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- 1 Patient experiences of fertility clinic closure during the COVID-19 pandemic: Appraisals, coping
- 2 and emotions

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- 4 Running title: Coping with fertility COVID-19 clinic closure
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17	Abstract
18	Study Question
19	What are appraisals, coping strategies and emotional reactions to COVID-19 fertility clinic closures?
20	Summary Answer
21	Clinic closure was appraised as stressful due to uncertainty and threat to the attainability of the
22	parenthood goal but patients were able to cope using strategies that fit the uncertainty of the
23	situation.
24	What is known already
25	Psychological research on COVID-19 suggests people are more anxious than historical norms and
26	moderately to extremely upset about COVID-19 fertility treatment cancellation.
27	Study design, size, duration.
28	Cross-sectional design. Mixed-methods, English, anonymous, online survey posted from April 09 to
29	April 21 to social media. Eligibility criteria was being affected by COVID-19 fertility clinic closure, 18
30	years of age or older and able to complete survey in English. In total 946 people clicked on the
31	survey link, 76 did not consent, 420 started but did not complete survey, and 450 completed (48%
32	completion, 446 women, 4 men).
33	Participants / materials, setting, methods
34	Overall 74.7% (n=336) were residents in the UK with average age was 33.6 years (SD=4.4) and
35	average years trying 3.5 years (SD=2.22). The survey comprised quantitative questions about
36	intensity of appraisal and emotions, and ability to cope with clinic closure. Open-text questions
37	covered understanding of COVID-19 and its effect on reproductive health and fertility plans,
38	concerns and perceived benefits of clinic closure, and knowledge about closure. Sociodemographic
39	information was collected. Descriptive and inferential statistics were used on quantitative data.
40	Thematic qualitative analysis (inductive coding) was performed on the textual data from each
41	question. Deductive coding grouped themes from each question into meta-themes related to
42	cognitive stress and coping theory.
43	Main results and the role of chance
44	Most patients (82.2%, n=367) had tests or treatments postponed, with these being self (41.6%,
45	n=186) or publicly (46.8%, 209) funded. Patients appraised fertility clinic closure as having potential

Most patients (82.2%, n=367) had tests or treatments postponed, with these being self (41.6%, n=186) or publicly (46.8%, 209) funded. Patients appraised fertility clinic closure as having potential for a more negative than positive impact on their lives, and to be very or extremely uncontrollable and stressful (p ≤ .001). Most reported a slight to moderate ability to cope with closure (11.9% not at all able). Data saturation was achieved with all open-text questions with 33 broad themes identified and four meta-themes linked to components of the cognitive stress and coping theory. First, participants understood clinic closure was precautionary due to unknown effects of COVID-19 but

) [some felt clinic closure was unfair relative to advice about getting pregnant given to the public.
52	Second, closure was appraised as a threat to attainability of the parenthood goal largely due to
53	uncertainty of the situation (e.g., re-opening, effect of delay) and intensification of pre-existing
54	hardships of fertility problems (e.g., long time waiting for treatment, history of failed treatment).
55	Third, closure taxed personal coping resources but most were able to cope using thought-
56	management (e.g., distraction, focusing on positives), getting mentally and physically fit for next
57	treatments, strengthening their social network, and keeping up-to-date. Finally, participants
58	reported more negative than positive emotions (p \leq .001) and almost all participants reported stress,
59	worry and frustration at the situation, some expressed anger and resentment at the unfairness of
50	the situation, and a minority reported intense feelings of hopelessness and deteriorating wellbeing
51	and mental health.
52	Limitations, reasons for caution
53	The survey captures reactions at a specific point in time, during lockdown before clinics announced
54	re-opening. Participants were self-selected (e.g., UK residents, women, 48% starting but not
65	completing the survey) which may affect generalisability.
66	Wider implications of the findings
57	Fertility stakeholders (e.g., clinics, patient support groups, regulators, professional societies) need to
58	work together to address great uncertainty from COVID-19. This goal can be met proactively by
59	setting up transparent processes for COVID-19 eventualities and signposting to information and
70	coping resources. Future psychological research priorities should be on identifying patients at risk of
71	distress with standardised measures and developing digital technologies appropriate for realities of
72	fertility care under COVID-19.
73	Study funding / competing interests
74	University funded research. Outside of submitted work Professor Boivin reports personal fees from
75	Merck KGaA , Merck AB, Theramex, Ferring Pharmaceuticals A/S, grants from Merck Serono Ltd,
76	outside the submitted work and that she is co-developer of Fertility Quality of Life (FertiQoL) and
77	MediEmo app. Outside of submitted work Dr. Mathur reports personal or consultancy fees from
78	Manchester Fertility, Gedeon Richter, Ferring and Merck. Outside of submitted work Dr. Gameiro
79	reports consultancy fees from Ferring Pharmaceuticals A/S and grants from Merck Serono Ltd.

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Introduction

The COVID-19 pandemic caused fertility clinic closures worldwide. More than a million cycles of fertility treatment are typically performed every year with many patients affected by unexpected clinic closure (Adamson et al. 2018). Guidance about COVID-19 emerged mid-March from professional societies (e.g., European Society for Human Embryology, America Society for Reproductive Medicine, British Fertility Society, ESHRE, ASRM, BFS, respectively) with often abrupt closures following. In the UK, the government regulator (HFEA) issued direction to end all treatments by mid-April (with some exceptions for cancer patients) which meant that patients could not access treatment and, depending on timing, cycles in progress were abandoned or converted to freeze all. Although clinics are re-opening worldwide, much uncertainty remains for patients about how fertility services will resume, the prioritisation of waitlists, or potential re-closure for "second wave" COVID-19. A vaccine is not expected for some time though some are promising. Professional societies have jointly affirmed the importance of fertility care and principles to guide how it could be delivered safely (Veiga et al. 2020). Given this uncertainty, the distress it can cause, and numbers potentially affected, the aim of the present study was to gather data about patient experiences of COVID-19 fertility clinic closures to inform on present and future needs of patients.

According to stress and coping theory, imbalance between appraisal of a threat and ability to cope with it is what leads to stress reactions (Lazarus & Folkman, 1984). People facing disasters generally experience more stress than usual, but remarkably most cope and recover, with some eventually seeing benefits from the situation (e.g., personal strength) (Pfefferbaum & North, 2020). Research to date on experiences of COVID-19 in the general population indicates more anxiety and depression among respondents than historical norms (online survey, Nelson, 2020), worry about becoming mentally unwell due to uncertainty and loss of control but nevertheless able to use coping efforts to manage the situation (online survey, Cowan et al. 2020). Factors associated with better mental health include receiving up-to-date information about the outbreak and lack of pre-existing health problems (online surveys, Cowan, 2020, Wang et al, 2020). To our knowledge peer-reviewed research on COVID-19 appraisals and emotions in infertile populations has not yet been published but a survey at an American centre posted that 85% of patients (n=253) were moderately to extremely upset about treatment cancellation and only a third supported a cancellation policy (Turocy et al. 2020, unpublished).

To have a more in-depth understanding of patient experiences the present study used an online mixed method survey (quantitative-qualitative) to collect data on experiences of COVID-19 fertility clinic closures.

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Methods

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121 Participants

Eligibility criteria were being a patient affected by fertility clinic closure, 18 years of age or older and ability to respond in English. In total 946 people clicked on the survey link, 76 did not consent, 420 started but did not complete the survey, and 450 completed (all female except 4 men). Power calculations were not performed due to uncertainty of any quantitative effects. Table 1 shows the demographic characteristics of the final sample.

