



Fertility Network UK survey

The impact of fertility challenges and treatment

October 2022

**Dr Nicky Payne
Associate Professor of Psychology
Middlesex University**

Contents

| | |
|---|----|
| List of Figures | 3 |
| Executive summary | 4 |
| Key findings | 4 |
| Key recommendations | 5 |
| Background | 6 |
| The project brief | 7 |
| The survey | 7 |
| Data collection | 8 |
| Findings | 8 |
| Demographic and treatment information | 9 |
| Funding for past, present or future treatment | 10 |
| Impact of fertility problems and treatment | 14 |
| Support for fertility problems and/or treatment | 18 |
| Work and treatment | 20 |
| Conclusions | 23 |
| Funding for past, present or future treatment | 23 |
| Support for fertility problems and/or treatment | 24 |
| Impact of fertility problems and treatment | 25 |
| Work and treatment | 26 |
| Key recommendations | 27 |
| References | 28 |

List of Figures

| | |
|--|----|
| Figure 1: Treatment status | 9 |
| Figure 2: Groups based on treatment status | 10 |
| Figure 3: Reasons for going abroad | 11 |
| Figure 4: Number of IVF/ICSI cycles received so far | 12 |
| Figure 5: Additional tests or treatments requiring payment | 13 |
| Figure 6: Levels of support received from significant others | 14 |
| Figure 7: Impact of fertility problems and/or treatment on relationships | 15 |
| Figure 8: Worries about treatment | 16 |
| Figure 9: The psychological impacts of fertility problems and/or treatment | 17 |
| Figure 10: When counselling and support were sought | 19 |
| Figure 11: Lifestyle changes made | 20 |
| Figure 12: Reasons for non-disclosure to their employer | 22 |
| Figure 13: Methods used to manage time off work | 23 |

Executive Summary

Fertility challenges and the use of assisted conception are increasing. Yet access to funded treatment and associated supports, such as counselling, is often limited, so the financial impacts of treatment are problematic for many people. Combining the demands of employment and treatment may also be problematic, especially as pre-conception care is not a statutory right, so formal guidance and policies to support people having treatment is still lacking in many workplaces. Overall, fertility problems and treatment have been found to cause high levels of distress, which is of particular concern as significant distress may undermine treatment outcomes and adjustment to parenting. Furthermore, the cessation of assisted conception services during the COVID19 pandemic may have impacted on subsequent access to funded treatment and associated supports, as well as escalating levels of distress.

In order to examine the impact of fertility challenges and treatment, an online survey was conducted between April and July 2022 to examine the psychological, emotional and relationship impacts of treatment, funding and support issues, and experiences of combining treatment and work. The same survey was conducted in 2016.

The survey received 1,279 responses. Respondents were mainly white (93%), women (98%) in a heterosexual relationship (90%). The average current age of respondents was 36.6 years and the average age when they started treatment was 33.7 years, and they had on average been trying to conceive for 4.1 years. 69% were living in England, 18% in Scotland, 7% in Wales and 6% in Northern Ireland.

Key findings

- 63% of respondents paid for at least part of their treatment (9% more than in the 2016 survey)
- Respondents spent on average £13,750 on investigations and treatment (compared to £11,378 in the 2016 survey). 12% spent more than £30,000 and in a few cases (0.5%) over £100,000
- 83% of respondents felt sad, frustrated and worried often or all the time as a result of fertility problems and/or treatment, 47% experienced feelings of depression often or all the time, and 10% experienced suicidal feelings often or all the time. However, a further 30% reported suicidal feelings sometimes or occasionally, so in total 40% experienced suicidal feelings.
- 59% reported some detrimental impact of fertility problems and/or treatment on the relationship with their partner (11% less than in the 2016 survey) and in a few cases (2%) the relationship ended, but 89% of partners provided a great deal of support.
- 51% received counselling (7% more than in the 2016 survey), but 59% of these had to fund some of it themselves, and yet 78% would like to have counselling if it was free.
- 27% attended a support group (10% more than in the 2016 survey), yet 47% of those who did not attend would like to have attended had there

- been one nearby. 44% sought support from Fertility Network UK (16% more than in the 2016 survey).
- 75% felt their GP did not provide sufficient information about fertility problems and treatment and 7% were not sure, so only 18% were satisfied with what was provided (8% less than in the 2016 survey).
 - 58% felt concerned that treatment would affect their career prospects (8% more than in the 2016 survey), 36% felt their career was damaged as a result of treatment, and 15% either reduced their hours or left their job.
 - 77% disclosed to their employer but only 47% of these said that reasonable adjustments were made, only 45% felt they received really good support from their employer and only 25% reported the existence of supportive workplace policy (and 19% were not sure whether there was policy).

While there were increases in the number of respondents receiving counselling, attending a support group, and seeking support from Fertility Network UK, and a reduction in reports of relationship impacts of fertility problems and/or treatment, overall the figures have changed little since the survey in 2016, and there has been an increase in the number of respondents having to pay for at least part of their treatment. Access to NHS-funded fertility treatment and psychological support remain problematic for some respondents. Reports of distress and suicidal thoughts remain worryingly high. Additionally, while in recent years there appears to have been increasing interest from employers in supporting employees experiencing fertility challenges, the number of survey respondents reporting career concerns and lack of workplace policy and support while having fertility treatment has not reduced since 2016.

Key recommendations

- Regional differences in access to NHS-funded treatment and criteria for individual eligibility should be reconsidered.
- Work is needed to educate and inform GPs so they are more able to support patients, and care plans should be built around continuous tailored care and improved communication.
- Access to funded counselling is needed, and a whole clinic approach is advised, with all clinic staff involved in understanding client preferences regarding support and in detecting and addressing patients' behavioural, relationship, emotional and cognitive needs throughout the fertility journey.
- Access to inclusive support groups should be available from an early stage of the fertility journey, and GPs and fertility clinics could be involved in raising awareness of their existence.
- Workplace policy for fertility treatment is needed, and this should be combined with guidance to assist line managers who may have limited understanding of the support needs of employees undergoing treatment.

Background

Latest reported statistics from the HFEA show that during 2019 almost 53,000 patients had 69,000 fresh and frozen IVF cycles and 5,700 donor insemination cycles in licensed fertility clinics in the UK (HFEA, 2019). These figures have been rising for many years, so more women and men are pursuing this physically, psychologically and financially demanding journey.

Both women and men having treatment have been found to experience high levels of distress with women experiencing more distress than men (Greil et al., 2010). A Fertility Network UK survey in 2016 (Payne et al., 2021) found that respondents reported feeling on average sad, frustrated and worried almost 'all of the time', and 42% had experienced suicidal feelings at least 'occasionally'. Those most at risk of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment, who spent longer trying to conceive, who experienced some strains in the relationship with their partner, and who had less support from significant others. The cessation of treatment due to the COVID19 pandemic is likely to have exacerbated distress levels. For example, Payne et al. (2022) found that in 2020, 50% of women whose treatment was postponed or cancelled experienced clinical levels of anxiety and/or depression. A Fertility Network UK survey (2021a) supports the harmful impact of the delays to treatment caused by the pandemic. There is some evidence that distress may affect treatment outcomes (Purewal et al., 2018) and later adjustment to parenting (Sydsjo et al., 2002).

There is also some evidence that psychological intervention is associated with higher pregnancy rates (Frederiksen et al., 2015). It is a requirement that counselling is 'offered' to patients seeking fertility treatment in the UK (HFEA, 2019; NICE, 2013). However, Fertility Network UK's 2016 survey found that only 45% of respondents had received counselling, 54% of these had to fund at least some of it themselves, and yet 75% said they would like counselling if they did not have to pay for it. Additionally, only 17% of respondents had attended a support group, although 50% would like to have attended had there been one nearby, and 28% sought support from Fertility Network UK. A Fertility Network UK survey (2021a) and Payne et al. (2022) found that access to counselling and support was even more limited during the pandemic.

The financial impacts of treatment are also problematic. While NICE (2013) recommends three full cycles be offered to those eligible aged under 40 years and one full cycle to those eligible aged 40-42 years, in practice the number of cycles offered and eligibility criteria differ across the UK and frequently fall short, with, perhaps, the exception of Scotland (HFEA, 2019). Fertility Network UK's 2016 survey found that 54% of respondents were having to pay for at least some of their treatment and they spent on average £11,378, with 10% spending over £30,000.

Another problematic issue is difficulties experienced in combining treatment and work. In the UK, employees have a right to absences for pre-natal and post-natal care and the right to request flexible working, but pre-conception

care is not a statutory right, so formal guidance and policies to support people having treatment is still lacking in many workplaces. Research has found that employees having treatment have been found to experience conflict between the demands of work and the time and emotional demands of treatment. Workplace support and job flexibility were important for managing this conflict but experiences of support varied considerably, and people also had concerns about having to disclose to request support, due to fears about privacy and stigma, intrusion, and career concerns (Payne et al., in preparation; van den Akker et al., 2017).

