from self or partner, health condition from self or partner, being gay, not having a partner, or other (in which case they were asked to specify in an open question), and to explain in their own words why they could not conceive the children they wished to have (open question). Based on these responses we classified participants as 'medical/infertility with treatment' if they could not conceive spontaneously AND reasons referred to fertility problems or health condition AND had done fertility treatment; as 'medical/infertility without treatment' if they could not conceive spontaneously AND reasons referred to fertility problems or health condition AND had not done fertility treatment; and as 'by circumstance' if they could conceive spontaneously and textual responses made no reference to fertility or health problems OR if they could not conceive and reasons were 'being gay' or 'not having a partner' or delay in actively trying to conceive (open question data).

**Table 1.** Sample socio-demographic characteristics (N = 410)

| **Socio-demographics** | |
| --- | --- |
| | **Mean (SD) [range]** |
| Age (years) | 35.06 (8.57) [19-63] |
| | **N (%)** |
| Women | 408 (99.5) |
| In relationship | 372 (91.4) |
| University education | 247 (62.8) |
| Employed part/full time | 302 (74.8) |
| Country of residence | |

| | |
|---|---|
| United Kingdom | 356 (86.8) |
| The Netherlands | 11 (2.7) |
| Ireland | 8 (2.0) |
| USA | 7 (1.7) |
| New Zealand | 4 (1.0) |
| Other | 24 (5.9) |

**Fertility history**

| | N (%) |
|---|---|
| Parental status | |
| Childless | 215 (52.4) |
| With children | 195 (47.6) |
| Biological children only | 188 (96.4) |
| Adopted children only | 7 (3.6) |
| Biological and social children | 2 (1.0) |
| | **Mean (SD) [range]** |
| Nr of children | 0.71 (0.97) [0-6] |
| Nr of desired children | 2.61 (1.27) [0-12] |
| | **N (%)** |
| Tried to conceive | 373 (91.9) |
| Could conceive spontaneously | 72 (17.6) |
| Did fertility treatment | 177 (43.4) |
| Stopped trying to conceive | 197 (48.0) |
| Pathway to unmet parenthood goals | |
| Medical/infertility with treatment | 173 (42.2) |
| Medical/infertility without treatment | 168 (41.0) |
| Unfavourable circumstance | 69 (16.8) |

*Variables of the 3TM.* Predictors were age, having stopped trying to conceive, importance of parenthood, parental status, and social support. Mediators were meaning-making, acceptance and pursuit of new goals. Outcomes were mental health (presence or

absence of disease/distress), hedonic (subjective experience of pleasure) and eudaimonic (subjective perception of self-realization and pursuit of one's intrinsic goals) wellbeing (Ryan and Deci, 2001). All variables were assessed with sound questionnaires previously used in reproductive psychological research, with very good internal consistency (all Cronbach's alpha ≥ 0.79, see Table 2) and for which final scores indicate more of the variable.

Importance of parenthood: single-item question taken from the IFDMS (Fulford et al., 2013), 'How important is parenthood to you?' with a likert-type response scale ranging from 1 (not at all) to 5 (very important).

Social support: social support subscale of the SCREENIVF (Verhaak et al., 2010), a five-items (e.g. 'When I feel sad there is always someone I can talk to') scale with a response scale ranging from 0 (nearly never) to 4 (often). The summed total score range was 5-20.

Meaning-making: Positive reframing, a meaning-making coping strategy associated with better adjustment to definitive childlessness (Kraaij et al., 2009, Lechner et al., 2007), was assessed with the well-established brief-COPE Inventory subscale (Carver, 1997). The averaged total score range was 1 (I haven't been doing this at all) to 4 (I 've been doing this a lot).

Acceptance: 6-item acceptance subscale of the SCREENIVF (Verhaak, Lintsen, Evers and Braat, 2010). The items were adapted to focus on the UPG (e.g., 'I can deal with the consequences of not realizing my parenthood goals') instead of infertility. The response scale was 1 (do not agree) to 4 (strongly agree) and the summed total score range was 6-24.

Pursuit of new life-goals: reengagement scale of the Goal Disengagement and Goal Reengagement Scale (GDGRS; Wrosch et al., 2003), which assesses the ability to identify (e.g. 'I think about other new goals to pursue.'), commit (e.g. 'I start working on other new goals.'), and pursue new goals (e.g. 'I convince myself that I have other meaningful goals to pursue.'). The summed total score range was 6-30.

Mental health: Mental Health Inventory (MHI-5; Ware et al., 2000), a 5-item scale that asks individuals how they felt during the last 4 weeks (e.g. 'Have you felt calm and peaceful?'). We used a 5-point response scale (1-not at all to 5-extremely) instead of the original 6-point scale (1-none of the time to 6-all of the time). Negatively formulated items were inverted, items were summed and linearly transformed to range from 1-100. The MHI-5 is predictive of mental health problems and associated help-seeking behaviour (Hoeymans et al., 2004).

Hedonic wellbeing: World Health Organization Wellbeing Index (WHO-5; Topp et al., 2015), a five-item (e.g., 'I have felt active and vigorous') measure answered regarding the last 14 days, on a 0 (none of the time) to 5 (all of the time) response scale. Items were summed and linearly transformed to range from 0-100. WHO-5 has good clinometric properties and captures change in wellbeing over time and between groups. Cut-off scores of ≤50 and ≤28 indicate difficulties adjusting and clinical depression, respectively (Topp, Østergaard, Søndergaard and Bech, 2015). UK norms indicate a mean of 61 for women

aged 18 or more (European Foundation for the Improvement of Living and Working Conditions, 2016).

<u>Eudaimonic wellbeing</u>: Questionnaire for Eudaimonic Wellbeing (QEWB; Waterman et al., 2010)), 21-items that assess self-discovery, development of one's potentials, purpose and meaning in life, pursuit of excellence, intense involvement an enjoyment of activities. The response scale is 0 (strongly disagree) to 4 (strongly agree). The total summed score range was 0-84. The QEWB has proved valid to assess eudaimonic wellbeing and distinguish it from hedonic wellbeing. A sample of 4162 American university female students with an average aged of 21 reported average scores of 55.24 (SD=10.19) (Waterman, Schwartz, Zamboanga, Ravert, Williams, Agocha, Kim and Donnellan, 2010).

**Statistical analysis**

We used descriptive statistics to describe the sample socio-demographic background, fertility history and variables of the 3TM. To investigate group differences in the 3TM variables according to participants' pathway to UPG we conducted $\chi^2$ tests and one-way ANOVAs with pathway to UPG (fertility/health problems with treatment, fertility/health problems without treatment, unfavourable circumstances) as between-subject factor and using Bonferroni correction for multiple comparisons.

To test the 3TM model we conducted explanatory modelling, more specifically path analysis with maximum likelihood estimation (using IBM SPSS AMOS v23 software) of our causal hypothesis: we drew arrows from all 3TM predictors to all mediators and from these to all outcomes, we covariated the residuals of all mediators (as we hypothesized these were associated) and of all outcomes (as they all measure constructs of psychological adjustment). We also drew arrows between social support and all outcomes due to the extensive evidence on the direct protective role of social support for adjustment (Harandi et al., 2017). We first tested the model (Model 1) controlling for all socio-demographic variables (age, gender, relationship status, education, employment) correlated ($p < .05$) with at least one outcome and covariating all predictors. We then refined the model (Model 2) by removing all non-significant associations between covariates and outcomes and covariations between predictors, as well as predictors without significant associations with mediators.

We considered the following criteria as evidence of the 3TM model validity: 1) moderate positive regression weights ($\beta \geq .20$) between all mediators (meaning-making, acceptance and pursuit of new goals) and at least one outcome (mental health, hedonic and eudaimonic wellbeing). In psychological research $\beta < .20$, $\beta < .30$, and $\beta \geq .30$ thresholds are recommend to indicate weak, moderate and strong associations (Hemphill, 2003); 2) moderate positive covariations between all mediators; 3) chi-squared statistic ($\chi 2$, sensitive to sample size) is statistically non-significant; 4) Bentler comparative fit index (CFI, not sensitive to sample size) is greater than 0.95; and 5) the Steiger–Lind root mean square error of approximation (RMSEA, corrects for model complexity) is below 0.06, with the lower value of its 90% confidence interval being below 0.05 and the higher value below 0.08 (Hu and Bentler, 1998). Missing data was lower than 20% for all variables except social support (23.9%) and eudaimonic wellbeing (25.6%). As recommended (Zhang and

Savalei, 2020), we cross-checked fit indices estimated with Full Information Maximum Likelihood (without data imputation) against estimated with Expectation-Maximization data imputation, which assumes that data are missing at random (i.e., missings associated with measured data but not with unmeasured data; Graham, 2009).

Finally, to test if the 3TM main assumptions hold regardless of pathway to a UPG, its structural invariance was tested across the three pathway to UPG groups (fertility/health problems with treatment, fertility/health problems without treatment, unfavourable circumstances). A statistically significant χ2 difference between the constrained (regression weights are equal across the three pathway to UPG groups) and unconstrained (regression weight may vary across the three pathway to UPG groups) models indicates invariance does not hold (Byrne, 2010), as does a CFI difference equal or greater than 0.01 (Cheung and Rensvold, 2002).

**Results**

***Differences in the Three Tasks Model variables according to pathway to a UPG.***

Table 2 presents descriptive statistics for the variables of the 3TM for the total sample and according to pathway to UPG.

Overall participants considered parenthood to be very important and reported mid-range scores for social support, meaning making, acceptance and pursuit of new goals. Wellbeing scores were lower than those reported in norms or questionnaire validation data. Based on the WHO-5 cut-off scores, 62% of participants were experiencing poor wellbeing and 32% were clinically depressed.

People with fertility or other health problems who did treatment were older and more likely to have stopped trying to conceive than those who did not do treatment and those with unfavourable circumstance. People with fertility or other health problems who did treatment reported better mental health and eudaimonic wellbeing than those who did not do treatment. No other statistically significant group differences were found.

***Test of the Three Tasks Model validity***

Table 3 describes validity criteria for the initial (Model 1) and refined (Model 2) models tested, with and without data imputation. Goodness of fit indices ($\chi^2$, CFI, RMSEA) indicate the initial model (Model 1) showed good fit to the data, and the refined model (Model2) showed very good fit.

**Table 2.** Descriptive statistics for the variables of the Three Tasks Model (3TM) for the total sample and according to pathway to unmet parenthood goal (N = 410)

| | Cronbach's alpha | Total sample (N = 410) | Fertility/health problems with treatment (n = 173) | Fertility/health problems without treatment (n = 168) | Unfavourable circumstances (n = 69) | $\chi^2$ or F-statistic, effect size ($\eta^2_p$) |
|---|---|---|---|---|---|---|
| **Predictors** | | | | | | |
| Age in years, M(SD) | NA | 35.06 (8.57) | **38.91 (8.12)[a]** | **31.94 (7.55)[a]** | **32.69 (8.16 [a]** | **35.931, .153**\*\*\* |
| Stopped trying to conceive, N(%) | NA | 197 (48.0) | **109 (63.0)[a]** | **68 (40.5)[a]** | **20 (29.0) [a]** | **29.409**\*\*\* |
| With children, N(%) | NA | 195 (47.6) | 84 (48.6) | 72 (42.9) | 39 (56.5) | 3.780 |
| Importance of parenthood, M(SD) | NA | 4.67 (0.73) | 4.67 (.73) | 4.64 (.75) | 4.62 (.84) | .810, .004 |
| Social support, M(SD) | | 13.85 (4.25) [5-20] | 13.90 (4.23) | 14.00 (4.37) | 13.36 (4.05) | .435, .003 |
| **Mediators** | | | | | | |
| Meaning making, M(SD) | .79 | 2.54 (0.99) [1-4] | 2.59 (.98) | 2.48 (.97) | 2.56 (1.03) | .514, .003 |
| Acceptance, M(SD) | .94 | 13.12 (5.20) [6-24] | 13.42 (5.39) | 12.71 (5.07) | 13.37 (5.01) | .777, .004 |
| Pursuit of new goals, M(SD) | .93 | 19.64 (6.06) [6-30] | 20.43 (6.10) | 18.89 (5.91) | 19.47 (6.18) | 2.361, .014 |
| **Outcomes** | | | | | | |
| Mental Health | .87 | 47.89 (23.78) | **51.108 (23.25)[b]** | **43.95 (23.66)[b]** | 49.37 (24.35) | **3.723, .020**\* |
| Hedonic Wellbeing, M(SD) | .89 | 41.86 (20.62) | 43.36 (20.05) | 40.19 (20.37) | 42.03 (22.53) | .896, .005 |
| Experiencing poor wellbeing, N(%) | NA | 228 (62.3) | 91 (58.3) | 99 (67.3) | 38 (60.3) | 2.745 |
| Clinically depressed, N(%) | NA | 118 (32.2) | 49 (31.4) | 50 (34.0) | 19 (30.2) | .386 |
| Eudaimonic Wellbeing, M(SD) | .86 | 49.72 (11.15) | **51.81 (11.43)[b]** | **48.22 (11.11)[b]** | 47.60 (9.62) | **4.495, .029**\* |

**Legend.** NA = Not applicable, \*p<.05, \*\*p<.01, \*\*\*p<.001. M = mean, SD = standard deviation, $\eta^2_p$ = partial eta-squared, [a]fertility/health problems with treatment < fertility/health problems without treatment and unfavourable circumstances; [b]fertility/health problems without treatment < fertility/health problems with treatment. Multiple-comparisons conducted with Bonferroni correction. Significant differences highlighted in bold.

**Table 3.** Results of the Three Tasks Model (3TM) validity criteria for the initial (Model 1) and refined (Model 2) models tested, with and without data imputation.

| 3TM validity criteria | Model 1 | | Model 2 | |
|---|---|---|---|---|
| | No data imputation | Data imputation | No data imputation | Data imputation |
| Moderate positive regression weights (β≥.20) between all mediators and at least one outcome | β (MM →MH) =.088<br>β (MM →HWB) =.079<br>β (MM →EWB) =.186**<br>β (A →MH) =.142**<br>**β (A →HWB) =.238\*\*\***<br>β (A →EWB) =-.094<br>**β (PNG →MH) =.204\*\*\***<br>β (PNG →HWB) =.189***<br>**β (PNG →EWB) =.375\*\*\*** | β (MM →MH) =.088<br>β (MM →HWB) =.079<br>β (MM →EWB) =.197***<br>β (A →MH) =.135**<br>**β (A →HWB) =.231\*\*\***<br>β (A →EWB) =-.101*<br>**β (PNG →MH) =.219\*\*\***<br>β (PNG →HWB) =.199***<br>**β (PNG →EWB) =.399\*\*\*** | β (MM →MH) =.092<br>β (MM →HWB) =.084<br>β (MM →EWB) =.198***<br>β (A →MH) =.148**<br>**β (A →HWB) =.244\*\*\***<br>β (A →EWB) =-.100<br>**β (PNG →MH) =.202\*\*\***<br>β (PNG →HWB) =.190***<br>**β (PNG →EWB) =.380\*\*\*** | β (MM →MH) =.086<br>β (MM →HWB) =.080<br>**β (MM →EWB) =.205\*\*\***<br>β (A →MH) =.143**<br>**β (A →HWB) =.240\*\*\***<br>β (A →EWB) =-.104*<br>**β (PNG →MH) =.217\*\*\***<br>β (PNG →HWB) =.199***<br>**β (PNG →EWB) =.404\*\*\*** |
| Moderate positive covariations (cov≥.20) between mediators | **cov (MM, A) =.402\*\*\***<br>**cov (MM, PNG) =.443\*\*\***<br>**cov (A, PNG) =.448\*\*\*** | **cov (MM, A) =.428\*\*\***<br>**cov (MM, PNG) =.469\*\*\***<br>**cov (A, PNG) =.472\*\*\*** | **cov (MM, A) =.405\*\*\***<br>**cov (MM, PNG) =.444\*\*\***<br>**cov (A, PNG) =.444\*\*\*** | **cov (MM, A) =.428\*\*\***<br>**cov (MM, PNG) =.469\*\*\***<br>**cov (A, PNG) =.472\*\*\*** |
| $\chi^2$ is non-significant | $\chi^2(21) = 29.301$* | $\chi^2(21) = 30.473$** | **$\chi^2(24) = 28.147$** | **$\chi^2(24) = 29.633$** |
| CFI > 0.95 | **CFI = 0.99** | **CFI = 0.99** | **CFI = .997** | **CFI = .997** |
| RMSEA<0.06, 90%LCI<0.05 & 90%HCI<0.08 | **RMSEA = .048**<br>**90%CI [.021, .074]** | **RMSEA = .050**<br>**90%CI [.024, .076]** | **RMSEA = .021**<br>**90%CI [.000, .047]** | **RMSEA = .024**<br>**90%CI [.000, .049]** |

**Legend**. 3TM = Three Tasks Model of Adjustment to Unmet Parenthood Goals; β: regression weight, cov: covariance, $\chi^2$: chi-squared statistic, CFI: Bentler comparative fit index, RMSEA: Steiger–Lind root mean square error of approximation, CI: confidence interval, LCI: lower value of confidence interval, HCI, higher value of confidence interval; *p<.05, **p<.01, ***p<.001. Bold entries indicate results meet pre-specified validity criteria.

Overall the refined model without data imputation met all but one validity criteria (associations between meaning-making and eudaimonic wellbeing were just below the threshold to be considered moderate) and met all when missing data was imputed.

The refined model (Model 2) is also represented in Figure 1. Results show weak to moderate positive associations between meaning-making and eudaimonic wellbeing, weak positive associations between acceptance and mental-health, and moderate positive associations between acceptance and hedonic wellbeing. Pursuit of new goals shows positive moderate associations with mental-health, positive weak to moderate associations with hedonic wellbeing and strong associations with eudaimonic wellbeing. Covariations between the model mediators were all positive and strong. Analysis of Figure 1 also indicates that, as predicted, age, having stopped trying to conceive, having children and higher social support were positively associated with the 3TM mediators, while attributing high importance to parenthood was negatively associated. The strength of these associations varied from weak (age) to strong (social support). Direct moderate positive associations between social support and all the outcomes were also found. Finally, there were moderate to strong covariances between the model outcomes. The model predictors explained from 22 to 33% of the variance observed in the 3TM mediators. Together, predictors and mediators explained 35 to 43% of the observed variance in outcomes.

### *Test of the Three Tasks Model invariance according to pathway to UPG*

The goodness of fit indexes for the refined model (Model 2, no data imputation) with unconstrained regression weights were $\chi^2(72) = 127.850$, p < .001, CFI = .957, and with constrained regression weights were $\chi^2(134) = 190.482$, p = .001, CFI = .956. The difference in fit was not statistically significant ($\chi^2_{dif}(62) = 62.632$, p = .454) and the CFI difference was lower than 0.01 ($CFI_{dif} = .001$), indicating that the model was invariant across participants with different pathways to UPG. Comparison of the unconstrained and constrained refined model with data imputation presented similar results (data not shown).
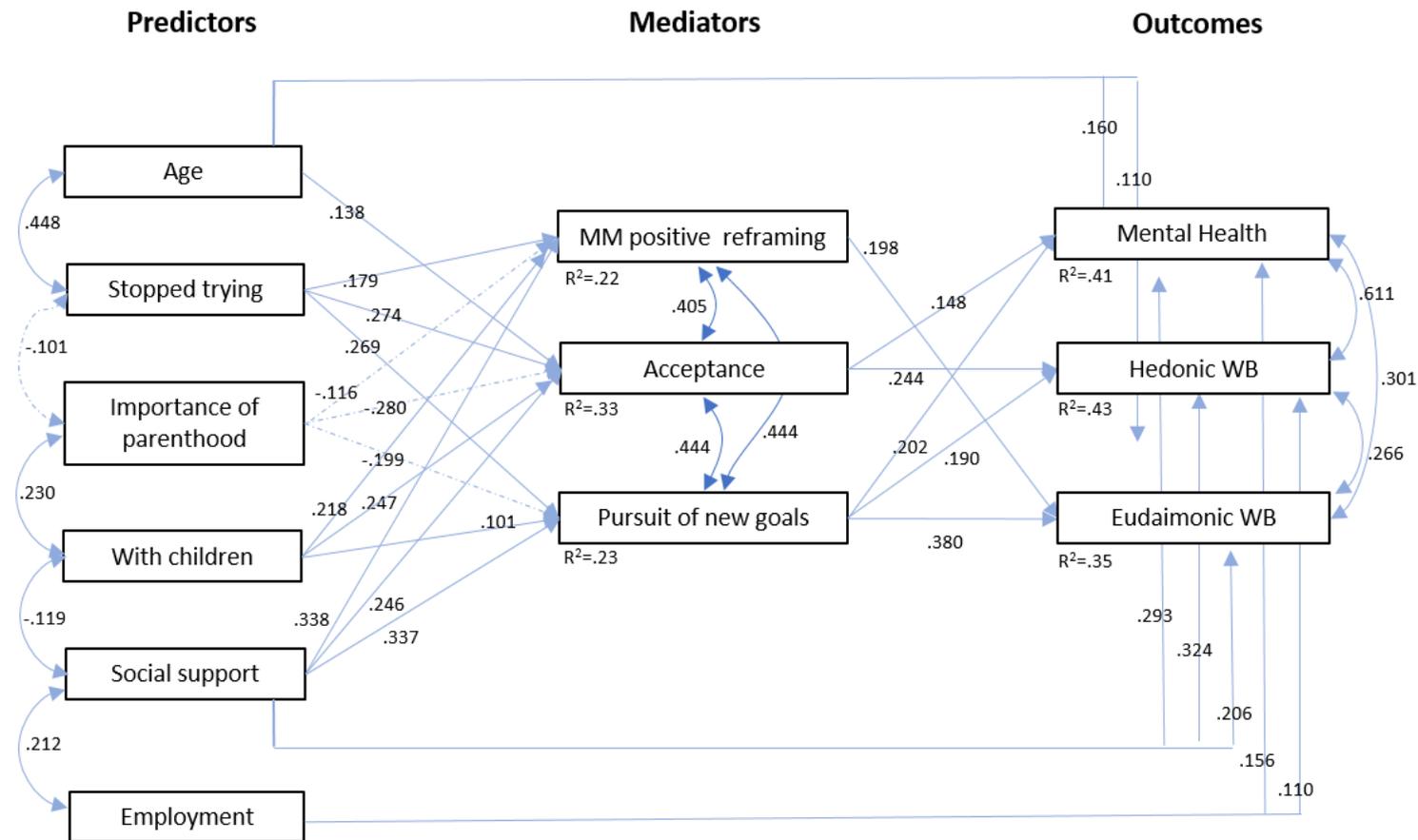
**Figure 1.** Path model testing the Three Tasks Model of Adjustment to Unmet Parenthood Goals (3TM, Model 2, no data imputation), controlling for socio-demographic variables correlated with at least one of the outcomes (age, employment status). Model fit was $\chi^2(24) = 28.147$, p =.253, CFI = 0.997, RMSEA = .021 90%CI [.000, .047]. Continuous and dashed unidirectional arrows represent statistically significant positive and negative regression weights, respectively. Continuous bidirectional arrows represent statistically significant covariation indexed. MM = meaning-making, WB = wellbeing. $R^2$ indicates the variable's proportion of variance explained by its predictors.

**Discussion**

Results show that people who self-identify as having a UPG experience low wellbeing, confirming the need to develop adequate support for this population. This study provides the first empirical evidence that psychosocial support tailored to patients finishing unsuccessful fertility treatment and, more generally, people with a UPG, should focus on exploration and pursuit of fulfilling alternative life goals, promotion of willingness to experience one's UPG without avoidance or struggle, and exploration of positive meanings regarding one's UPG. Supportive social networks seem to play a critical role in empowering people to engage with these three tasks and should therefore also be considered in support initiatives. Psychosocial interventions informed by the 3TM are expected to promote adjustment at different levels, from decreasing psychopathologic symptoms (mental health) to improving daily wellbeing (hedonic wellbeing) and fulfilment in life (eudaimonic wellbeing). Overall results support the 3TM is a valid therapeutic framework to address UPGs, regardless of how these came to be.

This study indicates that one's perception of not having been able to have the children they wished for translate in poor wellbeing, regardless of the pathways leading to this perception. Our participants reported overall lower levels of wellbeing than found in the general population and high incidence of clinical depression. Contextual factors framing such perceptions seem to be important. Personal pathways marked by the opportunity to actively try to conceive, success in having at least one child and relinquishment of such efforts seem to facilitate adjustment. This highlights the importance of having good access to fertility care, good advice and control over decisions to stop trying and favourable social contexts that, among other things, allow individuals to take ownership of such decisions without social costs (e.g., stigma). It also suggests that the current impact of COVID-19 on fertility plans, for instance due to disruption of fertility care provision (Boivin et al., 2020) or economic uncertainty (Luppi et al., 2020) may have a lasting impact on many people, making UPG support initiatives timely.

Results indicate that effective tailored support to UPGs is needed and should prioritize pursuit of alternative goals to parenthood, acceptance of UPG and, to a lesser extent, creation of positive meaning related to this loss. Promoting a favourable social context that empowers individuals to engage with these three psychological tasks also seems crucial. In Table 4 we present research-informed suggestion to achieve these therapeutic goals. As indicated by the strong covariations found between mediators (see Table 3), these therapeutic goals are highly interrelated and should be approached in an integrated way. Our results do not support the hypothesis that particular pathways to UPGs may make it harder for individuals to engage in these psychological tasks (i.e., no significant group differences in the 3TM mediators were found) or experience less benefit from it (i.e., the model was invariant across groups), further supporting their use in interventions. Pursuit of alternative goals has been consistently associated with psychological benefits regardless of if individuals are trying to have children or stopped (Mesquita

da Silva, Boivin and Gameiro, 2016), but many patients report feeling stuck and not knowing how to start this process. The only existing intervention targeting UPGs (not available for use) shows that it is feasible to engage definitive childless women in formulating new goals and increasing self-efficacy to pursue such goals, and that this contributes to decreasing depressive symptoms (Kraaij et al., 2016). Our results suggest that (re)engaging with life goals other than parenthood will also positively impact hedonic and eudaimonic wellbeing, which is consistent with patients' perception that new goals distract them from the pain and become more rewarding with time (Gameiro and Finnigan, 2017).

**Table 4.** Suggestions for therapeutic activities underlying psychosocial support tailored to an unmet parenthood goal (UPG)

| Therapeutic goals | Therapeutic activities |
|---|---|
| Promotion of pursuit of alternative fulfilling life goals | • Inform that most people with a UPG develop new fulfilling life goals and that maintaining such goals, regardless of actively trying to conceive or not, gives a sense of purpose and contributes to wellbeing<br>• Promote an adventurous attitude towards trying new things in life for 'fun' instead of 'obligation', while highlighting those goals do not need to be grandiose<br>• Apply value clarification and congruent goal definition techniques<br>• Address idiosyncratic barriers to pursuit of new goals identified<br>• Promote long-term committed action towards goals identified as personally relevant and rewarding<br>• Promote insight about experiential avoidance and how it can impact on committed action |
| Increase acceptance of the UPG | • Validate and normalise the loss and grief experience associated with a UPG<br>• Inform that most people adjust to a UPG and, with time, find renewed personal balance and meaning in life<br>• Address future orientated fears and concerns, e.g., one will not be able to bear the suffering, 'what next?', lack of legacy, etc.<br>• Increase insight about thoughts, feelings, bodily sensations and behaviours associated with UPG grief<br>• Apply techniques known to increase acceptance, for instance mindfulness, self-compassion, cognitive-defusion<br>• Address idiosyncratic barriers to acceptance, e.g., guilt or regret about previous conception (non)attempts, social pressure for parenthood, etc. |
| Promote construction of positive meaning related to one's UPG | • Promote benefit finding about previous conception (non)attempts<br>• Promote the use of adaptive cognitive restructuring strategies, e.g., reattribution, positive reframing, downward comparison, etc., and address the use of non-adaptive strategies, e.g., denial, wishful thinking, self-judgement, etc. |

| | |
|---|---|
| | • Promote insight about social pressure for and idealization of parenthood |
| | • Promote positive restructuring of hold beliefs closely related with the UPG experience, such as about family, marriage, parenthood or gender roles |
| | • Promote re-evaluation of life values (value clarification) and priorities |
| Promote favourable social contexts | • Promote social links with other people with UPGs |
| | • Promote social links with people pursuing same alternative goals |
| | • Promote cognitive-defusion from insensitive comments related to one's UPG |
| | • Promote positive communication skills about one's UPG, e.g., how to address insensitive comments |
| | • Promote use of value clarification to redefine how one presents themselves to others, e.g., their UPG status does not need to be their 'master status' |

Acceptance is perceived by people with a UPG as a central task in order to 'move on' and rebuild hope towards the future (Chauhan et al., 2020, Fieldsend and Smith, 2020). Consistently with acceptance literature, our results show it is associated with better mental-health and hedonic wellbeing. Acceptance of the emotional suffering associated with the UPG seems to be the most challenging aspect for people (Gameiro and Finnigan, 2017), which suggests that psychological techniques aiming at increasing insight of and easing contact with difficult thoughts, feelings and bodily experiences, for instance mindfulness and cognitive-defusion, can be particularly useful, as already established with patients undergoing fertility treatment (Galhardo et al., 2013).