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[insert Table 1 about here]

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Materials

The quantitative-qualitative English, anonymous, online survey was created using Qualtrics (Qualtrics, Provo UT). Quantitative questions were from the daily record-keeping form (Boivin & Lancastle, 2010) which was designed from cognitive stress and coping theory (Lazarus and Folkman, 1984; Peacock & Wong, 1990). Five single appraisal items asked whether clinic closure could have a positive or negative impact for the person (primary appraisal), was controllable or stressful, and whether the person had the resources to cope with the situation (secondary appraisal). A further eight single items asked about intensity of emotional reactions associated with threat (nervous, worried), harm (sad, discouraged), challenge (positive, hopeful) and benefit (relieved, happy). The appraisals and emotions were rated on a five-point response scale (1 not at all to 5 extremely) where higher scores indicated more of the attribute. The response scale differed from the original four-point response scale in Boivin and Lancastle (2010) and we used only 8 of the 16 DRK items. Due to using single items reliability could not be computed. Open text questions (without character limits) asked participants to indicate, in their own words, their understanding of COVID-19 and its reproductive impact, perceptions of closure (i.e., who decided, when clinics would re-open, desired information), its impact on fertility plans, fears and concerns related to closure, ways of coping with closure, and any perceived benefits from the closure. Background information was collected (e.g., gender, age, relationship status, financial risk due to COVID-19 and fertility status, treatment funding). The School of Psychology, Cardiff University provided study ethical review and approval.

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Procedure

A draft survey was generated and submitted to our professional and patient group collaborators (British Fertility Society, Fertility Network UK, British Infertility Counselling Association). Comments were integrated and the revised draft uploaded to Qualtrics and distributed. Webmasters at five charities and social influencers in the fertility domain were contacted to help distribute the survey via social media from April 09 to 21, 2020. Two webmasters could not distribute due to full social media schedules and prioritising their own surveys. Upon clicking the survey link an information and consent form was presented. There was no time limit on survey completion, but interrupted surveys had to be completed within one week of last input. At the end of the survey participants were thanked, debriefed and provided with links to support resources.

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Data analysis

Descriptive and inferential statistics were used on quantitative data. A within-subject analysis of variance (ANOVA) was used to compare appraisals and emotions rated by the same person. Significant main effects were followed-up with Bonferroni adjusted paired t-tests. Qualitative analysis was used on textual data according to the method of Braun and Clarke (2006) with first steps being familiarisation with data, inductive coding (attaching meaningful labels to textual data segments) and reviewing coding with colleagues. Coding was carried out until no new codes (variation in data) were identified (i.e., data saturation reached). Codes were then organized into themes that captured a recurrent more abstracted idea present in the data. Meta-themes according to stress and coping theory (Lazarus & Folkman, 1984) were then deduced from themes occurring across questions. Given the rapid response nature of the survey JB, CH and SG were all first coders and code reviewers on at least one question. Authors came together multiple times across the coding process for peer debriefing, to reflect, discuss, review, and name the themes emerging from the data. Themes were cross-checked against the extracts of data. Textual data analysis was presented as a summary accompanied by a thematic map and illustrative verbatim quotations. Within illustrative quotations the use of [...] indicated part of the quotation was not presented because it was not relevant whereas (text) indicated additional text was added for clarity (i.e., readability, comprehensibility). Grammatical errors were corrected. Participant number was indicated with P.

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Results

Sample fertility characteristics

182 Table 2 shows fertility and treatment characteristics for the sample. For the majority (> 80%) the 183 clinic was closed at the time of the survey and treatments or testing postponed. 184 185 [insert Table 2 about here] 186 187 Experiences of fertility clinic closures 188 Inductive coding revealed 33 themes for the open-text questions. Figure 1 shows the meta-thematic 189 map relating themes generated across questions to the four main components of the cognitive 190 stress and coping theory. According to theory, people first appraise an event (i.e., closure) as having 191 the potential of threatening wellbeing, and then appraise whether they have the resources to cope 192 with stressor. Imbalance between these appraisals can trigger diverse stress reactions 193 (psychological, physical, behavioural). Supplementary Table 1 shows main and meta-themes with 194 illustrative quotes, and Supplementary Tables 2 to 7 shows coding for each question. 195 196 [insert Figure 1] 197 198 I. Experience and appreciation of uncertainty in COVID-19 and context for fertility clinic closure 199 200 The context of clinic closure was understood to be precautionary and due to uncertain effects of 201 COVID-19 on fertility, pregnancy and baby health, government guidance to stop non-essential 202 treatments, and health service staffing issues (e.g., redeployment). Among those responding 203 (n=399), patients understood the decision to close clinics involved the government or its regulator 204 (hereafter "government", 64.7%, n=258), professional societies (20.1%, n=80), clinics (15.8%, n=63), 205 the health service (6.5%, n = 26), with a proportion being unsure (11.5%, n = 46). At the time of the 206 survey, recollection was that no details ("nothing") was provided about re-opening. 207 208 The nature of evidence used to express views on COVID-19 effects varied in quantity-and source (see 209 Supplementary Table 1). Participants were in agreement regarding the belief that: pregnancy 210 reduced immunity to fight off COVID-19, fever or illness in early pregnancy was damaging to the 211 foetus, COVID-19 in late pregnancy could cause pre-term delivery and it would be difficult to treat 212 pregnant women (e.g., use of ventilator). In contrast, mixed agreement was expressed about risk of 213 contracting COVID-19, vertical transmission between mother and foetus, increased risk of 214 miscarriage, or affected mothers giving birth to unhealthy babies. In the few occasions fertility 215 effects were mentioned these were for an effect on sperm quality (usually due to fever).

Participants understood that clinic closure had been necessary. ["It's a necessary evil to help stop the death toll from COVID-19 rising even higher. P74"]. When asked about possible benefits of closure about half the sample reported at least one, with most referring to safety of healthcare staff and the general population, and reduced strain on healthcare services. ["Personally none, but in holistic terms there are more staff to help with the pandemic [...] P71"].

Unfairness at clinic closure was expressed for diverse reasons. First, it was perceived as discriminatory that people dependent on clinics to achieve pregnancy were treated differently than those able to do so without treatment: ["Get the clinics open. If not, start telling everyone not to conceive otherwise this is a massive breach against our human rights. P163"]. Linked to this was the view that COVID-19 could have been handled differently ["It was cruel to stop treatment halfway through and before the (regulator's) deadline. P66"] and that clinics could provide "[...] at least some treatments safely even if on a reduced scale. P243". Second, unfairness was expressed at the closure decision not being well founded ["...it felt like the decision to stop IVF treatments was based on very little evidence. P243"] or based on remote evidence ["...some arbitrary decision made by the distant international organization.... P254"]. Participants also perceived fertility services not being considered essential as unfair ["(fertility treatment) is not deemed as essential service but yet garden

centres and off license can remain open. It feels like the government don't care. P168"].

II. Negative appraisals of clinic closure

Figure 2 shows descriptive data for appraisals. The main effect of appraisal in within-subject ANOVA was significant (F(4, 1764)=1074.37, p < .001). Bonferroni adjusted paired t-tests showed all appraisals were significantly different from each other (p < .001) except for perceived negative impact and stressfulness (p = .412) which were both highest, and between positive impact and controllability (p = .082) which were both lowest.

[insert Figure 2 about here]

Textual analysis showed that clinic closure was appraised as a threat to the attainability of the parenthood goal because it meant the possible end to hopes and dreams to get pregnant (with own eggs), to become a parent, or give a child a sibling. Participants perceived missing out on their one or very last opportunity to become pregnant ("running out of time"). Delay was also appraised as a loss

that participants were processing: "It's painful to think [...] we will have gone through another year without a child. P210".

