Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

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Dissertation submitted in partial fulfilment of the requirement for the degree of DClinPsy at Cardiff University and the South Wales Doctoral Programme in Clinical Psychology

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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Target Journals for Publication

The target journals are:

Systematic literature Review: The Journal of Counselling and Consulting Psychology

Empirical Report: Human Reproduction

Summary of Thesis

This thesis investigates the adjustment processes to involuntary childlessness and the psychological distress associated with unmet parental goals.

Paper one reports a systematic review of quantitative studies looking at how trauma theory informs the clinical understanding of adjustment to involuntary childlessness. This yielded eight studies which were reviewed and rated using a quality appraisal tool. The data extracted, focused on the prevalence of trauma and post traumatic growth to infertility. No studies included, focused their research on cohorts of women who identified as being involuntarily childless through delayed childbearing or circumstantial reasons. The findings suggested that for women who are, infertile, who had accessed or were accessing fertility treatment and were childless, trauma theory can aid clinical understanding of both their experience of infertility distress and adjustment to involuntary childlessness.

Paper two describes a three round, online Delphi Study which investigated, infertility practitioners' clinical experience of psychological distress associated with unmet parental goals, following unsuccessful fertility treatment. Nine practitioners, from five countries participated, rating 58 statements on the presentation and nature of distress observed in the post treatment phase. Infertility practitioners perceived distress to be associated with statements concerned with individual's identity and relinquishing the desire for biological children. The fertility practitioners agreed that the core element of therapy was to facilitate meaning making, acceptance and pursuit of new life goals.

Paper three provides a critical account of the strengths and limitations of both the systematic review and empirical paper. The theoretical and clinical implications of the research included addressing pertinent issues, which arose during the research process. Finally, the competencies developed from conducting this research will be described in relation to becoming a clinical psychologist.

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Empirical Project

Word count

Systematic Review = 7976

Empirical project = 7455

Critical Review Paper = 7295

(Excluding tables, figures, references)

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Systematic Review

Empirical Paper

How does trauma theory inform clinical understanding of the adjustment to involuntary childlessness?

A systematic review

Manuscript prepared in accordance with APA, Journal of Counselling and Consulting Psychology submissions guidelines.

Max word count for journal submission: 8000 words
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(excluding abstract, tables, figures and references)

(Appendix A for manuscript submission checklist)

Abstract

Objectives: Involuntary childlessness is the denied opportunity to fulfil biological parenthood; either as a result of biological mechanisms, infertility, personal circumstances or delayed childbearing. This experience is increasingly understood to be traumatic or to be a traumatising life event. This review aimed to examine how trauma theory has informed research relevant to clinical understanding of adjustment to involuntary childlessness.

Method: Five databases (PsychInfo, Medline, Embase, Assia and Scopus) were systematically searched in February 2018 for empirical research incorporating trauma, trauma theory and involuntary childlessness.

Results: Eight papers met the inclusion criteria for the final narrative review, their quality was assessed and data extracted. The findings were of mixed quality, reporting on prevalence and application of trauma theory to infertility distress and on post traumatic growth associated with the infertility experience.

Conclusion: The review concluded that the findings should be treated with caution but that there was mounting evidence that trauma theory can aid clinical understanding of both the experience of infertility distress and adjustment to involuntary childlessness.

Keywords*:* Involuntary childlessness, infertility, trauma, PTSD, post traumatic growth, systematic review

Introduction

Childlessness

Childlessness is an important issue (Carmichael & Whittaker, 2007) and one that warrants further attention in understanding its psychological impact (Craig et al., 2014; Koert & Daniluk, 2017). Childlessness describes a person or couple who do not have children (Shaprio, 2014). The number of adults without children has grown significantly (Craig et al., 2014; Pesando, 2017) with a global trend of increased childlessness among women born during the 1960's, 1970's and 1980's (Craig et al., 2014). Within the United Kingdom, the levels of infertility and childlessness are higher than other European countries (Berrington, 2017) with a reported 18% of women born in 1971 who have remained childless as they pass childbearing age (Office of National Statistics, 2017).

There are multiple reasons for childlessness (Tocchioni, 2018), influenced by both couple dynamics (e.g. Jalovaara and Fasang 2017), intrapersonal issues (e.g. Letherby, 2002), socio-economic factors (e.g. Berrington, Stone, & Beaujouan, 2015) alongside a growing trend for women to delay child bearing (Letherby; 2002; Buhr & Huinink, 2017). For women in particular, the experience of being childless is hypothesised to be very different depending on the 'topology' in which childlessness occurs (Turnball, Graham & Taket, 2016), for instance, depending on personal attributions (Shreffler, Greil & McQuillian, 2017), desire for children (Becker, 2000) and the socio-cultural discourses placed on motherhood (Bell, 2013; Pesando, 2018). Two topologies are prevalent in the childlessness literature (Turnball et al., 2016), firstly, voluntarily childlessness, in those who have chosen to be child free and not parent (Shaprio, 2014); second, involuntarily childlessness which is a broad construct which is made up of, incorporating childlessness because of biological mechanisms either associated with infertility, physical health conditions or with injury which prevents spontaneous

conception or viable pregnancy (Lucas et al., 2014). Infertility is diagnosed after one year of unprotected intercourse, and further categorised into primary, secondary, explained, or unexplained (Evers, 2002; National Institute for Health and Clinical Excellence; NICE, 2013). Involuntary childlessness also includes those women who are childless because of personal circumstances (Letherby, 2002), which may arise from being in a same sex relationship or through delayed childbearing (Turnball et al., 2016). As Notkin (2015) describes in her personal account, childlessness by circumstance refers to when predefined conditions and values are not in place so an individual might delay parenthood (e.g. love, marriage, financial security) and find themselves "unknowingly and unwittingly becoming permanently childless" (Koert & Daniluk, 2017, p343). Collectively, infertility and involuntary childlessness are characterised as undesired and distressing in nature.

Involuntary childlessness can precipitate a distressing life crisis (Oddens, Tonkelaar, & Nieuwenhuyse, 1999) and infertility has been described as distressing and traumatic (Schwerdtfeger & Shreffler, 2009; Yu et al., 2014), for instance, as one of the most stressful events for a couple (Klonoff-Cohen, Chu, Natarjan & Sieber, 2001); with an intensity, both emotional and physical, that equals that of other reported traumatic events (Freideriksen, Farver-Vestergaard, Skovgård, Ingerslev & Zachariae, 2015). Furthermore, the psychological impact has been found to still persist 20 years after unsuccessful fertility treatment (Wirtberg, Moller, Hogstrom, Tronstad, & Lalos, 2007) and for those childless due to postponement, to be associated with an increased sense of responsibility and regret (Koert & Daniluk, 2017).

Much of the evidence pertaining to adjustment to involuntary childlessness focuses on women (Gameiro et al., 2014) who have experienced failed fertility treatments (Boivin, 2003; Greil, Slauson-Blevins & McQuillian, 2010). It draws on theoretical constructs from stress and coping (Lazarus & Folkman, 1984) and grief and loss models (Daniluk, 2001). Studies

are predominantly cross-sectional in design and have limited comparison samples (Greil et al., 2010). In addition, participants are commonly active treatment seekers, invested in achieving their child wish (Gameiro & Finnegan, 2017). Little is known about psychological adjustment processes in cohorts facing permanent childlessness as a result of delayed childbearing (Koert & Daniluk, 2017) or about how adjustment to involuntary childlessness is affected or mediated by short or long-term exposure to psychological trauma.

Psychological trauma

Psychological trauma is often associated with the experience of an extremely stressful, distressing event or circumstances which could be interpreted as harmful or life threatening (APA, 2018). These events can be one off and catastrophic or prolonged, with associated developmental significance if they occur in early life (Herman, 1992; Reswick et al., 2012). Trauma from one off events and adverse childhood experiences (ACEs), impacts on neurological development, fundamentally altering the nervous, hormonal and immunological systems which affects sensory, emotional and cognitive processing systems (van der Kolk, 2015). The type and amount of exposure to trauma is influential in the development of post-traumatic stress disorder [PTSD]. PTSD has a multifactorial etiology (Brewin, Andrews & Valentine, 2000) which involves re-experiencing, avoidance, emotional numbing and hyperarousal symptoms (APA, 2013). Complex PTSD features clusters of symptoms which relate to emotional dysregulation, negative self-cognitions and interpersonal difficulties (Giourou et al., 2018). Furthermore complex PTSD, especially as result of cumulative exposure to multiple or repeated forms of stress, trauma or mistreatment, has been shown to affect multiple affective and interpersonal domains (Cloitre et al, 2009).

Trauma has been described as a different construct to that of loss and complicated grief even though they have both been described as stress-response syndromes (Maercker & Znoj, 2010). Complicated grief is characterised by the intense yearning and longing for the loved one and unfulfilled wishes (e.g. the loss of an unborn child in regards to involuntary childlessness (Daniluk, 2001)), with the loss becoming a significant focus in an individual's lives (e.g. the reported inability to achieve emotional acceptance of childlessness (Volgsten, Svanberg & Olsson, 2010)).

Trauma however, is conceptualised by intrusive symptoms (Maercker & Lalor, 2012) such as flashbacks, nightmares and distressing memories (e.g. the invasive nature of fertility treatment procedures) which cause autonomic changes (Maercker & Znoj, 2010). There is also avoidance (e.g. avoidance of others' (perceived) fertility (Lechner, Bolman & van Dalen, 2007; Volgsten et al., 2010)) as well as changes to cognition and mood (e.g. feelings of guilt and shame, and reduced sense of worth at being unable to have children (Volgsten et al., 2010; Koert & Daniluk, 2017)). There may also be alterations in arousal and reactivity (Pai, Sursi & North, 2017), with increase hypervigilance (e.g. for pregnant women and children) and decrease pleasure in activities and increased social isolation.

Complex PTSD, including that associated with ACEs, has long lasting impact on health outcomes (Felitti et al., 1998; Public Health Wales, 2015), negatively impacting on mental and physical health across the lifespan (BPS, 2016b). Epidemiology studies in the UK, show a higher than anticipated prevalence rate of adults with a history of ACES; with 49% experiencing at least one ACE and 14% four or more ACES in Wales (PHW, 2015). There is also an increased prevalence of adversity, in the history of those referred to mental health and physical health services (Bellis et al., 2014) and therefore Sweeny et al., (2016) argue that ACEs are one of the greatest unaddressed public health crises across the lifespan and inclusive of cohorts of childbearing age.

Trauma and infertility

A reported 15% of women suffer reproductive trauma (Bhat & Byatt, 2016), which is defined as trauma resulting from infertility or perinatal loss, or as a combination of both. Reproductive trauma is also associated with depression, anxiety and PTSD symptoms (Rockliff et al., 2014; Daugirdaitė, van den Akker & Purewal, 2015 et al., 2015). There is little evidence that trauma experience is directly causally related to infertility and childlessness (Santos, Sobral, & Martins, 2017) and this review excludes papers on reproductive trauma or that attempt to examine this as a causal factor. Instead, it is hypothesised that the psychological adjustment processes displayed by individuals who are infertile or involuntarily childless will differ if they do or do not have historic or ongoing experience of trauma (Harville & Boynton-Jarrett; 2013; Jacobs, Boynton-Jarrett & Harville, 2015). Moreover, leaving aside the neuro-psycho-immunological impact of trauma on the body (Li, Knox & O'Byrne, 2010), the experience of trauma has been found to be associated with several psychosocial risk factors which may influence achieving parenthood (Rockliff et al., 2014) through their developmental influence on adult attachments (Harville et al., 2013), emotional regulation (Verhaak et al., 2007; Rockliff et al., 2014), identity and inter-personal communication (Gourounti et al., 2012). If as Greil et al. (2010) have argued, studies of involuntary childlessness and infertility should conceptualise failure to achieve parenting goals in psychosocial terms, then trauma theory constructs may offer an alternative to stress and coping (Lazarus and Folkman, 1984) or grief and loss models (Boelen, 2016; Stroebe, Schut, & Boerner 2010) in understanding the adjustment process. Involuntary childlessness within the literature has predominately been viewed as a medical and biological phenomenon (Joy & McCrystal, 2015) which has psychological consequences (Greil et al., 2011). This characterisation minimises the socially constructed experience associated with involuntary childlessness (Letherby, 2002; Bell, 2013). Psychological distress is categorised as a

consequence of infertility or infertility treatment processes; as opposed to being located in the psychological and social functioning of individuals and dyads who are adjusting to a change in their reproductive story and journey to parenthood (Jaffe, 2017).

Trauma in the reproductive journey is said to threaten 'sense of self' and adult identity within a pronatalist society; were procreation is a dominant discourse and societal ideologies construct motherhood (Turnball et al., 2016). In this context navigation and adjustment to childlessness is complex and can take time (Su & Chen, 2006). Furthermore, research tends not to distinguish between the topologies of involuntary childlessness (Koert & Daniluk, 2017; Shreffler et al., 2017) making it difficult to determine factors unique to adjustment to this traumatic experience. In addition, there is little agreement on what constitutes adjustment within the trauma literature regarding infertility. For instance, is it based on low levels of intrusion and avoidance or more specific thoughts associated with regret and responsibility which impact on the adjustment process which have been better defined in the grief and coping literature-base.

Rationale of the review

The evidence base would suggest that involuntary childlessness, and its meaning for an individual or couple, varies according to socio-cultural values held about parenthood in their community (Turnball et al., 2016). Furthermore, the desire to have children (Shreffler et al., 2017) and the task of disengaging from blocked parental goals (da Silva, Boivin & Gameiro, 2016) can become more complex in this socio-cultural context. Alongside this, there is growing understanding of trauma and associated processes of post-traumatic growth and depreciation (Cann et al 2010) and emergent focus on how this might impact adjustment in relation to failed infertility treatment (Schmidt et al., 2005). Therefore, this review looks to extend the infertility literature by critically appraising studies of how trauma and post

traumatic growth impact on adjustment to involuntary childlessness. The aim is to address the following question: How does trauma theory inform clinical understanding of adjustment to involuntary childlessness?

Methodology

Systematic search

A systematic search of the literature was conducted using five databases including Medline, PsycINFO, Embase, ASSIA and SCOPUS (February 2018). The databases were selected specifically to align with the aims: PsycINFO to include studies addressing the psychological aspects of involuntary childlessness and to incorporate different theoretical models of trauma; Medline and Embase for their superior Medical Subjective Headings (MeSH) search facilities incorporating bio-medical, clinical medicine and health articles; ASSIA and SCOPUS for wider socioeconomic and cultural perspectives on childlessness and trauma. References of papers were also searched by hand and a leading author in infertility was contacted regarding the review question, additional papers were then included.

Search Terms (with truncations) were adapted from the Ovid databases (i.e. Medline, PsycINFO and EMBASE) and adapted accordingly for each database. The following keywords were used in in title/abstract search: “Childlessness” or “involuntary childlessness” or “infertile” or “nulliparous” or “delayed motherhood” and “trauma” or “PTSD” or “complex trauma” or “posttraumatic growth” or “adjustment” or “benefit finding”. The detailed search strategy is presented in Appendix B. From the initial scoping searches, a number of terms relating to trauma and post-traumatic growth were removed from the search stream, as these were found to narrow the search. Similarly, different combinations of the search streams were trailed with the Boolean operators, in order to optimise the search process. No geographical or publication date parameters were placed on the search due to the fact that childlessness and trauma are both global experiences and not limited in time. No restrictions were placed on the type of literature or language of the publication initially. The

search was checked by identifying if three articles were present; these had been previously identified as being eligible for the review.

Inclusion and exclusion criteria

For inclusion, studies had to define childlessness as involuntary, either as a result of infertility or social circumstances; investigate cognitive, emotional, physical or behavioural presentations of trauma; establish trauma reactions through a clinical measure, or a diagnosis that met DSM-V diagnostic criteria for PTSD (APA, 2013); propose a clinical or theoretical model to explain the bio-psycho-social components of trauma on involuntary childlessness, or specifically report traumatic growth (implying a trauma response) to elucidate the findings of the studies. Studies were excluded if: involuntary childlessness was a result of reproductive trauma (miscarriage, abortion or death of the child); no clinical measures were used; or if an article was a review of the literature.

Table 1: Full inclusion and exclusion criteria

	Inclusion	**Exclusion**
Population	Childless and/or infertile women of childbearing age (e.g. 16yrs plus) Primary infertility women Infertile couples	Childlessness due to miscarriage, abortion or death of child. Papers referencing non- humans. Individuals with secondary infertility.
Intervention **(Exposure)**	Current experience of childlessness Experience of unsuccessful infertility treatment. Primary infertility Theory of trauma or post-traumatic growth applied	Childlessness is resolved through Artificial Reproductive Technologies [ART], adoption, fostering and /or surrogacy.
Comparisons	Individuals with children Fertile individuals/couples with children (e.g. adoption or secondary infertility)	No trauma reactions are reported. Main focus is on depression, stress and anxiety
Outcome	Measure of trauma symptomatology on validated measures Diagnoses of PTSD Qualitative data of traumatic experience and symptoms Single-case data	No validated measures of trauma symptomatology or post traumatic growth. No qualitative data of traumatic experiences and symptoms.
Study Design	Quantitative and qualitative studies	Conference abstracts, books, editorials & literature reviews

Data extraction

Relevant information was extracted by a standardised data protocol to characterise the set of studies (The European Society of Reproductive and Embryology, ESHRE; 2018). This included (where possible) information regarding: author and country of study; design (cross-sectional or longitudinal); type (infertile or childless by circumstance) and size of involuntary childless group and control groups; predisposing traumatic event(s) described in line with DSM-V, criterion A for PTSD (APA, 2013); self-reported measures; conceptual models of trauma including a focus on PTG; and reported outcomes.

Quality appraisal

ESHRE recommend the use of a checklist to rate the strength and quality of scientific evidence within a study (ESHRE, 2017). The 'Evidence-base Librarianship (EBL) critical appraisal tool' (Appendix D; Glyn, 2006) was chosen to appraise the studies. This tool assesses four domains: population, data collection, study design and results. Overall selection, performance and detection bias, construct validity and reliability are assessed, through a series of prompt questions. Each question is answered by ticking either "yes", "no", "unclear", or "not applicable". Percentages are then calculated for individual domains and overall study validity using the formula [Y/T $\geq$75% or N/U $\leq$ 25%], where a score of less than 75% indicates the paper has omissions or is of poor validity and reliability. This tool was selected due to being versatile, enabling comparison of different study designs (Eldredge, 2006); it has demonstrated ability to determine the validity, applicability and appropriateness of a study and whether it incorporated elements of good clinical practice.

The primary researcher conducted quality assessment and data extraction for all studies and additionally an independent reviewer conducted a quality assessment of 2 papers (25%). Any discrepancies between the two reviewers were discussed and agreement was reached. All eligible studies were included in the review, regardless of the quality score they received.

Results

Search results

With duplicates removed, 1086 studies were identified, with 1049 articles excluded based on their titles and abstracts. Full text papers of the relevant studies were obtained, read and retained if they met the full inclusion criteria stated in the PICO Table 1. Figure 2 depicts the flow of information through the search and selection process. Studies that did not meet the inclusion criteria were classified according to reasons for exclusion and can be found in Appendix C.

The search strategy identified 38 studies, of which 6 met the inclusion criteria (Table 1), a further two studies were identified through reviewing the references of the eligible studies. A total of eight studies where reviewed. All studies included childless participants, and either focused on PTSD symptoms as defined by the DSM-V (APA, 2013) or on the construct of post-traumatic growth (Tedeschi & Calhoun, 1996) following infertility treatment. There were a total of 2406 childless women (range 31 to 1455) in the eight studies with ages spanning 21 to 45years[1]. Women's involuntary childlessness was characterised as due to: '*infertility diagnoses', 'nulliparity*' or '*not yet attempted to conceive but had a known infertility difficulty*'. Five studies reported on race and ethnicity (Schwerdtfeger et al., 2009; Paul et al., 2010; Bradow, 2012; Corley-Newman, 2016; Tirabassi, 2017). Studies were conducted across three countries with potentially differing socio-cultural values and prenatal narratives (USA, n= 5; China, n= 2; Iran, n=1). Recruitment of participants varied, with opportunistic sampling from non-clinical community samples, online methods, traditional advertising, and via derivation from cohort datasets (n=3) papers. Clinical samples were recruited from medical and/or reproductive health settings (n=5).

[1] Based on five studies reporting on age range.

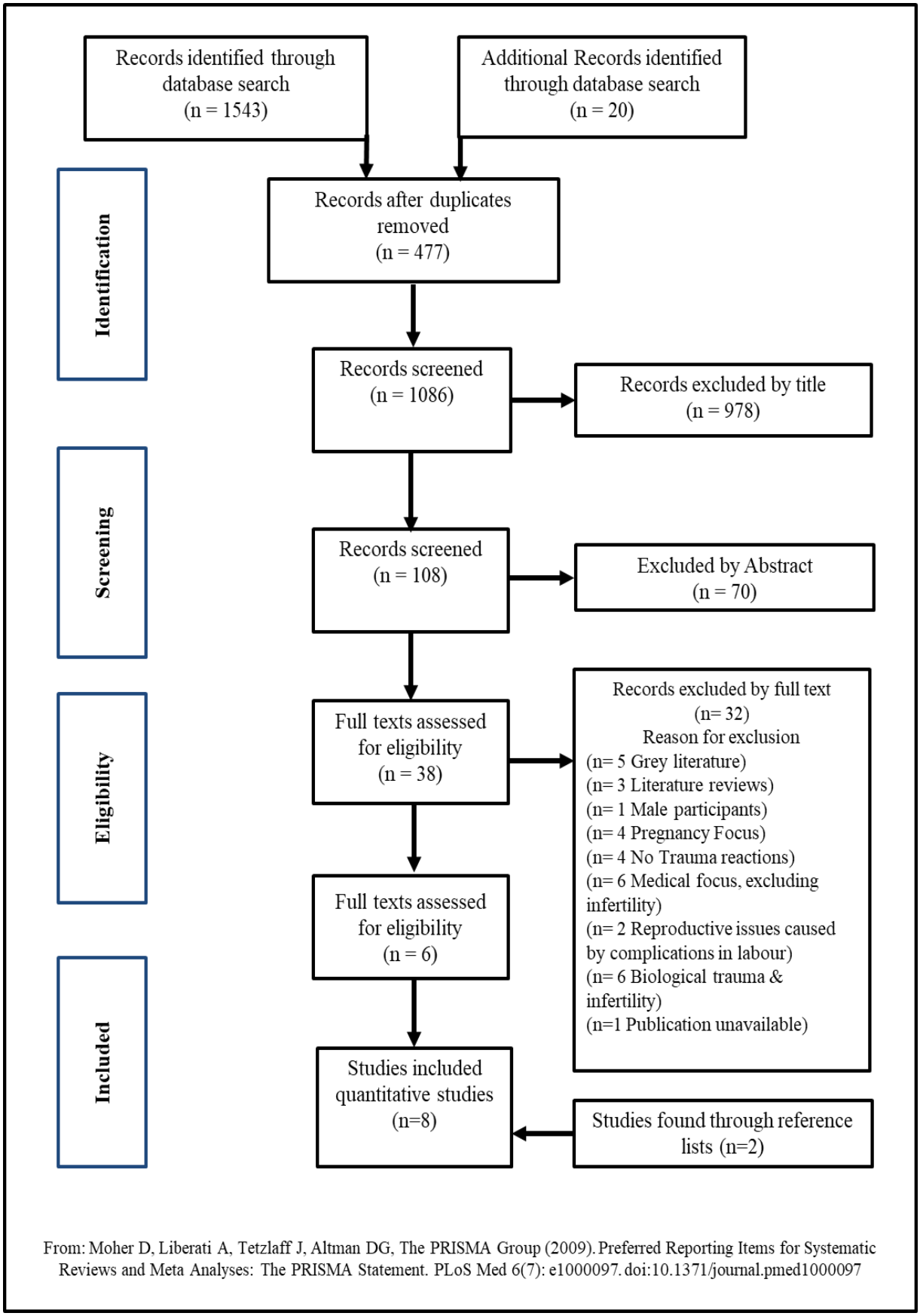

Figure 1. PRISMA diagram of the reporting items for a systematic review

Seven studies were cross-sectional in design; one was a cohort study which had four comparison groups (Schwerdtfeger et al., 2009). The involuntary childless group in this study was compared with: women with no fertility issues, mothers who experienced pregnancy loss, childless women who experienced a pregnancy loss and women who perceived themselves as infertile. Seven studies reported demographic covariates: age; ethnicity; type and duration of infertility; education level and occupational status. One study reported on perceived length and strength of the couple's relationship, using a marital adjustment scale (Ghafouri et al., 2016). Two studies focused on prevalence of PTSD symptoms in women who had accessed (Tirabassi, 2017) or had finished fertility treatment (Bradow, 2012). Four studies examined positive coping, resilience and social support as correlates of infertility-related PTG (Paul et al., 2010; Yu et al., 2014; Ghafouri et al., 2016; Kong et al., 2018).

All studies (n=8) elicited the experience of PTSD or trauma, and its psychosocial impact through self-reported measures. The Post-Traumatic Stress Disorder Checklist (PCL-5; Weathers et al., 2014) was used in three studies; this measure is psychometrically sound and effective in determining PTSD (Boivin et al., 2016). One study assessed for historic traumatic events prior to starting fertility treatment using the Trauma History Questionnaire (THQ); whilst another screened participants for previous mental health diagnosis, treatment and/or previous traumatic experiences within their demographic questionnaire (Bradow, 2012). In one study, Cordova, Cunningham, Carlson, & Andrykowski, (2001) a two question proxy was used to assess whether or not the respondents' experience met the diagnostic criteria for trauma; a subjective perception of threat of death, physical injury to self or others, and if this elicited a response of intense fear or helplessness. This approach has been shown to have good validity and reliability (Paul et al., 2010).

Three studies examined current co-morbidity of mental health and well-being through the use of additional screening tools (Schwerdtfeger et al., 2009; Corley-Newman, 2016; Kong et al., 2018); with which, one study (Corley-Newman, 2016) combined the FertiQoL questionnaire. This is a specific, internationally validated measure for assessing quality of life in infertile individuals (Boivin, Takefman, & Braverman, 2011).

Four studies focused on the extent to which post-traumatic growth [PTG] was linked to the experience of infertility (e.g. Paul et al., 2010; Yu et al., 2014; Ghafouri et al., 2016; Kong et al., 2018). The Post Traumatic Growth Inventory [PTGI] by Tedeschi and Calhoun (1996) or equivalent, Chinese version (Wang, Chen, Wang, Liu, 2011) was used to measure salutogenic processes across five domains: relating to others; new possibilities; personal strength; spiritual change and appreciation of life. High scores across the domains indicated greater PTG (Paul et al., 2010). Measures of resiliency, marital adjustment, positive coping, difficulties with emotional regulation and religious coping were used within five studies, with four examining them as potential correlates of PTG. As study results showed heterogeneity between variables, covariates, correlates and confounding variables, a statistical approach to synthesising the findings is prevented. All eight studies were homogenous, in that they neither focused on, nor provided, a medical intervention to resolve infertility within their methodology, even though five studies recruited their participants through fertility clinics.

All studies defined infertility as the primary cause of childlessness in their participants. Prevalence of trauma was explored in two studies; with one study looking at prevalence in both women with primary and secondary infertility. Schwerdtfeger et al.'s, (2009) study focused on an involuntary childless group of women, who perceived themselves to be infertile. None of the papers that met the inclusion criteria took as their objective to study cohorts who identified as involuntary childlessness through delayed childbearing or

circumstantial reasons. Therefore this narrative review has unfortunately to confine itself to findings from groups of women who are infertile, who had accessed or were accessing fertility treatment and were childless. The psychological concepts relating to adjustment following infertility are heterogeneous across the studies; ranging from prevalence and severity of trauma reactions to infertility; emotional regulation difficulties through to adaptive psychosocial support and increased well-being and post traumatic growth.

Assessment of bias

Quality ratings were determined, tabulated and presented in Table 2. The EBL tool yielded validity ratings from 48% through to 83%. Two studies scored in the 'poor' range (total score <75%), two studies scored 75% and a further four scored above 75%. The population domain scores for validity showed selection bias errors, predominately due to self-selection and opportunity sampling and this compromised the generalisability of study findings. Scores for study design were influenced by the use of datasets and cross-sectional designs; the latter being considered to produce weaker evidence within the traditional hierarchy of evidence-based research (Greenhalgh, 2014). Overall, data collection within the studies varied in quality scores (60% to 100%); the research methodology was not always described in replicable detail and timing of data collection was often inadequately specified. The results section showed a range of quality scores (50%-83%), with variable attempts to control for covariates of confounding factors or to optimise the generalisability of the findings. (See Appendix E for individual quality rating scores). Construct validity (Cronbach alpha) and reliability (Coefficient alpha) was reported for all measures in the eight studies

Table 2: Quality rating scores for individual section and total validity

	Quality rating scores					
Study	**Section A: Population**	**Section B: Study Design**	**Section C: Data Collection**	**Section D: Results**	**Total Score ≥75%**	**Valid Yes/No**
Bradow (2012)	77.8%	87.5%	100.0%	66.7%	82.1%	Yes
Corley-Newman (2016)	83.3%	85.0%	100.0%	66.7%	83.3%	Yes
Ghafouri et al., (2016)	50.0%	37.5%	80.0%	50.0%	48.0%	No
Kong et al., (2018)	66.7%	71.4%	80.0%	83.3%	75.0%	Yes
Paul et al., (2010)	50.0%	85.7%	100.0%	83.3%	79.2%	No
Schwerdtfeger et al.,(2009)	66.7%	75.0%	60.0%	66.7%	67.9%	No
Tirabassi, (2017)	66.7%	87.5%	100.0%	50.0%	76.0%	Yes
Yu et al., (2014)	50.0%	85.7%	100.0%	66.7%	75.0%	Yes

Note:

Section Validity Score

Calculation for overall validity:
(Y+N+U=T)

Calculation for section validity: (Y+N+U=T)
Y/T <75% or if N+U/T > 25% Conclusion:
the section identifies significant omissions.
The study's validity is questionable.

If Y/T ≥75% or if N+U/T ≤ 25% then you can safely conclude that the study is valid.

Glynn, L. (2006). A critical appraisal tool for library and information research. *Library Hi Tech, 24 (3):* 387-399: doi.org/10.1108/07378830610692154

Table 3: Characteristics of all included studies

Study	Objectives	Study design	Participants (average age)	Methods	Results
Bradow (2012), USA	Examine the prevalence of PTSD in those that are diagnosed with infertility and/or receiving infertility treatment, including primary infertility and secondary infertility.	Cross-sectional	*N*=56 primary infertility	Survey included the PCL-C, demographic information. Qualitative information was gathered about the experience of infertility.	46% of participants with primary infertility met the caseness for clinical PTSD. Qualitative data suggests infertility diagnosis and treatment is a traumatic event which can lead to an experience of PTSD symptoms.
Corley-Newman (2016), USA	Examine the potential functional relationship between infertility treatment, psychological intervention, and PTSD in medically diagnosed infertile women in the United States	Cross-sectional	*N* = 31 age range 24-34yr	Survey included FPI, PCL-5, FertiQoL and demographic questionnaire	Indication that fertility treatment increases PTSD symptomatology in diagnosed infertile women who do not receive psychological intervention throughout their treatment. Type of fertility treatment does not impact on PTSD symptomatology who receives fertility treatment. It is likely that factors such as relationship concern and physical health contributed to increased PTSD symptoms among the studied population.
Ghafouri et al., (2016), Iran	To model the relation between martial adjustment and posttraumatic growth through the mediation of religious coping strategies in infertile couples	Cross-sectional	*N*= 176 (30.23 ± 5.93).	Surveys included, DAS, PTGI, and the Religious Coping Strategies Inventory	Significant positive relationships between marital adjustment and both positive religious coping strategies and PTG. A significant positive relationship between positive religious coping strategies and PTG was also detected. Positive religious coping strategies were observed to play a mediatory role between marital adjustment and PTG.

Study	Objectives	Study design	Participants (average age)	Methods	Results
Kong et al., (2018), China	Examines the relationship between posttraumatic growth, resilience and social support alongside the mediating role of positive affect.	Cross-sectional	*N* = 1455 (no average age data)	Survey including PTGI, PSSS (Chinese version), PANAS and demographic information	Indicates that positive affect plays a mediating role in the relationship between resilience, social support and post traumatic growth.
Paul et al.,(2010), USA	Examine the relationship between infertility and PTG.	Cross-sectional	*N= 121* (35.5yrs)	Survey including PTGI, SSQ and demographics including measure of stressfulness of the event	Infertility was found to be a highly stressful event. 49% of participants reported their infertility to meet the criteria for trauma. Therefore PTG occurs in relation to the overall experience of infertility.
Schwerdtfeger et al.,(2009), USA	Examine women's experience of infertility in the context of childlessness and that IC may be classified as a traumatic stressor for women.	Cohort Study	*N*= 239 age range 21-45yrs	Data extracted from data set, included CES-D, self-esteem and life satisfaction questions.	Childless women, in a nonclinical sample, reported significantly worse mental health than mothers. Infertility was associated with long lasting effects on women's mental health. Infertility was described as distressing, difficult and a traumatic life event.
Tirabassi, (2017), USA	Examined exposure to traumatic events, emotion regulation difficulties, and avoidant coping to fertility stressors as predictors of traumatic stress among women attending a fertility clinic	Cross-sectional	*N = 42 (31.6 years)*	Survey including, demographic information, THQ, DERS, SCI-S and PCL-5	Greater exposure to traumatic events and emotion regulation difficulties predicted trauma reactions. Avoidant coping to fertility related stressors did not predict PTSD symptoms. Emotion regulation difficulties significantly moderated the relationship between exposure to potentially traumatic events and traumatic symptoms in this study.