Individuals with a UPG see the construction of positive meanings about their UPG as part of their healing process. However, in our study meaning-making was only linked to better eudaimonic wellbeing. This is at least partially related with the limitations of how it was operationalized. To assess meaning-making one can focus on the appraisal of the stressor that triggers the need to make meaning, on the strategies used to make meaning and on the meaning made (Park and George, 2013). We only assessed one meaning-making strategy that we know is adaptive in the context of UPGs (Kraaij, Garnefski and Schroevers, 2009, Lechner, Bolman and van Dalen, 2007), but individuals refer using many others, for instance reattribution (finding reasons for why the UPG happened and who or what is responsible), value clarification (reassessing priorities in life), downward comparison (judging oneself as well off in comparison to other real or hypothetical people), re-structuring of beliefs associated with the UPG (e.g., parenthood, family, etc.), or developing more realistic views of the world (e.g., less predictable, fair, safe) (Gameiro and Finnigan, 2017). Therapeutic support can target any of these strategies while also preventing the use of non-adaptive strategies sometimes used, as denial (Throsby, 2001) or self-judgement (Galhardo et al., 2011).

Finally, the strong associations found between social support and the 3TM mediators and outcomes support the need to address one's social context. More specifically, promoting supportive networks can help propel people towards their goals and accepting their UPG (Martino et al., 2017, Su and Chen, 2006). On the contrary, some social contexts may hinder people's ability to make meaning. Helping individuals to develop insight of such contexts (e.g., pressure for parenthood, socio-cultural assumption) and promoting cognitive-defusion can then be helpful. Patient centred approaches to care also require a focus on social support, as individuals consistently refer to the value of connecting with other people in their circumstances to overcome feelings of social isolation and share effective coping strategies (Malik and Coulson, 2013, Stenström, 2020).

Clarity about therapeutic goals and strategies to address the impact of UPGs should enable the future development and evaluation of evidence-based support interventions for this heterogeneous and growing population. While people who did not do fertility treatment and faced unfavourable circumstances would need to proactively access such support, it should be offered to all fertility patients. Indeed, it is important for the field to recognise that positive experiences of treatment need to include its immediate and longer-term aftermath, even if patients are no longer at clinics. Overall, it seems clear from both research and patient advocacy initiatives that there is high demand for support to UPGs. However, there is little evidence on when, how and what type of support people desire, and therefore how to best translate the therapeutic recommendations in this article into interventions. Within fertility clinics, it would be important to explore staff and patients' acceptability of implementing both prevention (i.e., preparation for possibility of unsuccessful treatment) and intervention (i.e., support after unsuccessful treatment) approaches and in which format, as more emphasis is being put on online support due to COVID-19 (World Health Organization, 2020). To support those outside the healthcare system, some of the challenges will be to decide between developing interventions that are inclusive of people with different pathways to a UPG and parental status versus if to cater to each group; how to address barriers to support-seeking, for instance, lack of insight regarding or avoidance of grief (Fieldsend and Smith, 2020), stigma (Slade et al., 2007) or even practicalities (e.g., travelling distance, cost); or even how to ensure proper referral processes with mental-health services for those more profoundly affected, that are based on solid understanding of the impact UPGs can have on mental-health (i.e., from sadness, to clinical depression, to suicide ideation) (Boivin, Harrison, Mathur, Burns, Pericleous-Smith and Gameiro, 2020).

**Strengths and limitations**

This is a theory-led study that applied guidelines for explanatory modelling (Shmueli, 2010) in order to test the 3TM on a heterogeneous group of people faced with a UPG. The sample was well powered and model validy criteria were defined a-priori. All psychological constructs were assessed with widely used and sound

questionnaires. A holistic assessment of psychological adjustment was considered, which allowed differentiation between psychological functioning (mental health, hedonic wellbeing) and perceptions of life fulfilment (eudaimonic wellbeing). The use of a different response scale in the MHI-5 is a limitation of this study, which affects the scales' criteria validity. In other words, we could not compare our MHI-5 scores with normative or other studies' data, nor could we report on the prevalence of mental health disorders in our sample. However, the items remained unchanged, and therefore so did the scale's validity and reliability. Indeed, its covariation with WHO-5, another measuring of psychological functioning was .611 but with a measure of eudaimonic wellbeing was only .301, and reliability was .87. The sample was self-selected from social-media and support groups and this affects generalisability, in particular for men, as only two participated. Nonetheless, overall adjustment and experiences of the UPG were consistent with existing literature (Gameiro and Finnigan, 2017). Assessment of meaning-making was sound but not comprehensive enough and future studies should strive to better map the meaning-making processes through which positive change is achieved. The data supports the theoretical model tested but definite causal conclusions need to be based on prospective research with mediators being assessed prior to outcomes. Alternatively, experimental testing of psychological interventions based on the 3TM can also provide evidence in support of its causal claims.

**Conclusion**

The 3TM is a valid therapeutic framework to address UPGs, regardless of how these came to be. Its main therapeutic goals can be achieved by implementing already existing therapeutic techniques that have been proved efficient within clinical and health psychology, and some even within the context of reproductive health (e.g., positive reappraisal coping, mindfulness, goal definition, etc.). This evidence is promising for the development of evidence-based interventions to support people with UPGs. The field urgently needs to broaden existing support from promoting fertility health to also address definitive parenthood goal loss.

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# Appendix B: Prospective Acceptability Study – Participant Information Sheet, Consent form, questionnaires and debrief form

## Participant Information Sheet

**Thank you for considering participating in this study.**

**The School of Psychology at Cardiff University** and **FertilityNetworkUK** co-produced the **Finding More to Life (MtL) Self-Help Guide** to support people who are not able to have a child or as many children as they would like.
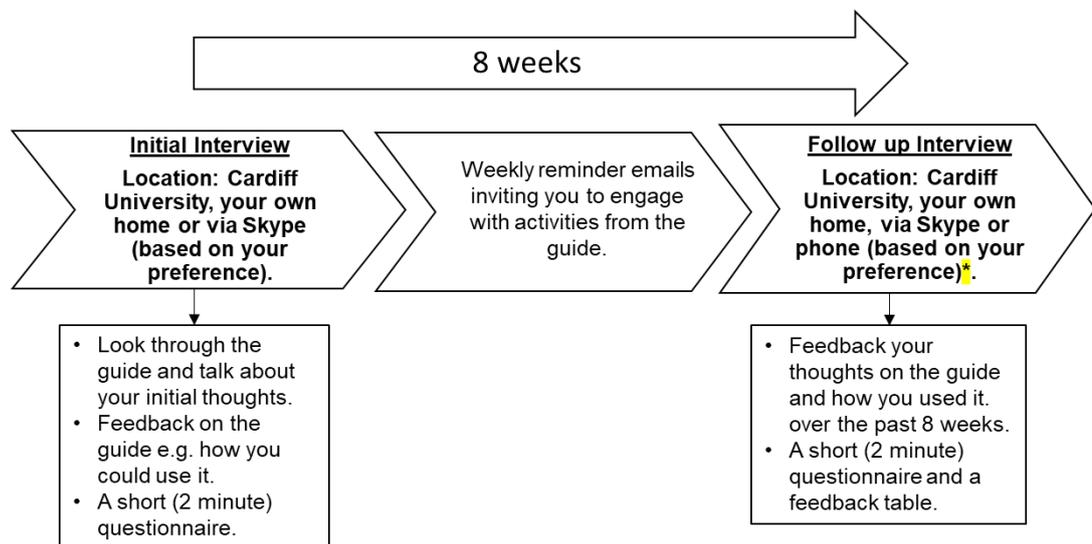
**In this study we would like to obtain your feedback about the MtL Self-Help Guide so that we can improve it.**

**Your participation includes doing two 1-hour interviews** (via skype, phone, or in person, as you prefer), the first to tells us what you think of the Self-Help Guide and how you might use it, and the second to let us know about your experience of using it. In between the interviews you will receive weekly emails inviting you to look at a particular activity in the Self-Help Guide.

**You will receive a £50 voucher for your participation.**

**You can withdraw at any point without having to give a reason and will still receive the voucher.**

The diagram below presents the study in more detail.

8 weeks

**Initial Interview**
Location: Cardiff University, your own home or via Skype (based on your preference).

- Look through the guide and talk about your initial thoughts.
- Feedback on the guide e.g. how you could use it.
- A short (2 minute) questionnaire.

Weekly reminder emails inviting you to engage with activities from the guide.

**Follow up Interview**
Location: Cardiff University, your own home, via Skype or phone (based on your preference)*.

- Feedback your thoughts on the guide and how you used it. over the past 8 weeks.
- A short (2 minute) questionnaire and a feedback table.

Each interview will last approximately **one hour** but you can stop whenever you wish.

* In circumstances where an interview can not be arranged due to limited time, the interview questions can be sent via an online questionnaire

**We are really interested in your thoughts and experiences of the Self-Help Guide and will use any information you provide to us to make this guide as useful as possible.**

Your responses from both interviews will be **AUDIO-RECORDED** and stored (transcribed) **CONFIDENTIALLY** on a password protected University computer. Only the researchers on this project will be able to access your data (interview responses). Your data will be anonymised one month after the survey has closed and after this point, no-one will be able to trace your information back to you. You can ask for the information you have provided to be deleted/destroyed at any time up until the data has been anonymised and you can have access to the information up until the data has been anonymised.

**What are the possible disadvantages and risks of taking part?**

We acknowledge that some of the activities in the Self-Help Guide might make you feel emotional as you may reflect on your own personal experience. Therefore, we stress that you can withdraw from the study whenever you like without having to give any reason, including during an interview. Contact details for the researchers and other support services will also be provided.

**What are the possible benefits of taking part?**

By taking part in this study, you will be introduced to the support tool (the MTL Self-Help Guide) which has been specifically designed for people in your situation and engaging with this Self-Help Guide is expected to facilitate your journey of acceptance of your unfulfilled desire for (more) children.  Moreover, past research has shown that participating in research interviews can help participants to understand their own thoughts and emotions.

**What should I do if there is a problem during my participation?**

If you have any problem or any concern about our study, please contact:

The contact details of the researcher of this study: Beth Rowbottom, PhD Student, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT Email: rowbottomb@cardiff.ac.uk

The contact details of the supervisor of this study: Dr Sofia Gameiro, Senior Lecturer, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT, Email: gameiros@cardiff.ac.uk     Tel: +44 (0)29 2087 5376

This project has been reviewed and ethically approved by SREC (School Research Ethics Committee), School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT Email: psychethics@cardiff.ac.uk     Tel: +44 (0)29 2087 0360

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk. The lawful basis for the processing of the data you provide is consent.

# Consent form

I understand that this study aims to test the acceptability of the **More To Life Self-Help Guide** for people who have unmet parenthood goals (by not being able to have a child or as many children as they would want).

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with Dr Sofia Gameiro.

I understand that the information provided by me will be audio-recorded (for example recorded via Skype) and transcribed. This information will be held confidentially, such that only the researcher and supervisor can trace this information back to me individually. I understand that my data will be anonymised one month after the study has finished and that after this point no-one will be able to trace my information back to me.  The anonymous information will be retained indefinitely. I understand that I can ask for the information I provide to be deleted/destroyed at any time up until the data has been anonymised and I can have access to the information up until the data has been anonymised.

I understand that some of the activities might make me feel emotional as I may reflect on my own personal experience and that I am free to withdraw at any time. I understand that I may be asked questions about my sexual orientation, but I can choose not to answer these questions. I also understand that at the end of the study I will be provided with additional information (including support services) and feedback about the purpose of the study.

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk  The lawful basis for the processing of the data you provide is consent.

I consent to participate in the study conducted by Beth Rowbottom School of Psychology, Cardiff University with the supervision of Dr Sofia Gameiro.


Signed: _____


Date: _____

# Consent form

(for completing the online qualitative questionnaire)

I understand that overall this study aims to test the acceptability of the More To Life Self-Help Guide for people who have unmet parenthood goals (by not being able to have a child or as many children as they would want).

I understand that participation online questionnaire is entirely voluntary and that I can withdraw at any time by closing the browser window, without giving a reason.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with Dr Sofia Gameiro.

I understand that the information provided by me will be collected via an online questionnaire. This information will be held confidentially, such that only the researcher and supervisor can trace this information back to me individually. I understand that my data will be anonymised one month after the study has finished and that after this point no-one will be able to trace my information back to me. The anonymous information will be retained indefinitely. I understand that I can ask for the information I provide to be deleted/destroyed at any time up until the data has been anonymised and I can have access to the information up until the data has been anonymised.

I understand that at the end of the study I will be provided with additional information (including support services) and feedback about the purpose of the study.

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk  The lawful basis for the processing of the data you provide is consent.

I consent to complete this online questionnaire created by Beth Rowbottom School of Psychology, Cardiff University with the supervision of Dr Sofia Gameiro.


Signed: _____


Date: _____

## QUESTIONNAIRES

### DEMOGRAPHIC DETAILS

| GENDER | RELATIONSHIP STATUS | EDUCATION | EMPLOYMENT |
|---|---|---|---|
| □ Female | □ Single | □ No high school | □ Unemployed |
| □ Male | □ Married | □ High school | □ Part time |
| □ Other | □ In relationship, no cohabiting | □ Undergraduate degree | □ Full time |
| □ Prefer not to say | □ In relationship, cohabiting | □ Postgraduate degree | □ Student |
| | □ Divorced/separated | □ PhD | □ Other (please state) |
| | □ Widow | □ Other (please state) | |
| **AGE** | □ Prefer not say | | |
| years | | | |
| □ Prefer not say | | □ Prefer not say | □ Prefer not say |

**Your journey so far**

| Do you have biological children? | Have you actively tried to conceive a child in the past? | Can you conceive spontaneously (by having sexual intercourse with a partner of the opposite sex)? |
|---|---|---|
| □ Yes | □ Yes | □ Yes |
| □ No | □ No | □ No |
| □ Prefer not say | □ Prefer not say | □ Prefer not say |
| If yes, how many? | | **If no, please explain why you cannot conceive (using as many options as you want):** |
| | **Have you engaged in fertility treatment to conceive?** | □ I have fertility problems. |
| **Do you have adopted children?** | □ Yes | □ My partner has fertility problems. |
| | □ No | □ I have a health condition that stops us from being able to conceive. |
| □ Yes | | |
| □ No | □ Prefer not say | □ My partner has a health condition that stops us from being able to conceive. |
| □ Prefer not say | | |
| If yes, how many? | If yes, how long ago did you finish treatment?    years    months | □ I identify as LGBT+. |
| | | □ I don't have a partner. |
| | | □ Other (please state): |

**INITIAL INTERVIEW QUESTIONS**

Key

Acceptability                                          Usefulness/helpfulness

Accessibility                                          **SA** – Social Acceptance

Appropriateness / content                              **SI** – Social Importance

Aesthetics

Materials = information provided about the evidence/research behind the activities.

Activity = the weekly activity and its content.

<u>**Instructions**</u>

The following instructions will be read to the participant:

As you were informed on the consent form and information sheet, in this interview I will ask you question about the More To Life (MtL) Self-Help Guide, which has been created to help individuals who have been unable to achieve the family that they desire.

As mentioned on the consent form, this interview is being audio recorded. After, it will be transcribed to a text document and your name will be replaced by a pseudonym (false name) to ensure that your data remains anonymous. The audio record will be destroyed. You can tell us to delete your data until the moment it becomes anonymous.

The information given in this interview is confidential and, apart from the research team (myself and Sofia Gameiro, my supervisor), no one will have access to it. In case you experience strong negative feelings during the interview, please let me know so I can give you some support contacts. We really appreciate your contribution to this study.

(If interview taking place in Tower Building (Psychology) at Cardiff University) If a fire alarm sounds during this interview, please follow the instructions of the researcher and we will evacuate the building safely.

Please complete the demographic details form provided (See separate form).

The More To Life (MtL) Self-Help Guide has been created to help individuals who have been unable to achieve the family that they desire. We hope that completing all the activities within this Self-Help Guide may help people move forward from pain and grief and lead a fulfilling and meaningful life. This MtL Self-Help Guide is the topic of interest and you (the participant) are the 'work domain expert and primary speaker' and I (the researcher) am the listener and learner. It is important to note that we are testing the materials and not you! This is not a test and there are no right or wrong answers. We are just interested in what you think and feel and we want to know your opinions.

You (the participant) will need to work through the web pages and activities on this website while describing what you are thinking as you do this. After this, I (the researcher) will ask you a series of questions about certain aspects of the Self-Help Guide. Then you will be invited to fill out a short questionnaire. If you do not wish to answer a question, during the interview or on the form, you/we can just skip to the next question.

You can practice the 'think aloud' technique prior to the main task starting if you wish, we can use the support page on Fertility Network UK.

This session is not expected to last longer than one hour. You can stop the session at any time and you don't have to give me a reason.

Before we start, do you have any questions?

**Overall acceptance questions:**

1. Do you think the materials/activities are useful? Why? SI
2. Do you think the information provided in the materials/activities is comprehensive? Why? SA
3. Do you think the language used in the materials/activities is appropriate? Why? SA
4. Do you think the materials/activities are user friendly (e.g. easy to access and navigate through)? Why? SA
5. Do you think the materials/activities look appealing? Why? SA

**Planned use questions:**

From what you have seen of the MtL Self-Help Guide so far:

1. Do you find the Self-Help Guide easy or difficult to use? Why? **(SA)**
2. What are the main benefits you would expect from using this Self-Help Guide? **(SI)**
3. Do you think using this Self-Help Guide could have any negative affect on you? **(SI – harm experienced?)**
4. Which aspects of the Self-Help Guide do you like most? Why? **(SA)**
5. Which do you like the least? Why? **(SA)**

How will you use the MtL Self-Help Guide:

1. How do you envision using this Self-Help Guide? SI
2. How do you think you will fit the activities into your weekly routine? SI
3. How do you think you will access the materials/activities (e.g. print them out, access on computer etc.)? SA
4. Do you think you will do these activities alone or with your partner (if relevant), if so how? SA

Suggestions for improvements and comments

Can you provide any suggestions for improvement?

Do you have any further comments that you would like to add?

Quantitative Questionnaire

Do you agree with following statements? (Adapted from Taranoski and Simonion (1992) (6-point Likert scale – 1 = strongly disagree, 6 = strongly agree) (This measure of acceptability has good reliability (internal consistency of 0.98) (Carter, 2007)):

**Overall, I like this MtL Self-Help Guide.**

1   2   3   4   5   6

Strongly disagree     Strongly agree

**Overall, the MtL Self-Help Guide seems helpful**

1   2   3   4   5   6

Strongly disagree     Strongly agree

**I am willing to use the MtL Self-Help Guide.**

1   2   3   4   5   6

Strongly disagree     Strongly agree

(adapted from (Lancastle & Boivin, 2008)

**How confident would you be to recommend the MtL Self-Help Guide to someone else in the same/similar situation?**

1          2          3          4          5          6

Not at all          Somewhat          Extremely

**How suitable do you think the MtL Self-Help Guide is for people with an unmet child wish?**

1          2          3          4          5          6

Not at all          Somewhat          Extremely

**Instructions for the next two months (these will be handed to the participant at the end of the interview and/or sent via email):**

We would now like to invite you to use the **More to Life Self-Help Guide** over the next two months.

There are eight activities to complete and all the information about the Self-Help Guide and activities can be found on this website - http://fertilitynetworkuk.org/for-those-facing-the-challenges-of-childlessness/support/10074-2/support-materials/

We will send you a reminder email each week to let you know which activity can be completed that week. This email will also include the PDF version of the activity.

Each activity can take approximately 30 minutes, but you can take as long as wish. Some activities will ask you to engage with them more regularly in order to make small everyday steps on your journey.

We will arrange another interview session in two months' time to collect your views and experiences on using the More to Life Self-Help Guide during this period.

Here are some support contact details:

**Fertility Network UK**

http://fertilitynetworkuk.org/for-those-facing-the-challenges-of-childlessness/

Email- info@fertilitynetworkuk.org

Tel- 01424 732361

If you are worried about your mental health, please contact your **GP or NHS mental health** online https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/ **Error! Hyperlink reference not valid.**

You can also contact the researcher or supervisor at any time during the study:

Beth Rowbottom, PhD Student, email: rowbottomb@cardiff.ac.uk

Dr Sofia Gameiro, Supervisor, email: gameiros@cardiff.ac.uk  Tel: +44 (0)29 2087 5376

**Do you have any questions?**

**FOLLOW UP INTERVIEW QUESTIONS**

**Instructions**

The following instructions will be read to the participant:

As you were informed on the consent form and information sheet at the start of this study, in this interview I will ask you question about the More To Life (MtL) Self-Help Guide, which has been created to help individuals who have been unable to achieve the family that they desire.

As mentioned on the consent form, this interview is being audio recorded. After, it will be transcribed to a text document and your name will be replaced by a pseudonym (false name) to ensure that your data remains anonymous. The audio record will be destroyed. You can tell us to delete your data until the moment it becomes anonymous.

The information given in this interview is confidential and, apart from the research team (myself and Sofia Gameiro, my supervisor), no one will have access to it. In case you experience strong negative feelings during the interview, please let me know so I can give you some support contacts. We really appreciate your contribution to this study.

(If interview taking place in Tower Building (Psychology) at Cardiff University) If a fire alarm sounds during this interview, please follow the instructions of the researcher and we will evacuate the building safely.

Please can you tell us if any of your personal details on this form (show original completed form) have changed in the past two months?

The More To Life Self-Help Guide has been created to help individuals who have been unable to achieve the family that they desire. We hope that completing all the activities within this Self-Help Guide may help people move forward from pain and grief and lead a fulfilling and meaningful life.

I (the researcher) will ask you (the participant) a series of questions about the MtL Self-Help Guide that you have been using over the past two months. Some of these questions will be the same as the ones asked at the initial interview as we are interested in what you think now you have had more time to use the Self-Help Guide. Remember it is the Self-Help Guide we are assessing and not you. This is not a test and there are no right or wrong answers. We are just interested in what you think and feel and we want to know your opinions.

You will then be asked to fill out a short questionnaire and feedback table for the activities. If you do not wish to answer a question, during the interview or on the form, you/we can just skip to the next question.

This session is not expected to last longer than one hour. You can stop the session at any time and you don't have to give me a reason.

Before we start, do you have any questions?

**FOLLOW UP QUALITATIVE QUESTIONNAIRE**

**(if an interview is not possible)**

**Instructions**

The following instructions will be provided at the beginning of the questionnaire:

As you were informed on the consent form and information sheet at the start of this study, in this questionnaire you will be asked question about the More To Life (MtL) Self-Help Guide, which has been created to help individuals who have been unable to achieve the family that they desire.

You will be asked to enter your unique ID from the first online questionnaire you completed. This will allow us to ensure your data remains confidential.

The information given in this questionnaire is confidential and, apart from the research team (myself and Sofia Gameiro, my supervisor), no one will have access to it. In case you experience strong negative feelings during the questionnaire, please refer back to the support contact details provided below.

The More To Life Self-Help Guide has been created to help individuals who have been unable to achieve the family that they desire. We hope that completing all the activities within this Self-Help Guide may help people move forward from pain and grief and lead a fulfilling and meaningful life.

This questionnaire contains a series of questions about the MtL Self-Help Guide that you have been using over the past two months. Some of these questions will be the same as the ones asked at the initial interview as we are interested in what you think now you have had more time to use the Self-Help Guide. Remember it is the Self-Help Guide we are assessing and not you. This is not a test and there are no right or wrong answers. We are just interested in what you think and feel and we want to know your opinions.

You will then be asked to fill out a short questionnaire and feedback table for the activities. If you do not wish to answer a question, during the questionnaire, you can just skip to the next question.

This questionnaire should not last more than 40 minutes. You can stop questionnaire at anytime by closing the browser window.

Here are some support contact details:

**Fertility Network UK**

http://fertilitynetworkuk.org/for-those-facing-the-challenges-of-childlessness/

Email- info@fertilitynetworkuk.org

Tel- 01424 732361

If you are worried about your mental health, please contact your **GP or NHS mental health** online https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/

**Questions**

Please can you tell us if any of your personal details on this have changed in the past two months?

**Please enter your unique ID: _____**

**The following questions will be included in both the interview or the qualitative questionnaire:**

**General questions:**

1. What are your thoughts and opinions about the Self-Help Guide now that you have had more time to look at it and complete the activities?

2. What do you think is important for us to know about your experience of using the Self-Help Guide over the past two months?

**Overall acceptance questions:**

1. Did you think the materials/activities were useful? Why?
2. Did you think the information provided in the materials/activities was comprehensive? Why?
3. Did you think the language used in the materials/activities was appropriate? Why?
4. Did you think the materials/activities were user friendly (e.g. easy to access and navigate through)? Why?
5. Did you think the materials/activities looked appealing? Why?

**Actual use of MtL Self-Help Guide questions:**

Now that you have had more time to look at and use the Self-Help Guide:

1. Can you describe how you have used the Self-Help Guide over the past two months?
2. Did you find the Self-Help Guide easy or difficult to use? Why? **(SA)**
3. What activities did you find useful or not useful? Why?
4. Which activities did you find easy or difficult? Why?
5. Are there any activities that you would take out of the Self-Help Guide? Why?
6. What did you think are the main benefits were from using this Self-Help Guide? **(SI)**
7. Did you think this Self-Help Guide had any negative affect on you? **(SI – harm experienced?)**
8. Which aspects of the Self-Help Guide did you like most? Why? **(SA)**
9. Which did you like the least? Why? **(SA)**
10. Is there anything else about how you used the guide that you think is relevant for us to know?

How you used the MtL Self-Help Guide:

1. How did you fit the activities into your weekly routine?
2. How did you access the materials/activities (e.g. print them out, access on computer etc.)?
3. Did you do these activities alone or with your partner (if relevant), if so how?

Suggestions/comments

Can you provide any suggestions for improvement?

Do you have any further comments that you would like to add?

<u>Quantitative Questionnaire</u>

Do you agree with following statements? (Adapted from Taranoski and Simonion (1992) (6-point Likert scale – 1 = strongly disagree, 6 = strongly agree) (This measure of acceptability has good reliability (internal consistency of 0.98) (Carter, 2007)):

**Overall, I liked the MtL Self-Help Guide.**

1     2     3     4     5     6

Strongly disagree                              Strongly agree

**Overall, the MtL Self-Help Guide was helpful**

1     2     3     4     5     6

Strongly disagree                              Strongly agree

(adapted from (Lancastle & Boivin, 2008)

**How confident would you be to recommend the MtL Self-Help Guide to someone else in the same/similar situation?**

1   2      3      4      5      6

Not at all      Somewhat      Extremely

**How suitable do you think the MtL Self-Help Guide is for people with an unmet child wish?**

1   2      3      4      5      6

Not at all      Somewhat      Extremely

**Suppose you felt that you were struggling with coming to terms with your unmet child wish again in the future, would you be willing to use the MtL Self-Help Guide again?**

1      2      3      4      5      6

Not at all      Somewhat      Extremely

**Are you satisfied with the outcomes you obtained from using the MtL Self-Help Guide?**

**(Social Importance)**

1      2      3      4      5      6

Not at all      Somewhat      Extremely

Please now complete the following activity feedback table:

- Please indicate by ticking the box whether you only read the activity or whether you completed the activity.
- Please use the circles to indicate how much you agree or disagree with each statement at the top of the table.

Participant will be handed the debrief form at the end of this session.

**FEEDBACK TABLE FOR ACTIVITIES**

| ACTIVITY | This activity was useful. | | | | | This activity was challenging. | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **1 Be kind to yourself**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **2 Begin to heal**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **3 Look for light in the darkness**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **4 Reconnect with the things you enjoy**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **5 Find what is important to you**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **6 Make your plan**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **7 Commit to your plan**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |
| **8 Bring it all together**<br>READ ACTIVITY ONLY □<br>COMPLETED ACTIVITY □ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ | Strongly Disagree<br>○ | Disagree<br>○ | Neutral<br>○ | Agree<br>○ | Strongly Agree<br>○ |

# Debrief Form

This study is part of research testing a model which has been proposed to develop support for people who have not being able to have a child or as many children as they would like. The **Three Task Model of Adjustment** (Gameiro & Finnigan, 2017) suggests that three tasks (acceptance, meaning making, pursuit of new life goals) could help people adjust to realising their unmet parenthood goals by improving their mental health and wellbeing.