Fertility Network UK's 2016 survey (Payne et al., 2019) found that 50% of respondents felt concerned that treatment would affect their career prospects, 33% felt their career was damaged as a result of treatment, and 19% had to reduce their work hours or quit their job. 72% disclosed to their employer but only 41% subsequently received really good support, and 23% reported the existence of supportive workplace policy. A more recent Fertility Network UK survey with Fertifa (2021b) obtained similar findings.

The project brief

Fertility Network UK commissioned Middlesex University to conduct a survey to examine the impacts of fertility challenges and treatment in order to update the survey conducted in 2016, which in turn updated a survey conducted in 1997. Specifically, Fertility Network UK hoped to gather information on:

- Emotional and psychological impacts of experiencing fertility challenges and of treatment
- How it affects relationships with partner, friends, family and colleagues
- How it impacts work and career, and how supportive employers are
- Access to counselling and other supports
- Access to NHS-funded fertility treatment

Fertility Network UK wished the survey to be applicable to a broad range of individuals including those who have fertility challenges but are not having treatment, those who have received or are currently having treatment or who are planning or awaiting treatment, and those who have completed their fertility journey, whether it has been successful or they have had to accept involuntary childlessness.

The Survey

Apart from removing a few questions to reduce the length, the survey was the same as the one used in 2016. The online survey was launched in April 2022 and ran until the end of July 2022. The survey received approval from the Middlesex University Psychology Research Ethics Committee and respondents had to select to consent to participate in order to proceed after reading information about the survey and their rights.

The survey (see Appendix) was divided into five sections:
Section 1: Demographic, fertility and treatment information

Section 2: Information about past, present or future treatment

Section 3: Support for fertility problems and/or treatment, including from friends, family, colleagues, counselling, Fertility Network UK, support groups, and lifestyle advice

Section 4: Impact of fertility problems and/or treatment, including on relationships and also psychological impacts. Psychological impacts were assessed by 19 indicators of distress, such as depression, anxiety and suicidal feelings. Responses to these 19 items were summed to form an overall measure of distress.

Section 5: Work and treatment, including the impact of treatment on work, reasons for non-disclosure, availability and use of policies and support received.

Data collection

With mass electronic distribution it is not possible to know the number of potential respondents who saw the survey link, but 1,727 respondents accessed the survey, and there were 1,279 responses to the first half of the survey (a 74% response rate), decreasing to 1,239 before questions concerning impact of fertility challenges and treatment (a 71% response rate). Additionally, 1,050 respondents who received treatment while working completed questions about combining treatment and work.

Fertility Network UK promoted the survey through social media, website and digital magazine/newsletter. It was also sent to clinics, shared with sister organisations and other professional organisations. Staff shared the survey link directly with their individual contacts, with fertility groups and with volunteers, all of whom were asked to cascade the dissemination in turn to their contacts. It was also posted on the Fertility Friends support forum.

Findings

There are some limitations to the findings that should be acknowledged and borne in mind when interpreting the results. The sample was self-selected and the response rate is unknown, so we do not know the extent to which the findings can be generalized to all people experiencing fertility challenges or having fertility treatment. The sample is limited in terms of diversity, so the views of men, same sex couples and minority ethnic groups are not sufficiently represented. Additionally, surveys rely on self-reports, which are based on subjective perceptions and recall, and may not always be accurate. Finally, as the survey was taken at a single point in time we cannot know, for example, what 'causes' distress but can only discuss associations, and comparisons made to the 2016 survey are limited by the fact that responses in 2016 were from a different group of respondents.

Demographic and treatment information

98% of respondents were women. 90% were in a heterosexual relationship (with 6% in a same sex relationship, 4% single). 69% were living in England (with 18% in Scotland, 6% in Northern Ireland and 7% in Wales). 93% were white (with 2% mixed heritage, 4% Asian and 1% black). The average current age of respondents was 36.58 years (*SD* 5.31) and the average age when they started treatment was 33.68 years (*SD* 4.43) with the oldest being 57 years of age at the start of treatment.

Respondents had on average been trying to conceive for 4.1 years (*SD* 2.7), with 67% trying for less than 5 years, 27% for 5-9 years and 6% for 10 years or more. Figure 1 shows treatment status, with respondents able to select multiple responses (e.g. a women may have experienced successful and unsuccessful treatment and miscarriage).

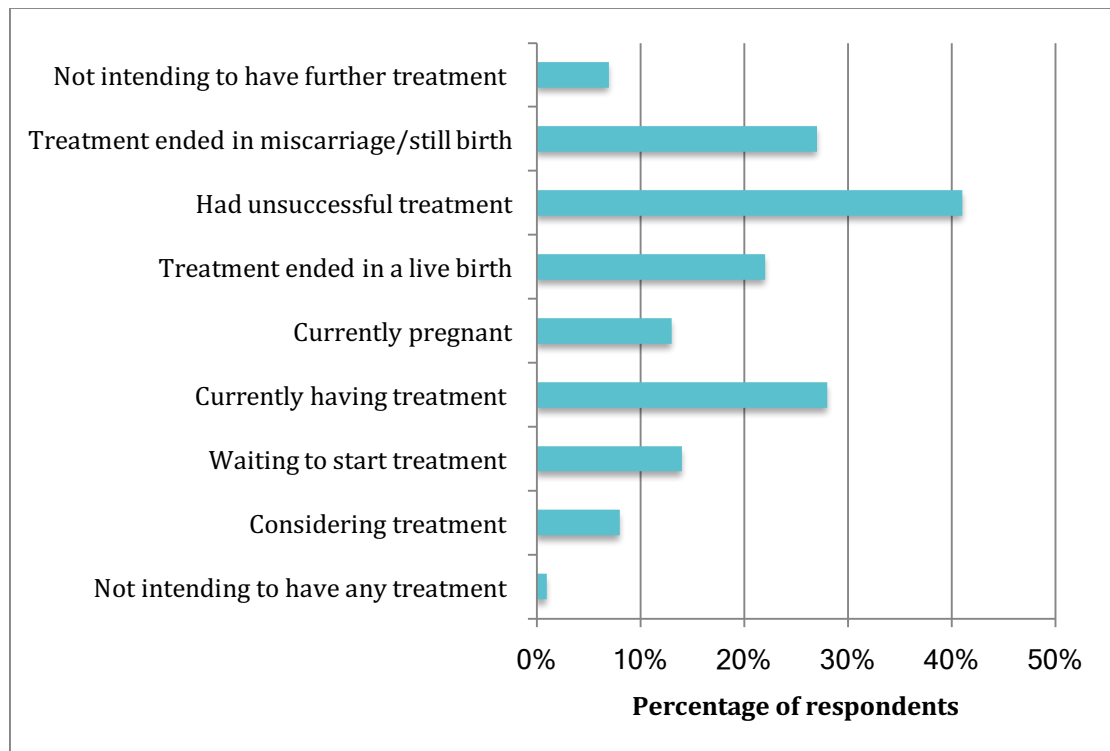


Figure 1: Treatment status

For the purpose of further analysis, respondents were also separated into five discrete groups based on their responses shown in figure 1. These five groups are shown in Figure 2. Similar levels of distress were reported by four of the five groups, with only those who had treatment ending in a live birth reporting statistically significantly lower levels of distress ($F = 8.16, p < .001$).