Two characteristics of the situation made threat and loss appraisals stronger. First, uncertainty overall, and especially regarding the impact of treatment delay on fertility (e.g., egg quality, lower ovarian reserve) and success rates ["By the time clinics reopen I may no longer have any eggs left at all. P14"; "my eggs will be in decline therefore reducing the success rate of IVF being successful even further". P117]. Uncertainty about personal circumstances were also expressed (e.g., reaching age limit, see Supplementary Table 1). A second situational characteristic linked to threat appraisals was closure being an additional burden on top of what patients had already experienced due to fertility problems. The sense of waiting on top of waiting was described as being an unacknowledged challenging process in fertility treatment ["[...] just feels like another setback and waiting game and you get plenty of this in the awful world of infertility. P332"; "... Infertility is cruel as it is let alone combined with COVID-19. P142"]. People also referred to accumulated past disappointments (miscarriages, treatment failures) to which COVID-19 was now added, making " ... this (clinic closure) is not easy to take. P32". When asked, some participants did see that closure could have benefits such as providing an opportunity to process difficult emotional experiences before re-starting ["[...] I can grieve my previous losses. P229", "[...] give me more time to process the grief associated with using a donor [...] P426"].

III. Coping with clinic closure is taxing

Figure 2 shows that participants reported slight to moderate ability to cope with the situation (coping significantly lower than scale mid-point, t(445)=16.03, p<.001). Coping efforts were most often directed at managing the uncertainty of waiting, the perceived threat to attainability of the parenthood goal, and perceived losses.

Textual analysis showed people mostly used thought-management strategies especially in relation to coping with uncertainty and waiting (see Supplementary Table 1). These included keeping busy (distraction coping), and focusing on the present (e.g., yoga, meditation, mindfulness), the positives (e.g., positive reappraisal coping, valuing the small things in life, reading positive stories), or what could be controlled. People also compared themselves to others (perspective taking) in worse situations ["I can't feel sorry for my situation and treatment stopping mid-cycle. I've friends who are NHS staff treating covid-19 patients, that's scarier ... Perspective is needed here. P64"] but this was

not always possible ["[...] not being able to try again feels much worse than COVID-19. P444"]. Thought avoidance and denial were also used ["I am trying not to think at all about a future I cannot control. P80"; "Denial. I try to convince myself this will be over very soon and that a 2-month delay is meaningless. P150"]. A few were accessing therapy or counselling ["I contacted the counselling service of the clinic. It is helpful to a degree to have some special time to talk about it and reflect. P134"].

A common strategy focused on getting mentally and physically ready for clinic re-opening by exercising, having a healthy diet, managing weight and taking vitamins and supplements, in order to maximise chances of success of next treatments. Giving the body a rest from the past burden of treatment was seen by some as a benefit of closure. The reverse was also true with reverting to "... using bad habits to cope. P217" being mentioned ["I fell into a slump of drinking wine, eating rubbish and not exercising, not being able to sleep [...] P281"].

Participants reported strengthening their social support network by staying close and communicating with their partner, reaching out and maintaining contact with friends and family. Many participants used social media for support ["[...] we met through the hospital support group and have continued this during covid-19 via WhatsApp groups. P411"]. These participants were reassured they were not alone and felt understood because ["[...] most others don't understand the difficulties we are experiencing. P248"]. For a minority these were spaces to express frustrations and share indignation ["I am on a number of fertility forums. We all feel the same. Victimised and robbed of our human rights [...] P28"]. Not all social contact was seen as positive: ["I cannot speak to or see via the internet any friends with young children, and I have had to block them all... P313].

Information gathering was also an important coping strategy. The ability to communicate and get updates from clinics was perceived as integral to forming accurate threat appraisals and essential to coping. Participants kept up-to-date about clinics re-opening by directly asking for updates and advice from clinics or organisations (e.g., government), by following social media, checking clinic websites, reaching out to consultants or voicing concerns to clinics. Diverse proactive clinic initiatives (e.g., personal call, Q&A sessions, webinars, clinic Facebook page for patients, dedicated line for questions) were perceived as helpful. Perceived benefits of receiving updated clinic information were mental wellbeing, preparation for treatment, and to counter social media (mis)information. Communication was sometimes perceived to be problematic. Participants were told that clinics would update regularly but updates were not posted and patients felt "left in the

dark", "left hanging", "forgotten" "dropped off with no follow-up", which was difficult ["I know it's hard for them to predict but it's just not good for any of us to have no hope! P102"]. The main information participants wanted was when clinics would re-open (even a rough estimate) and prioritisation of the waitlist. Comments suggested tailored information might be needed for subgroup of patients who were not officially on waitlist because awaiting results, using medication (e.g., ovulation induction), cross-border reproductive care, or egg donors (shortage of donors expected). Finally, some participants coped by being the providers of information, active in groups that raised awareness of their own and others' situation with professional societies and government, with variable success.

Whilst most reported coping with the situation, 11.9% (n=53) did not feel they had the resources to cope with clinic closure (reported on quantitative scale) which was reflected in textual replies that nothing was helpful and that coping in this situation was very difficult despite trying ["[...] I find my mind wanders and I start thinking about never being a mum etc. I try to focus on something else but it's very difficult. P30"]. Coping was also described as being ineffective. Paradoxically, a few participants found comfort in the idea that there was nothing they could do. ["I am aware there is nothing I can do, so there is a small amount of comfort in that [...]. P184"].

IV. Stress reactions despite coping efforts

Quantitative emotion analysis (see Figure 3) using within-subjects ANOVA showed the main effect of type of emotion was significant (F(3.00, 1332.17)=1054.57, p<.001, Greenhouse-Geiser adjusted degrees of freedom). Harm (sad, discouraged) and threat emotions (nervous, worried) were most intense compared to challenge (positive, hopeful) and benefit (relieved, happy) emotions. Post hoc tests using the Bonferroni correction revealed that all emotions were significantly different from each other (p<.000) except for nervous and discouraged, and relieved and happy. Strong emotional terms were used about clinic closure (e.g., devastated, heartbroken) and of high intensity ("through the roof P114", "shattered our world P243", "horrendous P19").

Textual analysis showed that clinic closure was taxing but manageable for most. A range of stress reactions was reported (see Supplementary Table 1). Participants referred to stress, worry and frustration about clinic closure, usually linked to strain of uncertainty ["...hate the uncertainty... P232", "not knowing ... is agonising P104"]. Uncertainty also entrained rumination with unanswerable 'what if' questions ["I have a lot of 'what if' questions, such as what if we were at a

private clinic that was still operating, what if my cycle started earlier and we could have seen treatment through etc. P26"]. Perceptions that clinic closure was unfair (see section I) were echoed in feelings of resentment (implicit, explicit) towards experiences of pregnancy and parenting in others ["[...] but then I see other people getting naturally pregnant and can't help feeling how it's so unfair and unjust. Feel angry and a deep, deep sadness. P86"]. Fewer participants expressed deeper hopelessness, sadness, depressive feelings and lack of control. A minority were starting to acknowledge they might have to come to terms with being childless ["...I won't be able to have my own children and face the feelings and emotions that go with that. P141"]. The situation occasionally caused people regret ["It's particularly hard knowing that with a different partner I probably could've had the children that I wanted when I wanted them and been happy P217"]. Those most affected referred to deterioration in mental health ["my mental health is spiralling out of control [...]. P66"] or impacts on relationship ["Fear of the strain it may put on my marriage. P290"]. Approximately half of participants could not report any personal benefits when asked, and a few felt clinic closure would require serious long-term support ["... It's [closure] just going to cause a number of people needing antidepressants, counselling and therapies perhaps lifelong. P28"]. Four participants reported suicidal ideation ["Not only this but (closure has) had huge impact on my mental health and put me into a deep depression, causing suicidal thoughts that I never experienced before in my life and never thought it can happen to me. P331"].

