





## Psychology and counselling

# Discussing the possibility of fertility treatment being unsuccessful as part of routine care offered at clinics: patients' experiences, willingness, and preferences

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## ABSTRACT

**STUDY QUESTION:** Are patients willing to discuss the possibility of treatment being unsuccessful as part of routine care offered at clinics, and what are the factors associated with this willingness?

**SUMMARY ANSWER:** Nine in every 10 patients are willing to discuss this possibility as part of routine care, with willingness being associated with higher perceived benefits, lower barriers, and stronger positive attitudes towards it.

**WHAT IS KNOWN ALREADY:** Fifty-eight percent of patients who complete up to three cycles of IVF/ICSI in the UK do not achieve a live birth. Offering psychosocial care for unsuccessful fertility treatment (PCUFT), defined as assistance and guidance on the implications of treatment being unsuccessful, could reduce the psychosocial distress patients experience when it happens, and promote positive adjustment to this loss. Research shows 56% of patients are willing to plan for an unsuccessful cycle, but little is known about their willingness and preferences towards discussing the possibility of definitive unsuccessful treatment.

**STUDY DESIGN, SIZE, DURATION:** The study was of cross-sectional design, comprising a theoretically driven and patient-centred bilingual (English, Portuguese) mixed-methods online survey. The survey was disseminated via social media (April 2021–January 2022). Eligibility criteria included being aged 18 or older, waiting to or undergoing an IVF/ICSI cycle, or having completed a cycle within the previous 6 months without achieving a pregnancy. Out of 651 people accessing the survey, 451 (69.3%) consented to participate. From these, 100 did not complete 50% of the survey questions, nine did not report on the primary outcome variable (willingness), and 342 completed the survey (completion rate 75.8%, 338 women).

**PARTICIPANTS/MATERIALS, SETTING, METHODS:** The survey was informed by the Health Belief Model (HBM) and Theory of Planned Behaviour (TPB). Quantitative questions covered sociodemographic characteristics and treatment history. Quantitative and qualitative questions gathered data on past experiences, willingness, and preferences (with whom, what, how and when) to receive PCUFT, as well as theory-informed factors hypothesized to be associated with patients' willingness to receive it. Descriptive and inferential statistics were used on quantitative data about PCUFT experiences, willingness, and preferences, and thematic analysis was applied to textual data. Two logistic regressions were used to investigate the factors associated with patients' willingness.

**MAIN RESULTS AND THE ROLE OF CHANCE:** Participants were, on average, 36 years old and most resided in Portugal (59.9%) and the UK (38.0%). The majority (97.1%) were in a relationship for around 10 years, and 86.3% were childless. Participants were undergoing treatment for, on average, 2 years [SD = 2.11, range: 0–12 years], with most (71.8%) having completed at least one IVF/ICSI cycle in the past, almost all (93.5%) without success. Around one-third (34.9%) reported having received PCUFT. Thematic analysis showed participants received it mainly from their consultant. The main topic discussed was patients' low prognosis, with the emphasis being put on achieving a positive outcome. Almost all participants (93.3%) would like to receive PCUFT. Reported preferences indicated that 78.6% wanted to receive it from a psychologist/psychiatrist/counsellor, mostly in case of a bad prognosis (79.4%), emotional distress (73.5%), or difficulties in accepting the possibility of treatment being unsuccessful (71.2%). The preferred time to receive PCUFT was before initiating the first cycle (73.3%), while the preferred format was in an individual (mean = 6.37, SD = 1.17; in 1–7 scale) or couple (mean = 6.34, SD = 1.24; in 1–7 scale) session. Thematic analysis showed participants would like PCUFT to provide an overview of treatment and all possible outcomes tailored to each patient's circumstances and to encompass psychosocial support, mainly focused on coping strategies to process loss and sustain hope towards the future. Willingness to receive PCUFT was associated with higher perceived benefit of building psychosocial resources and coping strategies (odds ratios (ORs) 3.40, 95% CI 1.23–9.38), lower perceived barrier of triggering negative emotions (OR 0.49, 95% CI 0.24–0.98), and stronger positive attitudes about PCUFT being beneficial and useful (OR 3.32, 95% CI 2.12–5.20).

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**LIMITATIONS, REASONS FOR CAUTION:** Self-selected sample, mainly composed of female patients who had not yet achieved their parenthood goals. The small number of participants unwilling to receive PCUFT reduced statistical power. The primary outcome variable was intentions, and research shows a moderate association between intentions and actual behaviour.

**WIDER IMPLICATIONS OF THE FINDINGS:** Fertility clinics should provide patients with early opportunities to discuss the possibility of their treatment being unsuccessful as part of routine care. PCUFT should focus on minimizing suffering associated with grief and loss by reassuring patients they can cope with any treatment outcome, promoting coping resources, and signposting to additional support.

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## Introduction

For many fertility patients, ART represents their last chance to achieve parenthood. In the UK, a total of 113873 women started IVF/ICSI treatment between 1999 and 2008, and 58% (66393) did not achieve a live birth after three complete cycles (McLernon *et al.*, 2016b)—the recommended number of funded cycles by the NICE (National Institute for Health and Care Excellence) guidelines (NICE, 2017). The proportion of people who fail to achieve parenthood with ART may vary across countries due to restrictions to treatment access (Berg Brigham *et al.*, 2013), but even the most optimistic estimations show that, on average, at least two in every 10 fertility patients end treatment (up to seven cycles) without a live birth (McLernon *et al.*, 2016a). Undergoing fertility treatment is physically and emotionally demanding (Verhaak *et al.*, 2007; Gameiro *et al.*, 2015) and ending it without a child triggers an intense and protracted grief process (Daniluk, 2001; Volgsten *et al.*, 2010) associated with impaired wellbeing and mental-health (Gameiro and Finnigan, 2017). Given the high likelihood of treatment being unsuccessful and its impact on wellbeing, many argue that patients should be informed about this (and other) adverse outcomes as part of providing informed consent (Bernat, 2004; Michel and Moss, 2005). Others argue patients should be warned and prepared in advance for this possibility, as well as supported through it in its immediate aftermath (Wischmann and Thorn, 2022). However, this is not common practice in fertility care (Peddie *et al.*, 2005; Carson *et al.*, 2021; Harrison *et al.*, 2022). Studies suggest the possibility of treatment being unsuccessful is only discussed with a minority of patients under very specific circumstances, particularly treatment futility, very poor prognosis, or after repeated cycle failure (Peddie *et al.*, 2005; Ethics Committee of the American Society for Reproductive Medicine, 2019), and that around 4 in 10 patients feel they did not receive all the information they needed to make informed-decisions (Peddie *et al.*, 2004).

Psychosocial fertility care aims to manage the psychological and social implications of infertility and its treatment (Gameiro *et al.*, 2015). In this study, we focused on how psychosocial care can address the implications of fertility treatment being unsuccessful, hereafter referred to as psychosocial care for unsuccessful fertility treatment (PCUFT) and defined as assistance and guidance from healthcare professionals (HCPs) aimed at helping patients to develop coping strategies known to facilitate emotional and social adjustment to this event. Depending on how PCUFT is approached and structured, evidence suggests its

provision can have several benefits for most patients. First, by informing patients about what are typical reactions to unsuccessful treatment, PCUFT can validate such reactions and potentially reduce these by process of negative discounting, whereby people are already expecting adverse consequences from an event are less impacted by it (Thomas *et al.*, 2000; Waller *et al.*, 2014). Information about available support and adaptive coping strategies can also be provided, better equipping patients to cope (Boivin, 2003). Second, by discussing the possibility of treatment being unsuccessful, PCUFT can contribute to managing patients' expectations about the treatment outcome, which have been shown to be overoptimistic (Miron-Shatz *et al.*, 2021; Devroe *et al.*, 2022). PCUFT can also promote agency in adversity and a (more) hopeful outlook towards the (undesired) future (Snyder, 2002; Su and Chen, 2006) by reassuring patients that most people faced with unsuccessful treatment can reach personal balance and rebuild a fulfilling and meaningful life (Gameiro and Finnigan, 2017). Third, PCUFT can foster positive perceptions of end-of-treatment care and promote patients' willingness to uptake support in the aftermath of treatment (if needed) (Daniluk, 2001; Volgsten *et al.*, 2010; Gameiro and Finnigan, 2017).