The **More To Life (MtL) Self-Help Guide** from this study aims to help people engage in the three tasks mentioned above (acceptance, meaning making and pursuit of new life goals). We hope that using the MtL Self-Help Guide over a couple of months will help people move through their grief of not being able to achieve the family they desire and towards a more fulfilling life. The information we gather from you in this study will assist us in improving this self-help guide further, ensuring that it is presented in the most acceptable and useful way to provide support for people with unmet parenthood goals.

Your responses from the interviews will be stored confidentially on a password protected University computer. Only the researchers on this project will be able to access your data (interview responses). Your data will be anonymised one month after the survey has closed and that after this point, no-one will be able to trace your information back to you. You can ask for the information you have provided to be deleted/destroyed at any time up until the data has been anonymised and you can have access to the information up until the data has been anonymised.

If you feel you would like support after doing this questionnaire, we have provided the contact details for Fertility Network UK Email- info@fertilitynetworkuk.org Tel- 01424 732361

If you are worried about your mental health, please contact your GP or NHS mental health online.

If you would like to read more about this model, and what it has hypothesised, please look at the following paper on Google Scholar: Gameiro, S., & Finnigan, A. (2017). Long-term adjustment to unmet parenthood goals following ART: a systematic review and meta-analysis. *Human Reproduction Update*, *23*(3), 322-337.

If you would like to get in touch with the researcher and supervisor of this study, please use the contact details below.

| **Bethan Rowbottom** | **Dr Sofia Gameiro** |
|---|---|
| PhD Student | Senior Lecturer |
| School of Psychology | School of Psychology |
| Cardiff University | Cardiff University |
| Tower Building | Tower Building |
| Park Place | Park Place |
| Cardiff | Cardiff |
| CF10 3AT | CF10 3AT |
| Email: rowbottomb@cardiff.ac.uk | Email: gameiros@cardiff.ac.uk |
| | Tel: +44 (0)29 2087 5376 |

Details of further contact:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT

Tel: +44 (0)29 2087 0360

Email: psychethics@cardiff.ac.uk

# Appendix C: Prospective Acceptability Study - Detailed table of themes generated from T1 and T2

Table 1 - Themes generated from the first assessment moment (T1)

| Themes | Positives | Negatives | Suggestions for improvement |
|---|---|---|---|
| **Intervention meets the needs of users** | | | |
| *Intervention is helpful and useful* | • **intervention useful or helpful overall (100%)** and to work through feelings (33%), find meaning (17%) and to trigger self-awareness (17%)<br>• **Intervention useful for someone who was ready to try and overcome their experience (50%)** | No participants said that the intervention would not be at all helpful or useful (0%) | • More practical advice (33%)<br>• Affirmations or rewarding phrases (17%)<br>• Some participants suggested additional content to make it more useful (50%) |
| *Expected effects from using the intervention* | • finding a way to move forward (50%)<br>• reframing things in a different way (25%)<br>• identifying areas not thought about before (17%) | • **engaging with the intervention could be emotionally challenging (50%), painful or upsetting (25%)** feeling concerned by some of the content (17%) | • **contact details for further support in the intervention (33%)**<br>• further clarification that the intervention could bring up difficult emotions (17%) validation and reassurance throughout intervention (17%) |
| *Connecting with others is important* | • expect to connect with others in the same situation (25%)<br>• **use the intervention to feel less alone (42%) so it is good to know what others experience (33%)** | *Intervention currently doesn't include information about how to connect with others.* | • ways to connect with others (17%)<br>• incorporate other people's experience of using the intervention into the content (8%) used as a tool in a group support session or an online chat community (17%) |
| *Partners, males and couples using the intervention* | • nice to see men and women's experience affirmed (17%)<br>• intervention may appeal to male perspective because it is clear and straightforward (8%) | • Women did not think that men would want to engage with the intervention (58%) *No men took part in this study.* | • activities for men (8%)<br>• activities for couples (8%) |
| **Working through the UPG experience** | | | |
| *Journey* | **referred to a journey (100%), including own experience (75%), assigning definitive timescale (25%) or the intervention itself being a journey (58%)** ● **usefulness of the intervention depends on where one is on their journey (67%) and accessing intervention indicates a** | | |

| Themes | Positives | Negatives | Suggestions for improvement |
|---|---|---|---|
| | **desire to work through experience (17%) ●  expected effects or use of intervention dependent on where one was on their journey (92%), finding the intervention distressful or overwhelming if at the beginning of the journey or 'not ready' (17%)** | | |
| *Intervention has a framework or structure to help a person experiencing UPG (including organisation)* | A framework or structure (which was easy to navigate (58%): <br>• **to work through and move forward (92%)** <br>• for thoughts (50%) and to help clarify things (50%) <br>• to work through grief and pain (33%) <br>to follow to find other paths or goals (17%) | • 'flow' of the intervention was not clear (42%) <br>feeling lost using the intervention (33%) | • clearer architecture of structure or framework of the intervention (33%) <br>clearer flow, including next and back buttons (8%) and something to clearly close the intervention off (8%) |
| **Intervention is appropriate** | | | |
| *Intervention is accessible and easy to use* | • easy to read and understand (58%) <br>• easy to use (58%) <br>• aspects of the presentation were appealing (92%) <br>• delivery as an online self-help intervention was good (50%) | • aspects were not accessible (42%) <br>• not easy to read and understand (33%) <br>• not easy to use (17%) | • better explanations on how to use to intervention (33%) <br>• some language should be amended (33%) <br>• the option to download or print the entire intervention as a workbook (17%) or an audio version (17%) |
| *Intervention is relatable and comprehensive* | • **content felt relevant and relatable (100%)** <br>• intervention was comprehensive (100%) and language was appropriate (75%) <br>• acknowledged the UPG experience and that engaging with the intervention may be challenging (67%) <br>• good that the intervention is research based (33%) <br>Participants regarded the quotes in a positive way (e.g., comforting) (58%) | • Some content was not relatable (25%) and was even concerning (17%) <br>**disliked the use of the word 'more' and the references to those who already had children (42%)** | • **acknowledgement that the intervention has been developed for two groups (8%)** <br>• **two separate interventions for childless individuals and parents with an UPG (8%)** <br>**Make sure all language is inclusive (8%)** |
| *Thinking about using the intervention* | • ● **use the intervention individually (100%)** ● set time aside to allow them the space to complete the activities (50%) ● **print off the activities or use a notebook and pen for activities (75%)** | | |

Note. Percentage indicates percentage of participants.

Table 2 - Themes generated from second assessment moment (T2)

| Themes | Positives | Negatives | Suggestions for improvement |
|---|---|---|---|
| **Intervention meets the needs of users** | | | |
| *Intervention is helpful and useful* | • Intervention is helpful (64%) e.g., gaining understanding of oneself and think about how to move forward<br>• Intervention is useful (82%) e.g., to look at all aspects of the experience | • Intervention was not considered useful to partner by participants (45%)<br>• One participant felt that certain aspects were not helpful (9%) | • Information about using the intervention with others to make it even more useful (36%) (see connecting with others) |
| *Engaging with the intervention had a positive effect for most participants* | • No negative effect was reported (64%)<br>• Any emotions experienced were unsurprising and part of the process (36%)<br>• Focussing on values was beneficial (36%)<br>• Finding fulfilment in other ways (27%) and 'feeling better' in general (27%) | • Intervention had a negative emotional effect, such as getting upset (27%) and emotional challenge required to engage with intervention is not well explained (27%)<br>• Engaging with the intervention was (emotionally) challenging (45%) | • Provide additional support for those who may experience negative emotions (27%) |
| *Connecting with others* | • 'What most people experience' section can reduce loneliness (9%)<br>• Talking about activities with partner (during or after) was good (18%) | • Completing activities alone can be isolating and raw (9%) | • Develop the intervention to facilitate use with others (45%) |
| **Working through the UPG experience** | | | |
| *Journey* | • Referred to experience as a journey (64%)<br>• Where one is on their journey influences experience of the using the intervention (64%)<br>• Could better to complete intervention at beginning of journey (36%) or it may be more difficult to complete at beginning of journey (27%) | | |
| *Intervention provides structure and this structure flows well or makes sense (including weekly schedule and reminder emails)* | • All activities should remain in the intervention (82%)<br>• The order of the activities currently flows well (45%)<br>• Structure to work through was beneficial (45%)<br>• Process that the intervention takes a person through was liked by participants (18%)<br>• Weekly schedule worked well (64%)<br>• Reminder email is useful and should be kept (55%) | • Removal of two activities (18%)<br>• Online materials were not accessed since first interview (45%) (not all participants asked)<br>• Weekly schedule is too quick (27%)<br>• Weekly schedule is too slow (9%)<br>• Only one participant was able to complete the activities weekly (9%) | • Additional activities to be included (18%), for example to provide support for feelings of resentment or anger.<br>Change weekly schedule (36%) to include fortnightly, monthly or yearly, or no timescale. |

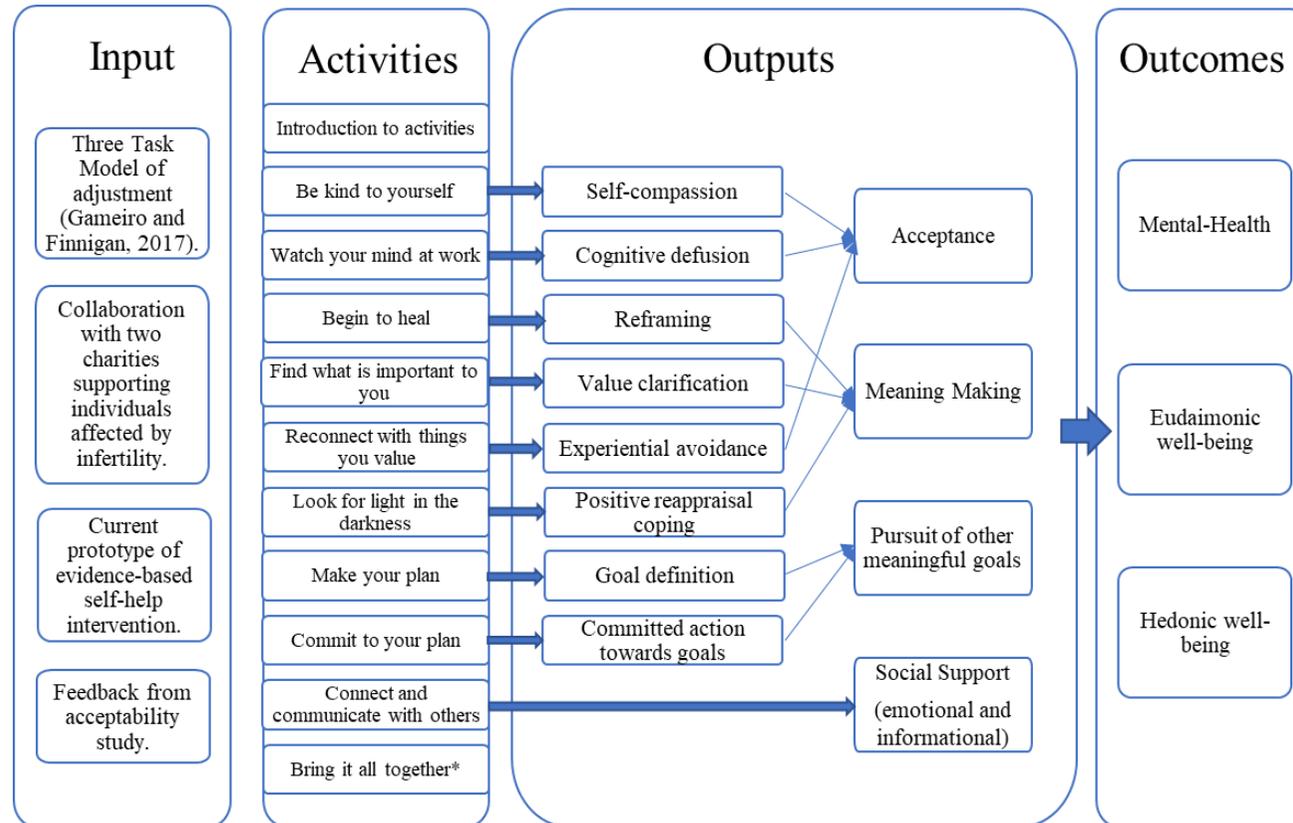| Themes | Positives | Negatives | Suggestions for improvement |
|---|---|---|---|
| **Intervention is appropriate** | | | |
| *Intervention is accessible but digital interaction could be improved* | • Access is easy and straightforward (73%)<br>• Ability to download and print activities at any time is good (27%)<br>• Intervention looks appealing (45%)<br>• Intervention was easy to use (45%) and easy to do (45%) | • Intervention is difficult to read and understand (36%)<br>• Current digital access and interaction is poor (36%)<br>• Current method (e.g., printing activities) to use the intervention was not appealing (18%) | • Navigation needs to be improved and made clearer (36%)<br>• Enhance digital interactivity, e.g., annotation and access on phone or tablet (27%) |
| *Intervention is a comprehensive and appropriate support tool* | • Intervention is comprehensive (73%)<br>• Overall, the language is appropriate (82%)<br>• Intervention felt appropriate for someone with an UPG (82%) and including providing tailored support for this experience (45%) | • Some language was not appropriate (27%)<br>• Language referring to 'more' children makes a childless person uncomfortable (9%) | • Providing more information or better explanations of emotions involved in engaging with intervention (27%)<br>• Some language needs to be made simpler and more straightforward (18%) |
| *Thoughts about actual use of the intervention* | • Used individually (91%) or used with partner verbally (9%)<br>• Did not complete all activities as did not find some acceptable (36%)<br>• Engaged with intervention digitally (45%) or printed out the activities (55%)<br>• Wrote in notebooks or on print outs (45%)<br>• Set time aside to complete the activities (64%) and used own reminders or do list to remember to engage with intervention (18%) | | • Suggestions to help with using the intervention included providing more information about how the intervention could be used (45%) |

Note. Percentage indicates percentage of participants.

**Appendix D: Prospective Acceptability Study - Detailed table of data integration matrix of qualitative and quantitative data**

| Meta-Themes | QUALITATIVE DATA (Themes) | QUANTITATIVE DATA (Survey responses) | Degree of convergence | Comments |
|---|---|---|---|---|
| **Intervention meets the needs of users** | *Helpful and useful* | Responses showed participants thought the intervention was helpful. Responses showed each activity was perceived as useful to some extent. | PA | Qualitative data and quantitative data indicated that participants strongly endorsed the helpfulness and usefulness of the intervention, but some quantitative data suggested there is an opportunity to improve the usefulness of certain activities further. |
| | *Activities perceived to trigger logic model mediators and outputs* | Responses showed participants were satisfied with outcomes. | AG | Qualitative data provided examples of the benefits and skills participants gained using the intervention and the quantitative data showed that participants were satisfied with the outcomes they had self-described, providing an overall positive evaluation. |
| | *Connecting to others is important* | N/A | S | The importance of connection to others was highlighted only in the qualitative data but the differing nature of the data sets mean that it is unsurprising that this was not present in the quantitative data. |
| **Working through the UPG experience** | *Prompts engagement with a challenging process* | Responses showed each activity was perceived as challenging to some extent. | AG | Qualitative data revealed participants concerns over a perceived challenge and this was supported by quantitative data rating each activity as challenging to some extent. |
| | *The UPG experience is a journey* | N/A | S | The 'journey' metaphor was highlighted only in the qualitative data, but the differing nature of the data sets mean that it is unsurprising that this was not present in the quantitative data. |
| | *Activities provided a beneficial structure to work through* | N/A. | S | The qualitative methods enabled participants to broadly discuss the benefits of the intervention and a majority outlined that the structured support was a key benefit. The differing nature of the data sets indicate that it is unsurprising that this was not present in the quantitative data. |
| **Intervention is appropriate** | *Ease of use and accessibility* | Responses showed participants liked intervention overall. | AG | Qualitative data provided examples of aspects of the intervention participants liked and the quantitative data supported these with a high overall rating of whether participants liked the intervention. |
| | | | AG | Qualitative data enabled the researchers to evaluate how users would engage, and did engage, with the intervention from participants' detailed descriptions and the |

| Meta-Themes | QUALITATIVE DATA (Themes) | QUANTITATIVE DATA (Survey responses) | Degree of convergence | Comments |
|---|---|---|---|---|
| | | Responses showed participants were willing to use intervention (T1). Responses showed all participants read and 67% completed the activities. Responses showed participants were willing to use intervention again (T2) | | quantitative data demonstrated to what extent they engaged. Furthermore, a willingness to use the intervention again suggests that certain aspects were considered as worthwhile revisiting, if required. Taken together, these data provided an overall depiction of acceptability. |
| | *Comprehensive and appropriate* | Responses showed participants were confident to recommend intervention to others.<br><br>Responses showed participants thought intervention was suitable for people with UPG. | AG | Qualitative data indicated that the participants strongly felt that the content was comprehensive and appropriate, and the quantitative data demonstrated an increase in confidence to recommend the intervention to others and ratings of suitability for individuals with a UPG between T1 and T2, which supported this. |
| | *Used individually* | N/A | S | References to individual use were only present in the qualitative data but the differing nature of the data sets mean that it is unsurprising that this was not present in the quantitative data. |

Note. AG = Agreement; PA = Partial Agreement; S = Silence. Categorisation of degree of convergence based on typification outlined by Farmer, Robinson and Eyles (2006).

**Appendix E: Prospective Acceptability Study – Logic Model Version 2**



| Input | Activities | Outputs | Outcomes |
|---|---|---|---|
| Three Task Model of adjustment (Gameiro and Finnigan, 2017). | Introduction to activities | | Mental-Health |
| | Be kind to yourself | Self-compassion | |
| | Watch your mind at work | Cognitive defusion | Acceptance |
| Collaboration with two charities supporting individuals affected by infertility. | Begin to heal | Reframing | |
| | Find what is important to you | Value clarification | Meaning Making |
| | Reconnect with things you value | Experiential avoidance | |
| Current prototype of evidence-based self-help intervention. | Look for light in the darkness | Positive reappraisal coping | Pursuit of other meaningful goals |
| | Make your plan | Goal definition | |
| | Commit to your plan | Committed action towards goals | |
| Feedback from acceptability study. | Connect and communicate with others | Social Support (emotional and informational) | Eudaimonic well-being |
| | Bring it all together* | | Hedonic well-being |

Note. Thicker arrows demonstrate the output that each activity aims to target, and the thin arrows indicate the mechanism that these outputs aim to facilitate. *Synthesis activity to encourage users to reflect back on their progress.

# Appendix F: Childless by circumstance adjustment and support needs - Participant Information Sheet, Consent form, questionnaires and debrief form

## Patient Information Sheet

Thank you for considering participating in this study.

This study is about the experience of not being able to have the children one wished for due to unfavourable circumstances, such as not having a partner or not finding the right partner, your partner doesn't want a child, illness or not feeling financially secure.

It is an anonymous survey concerned with your experiences of involuntary childlessness and the support you may need as a consequence. The responses you give in this survey will be vital to shape this research and help make improvements in the care and support given to people who are childless by circumstance.

The survey will be online and will take XX minutes.

You will have the opportunity at the end to be entered into a prize draw to win one of four £30 Amazon vouchers.

The different sections of the survey ask you about:

SECTION 1: Your background

SECTION 2: Your experience of childlessness

SECTION 3: Your adjustment to childlessness

SECTION 4: Your support needs

Please remember that for your answers to be used you must click the SUBMIT button at the end of the survey.

Your participation is entirely voluntary, and you may omit any question you do not wish to complete. If you decide to participate, you can withdraw from the study at any time by closing the survey window or contacting the lead researchers (rowbottomb@cardiff.ac.uk or gameiros@cardiff.ac.uk).

Your data will be collected anonymously so there will be no way of tracing your responses back to you. The anonymous data will be made publicly accessible (e.g., through patient support groups), used for scientific purposes (e.g., research publications to develop information) and retained indefinitely in accordance with the Data Protection Act 1998.

What are the possible disadvantages and risks of taking part?

We acknowledge that some of the questions in the survey might make you feel emotional as you reflect on your own personal experience. Therefore, we stress that you can withdraw from the study whenever you like without having to give any reason. Contact details for the researchers and other support services will also be provided.

What are the possible benefits of taking part?

Past research has shown that participating in research surveys can help participants to better understand their own thoughts and emotions.

What should I do if there is a problem during my participation?

If you have any problem or any concern about our study, please contact:

The contact details of the researcher of this study: Beth Rowbottom, PhD Student, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT Email: rowbottomb@cardiff.ac.uk

The contact details of the supervisor of this study: Dr Sofia Gameiro, Senior Lecturer, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT, Email: gameiros@cardiff.ac.uk
Tel: +44 (0)29 2087 5376

This project has been reviewed and ethically approved by SREC (School Research Ethics Committee), School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT Email: psychethics@cardiff.ac.uk      Tel: +44 (0)29 2087 0360

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk. The lawful basis for the processing of the data you provide is consent.

## Consent form

I understand that this study aims to find out about people's experience of being childless by circumstance and gather information about their support needs.

I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason (by closing the survey window or contacting the lead researchers (rowbottomb@cardiff.ac.uk or gameiros@cardiff.ac.uk) and I can omit any question.

I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with Dr Sofia Gameiro.

I understand that my data will be collected anonymously so there will be no way of tracing my responses back to me. The anonymous data will be made publicly accessible (e.g., through patient support groups), used for scientific purposes (e.g., research publications to develop information) and retained indefinitely in accordance with the Data Protection Act 1998.

I understand that some of the questions in the survey might make me feel emotional as I may reflect on my own personal experience, but I am free to withdraw at any time and I also understand that at the end of the study I will be provided with additional information (including support services) and feedback about the purpose of the study.

The data controller is Cardiff University and the Data Protection Officer is Matt Cooper CooperM1@cardiff.ac.uk  The lawful basis for the processing of the data you provide is consent.

I consent to participate in the study conducted by Beth Rowbottom School of Psychology, Cardiff University, with the supervision of Dr Sofia Gameiro.

Signed: _____

Date: _____

# Questionnaires

Eligibility questions:

Please confirm that you consider yourself to be childless by circumstance. By this, we mean that:

You identify as being permanently childless

AND

You presumed you were fertile during your childbearing years

AND

Your childlessness is due to unfavourable circumstances, for instance you don't have a partner or didn't find the right partner, your partner doesn't want a child, you are gay, you didn't feel financially secure etc

- YES
- NO

Please confirm that you are age 35 and over:

- YES
- NO

SECTION 1: YOUR BACKGROUND

<u>Sociodemographic questions</u>

What best describes your gender?

o Female
o Male
o Prefer to self-describe: _____
o Prefer not to say

How old are you:

Please state in years _____

o Prefer not to say

What is your country of residence? _____

Which best describes your current relationship status?

o Single
o In relationship, married or cohabiting
o In relationship, but not married nor cohabiting
o Divorced/separated
o Widowed
o Other, please specify:
o Prefer not to say

Which best describes your education?

o No education
o Primary/elementary school
o Secondary/High School

- o  Post-secondary school, for example, sixth form, college, trader or technical apprenticeship (e.g., BTEC)
- o  Undergraduate Degree
- o  Postgraduate Degree
- o  Other - Please specify: _____
- o  Prefer not to say

Which best describes your employment status?

- o  Unemployed
- o  Employed/self-employed (part time or full time)
- o  Student
- o  Retired
- o  Other - Please specify: _____
- o  Prefer not to say

Questions evaluating UPG:

Do you still wish to have children?

- -  Yes
- -  No

How important is parenthood to you?
- -  1 (Not at all)
- -  2
- -  3 (Important)
- -  4
- -  5 (Very important)
- -  Prefer not to say

SECTION 2: YOUR EXPERIENCE OF CHILDLESSNESS

Please can you explain how you have become childless by circumstance? [Adapted from Tonkin, 2010].

Do you think people who are childless by circumstance experience unique challenges, when compared to those who are childless because of infertility/health issues? Please explain in as much detail as you can [RQ]

Do you think you have or will be able to come to terms with your childlessness? Please explain in as much detail as you can [RQ].

What do you think has helped or can help you to come to terms with your childlessness? Please explain in as much detail as you can [RQ].

Please tell us anything else you think it is important about your experience of being childless by circumstance [RQ].

SECTION 3: YOUR ADJUSTMENT TO CHILDLESSNESS

**SCREENIVF** (Verhaak et al., 2010) - Acceptance

Please answer the following questions about your **acceptance** towards **being childless** by selecting the number that corresponds with the comment that fits your feelings towards each statement the most:

|  |  | 1<br>Do not agree | 2<br>Agree a little bit | 3<br>Agree | 4<br>Strongly Agree | Prefer not to say |
|---|---|---|---|---|---|---|
| 1 | I can deal with the consequences of my childlessness | ○ | ○ | ○ | ○ | ○ |
| 2 | I have learned to live with my childlessness | ○ | ○ | ○ | ○ | ○ |
| 3 | I have learned to accept my childlessness | ○ | ○ | ○ | ○ | ○ |
| 4 | I can accept my childlessness | ○ | ○ | ○ | ○ | ○ |
| 5 | I think I can cope with my childlessness, even though it will not be solved | ○ | ○ | ○ | ○ | ○ |
| 6 | I can cope well with my childlessness | ○ | ○ | ○ | ○ | ○ |

Please give examples or provide detail that supports your answers.

**COPE Scales** (Carver et al., 1989) -  Meaning Making

The following questions ask you to indicate what you have been **generally doing** regarding the fact that you are childless.

Respond to each of the following items by selecting the number that best describes what YOU usually DO when you experience distress for being childless. There are no 'right' or 'wrong' answers, so choose the most accurate answer for **YOU**- not what you think 'most people' would say or do.

|  |  | 1<br>I usually don't do this at all | 2<br>I usually do this a little bit | 3<br>I usually do this a medium amount | 4<br>I usually do this a lot | Prefer not to say |
|---|---|---|---|---|---|---|
| 1 | I try to see it in a different light, to make it seem more positive | ○ | ○ | ○ | ○ | ○ |
| 2 | I look for something good in what is happening | ○ | ○ | ○ | ○ | ○ |
| 3 | I have learned something from the experience | ○ | ○ | ○ | ○ | ○ |
| 4 | I try to grow as a person as a result of the experience | ○ | ○ | ○ | ○ | ○ |

Please give examples or provide detail that supports your answers.

**Goals Adjustment Scale** (reengagement only) (Wrosch et al., 2003) - Pursuit of New Life Goals

During their lives, people cannot always attain what they want and are sometimes forced to stop pursuing the goals they have set.
**We are interested in understanding how you are reacting to not having children.**
Please indicate the extent to which you agree or disagree with each of the following statements, as it usually applies to you.

|   |   | 1 Strongly disagree | 2 Disagree | 3 Neutral | 4 Agree | 5 Strongly agree | Prefer not to say |
|---|---|---|---|---|---|---|---|
| 1 | I have convinced myself that I have other meaningful goals to pursue | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have started working on other new goals | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I think about other new goals to pursue | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I have sought after other meaningful goals | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I have told myself that I have a number of other new goals to draw upon | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I have put effort toward other meaningful goals | ○ | ○ | ○ | ○ | ○ | ○ |

Please give examples or provide detail that supports your answers.

**MHI-5** (Veit & Ware, 1983)- Mental health

Using the 1-5 scale below, indicate your response by placing the appropriate number on the line preceding that item.

**How much of the time, during the last month, have you…?**

|   |   | 1 All of the time | 2 Most of the time | 3 A good bit of the time | 4 Some of the time | 5 A little of the time | 6 None of the time | Prefer not to say |
|---|---|---|---|---|---|---|---|---|
| 1 | '...been a very nervous person?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | '…felt calm and peaceful?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | '…felt downhearted and blue?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | '...been a happy person? | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | '...felt so down in the dumps that nothing could cheer you up?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**WHO-5** (World Health Organisation , developed at Psychiatric Research Unit, Mental Health Centre North Zealand, Hillerød, Denmark)- Hedonic Well-being

Please indicate for each of the five statements which is closest to **how you have been feeling over the past two weeks. Notice that higher numbers mean better well-being.** Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, choose the box with the number 3 in it.

|   |   | 0 At no time | 1 | 2 | 3 | 4 | 5 | Prefer not to say |
|---|---|---|---|---|---|---|---|---|

| | | | Some of the time | Less than half of the time | More than half of the time | Most of the time | All the time | |
|---|---|---|---|---|---|---|---|---|
| 1 | I have felt cheerful and in good spirits | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have felt calm and relaxed | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I have felt active and vigorous | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I woke up feeling fresh and rested | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | My daily life has been filled with things that interest me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**Flourishing Scale** (Diener et al., 2010) - Eudaimonic wellbeing

Below are eight statements with which you may agree or disagree. Using the 1–7 scale below, indicate your agreement with each item by indicating that response for each statement.

| | | 1 Strongly disagree | 2 Agree | 3 Slightly disagree | 4 Neither agree nor disagree | 5 Slightly agree | 6 Agree | 7 Strongly agree | Prefer not to say |
|---|---|---|---|---|---|---|---|---|---|
| 1 | I lead a purposeful and meaningful life | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | My social relationships are supportive and rewarding | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I am engaged and interested in my daily activities | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I actively contribute to the happiness and well-being of others | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I am competent and capable in the activities that are important to me | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I am a good person and live a good life | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| 7 | I am optimistic about my future | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | People respect me | ○ | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**Social Support**

These statements are about your **social relationships**. Please chose the response that most closely matches with how you feel about your social relationships.