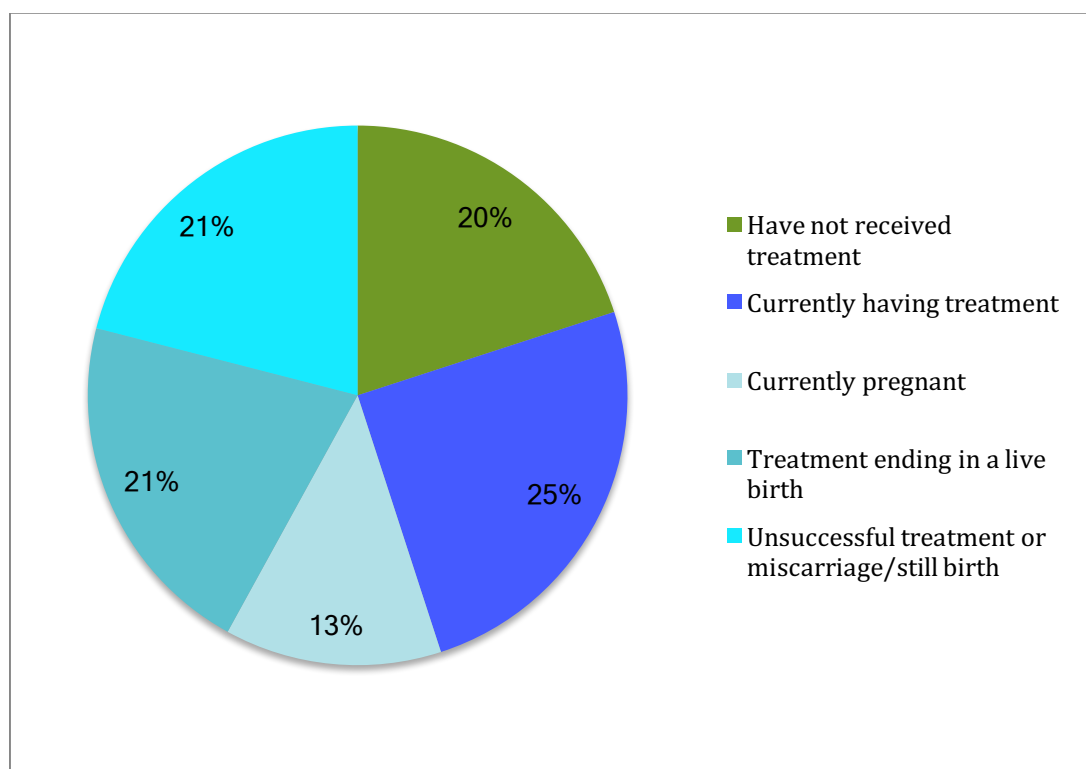


Figure 2: Groups based on treatment status¹

Of those who had or were due to begin treatment, 86% had IVF/ICSI, 13% IUI and 19% were prescribed Clomid. 10% used donor eggs, 9% donor sperm and 1% donor embryos (respondents were able to select multiple responses).

Funding for past, present or future treatment

35% of respondents had or planned to have NHS-funded treatment, 41% private treatment, 22% a mix of both and 2% were not sure yet. Thus 63% of respondents were having to pay for at least part of their treatment (9% more than in 2016).

¹ The five groups comprise the following from Figure 1: 'Have not received any treatment' comprises those not intending to have any treatment and those considering or waiting to start treatment. 'Currently having treatment' comprises those currently having treatment, some of whom had one or more previously unsuccessful outcomes. 'Currently pregnant' comprises those currently pregnant, some of whom had one or more previously unsuccessful outcomes. 'Treatment ending in a live birth' comprises those with a successful treatment outcome, some of whom also had one or more previously unsuccessful outcomes. 'Unsuccessful treatment or miscarriage/still birth' comprises those who had one or more unsuccessful outcomes and were either not intending to pursue further treatment or were undecided.

Of those who were not able to access NHS-funded treatment, 51% said they did not meet the criteria, 25% said the waiting time was too long, 8% said their area did not offer funded treatment, and 33% gave 'other' reasons (respondents were able to select multiple responses). Many of the 'other' reasons given were also related to not meeting the criteria or waiting times. The most commonly reported 'other' reasons were: BMI being too high; already having a child; partner already having a child; being too old (due to delays related to the pandemic, other delays, or their region having a lower age limit); chances of conceiving being low due for medical reasons; being in a same sex relationship or being single; and losing funding due to separating from a partner. Other reasons were delays in accessing NHS-funded treatment due to the COVID-19 pandemic, or having to wait to be referred due to not trying to conceive for long enough. Also some respondents reported not being entitled to more than one NHS-funded cycle in their region.

86% of respondents had or planned to have treatment in the UK only, 4% abroad, 6% in both and 4% were not sure yet. Key reasons for going abroad shown in figure 3 were reduced cost and waiting times (respondents were able to select multiple responses).

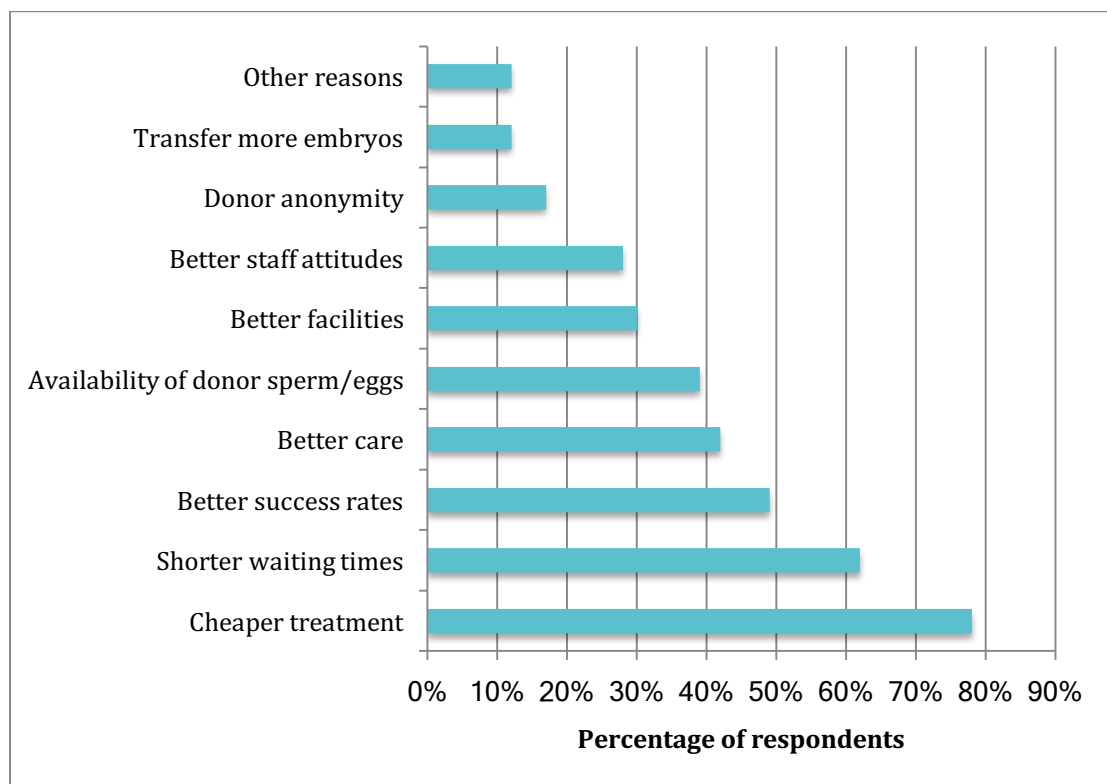


Figure 3: Reasons for going abroad

Of those who had already had IVF/ICSI, the number of cycles they received is shown in Figure 4. On average respondents had received 2.56 (*SD* 2.16) cycles of private IVF and 1.42 (*SD* .80) cycles of NHS IVF. The average total number of cycles across NHS and private was 2.54 (*SD* 2.07) with 39% of respondents receiving one cycle, 24% receiving two, 17% receiving three and 21% receiving more than three cycles. Further analysis indicated that respondents living in Northern Ireland had received on average fewer NHS-funded cycles compared to those living in Scotland ($F = 3.32, p = .02$). This was the only statistically significant difference between the nations of the UK. However, it should be noted that these are the number of cycles received at the time of completing the survey, so some respondents would be entitled to more NHS-funded cycles. Also, in addition to the full cycles reported here, some respondents also had frozen embryo transfers or IUI.