However, PCUFT can also be perceived to have risks. Discussing the possibility of treatment not working can trigger unnecessary anxious reactions in patients, 'crush' their optimism and, therefore, undermine their engagement with treatment (Harrison *et al.*, 2021; Devroe *et al.*, 2022). This may be particularly true for a proportion of patients who become more committed to achieving their desire for children as they progress through treatment (Rauprich *et al.*, 2011; Carson *et al.*, 2021). PCUFT can also be costly for HCPs, as discussions about health-related 'bad news' are known to be taxing (Boivin *et al.*, 2017). Although most HCPs consider discussions about the possibility of treatment being unsuccessful imperative (Sousa-Leite *et al.*, 2022), many fear that addressing this possibility may trigger negative performance evaluations from patients (Fedele *et al.*, 2020). Addressing this topic may also trigger feelings of frustration and powerlessness in HCPs, who may feel responsible for the treatment outcome, as well as the weight of responsibility of potentially influencing such an important patient decision (Meier *et al.*, 2001; Fedele *et al.*, 2020).

The Health Belief Model (HBM) and Theory of Planned Behaviour (TPB) offer comprehensive frameworks to understand how patients form their intentions regarding the uptake of healthcare provisions (Rosenstock, 1974; Ajzen, 1985). Existing

evidence supports the validity and reliability of HBM- and TPB-based surveys to explain this uptake (e.g. McEachan et al., 2011). According to the HBM, patients will be willing to receive PCUFT if they think their chances of experiencing unsuccessful treatment and therefore of not achieving their genetic parenthood goals are high (susceptibility), if they think this will negatively affect their life (severity), if they perceive PCUFT to be beneficial and do not see relevant barriers to its uptake, and if specific cues to action trigger them to consider it (e.g. starting last funded IVF cycle). According to the TPB, patients will be more willing to receive PCUFT if they have positive attitudes about it (e.g. beneficial, useful), think significant others would want them to uptake it (social norms), and feel able to receive it (perceived behavioural control).

To better understand with whom, what, how and when PCUFT should be delivered at clinics, it is important to understand patients' views and preferences about it. This patient-centred approach is also recommended given the increased demand and resulting commercialization of fertility care (Ghinea et al., 2022). Research meta-synthesis shows patients desire information about all treatment-related aspects, including adverse events, and consider the current level of information provision insufficient (Dancet et al., 2010). Despite the potential threatening aspect of PCUFT, survey research shows patients are willing to discuss possible adverse outcomes of treatment (e.g. unsuccessful cycle attempts), especially if it helps them to prepare for such eventualities (Peddie et al., 2005; Harrison et al., 2021). As patients progress through repeated unsuccessful cycles and develop awareness that treatment may not work, they may become more receptive to PCUFT (Pedro et al., 2018). Many people revise down their parenthood goals (and desire) as these are seen to be less achievable (Liefbroer, 2009; Sousa-Leite et al., 2019). However, evidence from qualitative studies also suggests some patients avoid such discussions (with partner, HCPs), as they think they need to remain committed to treatment to be able to conceive (da Silva et al., 2020). These data suggest patients may have different preferences towards PCUFT and that individual preferences may also vary according to the stage of treatment and/or perceived likelihood of success.

The present study aimed to investigate patients' experiences, willingness, and preferences to discuss the possibility of treatment being unsuccessful as part of routine care offered at clinics, in particular: patients' experiences of having received PCUFT, their willingness to receive PCUFT and their preferences about with whom, what, how, and when it should be delivered. Findings can help HCPs and clinics to reflect about whether they want to offer this care to their patients and how it should be integrated into current models of psychosocial care.

## Materials and methods

### Design

A cross-sectional, bilingual (English, Portuguese), mixed-methods (quantitative-qualitative), anonymous, and web-based survey was designed. Reporting follows Sharma et al. (2021) recommendations.

### Participants

Inclusion criteria were being an adult (aged 18 or older) and being on the waiting list to initiate an IVF/ICSI cycle, currently undergoing a cycle, or having completed one within the previous 6 months without achieving a pregnancy. Exclusion criteria were not being able to read and write English or Portuguese. A non-probability sample was used. A priori power calculations

computed for logistic regression to investigate factors associated with willingness to receive PCUFT (not willing, willing) estimated that a minimum total sample size of 305 was required to detect small effect sizes ( $\alpha = 0.05$ , power = 0.9) (Faul et al., 2007).

### Materials

The survey was informed by the HBM and TPB (Rosenstock, 1974; Ajzen, 1985, 2006) and organized into four sections: sociodemographic characteristics and treatment history; experiences of having received PCUFT; willingness and preferences to receive PCUFT; and factors associated with willingness to receive PCUFT.

#### Sociodemographic characteristics and treatment history

Questions on sociodemographic characteristics included age, gender, country of residence, education and occupational status, relationship status, and duration (when there is one). Questions on treatment history included current treatment situation (waiting to initiate an IVF/ICSI cycle, undergoing a cycle, having completed one within the previous 6 months without achieving pregnancy), time undergoing treatment (in years), number of IVF/ICSI cycles performed in the past, whether participants had achieved a live birth from previous IVF/ICSI, parenthood status (no children, biological, adopted, stepchildren), the strength of child desire (from 1: no desire at all to 10: very strong desire), and whether participants considered other pathways to achieve parenthood (no, adoption, other—please specify).

#### Experiences of having received PCUFT

The survey stated that PCUFT aims to 'support patients in developing coping strategies known to facilitate emotional and social adjustment in case of treatment being unsuccessful and that it happens in advance of this eventuality, i.e. anytime since the first appointment at the fertility clinic until the end of all treatment cycles'. For simplicity, in the survey questions, we used terminology such as 'counselling', 'talk about', or 'discuss' the possibility of treatment being unsuccessful when referring to PCUFT. Unsuccessful treatment was defined as 'all cycles of treatment being unsuccessful'.

Participants were asked if they remember having received PCUFT (no, yes) and with whom they talked about this possibility, and to describe what they were told (open-ended questions).

#### Willingness and preferences to receive PCUFT

Participants were asked whether they would be willing to receive PCUFT (no, yes). Four quantitative and three open-ended questions assessed their preferences about PCUFT, focusing on the HCP participants would feel more comfortable receiving PCUFT from (list of five professionals, e.g. psychologist/psychiatrist/counsellor; multiple responses allowed), what they would like to address in a PCUFT session, what could make receiving PCUFT easier for them (open-ended questions), and to rate the usefulness of different formats to receive PCUFT (five formats presented, e.g. self-help resources, response scale ranging from 1: extremely useless to 7: extremely useful). Participants were additionally asked about valid reasons to receive PCUFT (list of five reasons, e.g. 'If the chances of treatment being successful are very low—bad prognosis'; multiple responses allowed), what would be the best time to receive PCUFT (before initiating the first IVF/ICSI cycle, after it being unsuccessful, before initiating the last cycle) and reasons to choose that time (open-ended question).



### Factors associated with willingness to receive PCUFT

Questions assessing HBM variables were specifically designed for this study but based on similar formulations previously used in reproductive research (Ter Keurst *et al.*, 2016; Sousa-Leite *et al.*, 2019). Susceptibility: participants were asked to rate the chance of their fertility treatment being successful and the likelihood of having (a)nother child (considering other ways to have children) on a 0–100% scale. Severity: participants were asked to rate how painful it would be if they could not have (a)nother child with fertility treatment and not have (a)nother child (considering other ways to have children) on scales ranging from 1: not painful at all to 7: extremely painful. Benefits and barriers: participants were asked what the benefits of PCUFT are (open-ended question) and, after, to rate 18 benefit statements (e.g. 'be informed about how most people react in the short and long term when their treatment is unsuccessful') on scales ranging from 1: strongly disagree to 7: strongly agree. The same procedure was applied to measure perceived barriers with 11 barrier statements (e.g. 'patients may not be emotionally prepared to contemplate the possibility of treatment being unsuccessful'). The list of benefits and barriers was developed by the research team based on a systematic review of adjustment to unsuccessful treatment (Gameiro and Finnigan, 2017) and research on end-of-life counselling (Boulton *et al.*, 2001; Burns, 2004; Clayton *et al.*, 2005; Brighton and Bristowe, 2016). Cue to action: having completed the second unsuccessful cycle or starting/undergoing the third (recommended number of cycles) or higher cycles of treatment after previous attempts being unsuccessful, under the assumption the third cycle would cue patients to the possibility of treatment being unsuccessful.

Questions assessing the TPB variables followed Ajzen (2006) guidelines. Attitudes: participants were asked to rate how beneficial and useful PCUFT is on scales ranging from 1: extremely harmful/useless to 7: extremely beneficial/useful. Social norms: participants were asked to rate seven statements (e.g. 'I think my partner would want us to be counselled in advance about the possibility of treatment being unsuccessful') on scales ranging from 1: strongly disagree to 7: strongly agree. Perceived behavioural control: participants were asked one question about the difficulty of receiving PCUFT on a scale ranging from 1: extremely difficult to 7: extremely easy, and another asking them to rate three statements (e.g. 'I am confident that I know how to access counselling about the possibility of treatment being unsuccessful') on scales ranging from 1: strongly disagree to 7: strongly agree.