Questions developed from the literature (Tonkin 2014) (Hadley, 2019b) :

| | 1 (Nearly never) | 2 (Sometimes) | 3 (Regularly) | 4 (Often) | Prefer not to say |
|---|---|---|---|---|---|
| My friends and family understand my feelings about my childlessness | ○ | ○ | ○ | ○ | ○ |
| I have friends and family I can talk to about my childlessness. | ○ | ○ | ○ | ○ | ○ |
| I feel isolated because of my childlessness. | ○ | ○ | ○ | ○ | ○ |
| I feel that I am treated differently because I am childless. | ○ | ○ | ○ | ○ | ○ |

Please give examples or provide detail that supports your answers.

SECTION 4: YOUR SUPPORT NEEDS

(Researcher generated questions)

Do you feel you need professional/formal support (e.g. a mental health professional etc.) to cope with your childlessness?

- No
- Yes

Please explain in as much detail as you can: _____

Do you feel you need informal support (e.g. the opportunity to talk or share experiences with other people who have/are going through similar issues through online forums, blogs etc) to cope with your childlessness?

- No
- Yes

Please explain in as much detail as you can: _____

Would you consider using an online app to manage the psychological and social implications of **being childless by circumstance**?

- Yes
- No

Please explain in as much detail as you can: _____

What content or features would you want the app to include? Please describe in as much detail as you can: _____

Current Situation

To which degree do you think your wellbeing is being affected by the current COVID situation?

1 - Very negatively affected
2 – Negative affected
3 – Not negatively nor positively affected
4 – Positively affected
5 – Very positively affected

To which degree do you think your experience of being childless by circumstance is being affected by the current COVID situation?

1 - Very negatively affected
2 – Negatively affected
3 – Not negatively nor positively affected
4 – Positively affected
5 – Very positively affected

If you have any further comments about how the current pandemic is affecting you in relation to your childlessness, please explain in as much detail as you can:

Please provide your email address if you would like to be contacted to provide feedback to us during the development of a self-help intervention for men and women who are childless by circumstance:
_____

Please provide your email address if you would like to be entered into the prize draw:
_____

## Debrief Form

Currently there is not much research that focuses on people's experience of being childless by circumstance. By answering the questions in this study, you have provided information that will help researchers gain a better understanding of the childless by circumstance experience, which in turn will help us develop support for those who need it.

This study is also part of research testing a model which has been proposed to develop support for people who have not being able to have a child or as many children as they would like. The **Three Task Model of Adjustment** (Gameiro & Finnigan, 2017) suggests that three tasks (acceptance, meaning making, pursuit of new life goals) could help people adjust to realising their unmet parenthood goals by improving their mental health and wellbeing. We have asked you some questions about these tasks to see whether you have engaged with these tasks and how they may have changed the way you feel.

Based on this model, we have developed an online self-help intervention, which can be found at this website: https://fertilitynetworkuk.org/life-without-children/finding-more-to-life-self-help-guide/. We hope that using the intervention over a couple of months will help people move through their grief of not being able to have a child and towards a more fulfilling life. The information we gather from you in this study will assist us in improving this self-help guide further, ensuring that it is presented in the most acceptable and useful way to provide support for people with unmet parenthood goals, including those who are childless by circumstance.

Thank you again for your time. We would like to assure you that all the data you have just provided to us will be held anonymously so it will be not be able to be traced back to you. The data collected and

the results of the study will be used for scientific purposes and will be made publicly accessible (e.g., research publications).

**Additional information and support**
It was important to ask you a range of questions, some of which were personal and may have been upsetting, if you would like more information or support about childlessness please see the following (Cardiff university is not responsible for the content of these external sites):
More To Life Website - https://fertilitynetworkuk.org/life-without-children/

 Email - catherine@fertilitynetworkuk.org

 Tel – 0121 323 5025

If participation in this survey has caused any concerns, please contact your GP in the usual way or NHS mental health online.

If you would like to get in touch with the researcher and supervisor of this study, please use the contact details below.

**Bethan Rowbottom**                              **Dr Sofia Gameiro**

PhD Student                                        Senior Lecturer

School of Psychology                               School of Psychology

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Details of further contact:

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CF10 3AT

Tel: +44 (0)29 2087 0360
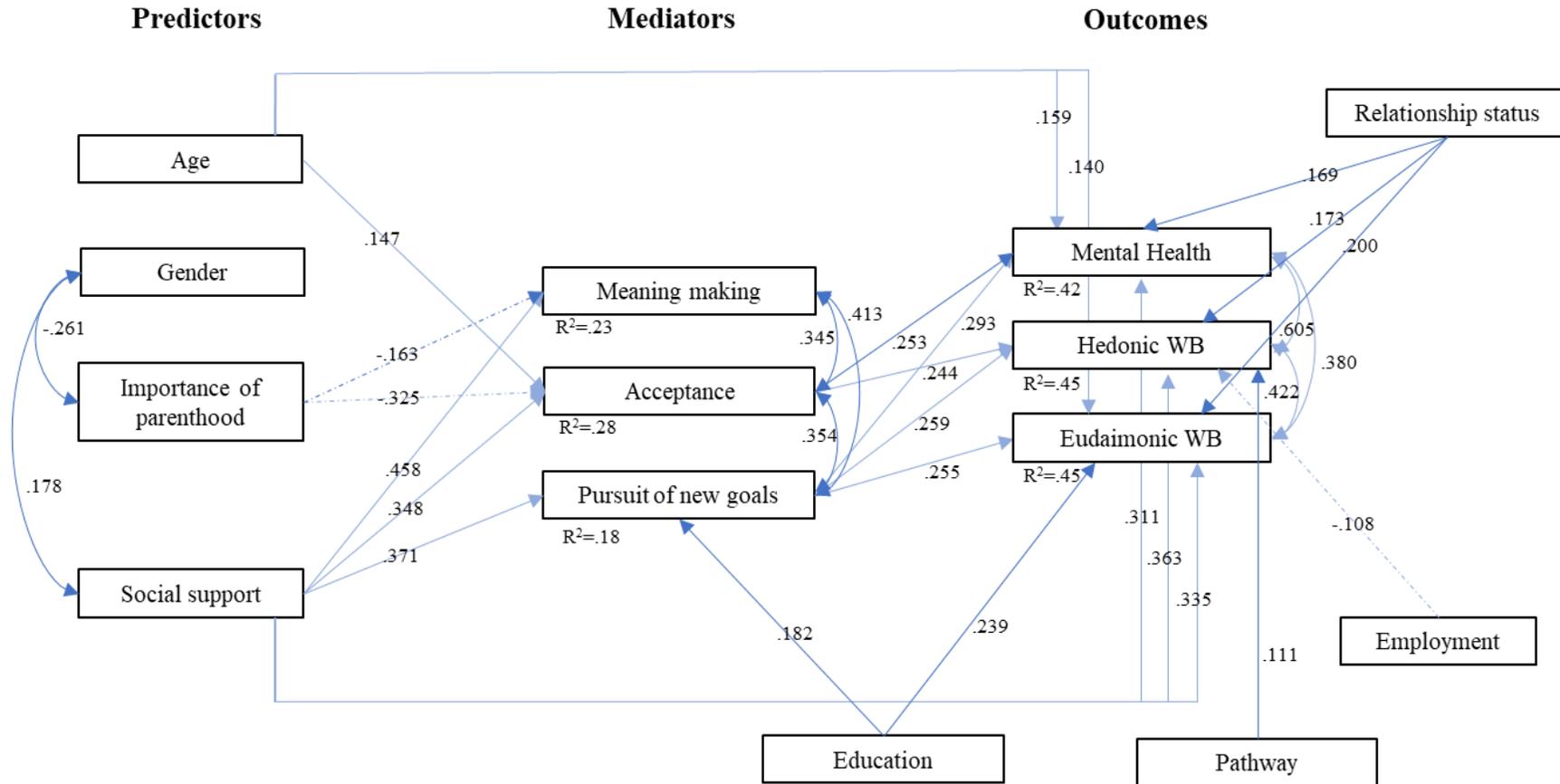
Email: psychethics@cardiff.ac.uk

## Appendix G: Childless by circumstance adjustment and support needs – Path model testing figures of Model 1 and 2
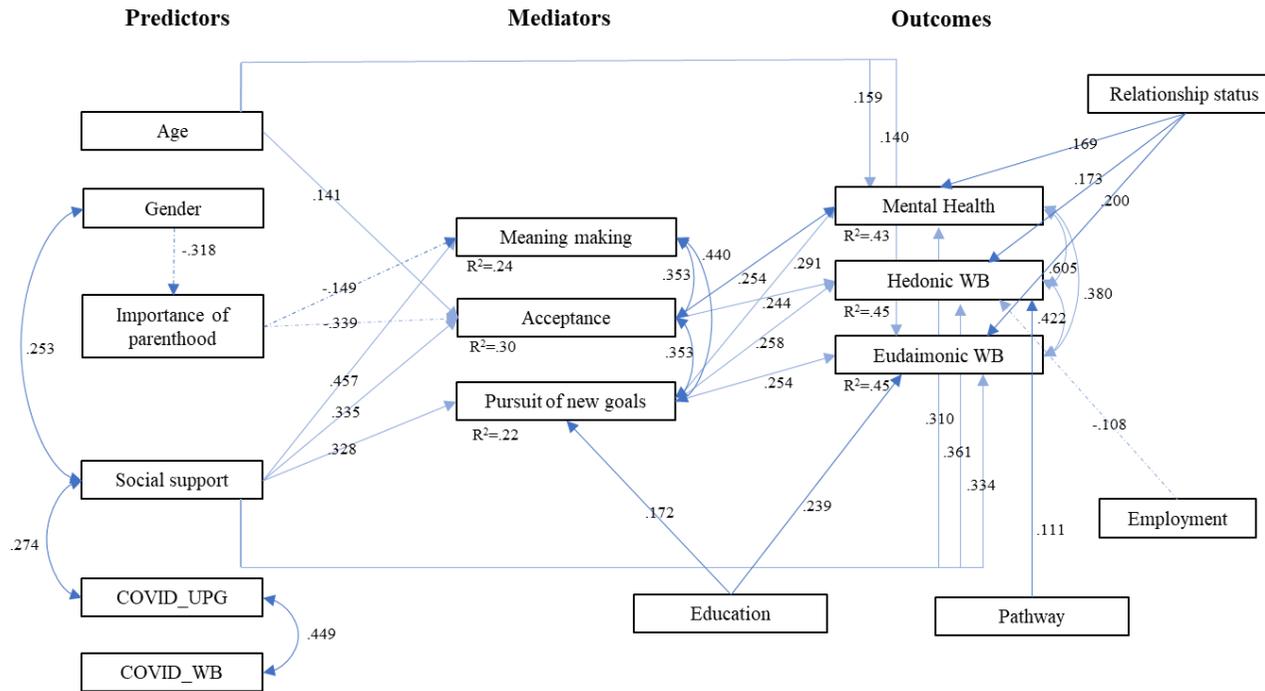
*Path Model Testing the Three Task Model of Adjustment (3TM) to unmet parenthood goals (Model 1)*
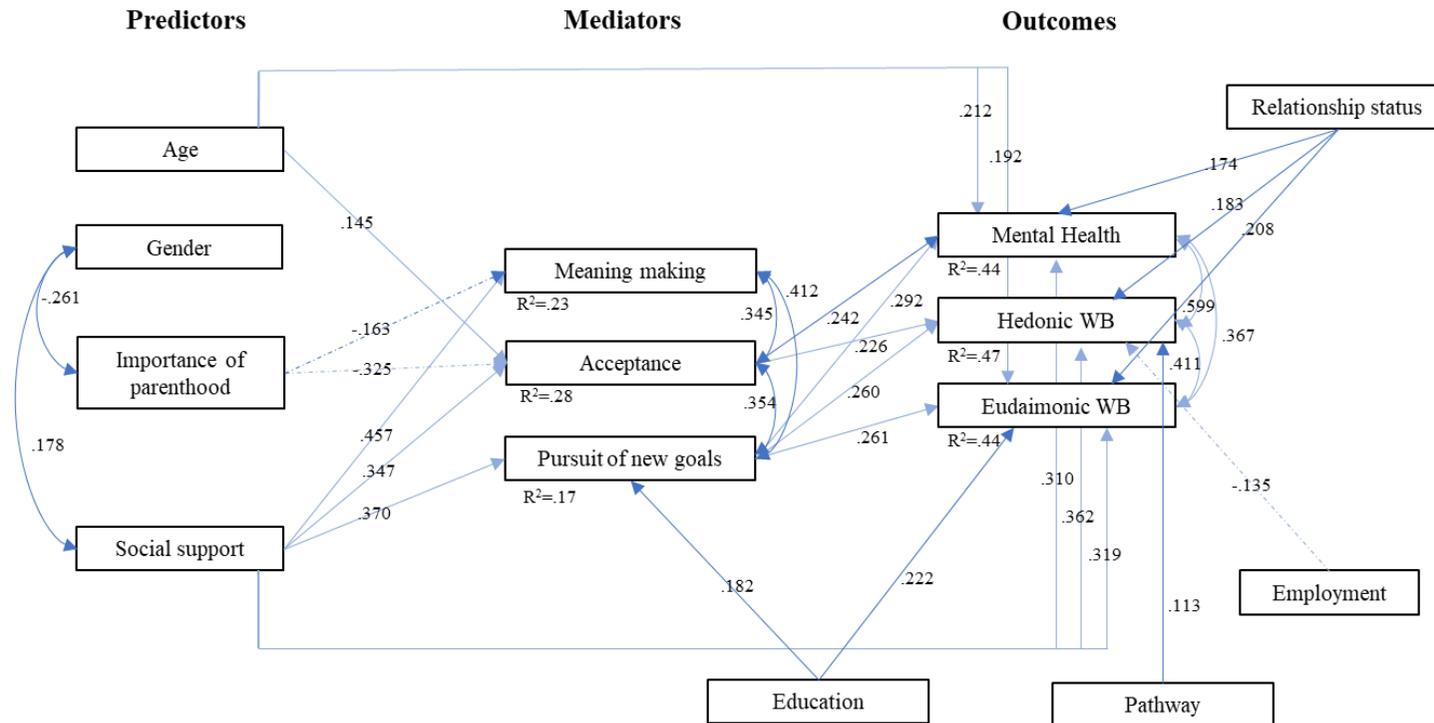


Note. Model controlled for relationship status, employment, education, and pathway to childlessness (fertility problems and/or treatment or not). Model fit was $\chi^2(48) =$ 87.808, $p < .001$, CFI = 0.930, RMSEA = .075 90%CI [.049, .099]. Continuous and dashed unidirectional arrows represent positive and negative regression weights, respectively. Continuous bidirectional arrows represent positive correlations. Only statistically significant paths shown in figure. WB = Wellbeing

*Path Model Testing the Three Task Model of Adjustment (3TM) to unmet parenthood goals (Model 2)*



Note. Model controlled for relationship status, employment, education, and pathway to childlessness (fertility problems and/or treatment or not). Model fit was $\chi^2(50) = 92.405$, $p < .001$, CFI = 0. 926, RMSEA = .076 90%CI [.051, .100]. Continuous and dashed unidirectional arrows represent positive and negative regression weights, respectively. Continuous bidirectional arrows represent positive correlations. Only statistically significant paths shown in figure. WB = Wellbeing

## Appendix H: Childless by circumstance adjustment and support needs – Path analysis figures of sensitivity analysis for COVID variable

*Path Model Testing the Three Task Model of Adjustment (3TM) to unmet parenthood goals (COVID variables as predictors)*



Note. Controlling for relationship status, employment, education, and pathway to childlessness (fertility problems and/or treatment or not)). Model fit was $X^2(73) = 107.50$, p = .005, CFI = 0.943, RMSEA = .057 90%CI [.031, .078]. Continuous and dashed unidirectional arrows represent positive and negative regression weights, respectively. Continuous bidirectional arrows represent positive correlations. WB = Wellbeing. COVID_UPG = xxx; COVID_UPG = XXX.

*Path Model Testing the Three Task Model of Adjustment (3TM) to unmet parenthood goals (COVID variables as covariates)*
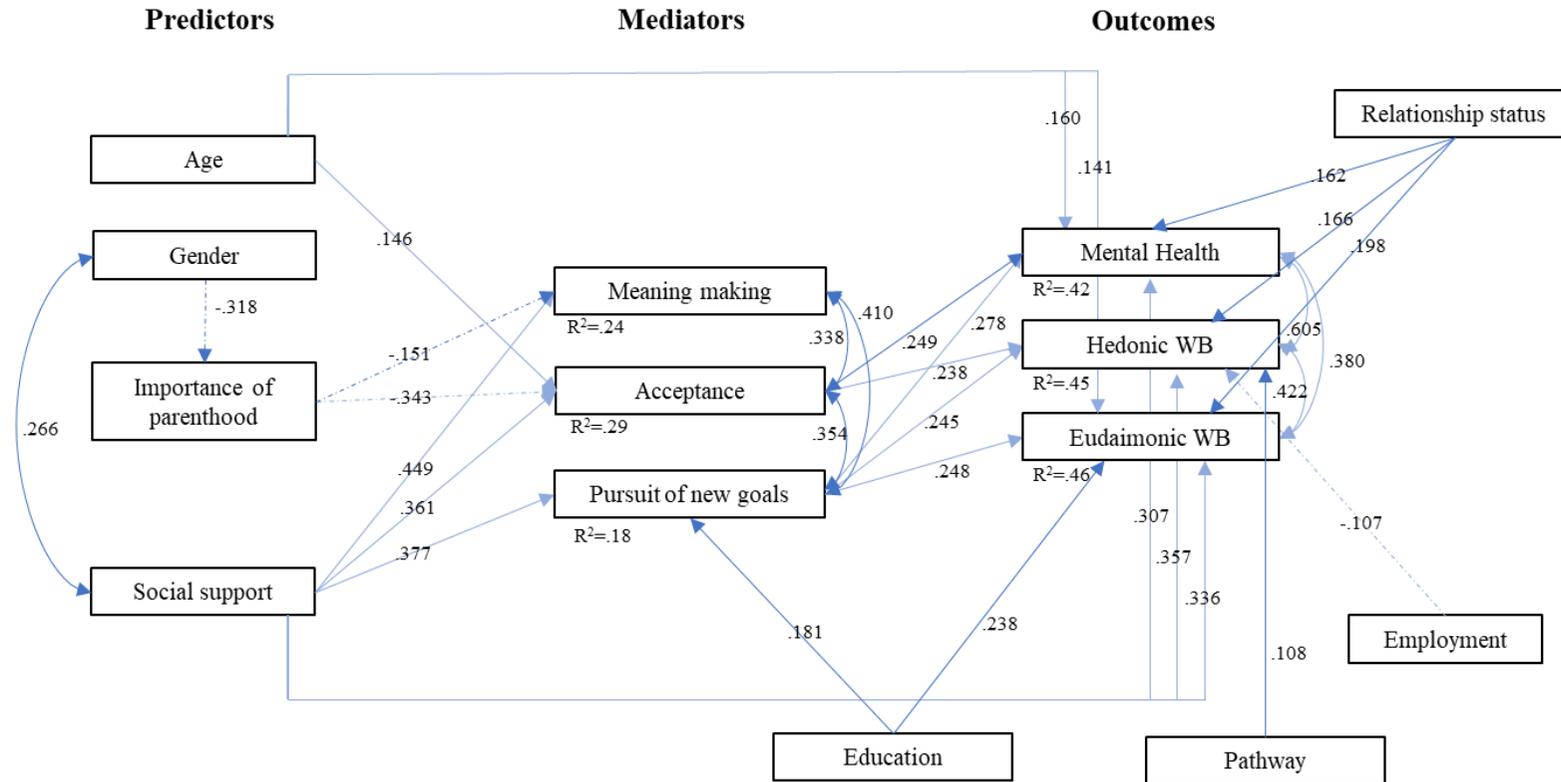


Note. Controlling for relationship status, employment, education, and pathway to childlessness (fertility problems and/or treatment or not)). Model fit was $X^2(75) = 126.98$, p < .001, CFI = 0.914, RMSEA = .068 90%CI [.047, .089]. Continuous and dashed unidirectional arrows represent positive and negative regression weights, respectively. Continuous bidirectional arrows represent positive correlations. WB = Wellbeing

## Appendix I: Development of the intervention – GUIDED checklist

GUIDED checklist (Duncan et al., 2020)

| | Items | Page where located |
|---|---|---|
| 1 | Report the context for which the intervention was developed. | 85-86 |
| 2 | Report the purpose of the intervention development process. | 86-89 |
| 3 | Report the target population for the intervention development process. | 125 |
| 4 | Report how any published intervention development approach contributed to the development process. | 87-88 |
| 5 | Report how evidence from different sources informed the intervention development process. | 86, 88 |
| 6 | Report how/if existing published theory informed the intervention development process. | 93-94 and 100-102 |
| 7 | Report any use of components from an existing intervention in the current intervention development process. | N/A |
| 8 | Report any guiding principles, people or factors that were prioritised when making decisions during the intervention development process. | 96-97 and 111-112 |
| 9 | Report how stakeholders contributed to the intervention development process. | 94-96 and 109-111 |
| 10 | Report how the intervention changed in content and format from the start of the intervention development process. | 97-98 and 113 |
| 11 | Report any changes to interventions required or likely to be required for subgroups. | N/A |
| 12 | Report important uncertainties at the end of the intervention development process. | 120, 122, 123 |
| 13 | Follow TIDieR guidance when describing the developed intervention. | 114-116 |
| 14 | Report the intervention development process in an open access format. | N/A |

**Appendix J: Development of the intervention – PowerPoint presentation for consultation exercise**

Conceptual overview
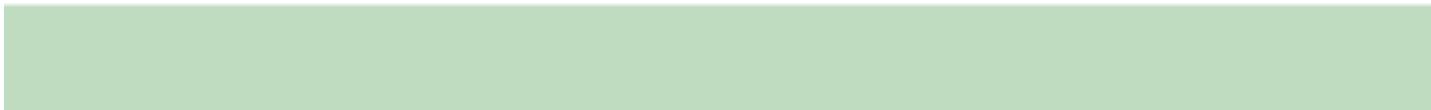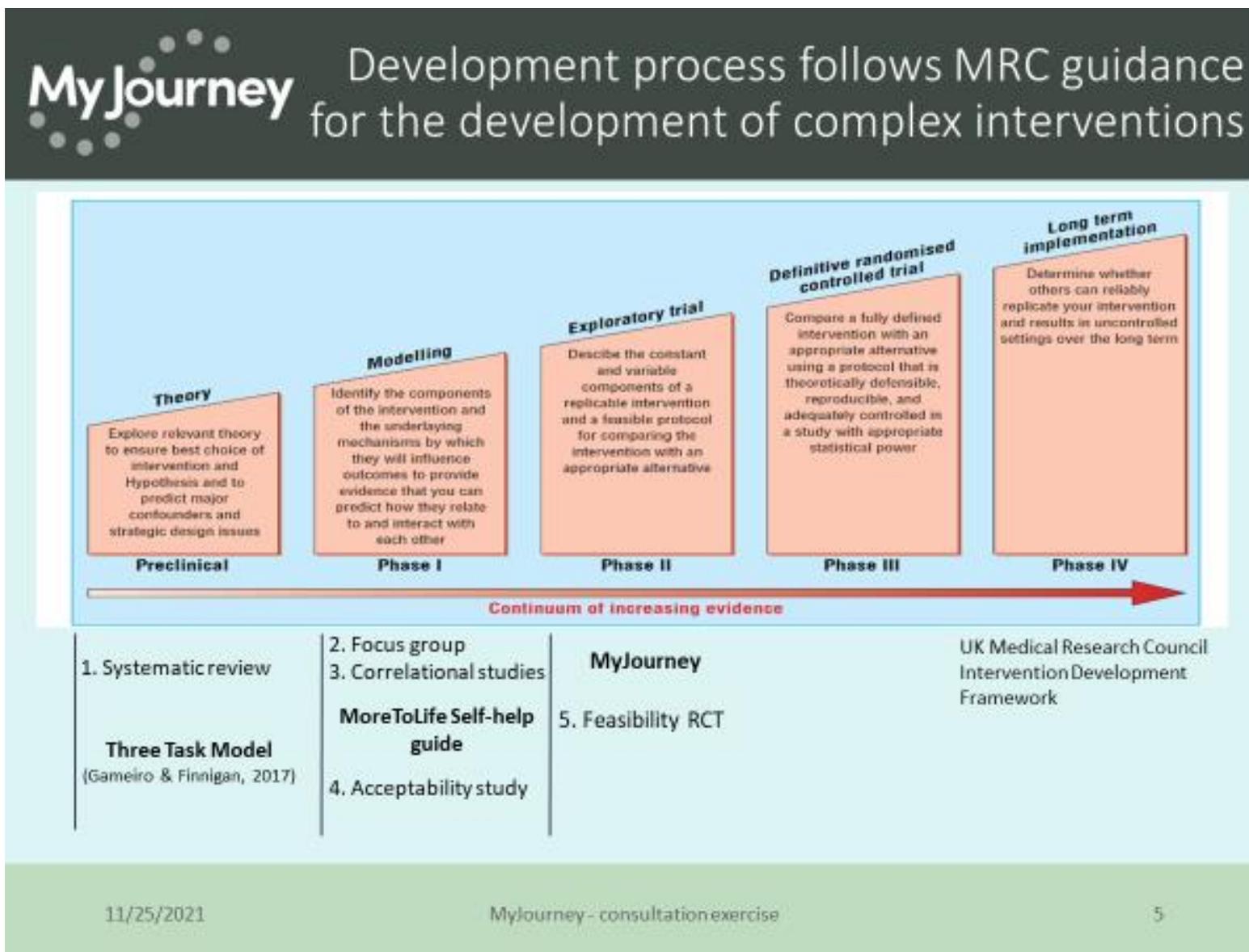
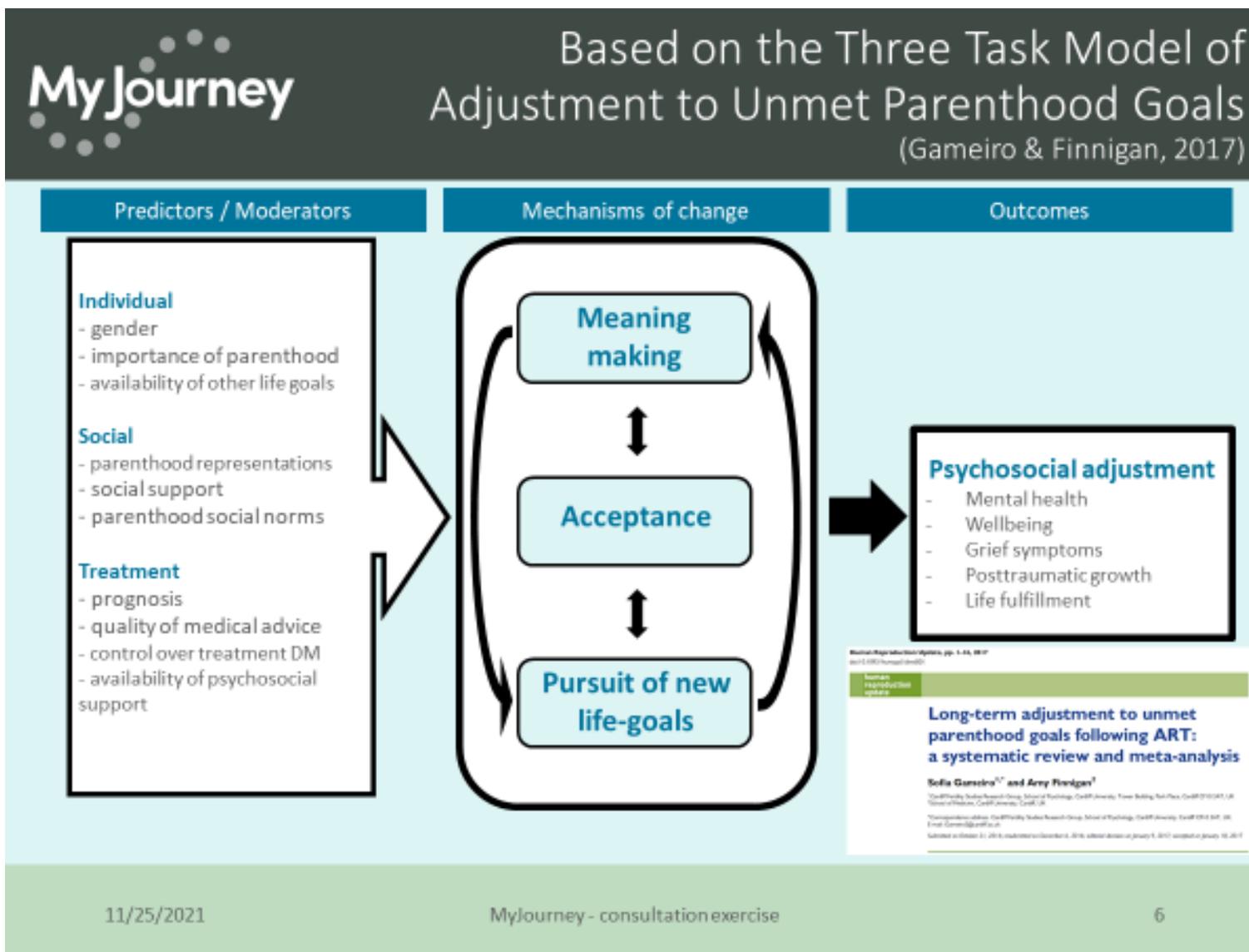**MyJourney**                          We will ask your opinion about

- Do you think MyJourney meets the needs of individuals who have not had the children they desired?