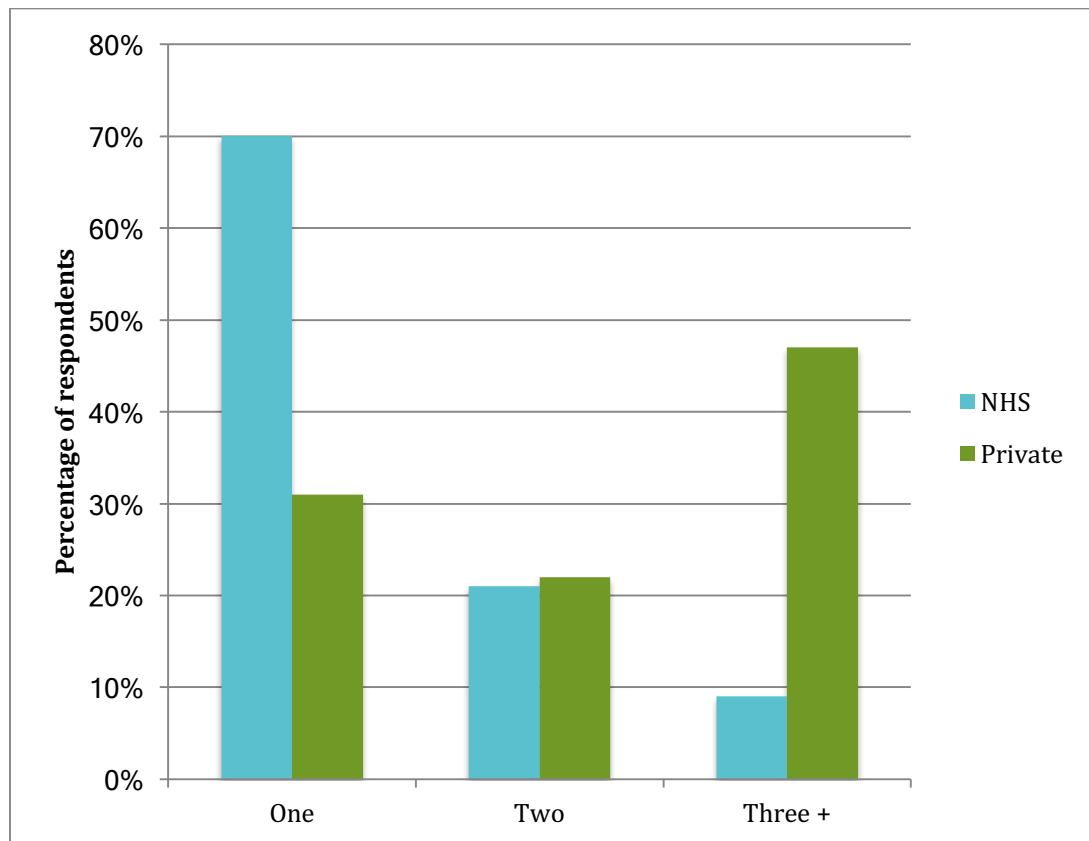


Figure 4: Number of IVF/ICSI cycles received so far

Of those who paid for additional tests or treatments 77% were requested as part of private treatment, 13% as part of NHS treatment and 10% as part of both (so 8% more than in the 2016 survey were having to pay for some tests or treatments as part of NHS-funded treatment). The main additional tests or treatments are shown in Figure 5 (respondents were able to select multiple responses).

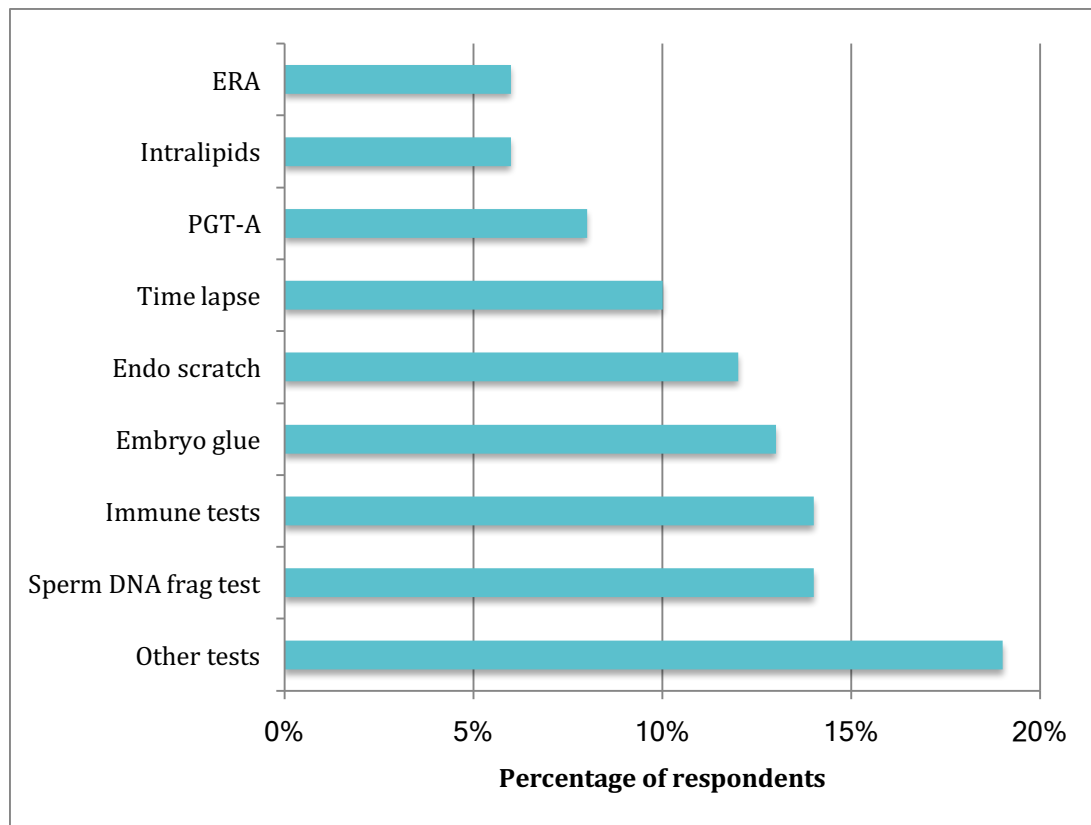


Figure 5: Additional tests or treatments requiring payment

70% of respondents had paid for investigations and treatment. They had spent on average £13,750 (SD 17,825), which is over £2,000 more than in Fertility Network UKs 2016 survey when the average was £11,378. Of these, 34% of respondents spent less than £5,000, 16% spent £5-9,000, 24% spent £10-19,000, 8% spent £20-29,000 and 12% spent more than £30,000 and in a few cases (0.5%) over £100,000.

Impact of fertility problems and treatment

92% of respondents disclosed to at least some of their friends and some of their family and 71% disclosed to at least some work colleagues. Of the people to whom they disclosed, partners provided the most support followed by family, friends and then colleagues. Levels of support are shown in figure 6. Respondents who reported 'a great deal' of support from partner, family, friends or colleagues had statistically significantly lower levels of distress than those who received only 'a bit' of support or no support (partner $F = 5.98$, $p = .003$; family $F = 11.99$, $p < .001$; friends $F = 16.96$, $p < .001$; colleagues $F = 12.96$, $p < .001$).

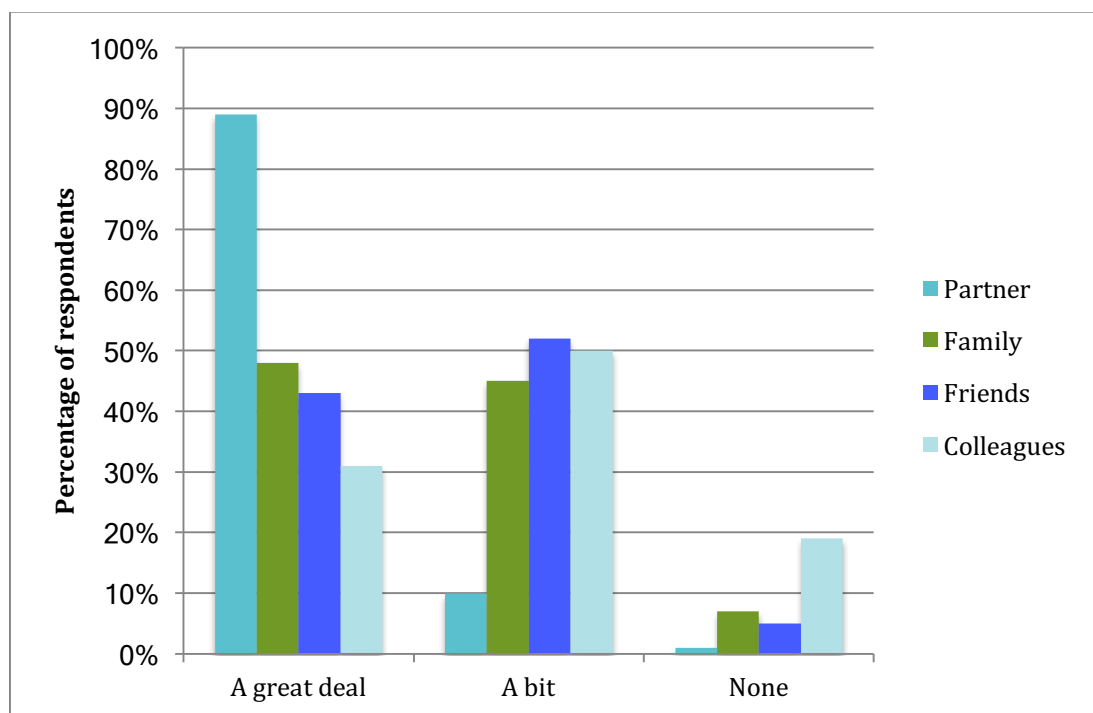


Figure 6: Levels of support received from significant others

Fertility problems and/or treatment had an impact on some relationships. Figure 7 shows that the majority of relationships with friends, family and work colleagues were unchanged or mixed, although a number of friendships ended. Relationships with a partner were also mixed but were sometimes improved as a result of the experience. For example, 39% of respondents reported their relationship with their partner was improved or unchanged, 16% said it was strained or ended, and 43% said it was strained initially or was mixed. Therefore, for 59% of respondents, fertility problems and/or treatment had some detrimental impact on their relationship with a partner (although this was 11% less than in the 2016 survey). Further analysis showed that this was associated with higher distress levels ($F = 27.94, p < .001$), such that those whose relationship was improved or unchanged experienced statistically significantly lower level of distress, whereas those whose relationship ended or was initially strained, even though it later improved, experienced statistically significantly higher levels of distress.