Study	Objectives	Study design	Participants (average age)	Methods	Results
Yu et al., (2014), China	Examine the relationship between PTG, resilience, social support and positive coping in relations to infertility.	Cross-sectional	*N*= 182 (30.5yrs)	Survey including PTGI, CD-RISC, MSPSS, SCQ-P and background demographic survey.	Indicates that PTG is positively associated with resilience, social support and positive coping for infertile individuals.

NOTE:
IC, Involuntary Childlessness; PCL-C, The Post-Traumatic Stress Disorder Checklist- civilian version; FPI, Fertility Problem Inventory; PCL-5, PTSD Checklist for DSM-V; FertiQoL, Fertility Quality of Life; PTG, Post Traumatic Growth; DAS, Dyadic Adjustment Scale; RCOPE, Religious Coping Inventory; CES-D, Centre for Epidemiological Studies Depression Scales; THQ, The Trauma History Questionnaire; DERS; The Difficulties in Emotion Regulation Scale; SCI-S; The Coping Strategies Inventory- Short Form; PTGI, Post Traumatic Growth Inventory; SSQ; Social Support Questionnaire; MSPSS; Multidimensional Scale of Perceived Social Support; CD-RISC, Connor – Davidson Resilience Scale (CD-RISC); PSSS, Perceived Social Support Scale; SCQ-P, Positive Simplified Coping Style Questionnaire; PANAS, The Positive and Negative Affect Schedule.

The narrative results, will describe the assimilated and synthesized findings of the papers (Boland, Cherry & Dickson, 2014) and are reported under three main themes: 1) infertility as traumatic experience; 2) Post traumatic growth and infertility; and 3) Emotional regulation and adjustment.

1. Infertility as a traumatic experience

The experience of infertility was found to be an extremely stressful event (Paul et al., 2010; Ghafouri et al., 2016) which was rated as highly stressful by participants in the studies (Paul et al., 2010; Yu et al., 2014; Kong et al., 2018). In three studies, the level of stress was likened to that of traumatic events such as the sudden death of a loved one by homicide or experience of breast cancer (Berger & Weiss, 2006; Calhoun et al., 2000). Paul et al., (2010) reported that 49% of their participants' stress levels met criteria for PTSD and they attributed this to studying participants when under medical care and experiencing repeated infertility treatment failures which, they argued, linked to feelings of learned helplessness (Paul et al., 2010). Bradow, (2012) reported 46% of participants met caseness for clinical PTSD post fertility treatment, as determined by completing the PCL-C. This study sample was more representative and the results could be generalised, compared to Paul et al., (2010); this study's findings may have more clinical value as a result. Tirabassi, (2017) speculated that it would be likely, given that prevalence of exposure to traumatic events within the general population, for some women seeking fertility treatment to have experienced prior traumas. Tirabassi, (2017) findings showed 85% of women (n=57) prior to commencing fertility treatment endorsed one or more potentially traumatising events on the HTQ, with 5% obtaining clinical caseness for PTSD.

Tirabassi, (2017) proposed that ongoing difficulty with emotional regulation processes was a predictor of infertility distress and of developing traumatic stress symptoms

for infertile women. Schwerdtfeger et al., (2009) reported finding greater levels of depression for infertile and involuntarily childless women, compared to women who were mothers and reported no reproductive difficulties, and mothers who had experienced a reproductive loss ($p < .001$). They concluded that their findings showed infertility to be a distressing event for women within the general population, which was likely to have ongoing negative repercussions on an individual's mental health. Unfortunately they did not screen for PTSD prevalence and their paper was rated as poor quality meaning that their results should be treated with caution.

In addition, two studies attempted to establish if PTSD symptoms were different depending on the type of fertility treatment received or category of infertility reported (Corley-Newman, 2016; Bradow, 2012). Corley-Newman, (2016) found that individuals who had received advanced infertility treatments (e.g. In Vitro Fertilisation, gamete or zygote intrafallopian transfer) self-reported significantly higher PTSD symptomatology scores on the PCL-5 questionnaire than those from women who had not received these forms of treatment. Infertility treatment had a statistically significant relationship with PTSD symptomatology, but only for those participants who received no psychological treatment during fertility treatment. This lack of psychological intervention, paired with the individual's infertility treatment protocol, increased PTSD symptomatology in medically diagnosed infertile women (Corley-Newman, 2016).

Furthermore, the level of PTSD symptomatology for individuals experiencing advance fertility treatment could be predicted, based on two sub scores of the FertiQol questionnaire (e.g. mind and body and social concern) and two sub scores on the Fertility Problem Inventory (e.g. social and relationship concern). Corley-Newman, (2016) concluded that relationship concerns and physical health may contribute to increased PTSD symptoms

among the women who participated in their study. Acknowledgements must be made for the small sample size (n=31) and confounding variables that were not accounted for in the data analysis. Additionally, Tirabassi, (2017) reported that, exposure to previous potentially traumatic events and emotion regulation difficulties were significant predictors of traumatic stress symptoms. Therefore, for women who have experienced previous traumas and struggled to utilise adaptive emotion regulation strategies, fertility treatment could potentially be traumatising.

Bradow, (2012), examined the prevalence of PTSD symptoms in women with primary infertility (e.g. who have never been able to conceive) and women with secondary infertility diagnosis (e.g. who had previously been able to conceive and carry a child to term); findings showed 53% of women who suffered with primary fertility, scored 44 or above on the PCL-C. These scores mapped to the three symptom criteria for diagnosing PTSD using the DSM-IV-TR (APA 2000): re-experiencing; avoidance; and hyperarousal and met clinical caseness for diagnosis. Bradow, (2012) acknowledged that their study was under powered due to small sample sizes within the two groups, therefore there is a potential for type I errors. These three studies were all considered to be of good quality on the EBL critical tool and were therefore clinically valuable for understanding the impact of trauma theory on adjustment.

2. Post traumatic growth and infertility experience

Table 4 shows the studies that invited participants to complete the PTGI in regarding their experience of infertility. Paul et al., (2010) reported a mean total PTG score of 51.79 (SD =23.4) whereas Yu et al., (2014) found a lower mean PTG score of 42.55 (SD = 16.83). However there was little attention to potential confounding variables in the analysis or reporting of these scores. Kong et al., (2018) reported the highest total mean PTGI score of

64.81 (SD = 16.20) derived from the largest sample but it lacked a clear description of the study's methodology. Ghafouri et al., (2016) did not give an overall PTG score and focussed instead on marital adjustment to infertility. A number of factors were reported which are clinically valuable in understanding adjustment processes. Paul et al., (2010) reported lower PTG scores for women who had no explanation for their infertility (e.g. 'unexplained infertility') and lower scores for women who were unemployed and experiencing primary infertility.

To identify which PTG domains were uniquely associated with infertility and to minimize the effect of confounding variables and correlates, individual domain scores were examined. Paul et al., (2010) found a significant and positive relationship between the PTG domain 'new possibilities' and individuals who attended infertility support groups. A positive correlation between number of years spent trying to conceive and number of pregnancy losses was associated with increased personal strength. Ghafouri et al., (2016) reported that the overall strength and functioning of an individual's marriage, as measured by the Dyadic Adjustment Scale [DAS] had a significant and positive relationship with increased PTG scores for domains of new possibilities, personal strength, spiritual change and appreciation of life ($p<0.01$). This study is limited by the lack of comparative data on individuals' marital adjustment during the infertility treatment period. These findings were consistent across the whole range of quality of the papers.

There were also positive correlations between spiritual change and PTG. Individuals who engaged with clergy counselling were reported to have higher PTG scores than those who did not (Paul et al., 2010). Similarly, Ghafouri et al., (2016) reported that individuals who used religious positive coping strategies scored highly for PTG. This relationship was purported to be mediated by perceived marital satisfaction. Ghafouri et al., (2016) also

speculated that religious coping strategies may enhance social support and relationships with others, which could subsequently enhance PTG. Both spiritualism and religion, in this context may make explicit a system of beliefs and values which if accepted, could inform the meaning attributable to infertility and create an aligned narrative (Ghafouri et al., 2016). However this paper was rated as poor in quality and further research may be need to test these finding. The last PTG domain, appreciation of life, also showed positive and significant relationships with the domains of the DAS (Ghafouri et al., 2016) and was correlated with infertility-related stress (Paul et al., 2010). Yu et al., (2014) reported that all of the PTGI five domains were positively associated with correlates of resiliency, positive coping and social support (all ps <0.05).

Table 4: Studies examining PTGI alongside confounding variables.

			Study			
			Ghafouri et al., (2016)	Kong et al., (2018)	Paul et al., (2010)	Yu et al., (2014)
Questionnaire	Sub domains	Confounding variables				
PTGI	Relating to others	Salutogenic processes	✓	✓	✓	✓
	New Possibilities		✓	✓	✓	✓
	Personal Strength		✓	✓	✓	✓
	Spiritual Change		✓	✓	✓	✓
	Appreciation of Life		✓	✓	✓	✓
CD-RISC	25 items assessed	Resilience				✓
CD-RISC -10	10 items assessed			✓		
RCOPE	Positive coping strategies	Coping	✓			
	Negative coping strategies		✓			
SCQ	Positive coping styles					✓
	Negative coping styles					✓
PSSS	Family support	Perceived social support		✓		
	Friend support			✓		
	Other support			✓		
MSPSS	Family support					✓
	Friend support					✓
	Other support					✓
SSQ	Perceived general support				✓	
	Number of sources of support				✓	
PANA	Positive affect scale	Affect		✓		
DAS	Marital satisfaction	Marital adjustment	✓			
	Marital cohesion		✓			
	Marital consensus		✓			
	Affective expression		✓			

2.1. Resilience and PTG

The Conor-Davidson Resilience (CD-RISC) 10 and 25 item scales, were used to measure resilience. Yu et al., (2014) reported that PTG was positively correlated with resiliency, with higher PTGI score significantly correlated with greater resiliency within

infertile individuals (Kong et al., 2018). Resilient individuals were described as appraising traumatic events as less threatening and exhibiting more cognitive flexibility, especially if they perceive themselves to have increased social support.

2.2 Social support and PTG

Social support emerged as another significant predictor of self-reported PTG in women with infertility. Two studies found overall perceived social support to be high in their participants (Yu et al., 2010; Kong et al., 2018), whilst Paul et al., (2010) reported that the number of sources of support was of average frequency (m= 23.51, range 1-54) but when satisfaction with these sources of support was high (m= 31.38, range 10-36) it was predictive of PTG. These three studies scored above 75% on the EBL critical tool, endorsing the validity of the findings. Furthermore, Paul, et al., (2010) reported that there was a difference between PTG social support and relationship support. Ghafouri et al., (2016) used structural equation modelling, which showed positive and significant effects between marital adjustment, positive coping strategies and increased PTG scores among infertile individuals.

2.3 Positive coping and PTG

Yu et al., (2014) reported PTG was positively correlated with self-reported use of positive coping, (measured by the Simplified Coping Questionnaire) more so than social support and resiliency. Positive coping was shown to play a mediating role between social support and PTG. These findings, however, were not contextualised by adequate demographic data collection and lacked external validity as they were from a convenience sample from one clinic. The results lack generalisability and the study's external validity is only good in terms of the socio-cultural group that was recruited. Ghafouri et al., (2016) reported a positive and significant relationship between religious positive coping strategies

and PTG. They proposed that religion may provide a way of enhancing coping with infertility, through facilitating meaning making, which is an important factor for PTG. Again this study explored a very specific form of coping strategy and lacked a comparator control group.

2.4 Positive affect and PTG

Kong et al., (2018) reported that PTGI scores were significantly correlated with resilience, social support and positive affect. They argued that individuals with high levels of resilience, perceive more support and may adopt positive coping skills, which therefore results in experiencing more positive affect (Kong et al., 2018). PTG was significantly correlated with positive affect, which they linked to increased cognitive flexibility, cognitive appraisal skills, personal and social resources and increase well-being (Kong et al., 2018). These findings are specific to a non-Western sample and therefore their speculation on the relationship between these variables requires testing further for replicability in western fertility clinics and social-cultural context.

3. Emotional regulation and adjustment

A number of studies looked at emotional regulation processes in relation to trauma symptoms and infertility. Tirabassi, (2017) found that emotional dysregulation was correlated with increased symptoms of traumatic stress and greater use of avoidant coping strategies related to fertility problems; with social withdrawal as a significant predictor of traumatic stress. It should be acknowledged that the author was aware of selection bias as two approaches were used during the recruitment phase and sample construction relied on clinic staff who were reluctant to mention the study to very distressed individuals. Symptoms of traumatic stress were generally low across the sample, who were predominately Caucasian,

educated and employed women. These issues may have impacted on the overall reported findings (Tirabassi, 2017) and were unaccounted for in the data analysis. Schwerdtfeger et al., (2009) identified the presence of emotional dysregulation, through measures of depression, self-esteem and overall life satisfaction. They found that involuntarily childless women reported lower levels of happiness and higher levels of loneliness, adjusting for differences between the control groups at baseline. Their findings can be generalised to the wider population of women who may be involuntary childless (with or without having fertility treatments) and that emotional dysregulation could be predictive of adjustment in the wider population.

Discussion

The aim of this paper was to systematically review and critically appraise the literature on how trauma theory might inform understanding of adjustment to involuntary childlessness. The review primarily focused on trauma reactions defined as PTSD and PTG from the infertility experience. Mediating variables of resilience, positive coping, social support and emotional regulation were also found to link with posttraumatic stress, PTG and infertility; therefore having clinical implications for how fertility counsellors and reproductive health clinics might use this evidence base to inform their practice.

Summary of evidence

Involuntary childlessness, which included childlessness due to biological mechanisms either associated with infertility, physical health conditions or injuries, were included for review but those associated with reproductive trauma were excluded. None of the studies identified focused on the experience of involuntary childlessness attributed to circumstances such as delaying conception attempts. The studies emergent from the literature search were concerned with infertile women who remained childless (with or without treatment) and who reported infertility to be extremely stressful and traumatic and to cause infertility related distress. Therefore in drawing conclusions, the evidence presented is not generalisable to the large cohort of involuntary childless women who were not studied.

All of the studies in the review reported the experience of infertility to be extremely stressful and comparable to a traumatic event. These results are in keeping with the emerging literature within this area (Gonzalez, 2000; Freiderikson et al., 2015). Two papers in this review reported that just under half of their participants met caseness for PTSD symptomology (Paul et al., 2010; Bradow, 2012). Furthermore, Corley-Newman, (2016)

found that impact of fertility problems on the participant's physical health was the strongest predictor of PTSD, which is in line with previous research findings, that suggested that stress of infertility treatment is equivalent to that experienced by women with cancer, AIDS, or heart disease, (Doma, Zuttermiester, & Friedman,1993; Frederiksen et al.,2015). None of the included studies specifically examined complex PTSD/trauma in relation to the infertility experience. Traumatic reactions were conceptualised as PTSD using the diagnostic criteria of DSM-IV-TR and DSM-V (APA, 2000; 2013). Bradow (2012) proposes that the conceptualisation of the trauma sequelae associated with infertility should be viewed from a complex trauma perspective; due to the cyclical, often prolonged nature of medical interventions and the potential threat of failure, causing cumulative effect of stress over time.

Another area of focus identified by the review was post traumatic growth and its occurrence in relation to the infertility experience. A number of variables were considered to be important in mediating positive changes. Resiliency, positive coping, social support were all found to be significant for PTG (Yu et al., 2014; Paul et al., 2010; Ghafouri et al., 2016; Kong et al., 2018). Furthermore, marital adjustment, religious coping strategies and positive affect were also reported to contribute to PTG (Ghafouri et al., 2016; Kong et al., 2018). Although PTG is conceptualised as a response to a traumatic event, as opposed to an adjustment process to infertility, there appears to be a theoretical relationship between the two psychological constructs (Yu et al., 2014), with this relationship perhaps being mediated by coping (Schmidt, Blank, Bellizzi, & Park, 2012). Active coping strategies, such as self-care behaviours, have been found to enhance adherence to healthcare recommendations and limit the likelihood of disease acquisition (Schmidt et al., 2012). It should also be noted that that these relationships are reliant on the self-report of female participants and that there is no attempt in any of these studies on PTG to seek corroboration from the dyad, from an

informant (relative, friend, health care professional) or to gain the perspective of men who are also experiencing blocked parenting goals.

This review also proposed that the psychological adjustment processes displayed by individuals who are infertile or involuntarily childless will differ if they do or do not have historic or ongoing experience of trauma. Given that the majority of the general population in developed countries present with a high risk of having had exposure to potentially traumatic or adverse childhood experiences (Breslau & Kessler, 2001; Kilpatrick, Resnick, Milanak, Miller, Keyes, & Friedman, 2013; PHW, 2015), it is likely that women attending a fertility clinic for treatment, will have also had such experiences (Tirabassi, 2017). The prevalence of trauma reactions prior to starting infertility treatment was found by Tirabassi (2017) to be high (85% of participants disclosed a traumatic experience and 5% met clinical caseness for PTSD). There was insufficient evidence to conclude that previous experience of trauma impacted on PTSD symptoms during or after infertility treatment (Tirabassi, 2017). However, for individuals who rely on maladaptive avoidant regulation strategies fertility treatment could potentially be experienced as traumatising, impacting on the overall adjustment process.

Quality assessment

Trauma is beginning to attract research attention within reproductive health literature and eight studies met the inclusion criteria for this review question. An examination of the excluded papers (Appendix C) showed that medically focused studies captured by the search string often omitted fertility as a covariate, or did not measure trauma, or trauma was associated with reproductive losses. Overall quality of the included studies was variable. Study designs tended to be stronger if validated measures were administered and covariates were accounted for.

The aim of this review was to examine trauma theory in relation to involuntary childlessness within the current literature, including evidence from cross-sectional and uncontrolled studies. Some studies recruited non-clinical samples and were conducted within naturalistic settings (e.g. away from infertility clinic samples). Findings indicate that little is known about the prevalence of trauma, or its impact on adjustment to childlessness and issues of infertility, in non-treatment seekers. Furthermore, post traumatic growth is a dynamic process which develops over time, therefore cross-sectional designs are limited in drawing firm conclusions and there is a need for research to include more longitudinal studies. Similarly, few studies employed control conditions, performed power calculations, recruited sufficient numbers of participants or used stratified or matched samples to allow their findings to be generalizable. Moreover, method and procedure reporting was often insufficient to allow replication. Future research would benefit from addressing these limitations.

Strengths and limitations

A strength of this review is that it was systematic. It generated eight studies from three countries focusing on trauma experiences or trauma theory for 2515 childless women experiencing infertility. Trauma theory constructs are gaining momentum in fertility research in the conceptualisation of infertility-distress. They are being considered separately as alternatives to stress and coping (Lazarus and Folkman, 1984) or grief and loss models (Boelen, 2016; Stroebe, et al, 2010) for exploring infertility experiences and associated adjustment process. A recent systematic review in 2015, concluded that no systematic evidence could be found in regards to the prevalence of post-traumatic stress or PTSD associated with failed IVF, concluding it to be non-existent in the research literature (Daugirdaitė et al., 2015). Thus this current review is clinically relevant and timely, given

emergent evidence on the prevalence of trauma and ACEs in the general population and their implications for neuro-psychoimmunology, physical and mental health (Oral et al., 2016; Sweeny et al., 2016).

A limitation of this review is the heterogeneity of the studies' focus, use of different terminology and measures. Another important limitation is that no study addressed circumstantial childlessness directly. Often childless women, who have not attempted to conceive, are excluded from research studies (Schwerdtfeger et al., 2009) which reflects wider methodological issues within the infertility literature (Greil et al., 2010). For a considerable time, reasons for childlessness have been merged together (Letherby, 2002; Bell, 2013). Furthermore, there have been definitional difficulties within studies, which have been misleading conceptually when applied to a clinical perspective. For example, 'reproductive trauma' has been defined as both 'infertility and perinatal loss' (Bhat & Byatt, 2016; p1.) whilst, clinically, it has been defined as the experience of a reproductive trauma as a psychological impact from infertility (Jaffe, 2017). These definition difficulties may be a legacy of the lack of psychosocial conceptualisation and the predominate view that infertility is a medical and biological phenomenon (Joy & McCrystal, 2015).

Sensitivity to being asked about traumatic experiences (BPS, 2016), compounded with the perceived social stigma of involuntary childlessness (Bell, 2013), and likelihood of avoidant coping strategies being used to managing distress (Tirabassi, 2017), should also be highlighted. These factors may potentially be reasons for selection bias in recruitment or subsequent drop out in studies of involuntary childlessness. Individuals with a history of trauma might be less inclined to take part in research (Jacobs et al., 2015) leading to the potential for under-reporting. There is an extensive literature on trauma and on the distressing, shaming and potentially re-traumatising nature of disclosure if the assessment

process is not well managed (British Psychological Society, 2016). Finally, this study focused on the explicit mention of trauma reactions, diagnosis or chronic and prolonged stress, which was defined as traumatic. Articles which implicitly addressed trauma, through examining the effects of depression, anxiety and stress could have been excluded. Another potential limitation of this review is the inclusion of doctorate theses. However these are less open to publication bias, as both significant and non-significant findings were reported.

Clinical implications

There are several clinical implications that can be inferred from the evidence from this review. Overall, findings show there is potential that trauma exposure can increase the risk of adjustment difficulties during fertility treatment (Tirabassi, 2017) or to involuntary childlessness (Bradlow, 2012; Corley-Newman, 2016). This has important implications for infertility practitioners, reproductive health clinics, and both primary and secondary care mental health services, in terms of identification of distress, and provision of therapeutic support.

Psychological interventions for PTSD and complex PTSD have a robust evidence-base, and are endorsed by clinical guidelines for best practice (NICE, 2005; BPS, 2016b). A variety of therapeutic approaches and treatment protocols exists (e.g. Foa, Keane, Friedman, & Cohen, 2010; Elhers & Clark, 2000; Shapiro, 2018). ESHRE, British Infertility Counsellors Association and NICE guidelines (2013) all endorse practice to address psychological distress associated with infertility and to deliver the most appropriate intervention to suit the individual's needs. Skilled practitioners draw from their training and core therapeutic modality skills to inform their therapeutic framework and interventions appropriate to a wide range of distress presentations. There is little more to guide

practitioners, as the evidence-base is still emerging for interventions for fertility-distress (Gameiro et al., 2015).

Moreover, treatment approaches to PSTD incorporate strategies that are referred to as 'stabilisation' approaches (Herman, 1992) which could offer a preventative approach to managing distress; promoting well-being and mitigating PTSD or trauma reactions associate with fertility treatment (Corley-Newman, 2016). These strategies, where appropriate, could be implemented early in the fertility treatment care pathway; to form a psychosocial stepped-care approach within fertility care (Gameiro et al., 2013) similar to that of mental health services in the UK (Matrics Cymru; National Psychological Therapies Management Committee, 2017). There is also a need to continue to evaluate both counselling and psychological interventions for fertility related distress; to develop interventions that promote psychological flexibility, cognitive reappraisal and PTG which derive from a robust evidence-base (Gameiro et al., 2015) and are underpinned by testable theories of infertility adjustment (Gameiro & Finnegan, 2017).

Given the prevalence and evidence of trauma and ACEs within the general population it would be prudent for fertility clinics to routinely screen for previous traumatic experience during pre-treatment assessment, using best practice guidance (British Psychological Society; BPS, 2016). This trauma-informed approach to service delivery (Sweeney et al., 2016) could mitigate infertility related-distress; especially as reproductive technologies are invasive and potentially re-traumatizing for individuals (Bradow, 2012). PTSD is also known to have a latent phase, where symptoms' onset is delayed by months or even years for some people (McNally, 2003). Therefore it is important for decision making and negotiating informed consent that fertility treatment is understood in the context of personal histories and emotion regulation skills. It is unknown if reproductive clinics endorse a trauma-informed service

delivery; given its emerging status within NHS mental health services, it could be assumed that reproductive clinics may not yet have moved towards such an approach.

There is also an established dose-responsive relationship between experiencing a number of ACEs and poor health outcomes (Hughes, Lowey, Quigg, & Bellis, 2016). Individuals who have experienced four or more ACEs, were five times more likely to suffer from low mental well-being of various kinds (Public Health Wales, 2015). There needs to be greater awareness of the psychosocial and distressing impact of involuntary childlessness (Domar et al., 1993; Bradow, 2012) across physical and mental health services. Especially, as individuals' mental health and wellbeing may be more vulnerable at transitional points in their lives (Baltes & Baltes, 1990) and may present regularly to services with subclinical presentations of distress. Turnball et al (2016) have also argued that social media has a part to play in influencing the dominant pronatalist discourse.

Future research

Further quantitative and qualitative research is needed in this area, which specifically focuses on the involuntary childlessness experience and adjustment process as a result of delayed childbearing and circumstance. In addition, the knowledge that trauma is present for women who are infertile and who have accessed fertility treatment warrants further attention in a non-clinical population of involuntary childless individuals (Schwerdtfeger & Shreffier, 2009). In the main body of fertility literature, the experiences of involuntary childless women of different ethnicities and of men have been underrepresented (Petok, 2015; Shreffler et al., 2017;), so extending research to improve understanding of their infertility experiences using trauma theory is paramount for developing clinical applications to their adjustment needs.

In addition, there is a growing literature on the neuro-psycho-immunological impact of trauma on the body (Li et al., 2010). Future research should look to combine this understanding, with examination of the impact of trauma on the reproductive system (Jacobs et al., 2015; Allsworth et al., 2004). Furthermore, psychosocial and constructivist theories should be applied to inform and contextualise the meaning of emergent and existing findings.

Conclusion

The use of trauma theory in understanding fertility distress and adjustment to involuntary childless is an emerging field which requires further research to inform the evidence base and which would benefit from studies with a longitudinal design. Notwithstanding the limitations reported in this review, the eight studies provide insight and tentative evidence that trauma theory can aid clinical understanding of adjustment processes but currently that understanding is limited to evidence based on the experience of medically diagnosed infertile women who seek fertility treatment.

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* = study included in the review.

Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

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(Appendix F for manuscript submission checklist)

Abstract

Study question: Taking a clinical perspective, to investigate fertility practitioners' views of patients' experience of distress, resulting from unsuccessful infertility treatment(s) where parental goals had been unfilled.

Summary answer: That therapeutic support is needed to support adjustment to involuntary childlessness and unmet parental goals.

What is known already: To our knowledge this is the first study to seek infertility practitioners' clinical views on the needs of individuals during the post fertility treatment phase.

Study design, size and duration: A three round, online Delphi study with infertility practitioners was conducted across five countries over the course of 2017 and 2018.

Participants/ materials, settings and methods: An international sample of infertility counsellors, psychologists and social workers took part (n=25 in Round I and finally nine in Round III). Practitioners ranked 58 statements regarding the presentation and nature of distress in the post treatment phase.

Main results: Out of the 58 statements, the expert panel agreed on 44 statements. Infertility practitioners perceived distress to be associated with statements concerned with individual's identity and relinquishing the desire for biological children. The expert panel agreed that the core elements of therapy were to inform meaning making, acceptance and pursuit of new life goals.

Limitations, reasons for caution: The high attrition rate between Rounds I and III across the Delphi process may have impacted on the level of agreement and consensus. Our results may reflect a western perspective on distress associated with the post treatment phase significantly reducing the generalizability.

Wider implications of the findings: Awareness that individuals may need to access psychosocial support after disengaging from the fertility clinic. Psychological interventions can support adjustment to involuntary childlessness.

Key words: childlessness; infertility; mental-health, adjustment, psychosocial adjustment; well-being, fertility counsellors, counselling, Delphi Study.

Note on terminology: Fertility practitioner was chosen in acknowledgment of the different professions that work therapeutically with infertility distress.

Introduction

Infertility distress

Much of the current knowledge on infertility distress focuses on the treatment phase (Haemmerli, Znoj & Barth, 2009), principally from a biomedical perspective (Letherby, 2002; Greil, 1997), with a focus on treatment outcomes (Boivin, 2003; Greil et al., 2011; Domar, 2015; Freiderikson, Farver-Vestergaard, Skovgård, Ingerslev & Zacharie, 2015), the stressors associated with treatment procedures (Shreffler, Greil & McQuillan, 2017) and the burden of infertility (Boivin, 2003; Lee et al., 2009). Little is known about the post treatment adjustment phase after unsuccessful infertility treatment (Gameiro & Finnegan, 2017) or the impact of lifelong distress associated with infertility (Wirtberg, Möller, Hogström, Tronstad & Lalos, 2007) or distress associated with unfulfilled parental goals (da Silva, Boivin & Gameiro, 2016).

Postponement of treatment and the emotional burden of infertility treatment(s) are the major reason for individuals discontinuing treatment (Gameiro, Boivin, Peronace & Verhaak, 2012) with an estimated 22% discontinuing prematurely (Gameiro et al., 2013). Studies have predominantly focused on the short-term impact of ceasing treatment and the adjustment process. However, less is known about the longer term impact (i.e. more than one year) on individuals' adjustment to unmet parental goals following unsuccessful fertility treatment. This is an emerging area of research (Gameiro & Finnegan, 2017).

For individuals where infertility treatment(s) have been unsuccessful, the failed fertility treatment represents the loss of biological parenthood (Gameiro & Finnegan, 2017) and can trigger intense and prolonged grief reactions (Daniluk, 2001). Gameiro & Finnegan's, (2017) meta-analysis, reported a moderate effect between individuals, who do

not manage to conceive with infertility treatment, experiencing poorer mental health and well-being afterwards in comparison to those who managed to conceive. Poorer wellbeing, (e.g. depression and negative affect) was evident in da Silva et al.'s, (2016) meta-analysis for individuals who continued to experience blocked parental goals. Ying, Wu and Loke, (2016) found that women who remained childless 4 to 9 years after unsuccessful IVF, reported lower satisfaction with their life. Furthermore, it is not the parenthood status, but the unresolved wish for children, which is associated with poorer wellbeing (Gameiro & Finnegan, 2017). For many, the desire to have children continues, long after treatment has ended (Verhaak, Smeenk, Evers, Kremer, Kraaimaat, Braat, 2007; Wischmann, Korge, Scherg, Strowitzki, & Verres, 2012; Gameiro et al., 2014), making it difficult to detach emotionally from the child wish (Volgsten, Skoog-Svanberg, & Olsson, 2010; da Silva et al., 2016).

A recent model of adjustment, the Three Task Model of Adjustment to Unmet Parental Goals (Gameiro & Finnegan, 2017) proposes three separate but inter-dependent psychological tasks that are supposed to be conducive to better adjustment in the context of unmet parenthood goals: acceptance, meaning making and pursuit of new life goals. The model draws on a qualitative review of patients own described experiences of adjustment. This process can be measured by improvements in mental-health and both hedonic wellbeing (e.g., wellbeing and reduction in grief symptoms) and eudemonic wellbeing (e.g. self-acceptance, personal growth and life fulfilment).

Theoretical paradigms from stress and coping theory (Lazarus & Folkman, 1984), self-regulation model (Heckhausen, Wrosch & Fleeson, 2001) and grief models (Stroebe & Schut, 1999; Boelen, van den Hout & van den Bout, 2006) have been applied to examine this adjustment process and movement through the different psychological tasks.

This adjustment process is variable for individuals. A number of studies report the prolonged experience of subclinical symptoms of psychological distress (Su & Chen, 2006) with one study reporting distress symptoms present after 20 years for those women, who had not fulfilled their parenthood wish through adoption or fostering (e.g.Wirtberg et al. 2007). Other studies, report that distress symptoms can present themselves as 'chronic sorrow' (Wirtberg et al., 2007), that distress peaks at times of different developmental stages (e.g. entering menopause, grandparent age).

It is apparent that psychosocial support could be vital in supporting individuals to adjust (Gameiro & Finnegan, 2017). Fertility counselling is a specialist role, which balances the psychological and therapeutic needs of the individuals/couples accessing fertility treatments alongside the social, legal and ethical implications of donor treatments (Joy & McCrystal, 2015). The European Society of Human Reproduction and Embryology [ESHRE], British Infertility Counsellors Association [BICA] and the National Institute for Health and Clinical Excellence [NICE] guidelines (2013), all specify that counselling should be offered to help manage the psychological distress associated with infertility before, during and post treatment (Figure 1.). Since 1990 it has been a legal requirement to routinely offer infertility counselling within UK based assisted reproductive clinics (Joy & McCrystal, 2015).