- What do you think about the proposed weekly engagement with Steps, and therefore ten-week duration of MyJourney?

- Are there any features that you think are missing?

- What you think about the option to have reminders, for example to
    - Receive self-compassionate statements
    - Monitor goal progression / value-based daily actions

- What do you think may be good strategies to disseminate MyJourney?

11/25/2021                     MyJourney - consultation exercise                     3

**MyJourney**

# MyJourney

## Guided tour

**Navigation Alert!** MyJourney is still being developed. Some content, features and design are not fully functional.

## MyJourney takes you through ten steps

These **Steps** are laid out in your **Map** and you should follow them in order. You can only take a step after you have finished the one before. We suggest you travel one step per week, but only you know your pace. Take the time you need!

### You are here

The first and last steps help you develop awareness of where you are in your journey. The other steps focus on building a different skill to help you navigate your journey of acceptance.

### Time to reflect

At each step you may be asked to reflect and write about your experience, to do mindfulness meditations, or to build new therapeutic skills either alone or with a loved one.

### At your own pace

You don't have to complete a step in one go. You can stop whenever you like and start again where you left off.

### Build new routines

At the end of each step you will be offered new suggestions to help practice the skill you are building. You can access these **Routines** at any time in your **Backpack**.

### New tools to take with you

When you have completed all ten steps, the **Crisis Tool** will help you remember the skills you need to deal with challenging problems or situations.

The Steps' content will flow on the slides the following ways
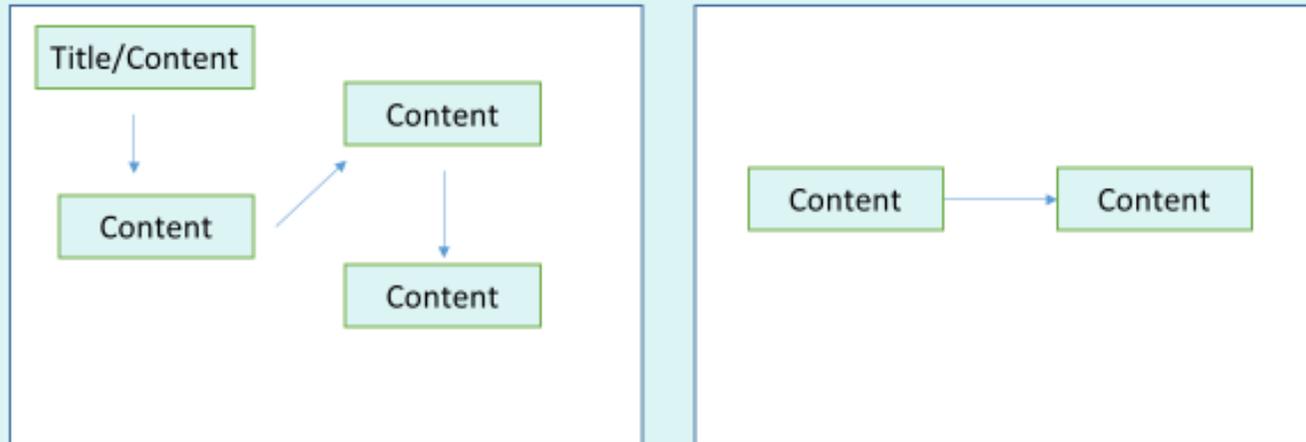
**Please note:** sometimes we had to split the content visible for the user in one screen across slides but we tried to keep the look and feel as close as possible to the real experience of using MyJourney.

# Step 1

**Your starting point**

Before you start taking steps in your journey, build awareness of how you feel now, at your departure point.

Most people going through your journey share a similar experience to yours. By developing awareness of your feelings now and at the end of your journey, you will be able to see how your feelings and life perspective can change.

## How do you feel now?

Please indicate for each of the five statements which is closest to how you have been feeling over the past 2 weeks.

...I have felt cheerful and in good spirits

...I have felt calm and relaxed

...I have felt active and vigorous

...I woke up feeling fresh and rested

...my daily life has been filled with things that interest me

## How do you see your life now?

All things considered, how satisfied are you with your life as a whole these days?

neutral

All things considered, how happy do you feel these days?

neutral

**Stop and be present**

Increasing your awareness through basic meditation will be a key part of your journey. You will start with a three-minute meditation to increase awareness of your breath, body, and mind. Sometimes meditation can be relaxing. Sometimes it can be difficult as it makes us more aware of what you are experiencing. If that happens, stay with it. Over time, your ability to stay with difficult experiences will increase, which is an essential part of your journey.

▶ 0:00 / 0:00

## How do most people in your situation feel?

Many others have travelled the journey you are now starting. Finding out about their experiences will give you an idea of what to expect along the way.

Most people in your situation...experience intense feelings of grief, pain, sadness, and loss. For some these feelings come paired with self-blame, regret, and criticism. Women usually find comfort in talking about their pain with a few carefully chosen friends but men can be more private in their suffering. **Although for many the sadness never completely goes away, with time most say it eases and becomes more bearable.**

    " This grief journey can be long because you may not
      understand you're grieving and people don't understand you
      are grieving what you thought your life was going to be like.

    " There is still this kind of longing, it's not as painful but it is
      still kind of there...

What emotions do you experience now? Write at least two emotions you usually feel when you think about your situation

I feel extremely sad and with no hope in the future
I feel angry at the health staff who advised me and guilty for not start trying earlier

How do these emotions feel in your body? If perhaps you feel angry, where do you feel this in your body? If you feel sad, where do you feel this in your body?

I feel a weight or pressure in my chest and a knot in my throat
When I am really angry I feel lightheaded and unable to get hold of my thoughts

In your journey, you will explore how to deal with difficult emotions and bodily sensations.

Most people in your situation...struggle to understand how and why they are in this situation. They ask themselves, would things have been different if I hadn't worked so hard? If I hadn't postponed my wish? Or paid more attention to my lifestyle? Or tried one more treatment? Many find it hard to look into the future and think about who they can become without their desired children. What kind of person, what kind of man or woman can they be now?

> " Where am I? Where am I going? Where am I supposed to be? What is my purpose? That is my biggest question. What am I doing? Why have I been put on earth?

> " Being a whole person, being a good person, having a meaningful life does not mean being a parent. You know, there's lots of ways that you can have a perfectly valid existence.

What story are your thoughts telling you now? Write at least two thoughts that usually come into your mind about your situation.

I fear my relationship will fall apart. We have been on hold for so long, how will it be now? What will unite us?
Why is this happening to me anyway? I have always been so careful about my health...

In your journey, you will reflect on the things you value in life and how these can help shape your future.

<!-- navigation bar -->

---

Most people in your situation...**find it hard to share their loss with others.** It may be difficult to talk with family members because they might also have been hoping for children. Some people struggle to cope with comments, questions, or other social contacts around children. Some end up avoiding these altogether. Others feel they must show they tried hard to have children to avoid being criticised. Most people feel they are constantly being faced with everyone's belief that everyone can have children.

> " It is difficult to talk to people, especially in your family, when no one else has experienced anything like this...

> " Being childless sent me down a whole path of social isolation and exclusion. I started excluding myself from things. I didn't want to go to weddings or christenings or get togethers or anything like that...

What are your contacts like with others now? Write down at least two words or short sentences that describe them.

It is hard to be with people anyway, with covid, in a way that has been a relief as I don't have to come up with excuses... I have grown apart from many friends who have children... it's not only that it is hard but their life styles changed so much...

In your journey, you will reflect on what can ease your contacts with others.

Most people in your situation...feel the need to 'move on' to escape pain, grief, and self-pity, but do not know how. Often they they just explore new jobs, activities, hobbies. It starts by being a way to avoid pain. With time, many people end up finding things that give them pleasure or a sense of purpose. **Most people agree that exploring new things helps them figure out who they can be without the children they wished for.**

> "...we've created this new life, we do a lot more travel... it's just the life we ended up with because of choosing to go down different routes and have sort of different adventures...

> " I have taken up new kinds of hobbies and interests and have met other people.

Have you tried to move on? If so, write what you have tried, even if it didn't work out.

> I feel my free time with entertainment, I used to go to the cinema and gigs a lot, but now that is not possible... Netflix has been my distraction... But this is just about being distracted... I feel my life is sort of empty, I don't know what to do, all I wanted was children, how do you replace that?

In your journey, you will find a way to nurture the things you care deeply about into new fulfilling life goals.

---

Most people in your situation...**find a way to let go of their wish for children and rebuild a happy and fulfilling life.** Everyone's journey is different. For some this journey takes around 2 years but others need more time. Letting go of grief is an important step towards recovery. It does not mean they don't care for children. It means they learned to live without them. With time people feel stronger, wiser, and better at appreciating the good things in life. They know they can still feel sad at times but that's OK and with time these feelings become less frequent and intense.

> " I found meaning in why I am childless and I truly believe that I am supposed to be advocating and speaking up for other people who are childless not by choice

> " I like who I am afterwards... I quite like my strength, my personal strength...

Your journey has already started. Only you can choose the direction for your life.

---

Stop and be present

It is OK if you found being in contact and writing about your experience difficult. We encourage you to repeat this mindfulness exercise as it can help ease what you are feeling now.

Remember: you can use this meditation during your day to get in touch with your experiences and to take a break and breathe.

> 0:00 / 0:00

---

Please answer the questions below to tell us what you think of this step.

**How useful was this step?**

Very much

**How challenging was this step?**

A moderate amount

**How are you feeling now?**

happy   inspired   calm   anxious   upset   sad

Submit
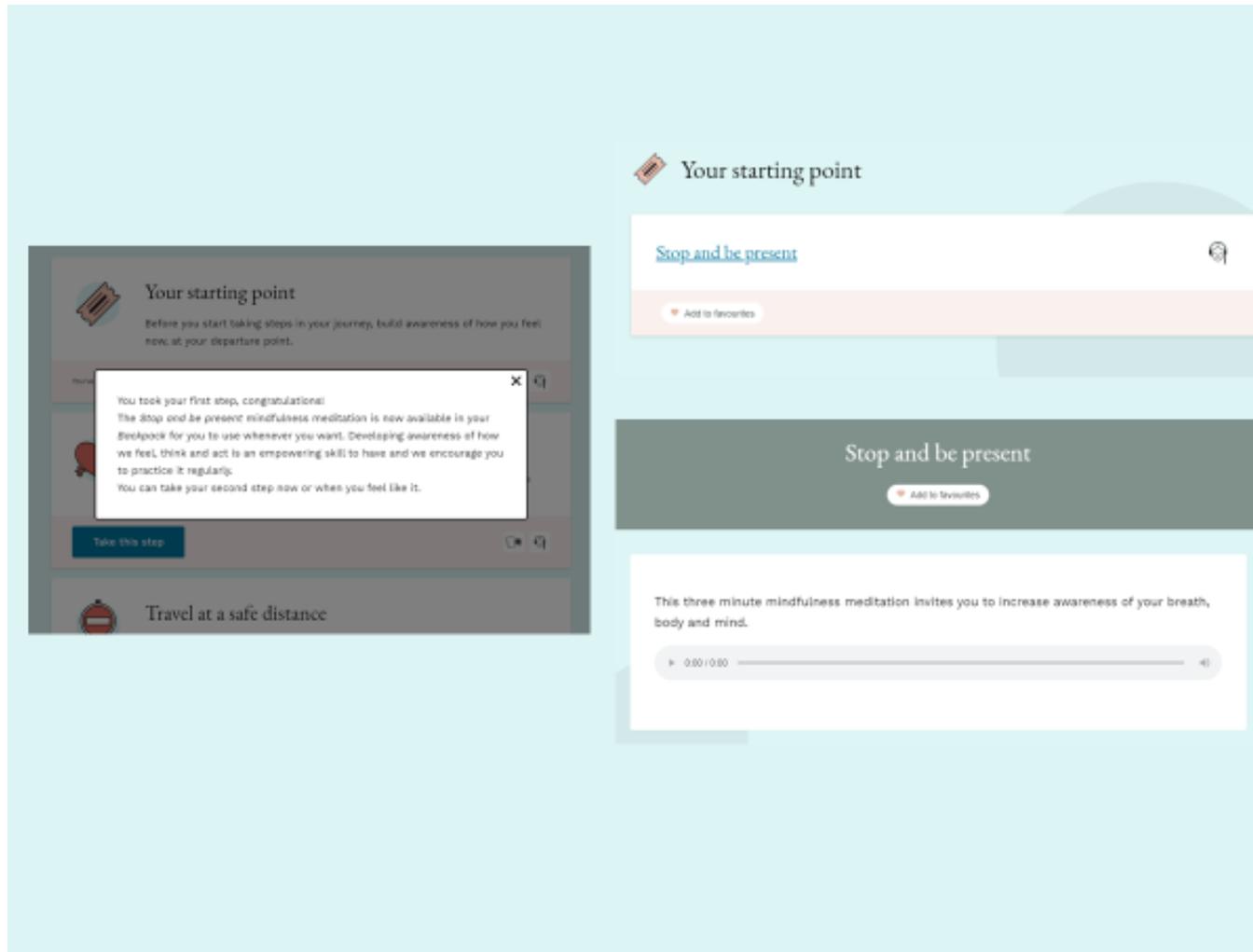
## Step 2

### Be kind to yourself

To make your journey easier, practice how you can be kind to yourself while travelling.

We all like to comfort the people we love when they are going through a hard time. But we often see being self-compassionate as self-indulgent or selfish. We may think that being critical or harsh with ourselves will keep us going through difficult situations. **Being self-compassionate means giving ourselves the same kindness and care we'd give to a good friend.** It often results in better acceptance of who we are and our experiences.

Your journey can trigger sadness, sorrow, and other difficult emotions. Often, we react to this by being self-critical. The result is that whenever we think about children we also feel other negative emotions like shame or guilt. By being self-compassionate, you let yourself feel the sadness of not having your desired children without judging yourself. This makes it easier to accept that sadness and put your energy into other valued things in your life.

> " I think you've really got to work on your self-love, you really have to be kind to yourself.

→

### Soothing Breathing Rhythm

It can feel unfamiliar to be self-compassionate so it is useful to practice it. This mindfulness meditation invites you to slow down your body and mind for a few moments, as if you were comforting yourself with a gesture of kindness.

▶ 0:00 / 0:00 ◀)

← →

Self-compassion involves treating yourself the way you would treat a dear friend who is struggling and facing a tough time. This may seem difficult but following the steps outlined below will give a better glimpse of what we are talking about.

**How self-compassionate are you normally?**

Try to think back to a time when a close friend felt really bad about themselves. What were they struggling with? How did you try to comfort your friend? Now think about what you typically do and say when you are trying to comfort people around you. How do you address them, what words and tone of voice do you use? Write your behaviours, words, tone of voice here:

Now think about when you feel bad about yourself. For instance, allow yourself to notice the painful thoughts or feelings you wrote down about your wish for children.

I feel extremely sad with no hope for the future.

. What other painful thoughts and feelings are you experiencing now? Write these here:

How do you usually react when you experience these? How do you treat yourself? Please think about what you usually do, what you say and the tone you use to talk to yourself. Write your behaviours, words, tone of voice here:

Is there a difference? If yes, why do you think that is? What may trigger you to treat yourself differently from how you treat others? Write your thoughts about this:

Now try to comfort yourself in the same way you usually comfort loved ones when they are suffering. Write the things you can tell yourself to ease the painful thoughts and feelings you wrote about your wish for children. Write as much or as little as you want:

How self-compassionate were you in this exercise?

Self-compassion is a skill you need to practice. Use this or the routines you will unlock to practice it!

←                                                                    →

You took your first step, congratulations!
The *Stop and be present* mindfulness meditation is now available in your *Backpack* for you to use whenever you want. Developing awareness of how we feel, think and act is an empowering skill to have and we encourage you to practice it regularly.
You can take your second step now or when you feel like it.

## Be kind to yourself

**Self-Compassionate Postcard**

♥ Add to favourites

**Loving Kindess Meditation**

♥ Add to favourites

### Self-Compassionate Postcard

♥ Add to favourites

Write a postcard to a friend, imagining they are having the same experience that you are, with the same emotions and thoughts. What would you say to a dear friend of yours about their desire for children? How would you ease and validate their suffering? Consider your facial expression, your tone of voice, the feelings that emerge from your caring self. After writing the postcard, you can put it down for a while and read it later, letting the words soothe and comfort you when you need it most. It can take a while to feel at ease writing to yourself in the voice of a good friend, but it definitely gets easier with practice. You can write as many self-compassionate postcards as you want. You can read them when you find you are being too self-critical.

### Loving Kindess Meditation

♥ Add to favourites

This brief mediation practice invites you to cultivate loving kindness towards yourself and others.

▶ 0:00 / 0:00                                                      🔊

# Step 3

**Travel at a safe distance**

Find out how to distance yourself from unhelpful thoughts you may encounter as you move forward on your journey.

We live in our thoughts like fish in water: because we have them all the time we don't even notice we are thinking. The problem is when we have negative thoughts about ourselves. Because we don't notice we are thinking, we believe we are as bad as we think we are. It is hard to challenge these thoughts because we would be challenging ourselves. However, we can create distance between ourselves and our thoughts by looking **at them** rather than **from within** them. **We just have to keep reminding ourselves that thoughts are just thoughts. They are not reality nor the truth.**

Your journey has probably been filled with painful self-doubt and critical thoughts. It is no surprise if you have stopped doing things or being in situations you know trigger such thoughts. But you may also have noticed they never really go away. In fact, they may have grown stronger with time. Our mind is a storyteller and we cannot control the stories it tells us. However, you can choose to watch your mind at work from a safe distance.

> " I think until you change your perspective you are going to focus on everything that makes you sad about not having kids.

When you are too close to your thoughts, you cannot see them clearly for what they are. Following the next steps will give a better idea of how to create distance between you and your thoughts.

Allow yourself to notice the painful thoughts you wrote about your wish for children. [THOUGHTS FROM step 1] Are you having other thoughts right now? Write them here?

Now bring your device and thoughts on the screen as close to your face as you can. Notice how it interferes with your ability to see both your thoughts and what is going on around you. Imagine going around all day like this. How difficult it would be to understand what is happening and to respond fully. This is **fusion**

Now slowly move your device away from your face until it is possible to read the thoughts you wrote down. Notice how it is easier to see them with some distance. Notice what happens as the space between you and your device increases; how you become aware of what is happening around you and how much easier it is to engage with it. This is **defusion**.

Pick just one of our thoughts shown above. To try to maintain this distance from this thought and get a different perspective it may be useful to keep asking yourself these questions:

- Is this thought made of words or images? What are these words or images saying?
- Label the thought: is it *descriptive* or *judgemental*? *Descriptive* thoughts focus on the concrete aspects of an experience, the things we can perceive with our senses i.e. see it, hear it, taste it, smell it, touch it. *Judgemental* thoughts make judgemnets or reach conclusions about that experience and are subjective. This means that different people can reach different conclusions. Depending on the circumstances, even the same person can reach different conclusions about the same situation.
- Am I stuck with this thought? Have I heard it lots of times? How old is this story? Is what my mind is saying helpful?
- Can I immediately notice when I am having this same repetitive, sticky thought? Maybe I can label it with a short sentence? For instance "There's my 'I am incompetent thought'".

Thoughts are just the result of your mind doing its job. By asking yourself these questions about each painful or unhelpful though you have, you will be more aware of your mind at work.

Sometimes just pausing and thanking your mind for the thought ("Thank you mind!") can help you move on with whatever you are doing, without getting tied up in unhelpful thoughts.

You finished the third of the ten steps of MyJourney. Congratulations! You have unlocked three new Routines in your Backpack. These will help you manage the difficult or unpleasant thoughts you have about your desire for children. Remember that these will probably never completely disappear, but you don't have to get stuck to them.

We recommend you practice your defusion skills for a week before you take another step.

These are the ten steps you will take on your journey with us.

Travel at a safe distance

I am having the thought that

Add to favourites

The weight in your backpack

Add to favourites

Watching Thoughts

Add to favourites

## Watching Thoughts

Add to favourites

This brief meditation invites you to watch your thoughts as they come and go, without judgement.

► 0:00 / 0:00

## I am having the thought that

Add to favourites

An easy way to defuse ourselves from our thoughts as we go about our daily lives is to add this phrase before each thought:

'I am having the thought that...'

For instance, if you suddenly think something like 'I will never be happy without children', try to replace this by 'I am having the thought that I will never be happy without children'.

Doing this will not get rid of negative thoughts, but can help you to realise that thoughts:

- are merely sounds, words, stories, bits of language, images passing through your head;
- are not always true: you do not have to believe them automatically;
- are not orders and may not be wise: you don't have to obey them nor follow them.

## The weight in your backpack

Add to favourites

Let's say you carry a backpack with you every step of your journey. Inside the backpack, write a single upsetting thought, feeling, memory or bodily sensation you've been struggling with. Look at it: does it trigger other difficult or painful thoughts, emotions or other experiences? If so, write them inside the backpack because they are also weight you are carrying. Keep doing this until you feel you have written everything you carry: there are no weight restrictions in this journey! The act of filling your backpack encourages willingness or acceptance. You are telling yourself: "I can and will carry the weight of this backpack. I can travel with this weight on my shoulders."

Each day this week take a look at your backpack and the things it contains. Try to recognise that it is okay to have all these thoughts, feelings, memories, bodily sensations (or whatever you are carrying) and still do what you want to do with your life. Ask yourself whether the weight is preventing you from living a meaningful, vital life, or whether you can carry it compassionately and willingly.

# Step 4

We invite you to think about your values: the things you care deeply about and form the basis for many of the choices you make. Your values are unique to you and cannot be right or wrong.They represent your ideal life if nothing stood in your way.

**Set your direction of travel**

Set the direction you want to travel by reflecting about the things you value the most.

Try to define your **value statements** for different domains of your life. You can skip any domains that aren't that important to you. After you fill in your values, try to rank them according to how important they are to you.

This could be the first time you have thought of values in this way and can feel like a huge task. Don't feel you should rush this. Remember to be kind to yourself if you can't complete it in one go. In fact, we recommend you do this step over a few days. We included some questions for each life domain to help you.

Life Area: [ Health / Physical Wellbeing ∨ ]

What are the things you really value in life? What matters most to you?
Our values bring meaning into our lives and help shape who we are. They are not things we achieve or possess. They are like a compass keeping us on track towards our north: the person we want to be or what we think a meaningful existence is.
There is no single path leading us towards our values. Sometimes we embark on a path just to find a deadend: this can be something we couldn't achieve or that we realised was not that fulfilling. When this happens, we can change our path, as long as we keep travelling in our chosen direction.

You may always have thought of having children as one of the most important goals in your life. But you may be less aware of why it is so important to you. What are the values that drive your desire for children? Can you still tune in with your values even if you cannot have the children you desire?
Reflecting about the thing you really value can help you consider how you can live a fulfilling and meaningful life.

*How do you want to look after your health? Sleep, diet, exercise, smoking, alcohol, etc. Why is this important?*
*How do you relax and unwind?By cooking, going for walks, doing yoga, etc.*
*What energises you?Running, group sports, watching a good movie, gardening, etc.*

[ Submit ]

Now, try to rank your values depending on how important they are to you.

> " I think a lot of people do question their spirituality when they're going through it, they do go back to that question of what's my meaning?

**1**  ✎ 🗑
Making sure I am taking care of myself, my mind and my body.

**2**  ✎ 🗑
Long-lasting, open and honest relationships

**3**  ✎ 🗑
Help my local community to be as sustainable as possible.

You finished the fourth of the ten steps of MyJourney. Well done!
You have unlocked three new Routines in your *Backpack*. These routines
give you tips to help you clarify your values.
It is important that you feel comfortable with the value statements you
defined for yourself before you continue on your journey, as it is impossible
to travel without knowing where you are heading.

These are the ten steps you will take on your journey with us.

⊘  Set your direction of travel

**Talk values**                                                                  🔖

♥ Add to favourites

**Think values**                                                                 🔖

♥ Add to favourites

**Act values**                                                                   ☰

♥ Add to favourites

### Talk values

♥ Add to favourites

It might be helpful to talk through this step with someone you are close to. Perhaps you
could even ask them to try to complete the table of value statements for themselves. You
can discuss how to support each other in living by your values. Seeing another person's value
statements may also help you come up with your own, if you are stuck.

### Think values

♥ Add to favourites

Before you move to the next step take some time to revisit your value statements and the
importance you attributed to them. Do you still feel the same way? Is there something
missing? Clarifying your values is a process that takes time. Along your journey it may be
helpful to revisit your value statements often until you feel you have them just right.

### Act values

♥ Add to favourites

Each day, pick one of the value statements from your table:

- On a scale from 1 (not at all) to 10 (completely), how consistent with that value were your
  actions today?
- What's the smallest simplest easiest action you could take, in the next 24 hours, that's
  consistent with that value? Can you try doing it?

# Step 5

## Illuminate your journey

Bring light into your journey by paying as much attention to the positive things in your experiences as you pay to the negatives

Our journey through life is not straightforward. Being human and experiencing love and happiness means we also experience difficult emotions. We all focus on the negative things in life and the difficult emotions they trigger. This is the nature of the human mind and it has kept us alive as a species for millions of years! However, negative experiences can (sometimes) have positive results, for instance: we grow as a person, we learn something new, we realise our strengths, or we get others' understanding and support.

Trying to see the positives in a difficult situation or experience is called **positive reappraisal.** Positive reappraisal makes negative thoughts and emotions more tolerable.

Not having the children you desired can lead to such sadness and pain that it's hard to think of any positives. This can take some time so don't be discouraged if you can't think of any immediately. However, most people do find positives that help them move forward in their journey. Here are a few examples:

" One of the biggest things I have come to understand is to appreciate myself, I am more comfortable with who I am now, and I think that a huge thing in healing is accepting who you are.

" My journey freed me from a lot of old beliefs, like one needs children to be a family.

" I was at the beach and incredibly sad but I could still feel the warmth of the sun on my skin. It struck me that, no matter how sad I may be feeling, I will always be able to feel good things too.

" The end of my fertility treatment meant someone else could have a go.

Many people in your situation feel like they are in a dark tunnel. When they think about their future they don't see light at the end of the tunnel. But what if you don't have to walk through the tunnel to find the light: what if you create light as you walk?

Look at the sentences below and think about what were, are, or can be your **points of light. What were, are or can be the positives of being in your situation?**

Choose only the questions that apply to your journey. It's OK if you can't think of anything straight away. This is a skill that takes practice, so don't be discouraged if you can't think of any straight away. If you are feeling stuck, you could talk to someone who knows you well. They might have noticed something positive that you haven't yet.

How do you feel every time you write a new **point of light**? Let yourself experience these emotions and the new thoughts, emotions and bodily sensations that may come with them

In the PAST, while I was trying to have the children I wished for...

I grew as a person

I became stronger

I learned something new

I experienced something positive

→

In the PRESENT, while trying to accept I won't have the children I wished for...

I can grow as a person

I can become stronger

I can learn something new

I can experience something positive

When I look into the FUTURE, I can anticipate some positives while I continue to explore how to live a valued and meaningful life without the children I wished for...

I will grow as a person

I will become stronger

I will learn something new

I will experience something positive

You finished another step and are now halfway through MyJourney. You should celebrate!