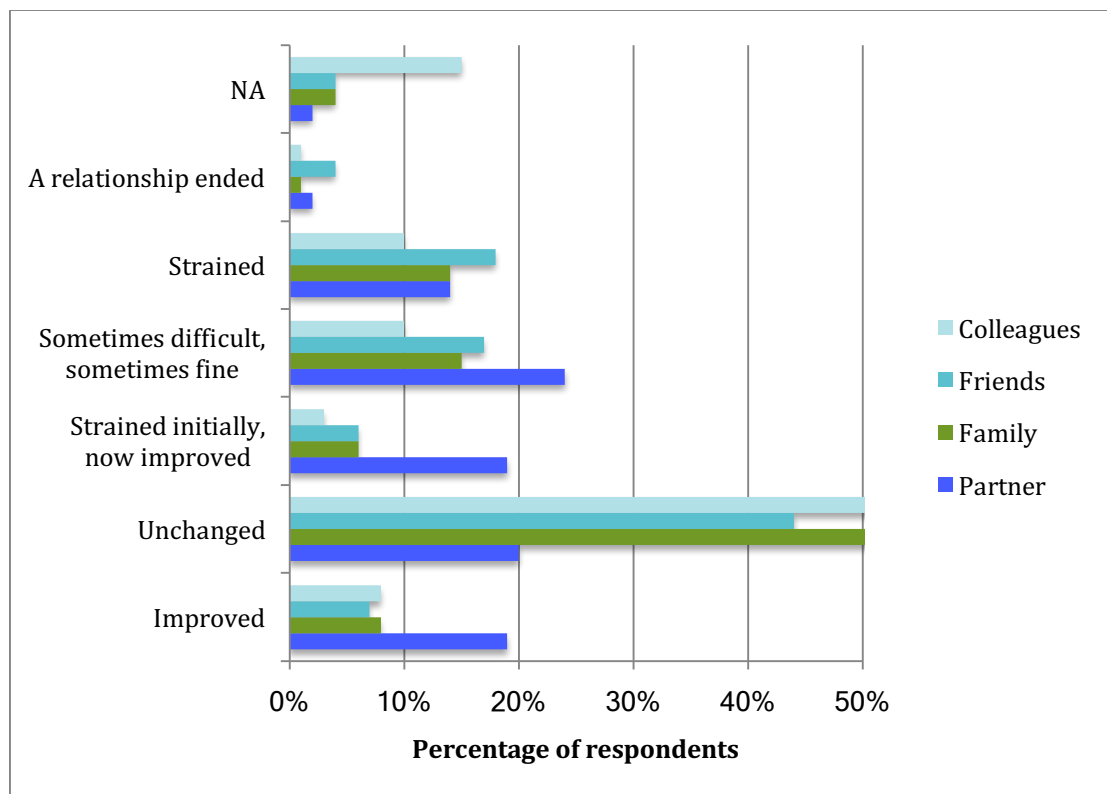


Figure 7: Impact of fertility problems and/or treatment on relationships

Key worries and the percentage of respondents reporting these are shown in Figure 8 (respondents were able to select multiple responses). Treatment uncertainty followed by impact on work, waiting times for treatment and funding for treatment were most often reported. 'Other' worries included the impact of COVID19 (e.g. the pandemic having delayed treatment or catching COVID19 delaying future treatment); fear of "failure" and childlessness; running out of time due to age; clinic competence, quality of care and communication; the impact of fertility treatment on physical and mental health and relationships; and being unable to lose weight.

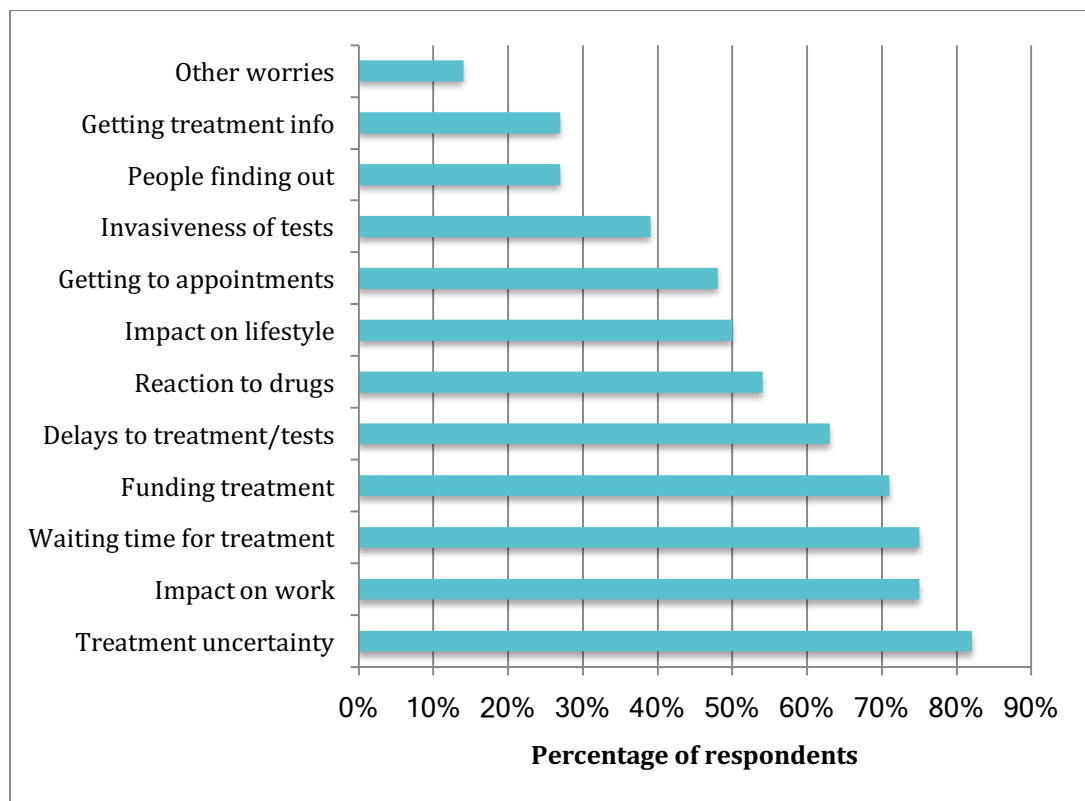


Figure 8: Worries about treatment

Figure 9 shows on average the frequency with which various psychological impacts of fertility problems and/or treatment were experienced (response options were 1 = not at all, 2 = occasionally, 3 = sometimes, 4 = often, 5 = all of the time), so a higher score means greater distress. The average score for fears and worries (4.26) means that this was experienced the most (on average 'often' experienced), whereas the average score for suicidal feelings (1.74) means this was experienced the least (on average 'occasionally' experienced). However, 83% of respondents felt sad, frustrated and worried 'often' or 'all the time' as a result of fertility problems and/or treatment, 47% experienced feelings of depression 'often' or 'all the time', and 10% experienced suicidal feelings 'often' or 'all the time'. A further 30% reported suicidal feelings 'sometimes' or 'occasionally', so in total 40% experienced suicidal feelings.