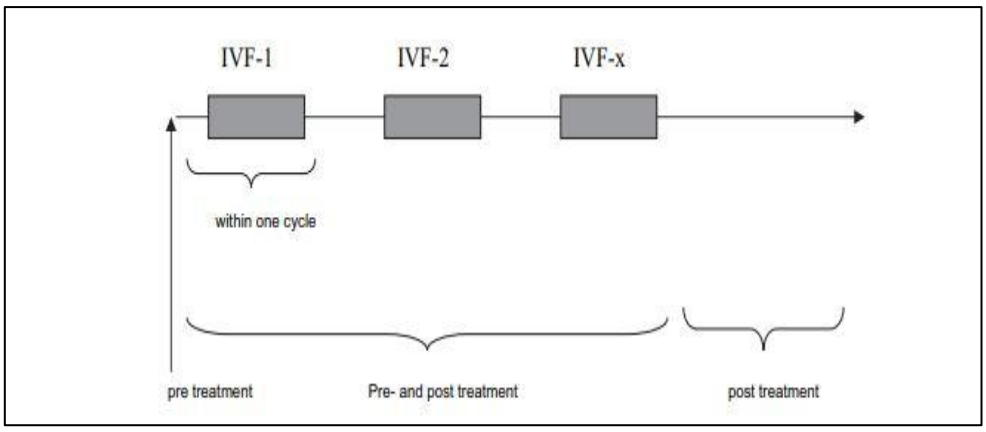

Figure 1. Different phases in the process of fertility treatment from Verhaak et al., (2007)

Post treatment counselling is important, as it can help individuals/couples define the endpoint to their treatment and facilitate the start of the adjustment process (Klock, 2015). The idiosyncratic nature of individuals'/couples' fertility experiences has direct implications for psychological support and best practice for fertility practitioners working therapeutically (Shreffler, et al., 2017). However, there is little to guide practitioners; as there are no recommended or evidence-based interventions focusing specifically on this stage of the fertility treatment pathway (Gameiro et al., 2015) and limited research which has explored the mechanisms that interplay after long term unsuccessful treatment (Gameiro & Finnegan, 2017). Skilled practitioners draw from their core therapeutic modality and training to inform their therapeutic framework and interventions in response to potentially a wide range of distress – e.g. grief work, self-criticism and blame, feelings of shame, identity/self-concepts for the future, acceptance, sexual, marital and other interpersonal problems (Norre & Wischmann, 2011).

Within healthcare settings evidence-base medicine is used to inform and guide clinical decision making which advises individual patient care (Greenhalgh, 2014). This evidence is generated through the triangulation of research evidence, patient preferences and

clinical expertise (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). Within reproductive medicine, there is a substantial evidenced-base of empirical studies (Gameiro & Boivin; in Covington, 2015) and understanding of patient experience of fertility and treatment (Greil, 2007; Verhaak, et al., 2007); but an under representation of studies which express the infertility counsellors/professionals' views on efficient and effective clinical practice (Covington, 2006). Although there is robust evidence from mental health and psychotherapy for practitioners to draw upon to shape their work with clients experiencing infertility distress; there is less guidance for the post treatment phase. Therefore it is important to know how fertility practitioners are implementing their practice.

The challenge of identifying the psychological needs of those in the post treatment phase, who have unmet parental goals and continue to experience distress, is that individuals have generally disengaged from fertility clinics (Gameiro & Finnegan, 2017). There is limited, if any, specialist mental health services for prolonged infertility distress that individuals can access through the National Health Service [NHS]. Additionally, studies report that most individuals do not meet criteria for clinically significant psychopathology (Shreffler, et al., 2017). Also, individuals may potentially score in the subclinical level for distress on routine clinical outcome measures (which are not sensitive to fertility specific distress) or when presenting to mental health /NHS settings. This would make them unlikely to be eligible for primary care mental health services. Frideriksen et al., (2015) stresses the importance of developing clinically meaningful categories of infertility distress which facilitate targeted psychological interventions. This would facilitate the development of a stepped care treatment pathway (Gameiro et al., 2013) which is appropriate for risk management and for the intensity and levels of distress experienced. Furthermore, without this understanding, distress associated with infertility, may be missed, when formulating with individuals who

have presented to mental health services for support, or for those seeking mental health support regarding infertility distress to NHS settings.

Aims of the Study

Therefore the aim of this study was to use Delphi methodology to consider the post treatment phase following unsuccessful infertility treatment and to elaborate the links between research and clinical practice. The Delphi will look to address two main research questions. Firstly, from a clinical perspective what are the individuals' challenges and difficulties in the post treatment phase? . Secondly, what are the practitioners' views on the therapeutic frameworks and interventions that their clients find helpful and that are efficient and effective in addressing individuals' challenges?

Methodology

An online 3-round Delphi study was implemented in order to (i) understand fertility practitioners' views of patients' experience of distress resulting from unsuccessful infertility treatment(s) where parental goals had been unfilled, (ii) to identify effective therapeutic techniques that practitioners used to support individuals in this context, and that they found helpful. Parenthood goals were defined as 'not having children or having fewer children than desired'.

Ethical approval was given by the South Wales Research Ethics Committee, on 20.09.17 SREC number: *EC.17.09.12.4943R* (Appendix G). Additional amendments to include an international sample were approved on 9.03.18. Participants were provided with written study information (Appendix H) and could contact the principal researcher with questions. Confirmation of consent was taken from interaction with the Delphi questionnaire. The hyperlink was contained in the initial recruitment email. All questionnaire data was treated as confidential, until the end of the Delphi, where it was converted to anonymous data. All Delphi questionnaires were constructed using a Qualtrics software package which allowed identification numbers to be generated upon interaction with the questionnaire. This enabled the researcher to remain removed from the data.

Expert Panel Formation

Practising fertility practitioners were recruited from the British Infertility Counselling Association, (BICA), the Human Fertilisation and Embryology Authority (HFEA) database of registered fertility clinics, and the International Infertility Organisation's (IICO) online directory. Additionally, emails were sent to researchers who have published clinical studies relating to patient distress in the post treatment phase. In total, 107 emails were sent. The initial recruitment email contained the hyperlink to the online Delphi Questionnaire. In

clicking on the link, participants confirmed their consent. Invited practitioners were based in the United Kingdom, Australia, Argentina, Japan, New Zealand, The Netherlands, Germany, Israel, Bulgaria and United States of America. The expert panel had all undertaken primary therapeutic qualifications (e.g. in psychology, counselling, social work and psychotherapy), additional therapeutic training, specific training in infertility counselling, and had been awarded or were working towards specialist infertility accreditation. They were all members of country specific, regulated, professional therapeutic and infertility counselling organisations. There is no consensus as to the optimum number of participants in a Delphi expert panel (Jorm, 2015). However a homogenous expert panel was desired (Keeney, Hasson & McKenna, 2011). Only infertility practitioners were considered, as opposed to other reproductive medicine professionals, to ensure high quality and relevant responses (Novakowski & Wellar, 2008).

Three Round Delphi

In Delphi Round I, the expert panel completed a demographic questionnaire. As well as age, gender, years of experience and country of practice; questions included clinical training, type of clinical setting and the levels of therapeutic input. These were followed by six open ended questions that were designed to elicit practitioners' opinions (Appendix K). To address research objective 1, two questions were asked about individuals' distress in the post treatment phase from a clinical perspective (e.g. *In your opinion why do these clients become stuck and experience on-going emotions associated with their unmet parenthood needs?)* and *(What do you think are the important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals?*).

Research objective 2, was addressed by a further two questions, which sought

practitioners' views on helpful therapeutic frameworks and interventions that were efficient and effective in addressing individuals' distress, (e.g. *What do you believe are the key 'ingredients' of therapy that address your clients' emotional distress?)* and that individuals find helpful (*Which therapy/counselling techniques/interventions do clients engage with and find helpful in reducing unwanted feelings of distress?*). Two further questions covered preferred therapeutic modality for the practitioner and any other additional information which had been missed. Analysis of the data, led to the development of 58 statements which formed Delphi Round II.

In Delphi Round II, 58 statements were presented to the expert panel to rate agreement (*1= strongly agreed, 2= somewhat agree, 3= neither agree nor disagree, 4=somewhat agree, 5= strong disagree).* The expert panel was asked to consider their responses in line with practice-based evidence and their professional clinical knowledge and experience (Jorm, 2015). Analysis of the data from Round II (reported below in results) was used to develop the questionnaire for Delphi Round III.

In Delphi Round III, the expert panel was asked to rerate 24 statements (selected based on the results from Round II) on how much they agreed on them. The expert panel was asked to consider this task, based on feedback from their own ratings for Round II, and that of the overall expert panel's responses; medians and percentage scores were obtained. This process of iteration was used to gain agreement on these remaining statements in the last round. A summary of the Delphi's findings was then feedback to the expert panel in the form of the Delphi Report (Appendix P).

Questionnaire Development

Construction of the questionnaire for Round I was grounded on the core competencies of psychological practice, reflecting a clinical cycle of assessment, formulation, intervention

and evaluation (British Psychological Society, 2008). An understanding of infertility distress aimed to identify unhelpful thoughts, behaviours, emotional dysregulation, and attachment issues. In addition, identified therapeutic processes related to change mechanisms. Therefore, the epistemology of this Delphi is grounded in a scientific-reflective clinical psychology paradigm.

Ideas for questions were extracted from a recent meta-analysis focusing on the post treatment period which developed the Three Task Model of Adjustment to Unmet Parental Goals (Gameiro & Finnegan, 2017) and from two systematic reviews, which both focused on the efficaciousness of psychological interventions during fertility treatment (Boivin, 2003; Freideriksen et al., 2015). A number of draft questions structured on the clinical cycle were identified and then checked for ambiguity, similarity and readability. Questions were discussed and refined to ensure uniformity and validity to the research aims. The final constructed Delphi questionnaire for Round I was reviewed by two research supervisors, with one supervisor having over 10 years of experience in fertility research, to check question alignment. An online readability checker was used to gauge the overall accessibility of the questions. A fertility counsellor working within a Welsh NHS fertility clinic was approached to review the questionnaire for accurate terminology, clarity of questions and application to clinical practice. Terminology within the questionnaire was amended in accordance with the fertility counsellor's feedback.

Consensus

The definition and criteria for consensus and agreement was determined *a prior* before the study commenced (Keeney et al., 2011). Consensus was defined by 100% agreement by the panel on a statement. Agreement was defined quantitatively, requiring 70% of the panel, rating each statement as either *'strongly agree'* or *somewhat agree' o*n a five

point Likert scale. This cut off for defining agreement has been used before in mental health consensus studies (Morgan & Jorm, 2009). In line with the literature, descriptive statistics of the median (Keeney et al., 2011) and overall percentage (Iqbal & Pipon-Young, 2009) was used to feedback to the expert panel in Round II questionnaire (Appendix, L). Furthermore, it was decided that consensus and agreement would not be a deciding factor for termination of this study, as disagreement might provide rich insight into current clinical practice.

Data analysis Round I

Round I used a qualitative method for data analysis. Thematic Analysis was used to code responses from the questionnaire using Braun and Clarke's (2006) protocol (Appendix N). Latent themes were generated for each individual question separately, by grouping statements together based on the expressed experiences or meaning. No additional meta-theorisation of the themes were undertaken (Patton, 1990) and sub-themes were not constructed from the latent themes (Braun & Clarke, 2006). Amalgamation may have reduced the number of statements which provided richness, of both cultural and clinical nuances. From these themes, a total of 58 statements were developed for Round II. Similar statements per theme were reduced to avoid duplication but keeping as true to the original meaning of the statements as possible. These statements were used to construct the content of the second Delphi questionnaire (Appendix L).

Data analysis Rounds II and III

Descriptive measures were used to analyse data from Rounds II and III, using SPSS version 23. Median and total percentage were calculated to determine the level of consensus or agreement. Percentages alone may not be sufficient to determine agreement (Meijering, Kampen, & Tobi, 2013; von der Gracht, 2012). Inferential statistics have been used to explore the relationship of agreement and consensus between expert panel members and

between Delphi rounds (Holey, Feeley, Dixon & Whittaker; 2007; Meijering et al., 2013; von der Gracht, 2012). The variances of responses were measured by interclass correlation coefficient, the Kendell Tau correlation examined how the expert panel agreed with themselves between Rounds II and III. Lastly, a non-parametric Wilcoxon signed rank T-Test scrutinised how the scores have changed across the Delphi rounds.

Results

Demographics

Twenty five panel members met the inclusion criteria and participated in Round I. The response rate was 61% out of total 46 initial responses. Overall, 24 (94%) were female and one male (6%). Of the 25 practitioners, there were eight (32%) psychologists, four (16%) psychotherapists, two (8%) social workers, one (4%) family doctor, five (20%) counsellors, one (4%) naturopathic practitioner, one (4%) systemic therapist and three (16%) individuals with PhD's. Four (8.7%) participants were excluded for not meeting the study inclusion criteria and a further four (8.7%) for only completing the demographic section and 13 (28%) were non-starters.

In Round I, the majority of practitioners (n=12) were aged 56 to 65years, practised in private fertility clinics (n=14) and provided brief (i.e. up to 6 sessions) or medium term (i.e. up to 20 sessions) therapeutic work. The range of infertility counselling experience across the expert panel was between 2 and 30 years. The majority of practitioners aligned themselves with a reflective-scientific epistemological stance; whilst a minority aligned themselves with a reflexive expert stance. All participants were unified by concerns for client well-being. This demographic pattern was observed across the two subsequent rounds indicating that the expert panel remained homogenous (Table 1). Questionnaires in Round II were completed by

13 practitioners (a response rate of 52%) and Round III by nine practitioners (a response rate of 69%).

Table 1: Demographics of the Expert Panel

Expert Panel Demographics		Delphi Round I		Delphi Round II		Delphi Round III	
Characteristics		(n=25)	%	(n=13)	%	(n=9)	%
Gender	Female	24	96	12	92.3	8	88.9
	Male	1	4	1	7.7	1	11.1
Age of	35 - 44yrs	5	20	3	23.1	2	22.2
Clinicians	45 - 55yrs	5	20	3	23.1	3	33.3
	56 - 65yrs	12	48	5	38.5	2	22.2
	65+	3	12	2	15.4	2	22.2
Country of	Argentina	1	4	~	~	~	~
Practice	Australia	5	20	2	15.4	1	11.1
	Bulgaria	1	4	1	7.7	~	~
	Germany	2	8	1	7.7	~	~
	Israel	2	8	2	15.4	2	22.2
	Japan	1	4	1	7.7	1	11.1
	New Zealand	1	4	1	7.7	1	11.1
	The Netherlands	1	4	~	~	~	~
	UK	9	36	4	30.8	4	33.3
	USA	2	8	1	7.7	1	11.1
Profession	Clinical Psychologist	7	28	6	46.2	6	66.7
	Psychologist	1	4	~	~	~	~
	Psychotherapist	4	16	1	7.7	1	11.1
	Social Worker	2	8	2	15.4	~	~
	Family Therapist/Family Doctor	1	4	~	~	~	~
	Counsellor	4	16	2	15.4	1	11.1
	Reproductive Counsellor	1	4	~	~	~	~
	Naturopath Practitioner	1	4	~	~	~	~
	PhD	2	8	1	7.7	1	11.1
	Systemic Therapist	1	4	1	7.7	~	~
	Unspecified	1	4	~	~	~	~
Clinical Practice	Private Clinic	14	56	8	61.5	5	55.6
Setting	NHS or Public Clinic	3	12	1	7.7	1	11.1
	Private clinic + sees NHS Clients	1	4	~	~	~	~
	NHS Clinic + self-funded Clients	2	8	1	7.7	1	11.1
	Private academic medical centre	1	4	1	7.7	~	~
	Private practice + within NHS/Public clinic	4	16	2	15.4	2	22.2
Therapeutic	Sign posting + 1 treatment session	1	4	~	~	~	~
Input	Brief therapy (up to 6 sessions)	5	20	3	23.1	2	22.2
	Medium therapy (up to 20 sessions)	5	20	2	15.4	2	22.2
	Long term therapy (i.e. over 1 year)	1	4	~	~	~	~
	Sign posting+brief therapy	2	8	1	7.7	1	11.1
	Sign posting + medium therapy	1	4	1	7.7	1	11.1
	From signposting to long term therapy work	3	12	2	15.4	2	22.2
	No time restrictions	3	12	1	7.7	~	~

All responses from Round I were coded using thematic analysis. Codes were collected and grouped into themes. A summary of the themes generated are presented in Figure 2. The results will be discussed in relation to the two main research questions.

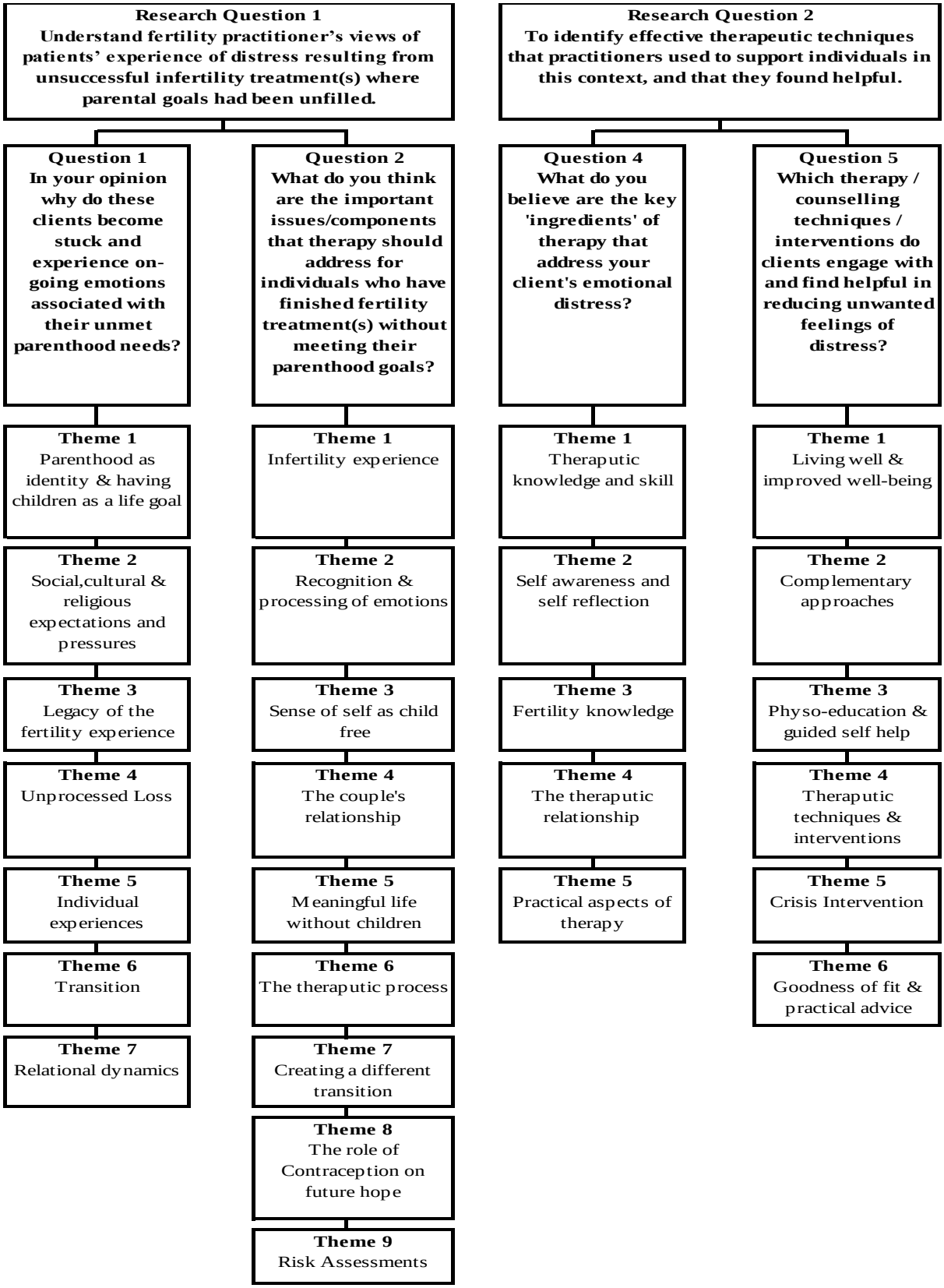

Figure 2. Diagrammatical representation of the generated themes from Delphi Round I.

Practitioners' conceptualisation of post fertility treatment distress

(Research Aim 1)

Round I

Eighteen qualitative themes concerning post-fertility treatment distress were generated from question 1 and question 2 of Delphi Round I. Expert panel members identified a number of reasons for the distress in the post treatment phase, presenting in their clinical practice. These were coded into seven themes (Appendix N): including issues around identity and having children as a life goal; the social and cultural context of childlessness and its impact on their clients (e.g. "*Our culture is very child-centered, reminders are everywhere, no culture is without fertility related stigma, and some deny the person-hood of childless individuals"*) issues associated with perceptions of and the treatment process itself (e.g.*"…ART promises success. Its representation in the media is not accurate and emphasizes success: if you persevere you'll succeed. Seldom there is information about the many faces of its price"*); difficulties associated with grief reactions and ambiguous loss (e.g. *Their loss (of imagined/lost children/parenthood role) endures beyond ending treatment*"); and under-developed emotional regulation strategies to deal with difficult emotions concerning the transition to a childless future (e.g. *Problems to disengage from parenthood life goal and refocus life goals*); and lastly relational and couple dynamics (e.g. panel member 9431: "*Loss of shared focus in their relationship"*). These themes provided a total of 22 statements that were presented to the Delphi panel in Round II.

Practitioners' responses to questions about the components of therapy which were important for addressing post fertility treatment distress were coded into nine separate themes (figure 2) including facilitating the recognition, permission and processing of emotions associated with childlessness such as loss, guilt, anger and sadness. Important components for

addressing couple issues and to help individuals focus on their sense of self as being child free and on moving towards new life goals were also included. Responses also focused on the qualities of the therapeutic process and the therapeutic relationship (Panel member 8880: "*A strong therapeutic alliance"*), within the core components of therapy. The responses generated a total of 18 statements that were presented to the Delphi panel in Round II.

Practitioners' views on effective therapeutic techniques

(Research aim 2)

Round I

Eleven qualitative themes were generated from responses to questions 4 and 5 of the Delphi Round I questionnaire. Five themes were generated from the responses to the question about key ingredient of therapy; taking into account, practitioners' therapeutic framework and preferred modality. Themes ranged from therapeutic knowledge and skills through to practical aspects of therapy (e.g. Skype therapy sessions). The therapeutic alliance was cited by the panel as being a key aspect during the post treatment phase. Nine statements were generated from these themes for Round II.

Table 2 depicts the frequencies of therapeutic frameworks and models drawn upon in the post treatment phase as established by **question 3**. Therapeutic models to formulate emotional distress, were excluded from the thematic analysis process and content analysis was used instead. It was assumed that preferred choice of modality would be determined by core and subsequent training, therefore consensus would not be determined during the Delphi process. Cognitive Behavioural Therapy (28%), Person Centered Therapy (28%),

Psychoanalytic and Psychodynamic (28%), loss and grief models (24%) and systemic principles (24%) were the most frequently cited models used to conceptualise psychological distress in the post treatment phase across all three rounds, follow by Acceptance and Commitment Therapy (16%), then attachment principles and Emotion Focused Therapy (12%).

Six themes were generated about interventions which practitioners felt clients engaged in and found helpful in reducing unwanted feelings of distress. Themes covered improving overall well-being through to ensuring a ‘good fit’ between client and therapist (Appendix N). Table 3 displays the frequency of clinical techniques and change mechanisms described in the responses from the expert panel. Therapeutic processes, trans-diagnostic techniques and model-specific change mechanisms were evident; mirroring the therapy models and frameworks. Cognitive restructuring (40%), relaxation exercises (20%), grief work (20%) and narrative principles (20%) scored highest.

Table 2: Therapeutic models and models listed by the Delphi panel

Therapy models listed by the expert panel*	Delphi Round I		Delphi Round II		Delphi Round III	
Cognitive Behavioural Therapy (CBT)	7	28	5	38.5	4	44.4
Person centred therapy (PCT) & Person-centred approaches	7	28	3	23.1	2	22.2
Psychoanalytic principles: including Psychodynamic approaches	7	28	5	38.5	3	33.3
Loss and Grief Models: including Worden's Grief Therapy Dual Process Model (Stroebe & Shut, 1999)	6	24	3	23.1	2	22.2
Systemic principles: including Systems Theory Couples Therapy	6	24	4	30.7	2	22.2
Acceptance and Commitment (ACT)	4	16	4	30.7	2	22.2
Attachment princples	3	12	2	15.4	1	11.1
Emotion Focused Therapy (EFT)	3	12	2	15.4	1	11.1
Compassion Focused Therapy (CFT)	2	8	2	15.4	2	22.2
Existential principles	2	8	2	15.4	1	11.1
Humanistic principles	2	8	1	7.7	~	~
No therapy model stated	2	8	~	~	~	~
Transactional Anaylsis (TA)	2	8	1	7.7	1	11.1
Behavioural Therapy	1	4	1	7.7	~	~
Crisis interventions	1	4	1	7.7	~	~
Dialectical Behavioural Therapy (DBT)	1	4	1	7.7	1	11.1
Gestalt principles	1	4	~	~	~	~
Narrative	1	4	1	7.7	~	~
Problem solving techniques	1	4	~	~	~	~
Reflexive practitioner	1	4	~	~	~	~
Stress and coping models	1	4	~	~	~	~
Trauma focused models	1	4	~	~	~	~
Total:	N=25	100%	N=13	100%	N= 9	100%

* Practitioners listed more than one model in their clinical practice

Table 3: Delphi panel's clinical practice preference

Therapeutic techniques and change mechanisms used in clinical practice*		Delphi Round I		Delphi Round II		Delphi Round III	
Psychoeducation	Handouts and diagrams on: anxiety, Grief trauma reactions	3	12	1	7.7	1	11.1
	Stress Reduction	3	12	1	7.7	~	~
Relaxation Techniques	Visualations/diaphragmatic breathing exercises	5	20	4	30.7	3	33.3
Mindfulness	Mindfulness exercises	3	12	1	7.7	1	11.1
Grief Therapy work	Honouring the loss Grief rituals	5	20	2	15.4	2	22.2
Model specific interventions	Cognitive Behavioural Therapy identifying cognitive bias cognitive restructing	10	40	5	38.5	4	44.4
	Behavioural Activation: new activities & exercise self care activities	4	16	2	15.4	1	11.1
	Accceptance and Commitment	3	12	3	23.1	2	22.2
	Compassion Focused Therapy self soothing compassion exercises	2	8	2	15.4	2	22.2
	Solution Focused Techniques	1	4	~	~	~	~
Trauma work	EMDR Trauma work (stabilisation and reprocessing)	3	12	3	23.1	3	33.3
Communication Systemic Principles	Transactional Anaylsis	1	4	1	7.7	1	11.1
	Couples therapy	1	4	1	7.7	1	11.1
	Psychodynamic Principles	1	4	~	~	~	~
	Narrative	5	20	3	23.1	1	11.1
	Art/Creative Therapy	2	8	~	~	~	~
Communication	Transactional Anaylsis	1	4	1	7.7	1	11.1
	Holistic approaches	1	4	~	~	~	~
Transdiagnostic therapy	Therapeutic alliance as a change mechanism	2	8	2	15.4	1	11.1
	Talking	3	12	~	~	~	~
	Imagery	1	4	~	~	~	~
	Normalisation	1	4	1	7.7	1	11.1
	Empathy	1	4	~	~	~	~
	Stone work	1	4	1	7.7	1	11.1
	Empty chair work	1	4	1	7.7	1	11.1
	Crisis interventions	1	4	1	7.7	~	~
		Total: N=25	100%	N=13	100%	N= 9	100%

** Practitioners listed more than one techniques or change mechanisms in their clinical practice*

Practitioners' conceptualisation of post fertility treatment distress

(Research Aim 1)

Round II

In Round II 40 statements were posed to the expert panel regarding post treatment distress, when infertility treatments had been unsuccessful (Table 4). Statements aligned to the question eliciting them in Round I and were organized by theme. For **question 1**, 17 statements reached an agreement score of ≤ 70%. Four statements reached consensus, obtaining a score of 100%. The expert panel was unanimous in their agreement of 92.3 per cent disagreement with one statement: '*On-going emotional distress after ending treatment will be the same as those experienced when a cycle has been unsuccessful'.* Statements which had reached 100 per cent consensus originated from four qualitative themes emergent in Round I (Themes: Social, cultural and religious; Individual experiences; Relational dynamics). Six statements which had not reached agreement went through to Round III.

For **question 2**, 10 statements reached agreement, of which five reached 100% consensus. **Question 2** prompted agreement that: therapy should be about a shared narrative and meaning of the infertility experience; it should be restorative in terms of accepting the body's limitations; it should be couple orientated; and future focused, fostering new life/couple goals. Eight statements that had not reached agreement were included in Round III.

Round III

By Round III a total of nine practitioners remained involved. Of the total statements remaining, a further nine statements moved over the 70 per cent agreement level, with one statement reaching 100% agreement indicating consensus. This iterative Delphi process of re-

rating, improved the percentage agreement for three statements elicited by **question 1**. These statements related to the nature of distress following prolonged treatment periods for women, that there should be disclosure of the true success rate of fertility treatments, and that distress is related to the impact of infertility on sexual function and sexual expression between the couple. Of interest, the expert panel did not agree on three statements; that counsellors were recommended too late; that fertility treatment was related to distress as a result of ongoing traumas and that distress would be proportionate to the number of cycles of treatment.

A further three statements relating to the components that therapy should address (**question 2)** reached the agreement percentage in Round III. These statements related to therapy for: feelings associated with infertility; feelings of failure; and the couple's relationship. Agreement decreased for two statements (69.3% - to 55.5% and 23.1% to 11.1%) in Round III. These were statements firstly that '*Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely'*. This statement takes a contemporary view of emotional regulation and its relevance to fertility distress; as opposed to eradicating these emotions. It aligns more to third-wave information processing models (CFT, ACT), where the skill is in sitting with distress (Galhardo & Pinto-Gouveia, 2016). The second statement was focused on discussing the future use of contraception with clients; the view being that not choosing to use contraception keeps the potential (false) hope of becoming parents alive.