Finally, some people reported more physical or behavioural stress reactions: ["The extra stress put upon an already intense situation [...] I have lost weight, unable to eat correctly, feeling nauseous the majority of the time due to anxiety...P155"]. Many people reported "crying every day. P292" or not being able to "sleep very well P217", for example.

Discussion

The COVID-19 fertility clinic closure was experienced as an exceptional event but is one likely to recur, or at minimum one that will substantially change delivery of fertility care worldwide. Results show that the precautionary need for clinic closure was understood but viewed as a significant threat to the attainability of parenthood goals. Most experienced significant stress reactions as judged by the wording of textual replies, suggesting coping was not optimised, and 11% reported feeling unable to cope on a quantitative measure. Managing fertility care under COVID-19 will require processes for COVID-19 eventualities and boosting patient coping resources. These processes are likely to involve communication strategies optimised for uncertain and unpredictable situations, expectation management and a stepped approach to psychosocial support. We make

suggestions to achieve these, which we believe apply in times of closure and future operations under COVID-19 circumstances. This study was a rapid assessment at an early time during clinic closure. Future research will need to assess longer-term psychosocial adjustment to COVID-19 using standardised measures of anxiety and depression and, support development and evaluation of interventions to address emerging support needs.

Clinic closure was a devastating event that taxed coping resources of participants reporting from the UK, Europe and North America). According to stress and coping theory, accommodative strategies (e.g., distraction, acceptance, positive reappraisal) are best suited to manage unpredictable and uncontrollable situations like clinic closure (Lazarus & Folkman, 1984) as these help people modify their view of the situation rather than try to change a situation they cannot change. Accommodative strategies have been shown to be effective for non-fertility and fertility-related stressors (e.g., waiting for pregnancy tests results, Ockhuijsen et al. 2014). Participants in the present study and other COVID-19 studies (Cowan, 2020) seem to intuitively use these strategies, alongside other forms of coping such as social support for validation and information-seeking to reduce uncertainty (e.g., checking in with forums, monitoring clinic information). However, the benefits of accommodative coping were not maximised as indicated by significant stress reactions. These results suggest that boosting and optimising the accommodative coping patients already do and encouraging wider stakeholders (patient groups, professional organisations, regulators) to intervene in a way that aligns with such efforts could extend coping benefits (e.g., ability to tolerate uncertain situation, wellbeing).

One way for clinics to boost coping resources is to achieve better signposting of information and present it in a way that matches patient preferences (e.g., format, gaps in knowledge). Coping and communication strategies for uncertainty are needed because uncertainty was a modifiable situational characteristic strongly associated with appraisals of closure being a threat. In other COVID-19 studies, regular up-to-date information was perceived to be especially useful (Wang et al., 2020, Cowan, 2020). Table 3 provides recommendations for information provision according to needs and preferences expressed by participants, and ways in which uncertain information could be presented more certainly. While we suggest signposting, we are aware of the complexities of information provision in the COVID-19 context. First, is identifying who can best deliver what information. Patients were monitoring multiple sources of information (e.g., governments, regulators, health organisations, professional societies, clinics) in addition to informal sources (social media, news). In principle, the body responsible for deciding whether clinics open or not (i.e.,

government, professional society or clinic) should be responsible for announcing closures and naming the trigger event(s) by which clinics will re-open (e.g., minimum effective [R]eproduction number, maximum number of new COVID-19 cases). The government/regulator could work with patient groups and professional organisations to collate and make resources readily available. Second, is the format of information. Results suggest personal contact (e.g., personal call or email) and personalised information (e.g., clinics will open on date X and you will be seen on date Y) were especially valued. Generic information on social media and websites was also appreciated. Third, clinic re-opening is not the end of the COVID-19 impacts for patients or clinics. As part of the new normal, clinics will have to make their processes resilient for the challenges of providing fertility care under COVID-19 and be transparent to patients who will need to adapt to these new processes. Already there is discussion and guidance about clinic operations (e.g., COVID-19 screening, triage, telemedicine, micro-teams, recurring closures) and the possibility that clinic closures will recur as part of managing COVID-19 flare-ups. To minimize disappointment patients will need to be forewarned on how their treatment experience will change, and of criteria that may lead to more change, delay or even termination in treatment cycle procedures (e.g., presence of COVID-19 symptoms, regulator announcement of clinics re-closure). We illustrate here with information sources from the UK and Europe due to our familiarity with these sources (see Table 3) but information specific to each country should be provided.

[insert Table 3 about here]

The results also suggest a need to support patients develop realistic expectations of fertility care constrained by COVID19 operational requirements. One warning for patients is that creation of new knowledge takes time and patients will often need to tolerate long periods of a no-change status in clinic updates. Information providers (clinics, regulators) can ease this waiting if dates for regular updates are clearly indicated and the change/no-change status is explicitly acknowledged. Even when information is provided, it is important to forewarn patients that it is subject to review due to the constant emergence of new evidence and rapidly evolving situation. Second, is addressing perceived unfairness of clinic closure as soon as voiced. This explanation could reflect that, as collaborators to the patient's parental project, fertility staff are partly responsible for the welfare of the child, which entrains specific legal constraints and duty of care not imposed on couples achieving pregnancy without treatment (Boivin and Pennings, 1994). However, such legal constraints (e.g., closure) are applied for the shortest period of time possible to achieve safety for all. Finally, patients often want personalised information and not just information, which is an expectation that often

cannot be met. For example, most patients worried about the effects of delay on their own chance of pregnancy. Patients should be reassured that in the majority of cases a delay of six months in fertility treatment is unlikely to harm the likelihood of live birth (Romanski et al. 2020). However, caveats need to be provided in that clinics cannot be sure that for this specific patient a delay of three or four months will not make a difference.

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In considering psychosocial support, a stepped approach to care is advocated according to psychosocial guidelines for staff in fertility clinics (Gameiro et al. 2015) and suggested best practice for the COVID-19 pandemic (Pfefferbaum & North, 2020). This stepped approach starts with prevention (e.g., screening), psychoeducation and low intensity psychological support (e.g., normalising information, modelling resilience, coping boosts, links to support groups) provided to all, with personalised support for specific vulnerabilities (e.g., counselling) and formal assessment for urgent support needs such as suicidal ideation (e.g., psychiatric support) provided to those with specific needs. The results of the present study suggested the need for all levels of service and, accordingly, Table 3 shows suggestions for psychosocial support at different levels of intensity and tailored to specific needs. An important issue is how to ensure vulnerable patients in need of urgent support are identified during this period when access to care is limited. In the present survey it was only possible to direct patients to resources in the debrief due to anonymous replies. However, clinics can proactively offer psychosocial support to any patients they identify (or have identified) as being at risk for high distress (e.g., via screening using generic standardised or disease specific measures) or to patients with history of traumatic events (e.g., miscarriage) that could be retriggered by the current crisis. Having information about patients' infertility related psychosocial vulnerability is always useful but particularly during unexpected crises that are expected to tax already stretched coping resources. Clinics that do not yet have screening or mood monitoring procedures in place should consider its implementation given established feasibility and usefulness of existing methods (e.g., SCREENIVF Ockhuijsen et al. 2017 van Dongen et al. 2012, FertiQoL Koert et al. 2019).