### Procedures

The survey was posted online using the Qualtrics software (Qualtrics, Provo, UT, USA) and distributed via social media adverts (e.g. Facebook, Instagram, Twitter) between April 2021 and January 2022. A gatekeeper letter with a direct link to the survey was sent to fertility charities (e.g. Fertility Network in the UK and APFertilidade in Portugal) and social influencers in the field (asking whether they would distribute the survey via social media). Participants were presented with information and consent forms by clicking on the survey link. No approach to preventing 'multiple participation' was used, but interrupted surveys had to be completed within a week of the last input. At the end of the survey, participants had the opportunity to enter a raffle of five €30 vouchers (emails provided were not linked to survey responses) and were presented with a debrief, which included links to support resources.

### Ethical approval

The Ethics Committees of the School of Psychology, Cardiff University (EC.20.11.10.6111RA), and the Institute of Public Health, University of Porto (CE21177) provided approval.

### Statistical analyses

We used descriptive statistics to describe the sample's sociodemographic characteristics and treatment history. To investigate patients' experiences of having received PCUFT and their willingness and preferences to receive it, we reported descriptive statistics on quantitative data and conducted thematic analysis on data from open-ended questions.

To identify common factors from the pre-defined list of benefits and barriers statements, we conducted two principal axis factor analyses with direct oblimin rotation.

To identify factors associated with patients' willingness to receive PCUFT, we ran two multivariate logistic regression analyses with the willingness to receive PCUFT (no, yes) as the dependent variable. Model 1 included the variables of the HBM (susceptibility, severity, common factors identified for benefits and barriers, cues to action), and Model 2 included the variables of the TPB (attitudes, norms, perceived behaviour control) as independent variables. We tested these theories separately because that is a common practice that allows meta-synthesis of effect sizes across studies and determines the explanatory power of each theory. The models were adjusted for those sociodemographic characteristics and treatment history variables associated with willingness to receive PCUFT. Statistics were standardized beta coefficients ( $\beta$ ), SE, and odds ratios (OR) with 95% confidence intervals (95% CI).

Thematic analysis followed Braun and Clarke (2006) recommendations. This approach assumes a flexible epistemological position but offers a systematic and comprehensive framework that allows a detailed account of the data. We adopted an essentialism epistemological position, by limiting the extent of research interpretation of the participants' experiences (Braun and Clarke, 2006). M.S.-L. and S.G. familiarized themselves with the data. Using an inductive approach, M.S.-L. systematically set initial codes (i.e. descriptive meaning labels) for each codable text segment across the entire data set. After, M.S.-L. organized these codes into sub-themes and main themes (i.e. more abstract representations of similar ideas). The team met several times during this inductive process to discuss the process (at the level of the coded data extracts), and disagreements on interpretation were discussed until consensus was achieved. When deemed necessary, themes were reviewed and refined to better integrate consensus in the team.

The prevalence of each main theme was determined by the number of different participants who endorsed the theme across each question. The main themes were presented with a detailed description and illustrative verbatim quotes—referenced by participant number (P). Portuguese quotes were translated into English (... ) indicates part of the quote was omitted as it did not add relevant information, and [text] indicates additional text was added to ease understanding.

### Results

#### Participants

Out of 651 people accessing the survey, 451 (69.3% acceptance rate) consented to participate. From these, 100 did not complete half of the survey questions, and nine did not report on the primary outcome variable (willingness to receive PCUFT). The final

sample consisted of 342 participants (75.8% completion rate). Those who did not complete the survey did not differ from those who did in any sociodemographic and treatment variables, apart from parenthood status, whereby the latter were more likely to not have children.

Table 1 describes participants' sociodemographic characteristics and treatment history. Participants were, on average, 36 years old, female, and most resided in Portugal and the UK. On average, they were undergoing treatment for 2 years. Most had performed at least one IVF/ICSI cycle, with a minority (6.5%) having achieved a live birth. Participants reported a very strong desire for parenthood, and more than half were willing to contemplate non-treatment options to achieve it, mainly adoption ( $n = 168$ ; 88.4%).

### Experiences of having received PCUFT

A total of 119 (34.9%) participants reported having received PCUFT. From those who provided textual data ( $n = 115$ ), qualitative analysis showed most referred having received PCUFT with their fertility consultant ( $n = 95$ , 82.6%), 11 (9.6%) with their psychologist, seven with their counsellor (6.1%), and nine (7.8%) with their nurse. Thirteen (11.3%) referred they discussed the possibility of unsuccessful treatment with their partner, family, or friends. Thematic analysis extracted three main themes about topics addressed during PCUFT. See [supplementary Table S1](#) for themes' detailed descriptions and illustrative quotes. Briefly, most participants who provided textual responses ( $n = 112$ )

received general and bespoke information about treatment low success rates ( $n = 68$ , 60.7%). Some participants endorsed a brief acknowledgement of the possibility of treatment being unsuccessful, though the focus of the discussion was on achieving a live birth ( $n = 44$ , 39.3%). A minority referred to having the opportunity to discuss the implications of treatment being unsuccessful (e.g. alternative paths for parenthood, adverse complications during treatment) ( $n = 29$ , 25.9%).

### Willingness and preferences to receive PCUFT

#### Willingness to receive PCUFT

The vast majority ( $n = 319$ , 93.3%) of participants were willing to receive PCUFT. Participants who were willing and not willing to receive PCUFT did not differ in any sociodemographic and treatment history variables, apart from the country. The proportion of participants willing to receive PCUFT was higher in Portugal than in the UK.

Supplementary Table S2 presents participants' preferences towards PCUFT.

#### Who should provide PCUFT?

The HCP with whom most participants would feel more comfortable receiving PCUFT was their psychologist/psychiatrist/counsellor ( $n = 268$ , 78.6%) or consultant (gynaecologist/obstetrician (GYN/OBS);  $n = 182$ , 53.4%).

**Table 1.** Descriptive statistics of sociodemographic characteristics and treatment history for the total sample, and according to willingness to receive psychosocial care for unsuccessful fertility treatment (PCUFT).

	Total (N = 342)	Not willing to receive PCUFT (n = 23)	Willing to receive PCUFT (n = 319)	( $\chi^2/t$ )
Sociodemographic characteristics	n (%)	n (%)	n (%)	
Age (in years) M (SD) [interval range]	35.65 (4.13) [25–51]	36.00 (4.46) [25–42]	35.63 (4.11) [26–51]	0.42
Female <sup>a</sup> n (%)	338 (99.12)	22 (100.00)	316 (99.06)	0.21
Country of residence n (%)				
Portugal	205 (59.94)	8 (34.78)	197 (61.76)	9.25*
UK	130 (38.01)	13 (56.52)	117 (36.68)	
Other (Angola, Germany, Greece, Ireland, Luxemburg, Sweden, Thailand)	7 (2.05)	2 (8.70)	5 (1.57)	
University education <sup>a</sup> n (%)	274 (80.59)	20 (86.96)	254 (80.13)	0.64
Employed n (%)	326 (95.32)	21 (91.30)	305 (95.61)	0.89
In a relationship n (%)	332 (97.08)	22 (95.65)	310 (97.18)	0.18
Duration (in years) M (SD) [interval range]	9.94 (4.76) [0–23]	9.85 (5.01) [0–18.50]	9.94 (4.75) [0–23]	−0.09
Treatment history				
Treatment stage <sup>a</sup> n (%)				
Waiting list to initiate an IVF/ICSI cycle	94 (27.57)	7 (30.43)	87 (27.36)	2.43
Undergoing an IVF/ICSI cycle	68 (19.94)	7 (30.43)	61 (19.18)	
Completed an IVF/ICSI cycle within the previous 6 months without achieving a pregnancy	179 (52.49)	9 (39.13)	170 (53.46)	
Time undergoing treatment <sup>a</sup> (in years) M (SD) [interval range]	2.12 (2.11) [0–12]	2.55 (2.34) [0–8.25]	2.09 (2.10) [0–12]	1.00
Number of IVF/ICSI cycles performed <sup>a</sup> n (%)				
0	96 (28.15)	5 (21.74)	91 (28.62)	3.36
1–3	200 (58.65)	12 (52.17)	188 (59.12)	
+3	45 (13.20)	6 (26.09)	39 (12.26)	
Achieved a live birth with treatment n (%)	16 (6.53)	3 (16.67)	13 (5.73)	3.27
Childless n (%)	295 (86.26)	19 (82.61)	276 (86.52)	0.28
Parenthood desire M (SD) [1–10]	9.61 (0.93) [2–10]	9.78 (0.42) [9–10]	9.60 (0.96) [2–10]	1.79
Contemplate other pathways for parenthood (e.g. adoption; gametes donation) n (%)	190 (55.56)	13 (56.52)	177 (55.49)	0.01

M, mean.