Table 4: Shows the results of Rounds II and III statements for questions 1 and 2

	Round II					Round III					
Delphi Statements: Question 1.	Mean	Median[a] (1-5 scale)	Inter-quartile Range	Standard Deviation	Percentage of agreement %	Mean	Median[a] (1-5 scale)	Inter-quartile Range	Standard Deviation	Percentage of agreement %	Round Agreement Achieved
Theme 1: Parenthood as identity and having children as a life goal											
Relinquishing the investment in parenthood is challenging because the childless identity is unacceptable	2.08	2	1	0.669	76.9	~	~	~	~	~	II
Relinquishing the investment in parenthood is challenging because it is unchartered territory	2	2	0	0.739	92.3	~	~	~	~	~	II
Relinquishing the investment in parenthood is challenging because it means loss of hope for an imagined future	1.25	1	1	0.425	76.9	~	~	~	~	~	II
Theme 2: Social, cultural and religious expectations and pressures											
The struggles of women who do not have children are poorly understood	1.75	1.5	1	0.965	84.6	~	~	~	~	~	II
Those that are childless are stigmatised and their personhood is diminished by society	1.75	2	1	0.452	100**	~	~	~	~	~	II

Table 4 *continued*	**Round II**					**Round III**					
Theme 3: Legacy of the fertility treatment											
On-going emotional distress is associated with the reinforcing nature of fertility treatments –'the next treatment might just be the successful one'	3.83	4	3	1.193	77	~	~	~	~	~	II
Theme 4: Unprocessed loss											
Individuals need to have their loss(es) acknowledged	1.17	1	0	0.389	92.3	~	~	~	~	~	II
Individuals need to be permitted to grieve openly and deeply.	1.25	1	1	0.452	92.3	~	~	~	~	~	II
Individuals need to learn skills to manage emotional distress associated with the loss of their fertility/embryo and/or their imagined child	1.42	1	1	0.793	84.6	~	~	~	~	~	II
Theme 5: Individual experiences											
There is a risk that individuals will relapse if they have co-existing mental health difficulties?	1.42	1	1	0.515	100**	~	~	~	~	~	II
Grief after ending treatment can activate past developmental traumas, losses and/or attachment issues for the individual	1.5	1.5	1	0.522	100**	~	~	~	~	~	II

On-going emotional distress after ending treatment will be the same as those experienced when a cycle has been unsuccessful?	4.15	4	1	0.555	92.3[b]	~	~	~	~	~	II
Individuals on-going emotional distress after ending unsuccessful treatment will be related to their beliefs about personal failure.	1.83	2	1	0.577	92.3	~	~	~	~	~	II
Theme 6: Transition											II
Individuals experience difficulty in accepting family life as it is, with its conflicts and lack of perfection.	2	2	1	0.853	76.9	~	~	~	~	~	II
Individuals will need to be facilitated to re-evaluate happiness and contentment	1.92	2	1	1.165	76.9	~	~	~	~	~	II
Theme 7: Relational dynamics											
On-going emotional distress after ending treatment is associated with beliefs about how committed and invested each individual in a couple was in having a child.	1.75	2	1	0.452	100**	~	~	~	~	~	II

Table 4 *continued*	**Round II**					**Round III**					
The individual's emotional response after ending treatment is associated with their beliefs about the impact of fertility treatment on their relationship.	1.83	2	1	0.577	92.3	~	~	~	~	~	II
Theme 3: Legacy of the fertility treatment											
On-going emotional distress after ending treatment is caused by prolonged fertility treatments for older women.	3.5	2	1	0.452	46.2	3.67	4	1	0.707	88.9*	III
Individuals need to be supported to recognise that fertility treatment is commonly unsuccessful and normalise this	4	5	2	1.414	61.5	4.11	5	2	1.269	77.8*	III
Counsellors are recommended too late to clients after unsuccessful fertility treatment	3	3	2	1.128	46.2	3.44	4	2	1.333	55.5	N
Theme 5: Individual experiences											
Individuals on going emotional distress after ending treatment will be a result of traumas associated with the fertility treatment procedures	2.5	2	1	0.905	53.8	2.33	2	1	0.500	66.7	N
Individuals on-going emotional distress after ending treatment will be associated with the number of unsuccessful cycles of infertility treatment.	2.92	3	2	0.793	38.5	2.78	3	2	0.833	44.4	N

Delphi Statements: Question 2	Round II					Round III					
Theme 7: Relational dynamics											
On-going emotional distress after ending treatment is associated with the impact of fertility treatment on sexual function and expression.	2.33	2	1	0.888	61.5	2.11	2	1	0.601	77.8*	III
Theme 1: Infertility experience											
Therapy is to develop a shared narrative of the end of their fertility treatment and the impact of involuntary childlessness	1.5	1	1	0.522	100**	~	~	~	~	~	II
Theme 2: Recognition and processing of emotions											
Therapy facilitates the desensitization and reprocessing of any traumas associated to infertility	3.5	4	2	1.382	76.9	~	~	~	~	~	II
Theme 3: Sense of self as child free											
Therapy is to help individuals put themselves back together	1.75	2	1	0.866	92.3	~	~	~	~	~	II
Therapy is to help individuals to reclaim their sexuality and body, accepting its fertility limitations	1.75	2	1	0.622	92.3	~	~	~	~	~	II

Theme 4: The couple's relationship											
Therapy facilitates the couple to learn to grieve together, and to respect each other's different ways of coping.	1.25	1	1	0.452	100**	~	~	~	~	~	II
Therapy must strengthen coping together, communicating with each other and the renegotiation of the couple's goals.	1.42	1	1	0.515	100*	~	~	~	~	~	II
Therapy must address problems that might have come up in the partnership because of the infertility or the treatment(s).	1.75	1.5	1	0.965	84.6	~	~	~	~	~	II
Theme 5: Meaningful life without children											
Therapy facilitates individuals to nurture areas of their life outside their fertility, living in line with their values and making committed action.	1.17	1	0	0.389	100**	~	~	~	~	~	II
Theme 6: The therapeutic process											
Therapy is instilling hope for the future and increasing an individual's psychological flexibility	1.42	1	1	0.669	92.3	~	~	~	~	~	II
Therapy should explore with individuals how they want to mark and signify the end of fertility treatment in the absence of formal markers such as maternity leave.	2	2	0	0.739	84.6	~	~	~	~	~	II
Theme 9: Risk assessments											

Therapy should monitor the normal reactions of grief and loss in case individuals move to persistent and clinical presentations of distress.	1.33	1	1	0.492	100**	~	~	~	~	~	II
Theme 1: Infertility experience											
Therapy is to help individuals see that infertility (primary or secondary) is not a failure	2.58	3	3	1.165	46.2	2.00	2	1	0.707	77.8*	III
Theme 2: Recognition and processing of emotions											
Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely.	3.75	4	3	1.545	69.3	3.22	4	4	1.716	55.5	N
Theme 4: The couple's relationship											
Therapy is about negotiating the impact of infertility on the couple rather than the individual	2.17	2	2	0.937	69.2	1.89	2	2	0.782	77.8*	III
Therapy must address sexual function or expression problems arising from fertility treatment.	2.08	2	2	0.900	61.5	1.56	2	1	0.527	100**	III
Theme 6: The therapeutic process											
The process of normalisation and validation through the therapeutic alliance is the most powerful aspect of the therapy process	1.67	1	2	0.888	69.2	1.78	2	2	0.833	77.8	III

Delphi Statements: Question 2	Round II					Round III					
Theme 7: Creating a different transition											
Therapy should explore alternative routes to fulfil parenthood.	1.92	2	2	0.900	69.2	2.00	2	1	0.707	77.8*	III
Theme 8: The role of contraception on future hope											
Therapy should facilitate discussion about not using contraception for those with unexplained infertility, and how it could prevent an individual's ability to accept their infertility.	2.83	3	2	0.937	23.1	2.78	3	1	0.667	11.1	N

Note: a = Median ranges from '1' strongly agree to '5' strongly disagree
b = the expert panel disagreed with the statement
** = Statement has reached agreement in this round (total percentage of agreement is ≤ 70%)*
***= 100% agreement the statement has reached consensus*
II = Agreement (≤70%) achieved in round II of the Delphi Study
III = Agreement (≤70%) achieved in round III of the Delphi Study
N = Statement did not reach agreement or consensus by the end of the Delphi Study

Practitioners' views on which are effective therapeutic techniques

(Research Aim 2)

Round II

Table 5 shows the remaining 18 statements that the expert panel rated for consensus. For question 4 'the key ingredients of therapy', two statements met agreement; there was high agreement for use of different types of techniques and change methods to regulate distress in the post treatment phase (92.3%) and acknowledgement that the timing for different interventions was important for the clinician to judge (84.6%). For question 5, out of the nine statements presented, five met agreement, with two meeting consensus for the use of comprehensive assessments and formulations to guide therapeutic interventions, and the use of distress tolerance strategies to help manage crisis and risk. The expert panel agreed (92.3%) that psychoeducation and guided self-help principles would be beneficial for emotional distress within the post treatment phase (Table 3). They also agreed that the match between the practitioner and client was important (91.7%). Seven statements from question 4 and three statements from question 5, which did not meet consensus were re-presented to the expert panel in Delphi Round III.

Round III

Question 4 showed the greatest number of statements which did not move into agreement, these statements mainly related to a number of themes from Round I. The statement '*therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience'* did not reach agreement, or that '*the therapeutic relationship is the only important ingredient in therapy'.* The theme 'practicalities of therapy' (e.g. therapy should be free, that it should be readily available,

contracted, reviewed regularly and delivered through different mediums) all remained under the 70% agreement by the end of the Delphi. Disagreement could be influenced by a number of factors; practitioners worked in private practice, therefore free therapy would compromise their business; the urbanization or otherwise of a country; the limited number of practitioners working in fertility; therapy accessibility; and the practitioners' ideas about the diverse mediums through which to deliver therapy. In some countries and treatment contexts it could also be that fertility counselling or fertility guided self-help is more accessible and preferred by individuals (e.g. Aarts et al., 2012). In total, 14 Statements did not reach agreement by the end of the Delphi study.

Table 5. Shows the results of Rounds II and III statements for questions 4 and 5

	Round II					Round III					
Delphi statements: Question 4	Mean	Median [a] (1-5 scale)	Inter-quartile Range	Standard Deviation	Percentage of agreement %	Mean	Median [a] (1-5 scale)	Inter-quartile Range	Standard Deviation	Percentage of agreement %	Round Agreement Achieved
Theme 1: Therapeutic knowledge and skill											
It is important that the therapist uses a variety of tools and change methods informed by a range of different theories.	1.5	1	1	1.168	92.3	~	~	~	~	~	II
A key ingredient of the therapy process is judging how to time therapy interventions.	1.67	1.5	1	0.778	84.6	~	~	~	~	~	II
Theme 2: Self-awareness and self-reflection											
It is important that the therapist is reflective and owns their perspective.	1.58	1	2	0.900	69.2	1.33	1	1	0.707	88.9*	III
Theme 3: Fertility knowledge											
The therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience.	2.67	2	4	1.775	32.2	3.22	4	3	1.481	66.7	N
Theme 4: The therapeutic relationship											
The therapeutic relationship and alliance is the only important ingredient.	2.42	2	1	0.996	53.8	2.22	2	2	1.093	55.6	N
Theme 5: Practical aspects of therapy											

It is important that therapy is free at the point of delivery	2.83	3	3	1.467	38.5	2.89	3	2	1.054	33.3	N
It is important that there is a clear therapy contract and to build in regular reviews of that contract.	2.5	2.5	1	0.798	53.8	2.11	2	2	1.054	66.7	N
It is important for the therapist to be flexible and available at short notice	2.5	2	2	1.000	61.5	2.44	2	2	1.014	66.7	N
Theme 5: Practical aspects of therapy											
It is important to be able to provide therapy via modes such as skype or telephone counselling.	2.5	2	1	0.905	61.5	2.00	2	1	0.866	88.9*	III
Delphi statements: Question 5	**Round II**					**Round III**					
Theme 3: Psycho-education and guided self-help											
Emotional distress associated with the post fertility treatment stage would benefit from psycho-education, relaxation and guided self-help principles.	2	2	0	0.739	92.3	~	~	~	~	~	II
Theme 4: Therapeutic techniques & interventions											
The therapeutic techniques and interventions would be determined by a comprehensive assessment and understanding of the emotional distress and its impact on the individual/couple.	1.5	1.5	1	0.522	100**	~	~	~	~	~	II
Theme 5: Crisis Intervention											
To facilitate distress tolerance strategies to help manage crisis/ risk and to keep people safe from harm.	1.58	2	1	0.515	100**	~	~	~	~	~	II

To refer onto mental health services during times of crisis?	1.83	2	2	0.835	75	~	~	~	~	~	II
Theme 6: Goodness of fit and practical advice											
The match between the therapist and client is important and clients should be supported to find who works for them.	1.33	1	0	0.888	91.7	~	~	~	~	~	II
Theme: 1 Living well and improved well-being											
To learn to live well with the distress of loss rather than to suppress it.	3.08	4	4	1.881	53.9	3.11	4	4	1.833	55.5	N
To encourage a healthy balanced lifestyle which involves living well with exercise and self-care	2.92	3.5	4	1.782	53.9	3.56	4	3	1.590	66.9	N
Themes 2: Complementary approaches											
To use alternative approaches (e.g. Chinese Medicine, Naturopathy, spirituality and hypnotherapy)	3.08	3	3	0.996	23.1	3.11	3	2	1.167	33.3	N

Note: a = Median ranges from '1' strongly agree to '5' strongly disagree
b = the expert panel disagreed with the statement
** = Statement has reached agreement in this round (total percentage of agreement is ≤ 70%)*
***= 100% agreement the statement has reached consensus*
II = Agreement (≤70%) achieved in round II of the Delphi Study
III = Agreement (≤70%) achieved in round III of the Delphi Study
N = Statement did not reach agreement or consensus by the end of the Delphi Study

Stability of group responses

A Wilcoxon matched-pairs signed ranks test was used to inspect consensus, establishing changes that occurred across the mean rank scores from Round II to Round III. This non parametric test has been shown to be suitable for use in Delphi studies (de Vet, Brug, Nooijer, Dijkstra, De Vries, 2005; von der Gracht, 2012). Results indicated that there was no statistically significant difference between statements in Round II and Round III (Data in Appendix O). Of interest, looking at the important components that therapy should address (**question 2**.) regarding the couple's relationship (Theme 4), for statement '*therapy must address sexual function or expression problems arising from fertility treatment'*, there was weak evidence of change between rounds ($Z = 1.732$, $p = 0.083$) which in Round III gained 100 per cent agreement. The raw data showed that a third of the expert panel (n=3) changed their rating from '*neither agree nor disagree*' to '*somewhat agree*' at Round III. Similarly, the statement regarding what therapy should address (Question 3.) and the practicalities of therapy (Theme 5) showed another weak change ($Z = 1890$, $p = 0.059$) for *'It is important to be able to provide therapy via modes such as Skype or telephone counselling'*, which moved to 88.9% agreement. The raw data showed that a third of the practitioners changed their positions, with two moving from '*neither agree nor disagree*' to '*somewhat agree*' and one practitioner moving from *'somewhat disagree'* to *'strongly agree'*.

Discussion

This study aimed to determine through expert consensus infertility practitioners' views on the clinical presentation of emotional distress in the post treatment phase; when fertility treatment(s) had been unsuccessful and parental goals were unmet. It also aimed to identify effective therapeutic techniques that practitioners used to support individuals in this context, and that they felt individuals engaged with to reduce their distress. The results of this Delphi study met these aims. Fifty-eight statements were identified from Round I on emotional distress and adjustment. Nine practitioners, practising within six countries completed all three rounds of this Delphi study. A total of 44 out of 58 statements met the agreement percentage by Round III. It was anticipated and natural that there would be a difference in opinions about clinical practice across practitioners and these differing perspectives will be outlined and discussed further.

Interpretation of the Findings

Overall, the findings reinforced a view that emotional distress associated with unmet parental goals was complex; which is consistent with the wider literature on unsuccessful infertility treatments (Verhaak et al., 2007; Wirtberg et al., 2007; Su & Chen, 2006). The expert panel endorsed the idiosyncratic nature of distress (Jaffe, 2017); that what is central are an individual's attributions (Shreffler, et al., 2017), desires (Becker, 2000) and goals of having children (da Silva et al., 2016). Infertility practitioners perceived distress to be associated with statements concerned with an individual's identity, (Letherby, 2002), adjustment to new life courses relinquishing a desire for biological children (Verhaak et al., 2007; Wischmann et al., 2012; Gameiro et al., 2014) and navigating the social, societal and cultural context of childlessness (Bell, 2013; Pesando, 2017). Practitioners discussed ambiguous loss and grief displayed by their clients. Furthermore, the expert panel views

represented a clinical picture of distress, which mirrored that of the evidence-based research on fertility distress (Gameiro & Boivin; in Covington, 2015). The nature of the distress described aligned with the moderators proposed in the theoretical model of infertility adjustment; the Three Task Model of Adjustment to Unmet Parental Goals (Gameiro & Finnegan, 2017). The expert panel agreed that the core elements of therapy were to guide individuals through the experience, which aligned to the three tasks; meaning making, acceptance and pursuit of new life goals (Gameiro & Finnegan, 2017).

Working therapeutically within such specialist area requires flexibility and diversification from the practitioner (Joy & McCrystal; 2015; Covington, 2015). A range of therapeutic models were suggested to formulate the distress of infertility and adjustment to blocked parental goals. Models stated in clinical practice aligned with stress and coping theory (Lazarus & Folkman, 1984), self-regulation model (Heckhausen, Wrosch & Fleeson, 2001) and grief models (Stroebe & Schut, 1999; Boelen, et al, 2006). The most frequently reported models, in this Delphi study, were CBT, Psychoanalytic principles and Person-Centered Therapy. These were followed by third-wave therapeutic approaches such as Acceptance and Commitment Therapy and Compassion Focused Therapy; both of which have an efficacious evidence-base for emotional regulation and mental health presentations (Leaviss, & Uttley, 2015; Swain, Hancock, Hainsworth, & Bowman, 2016). The expert panel indicated that third wave approaches were being applied clinically to understand the very specialist and nuanced difficulties presented by those who have remained childless despite their desire for parenthood (Peterson & Eifert, 2011; Cunha, Galhardo & Pinto-Gouveia, 2016).

The therapeutic interventions that practitioners used and felt were useful for engaging their clients were enumerated. The predominant session format was 1:1 or couple based. Two systematic reviews indicate the benefits of intervening therapeutically during fertility treatment. Boivin (2003) found group interventions, such as relaxation training and education were reported to be most helpful; whilst Friederiksen et al., (2015) advocated CBT and group therapy as efficacious in ameliorating psychological distress. Currently, there is only one study focusing on interventions in the post treatment phase (e.g. Kraaij, Garnefski, Fles,, Brands, van Tricht., 2016), this was a cognitive behavioural self-help coaching program, designed to improve depressed mood in women with a permanent unfulfilled child wish. Interestingly, therapeutic interventions delivered via a group format were not mentioned by the expert panel, which could imply that groups are not being routinely used. There could be a number of reasons for this. For instance, the initial Round I questions of the Delphi did not invite discussion about group work or perhaps, as practitioners worked independently within private practice, group work was a less frequently used form of therapy or a form of therapy which was more difficult pragmatically to resource when working outside a medical facility (Domar, 2015).

The expert panel agreed that important components of therapy were to offer a range of different change methods and to judge the timing of these interventions to fit with clients' needs. As psychological distress fluctuates, so different types of psychosocial interventions for relieving distress may be more appropriate at different times. It is believed that individuals will experience different levels of distress relating to infertility at different times during the infertility treatment care pathway and therefore different interventions are needed (Frederiksen et al., 2015). This is especially relevant for adjustment in the post treatment phase; where feelings of loss associated with infertility are recurrent and likely to be reactivated with varying intensity at different stages in an individual's life (e.g. onset of

menopause) and family life cycle (Wirtberg et al., 2007). Therefore there is a need that therapy should also provide an educational element that equips individuals/couples through developing resiliency/coping skills to maintain future well-being (Covington, 2015).

Across the Delphi process practitioners highlighted meaning making of the experience of ending fertility treatments and understanding the infertility experience from an individual and couple's perspective to be important in post treatment work. The expert panel placed a strong emphasis during Round I on the therapeutic relationship, as a change mechanism and the use of therapeutic processes of empathy, normalization and validation. This relationship was linked to allowing the individual the safety and space to grieve their loss. The therapeutic alliance was considered to be an important component within therapy as it normalized and validated the experience of distress in the post treatment phase. However, in Round II it missed the 70% agreement criteria, scoring 69.2%. This may be explained by the attrition rate and the loss of psychoanalytic practitioners between Rounds I and II. There was also a strong emphasis on working with the couple, as opposed to the individual focus that the Delphi questions took. The expert panel expressed a belief that the couple should learn to grieve together, be facilitated to develop new life goals and that any impact of treatment on intimacy should be addressed. One qualitative study highlighted the impact of treatment on sexual desire and how all women interviewed had felt that counselling should have been offered around this (Wirtberg et al., 2007).

The Delphi iterative process showed change in agreement with statements across Rounds II and III. It was observed that consistent with the aim of gaining consensus, practitioners made changes in the way that they rated some questions. It would be interesting to know the effects, if any, that participating in the Delphi had on practitioners' clinical practice. Does seeing a statement that refers to clinical practice that you initially

rated lower, act as a form of peer supervision; do some statements resonate and become a focus again in clinical practice? Does some form of conformity take place across the Delphi (Meijering, et al., 2013)? Unfortunately there is little scope within the data to assess what factors caused the possible changes in rating - whether it was conformity to the group responses or whether it formed an element of continuing professional development. It is beyond the Delphi study's methodology to determine these process related factors.

Strengths and Limitations

A strength of this study is that it recruited a panel of practitioners who were working therapeutically in the post fertility treatment phase and gathered perspectives gained through their work within several countries and health services. It enabled a rich representation of clinical practices of fertility practitioners and described the clinical needs of individuals, taking into account the cross-cultural norms surrounding childlessness. However some limitations also need to be acknowledged. Firstly, the composition of the expert panel; the majority were from Europe, Australasia, America and Asia. Therefore our results may reflective a western perspective on distress associated with the post treatment phase and may not be generalizable. The 'expert' panel participants were accredited by BICA, UK professional standards for fertility practitioners and therefore eligible practitioners practising in countries with no professional registration may have been excluded due to not holding an accreditation in fertility. All responses to rounds were requested in English which could have excluded practitioners from partaking in the study, and some questions may have been difficult to translate. Furthermore, the expert panel was determined by opportunity sampling through professional networks, fertility organizations and fertility clinics. Emails may not have reached all the practitioners in infertility clinics approached and some practitioners

may not have been permitted by their organization to partake in the research during work time.

Terminology across countries may be different and the definition of post treatment phase was not defined in the Delphi questionnaire as a specific time period as per the ESHRE guidelines (e.g. 1 year or more after patients undergo their last treatment cycle). Therefore the panel may interpret post treatment inconsistently when contributing their responses. In addition, qualitative responses in Round I were grouped together and similar statements were reduced to one thematic statement. This pragmatic approach was implemented to create a manageable number of statements for rating in Round II (Whitman 1990; Green, Jones, Hughes & Willimans, 1999). This may have altered the original verbatim responses' meaning, introducing bias toward the perspectives that were held by the researchers (Hanson et al., 2000).

Limitation of inferential statistics in Delphi is a commonly reported methodological weakness of this technique (von der Gracht, 2012; Meirjering et al., 2013; Diamond et al., 2014) as there is no consensus or guidance on the most appropriate statistical model to use (Holey, Feeley, Dixon & Whittaker, 2007; Keeney et al., 2012). This introduces a lack of stability in the statistical models used and forces the researchers to make assumptions as to the criteria for agreement and consensus (Diamond et al., 2014). Thus, compounded with attrition across the Delphi phases and a small residual sample size, this could mean findings were from an under-powered analysis and therefore there is potential for Type II errors. The high attrition rate between Rounds I and III across the Delphi process may also have led to non-response bias. This can have a significant detrimental effect on the accuracy of survey estimates (Fogliani, 1999). Cross tabulation was undertaken to determine inter-rater and between-rater agreement and to ascertain change in statements. Of those who did not

complete Round III, this process indicated that these panel members mainly gave '*strongly agree*' and '*somewhat agree*' ratings to the majority of statements and therefore might not have changed their positions if they had been retained for the last round.

Conclusion

Despite these limitations this study showed that infertility practitioners were working to support individuals in the post fertility treatment phase in a number of clinical and private settings. A diverse set of models and interventions were used to make sense of the experience and improve emotion regulation skills. Their practice appears broadly to conform to the principles of The Three task model of unmet parental goals (Gameiro & Finnegan, 2017) that is, to support individuals to accept their situation, make meaning from the experience and to pursue new life goals.

Future Research

Future research could include individuals who have accessed support for their post infertility related distress as very few studies specific to this group were found (Kraaij et al., 2016). This Delphi study could be replicated to include individuals who have terminated fertility treatments and who remain childless, as part of the expert panel. This could be beneficial and complement the findings provided from a practitioner's perspective and shape service provision based on insights from a more person- and couple-centered perspective (Domar, 2015). Furthermore, a different qualitative approach may help to capture the fertility practitioners' insights into the processes they use within the therapy room which has not been well served by the Delphi method. Interpretative Phenomenological Analysis could be used to investigate involuntary childless individuals' experiences from a therapists' and service users' perspective and what they feel creates

'insights' or which prompt re-formulation and re-attribution when each of the Tasks are pursued therapeutically. Lastly, future studies could look at different therapeutic modalities and how they could support adjustment, via using written disclosure or online self-help, or through accessing an online peer support group which is facilitated by fertility practitioners.

Clinical Implications

This Delphi Study indicated the importance of fertility counselling and that psychosocial interventions are beneficial in supporting adjustment processes. Evidence-based interventions which are guided by adjustment models are needed (Gamerio & Finnegan, 2017). In addition, practitioners emphasised the need for fertility clinics to be more realistic about the success rates of treatment, ensuring that individuals are prepared before treatment starts; as this may help to manage unrealistic expectations and adjustment from the beginning.

Therapeutic interventions which promote adjustment may have wider implications as they could be used to support those who are involuntarily childless as a result of delayed childbearing and/or circumstantial reasons. Greater education on reproduction in society is also vital to prevent ambivalence and undesired childlessness (Koert & Daniluk, 2017).

Practice generated research is important as it enriches the evidence-base (Sackett et al., 1996); thus allowing for the development of future interventions which are tailored to support individuals during the post treatment phase. It could provide interventions of ecological validity, with a better fit to the needs of individuals (Covington, 2006) with better alignment to current clinical resources within the context of fertility service provision.

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Critical review paper

Manuscript prepared in accordance with APA, Journal of Counselling and Consulting Psychology submissions guidelines.

Max word count for journal submission: 8000 words
Total word count of systematic review = 7295

(excluding tables, figures and references)

(Appendix A for manuscript submission checklist)

Introduction

This paper critically appraises the research presented so far. The appraisal will focus on and reflect upon the processes undertaken to complete the systematic review and empirical research project, retrospectively. It will also emphasize the strengths and limitations of the research and identify pertinent issues which arose through the process. Lastly, the paper will reflect on the experiences which have been influential in developing the author's research and clinical skills in relation to the core competencies of a clinical psychologist.

Paper 1: Systematic Review

Rationale for the topic

In developing a review question the aims were primarily influenced by the focus of the empirical project on the adjustment to involuntary childlessness. Also, the emerging area of psychological and the neuro-psycho-immunological impact of trauma and/or adverse childhood experiences (ACEs) within the reproductive literature. The author wanted to investigate the two together; trauma, fertility and childlessness, in relation to adjustment processes. The experience of involuntary childlessness has been described as being traumatic (Domar et al., 1993). In addition, infertility treatment procedures to overcome involuntary childlessness are invasive. They also have the potential to be (re-)traumatizing for some individuals (Corley-Newman, 2016) due life experiences. This combination, and the lack of a published review in this area (Daugirdaitė, van den Akker, Purewal, 2015), shaped the chosen review question. The author hoped that the review would also provide some context for paper two.

Initial ideas were structured around the literature base from both infertility and childlessness perspective focusing on the psychosocial needs and adjustment processes to failed infertility treatment (Daniluk 2001; Lechner, Van Balen, 2008; Greil et al., 2010; Gameiro & Finnegan, 2017). During the scoping searches a number of systematic reviews were found. Overall they summarised the adjustment processes to failed fertility and blocked parental goals through stress, coping, loss and grief models (Gameiro & Finnegan, 2017). They concluded that there is strong evidence to support that infertility is a distressing, stressful life event which can be traumatic in nature (Friedrikesen et al., 2015). However, trauma or complex post-traumatic stress disorder (PTSD) have been described as different constructs to that of loss and (complicated) grief, even though they have both been described as stress-response syndromes (Maercker & Znoj, 2010). Therefore, trauma theory constructs may offer an alternative in understanding the adjustment process which warrants further investigation (Daugirdaitė et al., 2015).

The search process

To optimise the studies captured for review a list of search terms were devised and piloted, based upon the preliminary scoping searches. The search stream was informed by the Three Tasks Adjustment Model to Unmet Parental Goals (Gameiro & Finnegan, 2017). Their original search stream was used to guide the development of the current one, which focused more on involuntary childlessness, trauma and post traumatic growth as opposed to theirs which focused on failed infertility treatment. Descriptors in the literature were considered across three core areas; psychological, biological/medical and social impact. From an initial sweep of the literature it was evident that the search stream was too generalised as it captured all aspects of infertility, including infertility procedures. However, after refinement by introducing the terminology ‘post traumatic growth’, the search became

too specific, and this had the potential to exclude studies. Therefore, search terminologies associated with PTG were removed (e.g. positive transformation, new possibilities, spiritual growth, and resiliency) to emphasise the theoretical aspects of the main subjects.

Furthermore, it was apparent that it would be useful to use a combination of the Boolean operators (or /and) to identify all relevant articles, especially as PTG is emerging within the fertility literature (Paul et al., 2010). Papers retrieved from this search stream included studies that were not printed in English and dissertation and conference abstracts. For the author to become widely read in this new topic area it was decided to manually screen for these studies, rather than changing the electronic database settings to exclude them from the search process. A defined time period or geographical area for the search were not considered; the impact on involuntary childlessness and trauma is a global experience which is shaped by social-cultural contexts and meaning. The author wanted to include the global impact to enrich and generalise the findings of the systematic review.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were developed from a detailed PICO table, which focused the search on a specific population, intervention, comparator and outcome, (Boland, Cherry, Dickson, 2014) to maximise all potential primary quantitative and qualitative studies in order to address the review question. The decision to relax the type of publication to include non-peer reviewed studies enabled three doctorate theses to be included. This widened the study selection, which was necessary due to the limited number of studies with this client group specifically focusing on the impact of PTSD and trauma within reproductive medicine (Daugirdaitė et al., 2015). Furthermore, it helped to reduce the effects of publication bias as both significant and non-significant results were reported.

Overall, studies generally focused on infertile participants seeking fertility treatment; however the outcome of these interventions were not targeted within this review. Therefore both infertility treatments and non-fertility treatment papers were included. The focus of trauma extended to the inclusion of post traumatic growth which is an emerging focus in relation to the infertility literature-base (Schmidt et al., 2005, Paul et al., 2010).

It became apparent, when reviewing studies for inclusion, that there is disparity within the reproductive literature, with a lack of focus on male infertility (Petok, 2015and even less in relation to male emotional adjustment to childlessness (Buhr, & Huinink, 2017) and the impact of circumstantial childlessness for men (Berrington 2017). No studies of infertility related to trauma and men were found during the search. This is an area that warrants further attention and future research, to ensure that men receive equity of care and access to effective psychological support.

This lack of studies aided the pragmatic decision to focus the review primarily on involuntary childlessness in women in the inclusion criteria. Additionally there is a greater focus on women's adjustment and couple well-being in the infertility literature (Greil et al., 2010) with women enduring more invasive infertility procedures in the pursuit of resolving childlessness. Furthermore, for involuntary childlessness caused by circumstances and delayed childbearing, there is greater predictability measuring the active reproductive period and accuracy when following a cohort of women in epidemiological studies, compared to males (Berrington, 2017). Papers focusing on the impact of physical health conditions and physical injury, which may impair infertility were also excluded (e.g. Cancer/genital injury) as it would be difficult to measure how much of the trauma reaction would be mediated by the experience of a life threatening condition or injury.

Quality appraisal tool

The decision of which quality assessment tool to use was guided by The European Society of Reproductive and Embryology [ESHRE], which recommends the use of the SIGN cohort studies checklist to rate the strength of scientific evidence within a study (ESHRE, 2017). SIGN is used for comparative cohort studies and, therefore, was not considered effective for the range and selection of empirical studies retrieved. Initially a quality tool, specifically for this review, was designed from the SIGN by the author, with a points system. However, this appeared to over-estimate the quality of the studies when compared with the SIGN guidance for scoring. It was interesting to note that the use of two quality appraisal tools, on the same set of papers, could provide such a contrast of rating results. This reinforces the range of results obtained from a variety of tools can produce in terms of intent, components, construction and psychometric properties (e.g. Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004).

As a result of this process, the 'EBL critical appraisal tool' (Glynn, 2006) was then selected due to its versatility to review different forms of methodologies (Eldridge, 2006) and it also incorporates features of the SIGN cohort studies checklist. In addition, its focus is applicable to direct clinical practice and provides an overall validity score (Glynn, 2006) and it has been shown to have good content and construct validity (Glynn, 2006). To reduce further bias in the quality assessment ratings, 30% of studies were appraised by an independent rater (NICE, 2012).

Method of analysis

The search stream identified a variety of studies for inclusion from the systematic selection. Meta-analyses are widely used in the synthesis of systematic reviews (Gopalakrishnan,& Ganeshkumar, 2013), however, the author's analyses led to the decision that this would not be appropriate. Given the aim to generate a clinical understanding, a narrative synthesis was undertaken, as this was felt to be more appropriate from the evidence extracted from the included studies.

The included papers were cross-sectional and questionnaire studies and were of mixed quality; two studies rated as poor through to two high quality studies. Poor quality was, in part due to the unrepresentative study samples, omissions regarding the methodology and lack of external validity of the findings. The EBL critical tool (Glyn, 2006) scored the three doctorate theses highly in overall quality. This may have been biased by the fact that the theses, which provided replicable detail and explanations throughout their methodology sections, therefore met more for the EBL prompt questions.

A variety of self-reported questionnaires (13 in total) were used across the studies. The variety of different questionnaires is considered a form of bias as there could be gaps in the nature of the constructs that are being assessed (Mehta et al., 2015). Furthermore, as all questionnaires were self-reported, they could be subject to potential faking, bias and distortions (Punch, 2003). These questionnaires do however provide insight into the experience of individuals experiencing infertility, trauma symptoms and post traumatic growth. They attempt to quantify the distress and/or positive growth; complementing studies that have used qualitative methods in understanding the experience of infertility and childlessness.

Another area that needs to be considered in the data analysis is that none of the studies identified focused on the experience of involuntary childlessness attributed to circumstances or delayed conception. This could be attributed to wider methodological issues within the infertility research (Greil, 2007) such as the prevailing clinic-based studies of treatment seekers, providing little information about more than half of the infertile population (Greil et al., 20l0). Secondly, that the different reasons for involuntary childlessness have generally been researched together (Letherby, 2002; Shreffler, Griel & McQuillian, 2017) and lastly, that nulliparous women, who have yet to attempt to conceive have generally been omitted from research studies on infertility (Schwerdtfeger & Shreffler, 2009).

Furthermore, involuntary childlessness and the experience of life events which are traumatic are global experiences (Turnball, Graham & Takert, 2016); yet the majority of fertility research is carried out in developing countries, within reproductive medical settings with samples of convenience (Greil et al., 2010). The demographic of those seeking fertility treatments are typically Caucasian, have attended graduate or further education and are in employment (Scheffler et al., 2018). They are also invested emotionally and financially in achieving their child goal and thus in seeking treatment (Gameiro & Finnegan, 2017). There are significantly fewer studies focusing on adjustment to infertility in different ethnic groups (Scheffler et al., 2018), and in developing countries (World Health Organisation, 2010; Van Balen, 2008). The author's lack of resource to be able to include non-English language papers, excluding three potential papers, could have contributed further to any bias; again prioritising the western pronatalist cultural views on childlessness and emotional distress in the papers reviewed (Greil et al., 2010; Turnball et al, 2016).