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Due to the present cross-sectional design, the psychological experiences reported could have been multiply determined and not just due to clinic closure. Reactions could be due to patients' history of infertility which is often associated with significant distress (Gameiro et al. 2016) and not *de novo* experiences. Similarly, it is possible that some reactions were due to other correlates of COVID-19 (e.g., confinement, social isolation) and not clinic closure per se, as these too have effects on wellbeing (e.g., stress, feelings of being inadequately informed) (Brook et al. 2020, Cowan, 2020).

Finally, this survey captured experiences in the middle of the pandemic and clinic closure and therefore reflect raw experiences which may change over time. Future studies should consider including fertile controls and longitudinal designs to differentiate effects due solely to clinic closure, and to understand how people adapt psychologically, and in their fertility planning, to COVID-19 and new ways of providing fertility care. We focused on the patient but staff too are facing unprecedented challenges (e.g., major changes to work schedule, setting, responsibilities; working with highly distressed patients; deployment to frontline, etc.) in a work environment already shown to be highly demanding (Boivin et al. 2017). Internal audits to assess and provide adequate support to staff should be considered of equal priority.

Psychological research priorities in times of COVID-19 are numerous and ours follow those expressed by international groups (Holmes et al. 2020). Particularly relevant to fertility care is developing strategies for monitoring mental health so we can understand prevalence in times of COVID-19 and causal mechanisms associated with poorer mental health trajectories additional to what is already known (see reviews in Gameiro et al. 2015). Monitoring should use generic measures with clinical cut-offs to capture possible clinical need in this population. Identifying resilience factors and support technologies that can be fitted to COVID-19 demands of social distancing, avoidance of in-clinic contacts or periods of isolation is certainly critical. New digital psychological interventions being tested, especially those that can both monitor and support, are especially valued.

Strengths and Limitations

A strength was that all participants were patients affected by clinic closure. The sample was self-selected from social media websites mainly associated with patient support groups and this profile may affect generalisability. Informative comparisons across gender and country was impossible because only 4 participants were men and the 25% of non-UK respondents were from 13 countries (see Table 1). However, background characteristics were in line with UK ART data, and psychological experiences were in line with recent COVID-19 studies (Cowan, 2020) and empirical work from cognitive theory of stress and coping, all of which increases confidence in findings. Attrition was 48% (started but uncompleted surveys) which is common in online studies and could be reduced in future studies putting background questions first, providing financial incentives and asking fewer questions (Howell, 2020). The mixed methods approach allowed us to collect theory driven quantitative data while giving patients the opportunity to voice experiences in their own words (qualitative data). The sample was large and we achieved saturation in thematic analysis of all questions. The mixed approach allowed us to contextualise quantitative scores with fertility specific

factors. While we took measures to strengthen thematic analysis (code checking, consistency between coders and saturation) it was a rapid qualitative assessment and deeper analysis could reveal more marginal but important issues. We made some adaptations (number of items, response scale) to the DRK emotion scale which makes average scores not comparable with other studies using it. Finally, patients provided their own account of information provided to them, but we do not know what information was actually provided for which a separate survey would be needed. **Conclusion** COVID-19 will undoubtedly change how fertility care is delivered worldwide for the foreseeable future, and we all need to be prepared for the impact such events produce for patients, namely great uncertainty and worry about attainability of parenthood goals. Patients intuitively used coping strategies suited to unpredictable and uncontrollable situations but fertility stakeholders (clinics, patient groups, government and regulators, health services, professional societies) could bolster patient coping by working together to set up transparent processes for COVID-19 eventualities and sign-posting information and coping resources. Psychological research priorities are to develop and evaluate digital technologies appropriate for realities of fertility care in COVID-19 situation. Author contribution J Boivin, C Harrison and S Gameiro conceptualised, designed and together executed all aspects of the study, drafted the manuscript and revised the manuscript. R Mathur, G Burns, A. Pericleous-Smith contributed to the design of study materials, recruitment of participants, review of draft manuscript, and revised the manuscript, and advised (respectively) on medical aspects, patient support, and counselling. **Funding: Cardiff University** Acknowledgements: Fertility Network UK, Fertility Europe, Fertility Matters Canada and social influencers willing to post survey links on their social media. References Adamson, G.D., de Mouzon, J., Chambers, G.M., Zegers-Hochschild, F., Mansour, R., Ishihara, O., Banker, M. and Dyer, S., 2018. International Committee for Monitoring Assisted Reproductive Technology: world report on assisted reproductive technology, 2011. Fertility and sterility, 110(6), pp.1067-1080.

Boivin, J. and Lancastle, D., 2010. Medical waiting periods: imminence, emotions and coping. Women's

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Health, 6(1), pp.59-69.

- Virginia Braun & Victoria Clarke (2006) Using thematic analysis in psychology, Qualitative Research in
- 557 Psychology, 3:2, 77-101.
- Boivin, J., Bunting, L., Koert, E., ieng U, C. and Verhaak, C., 2017. Perceived challenges of working in a fertility
- clinic: a qualitative analysis of work stressors and difficulties working with patients. Human Reproduction,
- 560 32(2), pp.403-408.
- 561 Brooks SK, Webster RK, Smith LE, et al. The psychological impact of quarantine and how to reduce it: rapid
- review of the evidence. Lancet 2020; 395: 912-20.
- 563 Cowan, K. Survey results: Understanding people's concerns about the mental health impacts of the COVID-19
- pandemic. MQ: Transforming Mental Health and the Academy of Mental Sciences, April 2020. The
- Academy of Medical Sciences. http://www.acmedsci.ac.uk/COVIDmentalhealthsurveys (2020), Accessed 14
- 566 May 2020.
- de Klerk, C., Hunfeld, J. A. M., Heijnen, E. M. E. W., Eijkemans, M. J. C., Fauser, B. C. J. M., Passchier, J., &
- Macklon, N. S. (2008). Low negative affect prior to treatment is associated with a decreased chance of live
- birth from a first IVF cycle. Human Reproduction, 23(1), 112-116.
- 570 Folkman, S. and Lazarus, R.S., 1984. Stress, appraisal, and coping (pp. 150-153). New York: Springer Publishing
- 571 Company
- 572 Folkman, S. and Moskowitz, J.T., 2000. Positive affect and the other side of coping. American psychologist,
- 573 55(6), p.647.
- 574 Gameiro S, Boivin J, Dancet EAF, de Klerk C, Emery M, Lewis-Jones C, et al (2015). ESHRE Guideline: Routine
- 575 psychosocial care in infertility and medically assisted reproduction A guide for fertility staff. Hum Rep,
- 576 30(11): 2476-85.
- Gameiro, S., van den Belt-Dusebout, A.W., Smeenk, J.M., Braat, D.D., van Leeuwen, F.E. and Verhaak, C.M.,
- 578 2016. Women's adjustment trajectories during IVF and impact on mental health 11–17 years later. *Human*
- 579 *Reproduction, 31*(8), pp.1788-1798.
- 580 Gnoth, C., Godehardt, D., Godehardt, E., Frank-Herrmann, P. and Freundl, G., 2003. Time to pregnancy: results
- of the German prospective study and impact on the management of infertility. Human reproduction, 18(9),
- 582 pp.1959-1966.
- 583 Holmes EA, O'Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a
- call for action for mental health science. Lancet Psychiatry 2020; published online April 15, 2020.
- $585 \hspace{1.5cm} \text{https://doi.org/10.1016/S2215-0366(20)30168-1} \\$
- Howell B (2020). (https://www.psychstudio.com/articles/dropout/)
- Human Fertilisation & Embryology Authority (HFEA, May 2019). Fertility treatment 2017: Trends and figures.
- 588 HFEA, London, May 2019.
- Koert, E., Takefman, J. and Boivin, J., 2019. Fertility quality of life tool: update on research and practice
- considerations. Human Fertility, pp.1-13.
- Nelson, B., Pettitt, A.K., Flannery, J. and Allen, N., 2020. Psychological and Epidemiological Predictors of COVID-
- 19 Concern and Health-Related Behaviors. (uploaded https://psyarxiv.com/)