<sup>a</sup> Valid percentages were reported (1–2 participants did not report on these variables).

<sup>b</sup> Fisher(–Freeman–Haton)'s Exact test was used when cells have expected count <5.

\*  $P < 0.05$ .

## What should PCUFT address and how?

Thematic analysis of aggregated data about what topics participants would like to address in PCUFT and valued PCUFT features revealed six main themes, described in detail with illustrative quotes in Table 2. The first extracted theme reflected a high need to discuss how to process loss and sustain a hopeful outlook towards the future, specifically the need to be informed about 'coping strategies' (Participant (P)40) to 'manage my [patients'] feelings around this' (P13). The second theme reflected that participants valued receiving an overview of treatment that acknowledges adverse outcomes. Such overview should provide information about individual prognosis (based on sociodemographic and medical circumstances), treatment procedures, and their possible adverse outcomes, such as 'low numbers of eggs collected, low numbers fertilised or the potential for having no embryo to transfer. I would have felt much more prepared emotionally if we had been given this information' (P156). The third theme showed that PCUFT should also offer and inform patients about available support ('what to do, where to drive, which professionals to contact', P23) and help them to contemplate 'other ways/possibilities of being able to fulfil the desire to be a mother' (P49). The fourth theme reflected a need for PCUFT to be easily accessible as a part of routine care 'without us [patients] having to do all the research and maybe struggle to get the counselling'

(P131) and offered in an empathic, open, and realistic way. The final two themes were less prevalent and reflected an overall dissatisfaction with the PCUFT received, particularly about 'the mental and emotional side of treatment and treatment failure (...) extremely poor over our [patients'] journey' (P105), and an ambivalence or unwillingness towards what PCUFT should address.

Offering PCUFT in an individual (mean 6.37, SD = 1.17, range: 1–7) or couple session (mean = 6.34, SD = 1.24, range: 1–7) was considered extremely useful and significantly more so ( $F = 215.69$ ,  $P < 0.001$ ,  $\eta_p^2 = 0.437$ ) than other types of delivery formats (self-help resources, moderated, or peer group sessions).

## When should PCUFT be provided?

The three most prevalent reasons to receive PCUFT were bad prognosis ( $n = 270$ , 79.4%), being distressed ( $n = 250$ , 73.5%), and having difficulties accepting the possibility of unsuccessful treatment ( $n = 242$ , 71.2%). The preferred time for PCUFT was before initiating the first IVF/ICSI cycle ( $n = 250$ , 73.3%). Most participants ( $n = 211$ ) provided reasons for their choice. Thematic analysis of the textual data provided revealed four main themes about why this was the preferred moment. Themes reflected a high need for an initial comprehensive picture of treatment that can support patients in making more informed decisions from the

**Table 2.** Themes relating to topics to address in psychosocial care for unsuccessful fertility treatment (PCUFT) and valued PCUFT features ( $n = 271$ ).

Theme, description (n, %)	Illustrative quotes
<b>Process loss and sustain a hopeful outlook towards the future</b> ( $n = 163$ , 60%): discussing coping strategies to use if treatment does not work, managing expectations about the treatment pathway, and fostering a hopeful outlook towards the future. To a lesser extent, acknowledging the emotional/relational burden of treatment and managing communication with others.	'How to cope with the loss' (P62); 'How to manage own expectations (...) ' (P98); 'I'd like to be given some hope that you will survive unsuccessful treatment and more on what feelings to expect during and after treatment' (P211); 'Definitely coping strategies with failure, my first embryo transfer was unsuccessful, and I was absolutely broken when it failed' (P40); 'Coping with the couple's guilt and expectations, how to manage the family members' expectations, how to deal with society and its questions (...) ' (P140).
<b>Overview of treatment that acknowledges adverse outcomes</b> ( $n = 104$ , 38%): discussing the patient's treatment plan in detail: individual prognosis, treatment procedures, and all possible adverse outcomes. Endorsed to a lesser extent, discussing why previous cycle attempts were unsuccessful and factors known to impact its outcome (e.g. lifestyle behaviours).	'Facts and figures that could relate to your specific situation' (P169); '(...) Instead of talking about what it will be like if everything goes well, it should also be addressed what can actually go wrong' (P14); 'What we felt we weren't given enough detail on is poor outcomes before we even got to transfer, such as low numbers of eggs collected, low numbers fertilised or the potential for having no embryo to transfer. I would have felt much more prepared emotionally if we had been given this information' (P156).
<b>Support sources and alternative life-goals</b> ( $n = 101$ , 37%): offering available support, in particular psychosocial support and over the whole treatment journey, and discussing other routes for parenthood and alternative life-goals (donation, surrogacy, adoption, childfree lifestyle).	'What to do, where to drive, which professionals to contact' (P23); '(...) I think it would be beneficial if this process was always followed by a psychologist (...) ' (P42); 'Other ways/possibilities of being able to fulfil the desire to be a mother' (P49); '(...) how can I live my happy life without children' (P79).
<b>Integrated in routine care</b> ( $n = 89$ , 33%): easily accessible as part of routine care. Delivered in a private and safe place, by an expert in fertility, in an empathic, open, and realistic way. Preferences to be delivered individually (with the partner, when there is one), but also valued the opportunity to listen and share their experiences with other fertility patients.	'Being given the option before the start of the treatment without us having to do all the research and maybe struggle to get the counselling (...) it would be easier to go through it' (P131); 'Approachable staff, who have empathy to how hard the process is (...) ' (P105); 'to talk to (...) someone who became a parent through adoption, or someone who is child-free after infertility and can speak from personal experience' (P203).
<b>Dissatisfaction with PCUFT received</b> ( $n = 35$ , 13%): some participants made comments about the PCUFT received. Overall, they felt they were not prepared for the adverse outcomes of treatment, that clinics tended to foster unrealistic optimistic expectations and provide lack of support throughout their fertility journey.	'(...) we are not prepared by a professional to overcome these situations (...) ' (P64); '(...) clinics supporting so much more with the mental and emotional side of treatment and treatment failure. I feel this has been extremely poor over our journey' (P105); '(...) IVF is sold as a near magic solution (...) ' (P205).
<b>Ambivalence and unwillingness towards PCUFT</b> ( $n = 22$ , 8%): some participants perceived they were already aware of the possibility of treatment not working or that would be too painful to approach it and therefore were not willing to do it so.	'I don't know how anyone could make that prospect better but more information on other options such as egg donors etc' (P241). 'It is tricky, to be honest, the pregnancy losses (clomid pregnancies) have been so hard to deal with (...) front loading discussion about failure too much would just stop you from starting' (P103).

Thematic analysis was done in aggregated data from what participants would like to address in a PCUFT session and what could make receiving PCUFT easier for them.  
P, participant number.

start of treatment ('the earlier you have all the information, the better in order to make educated decisions', P153,  $n=106$ ; 50.2%), to be better prepared to cope with unsuccessful cycle attempts and treatment ( $n=90$ ; 42.7%), to foster realistic expectations about the outcome of treatment ('not to have such a big shock, as we, couples, go in with many expectations and dreams and in the end, we literally take it with a bucket of ice water', P120,  $n=75$ ; 35.5%), and to understand how to access psychosocial support over the process ( $n=21$ ; 10.0%). Around two in every 10 participants ( $n=59$ ; 17.3%) only wanted to receive PCUFT after their first unsuccessful IVF/ICSI cycle or before initiating their last cycle. Thematic analysis revealed they considered PCUFT should be timed with the experience of adverse outcomes as the need for support is higher at these moments of distress and doubt. These participants also feared discussing unsuccessful treatment earlier could negatively impact their optimism and engagement with treatment.