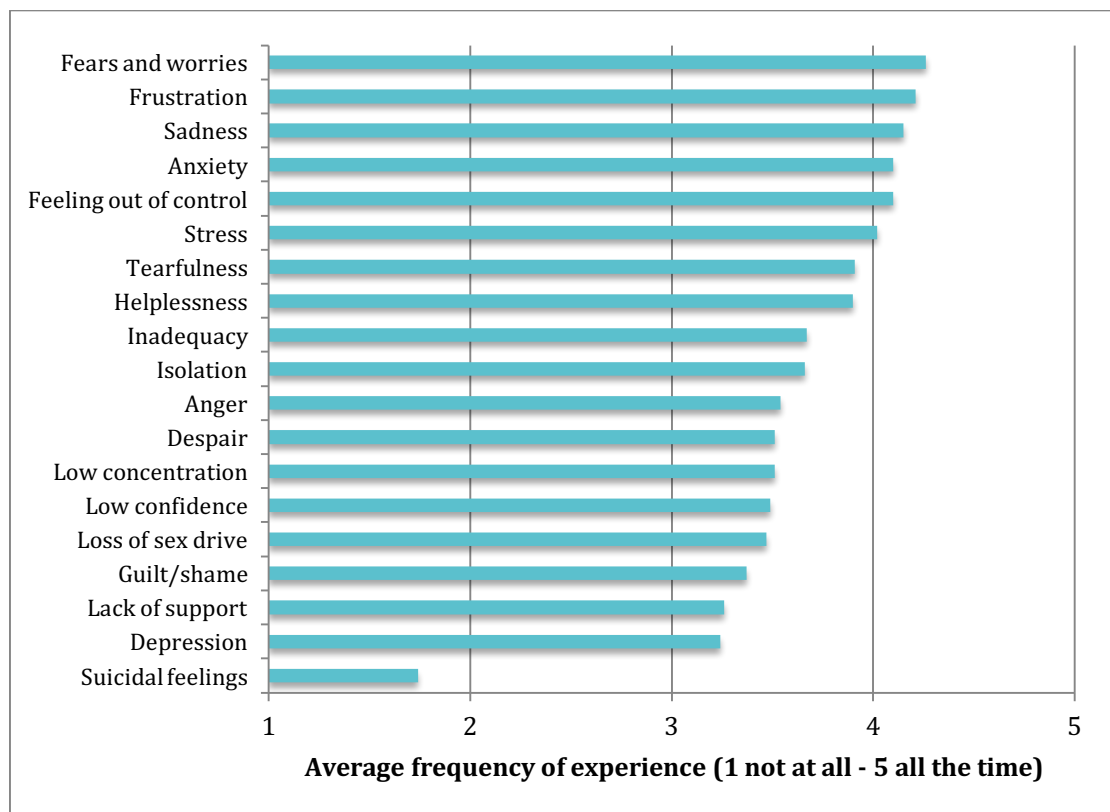


Figure 9: The psychological impacts of fertility problems and/or treatment

Support for fertility problems and/or treatment

78% of respondents reported they would like counselling if they did not have to pay for it (15% were not sure and only 7% said they would not want counselling). However, only 51% actually received counselling (although this is 7% more than in the 2016 survey). 41% of these had free NHS counselling, a further 13% had to top this up with additional private counselling and 46% had private counselling only. Thus 59% of those who received counselling had to pay for some or all of it themselves, this equates to 27% of the total sample paying for at least some counselling. 79% of those who received counselling found it helpful.

75% felt their GP did not provide sufficient information about fertility problems and treatment and 7% were not sure, so only 18% were satisfied with what was provided (8% less than in the 2016 survey). However, 68% felt they received positive help and support from their fertility specialist and clinic staff.

44% respondents sought support from Fertility Network UK (16% more than in the 2016 survey). 27% attended a support group (10% more than in the 2016 survey) but 47% of those who did not attend, would like to have attended had there been one nearby (42% were not sure and only 11% said they would not want to attend). Reasons for not attending a support group included: not feeling the need for this (reported by 26% of respondents), not having one in the local area (23%), not feeling able to open up in a group (21%) and 'other' reasons (30%). By far the most commonly reported 'other' reason was not being aware such groups existed or not knowing how to access them. Other reasons included not liking an online format; preferring other forms of support, especially those that are more anonymous; not being able to attend due to other commitments; feeling the group discussion was too negative or overwhelming; not having started treatment yet; and feeling excluded by being an LGBT couple.

Figure 10 provides details of when counselling and support were sought (respondents were able to select multiple responses).

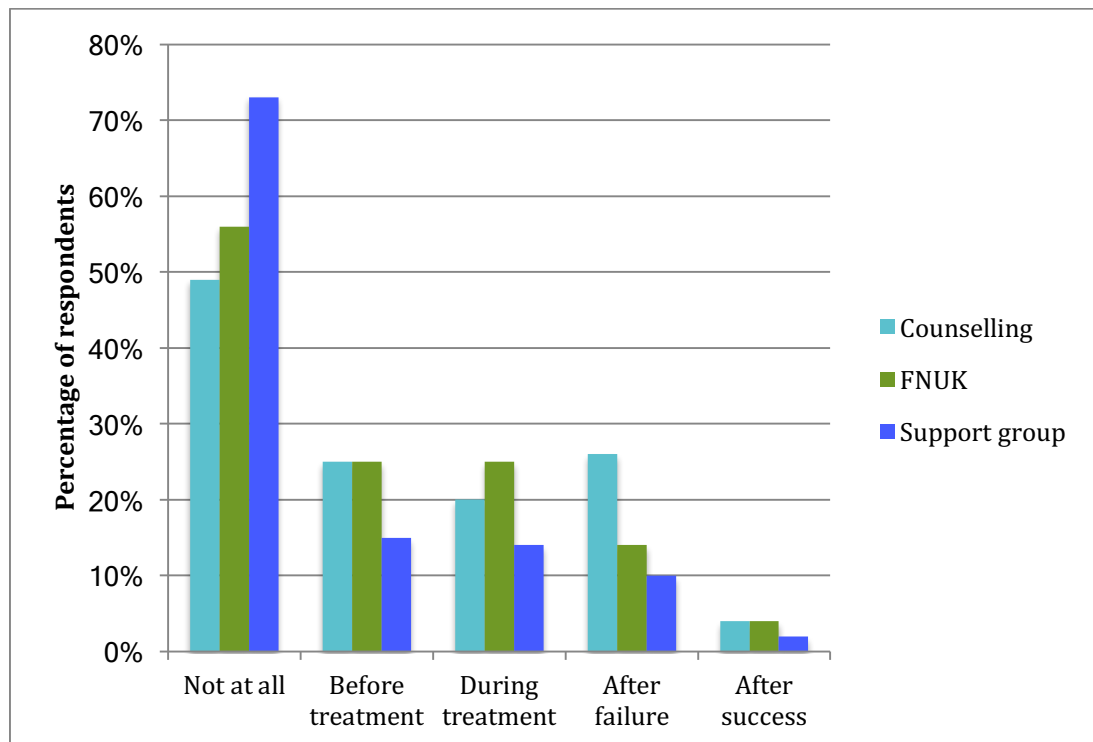


Figure 10: When counselling and support were sought

Respondents who sought counselling had statistically significantly higher overall distress levels ($F = 21.92, p < .001$) than those who did not, although there were no differences in distress levels between those who sought support from a group or from Fertility Network UK.

In addition to seeking support, 63% of respondents sought advice on changing aspects of their lifestyle (11% more than in the 2016 survey) and 93% actually made lifestyle changes. Key lifestyle changes shown in Figure 11 are dietary changes, increasing exercise and reducing caffeine and alcohol consumption (respondents were able to select multiple responses). The most commonly reported 'other' lifestyle changes were taking vitamins and supplements; having acupuncture or other alternative therapies; engaging in meditation, mindfulness or yoga; reducing exposure to toxins and chemicals in plastics, cleaning and beauty products; and changing job or work pattern.

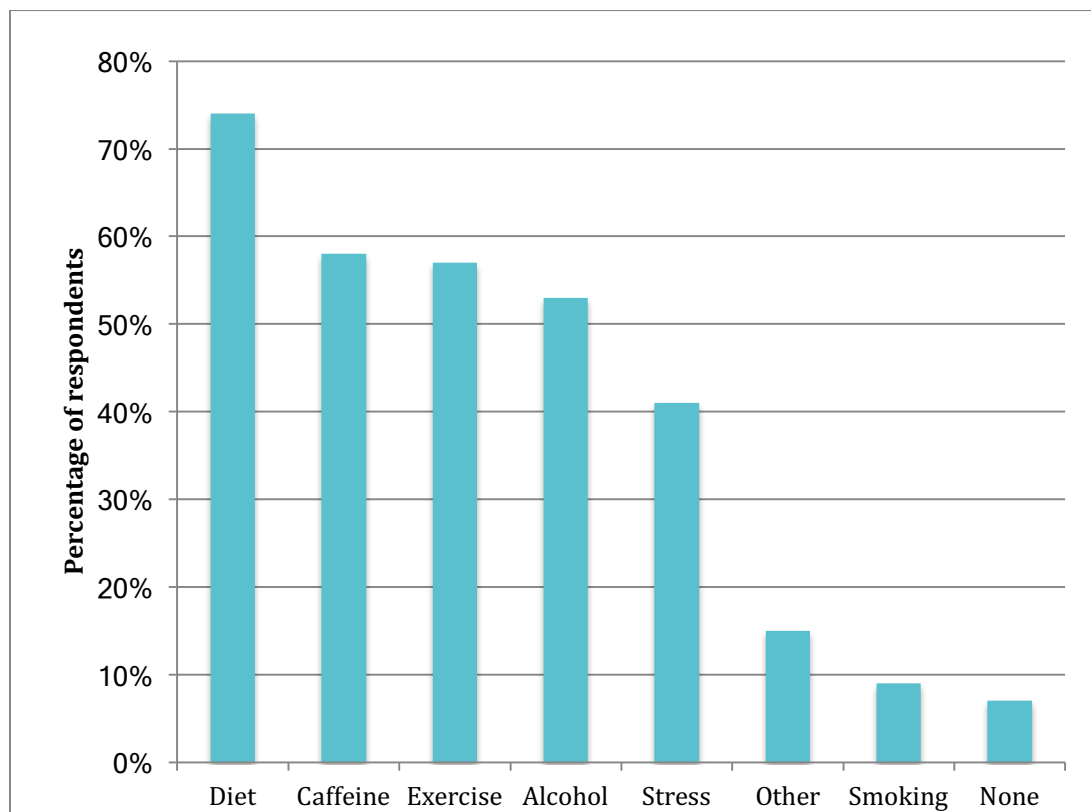


Figure 11: Lifestyle changes made

Work and treatment

Of the 1,050 respondents who received treatment while working, 80% worked full-time, 10% part-time, 5% were self-employed, and 5% left their job. Additionally, 10% reduced their hours.