593 Peacock, E. J., & Wong, P. T. (1990). The stress appraisal measure (SAM): A multidimensional approach to 594 cognitive appraisal. Stress medicine, 6(3), 227-236. 595 Pfefferbaum, B. and North, C.S., 2020. Mental health and the Covid-19 pandemic. New England Journal of 596 Medicine. 597 Ockhuijsen, H., van den Hoogen, A., Eijkemans, M., Macklon, N. and Boivin, J., 2014. Clarifying the benefits of 598 the positive reappraisal coping intervention for women waiting for the outcome of IVF. Human 599 Reproduction, 29(12), pp.2712-2718. 600 Ockhuijsen, H.D., van Smeden, M., van den Hoogen, A. and Boivin, J., 2017. Validation study of the SCREENIVF: 601 an instrument to screen women or men on risk for emotional maladjustment before the start of a fertility 602 treatment. Fertility and sterility, 107(6), pp.1370-1379. 603 Romanski, P.A., Bortoletto, P., Rosenwaks, Z., Schattman, G.L., 2020. Delay in IVF treatment up to 180 days 604 does not affect pregnancy outcomes in women with diminished ovarian reserve, Human Reproduction, 605 deaa137, https://doi.org/10.1093/humrep/deaa137 606 Turocy, J.M., Robles, A., Hercz, D., D'Alton, M., Forman, E.J. and Williams, Z., 2020. The emotional impact of 607 the SRM Guidelines on fertility patients during the COVID-19 pandemic. medRxiv. 608 Van Dongen, A.J.C.M., Kremer, J.A.M., Van Sluisveld, N., Verhaak, C.M., Nelen, W.L., 2012. Feasibility of 609 screening patients for emotional risk factors before in vitro fertilization in daily clinical practice: a process 610 evaluation. Hum Rep, 27(12): 3493-501. 611 Veiga, A., Gianaroli, L., Ory, S., Horton, M., Feinberg, E., Penzias, A. (2020). Assisted reproduction and COVID-612 19: a joint statement of ASRM, ESHRE and IFFS, Human Reproduction Open, Volume 2020, Issue 3, 2020, 613 hoaa033, https://doi.org/10.1093/hropen/hoaa033 614 Wang, C., Pan, R., Wan, X., Tan, Y., Xu, L., Ho, C.S. and Ho, R.C., 2020. Immediate psychological responses and 615 associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the 616 general population in China. International journal of environmental research and public health, 17(5), 617 p.1729.

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Table 1

Demographic characteristics of the sample

Demographic characteristics	Total sample (N=450)
Age M (SD)	33.65 (4.37)
Gender female % (n)	99.1 (446)
Married or cohabiting % (n)	91.8 (412)
Relationship length, years M (SD)	8.76 (4.27)
Financially at risk due to COVID-19, % (n)	
Yes	10.7 (48)
No	58.6 (262)
Maybe	30.6 (137)
Country of residence % (n)	
United Kingdom	74.7 (336)
Non-UK [∞]	24.9 (112)

Note. M=mean, SD=standard deviation. $^{\infty}$ Other Countries are Australia (n=1), Canada (n=11, 2.4%), Croatia (n=23, 5.1%) Germany (n=1), Ireland (n=27, 6.0%), Israel (n=2), Norway (n=1), New Zealnd (n=1) Poland (n=3), Romania(n=5), Switzerland (n=1), The Netherlands (n=1), United States (n=34, 7.6%), Not specified (n=1).

Table 2. Fertility and treatment characteristics of the sample.

Variable	Total sample (N=450)
Have children % yes (n)	16.9 (76)
Time trying to achieve pregnancy in years M(SD)	3.54 (2.22)
Is your clinic closed? n (%)	
Yes	81.6 (367)
No	2.2 (10)
Limited service	16.2 (73)
Treatment status n (%)	
Tests/treatments postponed	82.2 (370)
Not currently undergoing tests/treatment	3.8 (17)
Tests/treatments ongoing	3.6 (16)
Other	10.4 (47)
Treatment funding n (%)	
Costs covered (i.e., national health service)	46.8 (209)
Costs partially covered	4.3 (19)
Private	41.6 (186)
Other	7.4 (33)

Note. M=mean, SD=standard deviation

Figure 1

Clinic closure strongly taxes coping process

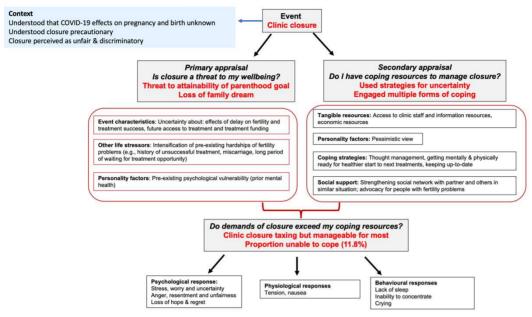


Figure 2

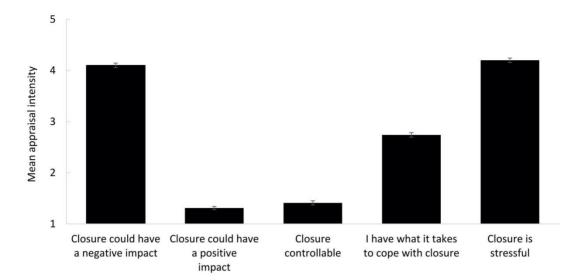


Figure 3

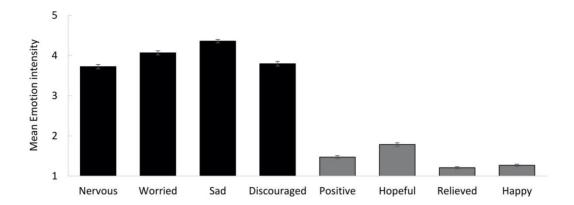


Table 3 Suggestions for provision of information and psychosocial support based on needs and preferences expressed by participants affected by clinics closure