## Factors associated with willingness to receive PCUFT

### According to the Health Belief Model

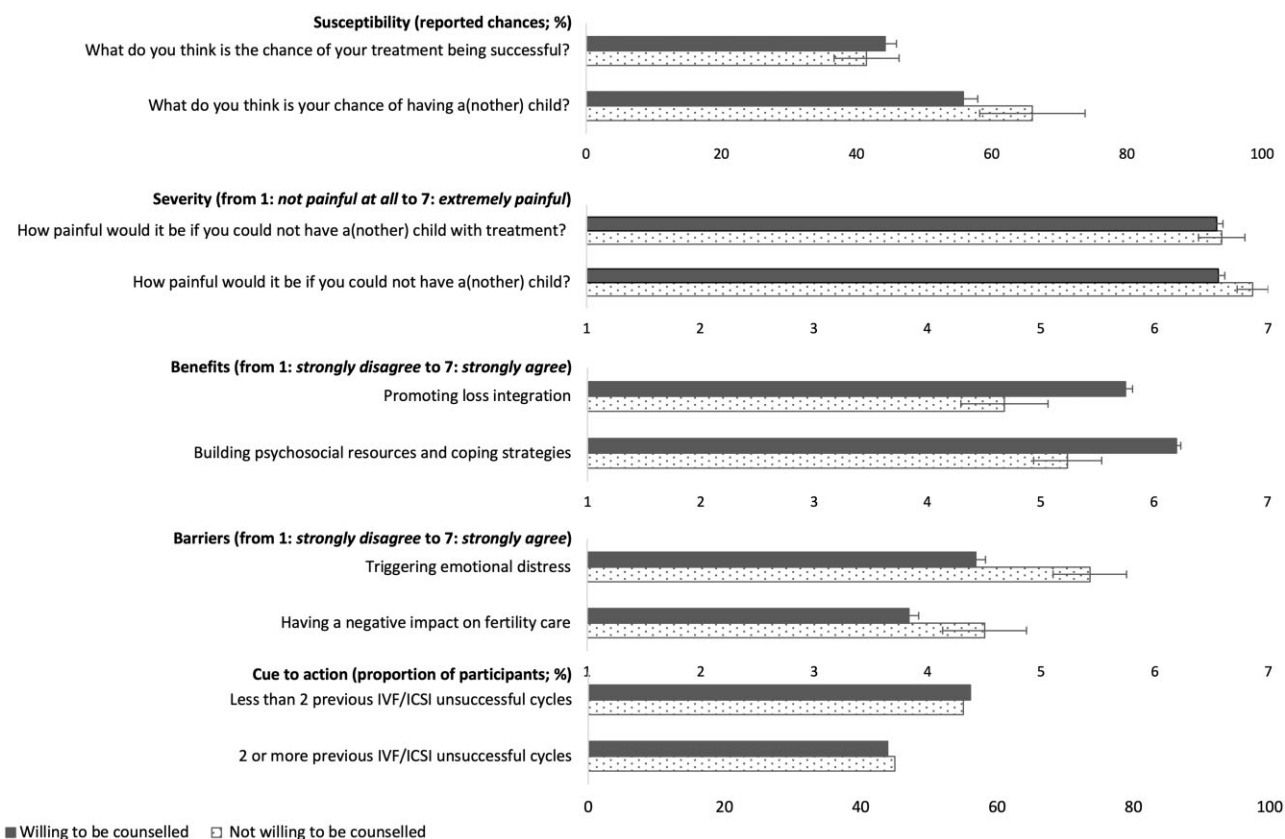
Figure 1 presents descriptive statistics for the HBM factors for participants willing and not willing to receive PCUFT. Supplementary Tables S3 and S4 present results of the factor analyses performed on benefits and barriers towards PCUFT. The factor analysis performed on the list of 18 benefits extracted two factors that explained 50% of the total variance. These were: promoting loss integration (nine items, Cronbach's  $\alpha=0.89$ , mean = 5.68, SD = 1.09, range: 1.33–7; e.g. 're-examine my hopes and motivations to become a parent') and building psychosocial

resources and coping strategies (nine items, Cronbach's  $\alpha=0.87$ , mean = 6.14, SD = 0.74, range: 2.11–7; e.g. 'discuss how to cope with difficult thoughts and emotions in the case of treatment being unsuccessful'). The factor analysis performed on the list of 11 barriers extracted two factors that explained 55% of the total variance. These were: triggering emotional distress (six items, Cronbach's  $\alpha=0.89$ , mean = 4.48, SD = 1.41, range: 1–7; e.g. 'patients may feel more anxious or sad during treatment') and having a negative impact on fertility care (five items, Cronbach's  $\alpha=0.83$ , mean = 3.87, SD = 1.38, range: 1–7; e.g. 'patients may think that expressing concerns or negative emotions about treatment may prevent them from doing treatment').

Results from the logistic regression testing associations between factors of the HBM and willingness to receive PCUFT (see Table 3) explained 27.54% (Nagelkerke  $R^2$ ) of the variance in willingness and showed that two factors predicted willingness: higher perceived benefit of building psychosocial resources and coping strategies (OR 3.40, 95% CI 1.23–9.38) and lower perceived barrier of triggering negative emotions (OR 0.49, 95% CI 0.24–0.98).

### According to the Theory of Planned Behaviour

Figure 2 presents descriptive statistics for the TPB factors for participants willing and not willing to receive PCUFT. Results from the logistic regression testing associations between factors of the TPB and willingness to receive PCUFT (see Table 3) explained 44.64% (Nagelkerke  $R^2$ ) of the variance in willingness and showed that one factor predicted willingness: stronger positive attitudes about PCUFT being beneficial and useful (OR 3.32, 95% CI 2.12–5.20).



**Figure 1.** Descriptive statistics for the Health Belief Model (HBM) factors for participants willing and not willing to receive psychosocial care for unsuccessful treatment (PCUFT). Higher scores indicate lower susceptibility, higher severity, and more perceived benefits and barriers. Error bars indicate 95% confidence interval around the mean.



**Table 3.** Multivariate logistic regression analysis testing associations between factors of the Health Belief Model and Theory of Planned Behaviour variables, respectively, and willingness to receive psychosocial care for unsuccessful fertility treatment (PCUFT).

	$\beta$	SE	OR	95% CI	
				Lower	Upper
<b>Model 1. Health Belief Model</b> $\chi^2(9) = 22.31, P = 0.008$ , Nagelkerke $R^2 = 0.275$					
Susceptibility	0.01	0.02	1.01	0.98	1.04
Severity	−0.21	0.49	0.81	0.31	2.10
Benefits—promoting loss integration	0.27	0.37	1.31	0.64	2.70
Benefits—building psychosocial resources and coping strategies	1.22	0.52	3.40*	1.23	9.38
Barriers—triggering emotional distress	−0.72	0.36	0.49*	0.24	0.98
Barriers—having a negative impact on fertility care	0.06	0.29	1.06	0.60	1.88
Cue to action—number of unsuccessful cycles in the past <sup>a,b</sup>	−0.26	0.69	0.77	0.20	2.97
<b>Model 2. Theory of Planned Behaviour</b> $\chi^2(5) = 63.97, P < 0.001$ , Nagelkerke $R^2 = 0.446$					
Attitudes	1.20	0.23	3.32***	2.12	5.20
Subjective norms	0.53	0.34	1.71	0.87	3.34
Perceived behaviour control	−0.24	0.26	0.79	0.47	1.32

Both models were adjusted for country of residence.

$\beta$ , beta coefficients; OR, odds ratios.

<sup>a</sup> 0: <2 IVF/ICSI unsuccessful cycles in the past; 1: two or more unsuccessful IVF/ICSI cycles in the past.

<sup>b</sup> Participants who did achieve a live birth with treatment in the past were excluded from this analysis.

\*  $P < 0.05$ , \*\*\*  $P < 0.001$ .

#### Attitudes (from 1: extremely harmful/useless to 7: extremely beneficial/useful)

Receiving CUFT would be beneficial

Receiving CUFT would be useful

#### Social norms (from 1: strongly disagree to 7: strongly agree)

Most people in my situation receive CUFT

I think my partner would want us to receive CUFT

General rule, I want to do what my partner thinks is best

I think my family and friends would want me to receive CUFT

General rule, I want to do what my family and friends think is best

I think HCPs at my fertility clinic would want me to receive CUFT

General rule, I want to do what HCPs of my fertility clinic think is best

#### Perceived Behaviour Control (from 1: strongly disagree/extremely difficult to 7: strongly agree/extremely easy)

If I wanted to receive CUFT, I have someone to turn to

Accessing CUFT depends only on me

I am confident that I know how to access CUFT

Receiving CUFT would be easy

■ Willing to be counselled □ Not willing to be counselled

**Figure 2.** Descriptive statistics for the Theory of Planned Behaviour (TPB) factors for participants willing and not willing to psychosocial care for unsuccessful fertility treatment (PCUFT). Higher scores indicate more of the construct. Error bars indicate 95% confidence interval around the mean. HCPs mean healthcare professionals.