You have unlocked two new Routines in your *Backpack*. These suggest new ways of finding positives in the difficult situations you may come across as you go through your daily life.

Being able to find the positives in a difficult situation will make these more tolerable and therefore should ease your journey. Once you feel this is a skill you have mastered you are ready to take your next step.

## Good daily vibes

♥ Add to favourites

We encounter difficult situations on a daily basis. As the day finishes and you are ready to go to sleep think about one difficult situation or moment of your day. Then focus on the positive results it might have had:

- Did you grow as a person?
- Did you become stronger?
- Did you learn something new?
- Did you experience something positive?

This can be very helpful when you are having a particularly difficult day or week. It can also help when you face situations that trigger negative emotions about children or any other aspects of your life.

## Feeling the positives

♥ Add to favourites

This brief meditation guides you to consider any benefits you may have gained from a challenging situation.

▶ 0:00 / 0:00

# Step 6

## Plan your route

Move forward in your journey by exploring new meaningful and joyful goals

By clarifying your values you have decided about the direction you want your journey to take. Now you can begin to plan your exact route towards that valued direction. A good way to do it is by setting **goals**. A value is like heading North and goals are the steps you take in that direction. For instance, you may have to cross a river or a valley while traveling North: these are goals. While goals can be 'crossed off' when done, values are never reached, there is always more travelling to do.

Having children is a goal that you have probably held onto tightly. Perhaps it has been, or still is, very difficult to let go. Instead of thinking about letting go of your wish for children, you can move your attention to pursuing other valued goals. This will help you become the person you want to be or help you live a meaningful life.

> " I went back into tutoring. I wanted to make a difference in some young people's lives, support and nurture them...Make sure that they are doing well, that they are getting what they want out of life...so that's meaningful for me.

Earlier on your journey you wrote value statements for different areas of your life (relationships, work / making a contribution, personal growth, and health / physical wellbeing) and ranked them according to how important they are to you. This was the value statement you ranked as most important:

### Health / Physical Wellbeing

Making sure I am taking care of myself, my mind and my body.

Do you still consider this value statement the most important? If not go to 'Setting your direction of travel' to update your value statements before you continue.

We invite you to set yourself a long-term goal that will enable you to act on this value. Once you decide what this is, you can set some short-term goals to help you get there. These goals need not be big or grand. Just something realistic that will help you move in the direction you want.

This could be the first time you are setting yourself goals in this way and can feel like a huge task. Don't feel you should rush this. Remember to be kind to yourself if you can't complete it in one go. In fact, as with your value statements, we recommend you do this step over a few days and include some tips below to help you.

Long-term goal:

To attend a yoga retreat next year.

Short-term goals:

Short-term goal 1:

Do at-home yoga sessions for three weeks.

Short-term goal 2:

Attend regular sessions at my local yoga studio.

Short-term goal 3:

Find five yoga retreats and pick the one that suits me best.

If you find that defining goals in this way is too formal or artificial you can think about them as the future steps you will take on your journey (check this ?pebble? in your backpack).

To continue defining goals to work towards your value statements, you can use the One step at the time routine that you will unlock at the end of this step.

Once you have set yourself these goals, ask yourself the following questions:

- Are these goals consistent with my value statement?
- Are these goals realistic? Is it practical to pursue them now?
- Will these goals bring me vitality, joy or fulfilment?
- Can I achieve at least one short-term goal within the next 3 months?

If your answer is NO to any of these questions you may need to adjust your goals. Setting goals doesn't mean setting rules or failing if you don't achieve them. Engaging in goals that are realistic and meaningful should give you a sense of purpose and fulfilment. If it just feels like another obligation in your life you can change your goals.

← →

🖼 Plan your route

Future steps                                                    📱

♥ Add to favourites

Enlist help                                                     👓

♥ Add to favourites

Fit new habits into your routine                                ☰

## Fit new habits into your routine

♥ Add to favourites

The ideal time to try something new may never come. A more practical way to move forward with your goals is to try to fit them into your routine. For example, if one of your goals was to learn a new skill, let's say a language: find an audio lesson you could listen to when you are in the car, public transport or walking. If one of your goals was to give yourself self-care each day: set a time in your diary to do this in the same way you set time for all your other daily activities.

## Future steps

♥ Add to favourites

It is impossible to commit to something unless we can see it clearly. To find meaning in your future you need to try to look at it. Imagine you are holding your Journey book. You know it well, as it brought you here. Looking at it, you notice you've already written some pages. You can see the events and experiences of your life so far. These include joy, but also the hardship and pain you have been experiencing. If you flip through the book, you notice the story ends abruptly. There is nothing written in the new chapter called "Tomorrow". That's right, your journey story from here has yet to be written. It is full of possibilities.
Now ask yourself this: What do I want the next page to say about me and my life? If I could put anything down on the next blank page of my Journey book, what would it be? Who do I really want to be from this moment on?
This is the place your commitment comes in. It needs to be specific and you need to become aware of it. What you write can be as simple as "I will spend fifteen minutes every day working with this app to change the course of my life." or "I always wanted to learn to play the piano. I will find a piano teacher and have one piano lesson every week.". Reflect about how what you write ties in with your value statements.

## Enlist help

♥ Add to favourites

The kind support of a loved person can help you move towards your goals. For instance, maybe you chose a new activity or hobby as one of your goals. You could ask a friend to come along and try it with you. It can also be helpful to talk about your goals with a family member or friend. They could maybe join in with you. Or you could let them know about things they could do to help you achieve the goal. In general, try thinking about ways in which involving others can help you reach your goals.

Will engaging with this person, place, activity or behaviour help you move towards your values? How? Describe it here:

Think about how you could take this step. Think about the thoughts and feelings you might struggle with (e.g. anxiety, emotional pain) when taking this step. On a good day, could you encourage yourself to take this step, making space for any unwanted emotions that may arise? What exactly would you do?

**If this step helps you move towards your values and you are willing to make space for the unwanted emotions it may trigger, then you should get up and take it.**

If you feel unwilling, ask yourself these questions:

- Does this really and truly matter to me?
- If YES, what is the cost of avoiding it or putting it off?
- If YES, what do I need to accept to be able to move forward?
- Would I rather have the vitality-draining pain of staying stuck or the life-enhancing pain of moving forward?

← →

✕

You just finished your seventh step. Well done for continuing travelling your journey.
Building acceptance is not an easy task. You now have two additional Routines in your Backpack that can help you do it.
It may take you time to be able to venture outside your comfort zone and it is important that you feel you have good reasons to do it. Meanwhile you can practice being in contact with unpleasant emotions.

---

⚠ Step out of your comfort zone

Acceptance aids

♥ Add to favourites

Stop and breathe in difficult situations

♥ Add to favourites

### Acceptance aids
♥ Add to favourites

Practice these exercises when you are alone and comfortable so you remember how to use them when you are outside your comfort zone, trying to accept a difficult situation.

- Take 10 breaths: 10 slow deep breaths, noticing sensations of lungs filling and emptying, allowing any uncomfortable thoughts you are experiencing to come and go as you focus on your breathing.
- Notice 5 things: 5 things you can see, 5 things you can hear, 5 things you can feel.

### Stop and breathe in difficult situations
♥ Add to favourites

This brief meditation can be used if you are faced with a difficult situation. It puts you in contact with the present moment as you develop awareness of what your body is telling you and a willingness to experience any pleasant or unpleasant sensations that arise.

► 0:00 / 0:00

# Step 8

### Invite others along.

Reflect about how you can bring others along in your journey.

The relationships we nurture with our loved ones are central to our wellbeing. They affect the way we think and feel about ourselves and the way we see the world. Even the sensations we experience in our body on a daily basis

Most people going through your journey share similar experiences about the way they relate with friends, family and the world in general. Like them, you may:

- Be unsure about who you are now and what your role in the world is;
- Find many social interactions challenging because they centre around children or people make comments that come across as insensitive;
- Desire to connect with others and talk about your experience but find it hard to share such a private and deep pain.

It can feel like a lonely journey at times. It is important to realise that we can feel lonely even when we have lots of social contact, receive well-meaning support or are in a relationship.

> " you do need somebody... you need a partnership of some kind, whether or not that's a friend who's experience is the same as you um, your partner, or somebody, you need someone...

←                                                                          →

It is hard to relate with others in the same way when your view of yourself changed in such a profound way. You used to know exactly who you wanted to be, but now struggle to understand who you are.

We invite you to develop an awareness of **who you are now**. It may come as a surprise to realize that you know more about who you want and can be than you think. More so to discover that you already are that person. You are your values. Remember: your values keep you on track towards your north, the person you want to be or what you think a meaningful existence is.

Read below the value statements you defined earlier in your journey. What do they tell you about who you are? Next time you introduce yourself to someone or you talk about your life, what will you say?

Fill the spaces below with a few keywords or short sentences that define you.

Health / Physical Wellbeing

**Making sure I am taking care of myself, my mind and my body.**

Who am I? Write a few keywords or short sentences that define you in a way that is consistent with your value statements.

*For instance, someone who wrote as value statement 'To be environmentally friendly' may describe themselves as 'committed to defending the environment and living in a sustainable way'.*

Relationships (with partner, family, friends, colleagues...)

**Long lasting and honest relationships**

Who am I? Write a few keywords or short sentences that define you in a way that is consistent with your value statements.

*For instance, someone who wrote as value statement 'To be environmentally friendly' may describe themselves as 'committed to defending the environment and living in a sustainable way'.*

Work / Making a contribution

**Helping the sustainability of my local community.**

Who am I? Write a few keywords or short sentences that define you in a way that is consistent with your value statements.

*For instance, someone who wrote as value statement 'To be environmentally friendly' may describe themselves as 'committed to defending the environment and living in a sustainable way'.*

Now bring these keywords or sentences together into a brief paragraph. This will summarise how you would like other people to know you. Tweak it until you feel comfortable saying it out loud and imagine saying it to others.

By talking about yourself and what matters to you, you may find out about shared values and interests you have with others. This may form the basis to new friendships or deepen current ones.

### 🔥 Invite others along.

**The wall of insensitive comments**
♡ Add to favourites

**Giving and taking meditation**
♡ Add to favourites

**Reacting to insensitive comments**
♡ Add to favourites

## Giving and taking meditation
♡ Add to favourites

This brief meditation invites you to imagine love and affection that your loved ones send you: taking time to breathe in their kindness and compassion and breathe out your appreciation for them and yourself.

## The wall of insensitive comments
♡ Add to favourites

It's possible that along your journey you had upsetting moments with family, friends and others. Even a caring friend or colleague can make comments that come across as insensitive. It might feel like sometimes the rest of the world just doesn't understand your pain.

We invite you to think about the last time you perceived a comment as insensitive. What was that comment? How did it make you feel? Gradually bring your awareness to what's going on inside you as you remember the comment. Gently notice what is happening in your mind and body and name each experience – thoughts, emotions, bodily sensations, impulses.

As each experience comes to your mind, picture yourself picking them up as if they were objects and placing them on a wall. This is your wall of insensitive comments. Once you placed all your experiences in the wall – turn and walk away from it. Watch yourself walking in your valued direction while the wall stays further and further behind.

Along your journey, you can deposit in your wall as many experiences as you want. In the future, when you hear other insensitive comments you can tell yourself - These are the experiences that this comment triggers for me. This thought, emotion, bodily sensation, impulse is familiar. I already have it in my wall. Or - This is a new thought, emotion, bodily sensation, impulse. Let me pick it up and add it to my wall.

## Reacting to insensitive comments
♡ Add to favourites

In general, people don't intend to be hurtful and inconsiderate. Depending on how you assess the situation that gave rise to a comment you felt was insensitive, there are different courses of action you can take.

Ask yourself these questions:

- Does the person know you and your journey?
- Why do you think the person is making that comment?
- Is this person usually compassionate (non-judgemental, kind and caring) towards you?
- Is strengthening your relationship with this person part of your value committed actions?

Depending on your answers to these questions, there are at least three different actions you can choose to take:

- **change the conversation:** quickly change the topic of the conversation without showing how insensitive or upsetting you found the comment and without opening a conversation about your journey;
- **Be direct and confrontational:** make it clear in your response that you found the comments upsetting or insensitive;
- **Open the conversation:** create the space or conditions to start a conversation about your wish for children. This implies explaining why you found the comment insensitive and hurtful. It also implies you feel comfortable enough to disclose your personal experience and share your thoughts and emotions about it. Regardless of how the person responds, sharing can be challenging or simply tiring.

Whatever the course of action you choose to take, make sure to ask yourself: how will this help you live a meaningful and fulfilling life?

## Stay on route

Stay on the values route you chose by sticking to your goals on a daily basis.

# Step 9

So far you have set your travelling direction by looking at your values. You have also moved forward by setting goals consistent with your values. The next step is to commit to these goals! **Committed action** can be difficult. It can bring up barriers in the form of unwanted feelings and thoughts or even failure. But if we think of our life as value driven, success is just keeping heading North.

Considering your journey so far, you may feel unsure whether you can commit to anything fully. We invite you to consider different ways of making sure you keep on track with goals that bring you vitality and purpose. With the skills you have gained you can approach new challenges, knowing you can handle setbacks along the way. And remember, you only have to commit one day at a time.

> " You just have to figure out your path... And then you have to embrace that path every day

These were the long and short-term goals you defined in 'Plan your route':

**Attend a yoga retreat next year**

- Do at-home yoga sessions for three weeks.
- Attend regular sessions at my local yoga studio.
- Find five yoga retreats and pick the one that suits me best.

**Are these still goals you aim to achieve? If not go to 'Plan your route' to update your goals before you continue.**

Focus on one of these short-term goals. Think about what is important about this goal. Imagine that you are at the point of achieving it now. Write here how that would make you feel (emotions, thoughts, bodily sensations):

Now come back to this moment in time. Imagine a step you can take right now towards that goal. It does not matter how big or small that step is, just that you can do it. Imagine you will stop reading this and take that step. Write here how that makes you feel (emotions, thoughts, bodily sensations):

What is that step? Write it here:

**Now that you have finished writing, take that step as soon as possible. After, embrace the vitality of doing it: all the emotions, thoughts, bodily sensations you experience.**

Well done if you took that step toward your chosen goal! If you could not take that step, here are two things that can help:

- Use your **defusion** and **acceptance** skills to gain new perspectives on the thoughts and emotions that might keep popping up and stopping you from moving forward.
- Use your **self-compassion** skills to recognise that sometimes things are hard and you are only human.

**Remember that all you have to do is take one single step everyday to keep going!**

You are reaching the end of your journey! Only one step to go!
By finishing this step you unlocked three new Routines in your *Backpack*.
Exploring these will help you feel motivated to continue to take on the challenges that will lead you in your valued direction in life.
Once you are satisfied about the actions you have been taking, no matter how small, you can start your last step.

These are the ten steps you will take on your journey with us.

### Stay on route

**Stay committed**

♥ Add to favourites

**Facing a dead end**

♥ Add to favourites

**Keep going**

♥ Add to favourites

#### Facing a dead end

♥ Add to favourites

We all experience dead ends in our journey:- it is just part of finding our way. Dead ends help us realise which goals may not work for us - not all goals will. There are many paths (goals) that will take us North (values). We won't know which are best for us until we walk them. Over the next few weeks, write down anything you think might hold you back from the goal you set above. Reflect on why this might be happening. Remember that steps can just be small! How many days or weeks have passed since you took a step towards your goal? Could it be time to try a new path? Is the goal still realistic? Is it still fulfilling? Is it time to replace it?

#### Stay committed

♥ Add to favourites

Use any of the following strategies to strengthen your commitment towards your goals:

- Set yourself reminders, for instance, using post its, notifications or screen shots on your phone;
- Set up rewards for sustaining efforts towards a goal for a week;
- Build a routine around your new goal to ensure you come back to it periodically;
- Think about how you can involve a compassionate friend that can support you in progressing towards your goals;
- Change your environment so that sustaining your goal becomes easier;
- Journal or talk to someone about your goal progression.

#### Keep going

♥ Add to favourites

When you feel the goal you have chosen above is in progress it may be time to take another challenge. Work through your value statements from most to least important setting long-term and short-term goals. Commit to these goals on a daily basis. This is not something that you will complete quickly. In fact, it is your life project and as you move through it, you know that you are living your valued life.

## Review your journey so far

At the end of your journey with us, reflect about what you have achieved so far and what you found useful.

# Step 10

You are at the end of your journey with us, but not at the end of your journey. As you continue travelling in your chosen direction, it is important to reflect about how you have changed so far and how you can keep positive change happening.

Answering the following questions will help you develop an awareness of which skills (steps) were most useful to you throughout your journey so far. You should continue to practice these skills often. You can continue using MyJourney to do it.

→

In your journey you have been trying to accept difficult emotions and bodily sensations triggered because you cannot have the children you desire.

At the start of your journey you experienced these emotions and bodily sensations:

I feel extremely sad with no hope for the future.

I feel a weight or pressure in my chest and a knot in my throat.

What emotions do you experience **now**?

How do these emotions feel in your body **now**?

Think about how your emotions and bodily sensations have changed. Below are your usefulness ratings for the steps that helped you develop acceptance. Do you still agree with these ratings or would you rate them differently now?

**When asked about usefulness of the step *Be Kind to yourself*, you stated : "Very much" how useful would you say it is now?**

Very much

**When asked about usefulness of the step *Travel at a safe distance*, you stated : "Very much" how useful would you say it is now?**

Very much

**When asked about usefulness of the step *Step out of your comfort zone*, you stated : "Very much" how useful would you say it is now?**

Very much

Considering all this, what do you think was most useful in helping you accept difficult emotions and bodily sensations?

← →

In your journey you have been trying to make sense of your past and present situation and explore how the things you value the most can help shape your future.

At the start of your journey you had these thoughts:

I fear my relationship will fall apart, we have been on hold for so long.

What thoughts do you have **now**?

In your journey you have been reflecting about how to ease your contacts with others.

At the start of your journey you described your contacts with others in this way:

I have lost friendships because of my childlessness.

How are your contacts with others **now**?

Think about how your thoughts have changed. Below are your usefulness ratings for the steps that helped you make meaning of your situation.

**When asked about usefulness of the step *Set your direction of travel*, you stated : "Very much" how useful would you say it is now?**

A moderate amount

**When asked about usefulness of the step *Illuminate your journey*, you stated : "Very much" how useful would you say it is now?**

A moderate amount

Considering all this, what do you think was most useful in helping you make sense of your past and present situation, and explore how the things you value the most can help shape your future?

Think about how your social contacts have changed. Below is your usefulness rating for the step that helped you manage your contacts with others.

**When asked about usefulness of the step *Invite others along*, you stated : "Very much" how useful would you say it is now?**

Very much

Considering all this, what do you think was most useful in helping you manage your contacts with others?

In your journey you have been trying to nurture the things you care deeply about into new fulfilling life goals.

At the start of your journey you did this:

I fill my free time with entertainment, I used to go to the cinema and gigs alot.

What do you do **now**?

When asked about usefulness of the step *Plan your route*, you stated : "Very much" how useful would you say it is now?

Very much

When asked about usefulness of the step *Stay on route*, you stated : "Very much" how useful would you say it is now?

Very much

Think about how your behaviours have changed. Below are the usefulness ratings for the step that helped you nurture the things you care deeply about into new fulfilling life goals.

Considering all this, what do you think was most useful in helping you nurture the things you care deeply about into new fulfilling life goals?

How can you sum up everything you found out in your journey so far?

I accept:

I believe:

I commit:

How often would you like to be reminded of your ABC?

Submit

×

Congratulations! You have taken all ten steps of MyJourney!
Moving forward, new difficult situations will confront you. Whenever this happens you can use your *Crisis Tool* that is now available in your *Backpack*. It will help you identify what is causing you stress and help you activate skills that are useful to cope with that situation.
Remember: you can continue using MyJourney for as long and how often you want. Now that you have taken control of your journey, you will be able to steer it towards your values, even if the path gets a bit rocky.

Many thanks for your collaboration!

## Appendix K: Development of the intervention – Logic Model Version 3

| Input | Activities | Outputs | | Outcomes |
|---|---|---|---|---|
| Activities based on Three Task Model of adjustment (Gameiro and Finnigan, 2017) and acceptance and commitment therapy (Hayes and Smith, 2005) and self-compassion (Neff and Tirch, 2013) therapeutic frameworks. | Your starting point | Validation of experience and intervention rationale | | Mental-Health |
| | Be kind to yourself | Self-compassion | Acceptance | |
| | Travel at a safe distance | Cognitive defusion | | |
| | Set your direction of travel | Value clarification | | Eudaimonic well-being |
| | Illuminate your journey | Positive reappraisal | Meaning Making | |
| | Plan your route | Goal definition | | |
| | Step out of your comfort zone | Experiential avoidance | Pursuit of other meaningful goals | Hedonic well-being |
| | Invite others along | Connectiveness skills | | |
| Developed by clinical psychologists. | Stay on route | Committed action towards goals | | |
| | Review your journey so far | Promote maintenance | Connection to others | |
| | Looking ahead kit | Crisis management | | |

Note. Thicker arrows demonstrate the output that each activity aims to target, and the thin arrows indicate the mechanism that these outputs aim to facilitate. *Synthesis activity to encourage users to reflect back on their progress

# Appendix L: Development of the intervention – commended features and content and all suggestions for improvement from consultation exercise

## Commended features and content

General comments about MyJourney:

- 'If this bring people together to realise that each journey is unique, but that the stages to go through or what they have to learn about themselves will be similar, then it will go a long way to fulfil needs'
- 'Nothing out there now for childless people so this is a positive thing'
- 'Feels like it could really help and the underlying model feels right'
- 'This is really powerful resource and brings everything into one place'
- 'Impressed, well developed, pleased by theoretical background, communicates with users in positive ways'
- 'Really good, needed necessary and comprehensive'
- 'Brilliant concept, really useful, huge gap out there for this type of support and COVID has accelerated the need for online, digital resources'
- 'MyJourney has taken everything I have embarked on over the last four years and put it in one place, can relate to a lot of things'
- 'It is a toolkit and leads a person to find the things that work for them, but will be interesting to see how it works without input from a real person'
- 'Looks really good, intriguing, like an adventure book you have as a kid, journey sounds exciting, even though it is a difficult journey'

| Feature or content | Comment and specific examples |
|---|---|
| Design and feel | Overall, the committee felt the design and feel of MyJourney was simple and visually appealing. For example, they commended the colours, icons and images used. |
| Perceived benefits of engaging with MyJourney | The committee felt MyJourney was comprehensive and perceived several benefits for users engaging with MyJourney, for example they are receiving a support that both aims to decrease distress and increase movement in life. Engaging with MyJourney could help increase awareness and clarity and could promote help seeking. Overall MyJourney was considered to be most useful to those seeking support and who were ready to move forward in their adjustment process. |
| Journey metaphor | The committee commended the journey metaphor, reporting that it was relatable and could promote adherence. It was also noted that unlocking steps as one moves through them (i.e., along a journey) could promote sustained engagement. |
| Language and readability | Some of the committee felt MyJourney had appropriate readability and the language was inclusive with the right tone. It was also noted that the psychological terms were well explained. |
| Accessible and no cost | Committee members liked that MyJourney was easy to access and navigate, that it was interactive, and that users could engage at their own pace and revisit if they wished. It was also noted that zero cost to users for access was a good feature. |
| Content and features meet the needs of people with UPGs | Committee members particularly felt that MyJourney met the needs of patients who were ending fertility treatment as many patients feel abandoned by their clinics at this stage. Overall, MyJourney covers the various aspects that need to be dealt with along the adjustment journey. |

| Steps were well received | Overall, the Steps were considered to be manageable. The sequence of the Steps made sense to committee members, and all Steps were judged as activities that could provide benefit. |
|---|---|
| Landing page | Overall, the committee felt the landing page was inclusive, practically presented, and user friendly. |
| Looking ahead kit (previously called Crisis tool) | The looking ahead kit was considered a good feature and one that consolidated the underlying theoretical model. Committee members liked that it was a feature that could be revisited and that it could help users work out what they needed to do in certain situations. |
| Wellbeing feedback | Committee members felt the wellbeing reporting feature was good and that users would be happy to complete the scales before each Step and track their wellbeing. |
| Length (proposed overall engagement) | It was noted that the recommended duration of 10 weeks (one Step per week) seemed appropriate, and it was recognised that moving this process would not be quick. |
| Signposting to other support | Signposting to other support resources was reported as a beneficial feature, that it is likely to be well received, and that it might promote help seeking. |
| Recommend to others | All committee members who were potential users would recommend to someone else in the similar situation. Professional committee members felt that fertility staff could signpost patients to this support. |

## Suggestions for improvement

### Design

| Improvement | Feasibility |
|---|---|
| Use images to convey content more visually | Not very feasible with financial constraints |
| Change colour or size of font in grey banner, not clear | Discussed – did not implement |
| More personalised – e.g. own avatar for their emojis so they are personalised | Not very feasible with financial constraints |
| Design – colours feel dull, title font seems old-fashioned | Discussed – did not implement |
| Hand (white) and face (looks like a woman) icons are not inclusive | Discussed – did not implement |
| Remove road sign icons | Discussed – did not implement |

### Barriers

| Improvement | Feasibility |
|---|---|
| Break down the text into more manageable sections | Can address by using more bullets / quotes IMPLEMENTED THIS |
| Rethink the word 'acceptance' in the tag line on landing page | Discussed – did not implement |
| Review complexity of language | Can address by reviewing all content IMPLEMENTED THIS |
| Landing page could be clearer | Can address by reviewing content IMPLEMENTED THIS |
| Queried whether for men | Can discuss how to make this clearer – AMENDED LANGUAGE |
| Map needs to be clearer (include numbers on steps to show sequence) | Can address with design IMPLEMENTED THIS |
| Consider whether mandatory writing is a barrier | Can discuss this to decide if mandatory text boxes will remain IMPLEMENTED THIS (mandatory text boxes no longer mandatory) |
| Barrier – entering personal information (audit trail) – make terms of data collection clear to reassure | Addressed with information we planned to provide anyway |

| | |
|---|---|
| Be clear about why users need to make an account | Can add some text on registration page – IMPLEMENTED THIS |
| Less accessible for those who don't like writing | Not feasible due to time and financial constraints |
| Make sure that examples given aren't too prescriptive | Discussed – IMPLEMENTED THIS |
| Be clearer on landing page that some never resolve issues that it is an ongoing process and experience | Discussed – IMPLEMENTED THIS |
| 'could not have children' might put off people who aren't quite ready to accept childlessness | Discussed – did not implement |
| Ten steps is too long | Discussed - did not implement |

| Additional improvements | Feasibility |
|---|---|
| Include diverse support recommendations | Can address by making sure contact details cover this IMPLEMENTED THIS |
| Responding to insensitive comments – more inclusive options | Can address this by adding more response options IMPLEMENTED THIS |
| Ask users if they have already sought professional help | Can include but how to monitor? – INCLUDED IN SURVEYS |
| Provision of group chat or sharing experiences | Not feasible due to time and financial constraints |
| Include examples where users are asked to write things down | Can address this with the hints we have already planned to do |
| Suggestion of 'Not ready button' | Can address by adding this button with additional content IMPLEMENTED THIS |
| Put ABC responses in backpack at the end, with date of completion | IMPLEMENTED THIS (but not the date stamp) |
| Users will want feedback on their well-being scores | Can address IMPLEMENTED THIS |
| Normalise feelings of sadness etc on Mood scale | Can address possibly with additional text – did not implement this |
| Faces on team page of people behind MyJourney | Can address this by adding to link on landing page IMPLEMENTED THIS |
| Add cis-men and cis-women if referring to these genders | Can address by adding where necessary IMPLEMENTED THIS |
| Repeat landing page figure and title through journey steps | Can address IMPLEMENTED THIS |
| Consider including men's coping styles more in the content | Not feasible due to time and financial constraints |
| Make it clearer what happens at the end of ten steps | IMPLEMENTED THIS |

## Steps

| Improvement | Feasibility |
|---|---|
| Step 7 - More support for 'Step out of comfort zone' | Can include by adding content IMPLEMENTED THIS |
| Step 8 - Recognise diverse cultures in 'Invite others along' and throughout the content | Can include by adding to content IMPLEMENTED THIS |
| Step 10 – more focus on tolerance of emotions etc rather than whether they have changed | Can include by amending content IMPLEMENTED THIS |
| Step 8 - Possibly change fire icon for 'Invite others along' | Can discuss - did not implement |
| Step 3 – use 'Describe, don't evaluate' | Can include this phrase IMPLEMENTED THIS |
| Step 3 – needs less writing – use quotes or visuals | Would have to be quotes given budget constraints – did not implement, need amount of text to describe the concept |

| Step 8 – change title and make three steps instead of two | Can include but need to discuss how – new title maybe 'Meeting others along the way' – IMPLEMENTED THIS |
| --- | --- |
| Step 7 – pull values through to this step | Can discuss – not possible in time and resource constraints |
| Step ?? – remove word 'domains' and change to 'area' – language too harsh | Can include this IMPLEMENTED THIS |