51% reported work affected their treatment (e.g. it was difficult to make appointments) and 84% reported treatment affected their work (e.g. it was difficult to concentrate). 58% felt it would affect their career prospects and 36% felt it did actually affect their career. Respondents who believed work affected treatment or treatment affected work or career ('a bit' or 'a lot') had statistically significantly higher levels of distress than those who reported no

affect of work on treatment/treatment on work or career (work affected treatment $F = 44.56, p < .001$; treatment affected work $F = 7.54, p < .001$; treatment may affect career prospects $F = 23.24, p < .001$; treatment affected career $F = 21.07, p < .001$ respectively).

77% of respondents disclosed to their employer or line manager. Of those who disclosed, only 47% said reasonable adjustments were offered (examples given when the question was asked included fridge for medications, quiet space to inject, ability to take calls at the last minute from the clinic), and only 45% felt they received 'a great deal' of support from their employer (a further 45% said they received 'a bit' of support). Respondents who reported no reasonable adjustments had statistically significantly higher levels of distress than those who reported adjustments ($F = 7.40, p = .007$). Respondents who received no employer support had higher distress levels than those who reported 'a great deal' of support ($F = 3.71, p < .025$). However, there was no difference in distress between those who reported no support and 'a bit' of support, so only 'a great deal' of support seems to help.

Only 25% of respondents reported their workplace had some policy relating to treatment (19% were not sure and 56% said it did not). Respondents who reported no policy had statistically significantly higher distress levels than those who reported policy or who weren't sure if there was policy ($F = 8.25, p < .001$).

The 23% of respondents who did not disclose, reported reasons for non-disclosure shown in Figure 12, with it being a private matter being the most commonly reported reason (respondents were able to select multiple responses). 'Other' reasons included not needing to disclose due to being self-employed or working flexibly; feeling an organization or line manager was not supportive or lacked compassion; fearing intrusion and not wanting to discuss something painful, especially if treatment was unsuccessful; and a lack of fertility policy.

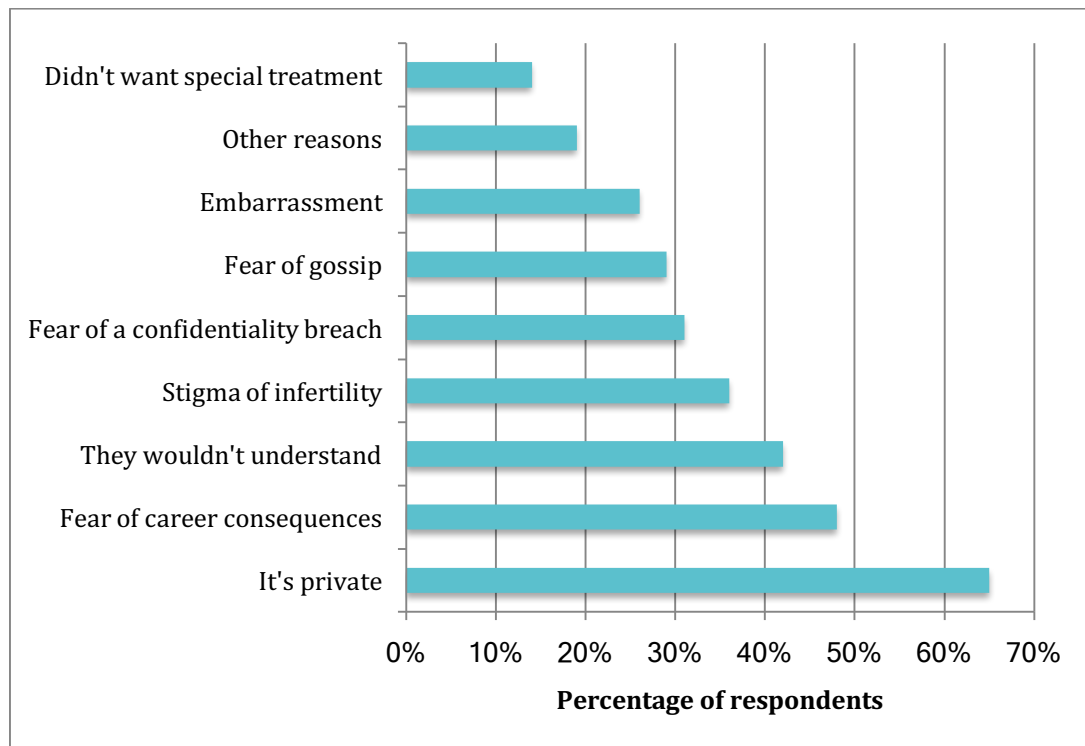


Figure 12: Reasons for non-disclosure to an employer

Time off work for treatment was managed in various ways, as shown in Figure 13, with annual leave, sick leave and informal flexible working being most commonly used (respondents were able to select multiple responses). 'Other' responses included using medical or special leave; being able to take time off anyway due to being self-employed, a company director or working from home; a supportive line manager enabling time off; and leaving a job or reducing hours.

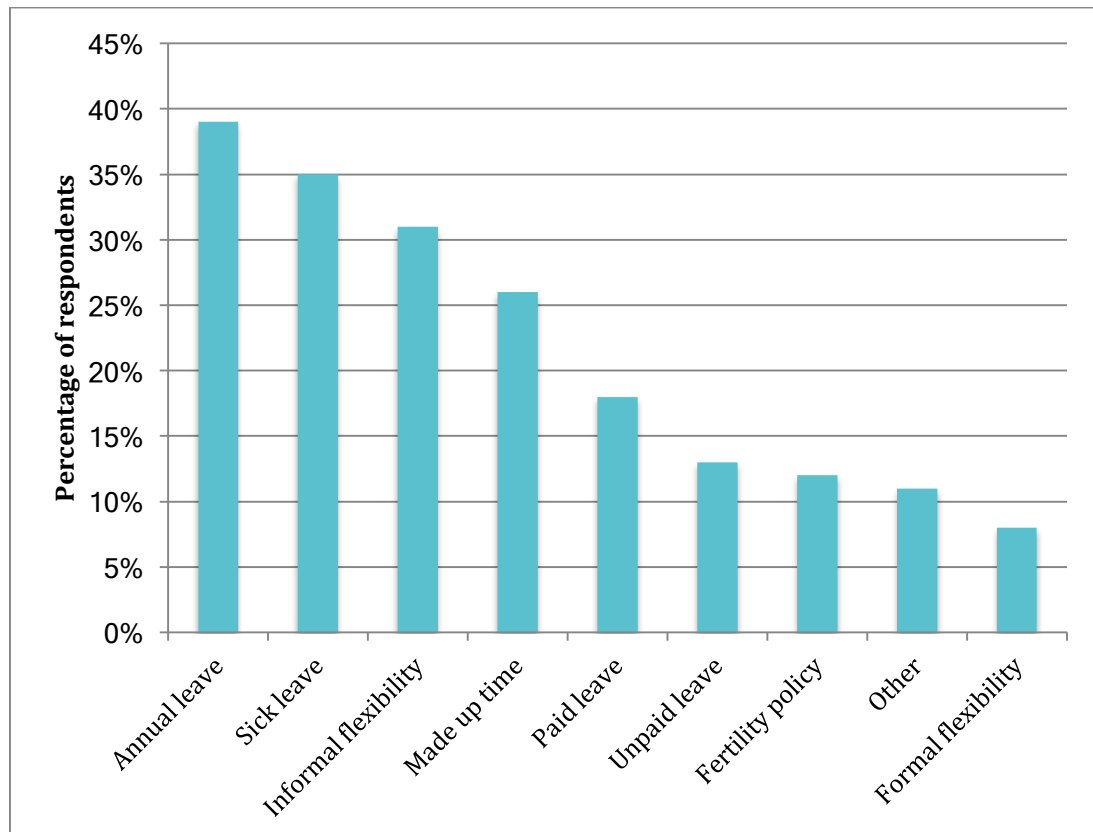


Figure 13: Methods used to manage time off work

Conclusions

Funding for past, present or future treatment

The findings suggest that lack of NHS funding is an issue, as 63% of respondents were having to pay for at least part of their treatment. This is 9% more than in Fertility Network UK's 2016 survey, suggesting the situation may have worsened. For half the respondents, not being able to access NHS-funded treatment was due to not meeting eligibility criteria, and for a quarter, it was due to waiting times. A third of respondents gave 'other' reasons. These reasons highlight that both eligibility criteria and waiting times vary across regions of the UK, and criteria are usually stricter than those recommended by NICE. Key reasons given for being denied NHS-funded treatment, which could be reconsidered in future, include already having a child/partner having

a child, such stringent body weight criteria, and the absence of a partner (for those who are single) or having a same sex partner.² Furthermore, delays to referrals or treatment, often due to the COVID19 pandemic, have led many couples to wait for years, and in some cases, until they are too old to meet eligibility criteria.