In addition a number of papers were unattainable despite exhausting normal

channels. Authors were contacted, inter-library requests made and numerous databases examined. One paper (e.g. a qualitative study looking at involuntary childlessness) which was relevant were reluctantly excluded from the review due to unobtainability.

Clinical Implications

Despite the limited findings of the review a number of implications for clinical practice were inferred. Services should be aware of the potential impact of trauma for individuals accessing reproductive clinics and undergoing treatment. Therefore it would be ethical for clinics to routinely screen for traumatic experiences prior to commencing treatment. There is a need for comprehensive psychosocial support, which facilitates emotional coping throughout the fertility care pathway (Gameiro et al., 2013). Specifically, interventions that promote psychological flexibility, cognitive reappraisal and PTG that have derived from a robust evidence-base are required (Gameiro et al., 2015). Reproductive clinics have a responsibility to ensure that decision making and informed consent to fertility treatment is understood in the context of client's personal history and emotion well-being. Furthermore reproductive clinics should be adverse in the management of disclosures associated with trauma and the impact this has on individuals and provide appropriate psychological support (BPS, 2016).

Future research

The overall results of this review highlight the need for further understanding in this area. Future research would benefit from attempting to address definition and methodological issues, including the use of longitudinal studies designed to better understand causal relationships, dynamic process on adjustment (Paul et al., 2010; Yu et al., 2014) and an increased use of non-clinic based samples (Greil et al., 2010). Furthermore,

more qualitative studies in this area would be helpful to enrich the findings with a better understanding of the personal and couple accounts of the impact of trauma and involuntary childlessness.

It would also be helpful to explore further, the role of marital adjustment and PTG (Ghafouri et al., 2016), because it cannot be assumed that each individual in the partnership shares the same parenting goals. It could be that those who report PTG had a strong marital bond but a weaker commitment to parenting goals. This could also mean that individuals may pursue infertility treatment with less vigour, and therefore this may be a confounding factor which is little studied but may impact on potential risk of trauma reactions.

Another finding (Tirabassi, 2017) showed emotional literacy, emotional regulation, cognitive re-appraisal, social support and coping styles to be indicative of adjustment processes for managing emotional distress associated with involuntary childlessness. Therefore clinically, being able to evaluate the experience of infertility, to access cognitive re-appraisal and behavioural resources that increased psychological flexibility and implement positive coping strategies would be helpful in formulating contributors to overall adjustment processes.

Conclusion

The results of this review are significantly limited, by both the lack of high quality papers and restricted empirical studies focusing on trauma reactions during or after infertility treatment (Corley-Newman, 2016) and the assessment and acknowledgment of predisposing traumatic experiences in individuals prior to seeking infertility treatment (Santos et al., 2017). The review presented findings for a subset of the population of people with infertility and trauma. Notwithstanding these limitations the findings are promising in

that the literature base in this area has developed since the systematic review conducted by Daugirdaitė, van den Akker and Purewal (2015). Whilst this review was able to make a number of recommendations regarding clinical practice, further high quality research is clearly required.

Paper 2: Empirical Paper

Identification of the research topic

My clinical experience has emphasised the lack of support in primary care services for emotional adjustment following unmet parental goals. Although, this is not commonly a reported presentation, there is a lack of awareness within mainstream mental health service of the needs of these individuals.

The authors research has shown there has been an under representation within the empirical literature to ascertain the views of practitioners working with infertility distress (Covington, 2006). To ensure robust evidence-base medicine continues to inform and guide clinical decision making (Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) this empirical project was interested in determining the view of fertility practitioners and understanding their daily clinical experiences. There is emerging area of research focusing on the adjustment processes after failed infertility treatment (Gameiro & Finnegan, 2017) and only one study to dates that focus on the psychological interventions for the post treatment phase (e.g. Kraaij, Garnefski, Fles, Brands, van Tricht, 2016). Therefore there is a lack of literature which supports the decision making of the fertility practitioners (Gameiro et al., 2015). Therefore, the epistemology of this Delphi is gounded in a scientific-reflective clinical psychology paradigm.

Reason for selecting Delphi Methodology

A Delphi study methodology was chosen to elicit opinions from fertility practitioners with clinical expertise derived from working with patients in the post treatment phase after unsuccessful fertility treatment(s). Delphi techniques seek to define consensus from a group of 'expert panel members' on a given topic (Diamond et al., 2014), usually when none already exist (Kennedy et al., 2012) by using a systematic process of questionnaire Rounds, interspersed with controlled feedback (von der Gracht, 2012). Delphi seemed appropriate choice, given the emerging evidence base on adjustment processes to the post fertility treatment stage (Gameiro & Finnegan, 2017) and no studies ascertaining fertility practitioners' clinical perspectives of emotional distress associated with adjusting to permanent childlessness.

Knowledge of the Delphi methodology

Delphi techniques have four core principles; anonymity between experts (Keeney, Hasson & McKenna, 2011); a process of iteration occurs from the controlled feedback (Meirjering, Kampen & Tobi, 2013); statistical analysis is used to create group responses to questionnaires and control feedback. The expert panel is then able to reconsider their own responses in light of this feedback (Diamond et al., 2014). Analysis of the data across successive Rounds not only provides a level of consensus, but its strength through the convergence of opinions (von der Gracht, 2012).

Since its inception in the 1950's as a forecasting technique (Keeney, Hasson & McKenna, 2011), Delphi has become a commonly used methodology; especially within healthcare (Trevelyan & Robinson, 2015; von der Gracht; Keeney et al., 2011) and within mental health research, where it has been used to improve diagnosis through to the

development of the content of an intervention (Jorn, 2012). The Delphi methodology can reduce recruitment bias, due to being able to include wide geographical remit (Tevelyan & Robinson, 2015) especially when delivered via the internet. Additionally, the format of delivery reduces psychosocial pressures of group dynamics and irrelevant communication, as well as promoting social learning and modification of prior judgments, through the safety of no face to face contact (von der Gracht, 2012).

Advantages of methodological approach

The main strength of Delphi is its ability to validate expertise and experience via the discovery of shared competencies and identification of agreement (Rupprecht, Birner, Gruber, & Mulder, 2011; Rowe & Wright, 1999). This is achieved by creating a panel of experts that are present throughout the process (Keeney et al, 2011; Diamond et al., 2014). Jorm (2015) advocates that this process has a valid place within evidence-based research; it is underpinned by multiple sources of theoretical and practical evidence. The Delphi is able to gain a group consensus (Hasson, Keeney & McKenna, 2000) which is free from subjective bias; reducing the limitations that impact other opinion based methodologies, for example focus groups. These can be easily influenced by dominant group members, group dynamics and irrelevant 'noise' of information (Dalkey, 1969). Furthermore the Delphi allows for open and truthful responses through the process (Keeney et al, 2011). The Delphi is flexible in its delivery, so was suited to being delivered electronically through online questionnaires. This allowed expert panel members to complete in their own time, removed any challenges of organising one to one clinical interviews to collect qualitative information and facilitated individuals in different countries to take part.

Furthermore, expert panelists are potential stakeholders in any outcome or intervention generated from the Delphi process (Jorm, 2015). This automatically promotes

the ecological validity of the findings, ensuring that the outcome is relevant, and therefore more desirable for the clinician to integrate into their clinical practice. Covington (2006) states that there is a need for greater collaboration between infertility counsellors and researchers in order to develop interventions that have better fit to patient needs.

Limitations of Delphi Methodology

Although Delphi studies regularly deliver accurate and valuable results, they are not without their critics (Winkler & Moser, 2016). A number of these concerns involve the lack of methodological guidance on implementing a Delphi study (Keeney et al., 2011; Meirjering et al., 2013; Diamond et al., 2014); the identification and selection of the expert panel (Jorm, 2015); how opinion changes in the expert panel occur across the Delphi Rounds (Keeney et al., 2012); and finally, the definition and measurement of consensus or agreement (von der Gretch, 2012; Meirjering et al., 2013; Diamond et al., 2014).

Whilst acknowledging these shortcomings at the beginning of the research process, the Delphi study methodology was still thought to be an appropriate methodology to address the study's overall research aims. It was felt that it would provide valuable contributions, where there is limited research (Kennedy et al., 2012), it would be able to elicit rich qualitative information from an under presented population, whose clinical practice is very specialised (Joy & MC Crystal., 2015). The information gained throughout the Rounds on emotional distress and clinical practice could then be re-evaluated by the expert panel for consensus, using self-reflection and the formal iteration process (Diamond et al., 2014).

Disadvantages of the methodological approach

The main disadvantages of this approach is the length of time that a Delphi study can take to conduct, especially if more than three Rounds are implemented (Jorm, 2015). Delphi

studies have also been described as complex, in terms of the administration involved in conducting one (Keeney et al., 2011) and they can be highly labour intensive for both the researcher and the expert panel alike. These factors can impact on the expert panel's motivation and investment in the study (Whitman, 1990); especially when practitioners are already under considerable time pressures from demanding services and clinical caseloads.

During this Delphi study, the largest attrition in the numbers of the expert panel was observed between Delphi Round I and II. Unforeseen delays were experienced during the whole process of running the Delphi and these may have had potential impact on the retention of the expert panel. These delays will be discussed in more detail in the recruitment and retention section, where the author will elaborate on how these issues were resolved.

The design of the Delphi Study

Within the literature there are many different variations of Delphi studies; this is due to the lack of universally agreed guidelines for the method (Keeney et al., 2011). To navigate this limitation, the author familiarised herself with Delphi studies, conducted in mental health research, which had looked to address consensus and used an expert panel group of professionals in a specific area of specialism. The '*Classic Delphi',* opposed to a modified approach, was decided upon (Dalkey & Helmer, 1963) using both qualitative and quantitative Rounds to elicit rich data. This was essential, as the main research aim was to ascertain practitioners' views on emotional distress. A modified approach, would have prevented views being elicited and would have been biased to the author's own ideas and focus.

In designing the Delphi, three Rounds only were considered. This was based on

pragmatic reasons and hoped to mitigate some of the disadvantages of the method, such as reducing the demands on practitioners' time and impact of attrition (Keeney et al., 2011; Diamond et al, 2014). Furthermore, it was decided *a priori* that consensus would not be a deciding factor for termination of this study, as disagreement might provide rich insight into current clinical practice.

A recent systematic review highlighted that there is a tendency for Delphi studies to terminate once they have reached consensus, yet the criterion for consensus is not adequately defined (Diamond et al.,2014). Therefore to address these comments in the current study, consensus was set and defined *a priori* as well.

Consensus and agreement

Another important consideration which influenced the study design has been the inconsistency within the literature in defining and specifying the criterion for achieving consensus (Diamond et al., 2014). Furthermore, von der Gracht (2012) states that there is a need to define between agreement and consensus; as these concepts have become blurred within the literature.

To address these concerns, the author set both the definition and criterion *a prior* and was guided by other published Delphi studies. Percentage agreement was chosen as the measure of consensus, as it is the commonly used definition (Diamond et al., 2014). Agreement would be defined by a statement reaching a level of 70% or more based on the panel scoring the top two measures (‘*strongly agreed’ or ‘somewhat agree’)* and consensus was defined as a statement scoring 100% agreement on the top two measures. This was determined based on the fact that if a definition of consensus is when the whole of the expert panel agrees on the same rating for an item, it makes it difficult for the Delphi study

to achieve consensus (Meijering et al., 2013). This was a pragmatic decision which has been employed by other Delphi Studies (Morgan & Jorm, 2009). The sum of 70% was chosen based on the findings from Diamond et al's., (2014) systematic review, which reported a median threshold of 70% to be the median score (range 50-97%).

The author acknowledges that statements might not reach agreement based on what could be considered an arbitrary cut off, which has no statistical value (Meijering et al., 2013; Diamond et al., 2014). However, ironically, there is no consensus within the Delphi literature on the most appropriate statistical measure for reporting a move towards consensus either (Murphy et al., 1998; Holey et al., 2007; Keeney et al., 2011; von der Gracht; Diamond et al., 2014) as it is unsure how different indices cope with the concept of conformity across the Rounds of the Delphi (Meijering et al., 2013). To aid reporting of agreement and consensus within this study, both the median and the interquartile range were used to feedback to the expert panel.

Expert Panel:

The expert panel is fundamental to the outcome of the Delphi study (Keeney et al., 2011). Considerations were given to the recruitment process, size of the expert panel and how to reduce the impact of retention and attrition. The definition of what constitutes an 'expert opinion' has been widely debated in the Delphi literature; with issues concerning terminology of who is an expert, determining a panel member's degree of expertise and recruiting panel members (Keeney et al., 2011). To address these issues, selection of panel members was based on the BICA professional registration criteria. This ensured that only registered and practising fertility practitioners were able to participate and that they were presumed to have the expertise given, being a member of a professional infertility body. Recruitment was initially going to be through the BICA membership list and reproductive

clinics. The criteria for taking part relaxed, dropping the need to have or be working towards the BICA infertility counselling accreditation as this is limited to the UK.

Recruiting participants within the UK was slow, there were delays with organisations sending out the study information due to needing to be screened, recruitment going up on social media and through the use of generic emails to fertility clinics. The main reasons for this change were to be more inclusive and so that practitioners in different countries would be eligible to participate. The author was recommended by her supervisor to approach members of the International Infertility Counselling Organization (IICO) to enhance recruitment and enrich the study further as it would be influenced by social-cultural contexts. Opening up the recruitment to the IICO had more impact initially on the numbers.

The size of the Delphi panel varies considerably, with no unanimous agreement over how many experts should be on the panel, studies have shown to have as little as four participants through to over 1000 (Cantrill et al., 1996). Ideally the expert panel needs to remain large enough to provide diversity of opinions (Keeney et al., 2012). Although the final expert panel consisted of nine practitioners, the main criteria of the panel being a homogenous group of practitioners remained present throughout the study (Novakowski & Wellar, 2008). In order to retain and hold motivation, individuals were informed when they would get the next Round, one reminder emails were sent whilst a Round was open and participants where given the opportunity to save and return to their questionnaires. The Delphi had a 52% response rate between Rounds I and II, this falls short of the recommended 70% needed to maintain rigor (Bork,1993;Sumsion,1998). Given that a Delphi study can have high attrition rates due to its multiple Rounds, the final Rounds had high response rates. However, there is a potential that the study was open to bias as a result of this attrition (Keeney et al., 2012).

Questionnaire Development across the Delphi

The demographic questionnaire was developed prior to the decision to include an international sample. In hindsight, a number of these questions should have been changed to reflect the new sample (e.g. *Please state the number of years' experience since qualifying from your accreditation in fertility counselling*). In addition it would have been helpful to have asked participants how long they had worked in infertility so a mean average could have been calculated. Also the use of age brackets meant that it was not possible to calculate the mean age of the practitioners within the expert panel.

Delphi Round I questions were based on three recent systematic reviews and questions were formulated to represent core elements of the clinical cycle (assessment, formulation, intervention and evaluation; BPS, 2016). Piloting the Delphi Round I questionnaire with a fertility counsellor working within a Welsh NHS fertility clinic was invaluable; changes were recommend to the use of terminology within questionnaire (e.g. infertility practitioners to fertility practitioners).

Questions in Round I were designed to be unambiguous (Holey at al., 2007) however they could have been open to translational misinterpretation by some individuals as English was not their first language. One practitioner made contact with the author to clarify the meaning of questions in Round I. Similarly, statements posed in Round II might have been affected by these issues. This may have biased the findings. However, it was felt that this did not limit the responses and brought a unique cultural context to the findings. Statements rating scale in Round II was designed to include both negatively and positively keyed rating scales to reduce acquiescence response bias.

In Delphi Round III, statements which reached an agreement percentage of 70% or more, were presented to the panel in a table format. They were not included in Round III for further ratings as this would of have Round III too long and could affect participation (Keeney et al., 2011).

Data Analysis

Thematic analysis using the Braun and Clarke (2006) protocol was used to analyse the qualitative questions from Round I. It is a common choice of analysis for qualitative sections within a Delphi (Dalkey & Helmer, 1963; Linstone & Turoff, 1975) and was deemed suitable in answering the study aims (Brady, 2015) due to its theoretically-flexible approach (Braun & Clarke, 2006). Furthermore, this analysis is underpinned by the underlying epistemology of social constructionism (Turnoff, 1975; Rauch, 1979); as it conceptualises the psychological sequelae of infertility distress and denied parenthood goals, through the familiarity of practitioners' therapeutic experiences. Consensus is therefore constructed and interpreted by the influences of our idiosyncratic experiences, training and social worlds (Dalkey & Helmer, 1963; Jorm, 2015). An inductive stance was taken to review the data, identifying latent themes (Braun & Clarke, 2003). The researcher attempted to reduce bias, acknowledging her own associations with the wider infertility literature. No additional meta-theorisation of the themes was undertaken (Patton,1990) and sub-themes were not constructed from the latent themes (Braun & Clarke, 2006). Amalgamation may have reduced the number of statements which provided richness, of both cultural and clinical nuances, within Round II.

Methodological papers provided a selection of inferential statistical tests that have been used in previous Delphi studies to determine concepts of stability and inter- and intra-reliability across Rounds II and III. Some researchers promote the use of a weighted or

Cohen's Kappa statistic (Holey et al., 2007), whilst others promote the use of Chi square (Chaffin & Talley, 1980), T-Tests and their non-parametric equivalents (von der Gracht, 2012). Others critique the use of Kappa, due to the fact it shouldn't be used with nominal data sets (Trevalyn & Robinson, 2015). There appears to be an ongoing debate regarding the most appropriate and accurate statistical approaches with little consensus or guidance.

Given the limitation of the final sample of participants (n=9) it was felt to be highly questionable to use inferential statistics as the results may be misleading, due to being underpowered and would be open to type two errors. Priority was given to reporting descriptive statistics between Rounds and cross-tabulation methods which reported inter- and intra- agreement between Rounds II and III of the Delphi. This manual calculation showed a number of trends; firstly, the greatest shift in ratings, and therefore shift to medians and inter-quartile ranges between Rounds II and III, was with the reversed scored items. Secondly, when individuals changed their position a number moved towards group consensus and a number moved their position away from the group consensus.

Consideration of an alternative methodology

In light of some of the methodological and recruitment issues encountered through this study an alternative approach, such as Interpretative Phenomenological Analysis (IPA) could have been conducted. Although this method would not be suitable to gain a consensus on practitioners' views it would be a useful approach to capture the experiential and qualitative nuances of the practitioners' roles and clinical work with individuals in the post treatment phase of treatment.

IPA is widely used in exploring health decision-making processes and can elicit rich qualitative information through a clinical interview which can be designed to focus on the

participant's accounts. This would provide greater opportunity to investigate the experiences of working clinically, especially to understand the complexity of this work and some of the challenges that the practitioner has to work through with their clients.

Strengths and limitations of the study

The strength of this study was that it recruited a panel of practitioners who were working therapeutically in the post fertility treatment phase and gathered perspectives gained through their work within several countries and different reproductive health services (e.g. public funded and private). As far as we know, this is the first time that a study like this has been conducted. This enabled a rich representation of clinical practice of fertility practitioners, describing the clinical needs of individuals, taking into account the cross-cultural norms surounding childlessness.

The main limitation of this study is that the process of the Delphi, by its nature seems to seem to systematically reduce the richness of the findings with each iterative Round. In a clinical context, like working in the post fertility phase, there may be a tendency for practitioners to conform to the standards of fertility counselling practice in their responses. There could be a potential that factors of social desirability are involved in the responses. The group of practitioners may be more likely to present a perspective which conforms to their perceptions of what is 'good' practice and what is 'effective' practice. Their ability to provide nuanced insights into the processes they use in the room are not best addressed through the Delphi method.

Limitations of the line of enquiry

During the research process there has been awareness of the limitations caused by the complexity of the definitions and terminologies within infertility literature base (Greil et

al., 2011). Infertility has been conceptualised through a western medicine perspective, with the extent of the literature, defining who is infertile by the nature of them accessing treatment (Greil et al., 2011). However, this focus has excluded a large proportion of individuals, who do not present to reproductive services; furthermore it doesn't distinguish between the biological condition of infertility and the social condition of involuntary childlessness (Matthews & Matthews, 1986) or when individuals are unable to acknowledge the infertility diagnosis. There is much more awareness of the diverse group impacted by infertility, such as childlessness through circumstances (Letherby, 2002; Greil et al., 2011; Turnball et al., 2016). Similarly, reproductive trauma is a misleading terminology as it incorporates multiple processes associated with still birth and infertility (Bhat & Byatt, 2016). It is hard to establish the relationship with trauma when multiple processes are amalgamated. Involuntary childlessness also includes circumstantial childlessness and infertility as a result of delayed childbearing, as well as infertility and biological mechanisms which prevent conception.

Suggested future research

In the empirical research it was suggested that future research could include individuals who had accessed support for post infertility related distress, and what elements of therapy were helpful or not for them. Currently there are very few studies which have explored the relationship between post fertility treatment, distress and psychological interventions, with only one study found for this specific area (e.g. Kraaij et al., 2016). Furthermore, it is unknown what type of psychological support would be acceptable to this client group, as many individuals may not seek professional support once leaving the fertility clinic. It was unknown within this empirical study, if practitioners were reflecting on clients who had started psychotherapy prior to discontinuing their fertility treatment or whether they had started therapy after treatment had been stopped. Therefore we do not

have an accurate picture of how many people seek support, or at what point in time, or whether therapy promotes adjustment at the significant transitional point of stopping treatment.

As the theoretical model of adjustment by Gameiro & Finnegan (2017) proposes, there are three psychological tasks which occur during the process of adjustment to blocked parental goals; these are meaning making, acceptance and pursuit of life goals. It would be interesting to test further this model through identifying fertility practitioners' and involuntarily childless clients' insights into the re-formulation and re-attribution when each of these tasks are pursued therapeutically.

Given the increasing number of adults who are remaining childless (Craig et al., 2014; Berrington, 2017), more research should focus on the clarity of defining the terminology within the literature, with more studies looking to identify the immediate and longer term implications and distress associated for this group (Buhr, & Huinink, 2017). Priority should also be given to understand the impact of childlessness on other under-represented groups such as those in same- sex relationships and different ethnic groups (Shreffler, Greil & McQuillan, 2017).

Clinical and service delivery implications

This section will focus on the implications of the empirical paper, which has focused on the adjustment process to involuntary childlessness. Firstly, the findings highlight the complex context of childlessness and the social-cultural and emotional impacts which affect individuals, regardless of the nature of how childlessness occurs. Furthermore, the attempt to fulfil an individual's desire for biological parenthood through fertility treatments is often extremely stressful, time consuming, restricted by financial resources and can be described

as a traumatic experience (Domar et al., 1993).

The current NICE guidelines for infertility (NICE, 2013) recommend the need for psychosocial support, before, during and after treatment. Yet there are no recommended evidence-base interventions (Gameiro et al., 2015) for practitioners to inform their clinical decision-making to support individuals during times of stress. Furthermore, the levels of distress can vary across the fertility treatment periods (Friedrikesen et al., 2015), therefore a stepped care approach would be beneficial across the care pathway (Gameiro et al., 2013).

The practitioners within the Delphi study described the need for fertility clinics to be more realistic about the success rates of treatment, ensuring that individuals are prepared before treatment starts; this may help to manage unrealistic expectations and adjustment from the beginning. This extends further to the wider societal perception of the successfulness of fertility treatments, based from '*miracle*' stories in the media, that *'treatment is 100% successful'* and that the reproductive time frame can be expanded as a consequence; with both practitioners and researchers emphasising the need that greater education on reproduction is vital to prevent ambivalence and undesired childlessness (Koert & Daniluk, 2017).

Furthermore, those individuals who are permanently childless through delayed childbearing and circumstantial reasons have been shown to experience poor mental health and well-being (Gameiro & Finnegan, 2017). Yet their specific adjustment needs are under researched and not well known (Koert & Daniluk, 2017). There are limited, if any, specific service provisions to help address their emotional distress relating to their childless status. They are a population who are under supported and also, as the rate of childlessness increases (Berrington, 2017), a growing population who may access psychological support

in the future. As the research highlights, the desire to be parents lives on (da Silva, Boivin & Gameiro, 2016), and is emotionally difficult to detach from, so at times this distress may peak, especially at different transitional times in one's life (Wirtberg, Möller, Hogström, Tronstad & Lalos, 2007). This chronic sorrow may be linked to other detrimental health-related behaviours as a way to cope with these feelings which, like the adverse childhood literature-base found, increases the need to access physical and mental health services (Oral et al., 2016).

Social perceptions of childlessness are still ones that reflect a narrative of '*personal choice*' and being '*career driven*' (Bell, 2013; Nokin, 2015; Turnball et al., 2016). Society neglects the different narrative; one that is often of hidden sadness and distress (Wirtberg,et al., 2007).

The author has had the experience of working within a secondary care service, which is structured as a trauma-informed approach (Herman, 1992). This could be a helpful model of care when considering infertility and the current care pathway; as it focuses on early identification of difficult life experiences and builds in stabilisation and emotional coping strategies to manage these experiences (Sweeny, Clement, Filson & Kennedy, 2016).

Dissemination

To maximise the reach of the findings, dissemination is planned via multiple approaches. As part of the Delphi study, a summary of the findings will be sent back to the expert panel members in the form of a Delphi Report which is part of the control feedback (Appendix P). It will be sent out to all members of the panel who completed the three rounds and who requested the final report.

Dissemination to professionals and academics will be targeted by submitting the systematic review for publication to the Journal of Consulting and Clinical Psychology. This is a peered review journal and part of the American Psychology Association, its current impact factor is 4.593 and its main remit are studies of a variety of populations that have clinical interest, including, but not limited, to medical patients and studies of psychosocial impact on health related behaviours.

The empirical paper will be submitted to the Journal of Human Reproduction, this is also a peer reviewed journal with an impact factor of five. It is the leading journal for reproductive medicine and science. The empirical paper abstract was submitted and accepted for poster presentation to the European Health Psychology, 32nd Annual Conference, which will be held in Galway in August 2018 (Appendix Q). Plans have been also made to share the study's findings with British Infertility Counselling Association (BICA) who were contacted to help with the recruitment of participants to the expert panel. BICA advertised the study to their membership and on their social network sites. It hoped that they will also publish a summary of the study's findings in their professional magazine.

To further highlight the findings of this thesis, and the gap in provisions for those affected by involuntary childlessness a letter has been drafted to the Improving Access to Psychological Therapies (IAPT) to highlight the ongoing needs that might be associated with undesired childlessness and the long term impact on emotional wellbeing.

Professional and personal reflection on the research process

Professional Development

It has been a privilege to work alongside practitioners from a number of different countries to understand their views about infertility distress from a clinical perspective. It was important to the author that the study was clinically relevant and strengthens the links between evidenced-base and practice-base evidence (Sackett, et al., 1996).

Throughout this empirical study, the author has gained the opportunity to experience and learn about the research process; from generating a line of inquiry through to the conceptualisation, implementation and interpretation of the results. This process has been facilitated by solving problems as they arose and through the supervisory relationship. This has provided a greater appreciation of the complexities and demands associated with conducting high quality research. The choice of methodology gave the author the opportunity to become proficient using a mixed method approach, to plan efficiently each process and navigate the challenges associated with them. On reflection, the author would have developed the thematic analysis within Round I to incorporate the use of sub-themes, as this may have reduced the duplication of themes that occurred over the four questions. Furthermore, as the research was guided by The Three Task Model to Unmet Parental Goals, there may have been greater alignment to the mediators described in the model and the three overarching psychological tasks for the adjustment (Gameiro & Finnegan, 2017).

Research is a core competency of a clinical psychologist; it allows for the transference of knowledge, and one that can influence and inform one's own clinical practice and that of others (British Psychological Society, 2016). This was evidenced by some feedback received from one of the Delphi participants.

"thank you for inviting me to take part in your important research. It gave me an opportunity to consider my clinical approach to patients at this crossroad.

...It would be interesting to explore the connection between clinical orientations (psycho-dynamic / cognitive behavioural/ interactional etc.) and perceptions of the aims and practices of therapy".

(Delphi Participant)

The process of conducting a systematic review has helped to develop the author's ability to synthesize the evidence base, taking into consideration the methodological quality of papers, and to become more critical of the findings. Allowing greater transference of knowledge, this is especially relevant when working in clinical services were there are still emerging professional guidelines.

Throughout the course of the study, the author has valued discussing the research with other health professionals' (although the author has always been mindful that the subject topic might be sensitive for some) having space to talk about the research focus, share commonly faced difficulties and, importantly, to facilitate discussions that challenge the societal rhetoric of childlessness (Letherby, 2002; Notkin, 2015; Turnball et al., 2016) has been a great benefit. As clinical psychologists, we are in a position to reflect on the impact of our work and the interface between professional and personal lives.

Personal reflections

Throughout the process of the research the author has reflected on her own position; of being female, childless and of childbearing age. Within social constructivism, how we view and understand concepts is shaped by the social worlds we live in; with multiple factors influencing these experiences, from observed and spoken information through unvoiced and unseen factors (Burnham, 2012). The author reflected on how this might have impacted on the research process through the privileging of certain information over others. Furthermore, these reflections extend more widely; to the reasons why practitioners may work in this area; in terms of why we might chose to work therapeutically in a certain area and how this might have shaped the research. Covington, (2015) reports that more than half of the fertility counsellors have a history of infertility, and 42% of psychologists have chosen to work in infertility due to their own experiences, adding to the validity of the research findings.

Lastly, as a trainee clinical psychologist, the research focus was shaped by the western, clinical psychology perspective of infertility distress, and in post treatment phase; based on the fact that the author has been influenced by the psychological models of loss and coping and adjustment (Gameiro & Finnegan, 2017).

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SYSTEMATIC REVIEW

APPENDIX A: Manuscript Submission Checklist

The journal of counselling psychology publishes theoretical, empirical, and methodological articles on multicultural aspects of counselling, counselling interventions, assessment, consultation, prevention, career development, and vocational psychology and features studies on the supervision and training of counsellors.

Particular attention is given to empirical studies on the evaluation and application of counselling interventions and the applications of counselling with diverse and underrepresented populations.

Manuscripts should be concisely written in simple, unambiguous language, using bias-free language. Present material in logical order, starting with a statement of purpose and progressing through an analysis of evidence to conclusions and implications. The conclusions should be clearly related to the evidence presented.

CHECKLIST FOR MANUSCRIPT SUBMISSION

Numbers following entries refer to relevant section numbers in the *Publication Manual*.

Format

- Have you checked the journal's website for instructions to authors regarding specific formatting requirements for submission (8.03)?
- Is the entire manuscript—including quotations, references, author note, content footnotes, and figure captions—double-spaced (8.03)? Is the manuscript neatly prepared (8.03)?
- Are the margins at least 1 in. (2.54 cm; 8.03)?
- Are the title page, abstract, references, appendices, content footnotes, tables, and figures on separate pages (with only one table or figure per page)? Are the figure captions on the same page as the figures? Are manuscript elements ordered in sequence, with the text pages between the abstract and the references (8.03)?
- Are all pages numbered in sequence, starting with the title page (8.03)?

Title Page and Abstract

- Is the title no more than 12 words (2.01)?
- Does the byline reflect the institution or institutions where the work was conducted (2.02)?
- Does the title page include the running head, article title, byline, and author note (8.03)? (Note, however, that some publishers prefer that you include author identification information only in the cover letter. Check with your publisher and follow the recommended format.)
- Does the abstract range between 150 and 250 words (2.04)? (Note, however, that the abstract word limit changes periodically. Check APA Journals Manuscript Submission Instructions for All Authors for updates to the APA abstract word limit.)

Paragraphs and Headings

- Is each paragraph longer than a single sentence but not longer than one manuscript page (3.08)?

- Do the levels of headings accurately reflect the organization of the paper (3.02–3.03)?
- Do all headings of the same level appear in the same format (3.02–3.03)?

Abbreviations

- Are unnecessary abbreviations eliminated and necessary ones explained (4.22–4.23)?
- Are abbreviations in tables and figures explained in the table notes and figure captions or legends (4.23)?

Mathematics and Statistics

- Are Greek letters and all but the most common mathematical symbols identified on the manuscript (4.45, 4.49)?
- Are all non-Greek letters that are used as statistical symbols for algebraic variables in italics (4.45)?

Units of Measurement

- Are metric equivalents for all nonmetric units provided (except measurements of time, which have no metric equivalents; see 4.39)?
- Are all metric and nonmetric units with numeric values (except some measurements of time) abbreviated (4.27, 4.40)?

References

- Are references cited both in text and in the reference list (6.11–6.21)?
- Do the text citations and reference list entries agree both in spelling and in date (6.11–6.21)?
- Are journal titles in the reference list spelled out fully (6.29)?
- Are the references (both in the parenthetical text citations and in the reference list) ordered alphabetically by the authors' surnames (6.16, 6.25)?
- Are inclusive page numbers for all articles or chapters in books provided in the reference list (7.01, 7.02)?
- Are references to studies included in your meta-analysis preceded by an asterisk (6.26)?