## Crisis tool / Looking ahead tool

| Additional things | Feasibility |
| --- | --- |
| Crisis tool – make clearer to use in advance of difficult situation | Can address with additional text IMPLEMENTED THIS |
| Crisis tool – relapse is normal, make this clear | Can address with additional text IMPLEMENTED THIS |

## Reminders

| Additional things | Feasibility |
| --- | --- |
| Reminders (SMS) to encourage engagement | Not possible in time and resource constraints |
| Reminders throughout that this is a difficult journey (perhaps not to send but just in content) | Can address this with additional content. IMPLEMENTED THIS |
| Make it more engaging – with notifications, interactive related to steps they are on but with flexibility | Not feasible due to time and financial constraints |
| Ensure reminders are empowering | Can discuss this IMPLEMENTED THIS |

# Appendix M: Randomised controlled feasibility trial – CONSORT checklist

CONSORT 2010 checklist of information to include when reporting a pilot or feasibility trial

| Section/Topic | Item No | Checklist item | Reported on page No |
|---|---|---|---|
| **Title and abstract** | | | |
| | 1a | Identification as a pilot or feasibility randomised trial in the title | 126 |
| | 1b | Structured summary of pilot trial design, methods, results, and conclusions (for specific guidance see CONSORT abstract extension for pilot trials) | N/A |
| **Introduction** | | | |
| Background and objectives | 2a | Scientific background and explanation of rationale for future definitive trial, and reasons for randomised pilot trial | 126-130 |
| | 2b | Specific objectives or research questions for pilot trial | 130-131 |
| **Methods** | | | |
| Trial design | 3a | Description of pilot trial design (such as parallel, factorial) including allocation ratio | 132 |
| | 3b | Important changes to methods after pilot trial commencement (such as eligibility criteria), with reasons | N/A |
| Participants | 4a | Eligibility criteria for participants | 133 |
| | 4b | Settings and locations where the data were collected | 132 |
| | 4c | How participants were identified and consented | 132-133 |
| Interventions | 5 | The interventions for each group with sufficient details to allow replication, including how and when they were actually administered | 133 |

| Section/Topic | Item No | Checklist item | Reported on page No |
|---|---|---|---|
| Outcomes | 6a | Completely defined prespecified assessments or measurements to address each pilot trial objective specified in 2b, including how and when they were assessed | 136-138 |
| | 6b | Any changes to pilot trial assessments or measurements after the pilot trial commenced, with reasons | N/A |
| | 6c | If applicable, prespecified criteria used to judge whether, or how, to proceed with future definitive trial | 136-138 |
| Sample size | 7a | Rationale for numbers in the pilot trial | 144 |
| | 7b | When applicable, explanation of any interim analyses and stopping guidelines | N/A |
| Randomisation: | | | |
| Sequence generation | 8a | Method used to generate the random allocation sequence | 144-145 |
| | 8b | Type of randomisation(s); details of any restriction (such as blocking and block size) | 144-145 |
| Allocation concealment mechanism | 9 | Mechanism used to implement the random allocation sequence (such as sequentially numbered containers), describing any steps taken to conceal the sequence until interventions were assigned | 144-145 |
| Implementation | 10 | Who generated the random allocation sequence, who enrolled participants, and who assigned participants to interventions | 144-145 |
| Blinding | 11a | If done, who was blinded after assignment to interventions (for example, participants, care providers, those assessing outcomes) and how | N/A |
| | 11b | If relevant, description of the similarity of interventions | N/A |
| Statistical methods | 12 | Methods used to address each pilot trial objective whether qualitative or quantitative | 145-147 |
| **Results** | | | |

| Section/Topic | Item No | Checklist item | Reported on page No |
|---|---|---|---|
| Participant flow (a diagram is strongly recommended) | 13a | For each group, the numbers of participants who were approached and/or assessed for eligibility, randomly assigned, received intended treatment, and were assessed for each objective | 148-149 |
| | 13b | For each group, losses and exclusions after randomisation, together with reasons | 148-149 |
| Recruitment | 14a | Dates defining the periods of recruitment and follow-up | 132 |
| | 14b | Why the pilot trial ended or was stopped | N/A |
| Baseline data | 15 | A table showing baseline demographic and clinical characteristics for each group | 150 |
| Numbers analysed | 16 | For each objective, number of participants (denominator) included in each analysis. If relevant, these numbers should be by randomised group | 165-170 |
| Outcomes and estimation | 17 | For each objective, results including expressions of uncertainty (such as 95% confidence interval) for any estimates. If relevant, these results should be by randomised group | 165-170 |
| Ancillary analyses | 18 | Results of any other analyses performed that could be used to inform the future definitive trial | 176-177 |
| Harms | 19 | All important harms or unintended effects in each group (for specific guidance see CONSORT for harms) | 180 |
| | 19a | If relevant, other important unintended consequences | N/A |
| **Discussion** | | | |
| Limitations | 20 | Pilot trial limitations, addressing sources of potential bias and remaining uncertainty about feasibility | 188-189 |
| Generalisability | 21 | Generalisability (applicability) of pilot trial methods and findings to future definitive trial and other studies | 188, 190 |
| Interpretation | 22 | Interpretation consistent with pilot trial objectives and findings, balancing potential benefits and harms, and considering other relevant evidence | 181-190 |

| Section/Topic | Item No | Checklist item | Reported on page No |
|---|---|---|---|
| | 22a | Implications for progression from pilot to future definitive trial, including any proposed amendments | 189-190 |
| **Other information** | | | |
| Registration | 23 | Registration number for pilot trial and name of trial registry | 132 |
| Protocol | 24 | Where the pilot trial protocol can be accessed, if available | 132 |
| Funding | 25 | Sources of funding and other support (such as supply of drugs), role of funders | N/A |
| | 26 | Ethical approval or approval by research review committee, confirmed with reference number | 132 |

## Appendix N: Randomised controlled feasibility trial – Participants information sheet, consent form, questionnaires, and debrief form

**Webpage information and Patient**[https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_1](https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_1)
**Information**[https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_2](https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_2)
**Sheet**

*We are currently running a trial that invites people to use MyJourney so that we can that we can find out about their experience of using it and investigate the effect it has on*

*Interested in taking part?*

Your participation would involve being assigned at random to either get immediate access to use *MyJourney* or after a ten-week period. If you meet the eligibility criteria, your answers to the online surveys will not determine which group you get allocated to. The study has a 2:1 allocation rate to the intervention. This means you are twice as likely to get immediate access to MyJourney than to have to wait to access it.

Once you have access, you will be able to use *MyJourney* at your own pace and will.

To find out about how people use *MyJourney* and the effect it has on people's wellbeing, **we need to hear about all different types of experiences and use.**

**To be eligible for this trial, you must be age 18 or over and have an unfulfilled wish for children.**

**Please click the button below to find out more information and enter the trial**

**JOIN TRIAL NOW**

**Feasibility trial of *MyJourney* – online support for people who have an unfulfilled wish for children**

Thank you for considering taking part in this study.

Cardiff University Fertility Studies Group, in collaboration with the Portuguese Fertility Association and Fertility Network UK, have developed an online interactive self-help program called *MyJourney*.

*MyJourney* provides step by step support to promote psychological adaptation to an unfulfilled wish for children. Its development was informed by research and carried out

You will be allocated to one of two groups (immediate access or access to use *MyJourney* after ten weeks). If you meet the eligibility criteria, your answers to the online surveys will not determine which group you get allocated to. The study has a 2:1 allocation rate to the intervention. This means you are twice as likely to get immediate access to MyJourney than to have to wait to access it. Depending on which group you are in, you will be invited to answer two (before you have used *MyJourney*) or three (before and after you have used *MyJourney*) online surveys. These surveys include questions about your demographic details, your adjustment to your unfulfilled wish for children and what you think about *MyJourney*. Each takes no longer than 20 minutes.

**Your completion of the surveys at each assessment moment is really important, regardless of if you were given access to MyJourney, how you have chosen to use it and how satisfied you are with it.**

**By taking part in this trial you could win one of ten £20 Amazon Vouchers at each assessment moment!**

**Your participation is entirely voluntary, and you can withdraw at any time, without giving a reason.**

We will request your email address and telephone number when you indicate your interest in the study and provide consent and we may use these details to send you reminders. Any information you provide will be held in compliance with GDPR regulations (See Privacy Notice below). Your data will be anonymised one month after the study has finished and after this point, no-one will be able to trace your information back to you. You can ask for the information you have provided to be deleted at any time up until the data has been anonymised and you can have access to the information up until the data has been anonymised.

**What are the possible benefits of taking part?**

*MyJourney*:

- is based on Contextual Cognitive and Behavioural Therapy, which has been proven to have therapeutic value in other areas of health and adjustment to stressful life events, having a long lasting and positive effect on wellbeing.
- has been developed specifically for people who have an unfulfilled wish for children.

Therefore, it is expected that engaging with *MyJourney* will facilitate the user's journey of adjustment to their unfulfilled wish for children. Moreover, past research has shown that participating in research can help participants to understand their own thoughts and emotions.

**What are the possible disadvantages and risks of taking part?**

Some of what *MyJourney* asks you to think about or write down might make you feel emotional as you may reflect on your own personal experience.

Contact details for the researchers and support services will be provided.

**What should I do if there is a problem during my participation?**

If you have any problem or any concern about our study, please contact:

The contact details of the researcher of this study: Beth Rowbottom, PhD Student, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT Email: rowbottomb@cardiff.ac.uk

The contact details of the supervisor of this study: Dr Sofia Gameiro, Senior Lecturer, School of Psychology, Cardiff University, 70 Park Place, Cardiff, CF10 3AT, Email: gameiros@cardiff.ac.uk          Tel: +44 (0)29 2087 5376

This project has been reviewed and ethically approved by SREC (School Research Ethics Committee), School of Psychology, Cardiff University, Tower Building, 70 Park Place, Cardiff, CF10 3AT Email: psychethics@cardiff.ac.uk          Tel: +44 (0)29 2087 0360

The data controller is Cardiff University and the Data Protection Officer is James

**Privacy Notice:**

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Beth Rowbottom, Sofia Gameiro and Ana Galhardo.

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only the research team will have access to this information. After one month the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

# Consent form

School of Psychology, Cardiff University

**Feasibility trial of *MyJourney* – online support for people who have an unfulfilled wish for children**

Consent form – Confidential data

I understand that my participation in this project will involve being randomly selected into either:

- a group who will use the *MyJourney* web app as I wish over the period of ten-weeks and answer online surveys before, immediately after and six-months after I have used it

    OR

- a group who will complete two surveys ten-weeks apart, after which I will get access to the *MyJourney* web app to use as I wish.

    I understand that if I meet the eligibility criteria, my answers to the online surveys will not determine which group I get allocated to. The study has a 2:1 allocation rate to the intervention. This means I am twice as likely to get immediate access to MyJourney than to have to wait to access it. I understand that participation in this study is entirely voluntary and that I can withdraw from the study at any time without giving a reason. I also understand that I can withdraw my data from the study up until the point the data is anonymised by contacting the researcher.

    I understand that I am free to ask any questions at any time. I am free to withdraw or discuss my concerns with the researcher, Beth Rowbottom or the supervisor, Sofia Gameiro.

    I understand that some of the steps in *MyJourney* might make me feel emotional as I may reflect on my own personal experience and that I am free to withdraw at any time. I understand that I may be asked questions about my ethnicity, but I can choose not to answer these questions.

    I understand that I may be sent reminders via email or SMS at each of the assessment moments and while I am using MyJourney.

    I understand that the personal data will be processed in accordance with GDPR regulations (see privacy statement below).

    I understand that at the end of the study I will be provided with additional information and feedback about the purpose of the study.

o  I consent to participate in the study conducted by Beth Rowbottom School of Psychology, Cardiff University with the supervision of Dr Sofia Gameiro.

    Please provide your email address. If you have more than one, please provide one you use and check often (at least once a week). This is the email we will use to contact you during the study:
    _____

o  I do not consent to participate in the study conducted by Beth Rowbottom School of Psychology, Cardiff University with the supervision of Dr Sofia Gameiro

**Privacy Notice:**

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The

lawful basis for processing this information is public interest. This information is being collected by Beth Rowbottom, Sofia Gameiro and Ana Galhardo.

The information on the consent form will be held securely and separately from the research information. Only the researcher will have access to this form and it will be destroyed after 7 years.

The research information you provide will be used for the purposes of research only and will be stored securely. Only the research team will have access to this information. After one month the data will be anonymised (any identifying elements removed) and this anonymous information may be kept indefinitely or published.

## Questionnaires

### Eligibility Questionnaire

*MyJourney* have been created for people who have an unfulfilled wish for children and this trial is to find out about how people use it and its effect of people's wellbeing. To find out whether taking part in this trial is suitable for you we will ask a few questions about your eligibility to take part.

Are you aged 18 or over?

-Yes
-No

Do you consider yourself to have an unfilled wish for children? By unfulfilled wish for children we mean you do not currently have nor expect to have the children you wished for.

-Yes
-No

Have you been diagnosed with a mental-health problem within the last 2 years (for instance, depression, bipolar disorder, schizophrenia and other psychoses, dementia, or developmental disorders, including autism)?

-Yes
-No

Are you currently receiving therapy (either psychotherapy or medication) for a clinically diagnosed mental-health problem?

-Yes
-No

Are you currently receiving support from a certified therapist or counsellor, either in individual or group format, specifically related to your unfulfilled wish for children?

-Yes
-No

To use *MyJourney* you need to read and understand written content and listen to audio files (in Portuguese or English). Are you able to do this?

-Yes
-No

Would you be unable to use an online web app for any other health problem?

-Yes

-No

Do you have access to a laptop, tablet or smartphone where you can use *MyJourney* on a regular (e.g. weekly) basis?

-Yes
-No

**Baseline Assessment Moment**

**Section 1: About your background**

Please provide a mobile number (this will be used only to send reminders about *MyJourney* and the online questionnaires): _____

What best describes your gender?

- o   Female
- o   Male
- o   Prefer to self-describe: _____

How old are you (please state in years): _____

What is your country of residence? _____ (can be optional)

Which best describes your current relationship status?

- o   Single
- o   In relationship, married or cohabiting
- o   In relationship, but not married nor cohabiting
- o   Divorced/separated
- o   Widowed
- o   Other, please specify:

Which best describes your education?

- o   No education
- o   Primary/elementary school
- o   Secondary/High School
- o   Post-secondary school, for example, sixth form, college, trader or technical apprenticeship (e.g., BTEC)
- o   Undergraduate Degree
- o   Postgraduate Degree
- o   Other - Please specify: _____

Which best describes your employment status?

- o   Unemployed
- o   Employed/self-employed (part time or full time)
- o   Student
- o   Retired
- o   Other - Please specify: _____

What best describes your ethnicity?

- o   White (English, Welsh, Scottish, Northern Irish, British, Irish, Gypsy or Irish Traveller, Any other White background)
- o   Mixed / Multiple ethnic groups (White and Black Caribbean, White and Black African, White and Asian, Any other Mixed / Multiple ethnic background)

o   Asian / Asian British (Indian, Pakistani, Bangladeshi, Chinese, Any other Asian background)
o   Black / African / Caribbean / Black British (African, Caribbean, Any other Black / African / Caribbean background)
o   Arab
o   Any other ethnic group

**Questions evaluating UPG:**

What is your parental status?

-   I do not have children. By children we mean biological or adopted children.
-   I have children
-   Other. Please describe:_____

Do you still have a child wish?

-   Yes
-    No

Have you engaged in fertility treatment as part of your journey (e.g. undergone fertility tests or received fertility treatment from a clinic such as IVF or ICSI)?

-   Yes
-   No

Which best describes your current journey status?

-   I'm not trying to accept I won't have the children I wished for and I've not thought about trying.
-   I'm not trying to accept I won't have the children I wished for but I'm thinking about trying.
-   I have just started trying to accept I won't the children I wished for.
-   In the last 6 months I've been trying to accept I won't have the children I wished for.
-   For longer than 6 months I've been trying to accept I won't have the children I wished for.

Would you be happy for the researchers of this study to contact you to ask additional questions (via phone or online interview) about MyJourney? If you agree and are selected, more information will be provided, and you can decide not to participate or to withdraw at any time.

-   Yes
-   No

How did you find out about *MyJourney*?

-   Fertility Network UK
-   Portuguese Fertility Association
-   Facebook
-   Twitter
-   YouTube
-   Other social media, please specify: _____
-   Recommendation from a friend
-   Search Engine
-   Other, please specify: _____

In the past, have you ever received support from a certified therapist or counsellor, either in individual or group format, specifically related to your unfulfilled wish for children?

-Yes

-No

In the past, have you ever used any type of support (i.e., <u>not from</u> a certified therapist/counsellor) for instance, peer group support, online support, self-help books to manage the psychological and social implications of your unfulfilled wish for children?

- Yes
- No

Are you currently using any other type of support (i.e., <u>not from</u> a certified therapist/counsellor), for instance, peer group support, online support, self-help books to manage the psychological and social implications of your unfulfilled wish for children?

- Yes
- No

*Section 2 – Adjustment to unfulfilled wish for children*

> **Note for Ethics Committee: All questions in section 2 are to evaluate limited efficacy.**

*Outcomes*

**WHO-5** (World Health Organisation , developed at Psychiatric Research Unit, Mental Health Centre North Zealand, Hillerød, Denmark)- HEDONIC WELL-BEING

Please indicate for each of the five statements which is closest to **how you have been feeling over the past two weeks. Notice that higher numbers mean better well-being.** Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, choose the box with the number 3 in it.

|   |   | 0 At no time | 1 Some of the time | 2 Less than half of the time | 3 More than half of the time | 4 Most of the time | 5 All the time | Prefer not to say |
|---|---|---|---|---|---|---|---|---|
| 1 | I have felt cheerful and in good spirits | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have felt calm and relaxed | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I have felt active and vigorous | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I woke up feeling fresh and rested | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | My daily life has been filled with things that interest me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**MHI-5** (Veit & Ware, 1983b) - MENTAL HEALTH

Using the 1-5 scale below, indicate your response by placing the appropriate number on the line preceding that item.

**How much of the time, during the last month, have you…?**

| | | 1<br>All of the time | 2<br>Most of the time | 3<br>A good bit of the time | 4<br>Some of the time | 5<br>A little of the time | 6<br>None of the time | Prefer not to say |
|---|---|---|---|---|---|---|---|---|
| 1 | '...been a very nervous person?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | '…felt calm and peaceful?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | '…felt downhearted and blue?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | '...been a happy person? | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | '...felt so down in the dumps that nothing could cheer you up?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

*Well-being (eudaimonic)* – Overall, to what extent do you feel the things you do in your life are worthwhile? (11 point scale, 0-10) ONS eudaimonic subjective well-being scale (Office for National, 2012)

*Satisfaction with life* - All things considered, how satisfied are you with your life as a whole these days? 1 "completely dissatisfied" - 10 "completely satisfied" (Ahrendt et al., 2017)

*Happiness* - Taking all things together on a scale of 1 to 10, how happy would you say you are? Here 1 means you are very unhappy and 10 means you are very happy. (Ahrendt et al., 2017)

**Post traumatic growth inventory – short form** (Cann et al., 2009)(Cann et al., 2009**)** – POST TRAUMATIC GROWTH

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your unfulfilled wish for children, using the following scale.

0 = I did not experience this change as a result of my unfulfilled wish for children.
1 = I experienced this change to a very small degree as a result of my unfulfilled wish for children.
2 = I experienced this change to a small degree as a result of my unfulfilled wish for children.
3 = I experienced this change to a moderate degree as a result of my unfulfilled wish for children.
4 = I experienced this change to a great degree as a result of my unfulfilled wish for children.
5 = I experienced this change to a very great degree as a result of my unfulfilled wish for children.

| | | 1 | 2 | 3 | 4 | 5 | Prefer not to say |
|---|---|---|---|---|---|---|---|
| 1 | I changed my priorities about what is important in life. | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have a greater appreciation for the value of my own life | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I am able to do better things with my life. | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I have a better understanding of spiritual matters. | ○ | ○ | ○ | ○ | ○ | ○ |

| 5 | I have a greater sense of closeness with others. | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I established a new path for my life. | ○ | ○ | ○ | ○ | ○ | ○ |
| 7 | I know better that I can handle difficulties. | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | I have a stronger religious faith | ○ | ○ | ○ | ○ | ○ | ○ |
| 9 | I discovered that I'm stronger than I thought I was. | ○ | ○ | ○ | ○ | ○ | ○ |
| 10 | I learned a great deal about how wonderful people are. | ○ | ○ | ○ | ○ | ○ | ○ |

*Mediators*

**Acceptance**

**SCREENIVF** (Verhaak et al., 2010) - ACCEPTANCE

Please answer the following questions about your **acceptance** towards your unfulfilled wish for children by selecting the number that corresponds with the comment that fits your feelings towards each statement the most:

|  |  | 1<br>Do not agree | 2<br>Agree a little bit | 3<br>Agree | 4<br>Strongly Agree | Prefer not to say |
|---|---|---|---|---|---|---|
| 1 | I can deal with the consequences of my unfulfilled wish for children | ○ | ○ | ○ | ○ | ○ |
| 2 | I have learned to live with my unfulfilled wish for children | ○ | ○ | ○ | ○ | ○ |
| 3 | I have learned to accept my unfulfilled wish for children | ○ | ○ | ○ | ○ | ○ |
| 4 | I can accept my unfulfilled wish for children | ○ | ○ | ○ | ○ | ○ |
| 5 | I think I can cope with my unfulfilled wish for children, even though it will not be solved | ○ | ○ | ○ | ○ | ○ |
| 6 | I can cope well with my unfulfilled wish for children | ○ | ○ | ○ | ○ | ○ |

**Self-compassion scale short form (SCS-SF)** (Raes et al., 2011) SELF-COMPASSION

Please respond to each item by marking one box per row.

| | | 1<br>Never | 2<br>Rarely | 3<br>Sometimes | 4<br>Often | 5<br>Always |
|---|---|---|---|---|---|---|
| 1 | When I fail at something important to me, I become consumed by feelings of inadequacy. (R) | ○ | ○ | ○ | ○ | ○ |
| 2 | I try to be understanding and patient towards those aspects of my personality I don't like. | ○ | ○ | ○ | ○ | ○ |
| 3 | When something painful happens I try to take a balanced view of the situation. | ○ | ○ | ○ | ○ | ○ |
| 4 | When I'm feeling down, I tend to feel like most other people are probably happier than I am. (R) | ○ | ○ | ○ | ○ | ○ |
| 5 | I try to see my failings as part of the human condition. | ○ | ○ | ○ | ○ | ○ |
| 6 | When I'm going through a very hard time, I give myself the caring and tenderness I need. | ○ | ○ | ○ | ○ | ○ |
| 7 | When something upsets me I try to keep my emotions in balance. | ○ | ○ | ○ | ○ | ○ |
| 8 | When I fail at something that's important to me, I tend to feel alone in my failure(R) | ○ | ○ | ○ | ○ | ○ |
| 9 | When I'm feeling down I tend to obsess and fixate on everything that's wrong. (R) | ○ | ○ | ○ | ○ | ○ |
| 10 | When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people. | ○ | ○ | ○ | ○ | ○ |
| 11 | I'm disapproving and judgmental about my own flaws and inadequacies. (R) | ○ | ○ | ○ | ○ | ○ |
| 12 | I'm intolerant and impatient towards those aspects of my personality I don't like. (R) | ○ | ○ | ○ | ○ | ○ |

Comprehensive Assessment of Acceptance and Commitment Therapy processes (CompACT)
(Francis et al., 2016)- OPENNESS TO THE EXPERIENCE (ACCEPTANCE AND DEFUSION)

Please indicate using the scale below, to what level you agree or disagree with the following statements:

| | | 0<br>Strongly<br>Disagree | 1<br>Moderately<br>Disagree | 2<br>Slightly<br>Disagree | 3<br>Neither<br>agree nor<br>disagree | 4<br>Slightly<br>Agree | 5<br>Moderately<br>Agree | 6<br>Strongly<br>Agree |
|---|---|---|---|---|---|---|---|---|
| 1 | I tell myself that I shouldn't have certain thoughts | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I try to stay busy to keep thoughts or feelings from coming | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | One of my big goals is to be free from painful emotions | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I go out of my way to avoid situations that might bring difficult thoughts, feelings, or sensations | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | Even when something is important to me, I'll rarely do it if there is a chance it will upset me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I work hard to keep out upsetting feelings | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 7 | I can take thoughts and feelings as they come, without attempting to control or avoid them* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | I am willing to fully experience whatever thoughts, feelings and sensations come up for me, without trying to change or defend against them* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| 9 | I get so caught up in my thoughts that I am unable to do the things that I most want to do | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|---|---|
| 10 | Thoughts are just thoughts – they don't control what I do* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**Meaning Making**

<u>**COPE Scales**</u> (Carver et al., 1989)- POSITIVE REFFRAMING

The following questions ask you to indicate what you have been **generally doing** regarding your experience of having an unfulfilled wish for children.

Respond to each of the following items by selecting the number that best describes what YOU usually DO when you experience distress related to your unfulfilled wish for children. There are no 'right' or 'wrong' answers, so choose the most accurate answer for **YOU**- not what you think 'most people' would say or do.

|  |  | 1<br>I usually don't do this at all | 2<br>I usually do this a little bit | 3<br>I usually do this a medium amount | 4<br>I usually do this a lot | Prefer not to say |
|---|---|---|---|---|---|---|
| 1 | I try to see it in a different light, to make it seem more positive | ○ | ○ | ○ | ○ | ○ |
| 2 | I look for something good in what is happening | ○ | ○ | ○ | ○ | ○ |
| 3 | I have learned something from the experience | ○ | ○ | ○ | ○ | ○ |
| 4 | I try to grow as a person as a result of the experience | ○ | ○ | ○ | ○ | ○ |

<u>Comprehensive Assessment of Acceptance and Commitment Therapy processes (CompACT) (Francis et al., 2016)(Francis et al., 2016) – MOTIVATION AND ACTIVATION</u>

Please indicate using the scale below, to what level you agree or disagree with the following statements:

|  |  | 0<br>Strongly Disagree | 1<br>Moderately Disagree | 2<br>Slightly Disagree | 3<br>Neither agree nor disagree | 4<br>Slightly Agree | 5<br>Moderately Agree | 6<br>Strongly Agree |
|---|---|---|---|---|---|---|---|---|
| 1 | I make choices based on what is important to me, | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | even if it is stressful* | | | | | | |
| 2 | My values are really reflected in my behaviour* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I am able to follow my long-term plans including times when progress is slow* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I can keep going with something when it's important to me* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I behave in line with my personal values* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I undertake things that are meaningful to me, even when I find it hard to do so* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 7 | I act in ways that are consistent with how I wish to live my life* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | I can identify the things that really matter to me in life and pursue them* | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**Pursuit of other meaningful goals**

<u>Goals Adjustment Scale</u> (reengagement only) (Wrosch et al., 2003) GOAL DEFINITION

During their lives, people cannot always attain what they want and are sometimes forced to stop pursuing the goals they have set.
**We are interested in understanding how you are reacting to having an unfulfilled wish for children.**
Please indicate the extent to which you agree or disagree with each of the following statements, as it usually applies to you.

| | | 1 Strongly disagree | 2 Disagree | 3 Neutral | 4 Agree | 5 Strongly agree | Prefer not to say |
|---|---|---|---|---|---|---|---|
| 1 | I have convinced myself that I have other meaningful goals to pursue | ○ | ○ | ○ | ○ | ○ | ○ |

| 2 | I have started working on other new goals | ○ | ○ | ○ | ○ | ○ | ○ |
|---|---|---|---|---|---|---|---|
| 3 | I think about other new goals to pursue | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I have sought after other meaningful goals | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I have told myself that I have a number of other new goals to draw upon | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I have put effort toward other meaningful goals | ○ | ○ | ○ | ○ | ○ | ○ |

**Committed action scale (CAQ-8)** (McCracken et al., 2015) COMMITTED ACTION

Below you will find a list of statements. Please rate the truth of each statement as it applies to you by circling a number. Use the following rating scale to make your choices. For instance, if you believe a statement is "Always True", you would circle the 6 next to that statement.

|  |  | 0 Never true | 1 Very rarely true | 2 Seldom true | 3 Sometimes true | 4 Often true | 5 Almost always true | 6 Always true |
|---|---|---|---|---|---|---|---|---|
| 1 | I can remain committed to my goals even when there are times that I fail to reach them (4) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | When a goal is difficult to reach, I am able to take small steps to reach it (5) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I prefer to change how I approach a goal rather than quit (7) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I am able to follow my long terms plans including times when progress is slow (8) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I find it difficult to carry on with an activity unless I experience that it is successful (12) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | If I feel distressed or discouraged, I let my commitments slide (21) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 7 | I get so wrapped up in what I am thinking or feeling that I cannot do the things that matter to me (22) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

| 8 | If I cannot do something my way, I will not do it at all (23) | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

*Moderator*

**Social connection**

<u>Fertility problem inventory – social concern subscale (Newton et al., 1999) SOCIAL CONNECTION</u>

The following statements express different opinions about an unfulfilled wish for children. Please indicate the degree to which you agree or disagree with each statement.

| | | 1<br>Strongly<br>Disagree | 2<br>Moderately<br>Disagree | 3<br>Slightly<br>Disagree | 4<br>Slightly<br>Agree | 5<br>Moderately<br>Agree | 6<br>Strongly<br>Agree |
|---|---|---|---|---|---|---|---|
| 1 | It doesn't bother me when I'm asked questions about children. | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | Family members don't seem to treat us any differently. | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | The holidays are especially difficult for me. | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | Family get-togethers are especially difficult for me. | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I can't help comparing myself with friends who have children. | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I still have lots in common with friends who have children. | ○ | ○ | ○ | ○ | ○ | ○ |
| 7 | I find it hard to spend time with friends who have young children. | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | When I see families with children I feel left out. | ○ | ○ | ○ | ○ | ○ | ○ |
| 9 | I feel like friends or family are leaving us behind. | ○ | ○ | ○ | ○ | ○ | ○ |
| 10 | It doesn't bother me when others talk about their children. | ○ | ○ | ○ | ○ | ○ | ○ |

**Ten – week follow up assessment moment**

*Section 1: Adjustment to unfulfilled wish for children*

> **Note for Ethics Committee: All questions in Section 1 are to evaluate limited efficacy.**
>
> **This section will include all questionnaires from Section 2 in baseline assessment moment.**
>
> **plus the following two questions.**

While taking part in this study, have you received support from a certified therapist or counsellor, either in individual or group format, specifically related to your unfulfilled wish for children?