## Open-ended responses about perceived benefits and barriers

Thematic analysis of responses about perceived benefits and barriers of PCUFT revealed five and three main themes, respectively, presented in Table 4. Overall, the prevalence of benefits-related themes was higher than barriers-related themes. Regarding benefits, the most prevalent theme reflected a perception that PCUFT could help patients to better cope with unsuccessful treatment ('Having information and tools that would allow me to accept this

possibility in a constructive and healthy way', P150), with some participants endorsing that 'it would be beneficial not to suffer so much in the end... in case it doesn't work' (P252). Two other themes reflected PCUFT could help patients make more informed and timely decisions about their treatment plan and process, including available future options ('If I would have been braced for the reality, I would have done things differently', P175) and manage realistic expectations about their treatment journey and its outcome. A minority of participants endorsed two other themes reflecting PCUFT



**Table 4.** Themes relating to perceived benefits (n = 213) and barriers (n = 163) of receiving psychosocial care for unsuccessful fertility treatment (PCUFT).

Theme, description (n, %)	Illustrative quotes
<b>Perceived benefits</b>	
<b>Better cope with unsuccessful treatment (n = 136, 64%):</b> help patients feel more equipped to cope with unsuccessful treatment (in particular with difficult loss-related emotions: frustration, sadness, guilt, helplessness), with many adding it would reduce the emotional impact (n = 41).	'(.) being able to prepare ourselves in the best way for its occurrence, physically and psychologically' (P27); 'Having information and tools that would allow me to accept this possibility in a constructive and healthy way' (P150); '(.) I think we should have faith and hope that everything will be fine but at the same time be prepared in case it doesn't work and doesn't look like the world has fallen on top of us (.)' (P252).
<b>Make more informed and timely decisions (n = 55, 26%):</b> help patients to be aware of the possibility of unsuccessful treatment and make more informed decisions about their treatment plan, including all available options and future alternatives.	'(.) would be in a better position to give informed consent (.)' (P246); 'To seek other options earlier (.)' (P132); 'If I would have been braced for the reality, I would have done things differently (.) I would have elected to prioritise other things and would have made IVF for round my life if I know the facts' (P175).
<b>Help managing expectations (n = 43, 20%):</b> help patients better manage expectations about the treatment journey and its outcome in a realistic way.	'Do not set expectations that are too high or even unrealistic' (P130); 'It would help build resilience and keep a reality check on how challenging treatment is and how low the success rates can be' (P160); 'Not having much hope not to suffer so much' (P221).
<b>Better cope with the emotional burden of treatment (n = 33, 15%):</b> patients would feel more prepared to face their treatment journey reducing the emotional burden it triggers.	'Not having to spend 15 days with uncertainty and fears' (P63); '(.) being able to cope with the stress and anxiety' (P117); 'A better mindset to going into something that will change your life' (P141).
<b>Have a safe place to discuss concerns (n = 19, 9%):</b> freely discuss and express their emotions and concerns in a safe and empathic environment, with someone and somewhere where to turn to when and if needed.	'(.) feeling supported during the process' (P56); '(.) having someone to talk to' (P96); '(.) Patients feeling they can approach and talk to the clinic when it fails rather than feeling alone' (P105); '(.) Knowing where to turn to if unsuccessful or a loss and already have a relationship with that person (.)' (P171).
<b>Perceived barriers</b>	
<b>No relevant disadvantages (n = 66, 40%):</b> perception there are no disadvantages from PCUFT (n = 53), or if any, does not outweigh the benefits (n = 13).	'I don't see a downside. I don't even consider it pessimism. I think it's putting everything on the table (.)' (P59); 'I understand it could be scary for some, but from personal experience I don't feel we were prepared properly or even at all, so don't feel there would be any disadvantages' (P105).
<b>Hinder engagement with treatment (n = 59, 36%):</b> 'crashing' patients' hope about a successful treatment outcome and preventing them from continuing treatment. Endorsed to a much lesser extent, PCUFT could be unnecessary, as, for some, treatment would succeed.	'Preparing for a negative outcome can discourage the process' (P83); 'May decide it's not worth the risk/cost but regret it later' (P97); 'Can push people too far out of the 'hopeful' feeling' (P111); 'May put people off treatment, which could otherwise may prove to be successful (.)' (P98).
<b>Triggering emotional distress (n = 48, 29%):</b> cause (unnecessary) distress or trigger difficult emotions (fears, helplessness), negatively impacting their overall wellbeing.	'Only the presence of the 'shadow' that you won't make it' (P84); 'Might cause panic and negative feelings, but they're part and parcel of fertility treatment anyway' (P109); 'anxiety, insecurity, fear' (P118).

P, participant number.

could also help them to better cope with the emotional burden of treatment (in particular, *'being able to cope with stress and anxiety'*, P117) and provide a safe space to discuss concerns (*'Patients feeling they can approach and talk to the clinic when it fails rather than feeling alone'*, P105). Regarding PCUFT barriers, the most prevalent theme reflected there were no perceived barriers or these were not relevant, as most participants *'don't see a downside (.) it's putting everything on the table'* (P59). Two other themes reflected PCUFT could hinder patients' engagement with treatment, as it *'can push people too far out of the 'hopeful' feeling'* (P111) and *'discourage the process'* (P83), and it could trigger emotional distress and impact patients' wellbeing during treatment.

Discussion

Findings from this study show that nine in 10 patients want to discuss the possibility of treatment being unsuccessful early on in their treatment pathway as part of routine care offered at clinics. Patients evaluate PCUFT as extremely beneficial and useful and consider current approaches to do so as insufficient. Patients expect PCUFT to empower them to discuss the 'bigger picture' of what treatment entails and how it fits with their overall goal of achieving parenthood, which implies considering the psychosocial implications of all possible treatment outcomes. Patients report barriers to receiving PCUFT, such as it negatively impacting their engagement with treatment or triggering negative emotions

but consider these do not outweigh expected benefits and may be minimized if PCUFT is offered according to their preferences: approached in a sensitive and hopeful way, tailored to individual circumstances, and delivered face-to-face in an individual/couple format. This reported high willingness contrasts with current provision and suggests a normative change towards routine provisions of PCUFT may be desirable.

Results show nine in every 10 patients want to receive PCUFT early in their treatment pathway. This high willingness contrasts with current provision, as only 35% of patients recalled having received PCUFT. Patients' high willingness to receive PCUFT is not dependent on their personal and treatment circumstances, nor on perceptions that treatment is unlikely to work for them. Instead, willingness reflects a positive evaluation of the value of PCUFT and careful consideration of its pros and cons, with perceived benefits outweighing anticipated adverse effects. These findings were consistently observed across patients' responses to theory-informed (HBM, TPB) quantitative and open-ended (qualitative) questions. Participants listed and endorsed multiple perceived benefits of engaging in PCFUT, from enabling them to better cope with unsuccessful treatment, if it happens, make more informed decisions during treatment, better manage expectations, and have a safe place to discuss concerns. A smaller proportion of participants named disadvantages in engaging in PCUFT, namely lessening their optimism towards treatment and triggering anxiety, with many stressing they did not

consider these outweighed the benefits. These results align with existing evidence showing patients value all types of information, including about adverse outcomes, and are willing to discuss these from the start of treatment (Peddie et al., 2005; Dancet et al., 2010; Harrison et al., 2021). The fact that many patients are willing to receive PCUFT from different fertility staff, and not uniquely from a mental-health professional, supports the conceptualization of PCUFT within holistic biopsychosocial and patient-centred models of care and indicates it should be delivered as part of routine psychosocial care by all staff who have direct contact with patients (Gameiro et al., 2015).

Patients also expressed a clear agenda about what PCUFT should address to achieve its perceived benefits. Such an agenda shows patients want to discuss the 'bigger picture' of treatment and how it fits with their overall goal of achieving parenthood. Responses suggest that a purely medical discussion of treatment is insufficient and that patients need to consider the psychological and existential implications of all possible treatment outcomes, so they can consider and attribute personal meaning to the different pathways they choose in the pursuit of parenthood, which is not limited to treatment (Leone et al., 2017). Such an approach has been reported as conducive to better adjustment in the case of treatment being unsuccessful (Gameiro and Finnigan, 2017).

PCUFT was perceived as an opportunity to discuss this 'bigger picture' of treatment, seen as essential to manage expectations, make decisions, and cope with treatment and its potential failure in a hopeful way. This is consistent with motivational theories highlighting that hopeful outlooks are not only achievable by focusing on 'desired' outcomes but also by fostering perceived agency to cope with 'undesired' outcomes (Snyder, 2002). This alternative view of being (or remaining) optimistic in the face of negative outcomes is also visible in research showing many patients arrive at clinics already planning to do multiple cycles (da Silva et al., 2020). Participants want to discuss such plans prior to starting treatment (Harrison et al., 2021, 2022), and alternative options different from doing more cycles, such as ending treatment or pursuing alternative parenthood paths (in the study's sample, 49% considered adoption), which can at times be the most congruent choice with patients' personal values (Peddie et al., 2004). Indeed, qualitative research suggests that fostering optimism only by focusing on achieving pregnancy (i.e. 'desired' outcome) or withholding information to protect patients can hinder their ability to sustain or reframe hope when pregnancy is not achieved (Peddie et al., 2005). It can even intensify decisional conflict around ending treatment in patients who saw themselves as open to a childfree lifestyle prior to engaging with it (Carson et al., 2021). Considering these findings and the significant proportion of patients who do not achieve pregnancy, even with multiple treatment cycles, it is crucial to gain a better balance between attention paid to 'desired' and 'undesired' outcomes to better ease patients' adjustment towards both possibilities.