Information resources*	Psychosocial resources
General clinic	Ensure staff are familiar with psychosocial care guidelines for fertility staff:
Centralise resources in a single webpage and keep consistency between contents here and	https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Psychosocial-care-guideline.aspx
those delivered via social media.	Proactively provide psychoeducation to manage uncertainty. Many websites exist with tips on
Actively monitor misinformation circulating about COVID-19 effects to rapidly and	coping with anxious thoughts, including those related to COVID-19 (written and audio).
unequivocally counteract it with patients.	https://www.nhs.uk/oneyou/every-mind-matters/anxiety/
Signpost patients to information subjected to regular updates, indicate dates for next update	https://www.nhs.uk/conditions/stress-anxiety-depression/moodzone-mental-wellbeing-
and explicitly acknowledge if update results in change or no-change for each topic. This may	audio-guides/
allow patients to leave aside uncertainty until the next update.	Some patients reported processing a feeling of loss over parenthood goals, for which online
Provide patients with a clear mechanism to voice their concerns (which may change as the	guidance is also available.
situation evolves). These can be addressed in information updates or support initiatives	https://fertilitynetworkuk.org/life-without-children/finding-more-to-life-self-help-guide
making it easy for clinics to identify and address common patient worries.	• Identify patients that are at risk for severe psychosocial distress and provide private and free-
Access to treatment	of cost access to fertility counselling, which can be found through national organisations.
Provide clear information about the status of the clinic and the services still accessible.	These patients too can benefit from psychoeducation about depressive symptoms and advice
Information should outline organisation of fertility treatment such as waiting lists,	about suicidal thoughts.
prioritization, change in practice, work hours, staffing. Patients can prepare in advance and	https://www.nhs.uk/conditions/stress-anxiety-depression/low-mood-and-depression/
manage their expectations of care.	https://www.nhs.uk/conditions/suicide/
Provide general information on the requirements clinics must meet for re-	https://www.bica.net
opening/operating to increase patient understanding of health and safety concerns.	• Connect people to national patient groups and those that work with specific sub-populations,
Examples from the BFS (UK) and ESHRE (Europe) are:	as well as counselling organisations. UK and European examples are:
https://www.britishfertilitysociety.org.uk/2020/05/06/arcs-and-bfs-u-k-best-practice-	https://fertilitynetworkuk.org
guidelines-for-reintroduction-of-routine-fertility-treatments-during-the-covid-19-pandemic/	http://www.fertilityeurope.eu
https://www.eshre.eu/Home/COVID19QApatients Health and safety	Note: *Model-UIZ Theresis and the consideration and the selection of the selection of
	Note. *Mainly UK illustrative examples provided but these could be substituted for national resources.
Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility, Provide trustworthy information sources about the effects of COVID-19 on fertility,	resources.
pregnancy and baby health to help patients keep up-to-date. Examples: https://cgf.cochrane.org/news/covid-19-coronavirus-disease-fertility-and-pregnancy	
https://www.rcog.org.uk/en/guidelines-research-services/guidelines/coronavirus-	
pregnancy/	
Reassure patients about medical issues (e.g., safety of stored gametes and embryos, effect of	
delay on pregnancy and success rates) keeping in mind that needs of sub-groups may be	
additional (e.g., cross-border, LGBTQ, third part reproduction).	
(og, cross soras, 2021 Q, and part reproduction).	

Supplementary Table 1 Meta-themes about fertility clinic closure emerging across questions and deduced from stress and coping theory

Meta-theme	Associated themes	Illustrative quotation
I. Experience and appreciation of uncertainty in COVID-19 and fertility clinic closure	 Clinic communications uncertain (reason and duration of closure), trigger events to re-open Information comes from variable sources and trustworthiness Unknown effects of COVID-19 on reproduction Clinic closure unfair 	Common uncertain wording used: "do not know", "unknown", "no idea", "indefinite", "not for foreseeable future", "unsure until further notice" "They tell me they don't understand the risks so can't risk getting me pregnant, yet this is contradicted with advice from chief medical officers that there is not thought to be further risks to bab.y P324" "I have no idea when treatment will start up again and if a backlog will cause further delays. I have no idea if this will mean that I don't ever have a child. P10" "Very unfair how the fertile population have not been advised to not get
II. Negative appraisal of clinic closure	 Threat to attainability of parenthood goal Delay as loss of family dream Uncertainty causes threat (e.g., effect of delay on fertility, patient prioritisation, unknown financial aspects such as fewer funded cycles, repeating costly diagnostic tests, refunds for interrupted cycles, affordability of treatment, after COVID-19 employment loss), and worry about stored gametes, access to donors, or reaching age limited for treatments History of fertility problems increase threat (i.e., long years of waiting, accumulated disappointments, putting lives on hold) Information reduces threat 	"I have felt for the first time that a natural family might not be possible for us. P80." "I cry most days that my dreams of being a family have been put on hold. P100" "I have just turned 40 my chances of IVF working could be gravely affected. It might mean I miss the window of opportunity P149" "There is going to be a high demand once clinics open again particularly NHS patients and waiting lists are very long as it isP 291" "I hope that my eggs are safe at the centre and it reassures me a bit to know I have eggs frozen but I don't know if the eggs will be safe if the centre is closed. P111" "It feels as though I've done nothing but wait throughout this whole (infertility) process. P40". Iife as "stuck", "at a standstill" or fertilty plans "pushed back" and "further from dream" of parenthood "I had really hoped to be pregnant again before the summer. P172"
III. Coping with clinic closure taxing	 Thought-management strategies for uncertainty Getting physically and mentally ready for treatment Strengthening social support network Keeping up-to-date Inability to cope (nothing helps) 	"I have been trying to practice mindfulness (acupuncture, yoga) helps me to live with stress and the emotions of fertility struggles. P424"; "I read up on a lot of positive stories helps a lot. P15"; "focusing on my work P123"; "[] having a failed cycle and trying to distract yourself and stay healthy during this pandemic is hard. P173"; "Considering what I am in control of. P5" "For me I am seeing this lockdown as an opportunity to look after myself, relax, eat well and prepare my body for my next cycle. P326",

		"Spending time with my partner. P397"; "My partner is amazing, and we deal with it together we communicate well with each other. P123", "Speaking to others online within the infertility community who understand exactly how I feel and many of whom are in the exact same position is about all that is helping me. P34", "Able to take a break for my body rather than move right into another cycle. P413" could be a benefit [] having a failed cycle and trying to distract yourself and stay healthy during this pandemic is hard. P173" "I have emailed politicians on a regular basisno replies. I have emailed (professional society) on a regular basisone very inadequate reply. I contacted a journalist who wrote an article which appeared on the front page of (national newspaper). These things helped me a bit but there's no action so hope is fading. P166" "Q&A with the clinic has been helpful. P45", "Speaking to the fertility nurse who has arranged a telephone appointment (was helpful). P90", "Webinars that are being provided by some fertility clinics and organisations have been very helpful in the past two weeks. P422", "Our clinic has been fantastic at keeping in contact including live Q and A's and zoom chats. P268"
IV. Stress reactions despite coping	 Stress, worry and frustration about uncertainty for almost all Feeling aggrieved, angry and resentment 	Extremely stressful, stressed, full of stress, building up frustration, extremely frustrated
efforts	 Deep hopelessness, sadness, depressive feelings and lack of control for some 	"Mostly I feel angry. Because we were so close. And the (regulator) have said we should have been allowed to finish. P214"].
	control for some	"Our world has collapsed and our hopes dashed. The planning and preparation
		for an anti-climax. P123"
		["dream snatched away P9"; "The light at the end of the tunnel is not there.

Note. Themes per survey questions shown in Supplementary files 2 to 7.

Supplementary Table 2 Themes identified about what patients understood were the effects of COVID-19 on fertility, pregnancy or the health of the baby (JB primary coder)

Uncertainty about effects	Undisputed possible	Disputed possible effects	Views on reason for closure	Clinic closure unfair
of COVID-19	effects			
Unsure, do not know, unknown, evidence lacking or limited, so unknown	Pregnancy reduces immunity for fighting virus	Pregnant women at higher risk (or not)	Precautionary	Pregnancy in infertile postponed but fertile people can attempt pregnancy, not told to stop trying, not advised to go on
No known or proven effects, low risk, no effects	Fever or illness dangerous in early pregnancy	Vertical transmission possible (or not)	Protect NHS (pressure on NHS, strain on NHS)	Delay could make it harder to conceive due to increased age
Many sources of evidence (clinic, government, media, social media, unspecified "they", heard about)	Pre-term labour if affected late pregnancy	Affected women give birth to unhealthy children (or not)	Clinic staff redeployed	Fertility treatment not considered essential care
Vague reference to harms	Difficult to treat in pregnancy (e.g., use of ventilator)	Increased chance of miscarriage (or not)	Doctors not able to help pregnant women	Additional stress of waiting for treatment
	Pregnant women should self-isolate Sperm quality reduced (due to fever)	Type of advice (e.g., C-sections, same as SARS) Maternal death	Lack of communication from clinic about why	Closure not based on good evidence/science
	Stress of having treatment or being pregnant during pandemic			