   -Yes
   -No

While taking part in this study, have you used any type of support (i.e., <u>not from</u> a certified therapist/counsellor) for instance, peer group support, online support, self-help books to manage the psychological and social implications of your unfulfilled wish for children?

-  Yes
-  No

*Section 2: Acceptability of MyJourney (intervention group only)*

> **Note for Ethics Committee: this section will be presented the intervention group only. These questions aim to evaluate the acceptability of the intervention and have been adapted from Lancastle and Boivin (2008) (indicated by \*) and developed in-house, based in previous feedback in the acceptability study (Rowbottom and Gameiro, in prep), and based on the values *MyJourney* aims to represent.**
>
> **Acceptability – (A)**
>
> **Implementation – (Im)**
>
> **Text in bold after questions will not be displayed to participants.**

Now that you have had ten-weeks to engage with *MyJourney*, we are interested in what you think about it and invite you to answer the following questions:

1.  I think *MyJourney* is successful in supporting my unfulfilled wish for children\* **(A): (VALUE: Empowering)**
    - Extremely
    - Very
    - A moderate amount
    - A little
    - Not at all
Please explain your answer in as much detail as possible:

2.  I intend to continue using *MyJourney*\* **(A)**:
    -  Yes
    -  No
Please explain your answer in as much detail as possible:

**3.** I would recommend *MyJourney* to someone else in a similar situation* **(A): (VALUE: Awareness)**

    -Yes

    - No

Please explain your answer in as much detail as possible:

5. *MyJourney* has a user-friendly interface **(A)**:
- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please explain your answer in as much detail as possible:

6. *MyJourney* is visually appealing **(A)**:

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please explain your answer in as much detail as possible:

7. How easy was it to understand the content on *MyJourney*?* **(A) (VALUE: Inclusive)**

- Extremely easy
- Very easy
- Somewhat easy
- Not so easy
- Not at all easy

Please explain your answer in as much detail as possible:

8. *MyJourney* is inclusive for those with an unfulfilled wish for children* **(A)**:

    - Extremely

    - Very

    - A moderate amount

    - A little

    - Not at all

Please explain your answer in as much detail as possible:

9. How much did you trust the content on *MyJourney*? **(A) (VALUE: Evidence-based)**

- A great deal
- A lot
- A moderate amount
- A little
- Not at all

Please explain your answer in as much detail as possible:

11. Reporting and receiving feedback about my wellbeing was helpful.

    - Extremely

    - Very

    - A moderate amount

    - A little

    - Not at all

Please explain your answer in as much detail as possible:

12. Assessing each step after doing it was helpful.

- Extremely
- Very
- A moderate amount
- A little
- Not at all

Please explain your answer in as much detail as possible:

13. Did you experience any issues when using *MyJourney*, such as bugs or finding *MyJourney* difficult to use? **(A) (Acceptability of content delivery)**

Please describe in as much detail as you can: _____

14. What did you like most about *MyJourney*? **(A) (From Acceptability study (Rowbottom and Gameiro in prep))**

Please describe in as much detail as you can: _____

15. What did you like least about *MyJourney*? **(A) (From Acceptability study (Rowbottom and Gameiro in prep))**

Please describe in as much detail as you can: _____

16. Did you think engaging with *MyJourney* for ten weeks was the right amount of time? **(A)** and **(Im) (From Acceptability study (Rowbottom and Gameiro in prep))**

Please describe in as much detail as you can: _____

17. If you didn't engage with all ten Steps in MyJourney, can you describe the reason(s) for this?

_____

18. Do you have any other comments you would like to tell us about *MyJourney*?

Please describe in as much detail as you can: _____

19. **Do you have any comments you would like to tell us about participating in this trial?**
You could comment on:
- How you were invited to participate.
- The questionnaires you were asked to complete (the content of the questions, duration or any other details).
- The emails you received.
- Any other aspect.
-
_____
_____

*Section: Current Situation (intervention and waitlist group)*

> **Note for Ethics Committee: this section will be presented to the waitlist and intervention group and has been added in response to the third UK lockdown and ever-changing situation of the COVID pandemic. These questions aim to find out more about how the pandemic is affecting participants wellbeing and their experiences of having an unfulfilled wish for children.**

1. To which degree do you think your well-being is being affected by the current COVID-19 situation?

1 (Very negatively affected)
2 (Negatively affected)
3 (Neither negatively nor positively affected)
4 (Positively affected)
5 (Very positively affected)

2. To which degree do you think your experience of having an unfulfilled wish for children is being affected by the current COVID-19 situation?

1 (Very negatively affected)
2 (Negatively affected)
3 (Neither negatively nor positively affected)
4 (Positively affected)
5 (Very positively affected)

3. If you have any further comments about how the current pandemic is affecting you in relation to your unfulfilled wish for children, please explain in as much detail as you can:

**Six-month follow up assessment moment**

*Section 1: Adjustment to unfulfilled wish for children*

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**Note for Ethics Committee: All questions in Section 1 are to evaluate limited efficacy.**

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**WHO-5** (World Health Organisation , developed at Psychiatric Research Unit, Mental Health Centre North Zealand, Hillerød, Denmark)- HEDONIC WELL-BEING

Please indicate for each of the five statements which is closest to **how you have been feeling over the past two weeks. Notice that higher numbers mean better well-being.** Example: If you have felt cheerful and in good spirits more than half of the time during the last two weeks, choose the box with the number 3 in it.

|   |   | 0 At no time | 1 Some of the time | 2 Less than half of the time | 3 More than half of the time | 4 Most of the time | 5 All the time | Prefer not to say |
|---|---|---|---|---|---|---|---|---|
| 1 | I have felt cheerful and in good spirits | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have felt calm and relaxed | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I have felt active and vigorous | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I woke up feeling fresh and rested | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | My daily life has been filled with things that interest me | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

**MHI-5** (Veit & Ware, 1983a) - MENTAL HEALTH

Using the 1-5 scale below, indicate your response by placing the appropriate number on the line preceding that item.

**How much of the time, during the last month, have you…?**

| | | 1<br>**All of the time** | 2<br>**Most of the time** | 3<br>**A good bit of the time** | 4<br>**Some of the time** | 5<br>**A little of the time** | 6<br>**None of the time** | **Prefer not to say** |
|---|---|---|---|---|---|---|---|---|
| 1 | '...been a very nervous person?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | '…felt calm and peaceful?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | '…felt downhearted and blue?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | '...been a happy person? | ○ | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | '...felt so down in the dumps that nothing could cheer you up?' | ○ | ○ | ○ | ○ | ○ | ○ | ○ |

*WELL-BEING (EUDAIMONIC)* – Overall, to what extent do you feel the things you do in your life are worthwhile? (11 point scale, 0-10) ONS eudaimonic subjective well-being scale (Office for National, 2012)

*SATISFACTION WITH LIFE* - All things considered, how satisfied are you with your life as a whole these days? 1 "completely dissatisfied" - 10 "completely satisfied" (Ahrendt et al., 2017)

*HAPPINESS* - Taking all things together on a scale of 1 to 10, how happy would you say you are? Here 1 means you are very unhappy and 10 means you are very happy. (Ahrendt et al., 2017)

Post traumatic growth inventory – short form (Cann et al., 2009) – POST TRAUMATIC GROWTH

Indicate for each of the statements below the degree to which this change occurred in your life as a result of your unfulfilled wish for children, using the following scale.

0 = I did not experience this change as a result of my unfulfilled wish for children.
1 = I experienced this change to a very small degree as a result of my unfulfilled wish for children.
2 = I experienced this change to a small degree as a result of my unfulfilled wish for children.
3 = I experienced this change to a moderate degree as a result of my unfulfilled wish for children.
4 = I experienced this change to a great degree as a result of my unfulfilled wish for children.
5 = I experienced this change to a very great degree as a result of my unfulfilled wish for children.

| | | **1** | **2** | **3** | **4** | **5** | **Prefer not to say** |
|---|---|---|---|---|---|---|---|
| 1 | I changed my priorities about what is important in life. | ○ | ○ | ○ | ○ | ○ | ○ |
| 2 | I have a greater appreciation for the value of my own life | ○ | ○ | ○ | ○ | ○ | ○ |
| 3 | I am able to do better things with my life. | ○ | ○ | ○ | ○ | ○ | ○ |
| 4 | I have a better understanding of spiritual matters. | ○ | ○ | ○ | ○ | ○ | ○ |
| 5 | I have a greater sense of closeness with others. | ○ | ○ | ○ | ○ | ○ | ○ |
| 6 | I established a new path for my life. | ○ | ○ | ○ | ○ | ○ | ○ |

| 7 | I know better that I can handle difficulties. | ○ | ○ | ○ | ○ | ○ | ○ |
| 8 | I have a stronger religious faith | ○ | ○ | ○ | ○ | ○ | ○ |
| 9 | I discovered that I'm stronger than I thought I was. | ○ | ○ | ○ | ○ | ○ | ○ |
| 10 | I learned a great deal about how wonderful people are. | ○ | ○ | ○ | ○ | ○ | ○ |

**Section 2: Acceptability of MyJourney**

> **Note for Ethics Committee: These questions are to evaluate the acceptability (A) of the intervention.**
>
> **Text in bold after questions will not be displayed to participants.**

We are interested to know what you think about MyJourney now, please answer the following questions:

1.  I intend to continue using *MyJourney** **(A)**:
       - Extremely
       - Very
       - A moderate amount
       - A little
       - Not at all

**2.** I would recommend *MyJourney* to someone else in a similar situation* **(A) (VALUE: Awareness)**
       - Extremely
       - Very
       - A moderate amount
       - A little
       - Not at all

3.  Over the past six-months, I have recommended *MyJourney* to a friend who is in a similar situation to me **(A)**:
    -   Yes
    -   No
    -   If yes, how many people? _____

4. Do you have any other comments you would like to tell us about *MyJourney*?

Please describe in as much detail as you can: _____

**Non-participation survey**

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**Note for Ethics Committee: these questions aim to provide insight into the:**

- **acceptability of the intervention and study procedures**
- **demand of intervention and study procedures**
- **implementation of intervention and study procedures**

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Thank you for your interest in this trial and your participation so far. We are interested in understanding why you do not (or no longer) wish to take part in this study.

Please describe all the reasons that contributed to your decision:

_____

Please tell us any other information that you think is relevant for us to know:

_____

## Debrief form

### Feasibility trial of *MyJourney* - support for people who have an unfulfilled wish for children

This study is part of research developing an intervention to support people with an unfulfilled wish for children. This intervention has been based on the **Three Task Model of Adjustment** (Gameiro & Finnigan, 2017) which suggests that three tasks (acceptance, meaning making, pursuit of new life goals) could help people adjust to realising their unmet parenthood goals by improving their mental health and wellbeing.

*MyJourney* aims to help people engage in the three tasks mentioned above (acceptance, meaning making and pursuit of new life goals). We hypothesise that using *MyJourney* over ten-weeks will help people develop acceptance towards not being able to achieve the family they desire and build skills to help them move towards a more fulfilling life. This will translate into improved mental health and wellbeing.

We[https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_3](https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH) hypothesised that participants allocated to the intervention group and use *MyJourney* will report an improvement in their mental health and wellbeing from before to ten weeks after having access, which will be sustained at least during 6 months (last assessment). We hypothesise that participants allocated to the waitlist control group will report similar mental health and wellbeing scores at the beginning of the study and ten weeks later, before they have engaged with *MyJourney*. We also hypothesise that participants who use *MyJourney* more often and for longer times will report a higher improvement than those who use it to a lesser extent.

We will also use the data[https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH PHD/WEB APP/Feasibility stuy/Ethics Proforma Supporting Document_C1858230_Rowbottom_Feasbility Study SGameiro.docx - _msocom_4](https://cf-my.sharepoint.com/personal/gameiros_cardiff_ac_uk/Documents/SHARE/BETH) from this study to plan a larger scale randomised controlled trial to test the efficacy of *MyJourney*.

Finally, the information we gather from you in this study will assist us in developing *MyJourney* further, ensuring that it is presented in the most acceptable and useful way to meet the needs of people with an unfulfilled wish for children.

Your data will be stored confidentially in accordance with GDPR regulations. Only the researchers on this project will be able to access your data. Your data will be anonymised one month after the survey has closed and that after this point, no-one will be able to trace your information back to you. You can ask for the information you have provided to be deleted at any time up until the data has been anonymised and you can have access to the information up until the data has been anonymised.

If you feel you would like support after doing this trial, we have provided the contact details for Fertility Network UK Email- info@fertilitynetworkuk.org Tel- 01424 732361

If you are worried about your mental health, please contact your GP or NHS mental health online.

If you would like to read more about this model, and what it has hypothesised, please look at the following paper on Google Scholar: Gameiro, S., & Finnigan, A. (2017). Long-term adjustment to unmet parenthood goals following ART: a systematic review and meta-analysis. *Human Reproduction Update*, *23*(3), 322-337.

If you would like to get in touch with the researcher and supervisor of this study, please use the contact details below.

| **Bethan Rowbottom** | **Dr Sofia Gameiro** | **Dr Ana Galhardo** |
|---|---|---|
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**Privacy Notice:**

The information provided will be held in compliance with GDPR regulations. Cardiff University is the data controller and James Merrifield is the data protection officer (inforequest@cardiff.ac.uk). The lawful basis for processing this information is public interest. This information is being collected by Beth Rowbottom, Sofia Gameiro and Ana Galhardo.

## Appendix O: Randomised controlled feasibility trial – Table of comparison of completers and non-completers at T2

| Variable | Completed FU M (SD) (N = 128) | Did not complete FU M (SD) (N = 91) | T test p value [CI] |
|---|---|---|---|
| Age, years | 37.45 (9.27) | 41.56 (9.43) | .002 [-6.66, -1.57] |
| | N (%) | N (%) | $\chi^{2a}$ p value |
| *Gender* | | | |
| Female | 107 (83.6) | 85 (93.4) | .086 |
| Male | 19 (14.8) | 5 (5.5) | |
| *Relationship status* | | | |
| Single | 24 (18.8) | 20 (22.0) | .557 |
| Relationship | 104 (81.3) | 71 (78.0) | |
| *Education* | | | |
| No degree | 28 (21.9) | 22 (24.2) | .689 |
| Degree (including UG and PG degree) | 100 (78.1) | 69 (75.8) | |
| *Employment* | | | |
| Unemployed (including student, retired, other) | 22 (17.2) | 12 (13.2) | .230 |
| Employed (part time/ full time) | 103 (80.5) | 79 (86.8) | |
| *Ethnicity^* | | | |
| White | 84 (93.3) | 52 (89.7) | .284 |
| Mixed Ethnicity | 2 (2.2) | 1 (1.7) | |
| Asian | 2 (2.2) | 2 (3.4) | |
| Black/African | 2 (2.2) | 2 (2.2) | |
| Arab | 0 (0.0) | 1 (1.7) | |
| Other | 0 (0.0) | 2 (3.4) | |
| *Country* | | | |
| United Kingdom | 47 (36.7) | 41 (45.6) | .009 |
| Portugal | 38 (29.7) | 30 (33.3) | |
| Rest of Europe | 34 (26.6) | 7 (7.8) | |
| USA | 5 (3.9) | 6 (6.7) | |
| Rest of World | 4 (3.1) | 6 (6.7) | |
| *Sustained child wish* | | | |
| No | 21 (16.4) | 14 (15.4) | .839 |
| Yes | 107 (83.6) | 77 (84.6) | |
| *Parental status* | | | |
| No children | 107 (83.6) | 81 (89.0) | .257 |
| Has children | 21 (16.4) | 10 (11.0) | |
| *Engaged in fertility treatment* | | | |
| No | 57 (44.5) | 29 (31.9) | .059 |
| Yes | 71 (55.5) | 62 (68.1) | |
| *Journey Status* | | | |
| Not trying to accept | 17 (13.3) | 15 (16.5) | .393 |
| Trying to or thinking about trying to accept | 105 (82.0) | 71 (78.0) | |
| Already accepted | 2 (1.6) | 4 (4.4) | |
| Other / Don't know | 4 (3.1) | 1 (1.1) | |
| *Engaged with support in the past* | | | |
| No | 63 (49.2) | 45 (49.5) | .973 |

| Variable | Completed FU M (SD) (N = 128) | Did not complete FU M (SD) (N = 91) | T test p value [CI] |
|---|---|---|---|
| Yes | 65 (50.8) | 46 (50.5) | |
| *Currently engaged with informal support* | | | |
| No | 98 (76.6) | 71 (78.0) | .800 |
| Yes | 30 (23.4) | 20 (22.0) | |
| *Recruited via Prolific* | | | |
| No | 87 (68.0) | 86 (94.5) | <.000 |
| Yes | 41 (32.0) | 5 (5.5) | |
| *Language* | | | |
| English | 90 (70.3) | 58 (63.7) | .306 |
| Portuguese | 38 (29.7) | 33 (36.3) | |
| **OUTCOMES** | *M (SD)* | *M (SD)* | **T test p value [CI]** |
| **Primary outcome** | | | |
| Hedonic wellbeing | 45.63 (19.78) | 42.86 (16.61) | .277 [-2.24, 7.78] |
| **Secondary outcomes** | | | |
| Eudaimonic wellbeing | | | |
| *Life is worthwhile* | 5.78 (2.41) | 5.69 (2.36) | .786 [-0.56, 0.73] |
| *Happiness* | 5.66 (1.85) | 5.32 (1.98) | .188 [-0.17, 0.86] |
| *Satisfaction with life* | 5.76 (1.91) | 5.45 (2.09) | .264 [-0.23, 0.84] |
| Mental Health | 53.72 (18.18) | 50.86 (17.85) | .249 [-2.00, 7.72] |
| Posttraumatic growth | 21.96 (10.50) | 22.21 (12.06) | .872 [-3.27, 2.78] |

## Appendix P: Randomised controlled feasibility trial – Detailed table of themes generated from process evaluation

| Meta theme | Theme | Feasibility Criteria | Endorsement | Quotes |
|---|---|---|---|---|
| *MyJourney is acceptable, meeting a perceived demand for support* | Having a UPG is difficult (80%) | Demand (INT) | Half (50%) referred the challenges of fertility issues, and childlessness, references the need to avoid certain people or situations. | *"I was just isolated with it, there was no one else going through it, there was no one else to talk to…my mental health really suffered, really really suffered at that time"* (IT2, 52, EN) |
| | | | Half (50%) have used alternative methods to cope with unfulfilled wish for children. | '*I did CBT um a couple of years ago, just to really help me overcome somethings'* (WL1, 43, EN) |
| | | | Most (70%) are members of peer support groups. | *"I am a member of a support group and I do regularly meet support group and talk about those sorts of things"* (IT5, 39, PT) |
| | Research this area is important (60%) | Demand (INT) | Around a third (30%) felt MyJourney was making childlessness more visible | *"it is such an important area that is hopefully becoming more and more known about"* (WL2, 42, EN) |
| | MyJourney satisfies need for support (80%) | Demand (INT) | Half (50%) hoped MyJourney would help them | *"I think the reason I wanted to get involved was because it's like, oh my god wow, somebody is helping, somebody is even acknowledging that this is a really difficult thing"* (IT2, 52, EN) |
| | | Acceptability (INT) | Half (50%) of participants felt MyJourney was supportive | *"you very quickly get support, it does feel very supportive, even though it's very individual"* (WL2, 42, EN) |
| | | Acceptability (INT) | Most (60%) felt the mindfulness meditations were a positive feature in MyJourney | *"I think the mediation part is awesome. It is very important for whom who practice, for whom has never practised, to who is not familiar with it… I found it very good"* (IT4, 37, PT) |
| | Most will revisit MyJourney in the future or think it will be useful for future cohorts (60%) | Acceptability (INT) | Just under half (40%) of participants plan to continue using MyJourney, and 20% reported using the tools they learnt in their daily life. | *"I think I probably will have another look at MyJourney and because I think, to remind myself of the good things I saw in it"* (WL1, 43, EN) |
| | | Acceptability (INT) | A third (30%) of participants referred to MyJourney being part of support that can | *"I think that's really hopeful as well that maybe generations that come afterwards that have more support and more recognition and more tools available"* (WL5, 48, EN) |

| Meta theme | Theme | Feasibility Criteria | Endorsement | Quotes |
|---|---|---|---|---|
| | | | be useful for people accessing it in the future | |
| | MyJourney appears to achieve desired outcomes (80%) | Acceptability (INT) | Most (70%) felt MyJourney was useful | "*teach yourself to sort of let go of some of it and its ok to leave some of those bits of luggage behind that are maybe not as relevant now or as important as they were or would have been earlier on in the journey...so that one was useful*" (IT1, 44, EN) |
| | | | Half (50%) felt MyJourney helps one to move forward | "*I suppose it's that journey bit, but it's that sort of moving, moving you forward and giving you those strategies and those supports to be able to do that*" (WL2, 42, EN) |
| *Flexible engagement with MyJourney was valued and practical, but this engagement was multidetermined.* | Participants value flexibility to engage with MyJourney (100%) | Practicalities (INT) | Almost half (40%) of participants liked that one could engage with MyJourney at a time and pace that suited, and two thirds (60%) said it was convenient to engage with | "*working through it at your own pace, and your own time, at your own pace is hugely beneficial*" (WL2, 42, EN) |
| | | Implementation (INT) | Most (60%) reported that they didn't engage with MyJourney with one Step per week as suggested | "*Even though it was on my own, with time, it took me some months… I found it very good*" (IT4, 37, PT) |
| | Engaging with MyJourney was mostly practical (60%) | Practicalities (INT) Acceptability (INT) | Half (50%) felt the online delivery of MyJourney was appropriate and practical. | "*This is one of the best parts, being always available*" (IT4, 37, PT) "*So I think an online intervention tool is really useful*" (IT1, 44, EN) |
| | | | Less than half (40%) referred to some less practical aspects, such as needing to use MyJourney on a larger screen | "*I engaged with it on my phone, which was a regret...in hindsight I wouldn't have put it on my phone, I would have yeah, used it on a larger screen device*" (IT3, 39, PT) |
| | Engagement is multidetermined (80%) | Demand (INT) | Most (60%) felt engagement with MyJourney was influenced by stage of grief | "*I just wonder whether the app might be just, even more useful for people at earlier stages in the journey*" (WL1, 43, EN) |
| | | Implementation (INT) | Just under half (40%) referred to barriers to engagement, such as technical issues (e.g., pop ups, reminders going to spam) | "*perhaps had the ones that had gone into spam, arrived, I'd perhaps, perhaps might of engaged a little bit more*" (IT4, 37, PT) |
| | | Implementation (INT) | Just under half (40%) felt engagement with MyJourney should not be rushed | "*I'm thinking maybe I'll give myself more than a week to do each step just to make sure I'm covering everything in the backpack*" (WL1, 43, EN) |

| Meta theme | Theme | Feasibility Criteria | Endorsement | Quotes |
|---|---|---|---|---|
| | Half of participants had minor suggestions for improvement (50%) | Acceptability (INT) | A minority (20%) felt MyJourney could be more user friendly. | "*there could possibly be some more work on the um on making it more customer friendly in a certain sense*" (WL5, 48, EN) |
| *The trial study procedures are practical.* | Study procedures are appropriate (100%) | Acceptability (SP) Practicalities (SP) | A majority (90%) felt the online questionnaires were appropriate, and not too demanding but half (50%) felt they were difficult | "*I thought the questionnaires were good, they asked the right kind of questions in the right way you know they were nicely asked and the wording was nice*" (WL3, 38, EN) |
| | | | A third (30%) reported understanding the requirement for randomisation, but 20% were disappointed they were allocated to waitlist control. | "*I knew I had a like, 50/50 chance of one or the other, and I thought yeah I'll participate irrespective of which group I get randomised into*" (IT1, 44, EN) |
| | | | More than a third (40%) were happy to contribute to further research in this area | "*I've really enjoyed them [studies], the last two I've done with yourselves, um and I've learnt a lot about myself...I'm quite happy to take part in other things you're wanting to do*" (WL3, 38, EN) |

## Appendix Q: Randomised controlled feasibility trial – Table of progression criteria and level met

| Feasibility Outcome | Progression Criteria | Criteria level met |
|---|---|---|
| | **Intervention** | |
| *Demand* | Green: >50% in the intervention group register and start using the intervention | Amber |
| | Amber: 10-50% in the intervention group register and start using the intervention (i.e., complete first Step) | |
| | Red: <10% in the intervention group register and start using the intervention | |
| *Acceptability* | Green: For all intervention group participants the average rating for is >4 (somewhat agree/very) for most acceptability variables. | Amber |
| | Amber: For all intervention group participants the average rating is >3 (neither agree nor disagree/a moderate amount) for most acceptability variables. | |
| | Red: For all intervention group participants the average rating is 1 (strongly disagree/not at all) for all acceptability variables. | |
| | Green: >50% of intervention group participants would recommend to others and intend to keep using | Green |
| | Amber: 10-50% of intervention group participants would recommend to others and intend to keep using | |
| | Red: <10% of intervention group participants would recommend to others and intend to keep using | |
| | Green: For all intervention group participants the average rating for most steps is >4 (very much) for usefulness and <2 (a little) for challenging. | Amber |
| | Amber: For all intervention group participants the average rating for most steps is >3 (moderately) for usefulness and <3 (moderately) for challenging. | |
| | Red: For all intervention group participants the average rating for all steps is >1 (not at all) for usefulness and <5 (extremely) for challenging. | |
| *Implementation* | Not criteria set. | |
| *Practicalities* | Green: > 50% intervention group participants receive sufficient dose within 10-week timeframe | Amber |
| | Amber: 10-50% intervention group participants receive sufficient dose within 10-week timeframe | |
| | Red: < 10% intervention group participants receive sufficient dose within 10-week timeframe | |
| *Adaptation* | No criteria set. | |
| *Limited efficacy* | No criteria set. | |
| | **Study Protocol** | |
| *Demand* | Green: >50% of participants who demonstrated an interest in the trial are eligible. | Green |
| | Amber: 30-50% of participants who demonstrated an interest in the trial are eligible. | |
| | Red: <20% of participants who demonstrated an interest in the trial are eligible. | |
| | Green: >50% of eligible participants are recruited. | |

| Feasibility Outcome | Progression Criteria | Criteria level met |
|---|---|---|
| | Amber: 30-50% of eligible participants are recruited | Green |
| | Red: <20% of eligible participants are recruited | |
| | Green: <20% lost to follow up | Amber |
| | Amber: 20%-80% lost to follow up | |
| | Red: >80% lost to follow up | |
| *Acceptability* | Green: >70% participants complete both assessment moment questionnaires | Amber |
| | Amber: 30-70% participants complete both assessment moment questionnaires | |
| | Red: <30% participants complete both assessment moment questionnaires | |
| *Implementation* | No criteria set. | |
| *Practicalities* | No criteria set. | |
| *Adaptation* | No criteria set. | |