Most patients favoured receiving PCUFT even though they agreed it might reduce their engagement with treatment or trigger negative emotions. Difficult discussions are common in healthcare settings, but patients seem resilient to have these, for instance, even about challenging topics such as end-of-life care. Even in this extreme context, acknowledging the likelihood and planning for adverse outcomes contributes to positive perceptions of care and better wellbeing (Leung et al., 2012; Brighton and Bristowe, 2016). While these data should reassure HCPs that they are meeting patients' preferences when approaching 'undesired'

outcomes, it is important to consider how to make these discussions easier for everyone involved. From the patients' perspective, such discussion should happen in a private and safe setting and be approached in a sensitive manner that considers their individual circumstances. Patients prefer to have face-to-face discussions that include their partners (when there is one) but are open to use self-help educational resources. Progressive approaches that empower patients to engage with the possibility of treatment not working at their own readiness and pace are seen as helpful (Rowbottom et al., 2022). Our results show that of crucial importance is that such discussions empower patients to sustain a hopeful outlook towards their future by building confidence that, as most patients who go through fertility treatment do (Gameiro and Finnigan, 2017), they can cope with any (desired or undesired) outcome. In what concerns a possible negative outcome, this can be achieved by providing information about normative grief reactions and long-term (positive) adjustment, addressing concerns and misconceptions, and providing coping resources and support contacts, all of which should empower patients to be flexible about alternative plans ('Plan B').

Delivering PCUFT according to patients' preferences can be challenging for HCPs. Therefore, it is relevant to know that there are evidence-based recommendations for approaching difficult discussions with patients, many of which provide step-by-step guidance to ensure interactions are positive and patient-centred. Examples are the SPIKES framework (i.e. a six-step protocol) for sharing bad news in fertility care (Leone et al., 2017; Mosconi et al., 2021) and fertility-specific empathic skills training (García et al., 2013). It is also relevant to be aware that patients refer to specific circumstances when PCUFT is particularly needed, namely when facing bad prognosis, emotional distress, and when patients anticipate acceptance will be harder. Patients who start treatment exhibiting higher levels of anxiety and depression, inflexibility or lack of acceptance of a childfree lifestyle, and poor social support are at higher risk for maladjustment and may therefore benefit more from PCUFT (Verhaak et al., 2010).

Another issue for professional discretion is when to offer PCUFT. Based on our results, we propose that, prior to treatment engagement, all patients should be offered the opportunity to discuss the possibility of treatment not working at that time or when they feel prepared. For those patients who decide on a multiple-cycle treatment plan before starting treatment (Harrison et al., 2022), emphasis on PCUFT should increase as they approach the end of that plan without a pregnancy. Some have suggested elsewhere that integrating multiple-cycle panning with PCUFT could help prevent decisional conflict about ending treatment (Harrison et al., 2022). Furthermore, HCPs should be aware that around two in 10 patients only feel prepared to receive PCUFT after one unsuccessful cycle or at later stages of treatment, as these patients might have more serious concerns about PCUFT impacting their engagement with treatment (Sousa-Leite et al., 2022). Finally, around one in 10 patients do not want to engage in PCUFT, which should be respected. The most supportive way to do this is to make oneself available to engage in this discussion if patients change their minds and offer resources they can choose to engage (or not) at their own time and pace (Leone et al., 2017; Mosconi et al., 2021).

Future work should aim to better understand what would make PCUFT acceptable and feasible to be implemented at clinics and focus on developing resources to support fertility patients and all staff in this endeavour. While psychologists and counsellors are better equipped to deliver PCUFT, 53% of patients in the study sample would feel comfortable doing it with their

consultant (with 15% stating they would only do it with them). Some resources are already available, for instance, as part of the MyJourney support tool (for patients: [www.myjourney.pt/patients](http://www.myjourney.pt/patients), for clinics: [www.myjourney.pt/clinics](http://www.myjourney.pt/clinics)) or offered by charities (e.g. Fertility Network UK developed a package for UK clinics). Future work should progress to evaluate the feasibility and efficacy of these tools in promoting adjustment during and after treatment.

## Strengths and limitations

This study is novel and targets an unaddressed need. It is theory-driven and patient-centred. The convenience sample of self-selected patients limits generalization of findings to the whole patient population. In particular, the sample is more representative of well-educated women interested in treatment-related issues (Benedict et al., 2019; Sousa-Leite et al., 2019; Harrison et al., 2021). Although research indicates men tend to follow their female partner's preferences, the overrepresentation of female participants limits conclusions about men's willingness to receive PCUFT (da Silva et al., 2020). The group of participants not willing to receive PCUFT was also small, which reduced power to detect weak correlations. Future replication should use more robust designs, for instance, discrete choice experiments. This study investigated willingness to receive PCUFT, which does not necessarily equate to behaviour (meta-synthesis indicate moderate associations (0.44–0.47)) (Armitage and Conner, 2001).

## Conclusion

Findings reveal that patients want to have discussions with HCPs about the possibility of treatment not working for them, even when they think such discussions are challenging. Findings suggest a normative change is needed so that PCUFT is offered as part of routine care provided by all fertility staff. Future work should focus on supporting staff in this endeavour by further investigating what would make PCUFT acceptable and feasible and developing and evaluating support tools for staff and patients.

## Supplementary data

Supplementary data are available at *Human Reproduction* online.

## Data availability

The data underlying this article will be shared on reasonable request to the corresponding author. The study survey questions (English, Portuguese) are available in OSF at <https://osf.io/mjdacf/>.

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## Authors' roles

All authors contributed to the conception and design of the study, contributed to the analysis and interpretation of the data, and reviewed and approved the final version of the report. S.G. and M.S.-L. executed the study and drafted all versions of the manuscript.

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## Conflict of interest

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## References

- Ajzen I. From intentions to actions: a theory of planned behavior. In: Kuhl J, Beckmann J (eds). *Action Control: From Cognition to Behavior*. Heidelberg: Springer, 1985, 11–39.
- Ajzen I. *TPB Questionnaire Construction*. 2006. <https://people.umass.edu/ajzen/pdf/tpb.measurement.pdf> (December 2022, date last accessed).
- Armitage CJ, Conner M. Efficacy of the theory of planned behaviour: a meta-analytic review. *Br J Soc Psychol* 2001;**40**:471–499.
- Benedict C, Hahn AL, Diefenbach MA, Ford JS. Recruitment via social media: advantages and potential biases. *Digit Health* 2019;**5**:1–11.
- Berg Brigham K, Cadier B, Chevreul K. The diversity of regulation and public financing of IVF in Europe and its impact on utilization. *Hum Reprod* 2013;**28**:666–675.
- Bernat JL. Ethical aspects of determining and communicating prognosis in critical care. *Neurocrit Care* 2004;**1**:107–117.
- Boivin J. A review of psychosocial interventions in infertility. *Soc Sci Med* 2003;**57**:2325–2341.
- Boivin J, Bunting L, Koert E, Ieng UC, Verhaak C. Perceived challenges of working in a fertility clinic: a qualitative analysis of work stressors and difficulties working with patients. *Hum Reprod* 2017;**32**:403–408.
- Boulton M, Boudioni M, Mossman J, Moynihan C, Leydon G, Ramirez A. 'Dividing the desolation': clients views on the benefits of a cancer counselling service. *Psychooncology* 2001;**10**:124–136.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101.
- Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016;**92**:466–470.
- Burns HL. Exit counseling. *Int Congress Ser* 2004;**1266**:264–269.
- Carson A, Webster F, Polzer J, Bamford S. The power of potential: assisted reproduction and the counterstories of women who discontinue fertility treatment. *Soc Sci Med* 2021;**282**:114153.
- Clayton JM, Butow PN, Arnold RM, Tattersall MH. Fostering coping and nurturing hope when discussing the future with terminally ill cancer patients and their caregivers. *Cancer* 2005;**103**:1965–1975.
- da Silva SM, Place JM, Boivin J, Gameiro S. Failure after fertility treatment: regulation strategies when facing a blocked parenthood goal. *Hum Fertil (Camb)* 2020;**23**:179–185.