Supplementary Table 3: Themes identified about what patients perceived were COVID-19 effects on their fertility plans" (JB primary coder)

Reactions	Loss of dream	Closure unfair	Perceived impacts	Uncertainty about	Communication about
				future	closure
Threat emotions:	Life on hold, limbo,	Double standard (fertile	Chance of pregnancy	Unsure impact of	Understand why closure (told
Anxiety, worry, stress,	standstill, pushed back,	people not told to abstain,	will get worse	delay on fertility	why closure, explained
uncertainty, fear	can't plan, further	ART not considered	(increased age, loss of	and treatment	closure, informed government
	from dream, stuck	essential, told my fertility	funded cycles,	success	action)
		is not important)	proliferated disease,)		
Harm emotions:	Loss of hope, no light	Closure on top of	Stress, anxiety and	Unsure when clinic	Clinic supportive because
Devastating, agonising,	at the end of tunnel,	accumulated hurts of	poorer mental health	re-opens	answered calls and questions,
heart-breaking,	hope dashed, snatched	infertility (miscarriage,			reassured top of list, kept us
suicidal ideation,	away	neonatal deaths, failed			updated
hopeless, sad,		treatments)			
desolation, feelings of					
grief (dreams)					
Anger & frustration	Missed opportunity,	Long-time waiting already	Re-visiting decisions	Unsure conditions	Clinic unsupportive because
(unfair)	denied peace of having	(trying naturally, waiting	(e.g., whether to	of treatment (e.g.,	of lack of communication on
	tried all we planned	for referral, test results,	continue, stay with	longer waiting lists,	future appointments, ongoing
		waitlist)	infertile partner)	prioritisation, NHS	treatment (e.g., clomid),
			& regret (e.g., delay for	funding, shortage	guidance and support,
			exams, to prepare	of egg donors,	interpretation of worrying
			mentally)	repeating costly	test results
				tests, cost of cycles	
Intensity of feeling	May never conceive,	No chance naturally (LGBT,	Changed social media		Clinic does not care,
strong	become parent,	biologically, PGD, need	habits		insensitive postings on social
	conceive with own	donor sperm)			media, only cares about
	eggs, have second child				money, conveyor belt
		Choice taken away	Trying to be positive,		
		(blanket closure, arbitrary)	increasing fitness		

Supplementary Table 4 Themes identified about information provided and needed (JB primary coder)

Uncertainty and diversity of information	Communication styles and	Desired information	Spontaneous evaluations of	
	channels		communication	
Reasons for clinic closure diverse	Diverse communication	Estimated time/date for	Feeling neglected	
(effects of COVID-19, guidance to stop non-	channels (call, email, website,	reopening (even		
essential treatments, and staffing issues such as	social media)	provisional)		
staff being redeployed or needed elsewhere, or				
too few staff for clinic operations).				
Duration of wait before reopening uncertain	Frequency of monitoring,	Prioritisation (already	Feelings about lack of	
("they do not know", unknown, no idea,	updating, "checking-in"	known, being considered,	communication (frustrating,	
indefinite, not for foreseeable future, until	(weekly, monthly, regularly)	own personal rank)	disappointing, neglected)	
further notice)				
Trigger event for clinics to re-opening diverse	Proactivity (patient to seek	Financial issues	Resentment at perceived	
(when regulator, government, guidelines permit	information, clinic to provide)	(continuation of public	unfairness (cycles stopped or not	
reopening, safe to do so, staff returned to normal		funding, need to repeat	started, lack of transparency from	
duties, non-essential services resumed, "as soon		costly tests, higher cost of	regulator, interferring with	
as possible", or when pandemic is over)		treatment)	autonomy)	
	Preferences (personalised	Needs of specific	Communication is positive (staff	
	information, delivered when	subgroups (cross border,	doing best to inform, give	
	and how told would be	on medication, people not	reassuring information)	
	delivered)	yet on waitlist, LGBT)		

Supplementary Table 5 Themes identified about fears, concerns or difficulties experienced dur to fertility clinic closure (SG primary coder)

Delay impacts	Uncertainty of delay	Time and waiting in	Delay could impact	Health of stored	Differences between
chances of pregnancy		infertility	mental-health and	material	fertile and infertile
			partnership		people
Lower chances of	The duration of delay	Time is crucial	Concerns about	State of stored	Differential
success due to age	is uncertain		current or eventual	material during	treatment of infertile
(quantity and quality			impact on mental	closure	vs fertile people
of eggs, AMH, uterine			health and		regarding pregnancy
receptivity)			partnership		
			(stopping midway is		
			stressful)		
Lower access to	Uncertainty is	Waiting is inherent to	Stress on top of stress	Consequences of	Clinic closure unfair,
treatment due to	stressful	infertility		frozen versus fresh	not well founded
backlog of patients,				cycles	
NHS lower capacity to					
reopen)					
Lower access to	Many "what if"	Waiting on top of	Need to be in good	What happens to	Difficult to see 'fertile
funding (older	questions	waiting	place mentally and	stored material if	world' during
patients reaching age			physically when	clinic closes	pandemic and
limit)			treatment restarts	permanently	discourse around
					"corona baby boom"
Loss of		Waiting is stressful	Stress could impact		
opportunity(ies)			future treatment		
			success		
		Being in limbo			

Table 6: Themes identified about how participants tried to overcome any of the fears, concerns or difficulties experienced (SG primary coder)

Managing thoughts	Keeping healthy for	Strengthening support	Keeping up to date	Nothing is helpful for
	future treatment	network		some
Wide variety of strategies for managing unhelpful thoughts, stress and worry (distraction, focusing on present through yoga, meditation, mindfulness, focusing on positives and benefits)	Exercise for coping (especially running)	Support from close people (partner, family, friends)	Being in contact with clinics and organizations	Inability to cope
Hard not to worry	Exercise, diet, and supplements to improve chances of pregnancy with trying naturally or future treatment	From others in same situation for validation	Mixed results from communications	Denial and hopelessness
Keeping perspective	Less restrictions during lockdown Going back or starting	Protesting together and being angry together, especially at unfairness	Information and communication perceived as very helpful Being proactive	Comfort in downward comparisons (others worse off) Comfort in know clinic
	unhealthy habits			staff helping others
			Infertile neglected, and	
			badly portrayed as	
			burdening system	
			(compared to fertile)	

Supplementary Table 7 Themes identified about possible benefits to come from COVID-19 fertility clinic closure (CH primary coder)

No benefits or unfair	Benefit to public and	Chance to improve personal	Forced break from	Process and grief
	national health service	health	treatment	
No personal benefits,	Staff will remain safe	Postponing pregnancy now would	Able to take a break for	Gives more time to get
cannot see any benefits	Prevent spread of virus	avoid stress of pregnancy during a	my body rather than move	over my past treatment
		pandemic	right into another cycle	
			(e.g., break from	
			hormones).	
No benefit and unfair	Medical staff and	Would avoid COVID-19 effects on	Forced time off to reset	Can grieve previous
because fertile can try to	equipment deployed to	pregnancy or baby (if these exist)	mentally	losses.
get pregnant	other departments			
		Improving physical and mental	Save more money for	More time to process
		fitness level generally and for	treatment	grief associated with
		future treatment		using a donor.
			Maybe might get pregnant	
			without any treatment	