Notes and Footnotes

- Is the departmental affiliation given for each author in the author note (2.03)?
- Does the author note include both the author's current affiliation if it is different from the byline affiliation and a current address for correspondence (2.03)?
- Does the author note disclose special circumstances about the article (student paper as basis for the article, report of a longitudinal study, relationship that may be perceived as a conflict of interest; 2.03)?
- Does the author note provide information about prior dissemination of the data and narrative interpretations of the data/research appearing in the article (e.g., presented at a conference or meeting, presented as part of a colloquia at a university, posted on a listserv, or shared on a website, including academic social networks like ResearchGate, etc.)?

- In the text, are all footnotes indicated, and are footnote numbers correctly located (2.12)?

Tables and Figures

- Does every table column, including the stub column, have a heading (5.13, 5.19)?
- Have all vertical table rules been omitted (5.19)?
- Are all tables referred to in text (5.19)?
- Are the elements in the figures large enough to remain legible after the figure has been reduced to the width of a journal column or page (5.22, 5.25)?
- Is lettering in a figure no smaller than 8 points and no larger than 14 points (5.25)?
- Are the figures being submitted in a file format acceptable to the publisher (5.30)?
- Has the figure been prepared at a resolution sufficient to produce a high-quality image (5.25)?
- Are all figures numbered consecutively with Arabic numerals (5.30)?
- Are all figures and tables mentioned in the text and numbered in the order in which they are mentioned (5.05)?

Copyright and Quotations

- Is written permission to use previously published text; test; or portions of tests, tables, or figures enclosed with the manuscript (6.10)? See Permissions Alert (PDF, 13KB) for more information.
- Are page or paragraph numbers provided in text for all quotations (6.03, 6.05)?

Submitting the Manuscript

- Is the journal editor's contact information current (8.03)?
- Is a cover letter included with the manuscript? Does the letter

  a. include the author's postal address, e-mail address, telephone number, and fax number for future correspondence?

  b. state that the manuscript is original, not previously published, and not under concurrent consideration elsewhere?

  c. inform the journal editor of the existence of any similar published manuscripts written by the author (8.03, Figure 8.1)?

  d. mention any supplemental material you are submitting for the online version of your article?

APPENDIX B: Detailed search stream for Ovid databases.

Search Strategy	Medline	PsycInfo	Embase
Childless*	1488	1490	2220
childlessness.mp. or CHILDLESSNESS/	1482	760	1070
Childlessness.ti,ab.	559	511	821
involuntary childless*.mp	126	110	212
involuntary childless*.ti,ab.	124	96	202
(Childless* not by choice).mp.	1479	1453	2206
Lifetime childless* ti,ab.	2	3	2
unintentional childless*.ti,ab.	2	1	12
Permanent* childless*.mp.	7	11	15
Undesire* childless*.mp.	3	0	10
"Social Infertility"	5	2	18
Delay* childbearing.mp.	407	84	540
Denied motherhood.mp.	1	0	2
Pass* childbearing age.mp.	0	0	0
nullipar*.mp.	9702	786	17501
Child* Free.mp	242	303	386
infertil*.mp.	77155	3290	123137
Barren.mp.	766	408	989
sterile.mp.	32289	1279	53782
(unsuccessful adj15 childless*).ti,ab.	7	1	13
Post-traumatic stress disorder.mp.	7136	9259	12037
Posttraumatic stress disorder.mp.	12823	34325	50800
Post traumatic stress disorder.mp.	7136	9259	12037
PTSD.mp.	16058	30795	25875
Acute stress disorder.mp.	458	943	1473
Complex trauma*.mp.	353	699	562
Complicated trauma*.mp.	66	11	101
Psychological* trauma*.mp.	1583	2064	2034
Emotion* trauma*	418	15252	779
Trauma*mp	326395	103777	480418
adversi*mp	4991	8343	7935
Post traumatic depreciation.mp.	0	0	0
Birth* Trauma*.mp.	1002	397	2060
Infertil* trauma*.mp.	0	3	1
Child*loss	162	260	215
Child*loss*.ti,ab.	174	222	219
Child* grief.mp.	40	183	54
Loss of parenthood.mp.	3	3	4
Extreme* stressful event*.mp.	4	10	8
Life changing event*.mp.	110	185	183

Stressful life event*.mp.	3373	5590	5028
salutogenic.mp.	324	468	452
Posttraumatic growth.mp.	573	2106	909
Post-traumatic growth.mp.	204	450	466
benefit finding.mp.	209	416	377
Attitude/ or Self Concept/ or perception* of change*.mp. or "Quality of Life"/	246841	78651	506466
Positive change*.mp.	4914	6163	7826
Positive psychological change*.mp.	48	109	89
Psychological adaption.mp.	7	15	28
Stress related growth.mp	47	232	83
(Growth or Development).mp	2731695	797520	4765384
Adjustment*.mp.	166804	106734	233287
WISDOM.mp.	5389	9853	7496
Flourish*	2497	4088	3560
Thrive.mp.	8275	2974	15800
Or/1-19	119191	7298	194304
Or/20-41	336016	128888	515615
Or/42-54	3104946	955869	5427151
55 and 56 and 57	205	79	517

[m.p. = title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
[ti,ab. = title & abstract]

APPENDIX C: Reasons for exclusion of full manuscripts

Author	Date	Title	Reason*
Allsworth, J.E., Zierler, S., Krieger, N. & Harlow, B.L.	2001	Ovarian function in late reproductive years in relation to lifetime experiences of abuse.	6
Allsworth JE, Zierler S, Lapane KL, Krieger N, Hogan JW, Harlow, B.L.	2004	Longitudinal study of the inception of perimenopause in relation to lifetime history of sexual or physical violence.	8
Bartlik, B., Greene, K., Graf, M., Sharma, G., & Melnick, H.	1997	Examining PTSD as a complication of infertility.	4
Bateman-Cass, C. S.	2000	The loss within a loss: Understanding the psychological implications of assisted reproductive technologies for the treatment of infertility.	1
Bhat, A. & Byatt, N.	2016	Infertility and Perinatal Loss: When the Bough Breaks.	2
Confino, E. & Radwanska, E.	1992	Tubal factors in infertility	2
Corley-Newman A. & Trimble, A.T.	2017	The relationship between infertility, infertility treatment, psychological intervention, and post-traumatic stress disorder.	1
Deshpande A., & Gambhir, R.	2017	Just the two of us: Involuntary childlessness, causes and consequences	9
Dobie, D.J., Kivlahan, D.R., Maynard, C., Bush, K. R., Davis, T.M., Bradley, K.A.	2004	Posttraumatic Stress Disorder in Female Veterans Association With Self-reported Health Problems and Functional Impairment.	6
Dobie, D.J., Maynard, C., Kivlahan, D.R., Johnson, K.M., Simpson, T. & David, A.C.	2006	Posttraumatic stress disorder screening status is associated with increased VA medical and surgical utilization in women.	6
Frappell-Cooke, W., Wink, P. & Wood, A.	2013	The psychological challenge of genital injury.	2
Golding, J.M.	1996	Sexual assault history and women's reproductive and sexual health.	6
Golding J., Gregory S., Iles-Caven Y. & Nowicki, S.	2017	The mid-childhood and adolescent antecedents of women's external locus of control orientation.	4
Golding, J.M., Wilsnack, S.C. & Learman, L.A.	1999	Prevalence of sexual assault history among women with common gynaecologic symptoms.	6
Gurian, B., Wexler, D. & Baker, E.H.	1992	Late Life Paranoia: possible association with early trauma and infertility	5

Harville, E.W. & Boynton-Jarrett R.	2013	Childhood social hardships and fertility: a prospective cohort study.	8
Jaffe, J.	2017	Reproductive trauma: Psychotherapy for pregnancy loss and infertility clients from a reproductive story perspective.	1
Jaffe, J., Diamond, M.O.	2011	When the reproductive story goes awry: Trauma and loss.	1
Jacobs M.B., Boynton-Jarrett R.D. & Harville E.W.	2015	Adverse childhood event experiences, fertility difficulties and menstrual cycle characteristics.	8
Khisa, A.M. & Nyamongo, I.K.	2012	Still living with fistula: an exploratory study of the experience of women living with obstetric fistula following corrective surgery in West Pokot, Kenya.	7
Kinyanda E., Musisi S., Biryabarema C., Ezati I., Oboke H., Ojiambo-Ochieng R., Were-Oguttu J., …& Walugembe J.	2010	War related sexual violence and it's medical and psychological consequences as seen in Kitgum, Northern Uganda: A cross-sectional study.	8
Koizumi, T., Saito, H. & Ishizuka, B.	2013	The effect of grief process on post-traumatic growth in women with primary ovarian insufficiency (POI).	1
Lucas, P.A., Page, P.R., Phillip, R.D. & Bennett, A.N.	2014	The impact of genital trauma on wounded servicemen: qualitative study.	3
Meltzer- Brody, S., Leserman, J., Zolnoun, D., Steege, J., Green, E. & Teich, A.	2007	Trauma and posttraumatic stress disorder in women with chronic pelvic pain.	6
Mendola R., Tennen H., Affleck G., McCann L. & Fitzgerald T.	1990	Appraisal and adaptation among women with impaired fertility.	5
Mezey, G., Bacchus, L., Bewley, S. & White, S.	2005	Domestic violence, lifetime trauma and psychological health of childbearing women	4
Motherwell, L. & Prudent, S.	1998	Childlessness and Group Psychotherapy: Psychological and Sociological Perspectives	5
Pal L, Bevilacqua K, Santoro NF.	2010	Chronic psychosocial stressors are detrimental to ovarian reserve: a study of infertile women.	8
Pottinger, A.M., Nelson, K. & McKenzie, C.	2016	Stressful events and coping with infertility: factors determining pregnancy outcome among IVF couples in Jamaica.	5
Romans, S., Belaise, C., Martin, J., Morris, E. & Raffi, A.	2002	Childhood abuse and later medical disorders in women.	6

Santos, C., Sobral, M.P. & Martins, M.V.	2017	Effects of life events on fertility diagnosis: comparison with presumably fertility men and women.	8
Seng, J.S., Sperlich, M., Low, L.K., Ronis, D.L., Muzik, M. & Liberzon, I	2013	Childhood abuse history, posttraumatic stress disorder, postpartum mental health, and bonding: a prospective cohort study.	4
Yeakey, M.P., Chipeta, E., Taulo, F. & Tsui, A.O.	2009	The lived experience of Malawian women with obstetric fistula	7

* Reasons for exclusion classified as: 1- Grey literature (n = 5); 2- Literature reviews (n =3); 3- Male infertility focus only (n=1); 4-Successful Pregnancy outcome (n = 4); 5- no trauma constructs described (n =4), 6 - Medical focus, excluding infertility (n= 6); 7- medical complications resulting from labour (n=2); 8- biological effect of trauma on infertility (n = 6); 9-publication unavailable (n =1).

APPENDIX D: EBL Critical Appraisal checklist proforma

EBL Critical Appraisal Checklist		Yes (Y)	No (No)	Unclear (U)	N/A
Section A: Population	Is the study population representative of all users, actual and eligible, who might be included in the study?				
	Are inclusion and exclusion criteria definitively outlined?				
	Is the sample size large enough for sufficiently precise estimates?				
	Is the response rate large enough for sufficiently precise estimates?				
	Is the choice of population bias-free?				
	If a comparative study:				
	Were participants randomized into groups?				
	Were the groups comparable at baseline?				
	If groups were not comparable at baseline, was incomparability addressed by the authors in the analysis?				
	Was informed consent obtained?				
Section B: Data Collection	Are data collection methods clearly described?				
	If a face-to-face survey, were inter-observer and intra-observer bias reduced?				
	Is the data collection instrument validated?				
	If based on regularly collected statistics, are the statistics free from subjectivity?				
	Does the study measure the outcome at a time appropriate for capturing the intervention's effect?				
	Is the instrument included in the publication?				
	Are questions posed clearly enough to be able to elicit precise answers?				
	Were those involved in data collection not involved in delivering a service to the target population?				
Section C: Study Design	Is the study type / methodology utilized appropriate?				
	Is there face validity?				
	Is the research methodology clearly stated at a level of detail that would allow its replication?				
	Was ethics approval obtained?				
	Are the outcomes clearly stated and discussed in relation to the data collection?				
Section D: Results	Are all the results clearly outlined?				
	Are confounding variables accounted for?				
	Do the conclusions accurately reflect the analysis?				
	Is subset analysis a minor, rather than a major, focus of the article?				
	Are suggestions provided for further areas to research?				
	Is there external validity?				

Calculation for section validity: (Y+N+U=T) **If Y/T <75% or if N+U/T > 25% then you can safely conclude that the section identifies significant omissions and that the study's validity is questionable. It is important to look at the overall validity as well as section validity.**	Calculation for overall validity: (Y+N+U=T) If Y/T ≥75% or if N+U/T ≤ 25% then you can safely conclude that the study is valid.
Section A validity calculation: Y/T = **Section B validity calculation: Y/T =** **Section C validity calculation: Y/T =** **Section D validity calculation: Y/T =**	Overall validity calculation:
General Comments:	

Glynn, L. (2006). A critical appraisal tool for library and information research, *Library Hi Tech*, 24 (3), 387-399.

APPENDIX E: Quality rating scores for sections of the EBL critical appraisal tool

		Study							
		Bradow, (2012) Corley-Newman, (2016)	**Ghafouri et al., (2016)**	**Kong et al.,(2018)**	**Paul et al.,(2010)**	**Schwerdtfeger et al.,(2009)**	**Tirabassi, (2017)**	**Yu et al.,(2014)**	
Population	Representative of all users?	Y	N	N	N	N	Y	N	N
	Inclusion & exclusion criteria clearly defined?	Y	Y	Y	Y	Y	Y	Y	N
	Adequate sample size?	Y	Y	Y	Y	U	Y	Y	U
	Adequate response rate?	Y	Y	Y	Y	Y	Y	Y	U
	Population bias free?	Y	Y	N	N	N	Y	N	Y
	If comparative:								
	Randomised groups?	N	N/A	N/A	N/A	N/A	N	N/A	N/A
	Comparable at baseline?	N	N/A	N/A	N/A	N/A	N	N/A	N/A
	If not, addressed in analysis?	N	N/A	N/A	N/A	N/A	N	N/A	N/A
	Informed consent?	Y	Y	U	Y	Y	U	Y	Y
Data Collection	Clearly described?	Y	Y	Y	Y	Y	Y	Y	Y
	Inter/intra-observer bias reduced?	Y	N/A	U	N/A	N/A	U	Y	N/A
	Instrument validated?	U	Y	Y	N/A	Y	Y	Y	Y
	Are the statistics free from subjectivity?	Y	N	N	Y	N	N	N	N
	Timing appropriate?	Y	Y	U	Y	Y	Y	Y	U
	Instrument included?	Y	Y	Y	Y	Y	Y	Y	N
	Clear questions?	Y	Y	Y	Y	Y	Y	Y	U
	Blinding of assessors?	Y	Y	U	U	Y	Y	Y	Y
Study Design	Appropriate method?	Y	Y	Y	Y	Y	Y	Y	Y
	Is there face validity?	Y	Y	Y	Y	Y	Y	Y	Y
	Detailed for replication?	Y	Y	N	Y	Y	N	Y	Y
	Ethics approved?	Y	Y	U	Y	Y	U	Y	Y
	Outcomes clear?	Y	Y	Y	Y	Y	Y	Y	Y
Results	All the results outlined?	Y	Y	Y	Y	Y	Y	Y	Y
	Confounding variables accounted for?	U	U	U	Y	Y	U	U	U
	Conclusions accurately reflect the analysis?	Y	Y	Y	Y	Y	N	Y	Y
	Is subset analysis a minor focus of the article?	Y	Y	Y	Y	Y	Y	N	Y
	Suggestions further research?	Y	Y	Y	Y	Y	Y	Y	Y
	Is there external validity?	N	N	N	N	N	Y	N	N

Y= Yes (item adequately addressed), N= No (item not adequately addressed), U= Unclear, N/A (not applicable)

EMPIRICAL REVIEW

APPENDIX F: Human Reproduction: Author Guidelines

Human Reproduction features full-length, peer-reviewed papers reporting original research, concise clinical case reports, as well as opinions and debates on topical issues.

Papers published cover the clinical science and medical aspects of reproductive physiology, pathology and endocrinology; including andrology, gonad function, gametogenesis, fertilization, embryo development, implantation, early pregnancy, genetics, genetic diagnosis, oncology, infectious disease, surgery, contraception, infertility treatment, psychology, ethics and social issues.

Guidelines for Clinical Studies

Studies involving humans or human material should have appropriate ethical approval and, where relevant, the patients' written informed consent. The editors reserve the right to refuse publication where the required ethical approval/patient consent is lacking.

Structure (listed in order of appearance in the published manuscript)

1. Title Page
Title: Should not exceed 25 words and should be specific and informative. Trade marks and proprietary terms are not allowed in the title.
Running title: Should not exceed 50 characters.
Authors: Give initials and family name of all authors.
(Please refer to the section ‘To accompany manuscript at submission’ for more details regarding authorship entitlements)

2. Abstract
All original research articles published in Human Reproduction are now required to have an extended abstract. The aim behind the change to this new format is to capture the essence, novelty and importance of each study, making the information more instantly available to readers. The abstract should clearly set out the research question, study design, findings, implications, funding and competing interests.
An editable template with further instructions is available here. Please complete all sections.

3. Key words

Up to five key words must be supplied by the author. The key words, together with the title and abstract, are used for online searches. They should therefore be specific and relevant to the paper.

4. Introduction
The introduction should be limited to the specific background necessary to show the importance and context of the current study. The objective of the study should be clearly stated in the final paragraph of the Introduction.

5. Materials and methods
The names and country of origin of all suppliers should be included.
Please use subheadings.
The study population and participants should be described.
A separate subheading the materials and methods should describe the statistical analyses.

6. Results
Unnecessary overlap between tables, figures and text should be avoided.
Please use subheadings for different sections.

7. Discussion
The discussion should begin with a succinct statement of the principal findings, outline the strengths and weaknesses of the study, discuss the findings in relation to other studies, provide possible explanations and indicate questions which remain to be answered in future research.

8. Author’s roles
Manuscripts must include details for the contributions of each of the authors, including participation in study design, execution, analysis, manuscript drafting and critical discussion

9. Acknowledgements
Personal acknowledgements should precede those of institutions or agencies.

10. Funding
With respect to funding of research, in line with the World Association of Medical Editors (WAME) guidelines the journal considers it the responsibility of the author to protect the integrity of the research record from bias related to the source of funding by fully declaring all sponsorships, the roles played by sponsors in the research as well as institutional affiliations and relevant financial ties.

11. Conflict of interest

Authors should include a conflict of interest statement on the manuscript detailing any potential conflicts of interest of any of the authors due to relationships with commercial/corporate interests – or that they have none to declare.

12. Reference list
References should be listed alphabetically. Please use the following style. Note that correct punctuation and journal abbreviations must be used in order to run the search programs used to edit the manuscript. Incorrectly typed references take a lot of time to correct, for which we reserve the right to charge. Up to 10 authors should be included after which et al . should be used. Refer to the following examples.

14. Tables
Tables should be uploaded as a separate document in an editable format.
Each table should be numbered consecutively with Roman numerals. Please avoid complex constructions. Each item of data should be in a separate cell and should be produced using Word or Excel format. Each table should be self-explanatory and include a brief descriptive title. Footnotes to the table indicated by superscript lowercase letters are acceptable but should not include extensive experimental detail. Reference to the tables in the text should be sequential (ie Table I, II etc).

Do not include more tables than is absolutely necessary - non-essential tables may be judged as being suitable for online-only publication.

15. Figure legends
Each legend must be self-contained, with all symbols and abbreviations used in the figure defined.

16. Figures
Figures should be uploaded as a separate file (or files) as .jpg or .tif files.
Full instructions on preparing the figures are available as part of the online submission instructions. Please follow these instructions carefully as failure to do so will delay publication of your manuscript (please note: the editors reserve the right to charge for extensive changes).
In preparing graphs authors should avoid background tints and 3D effects and maintain a consistent label size and aspect ratio (the x/y axis ratio) throughout a paper. Figure and axes titles should be clear and NOT in bold text. Do not include more figures than is absolutely necessary - non-essential figures may be judged as being suitable for online-only publication.

Human Reproduction **extended abstract <u>clinical</u> study manuscript**
Use MESH* terms in title and abstract.

Title: [if RCT, identify the trial as being randomised in title]

Abstract

Study question: [A SINGLE question (ending in a question mark), limited to the PRIMARY objective of the study ONLY (do not include secondary questions)]

Summary answer: [The main conclusion. A single sentence, this should be limited to the primary results of the study, without any discussion of their implications]

What is known already: [One or two short sentences]

Study design, size, duration: [RCT, cohort study, case control study, cross sectional study, diagnostic test; sample size calculation; total number of subjects involved; time period in which study was performed]

- If RCT: briefly describe size and duration, intervention(s), blinding, randomization procedure, allocation concealment
- If cohort study: briefly describe size and duration, prospective/retrospective, (lost to) follow-up, attrition
- If case control study: briefly describe number of cases and controls, duration, exposures
- If cross sectional study: briefly describe size
- If diagnostic test study: briefly describe size and duration, reference standard and comparator/index test, blinding

Participants/materials, setting, methods: [matching criteria (for matched studies), numbers exposed/unexposed, numbers of controls per case, distribution of severity of disease in those with target condition]

Main results and the role of chance:

- If RCT: include absolute event rates for primary outcome(s) among experimental and control groups, p value(s) and confidence intervals, relative risk reduction, number needed to treat or harm.
- If cross sectional study: include response rate
- If diagnostic test study: include sensitivity, specificity, positive and negative predictive values, likelihood ratios. Number needed to screen (if screening study)

Limitations, reasons for caution: [bias, confounding, power]

Wider implications of the findings: [generalisability to other populations, agreement/disagreement with literature, resolution of previous disparity, new insights]

Study funding/competing interest(s):

APPENDIX G: Ethics approval confirmation email

From: psychethics
Sent: 20 September 2017 14:17:19
To: Siobhan Moore; Jennifer Moses
Subject: Ethics Feedback - EC.17.09.12.4943R

Dear Siobhan,

The Ethics Committee has considered your revised project proposal: *Infertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study (EC.17.09.12.4943R).*

The project has now been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,
Mark Jones

School of Psychology Research Ethics Committee

Cardiff University
Tower Building
70 Park Place
Cardiff
CF10 3AT

Tel: +44(0)29 208 70360
Email: psychethics@cardiff.ac.uk
http://psych.cf.ac.uk/aboutus/ethics.html

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd
CF10 3AT

Ffôn: +44(0)29 208 70360
E-bost: psychethics@caerdydd.ac.uk

APPENDIX H: Approval for ethics amendments

Dear Siobhan,

The Ethics Committee has considered the amendment to your PG project proposal: Infertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study (EC.17.09.12.4943RA).

The amendment has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,
Mark Jones

School of Psychology Research Ethics Committee

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APPENDIX I: Participant information sheet

Information sheet

Title of Project: Infertility practitioners experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

You are invited to take part in this research study on the psychological presentations associated with unmet parental goals after unsuccessful fertility treatment. This study will be undertaken by Siobhan Moore as part of a Doctorate in Clinical Psychology. Please consider the following information before deciding whether to participate. If you would like more information about the project, please contact the researcher.

Thank you very much for taking the time to read this information sheet, your help is greatly appreciated.

The purpose of this study:

The focus of this Delphi study is to build a consensus from the collective perspectives from practitioners who have expertise working with psychological presentations associated with unmet parental goals following unsuccessful fertility treatment. This research methodology has been used widely across health research to inform practice, it is believed that this is the first time that it has been applied to research field of infertility.

Why have I been invited to take part?

We are looking for your opinion, as part of a confidential expert panel. You have been invited to participate in this study because you are a practicing clinician, working therapeutically in the field of fertility, you have: a recognisable counselling/clinical psychology, psychotherapy or counselling qualification at diploma level or above; 2 years post qualification experience; membership to a regulated professional body such as British Psychology Society (BPS) or British Association for Counselling and Psychotherapy (BACP) and awarded, or working towards, specialist accreditation in infertility and meet the British Fertility registration (or European equivalent).

What will happen?

If you agree to take part in the study you will become part of the expert panel and be asked to participate in a short demographic questionnaire followed by three rounds of online Delphi questionnaires. These questionnaires explore the panel's opinions about a number of areas

related to this specialised area of working. Questionnaire one is anticipated to take place during December 2017.

You will be asked to give your informed consent to participate at the beginning of the online questionnaire and prompted to complete a short demographical questionnaire before starting. Round One questionnaire should take 20 minutes to complete. You will also be given the opportunity to expand upon your answers and suggest further questions that you can put forward to the panel. You will have two weeks to complete and submit your considered responses. You may also receive a reminder to complete the questionnaire, should this be required.

All responses will be confidential and adhere to the Data Protection Act. Responses will be seen by the principle researcher and supervisors. These will be collated, and themes identified from the responses and evaluated to determine the panel's initial overall consensus. The development of the second questionnaire will be informed by these themes and the initial consensus. Three weeks after submission of the first questionnaire, you will receive an electronic link for the second questionnaire. This will contain your original responses and questions regarding areas which have not received consensus between the panelists. There may be additional questions, which have been suggested from the panel's initial response. You will have two weeks to complete and submit the questionnaire. Two weeks after submission of the second questionnaire, you will receive an electronic link for the final questionnaire. This will contain your original responses and questions regarding areas which still have not received consensus between the panelists. The response will be collated and evaluated and the overall data will be presented and reported within a final research report which will be sent to you.

Each individual panelist's responses will receive an individual code until the panel reaches final consensus. When that has been achieved the data will be fully anonymised and the codes will no longer allow individual participant's responses to be tracked by the researchers. The data will then be stored for 7 years in this fully anonymised format.

Do I have to Take Part?

There is no obligation to take part in this study and you may decline or withdraw from the study up to the end of the Delphi questionnaires before all the data is fully anonymised without the need of any explanation. There are no negative consequences in terms of your employment or professional registration if you chose to take part or if you choose to withdraw from this study.

What are the potential benefits of taking part?

We hope that being part of the Delphi panel you will benefit from becoming part of a new research which explores the concept of prolonged psychological distress from failed infertility experiences. Secondly, that your contribution provides concepts which will influence a guided self-help intervention to support these individuals. Should this intervention be developed, it will

be evidence-based as a result of your direct participation, making it potentially more suitable for use and of worth to the wider infertility counselling community.

What are the potential disadvantages of taking part?

There are minimal anticipated disadvantages to participating in the study. You will be asked to give an hour of your time over the course of three months. We acknowledge that working in the specialism of infertility counselling is a sensitive and emotive area. If you are affected by any concerns which are raised by this study we advise you to refer to your professional registrations' code of practice and to use clinical supervision in the first instance. We also encourage you to be aware of recommended health and safety precautions whilst working at the computer and completing the online questionnaires.

Will my taking part remain confidential?

Any data you give will be coded, protected and secured confidentially during the Delphi process. This is in order that your individual responses for each questionnaire can be sent back to you. All identifiable information will be kept locked away, separately from the Delphi questionnaire data. Only the researcher and supervisors will access to this information. Once all data has been collected, confidential information will be destroyed and the data will be fully anonymised. You may withdraw your data, up to the time that the data is fully anonymised.

Other members of the panel will not know who else is participating in the study. The public will also not be informed, and any quotes reported during the process will not identify the contributor. The data collected throughout the study will be kept for at least seven years from the end of the study in line with Cardiff University research policy.

Who is monitoring this study?

This study was reviewed and approved by the South Wales Research Ethics Committee, School of Psychology, Tower Building,70 Park Place, Cardiff, CF10 3AT on (20.09.17) SREC number: *EC.17.09.12.4943R*. It is also being regularly monitored by my supervisors to ensure of its quality and standard.

Who else is involved in this research?

If you have any further questions about taking part in the study or need further information please do not hesitate to contact the researcher (contact details below).

Project Lead: Siobhan Moore
Role: Trainee Clinical Psychologist
Email: Moores15@Cardiff.ac.uk
Telephone: 02920 870545

Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Academic Supervisor: Dr. Sofia Gamerio
Role: Lecturer
Email: GameiroS@cardiff.ac.uk
Telephone: +44 (0)29 2087 5376
Address: School of Psychology (College of Biomedical and Life Sciences) Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Academic Supervisor/Chief Investigator: Dr. Jenny Moses
Role: Consultant Clinical Psychologist/Academic Director
Email: Jenny.Moses@wales.nhs.uk
Telephone: +44 (0)29 2087 0582
Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

What if I have concerns about this research?

If you have any concerns or complaints about this study, please direct these in the first instance to: Reg Morris (Honorary Professor and Director of the Doctoral Programme in Clinical Psychology). Address: 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT. Telephone: +44 (0)2920 870582. You can also contact the South Wales Research Ethics Committee on email at psychethics@cardiff.ac.uk or by post to School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT. Telephone: +44 (0)29 2087 4007.

APPENDIX J: Invitation to participate in the research

Invitation to Participate in Research

Title of Project: Fertility practitioners experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

My name is Siobhan Moore and I am a Trainee Clinical Psychologist. I am working on a research study for my doctoral thesis exploring professionals' clinical experience of the psychological needs of individuals who continue to be affected by unsuccessful fertility treatment and associated unfulfilled parenting goals. Additionally, this study seeks to understand the types of clinical interventions, change methods and clinical models actively used by practitioners to promote well-being.

You are invited to be part of this study as you work in the area of fertility counselling. This study will require you to participate in three online questionnaires between December and February 2018. All information will be kept confidential and a summary of the results from the questionnaires will be available for dissemination to those who express interest in the findings.

If after reading through the attached information sheet you would like to participate, please clink on the link:

https://cardiffunipsych.eu.qualtrics.com/jfe/form/SV_dcXU4KS3Irbi95b

If you do not wish to partake, you do not need to do anything.

If you have any further questions about this study please contact me via email MooreS15@Cardiff.ac.uk or alternatively by leaving a message for me on 02920 870545.

I would be very happy for you to forward on this email with the link and information sheet attached to colleagues and through your professional networks. I am very grateful for your time and expertise and hope by partaking in this study you find that the process is interesting and reflective.

Yours sincerely

Siobhan Moore

APPENDIX K: Delphi Questionnaire I

Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

You have been invited to be a member of an Expert Panel on a Delphi Consensus Study. It is designed to let therapists pool their understanding of the psychological presentations and interventions used when individuals experience unmet parental goals following unsuccessful fertility treatment. By unmet parenthood goals we mean not having children or having less than desired.

As part of this Expert Panel, we are interested in your opinions about what works based on your clinical knowledge and practice. The study has three Phases and will involve completing a series of three sets of questionnaires over an 8 week period. The sets of questionnaires will take no more than 25 minutes in total to complete. Each set will be open for three weeks to collect your responses and build a consensus.

Your responses at Phase 1 will be assigned a randomly generated number to protect your identity. This number will be stored separately from your e-mail address. Your e-mail address is needed so that in Phases 2 and 3 of the study you can assist consensus to be reached by giving your opinion about the pooled understanding which is emerging from the summary of the Expert Panel's overall responses.

All Delphi Expert Panel members and their individual responses will remain anonymous to each other throughout this study. Only themes and percentages of consensus will be shared. Once the data collection period is complete, your email address will be deleted.

We apologise in advance but we are only able to accept responses to the questionnaires that are provided in English.

On completion of all three questionnaires, you will be placed into a prize draw for an Amazon book voucher.

Please press the arrow button if you are happy to continue

End of Block: Introduction

Start of Block: Consent Section

I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at anytime up to the end of Delphi Questionnaires without giving reason. If I choose to withdraw from the study there will be no adverse consequences.

I confirm that I have read and understood the participant information sheet. I have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily.

I understand that my responses will be assigned to a randomly generated number for the duration of the data collection period. Once all data has been collected my responses will be completely anonymised.

I understand that my email address will be collected and kept securely. It will only be used for the purpose of sending me the link to the next two questionnaires. Once all questionnaires have been completed my email address will be deleted.

- ○ I consent to participate in this study (1)
- ○ I do not wish to participate in this study (2)

Skip To: End of Survey If I understand that my email address will be collected and kept securely. It will only be used for... = I do not wish to participate in this study

My email address for the use for the Delphi Questionnaire is:

_____

End of Block: Consent Section

Start of Block: Demographic Section

Demographic Questionnaire

Please state if you are:

- ☐ Female (1)
- ☐ Male (2)
- ☐ Prefer not to say (3)

Please select the age bracket which best describes you:

- ○ 18 - 24 (1)
- ○ 25 - 34 (2)
- ○ 35 - 44 (3)
- ○ 45 - 55 (4)
- ○ 56 - 65 (5)
- ○ Over 65 (6)

Professional Qualifications:

Please list your main professional counselling, psychotherapy qualifications:

Have you undertaken an accreditation in fertility counselling?

- ○ Yes (1)
- ○ No (2)
- ○ I practice in a country where there is no recognised accreditation in fertility counselling (3)

Skip To: Q12 If Have you undertaken an accreditation in fertility counselling? = No

Skip To: Q11 If Have you undertaken an accreditation in fertility counselling? = Yes

Skip To: Q13 If Have you undertaken an accreditation in fertility counselling? = I practise in a country where there is no recognised accreditation in fertility counselling

Please state the number of years' experience since qualifying from your accreditation in fertility counselling

Are you working towards your accreditation in fertility counselling?