- Dancet EAF, Nelen WLD, Sermeus W, De Leeuw L, Kremer JAM, D'Hooghe TM. The patients' perspective on fertility care: a systematic review. *Hum Reprod Update* 2010;**16**:467–487.
- Daniluk JC. Reconstructing their lives: a longitudinal, qualitative analysis of the transition to biological childlessness for infertile couples. *J Couns Dev* 2001;**79**:439–449.
- Devroe J, Peeraer K, D'Hooghe TM, Boivin J, Laenen A, Vriens J, Dancet EAF. Great expectations of IVF patients: the role of gender, dispositional optimism and shared IVF prognoses. *Hum Reprod* 2022;**37**:997–1006.
- Ethics Committee of the American Society for Reproductive Medicine. Fertility treatment when the prognosis is very poor or futile: an Ethics Committee opinion. *Fertil Steril* 2019;**111**:659–663.
- Paul F, Erdfelder E, Lang AG, Buchner A. G\*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behav Res Methods* 2007;**39**:175–191.
- Fedele F, Caputo A, Cordella B, Muzii L, Pietrangeli D, Aragona C, Langher V. What about fertility staff emotions? An explorative analysis of healthcare professionals' subjective perspective. *Eur J Psychol* 2020;**16**:619–638.
- Gameiro S, Boivin J, Dancet E, de Klerk C, Emery M, Lewis-Jones C, Thorn P, Van den Broeck U, Venetis C, Verhaak CM et al. ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction—a guide for fertility staff. *Hum Reprod* 2015;**30**:2476–2485. 2015
- Gameiro S, Finnigan A. Long-term adjustment to unmet parenthood goals following ART: a systematic review and meta-analysis. *Hum Reprod Update* 2017;**23**:322–337.
- García D, Bautista O, Venereo L, Coll O, Vassena R, Vernaev V. Training in empathic skills improves the patient-physician relationship during the first consultation in a fertility clinic. *Fertil Steril* 2013;**99**:1413–1418.e1.
- Ghinea N, Wiersma M, Newson AJ, Walby C, Norman RJ, Lipworth W. Situating commercialization of assisted reproduction in its socio-political context: a critical interpretive synthesis. *Hum Reprod Open* 2022;**2022**:hoac052.
- Harrison C, Boivin J, Gameiro S. Talking about possible IVF/ICSI failure and need for multiple cycles in treatment planning: qualitative investigation of multi-cycle planning and its acceptability to patients and staff. *Hum Reprod* 2022;**37**:488–498.
- Harrison C, Gameiro S, Boivin J. Patient willingness, preferences and decision-making about planning for three complete cycles of IVF/ICSI treatment. *Hum Reprod* 2021;**36**:1339–1352.
- Leone D, Menichetti J, Barusi L, Chelo E, Costa M, De Lauretis L, Ferraretti AP, Livi C, Luehwink A, Tomasi G et al. Breaking bad news in assisted reproductive technology: a proposal for guidelines. *Reprod Health* 2017;**14**:87.
- Leung JM, Udris EM, Uman J, Au DH. The effect of end-of-life discussions on perceived quality of care and health status among patients with COPD. *Chest* 2012;**142**:128–133.
- Liefbroer AC. Changes in family size intentions across young adulthood: a life-course perspective. *Eur J Popul* 2009;**25**:363–386.
- McEachan RRC, Conner M, Taylor NJ, Lawton RJ. Prospective prediction of health-related behaviours with the theory of planned behaviour: a meta-analysis. *Health Psychol Rev* 2011;**5**:97–144.
- McLernon DJ, Maheshwari A, Lee AJ, Bhattacharya S. Cumulative live birth rates after one or more complete cycles of IVF: a population-based study of linked cycle data from 178,898 women. *Hum Reprod* 2016a;**31**:572–581.
- McLernon DJ, Steyerberg EW, Te Velde ER, Lee AJ, Bhattacharya S. Predicting the chances of a live birth after one or more complete cycles of in vitro fertilisation: population based study of linked cycle data from 113 873 women. *Br Med J* 2016b;**355**:i5735.
- Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA* 2001;**286**:3007–3014.
- Michel DM, Moss AH. Communicating prognosis in the dialysis consent process: a patient-centered, guideline-supported approach. *Adv Chronic Kidney Dis* 2005;**12**:196–201.
- Miron-Shatz T, Holzer H, Revel A, Weissman A, Tarashandegan D, Hurwitz A, Gal M, Ben-Chetrit A, Weintraub A, Ravhon A et al. 'Luckily, I don't believe in statistics': survey of women's understanding of chance of success with futile fertility treatments. *Reprod Biomed Online* 2021;**42**:463–470.
- Mosconi L, Crescioli G, Vannacci A, Ravalci C. Communication of diagnosis of infertility: a systematic review. *Front Psychol* 2021;**12**:615699.
- National Institute for Health and Care Excellence (NICE). *Fertility Problems: Assessment and Treatment*. London, UK: NICE Guideline CG156, 2017.
- Peddie VL, van Teijlingen E, Bhattacharya S. Ending in-vitro fertilization: women's perception's of decision making. *Hum Fertil (Camb)* 2004;**7**:31–37.
- Peddie VL, van Teijlingen E, Bhattacharya S. A qualitative study of women's decision-making at the end of IVF treatment. *Hum Reprod* 2005;**20**:1944–1951.
- Pedro J, Brandao T, Schmidt L, Costa ME, Martins MV. What do people know about fertility? A systematic review on fertility awareness and its associated factors. *Ups J Med Sci* 2018;**123**:71–81.
- Rosenstock IM. The health belief model and preventive health behavior. *Health Educ Monogr* 1974;**2**:354–386.
- Rauprich O, Berns E, Vollmann J. Information provision and decision-making in assisted reproduction treatment: results from a survey in Germany. *Hum Reprod* 2011;**26**:2382–2391.
- Rowbottom B, Galhardo A, Donovan E, Gameiro S. Feasibility randomized controlled trial of a self-guided online intervention to promote psychosocial adjustment to unmet parenthood goals. *Hum Reprod* 2022;**37**:2412–2425.
- Sharma A, Minh Duc NT, Luu Lam Thang T, Nam NH, Ng SJ, Abbas KS, Huy NT, Marusic A, Paul CL, Kwok J et al. A consensus-based checklist for reporting of survey studies (CROSS). *J Gen Intern Med* 2021;**36**:3179–3187.
- Snyder CR. Hope theory: rainbows in the mind. *Psychol Inq* 2002;**13**:249–275.
- Sousa-Leite M, Fernandes M, Reis S, Costa R, Figueiredo B, Gameiro S. Feasibility and acceptability of psychosocial care for unsuccessful fertility treatment. *Health Expect* 2022;**25**:2902–2913.
- Sousa-Leite M, Figueiredo B, Ter Keurst A, Boivin J, Gameiro S. Women's attitudes and beliefs about using fertility preservation to prevent age-related fertility decline—a two-year follow-up. *Patient Educ Couns* 2019;**102**:1695–1702.
- Su T-J, Chen Y-C. Transforming hope: the lived experience of infertile women who terminated treatment after in vitro fertilization failure. *J Nurs Res* 2006;**14**:46–54.
- Ter Keurst A, Boivin J, Gameiro S. Women's intentions to use fertility preservation to prevent age-related fertility decline. *Reprod Biomed Online* 2016;**32**:121–131.
- Thomas R, Daly M, Perryman B, Stockton D. Forewarned is forearmed – benefits of preparatory information on video cassette for patients receiving chemotherapy or radiotherapy – a randomised controlled trial. *Eur J Cancer* 2000;**36**:1536–1543.



- Verhaak CM, Smeenk MJ, Evers AWM, Kremer JAM, Kraaijmaat FW, Braat DDM. Women's emotional adjustment to IVF: a systematic review of 25 years of research. *Hum Reprod Update* 2007;**13**:27–36.
- Verhaak CM, Lintsen AM, Evers AW, Braat DD. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. *Hum Reprod* 2010;**25**:1234–1240.
- Volgsten H, Svanberg AS, Olsson P. Unresolved grief in women and men in Sweden three years after undergoing unsuccessful in vitro fertilization treatment. *Acta Obstet Gynecol Scand* 2010;**89**: 1290–1297.
- Waller A, Forshaw K, Bryant J, Mair S. Interventions for preparing patients for chemotherapy and radiotherapy: a systematic review. *Support Care Cancer* 2014;**22**:2297–2308.
- Wischmann T, Thorn P. When ART fails: figures, experiences, interventions and a plea for the 'plan B'. *J Assist Reprod Genet* 2022;**39**: 195–199.