- ○ Yes (1)
- ○ No (2)

Skip To: Q14 If Are you working towards your accreditation in fertility counselling? = Yes

Skip To: Q14 If Are you working towards your accreditation in fertility counselling? = No

Which country do you practice in?

Please indicate which professional body you are a current member of:

(You may tick more than one option)

- ☐ British Infertility Counsellors Association (BICA) (1)
- ☐ British Psychological Society (BPS) (2)
- ☐ British Association for Counselling and Psychotherapy (BACP) (3)
- ☐ Health and Care Profession Council (HCPC) (4)
- ☐ No professional registration (5)
- ☐ Other (Please specify) (6) _____

Area of practice:

Do you work with individuals...

(You may tick more than one option)

- ☐ Before fertility treatment? (1)
- ☐ Whilst receiving fertility treatment? (2)
- ☐ When fertility treatment has stopped? (3)
- ☐ All of the above? (4)
- ☐ None of the above? (5)

Skip To: End of Survey If Area of practice: Do you work with individuals... (You may tick more than one option) = None of the above?

How best describes your practice setting?

(You may tick more than one option)

- ☐ Private Fertility Clinic (1)
- ☐ NHS Setting / Public Setting (2)
- ☐ Private Practice (3)
- ☐ Third Sector/ Voluntary Organisation (4)
- ☐ Other (Please specify) (5) _____

In what setting would you work specifically with individuals who are experiencing distress after stopping unsuccessful fertility treatment?

(You may select more than one option)

- ☐ Private Fertility Clinic (1)
- ☐ NHS Setting / Public Setting (2)
- ☐ Private Practice (3)
- ☐ Third Sector/ Voluntary Organisation (4)
- ☐ Other (Please specify) (5)

When thinking about your work with individuals who have stopped unsuccessful fertility treatment, how best describes the level of therapeutic input you are able to offer?

(You may tick more than one option)

- ☐ Sign-posting/ onward referral to another service (1)
- ☐ One therapeutic session (2)
- ☐ Brief therapeutic work (i.e. up to 6 sessions) (3)

☐ Medium term therapeutic work (i.e. up to 20 sessions) (4)

☐ Long term therapeutic work (i.e. over 1 year if required) (5)

☐ Other (Please specify) (6)

How do you judge if your therapeutic work has been of benefit to clients who have stopped unsuccessful fertility treatment(s)?

If you use self-reporting questionnaires, please could you specify which ones:

Please indicate by ticking the box if you would be interested in receiving the finished Delphi Report

(Please note, if you click yes, your email address will be kept in a separate database for this purpose only)

○ Yes please (1)

○ No thank you (2)

End of Block: Demographic Section

Start of Block: Delphi Section

DELPHI ROUND ONE

We are only interested in the post fertility treatment period, when fertility treatment has not been successful and individuals do not meet their parental goals and experience emotional distress.

(We acknowledge the idiosyncratic nature of distress and want to know if there are core themes that you address with clients)

Drawing on your clinical knowledge, skills and experience, please respond to the following questions. You can list as many answers as you wish and they do not have to be in any particular order.

Q1. In your opinion why do these clients become stuck and experience on-going emotions associated with their unmet parenthood needs?
Please list below:

_____

Q2. What do you think are the important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals?
Please list below:
_____

Q.3 what models do you use to understand your clients' emotional distress?
Please list below:
_____

Q4. What do you believe are the key 'ingredients' of therapy that address your clients' emotional distress?

Please list below:
_____

Q5. Which therapy/counselling techniques/interventions do clients engage with and find helpful in reducing unwanted feelings of distress?

Please list below:
_____

Q6. When working with individuals who have stopped fertility treatment without meeting their parental goals, is there a specific focus/conversation/intervention that you might include within your practice which has not been captured by the above questions?

Please list below:
_____

End of Block: Delphi Section

APPENDIX L: Delphi Questionnaire II

Start of Block: Introduction

Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

Thank you for your responses to the first Delphi questionnaire, welcome back to round two.

This questionnaire is made up entirely from statements from the expert panel's responses to the questions posed in the first Delphi questionnaire. This asked you, the panel, to focus on the post fertility treatment period, when fertility treatment had not been successful and when individuals experience emotional distress as result of their unfulfilled parental goals.

Responses have been grouped together in themes using thematic analysis and collapsed down to a number of key statements. Please read the statements and choose the rating based on how much you agree with them.

This round of the Delphi Study should take 10 minutes to complete.

This questionnaire will be open until 23/02/2018. The responses will be analysed to create the last questionnaire.

On completion of all three questionnaires, you will be placed into a prize draw for an Amazon book voucher.

Please clink to continue

Start of Block: DelphiQ1

Question 1. According to the expert panel (all psychologists/counsellors who answered the first Delphi questionnaire), the following statements explain why clients become 'stuck' and experience on-going emotions associated with their unmet parenthood goals.

Please rate how much **YOU** are in agreement with these statements

Theme 1: **Parenthood as identity and having children as a life goal**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Relinquishing the investment in parenthood is challenging because the childless identity is unacceptable (1)	○	○	○	○	○
Relinquishing the investment in parenthood is challenging because it is unchartered territory (2)	○	○	○	○	○
Relinquishing the investment in parenthood is challenging because it means loss of hope for an imagined future (3)	○	○	○	○	○

Theme 2: **Social, cultural and religious expectations and pressures**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The struggles of women who do not have children are poorly understood (1)	○	○	○	○	○
Those that are childless are stigmatised and their personhood is diminished by society (2)	○	○	○	○	○

Theme 3: **Legacy of the fertility treatment**

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
On-going emotional distress after ending treatment is caused by prolonged fertility treatments for older women. (1)	○	○	○	○	○
On-going emotional distress is associated with the reinforcing nature of fertility treatments – 'the next treatment might just be the successful one' (2)	○	○	○	○	○
Individuals need to be supported to recognise that fertility treatment is commonly unsuccessful and normalise this (3)	○	○	○	○	○
Counsellors are recommended too late to clients after unsuccessful fertility treatment (4)	○	○	○	○	○

Theme 4: **Unprocessed loss**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Individuals need to have their loss(es) acknowledged (1)	○	○	○	○	○
Individuals need to be permitted to g deeply. (2)	○	○	○	○	○

Individuals need to learn skills to manage emotional distress associated with the loss of their fertility/embryo and/or their imagined child. (3)	○	○	○	○	○

Q7 Theme 5: **Individual experiences**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
There is a risk that individuals will relapse if they have co-existing mental health difficulties? (1)	○	○	○	○	○
On-going emotional distress after ending treatment will be the same as those experienced when a cycle has been unsuccessful? (2)	○	○	○	○	○
Grief after ending treatment can activate past developmental traumas, losses and/or attachment issues for the individual (3)	○	○	○	○	○
Individuals on going emotional distress after ending treatment will be a result of traumas associated with the fertility treatment procedures (4)	○	○	○	○	○
Individuals on-going emotional distress after ending treatment will be associated with the number of unsuccessful cycles of infertility treatment. (5)	○	○	○	○	○
Individuals on-going emotional distress after ending unsuccessful treatment will be related to their beliefs about personal failure. (6)	○	○	○	○	○

Q8 Theme 6: **Transition**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Individuals experience difficulty in accepting family life as it is, with its conflicts and lack of perfection. (1)	○	○	○	○	○
Individuals will need to be facilitated to re-evaluate happiness and contentment. (2)	○	○	○	○	○

Q9 Theme 7: **Relational dynamics**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The individual's emotional response after ending treatment is associated with their beliefs about the impact of fertility treatment on their relationship. (1)	○	○	○	○	○
On-going emotional distress after ending treatment are associated with the impact of fertility treatment on sexual function and expression. (2)	○	○	○	○	○
On-going emotional distress after ending treatment are associated with beliefs about how committed and invested each individual in a couple was in having a child. (3)	○	○	○	○	○

Start of Block: Delphi Question 2

Question 2. According to the expert panel, the following statements explain the **important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals**

Please rate how much **YOU** are in agreement with these statements

Theme 1: **Infertility experience**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy is to help individuals see that infertility (primary or secondary) is not a failure (1)	○	○	○	○	○
Therapy is to develop a shared narrative of the end of their fertility treatment and the impact of involuntary childlessness (2)	○	○	○	○	○

Q12 Theme 2: **Recognition and processing of emotions**

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewh at agree (4)	Strongly agree (5)
Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely. (1)	○	○	○	○	○
Therapy facilitates the desensitization and reprocessing of any traumas associated to infertility (2)	○	○	○	○	○

Q13 Theme 3: **Sense of self as child free**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy is to help individuals put themselves back together (1)	○	○	○	○	○
Therapy is to help individuals to reclaim their sexuality and body,	○	○	○	○	○

accepting its fertility limitations (2)

Q14 Theme 4: **The couple's relationship**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy is about negotiating the impact of infertility on the couple rather than the individual (1)	○	○	○	○	○
Therapy facilitates the couple to learn to grieve together, and to respect each other's different ways of coping. (2)	○	○	○	○	○
Therapy must address problems that might have come up in the partnership because of the infertility or the treatment(s). (3)	○	○	○	○	○
Therapy must address sexual function or expression problems arising from fertility treatment. (4)	○	○	○	○	○
Therapy must strengthen coping together, communicating with each other and the renegotiation of the couple's goals. (5)	○	○	○	○	○

Q15 Theme 5: **Meaningful life without children**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy facilitates individuals to nurture areas of their life outside their fertility, living in line with their values and making committed action. (1)	○	○	○	○	○

Q16 Theme 6: **The therapeutic process**

	Strongly agree	Somewhat agree (2)	Neither agree	Somewhat disagree	Strongly disagree

	(1)		nor (3)	(4)	(5)
Therapy is instilling hope for the future and increasing an individual's psychological flexibility (1)	○	○	○	○	○
The process of normalisation and validation through the therapeutic alliance is the most powerful aspect of the therapy process (2)	○	○	○	○	○

Q17 Theme 7: **Creating a different transition**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy should explore with individuals how they want to mark and signify the end of fertility treatment in the absence of formal markers such as maternity leave. (1)	○	○	○	○	○
Therapy should explore alternative routes to fulfil parenthood. (2)	○	○	○	○	○

Q18 Theme 8: **The role of contraception on future hope**

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
Therapy should facilitate discussion about not using contraception for those with unexplained infertility, and how it could prevent an individual's ability to accept their infertility. (1)	○	○	○	○	○

Q19 Theme 9: **Risk assessments**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Therapy should monitor the normal reactions of grief and loss in case individuals move to persistent and clinical presentations of distress. (1)	○	○	○	○	○

Q20 **Question 3.**
According to the expert panel, the following statements explain **the key ingredients of therapy which helps to address clients' emotional distress**
Please rate how much **YOU** are in agreement with these statements

Q21 Theme 1: **Therapeutic knowledge and skill**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
It is important that the therapist uses a variety of tools and change methods informed by a range of different theories. (1)	○	○	○	○	○
A key ingredient of the therapy process is judging how to time therapy interventions. (2)	○	○	○	○	○

Q22 Theme 2: **Self-awareness and self-reflection**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
It is important that the therapist is reflective and owns their perspective. (1)	○	○	○	○	○

Q23 Theme 3: **Fertility knowledge**

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
The therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience. (1)	○	○	○	○	○

Q24 Theme 4: **The therapeutic relationship**

	Strongly	Somewhat	Neither	Somewhat	Strongly

	agree (1)	agree (2)	agree nor disagree (3)	disagree (4)	disagree (5)
The therapeutic relationship and alliance is the only important ingredient. (1)	○	○	○	○	○

Q25 Theme 5: **Practical aspects of therapy**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
It is important that therapy is free at the point of delivery. (1)	○	○	○	○	○
It is important that there is a clear therapy contract and to build in regular reviews of that contract. (2)	○	○	○	○	○
It is important for the therapist to be flexible and available at short notice. (3)	○	○	○	○	○
It is important to be able to provide therapy via modes such as skype or telephone counselling. (4)	○	○	○	○	○

Q26. **Question 4:**
According to the expert panel, the following statements describe the **techniques and interventions that are helpful in supporting individuals in reducing unwanted feelings of distress.**
Please rate how much **YOU** are in agreement with these statements

Q27
Theme: 1 **Living well and improved well-being**

	Strongly disagree (1)	Somewhat disagree (2)	Neither agree nor disagree (3)	Somewhat agree (4)	Strongly agree (5)
To learn to live well with the distress of loss rather than to suppress it. (1)	○	○	○	○	○
To encourage a healthy balanced lifestyle which involves living	○	○	○	○	○

well with exercise and self-care (2)

Q28 Themes 2: **Complementary approaches**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
To use alternative approaches (e.g. Chinese Medicine, Naturopathy, spirituality and hypnotherapy) (1)	○	○	○	○	○

Q29 Theme 3: **Psycho-education and guided self-help**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
Emotional distress associated with the post fertility treatment stage would benefit from psycho-education, relaxation and guided self-help principles. (1)	○	○	○	○	○

Q30 Theme 4: **Therapeutic techniques & interventions**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The therapeutic techniques and interventions would be determined by a comprehensive assessment and understanding of the emotional distress and its impact on the individual/couple. (1)	○	○	○	○	○

Q31 Theme 5: **Crisis Intervention**

	Strongly agree	Somewhat agree (2)	Neither agree	Somewhat disagree	Strongly disagree

	(1)		nor disagree (3)	(4)	(5)
To facilitate distress tolerance strategies to help manage crisis/ risk and to keep people safe from harm. (1)	○	○	○	○	○
To refer onto mental health services during times of crisis? (2)	○	○	○	○	○

Q32 Theme 6: **Goodness of fit and practical advice**

	Strongly agree (1)	Somewhat agree (2)	Neither agree nor disagree (3)	Somewhat disagree (4)	Strongly disagree (5)
The match between the therapist and client is important and clients should be supported to find who works for them. (1)	○	○	○	○	○

End of Block: Delphi question 4

APPENDIX M: Delphi Questionnaire III

Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

Thank you for your response to the second Delphi questionnaire, welcome back to the final round.

This questionnaire is made up of two parts:

Part 1
The first part is a review of the statements and themes which the expert panel has agreed upon collectively. A minimum percentage of 70% was used to determine consensus on statements posed in questionnaire 2. The higher the percentage scored, the greater the agreement with the statement.

In total 34 statements scored 70% or more, meaning that the expert panel collectively agreed with these statements. The results presented in the tables are the median score (which shows the middle responses, ranging across a scale of 1 to 5) and the overall group percentage. There will be an opportunity for you to add any reflections on these findings at the end of the questionnaire, should you wish.

Part 2
The second part of the questionnaire is made up of the 24 statements where consensus was not reached. For each of these statements, you will see your original response and the expert panel's group response, with a Likert scale below; the Likert scale is provided to give you the opportunity to reconsider your response from round 2.

When reconsidering I ask you to consider the overall group response as a benchmark and, if you wish to change your response, to complete the Likert scale with your new response.
Please note, you do not have to change your original responses. If the Likert scale remains blank, it will be assumed that you do not wish to change your response.

This round of the Delphi Study should take 10 minutes to complete.

This questionnaire will be open until 09.04.2018.

The responses will be analyzed to create the end of Delphi Report, which will be distributed 4 weeks after the close of round 3 for those that have requested a copy.

Please click to continue

Question 1: The below statements have reached a total percentage of 70% or more, indicating that consensus has been reached on the statements relating to 'why clients become 'stuck' and experience on-going emotions associated with their unmet parenthood goals'.

Statements	**Median (on scale from 1-5)**	**Percentage agreement (%)**
Theme 1:Parenthood as identity and having children as a life goal		
Relinquishing the investment in parenthood is challenging because it is unchartered territory	2.00	92.3
Relinquishing the investment in parenthood is challenging because the childless identity is unacceptable	2.00	76.9
Relinquishing the investment in parenthood is challenging because it means loss of hope for an imagined future	1.00	76.9
Theme 2: Social, cultural and religious expectations and pressures		
The struggles of women who do not have children are poorly understood	2.00	84.6
Those that are childless are stigmatised and their personhood is diminished by society	2.00	100
Theme 3: Legacy of the fertility treatment		
On-going emotional distress is associated with the reinforcing nature of fertility treatments – 'the next treatment might just be the successful one'	4.00	77
Theme 4: Unprocessed loss		
Individuals need to have their loss(es) acknowledged	1.00	92.3
Individuals need to be permitted to grieve openly and deeply.	1.00	92.3
Individuals need to learn skills to manage emotional distress associated with the loss of their fertility/embryo and/or their imagined child.	1.00	84.6

Theme 5: Individual experiences		
There is a risk that individuals will relapse if they have co-existing mental health difficulties	1.00	100
On-going emotional distress after ending treatment will be the same as those experienced when a cycle has been unsuccessful	4.00	76.9 Disagreement with the statement
Grief after ending treatment can activate past developmental traumas, losses and/or attachment issues for the individual	2.00	100
Individuals on-going emotional distress after ending unsuccessful treatment will be related to their beliefs about personal failure	2.00	100
Theme 6: Transition		
Individuals experience difficulty in accepting family life as it is, with its conflicts and lack of perfection.	2.00	76.9
Individuals will need to be facilitated to re-evaluate happiness and contentment.	1.00	76.9
Theme 7: Relational dynamics		
The individual's emotional response after ending treatment is associated with their beliefs about the impact of fertility treatment on their relationship	2.00	92.3
On-going emotional distress after ending treatment is associated with beliefs about how committed and invested each individual in a couple was in having a child.	2.00	100

Question 2: The below statements have reached a total percentage of 70% or more, indicating that consensus has been reached on these statements relating 'to the important issues/component that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals'.

Statements	Median (on scale from 1-5)	Percentage agreement (%)
Theme 2: Recognition and processing of emotions		
Therapy facilitates the desensitization and reprocessing of any traumas associated to infertility	4.00	76.9
Theme 3: Sense of self as child free		
Therapy is to help individuals put themselves back together	2.00	92.3
Therapy is to help individuals to reclaim their sexuality and body, accepting its fertility limitations	2.00	92.3
Theme 4: The couple's relationship		
Therapy facilitates the couple to learn to grieve together, and to respect each other's different ways of coping.	1.00	100
Therapy must strengthen coping together, communicating with each other and the renegotiation of the couple's goals.	1.00	100
Therapy must address problems that might have come up in the partnership because of the infertility or the treatment(s).	1.00	84.6
Theme 5: Meaningful life without children		
Therapy facilitates individuals to nurture areas of their life outside their fertility, living in line with their values and making committed action.	1.00	100
Theme 6: The therapeutic process		
Therapy is instilling hope for the future and increasing an individual's psychological flexibility	1.00	92.3
Theme 7: Creating a different transition		
Therapy should explore with individuals how they want to mark and signify the end of fertility treatment in the absence of formal markers such as maternity leave.	2.00	84.6
Theme 9: Risk assessments		
Therapy should monitor the normal reactions of grief and loss in case individuals move to persistent and clinical presentations of distress.	1.00	100

Question 4: The below statements have reached a total percentage of 70% or more, indicating that consensus has been reached on these statements relating to the key ingredients of therapy which helps to address clients' emotional distress.

Statements	Median (on scale from 1-5)	Percentage agreement (%)
Theme 1: Therapeutic knowledge and skill		
It is important that the therapist uses a variety of tools and change methods informed by a range of different theories.	1.00	92.3
A key ingredient of the therapy process is judging how to time therapy interventions	2.00	84.6

Question 5: The below statements have reached a total percentage of 70% or more, indicating that consensus has been reached on these statements relating to the techniques and interventions that are helpful in supporting individuals in reducing unwanted feelings of distress.

Statements	Median (on scale from 1-5)	Percentage agreement (%)
Theme 3: Psycho-education and guided self-help		
Emotional distress associated with the post fertility treatment stage would benefit from psycho-education, relaxation and guided self-help principles.	2.00	92.3
Theme 4: Therapeutic techniques & interventions		
The therapeutic techniques and interventions would be determined by a comprehensive assessment and understanding of the emotional distress and its impact on the individual/couple	2.00	100
Theme 5: Crisis Intervention		
To facilitate distress tolerance strategies to help manage crisis/ risk and to keep people safe from harm.	2.00	100
To refer onto mental health services during times of crisis?	2.00	75
Theme 6: Goodness of fit and practical advice		
The match between the therapist and client is important and clients should be supported to find who works for them	1.00	91.7

Part Two: Statements presented again for rating

For each of the statements below, you will see the expert panels overall group response and your original response.

When reconsidering I ask you to consider the overall group response as a benchmark and, if you wish to change your response, to fill out the Likert scale with your new response. If the Likert scale remains blank, it will be assumed that you do not wish to change your responses. Please note you do not have to change your original responses if you do not wish.

This round of the Delphi Study should take 10 minutes to complete.

Question 1: The below statements relate to why clients become 'stuck' and experience on-going emotions associated with their unmet parenthood goals.

Theme 3: Legacy of the fertility treatment	**Your response from round 2**	**Expert Panel Response**
On-going emotional distress after ending treatment is caused by prolonged fertility treatments for older women		46.2% Strongly and Somewhat agreed

Theme 3: Legacy of the fertility treatment	**Your response from round 2**	**Expert Panel Response**
Individuals need to be supported to recognise that fertility treatment is commonly unsuccessful and normalise this		61.5% Strongly and Somewhat agreed

Theme 3: Legacy of the fertility treatment	**Your response from round 2**	**Expert Panel Response**

Counsellors are recommended too late to clients after unsuccessful fertility treatment		46.2% Strongly and Somewhat agreed

Theme 5: Individual experiences	**Your response from round 2**	**Expert Panel Response**
Individuals on going emotional distress after ending treatment will be a result of traumas associated with the fertility treatment procedures		53.8% Strongly and Somewhat agreed

Theme 5: Individual experiences	**Your response from round 2**	**Expert Panel Response**
Individuals on-going emotional distress after ending treatment will be associated with the number of unsuccessful cycles of infertility treatment.		38.5% Strongly and Somewhat agreed

Theme 7: Relational dynamics	**Your response from round 2**	**Expert Panel Response**
On-going emotional distress after ending treatment are associated with the impact of fertility treatment on sexual function and expression		61.5% Strongly and Somewhat agreed

Question 2: The next set of statements relates to the important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals.

Theme 1: Infertility experience	**Your response from round 2**	**Expert Panel Response**

Therapy is to help individuals see that infertility (primary or secondary) is not a failure.		46.2% Strongly and Somewhat agreed

Theme 1: Infertility experience	**Your response from round 2**	**Expert Panel Response**
Therapy is to develop a shared narrative of the end of their fertility treatment and the impact of involuntary childlessness		53.8% Strongly and Somewhat agreed

Theme 2: Recognition and processing of emotions	**Your response from round 2**	**Expert Panel Response**
Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely.		69.3% Strongly and Somewhat agreed

Theme 4: The couple's relationship	**Your response from round 2**	**Expert Panel Response**
Therapy is about negotiating the impact of infertility on the couple rather than the individual		69.2% Strongly and Somewhat agreed

Theme 4: The couple's relationship	**Your response from round 2**	**Expert Panel Response**

Therapy must address sexual function or expression problems arising from fertility treatment.		61.5% Strongly and Somewhat agreed

Theme 6: The therapeutic process	**Your response from round 2**	**Expert Panel Response**
The process of normalisation and validation through the therapeutic alliance is the most powerful aspect of the therapy process		69.2% Strongly and Somewhat agreed
Theme 7: Creating a different transition	**Your response from round 2**	**Expert Panel Response**
Therapy should explore alternative routes to fulfil parenthood.		69.2% Strongly and Somewhat agreed

Theme 8: The role of contraception on future hope	**Your response from round 2**	**Expert Panel Response**
Therapy should facilitate discussion about not using contraception for those with unexplained infertility, and how it could prevent an individual's ability to accept their infertility.		23.1% Strongly and Somewhat agreed

Question 4: The next set of statements relates to the key ingredients of therapy which helps to address clients' emotional distress.

Theme 2: Self-awareness and self-reflection	**Your response from round 2**	**Expert Panel Response**

It is important that the therapist is reflective and owns their perspective		69.2% Strongly and Somewhat agreed

Theme 3: Fertility knowledge	**Your response from round 2**	**Expert Panel Response**
The therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience		46.2% Strongly and Somewhat agreed

Theme 4: The therapeutic relationship	**Your response from round 2**	**Expert Panel Response**
The therapeutic relationship and alliance is the only important ingredient		53.8% Strongly and Somewhat agreed

Theme 5: Practical aspects of therapy	**Your response from round 2**	**Expert Panel Response**
It is important that therapy is free at the point of delivery.		38.5% Strongly and Somewhat agreed

Theme 5: Practical aspects of therapy	**Your response from round 2**	**Expert Panel Response**

It is important that there is a clear therapy contract and to build in regular reviews of that contract.		53.8% Strongly and Somewhat agreed

Theme 5: Practical aspects of therapy	**Your response from round 2**	**Expert Panel Response**
It is important for the therapist to be flexible and available at short notice.		61.5% Strongly and Somewhat agreed

Theme 5: Practical aspects of therapy	**Your response from round 2**	**Expert Panel Response**
It is important to be able to provide therapy via modes such as skype or telephone counselling.		61.5% Strongly and Somewhat agreed

Question 5: The next set of statements relates to the techniques and interventions that are helpful in supporting individuals in reducing unwanted feelings of distress.

Theme: 1 Living well and improved well-being	**Your response from round 2**	**Expert Panel Response**
To learn to live well with the distress of loss rather than to suppress it.		53.9% Strongly and Somewhat agreed

Theme: 1 Living well and improved well-being	**Your response from round 2**	**Expert Panel Response**

To encourage a healthy balanced lifestyle which involves living well with exercise and self-care		53.9% Strongly and Somewhat agreed

Theme 2: Complementary approaches	**Your response from round 2**	**Expert Panel Response**
To use alternative approaches (e.g. Chinese Medicine, Naturopathy, spirituality and hypnotherapy		23.1% Strongly and Somewhat agreed

If you would like to add any reflections about the statements from the feedback section, you can do in the free text box below.

Thank you for reviewing the statements. This is the end of the Delphi Consensus Study. If you have requested a copy of the report this will be sent to the email address supplied in Round 1 in four weeks' time.

Thank you once again for being part of this research project. Your clinical knowledge and expertise has been very valuable throughout this research project.

APPENDIX N: Qualitative themes generated from Delphi Round I

Table 1 Themes generated from Delphi Round I question 1.

Question 1: In your opinion why do these clients become stuck and experience on-going emotions associated with their unmet parenthood needs?

Identified Theme	Participants ID (n=25)	Participants Responses
Parenthood as identity and having children as a life goal	(ID: 1763)	Unmet parenthood may cause identity crisis
	(ID:3180)	Struggle to create a new identity that doesn't involve children
	(ID:3425)	Deep links between personal identity and parenthood
	(ID:9322)	Because their desire to be parents has often been life-long
	(ID:9322)	A childless identity is unacceptable, or at least a long and difficult transition
	(ID:6870)	Inability to meet / satisfy a long term value or life goal.
	(ID:2085)	Everything has been invested in having a baby to the detriment of the rest of their lives so that there is 'nothing to live for now'.
	(ID:1798)	Desire to become a parent is unmet clients show great despair. Parenthood is viewed as a way of growing and achieving a mature role in life.
	(ID:9431)	Loss of sense of self and purpose
	(ID:9068)	Usually these clients have been in treatment for many years, the fixation for a child is very strong, and even after the treatment is completed, this fixation remains, which is expressed in specific emotions, accumulated crises, infertility related stress
	(ID:8880)	They have highly developed motivations to have children and when these are thwarted they are distressed
Social, Cultural & Religious expectations and Pressures	(ID:1763)	Social pressure that people have an obligation to be parents.
	(ID:3180)	Societal pressure to become parents
	(ID:1784)	Stigma of being barren
	(ID:1784)	Being excluded because they have no children
	(ID:9653)	Lack of understanding from family friends and society in general.
	(ID:8880)	They are surrounded by peers who have had children and it becomes very difficult to have to admit that they have failed and they cannot join the "parents' club". They are not within a family or peer group that is supportive of their situation.

	(ID:5214)	Cultural influences, family mandates , religious issues, social sector, ethnicity
	(ID:9322)	Our culture is very child-centred, reminders are everywhere, no culture is without fertility related stigma, and some deny the person-hood of childless individuals.
	(ID:1784)	Cultural reasons that dictate a couple should have a child or the male should find another partner
	(ID:3180)	Societal pressure to become parents, struggle to create a new identity that doesn't involve children
	(ID 5988)	Motherhood is still regarded as essential for women in my country
	(ID:9322)	wider population insensitive to distress of childlessness
	(ID:6870)	Societal /Cultural expectations
	(ID:1798)	In prenatal societies there is social atmosphere and pressure to have children.
Legacy of the fertility treatment	(ID:5988)	There is no plan B developed with them during the fertility treatment
	(ID:2382)	They may have been too optimistic about the success of treatment
	(ID:8880)	These clients sometimes seem to have expectations that having a child are guaranteed. They are not ready for a lack of success.
	(ID:8880)	Clients can have a sense that because they live in an age when almost everything one wants can be obtained, they cannot believe that a baby has not happened.
	(ID:1798)	Media representation - ART promises success. It's representation in the media is not accurate and emphasizes success: if you persevere you'll succeed. Seldom there is information about the many faces of its price.
	(ID:5947)	Also, I think the nature of infertility treatment itself reinforces the "I can't stop" mentality as it objectifies pregnancy ("achieving" a pregnancy is like winning the lottery) and with the intermittent reinforcement of treatment and lack of MD feedback regarding 0% change of pregnancy, individuals feel that they cannot stop.
	(ID: 6870)	A sense of "holding on" to something just in case a miracle happens
	(ID: 8812)	Not sufficient reflection on unsuccessful treatment before and during medical treatment, not sufficient information and exploration about other options, counsellors are recommended too late to clients.
	(ID: 9693)	Projection onto the clinic in terms of them raises a concern about treatment.
	(ID:4629)	Preparedness to engage with counselling
	(ID:1798)	Stretching fertility - the public financing of the treatments until high age limit encourages continuation of treatments. A more "realistic" age limit and financing other forms of parenthood would encourage less "perfectionism".
	(ID:2085)	If debt has been incurred and divorce as well this can all be too overwhelming.
	(ID:2085)	I have found people from a lower economic background to have accepted and moved

		on more quickly perhaps because they have grown up used to living within the limits of their income for example. Whereas if money is no problem it can be harder to accept however much you throw at it is not going to happen. This may make it harder to let go of the dream and end up being destructive to lives. It would be hard to generalise about that really though.
Unprocessed loss	(ID:2382)	There has not been enough closure
	(ID:3977)	Not yet come to terms with the loss of their own fertility
	(ID: 3338)	unprocessed loss
	(ID:3180)	Unresolved and disenfranchised grief
	(ID: 9322)	Their loss (of imagined/lost children/parenthood role) endures beyond ending treatment
	(ID:2085)	They do not recognise they need to grieve deeply to be able to have a chance of moving on. Grieving may be resisted because of previous overwhelming griefs that get triggered by the infertility grief.
	(ID:9431)	Grief
	(ID:3459)	Loss and grief cycle
	(ID:3425)	Not having prior experience or developed skill sets to manage associated loss.
	(ID:1399)	Partly because of difficulties dealing with normal mourning process
Individual experiences	(ID:9653)	Lack of personal resources to help process the normal grief reaction.
	(ID:3425)	Encountering the unexpected circumstance of not achieving a desired outcome and not having prior experience or developed skill sets to manage associated loss.
	(ID:9653)	Co-existing mental or physical ill health. Unresolved childhood trauma
	(ID:9322)	Some clients have had existing mental health issues before treatment and experience deterioration if treatment unsuccessful
	(ID:5214)	Individual history
	(ID:4629)	General happiness and contentedness with relationship, friendships, work etc. Attitudes and expectations at beginning of treatment Predisposition towards depression or anxiety
	(ID:3459)	Powerlessness, Failure, Low self-esteem
	(ID:1798)	A common [personality] trait is perfectionism modern motherhood in general is characterized by perfectionism. This is true about women who are in fertility treatments as well. This trait would be expressed in different forms by the different personality styles.
	(ID:6870)	Difficulty tolerating distress / difficult emotions such as grief, sadness, anger, guilt,

		regret and shame
	(ID:1798)	Personal history colours the motivation to become a parent, gives it a meaning. It connects the desire to be a parent to the past (family of origin and culture in general) and to the future. History of loss of loved ones parent, sibling, spouse has its impact on the intensity of the desire for parenthood.
Transition	(ID:3338)	Difficulty to accept family life as it is, with its conflicts and lack of perfection
	(ID:1399)	Problems to disengage from parenthood life goal and refocus life goals
	(ID:6776)	Do not have the motivation to seek alternative directions or because they cannot clearly identify key issues.
	(ID:7819)	Other people's pregnancies and children are a constant reminder that they have failed and are childless, If they do not have a new focus; it is hard to move on.
	(ID:6870)	Not knowing how to move on and focus/re-focus on new or existing important goals and values
	(ID:9431)	Life has often become so focussed on having a family that all other areas of life have been neglected including relationships, work, hobbies, people often find they have to re-evaluate their outlook and expectations
Relational dynamics	(ID:9653)	Abusive relationships
	(ID:5947)	I feel some individuals become stuck because of fear over loss of their relationship if they are partnered and the partner is deeply invested in parenting
	(ID:3180)	Differences between partners regarding desire to have children or not.
	(ID:1399)	Partner relationship problems
	(ID:1399)	Marital relationship the importance of parenthood for each individual in the couple. Do they have hidden motives?
	(ID:9431)	Loss of shared focus in their relationship, Loss of healthy relationship.

Table 2 Themes generated from Delphi Round I question 2.

Question 2: What do you think are the important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals?

Identified Theme	Participants ID	Participants Responses
Infertility experience	(ID:8880)	The history of the clients' treatment. "Once we were having more serious trouble the clinic didn't want to know us"; We felt we couldn't tell our friends what was really happening."
	(ID:3338)	How they feel about ending the fertility journey. I ask all clients "What is it about your experience that is the most distressing?" Very different answers are often given: e.g. "My clinician was dismissive of my concerns"; 'Emotional process of the personal meaning another child had (when relevant)'
Recognition, permission and processing of emotions	(ID:5988)	Feeling guilty, feeling powerless, envy others who have become parents
	(ID:6870)	Identifying thoughts and feelings associated with the experience and unmet goals
	(ID:2085)	For those stuck in anger finding a focus for that anger, even making a complaint can be just what is needed
	(ID:3425)	Anger management, shame
	(ID:4629)	Depression/anxiety
	(ID:1798)	Explore the different emotions shame, lowered self-esteem - threat to femininity/masculinity, despair,
	(ID:1763)	Desensitization and reprocessing any traumas according to infertility.
	(ID:6870)	Normalising thoughts and feelings
	(ID:9431)	For some it is primarily loss, others it is anger.
	(ID:1798)	Mourn of childlessness fully grieving not having a child
	(ID:1978)	The quality of mourning is there a threat to mental health? Does mourning change to depression? Take up a feeling of an imaginary child's loss
	(ID:1784)	Have they mourned the loss of embryos/fertility
	(ID:2085)	I think very important to normalise their grief so they know they it is a legitimate response to their situation. To give time to the grieving process.
	(ID:9653)	Exploration of grief
	(ID:8812)	Include partner to support mourning
	(ID:5947)	Grieve the loss of the imagined child and how life would/could have been
	(ID:7819)	Grief work

	(ID:3425)	Grief
	(ID:4629)	Grieving
	(ID:2085)	For some developing/creating a ritual to mark their efforts to create and bring to birth a child are important. So that it can be thought of and remembered for all time but also put to rest with dignity and love.
	(ID:1798)	Explore unresolved issues from the past
Sense of self as child free	(ID:5947)	Re-establish sense of self as child free person.
	(ID:7819)	Re-defining themselves.
	(ID:3425)	Changed personal identity.
	(ID:6776)	What are my beliefs and values about my existence? Meaning and purpose in life.
	(ID:5988)	…body is not functioning the way it should; …feeling incomplete as a women/man.
	(ID:3459)	Putting self-back together.
	(ID:5947)	Explore positive aspects of not having a child
The couple's relationship	(ID:9653)	The impact on the couple rather than the individual
	(ID:3977)	Restructuring their life moving forward to the one they imagined they would have the strength of the couple's relationship. I don't focus on just the woman in these matters: if they are going to have a life together then the problem is a couple problem.
	(ID:8880)	My usual approach is to work with the couple, straight or gay.
	(ID:1784)	They both in agreement to end treatment. How they feel about ending the fertility
	(ID:2085)	journey.
	(ID:1784)	Within the couple learning to grieve together and also to respect each other's different ways of grieving
	(ID:5988)	Is communication between them open and also with others?
	(ID:5988)	Sexual problems arising from the treatment time.
	(ID:1978)	Any problems that might have come up in the partnership because of the infertility or the treatment.
	(ID:3425)	Explore and address communication between spouses and the strength of the couple.
	(ID:5947)	Changed relationships.
	(ID:9068)	Engage in couple's therapy (if partnered) to renegotiate couple's goals.
	(ID:6870)	couple life history reconstruction checking relationship coping
Meaningful life without children	(ID:3180)	Explore the meaning of involuntary childlessness for them, impact on their lives
	(ID:3338)	Emotional process of not having children (when relevant)

	(ID:3977)	Coming to terms with the loss of their own fertility
	(ID:8880)	The family of origin issues around forming families
	(ID:9068)	Acceptance (9068)
	(ID:2085)	… more of an accepting stage to validate the experience they have been through, If this can be explored and seen for what it is the danger of going away with a sense that it has been wasted time can be reframed and appreciated.
	(ID:9431)	My work tends to focus in one way or another on acceptance and compassion.
	(ID:2085)	…the experience of negotiating infertility as growthful for them both personally and as a couple, developing emotional muscles they never knew existed.
	(ID:1399)	refocus life goals
	(ID:1798)	Explore other channels to express creativity. Invest oneself in other purposes in life.
	(ID:8812)	Help to shift into life without children, psychosocial as well as practical support
The therapeutic process	(ID:9653)	Validation and normalisation of feelings.
	(ID:6780)	Validating same [thoughts and feelings]
	(ID:2085)	To stress it is unique for everyone so to give hope of finding their unique way through this.
	(ID:2085)	Sometimes it is possible when people are at more of an accepting stage to validate the experience they have been through. To meet them in wherever they are in their grief cycle.
	(ID:2525)	Work with the client to define what the important issues/components are for them.
	(ID:8880)	I ask all clients "What is it about your experience that is the most distressing?" Very different answers are often given: e.g. "My clinician was dismissive of my concerns"; "Once we were having more serious trouble the clinic didn't want to know us"; We felt we couldn't tell our friends what was really happening."
	(ID:8880)	A strong therapeutic alliance.
	(ID:6870)	…increasing hope for the future.
	(ID:2085)	To give hope of finding their unique way through this.
Creating a different transition	(ID:5214)	What life project do they have and what other desires do they have
	(ID:2382)	Resolution, Making new life goals
	(ID:9068)	Reconstruction - life without children or adoption
	(ID:2085)	For women in particular they have been eagerly anticipating the total change from working that motherhood will bring, so if there is going to be no maternity leave can there be another kind of change/gap year/transition into something else be honoured, as for some women the thought of another 20 years of the same is a death sentence.

	(ID:9431)	Whilst other people are ready to work on developing their life in a different direction.
	(ID:4629)	Problem solving, Life choices and planning
	(ID:3338)	Considering other options open to the couple.
	(ID:1798)	Explore issues around adoption
The role of contraception on future hope	(ID:2085)	For some it is important to think about contraception until the menopause. If it is unexplained infertility are they going to keep the door open by not using contraception or do they really want to close the door now because they are wanting to fully let go of being parents now.
Risk assessments	(ID:6870)	checking personal safety and coping / resilience
	(ID:1798)	The quality of mourning is there a threat to mental health? Does mourning change to depression? Is there interpersonal isolation?

Table 3 Themes generated from Delphi Round I question 4.

Question 4: What do you believe are the key 'ingredients' of therapy that address your clients' emotional distress?

Identified Theme	Participants ID (n=25)	Participants Responses
Therapeutic knowledge and skill	(ID:8812)	Be able to use various therapeutic schools
	(ID:2382)	Challenging cognitive distortions
	(ID1399)	Matching to specific vulnerability of individual patients
	(ID:3180)	A skilled repertoire of therapy tools to enable client to develop insight and move forward.
	(ID:7819)	Going at client's pace
	(ID:3425)	Flexibility in response.
	(ID:6776)	Hearing the history of unmet relationship and life expectations understanding patient expectations of their own values and contribution in life
Self-awareness and self-reflection	(ID:1763)	A belief the any distress is reasonable which arises according to infertility
	(ID:5214)	[To be] connected with your desire and unconscious feelings.
Fertility knowledge	(ID:5947)	Specific to this topic, the therapist must understand the details of infertility treatment.
The therapeutic relationship	(ID:1784)	Open questions, reflection, providing a safe place to talk, patience, active listening.
	(ID:5947)	Same as with any other type of therapy, trusting, neutral therapeutic relationship.
Practical aspects of therapy	(ID:9653)	A collaborative relationship with a clear contract of work, regularly reviewed and is available, free at the point of contact.
	(ID:8812)	Offer sessions on short notice, be flexible with sessions, include partner, offer telephone/skype counselling.

Table 4 Themes generated from Delphi Round I question 5.

Question 5: Which therapy/counselling techniques/interventions do clients engage with and find helpful in reducing unwanted feelings of distress?

Identified Theme	Participants ID (n=25)	Participants Responses
Living well and improved well-being	(ID:5947)	exercise and other self-care; trying new behaviours
	(ID:4629)	moving on, making future plans
Complementary approaches	(ID:3425)	Naturopathic holistic approaches (incorporating physical, emotional, spiritual and social aspects of an individual).
Psycho-education and guided self-help	(ID:1763)	Relaxation
	(ID:9653)	Handouts and diagrams of transition, trauma and grief curve,
	(ID:5988)	That is very different from individual to individual, most of the clients find it helpful that their reaction is normal.
	(ID:5947)	Meditation;
	(ID:2382)	relaxation techniques
	(ID:1399)	Mostly psychoeducation
	(ID:3338)	Focusing, body-mind techniques
	(ID:7819)	Practical advice based on what has worked for others, e.g. telling people what you need, how to choose the right people to talk to.
		Self-soothing, stress reduction and relaxation exercises, diaphragmatic breathing, visualisations, writing, poetry, artwork, craft work.
	(ID:7819)	Mindfulness, activity, talking, self-compassion, expressive emotion techniques (e.g. Journalling),
	(ID:1798)	Support therapy
Therapeutic	(ID:1763)	Talk counselling (client-centred), CBT, EMDR

techniques & interventions	(ID:1784)	Using the core conditions of PC Asking client to think about their negative thoughts of self-reflected on others and how that would feel. …Honouring their loss
	(ID:9653)	Handouts and diagrams of transition, trauma and grief curve, basic concepts of TA to enhance communication style, CBT to help challenge negative automatic thoughts and promote problem solving, empty chair work, imagery, immediacy, and stone work.
	(ID:5214)	Metabolizing the duel, the possible according to the lived reality
	(ID:5947)	Grieving in a safe place; meditation;
	(ID:2382)	Relaxation techniques, CBT
	(ID:9068)	Acceptance and mindfulness
	(ID:1399)	Cognitive Behaviour Therapy, more specific aspects like writing therapy or grief therapy ACT interventions
	(ID:3338)	Narrative Therapy, CBT
	(ID:3180)	Cognitive behavioural strategies to challenge thinking about being a failure,
	(ID:7819)	Normalising grief, Solution focused strategies
	(ID:3425)	Narrative,
	(ID:8880)	The relationship with the therapist is critical.
	(ID:9322)	I use few interventions beyond the therapeutic relationship and the dynamics within it. re-experiencing trauma, anger/loss cathartic work,
	(ID:7819)	Understanding the impermanence of thoughts and emotions
	(ID:6870)	Understanding where thoughts and emotions come from and that they are not always necessarily useful, ceremony to honour loss/ CBT Mindfulness
	(ID:4629)	Understanding anxiety and grief process Exploration of emotions, meaning and purpose
	(ID:2085)	Feeling understood, being given the time to express what they are feeling however unpalatable. Being helped top stay with uncertainty and helplessness. Knitting together a sense that a future is possible.

	(ID:9431)	My focus is not on reducing the distress which is very real and usually appropriate in the situation, my work focusses more on living well with that distress, finding a way to make it part of your narrative, not avoiding it or being overwhelmed: Acceptance. Working with some of the distorted thinking around issues such as guilt or blame for example is helpful using CBT techniques: challenging and reframing. If someone has an accurate picture that I snot overly influenced by thinking errors, then they can begin to accept their position and move towards a valued life.
Crisis Intervention	(ID:9653) (ID:8812)	Window of tolerance Crisis intervention
Goodness of fit and practical advice	(ID:8880)	The matching of therapist with clients is important. It is as important as the choice we all make in selecting our family doctor or specialist. If it is not working, then make another choice. This is how it operates in Australia, but I'm not sure if this is possible in the UK.

APPENDIX O: Table reporting the Wilcoxon Matched-Pairs Signed Ranks Test

Delphi statements:	Z Score	P Score
Question 1		
Theme 3: Legacy of the fertility treatment		
On-going emotional distress after ending treatment is caused by prolonged fertility treatments for older women.	0.000	1.000
Individuals need to be supported to recognise that fertility treatment is commonly unsuccessful and normalise this	0.000	1.000
Counsellors are recommended too late to clients after unsuccessful fertility treatment	-1.633	0.102
Theme 5: Individual experiences		
Individuals on going emotional distress after ending treatment will be a result of traumas associated with the fertility treatment procedures	0.000	1.000
Individuals on-going emotional distress after ending treatment will be associated with the number of unsuccessful cycles of infertility treatment.	0.000	1.000
Theme 7: Relational dynamics		
On-going emotional distress after ending treatment is associated with the impact of fertility treatment on sexual function and expression.	-1.414	0.157
Question 2		
Theme 1: Infertility experience		
Therapy is to help individuals see that infertility (primary or secondary) is not a failure	-1.518	0.129
Therapy is to develop a shared narrative of the end of their fertility treatment and the impact of involuntary childlessness	-1.000	0.317
Theme 2: Recognition and processing of emotions		
Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely	-1.342	0.180
Theme 4: The couple's relationship		
Therapy is about negotiating the impact of infertility on the couple rather than the individual	-1.342	0.180
Therapy must address sexual function or expression problems arising from fertility treatment.	-1.732	0.083
Theme 6: The therapeutic process		
The process of normalisation and validation through the therapeutic alliance is the most powerful aspect of the therapy process	-1.000	0.317
Theme 7: Creating a different transition		
Therapy should explore alternative routes to fulfil parenthood.	-0.577	0.654

Theme 8: The role of contraception on future hope		
Therapy should facilitate discussion about not using contraception for those with unexplained infertility, and how it could prevent an individual's ability to accept their infertility.	-0.577	0.654
Question 3		
Theme 2: Self-awareness and self-reflection		
It is important that the therapist is reflective and owns their perspective.	-1.633	0.102
Theme 3: Fertility knowledge		
The therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience.	-1.633	0.102
Theme 4: The therapeutic relationship		
The therapeutic relationship and alliance is the only important ingredient.	-1.414	0.157
Theme 5: Practical aspects of therapy		
It is important that therapy is free at the point of delivery	0.000	1.000
It is important that there is a clear therapy contract and to build in regular reviews of that contract.	-1.414	0.157
It is important for the therapist to be flexible and available at short notice.	-1.000	0.317
It is important to be able to provide therapy via modes such as skype or telephone counselling.	-1.890	0.059
Question 4		
Theme: 1 Living well and improved well-being		
To learn to live well with the distress of loss rather than to suppress it.	-1.000	0.317
To encourage a healthy balanced lifestyle which involves living well with exercise and self-care	-1.342	0.180
Themes 2: Complementary approaches		
To use alternative approaches (e.g. Chinese Medicine, Naturopathy, spirituality and hypnotherapy)	0.000	1.000

APPENDIX P: **DELPHI REPORT: SUMMARY OF THE FINDINGS**

Fertility practitioners' experience of the psychological sequelae of unmet parental goals after unsuccessful fertility treatment: A Delphi Consensus Study

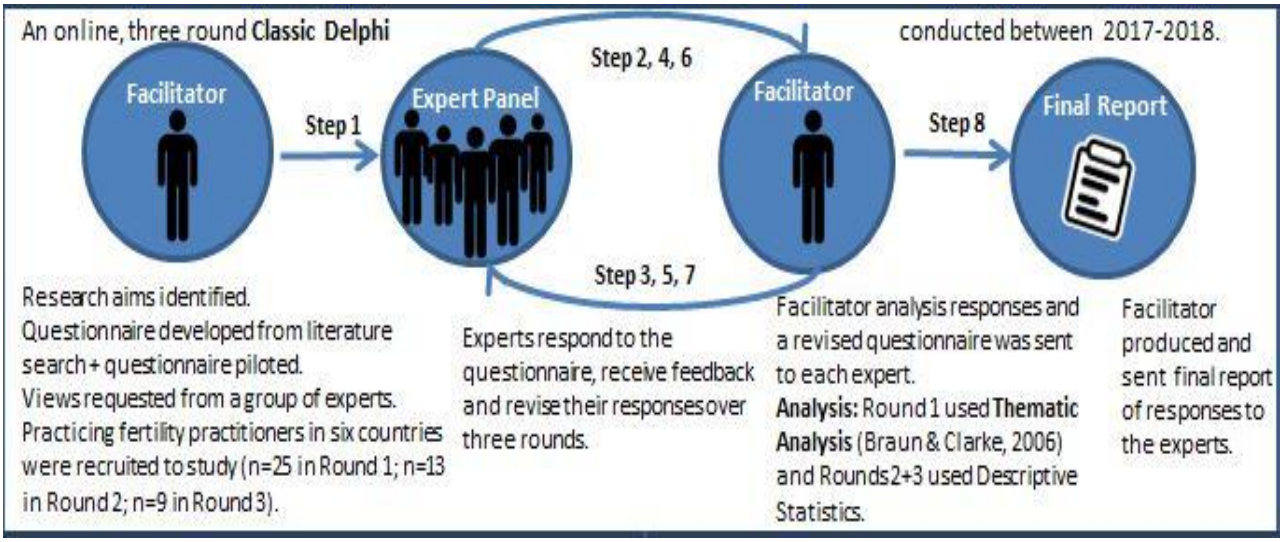
This Delphi Report concludes the study. It will present the research questions, a summary of the methodology and the key findings.

The purpose of the Delphi was to answer two research questions:

1) To understand fertility practitioners' views of patients' experience of distress resulting from unsuccessful infertility treatment(s) where parental goals had been unfilled.

2) To identify effective therapeutic techniques that practitioners used to support individuals in this context, and that they found helpful.

Delphi Methodology:



The Expert Panel

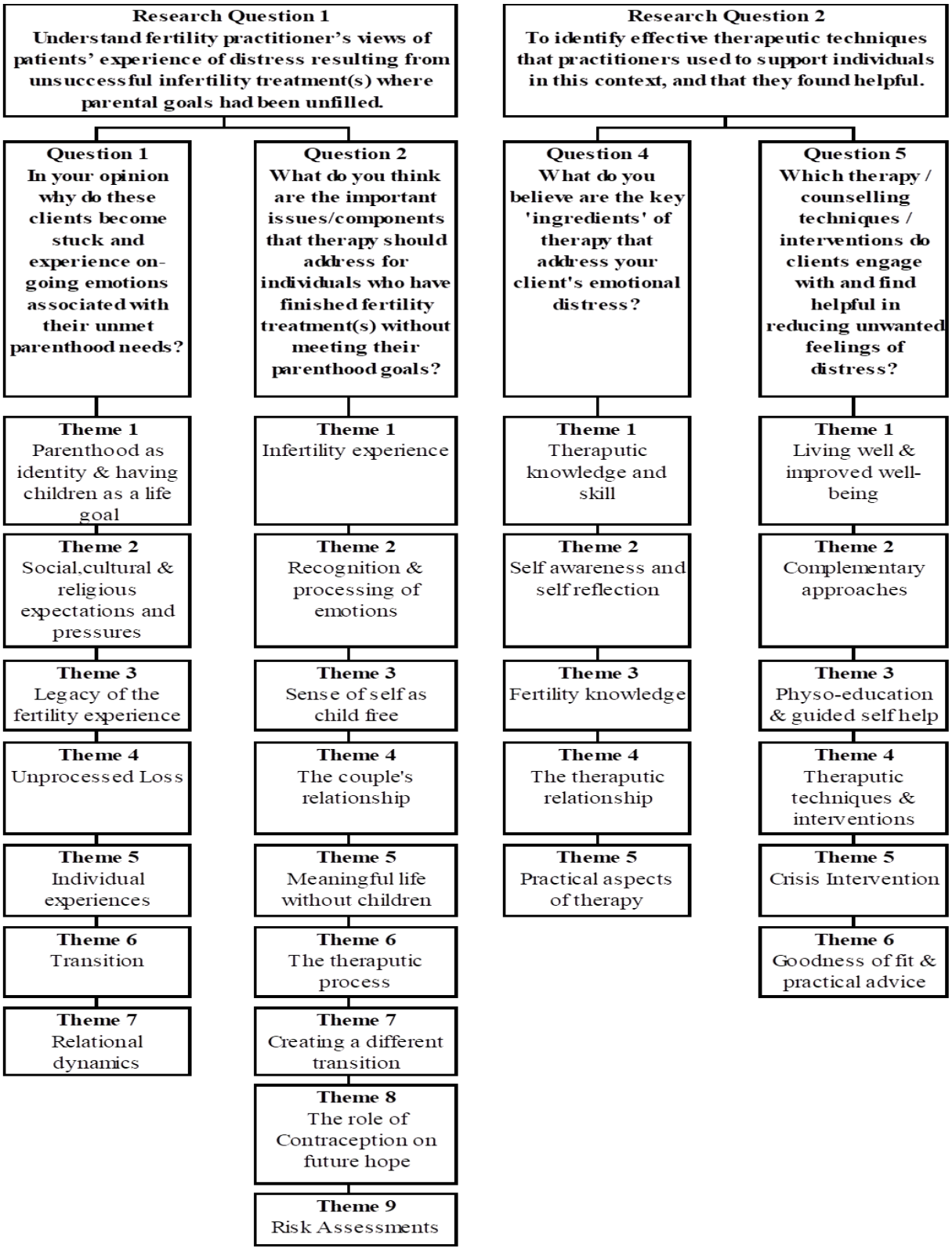
You were part of the expert panel. Your fellow panel members were all practicing fertility practitioners from the United Kingdom, Australia, Japan, New Zealand, Israel and United States of America.

Agreement and Consensus

Delphi works on gaining agreement and consensus between the Expert Panel. A percentage of 70% was used to determine agreement on statements posed in the three questionnaires. The higher the percentage scored, the greater the agreement with the statement. Consensus was determined when a 100% agreement was reached for a statement.

Delphi Round 1.

This round asked the expert panel to answer four qualitative questions. All responses from Round I were coded using thematic analysis for each of the questions. Codes were collected and grouped into themes. A summary of the themes generated are presented in Figure below.


Research Question 1
Understand fertility practitioner's views of patients' experience of distress resulting from unsuccessful infertility treatment(s) where parental goals had been unfilled.
Research Question 2
To identify effective therapeutic techniques that practitioners used to support individuals in this context, and that they found helpful.
Question 1
In your opinion why do these clients become stuck and experience on-going emotions associated with their unmet parenthood needs?
Question 2
What do you think are the important issues/components that therapy should address for individuals who have finished fertility treatment(s) without meeting their parenthood goals?
Question 4
What do you believe are the key 'ingredients' of therapy that address your client's emotional distress?
Question 5
Which therapy / counselling techniques / interventions do clients engage with and find helpful in reducing unwanted feelings of distress?
Theme 1 Parenthood as identity & having children as a life goal
Theme 2 Social,cultural & religious expectations and pressures
Theme 3 Legacy of the fertility experience
Theme 4 Unprocessed Loss
Theme 5 Individual experiences
Theme 6 Transition
Theme 7 Relational dynamics
Theme 1 Infertility experience
Theme 2 Recognition & processing of emotions
Theme 3 Sense of self as child free
Theme 4 The couple's relationship
Theme 5 Meaningful life without children
Theme 6 The theraputic process
Theme 7 Creating a different transition
Theme 8 The role of Contraception on future hope
Theme 9 Risk Assessments
Theme 1 Theraputic knowledge and skill
Theme 2 Self awareness and self reflection
Theme 3 Fertility knowledge
Theme 4 The theraputic relationship
Theme 5 Practical aspects of therapy
Theme 1 Living well & improved well-being
Theme 2 Complementary approaches
Theme 3 Physo-education & guided self help
Theme 4 Theraputic techniques & interventions
Theme 5 Crisis Intervention
Theme 6 Goodness of fit & practical advice

Delphi Round 2:

58 statements were presented to the expert panel for rating in this round. In total 34 statements scored 70% or more, meaning that the expert panel collectively agreed with these statements. Nine statements reached 100% consensus from the group. There were 24 statements where consensus was not reached and represented to the expert panel for review.

Main findings:

Question 1:

- 17 statements reached an agreement score of ≤ 70%.
- 4 statements reached consensus, obtaining a score of 100%.
- There was unanimous agreement of 92.3 per cent disagreement with one statement: '*On-going emotional distress after ending treatment will be the same as those experienced when a cycle has been unsuccessful'.*
- Statements which had reached 100 per cent consensus originated from four qualitative themes (Social, cultural and religious; Individual experiences; Relational dynamics).
- 6 statements which had not reached agreement went through to Round III.

Q**uestion 2:**

- 10 statements reached agreement,
- 5 reached 100% consensus.
- There was overall agreement that: therapy should be about a shared narrative and meaning of the infertility experience; it should be restorative in terms of accepting the body's limitations; it should be couple orientated; and future focused, fostering new life/couple goals.
- 8 statements that had not reached agreement were included in Round III.

Question 4:

- 2 statements met agreement; there was high agreement for use of different types of techniques and change methods to regulate distress in the post treatment phase (92.3%) and acknowledgement that the timing for different interventions was important for the clinician to judge (84.6%).

Question 5:

- 9 statements presented,
- 5 met agreement.
- 2 met 100% consensus (e.g. use of comprehensive assessments and formulations to guide therapeutic interventions, and the use of distress tolerance strategies to help manage crisis and risk).
- The expert panel agreed (92.3%) that psychoeducation and guided self-help principles would be beneficial for emotional distress within the post treatment phase.
- They also agreed that the match between the practitioner and client was important (91.7%).

Delphi Round 3:

24 statements were presented to the expert panel for rating in this round. In total 10 statements scored 70% or more, meaning that the expert panel collectively agreed with these statements. There were 14 statements where consensus was not reached at the end of the Delphi Study.

Main findings:

Question 1:

- 9 statements moved over the 70 per cent agreement level.
- 1 statement reaching 100% agreement indicating consensus.
- This iterative Delphi process of re-rating, improved the percentage agreement for three statements. These statements related to the nature of distress following prolonged treatment periods for women, that there should be disclosure of the true success rate of fertility treatments, and that distress is related to the impact of infertility on sexual function and sexual expression between the couple.
- The expert panel did not agree on three statements; that counsellors were recommended too late; that fertility treatment was related to distress as a result of ongoing traumas and that distress would be proportionate to the number of cycles of treatment.

Question 2:

- 3 statements relating to the components that therapy should address reached the agreement percentage. Statements related to therapy for: feelings associated with infertility; feelings of failure; and the couple's relationship.
- Agreement decreased for two statements (69.3% - to 55.5% and 23.1% to 11.1%). These were statements firstly that '*Therapy is to facilitate individuals to connect with the pain they are experiencing without becoming completely overwhelmed or trying to avoid it entirely'*. The second statement was focused on discussing the future use of contraception with clients; the view being that not choosing to use contraception keeps the potential (false) hope of becoming parents alive.

Question 4:

- Showed the greatest number of statements which did not move into agreement.
- Statements mainly related to a number of themes from Round I. The statement '*therapist must demonstrate basic medical knowledge of fertility conditions and understand the infertility treatment process and experience'* did not reach agreement, or that '*the therapeutic relationship is the only important ingredient in therapy'.*
- The theme 'practicalities of therapy' (e.g. therapy should be free, that it should be readily available, contracted, reviewed regularly and delivered through different mediums) all remained under the 70% agreement by the end of the Delphi.

Question 5:

- Three statements under the themes 'Living well and improved well-being' and 'Complementary approaches') did not reach agreement during this round.

Summary of findings

The expert panel collectively described the complexity of emotional distress associated with unmet parental goals and endorsed the idiosyncratic nature of distress. The exert panel highlighted the that an individual's attributions, desires and goals of having children play a central apart in understanding the distress that presents in your clinical setting.

The expert panel perceived distress to be associated with statements concerned with an individual's identity, adjustment to new life courses relinquishing a desire for biological children and navigating the social, societal and cultural context of childlessness. Practitioners discussed ambiguous loss and grief displayed by their clients. Furthermore, the expert panel views represented a clinical picture of distress, which mirrored that of the evidence-based research on fertility distress.

Across the Delphi process the expert panel highlighted meaning making of the experience of ending fertility treatments and understanding the infertility experience from an individual and couple's perspective to be important in post treatment work.

The expert panel placed a strong emphasis during Round I on the therapeutic relationship, as a change mechanism and the use of therapeutic processes of empathy, normalization and validation. This relationship was linked to allowing the individual the safety and space to grieve their loss. The therapeutic alliance was considered to be an important component within therapy as it normalized and validated the experience of distress in the post treatment phase. However, in Round II it missed the 70% agreement criteria, scoring 69.2%.

There was also a strong emphasis on working with the couple, as opposed to the individual focus that the Delphi questions took. The expert panel expressed a belief that the couple should learn to grieve together, be facilitated to develop new life goals and that any impact of treatment on intimacy should be addressed.

I would like to thank all the members of the Delphi expert panel who participated in one or all three rounds of the Delphi rounds.

This research is currently being written up for publication

Siobhan Moore
Clinical Psychologist in Training

APPENDIX Q: Poster for the European Health Psychology Society Conference, Galway, 2018

Fertility practitioners' experience of supporting patients with unmet parental goals after unsuccessful fertility treatment: A Delphi Study

Siobhan Moore, Dr Jenny Moses & Dr Sofia Gameiro
South Wales Doctorate Programme in Clinical Psychology & School of Psychology, Cardiff University

1. Background and Aims

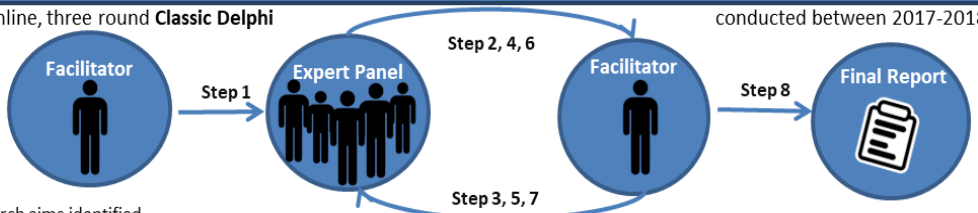
Unsuccessful fertility treatment represents the **loss of biological parenthood** (Gameiro & Finnegan, 2017) and can cause intense and prolonged grief (Danulik, 2001). Little is known about the **process of adjustment** following treatment (s) or distress associated with **unfulfilled parental goals** (da Silva, Boivin & Gameiro, 2016).

Infertility counselling is recommended (NICE, 2013), but there are **no recommended evidence-based interventions** (Gameiro et al., 2015) **to guide fertility practitioners** working therapeutically with those who have stopped treatment(s).

This research investigated **fertility practitioners' experiences of supporting patients with their distress** after unsuccessful infertility treatment(s) and effective therapeutic techniques that they use.

2. Method

An online, three round **Classic Delphi** conducted between 2017-2018.



Research aims identified.
Questionnaire developed from literature search + questionnaire piloted.
Views requested from a group of experts.
Practicing fertility practitioners in six countries were recruited to study (n=25 in Round 1; n=13 in Round 2; n=9 in Round 3).

Experts respond to the questionnaire, receive feedback and revise their responses over three rounds.

Facilitator analysis responses and a revised questionnaire was sent to each expert.
Analysis: Round 1 used **Thematic Analysis** (Braun & Clarke, 2006) and Rounds 2+3 used Descriptive Statistics.

Facilitator produced and sent final report of responses to the experts.

3. Results

Key themes of distress identified from fertility practitioners

Parenthood as identity & children a life goal; social, cultural & religious expectations & pressures; **legacy of the fertility treatment**; **unprocessed loss**, couple dynamics; **sense of self as child free; meaning of life without children**; the therapeutic process; creating a different transition & **recognition & processing of emotions.**

Key effective therapeutic processes & techniques reported by Fertility practitioners

Processes: *therapeutic relationship; practitioners' fertility & therapeutic knowledge; practitioners self reflection & awareness; practical aspects of accessibility.*
Interventions: *living well & improved well-being, complementary approaches; psycho-education & guided self help; crisis & distress tolerance interventions.*

Cognitive Behavioural Therapy (28%), Person Centred Therapy (28%), Psychoanalytic & Psychodynamic approaches (28%) were the primary therapeutic models used in post fertility treatment(s) support

4. Conclusion

Practitioners endorsed the **complexity of distress**; discussing the **presences of ambiguous loss** (Boss, 1999) and grief.

A diverse set of models and interventions were reported to make sense of the experience and improve emotional regulation skills.

Practitioners' agreed that the **core element of therapy** is to **make meaning, promote acceptance** and **pursue new life goals** (Gameiro & Finnegan, 2017).

5. Clinical Implications

Psychosocial interventions are vital in **supporting adjustment** after unsuccessful infertility treatment(s).

Evidence-based interventions which are guided by **adjustment models** and that are **ecologically valid** are needed. As studies report **prolonged experiences of subclinical distress** lasting up to 20 years for some women (Wirtberg et al., 2007).

Therapeutic interventions which **promote adjustment** may also be used to support those that are **involuntarily childless** as a result of other causations.