Another reason given for being denied further NHS-funded treatment was that only one treatment cycle was funded. The number of cycles offered falls short of NICE recommendations in many parts of the UK. In Scotland, Wales and Northern Ireland the level of funding is set nationally and only Scotland meets the recommendations of offering 3 full cycles to women aged under 40 years. In England funding is determined by Integrated Care Boards and some only offer one cycle. In Fertility Network UK's 2016 survey there was evidence that Scotland was funding more cycles than England and Northern Ireland. However, the only difference at the time of the current survey was between Scotland and Northern Ireland. Nevertheless, the 'postcode lottery', in terms of both number of cycles offered and eligibility criteria is an ongoing issue that needs attention.

The cost of treatment can be crippling, especially for those denied NHS treatment. Ten percent of respondents had spent more than £30,000 and in some cases (0.5%) over £100,000 on treatment. Almost a quarter of those having NHS-funded treatment still reported having to pay for some additional treatments or tests as part of NHS treatment, which is 8% more than in Fertility Network UK's 2016 survey. Although only 10% were seeking treatment outside of the UK, the top reason for doing so was reduced cost.

Support for fertility problems and/or treatment

Access to psychological support may also be an issue as only half of respondents received counselling (and 59% of these had to fund some of it themselves). Yet more than three quarters would like to have counselling if it was free. The number receiving counselling is 7% more than in Fertility Network UK's 2016 survey, suggesting some small improvements, but the number who have to fund this themselves has not reduced. 79% of those who received counselling found it helpful, emphasising the importance of psychological support. A whole clinic approach involving all staff in understanding client preferences regarding support and in detecting and addressing patients' needs would be advisable (Gameiro et al., 2015).

Just over a quarter of respondents had attended a support group, which is 7% more than in Fertility Network UK's 2016 survey, and 44% had sought support from Fertility Network UK, which is 16% more than in the 2016 survey. However nearly half would like to have attended a support group had there been one nearby. Although reasons for not attending a group reported by around a quarter of respondents were not feeling the need and not feeling able to open up in a group, the majority of the 30% of 'other' responses were

² It should be noted that single women and those in same sex relationships are also excluded from NICE guidelines unless they have first received privately funded IUI.

that they were not aware support groups existed or did not know how to access them. This suggests that increasing awareness of this form of support is crucial. Additional 'other' reasons suggest that in person groups are preferable, that these should be available at all stages of the fertility journey, and that they could be more inclusive or provide a specific offering to support LGBT couples.

Only 18% of respondents felt their GP provided sufficient information about fertility problems and treatment, which is 8% less than in Fertility Network UK's 2016 survey. Thus more work is needed to educate and inform GPs so they are more able to support their patients. Additionally, as 93% of respondents reported making lifestyle changes, GPs may also be well positioned to offer support for such changes as healthy eating and weight loss. Better communication between GPs and fertility specialists and clinics may also be helpful, as well as care focusing on both partners, including same sex couples.

Impact of fertility problems and treatment

Compared to Fertility Network UK's 2016 survey, the number of respondents experiencing negative psychological impacts of fertility problems and treatment does not appear to have changed. For example, 83% of respondents felt sad, frustrated and worried 'often' or 'all the time', 47% experienced feelings of depression 'often' or 'all the time', and 10% experienced suicidal feelings 'often' or 'all the time'. A further 30% reported suicidal feelings 'sometimes' or 'occasionally', so in total 40% experienced suicidal feelings.

Only those who had a pregnancy ending in a live birth had lower levels of distress but all other groups, including those who had not received treatment, were currently having treatment, and were currently pregnant had levels of distress similar to those who had only experienced unsuccessful treatment, miscarriage or still birth. This suggests that the entire fertility journey is equally distressing and psychological support beyond 'IVF counselling' is needed.

Furthermore, many respondents reported some detrimental impact of fertility problems and/or treatment on relationships with their partner, family, friends or colleagues. For example, 59% reported some detrimental impact on the relationship with their partner, such as the relationship being strained or mixed. Although this is 11% less than in Fertility Network UK's 2016 survey, this was linked to levels of distress. Only those whose relationship was improved or unchanged experienced lower level of distress, whereas those whose relationship ended or was initially strained, even though it later improved, experienced higher levels of distress. This suggests that some couples may also require additional psychological support beyond 'IVF counselling'.

Although fertility problems and/or treatment took its toll on some relationships, the vast majority (89%) of respondents reported receiving 'a great deal' of support from their partner. Although the vast majority also received at least

some support from family, friends and colleagues to whom they disclosed, less than half felt they received 'a great deal' of support. Only receiving 'a great deal' of support was linked to reduced levels of distress.

Work and treatment

The worries about treatment reported most frequently by respondents were uncertainty, impact on work, waiting times, funding and delays. Thus the impact of treatment on work was the second most frequently reported worry by three quarters of respondents. The vast majority of respondents (84%) felt that having treatment affected their day-to-day work, 58% felt concerned that treatment would affect their career prospects, 36% felt their career was actually damaged as a result, and 15% had to reduce their work hours or quit their job. Yet only a quarter of respondents reported the existence of supportive workplace policy. While just over three quarters disclosed to their employer, less than half said reasonable adjustments were offered and less than half received 'a great deal' of support from their employer (although 90% received at least some support). The most commonly used method to manage time off work was having to take annual leave.

Respondents who believed treatment affected work or career, who reported no policy, no reasonable adjustments, and no support all had higher levels of distress. These findings suggest that the understanding and support of employers is crucial. In recent years there appears to have been more interest from organisations in supporting employees with fertility challenges. Fertility Network UK's Fertility in the Workplace initiative supports employers and managers, as does Fertifa (which was set up in 2019). However, the findings of this survey differ little from Fertility Network UK's 2016 survey and suggest a lack of policy and support remains.

Of course in order to seek support (or use policy, where it exists) it is necessary to disclose. While the majority did disclose, just under a quarter did not, and the top reasons for this were a desire for privacy and fear of career consequences. Thus it is clear that workplace policy is needed, but this must be combined with guidance to assist line managers, who may have limited understanding of the needs of employees having fertility treatment.

In summary, while there were increases in the number of respondents receiving counselling, attending a support group, and seeking support from Fertility Network UK, and a reduction in reports of relationship impacts of fertility problems and/or treatment, overall the figures have changed little since Fertility Network UK's survey in 2016, and there has been an increase in the number of respondents having to pay for at least part of their treatment. Access to NHS-funded fertility treatment and psychological support remain problematic for some respondents. Reports of distress and suicidal thoughts remain worryingly high. Additionally, while in recent years there appears to have been increasing interest from employers in supporting employees experiencing fertility challenges, the number of survey respondents reporting career concerns and lack of workplace policy and support while having fertility treatment has not reduced since 2016.

Key Recommendations

Due to difficulties in accessing NHS-funded treatment for some people, regional differences in availability and criteria for individual eligibility should be reconsidered.

Work is needed to educate and inform GPs so they are more able to support patients. A subsequent care plan built around continuous tailored care and improved communication between GPs, fertility specialists and patients is advised, which should focus on both partners, including same sex couples.

Given the high levels of psychological distress and people experiencing suicidal feelings, access to funded counselling is crucial. A whole clinic approach is advised, with all clinic staff involved in understanding client preferences regarding support and in detecting and addressing patients' behavioural, relationship, emotional and cognitive needs before, during and after treatment.

Forms of support, other than counselling, such as support groups are also important. Access to inclusive support groups should be available from an early stage of the fertility journey, and GPs and fertility clinics could be involved in raising awareness of their existence.

As combining work and treatment is challenging and damage to career prospects is a concern, there remains a need for workplace policy for employees having fertility treatment. Policy must be combined with guidance to assist line managers who may have limited understanding of the support needs of employees undergoing treatment.

References

van den Akker, O., Payne, N., & Lewis, S. Catch-22? Disclosing Assisted Reproductive Technology treatment at work. *International Journal of Workplace Health Management*, 10(5), 364-375.

Fertility Network UK survey on the impacts of fertility problems (2016)

- Payne, N., Seenan, S. & van den Akker, O. (2019). Experiences and psychological distress of fertility treatment and employment. *Journal of Psychosomatic Obstetrics & Gynecology*, 40(2), 156-165.
- Payne, N., Seenan, S., & van den Akker, O. (2021). Experiences of involuntary childlessness and treatment in the UK: what has changed in 20 years? *Human Fertility*, 24(5), 333-340.

Fertility Network UK survey on the impact of COVID19 (2021a)

<https://fertilitynetworkuk.org/fertility-network-uk-survey-reveals-the-heartbreaking-impact-of-covid-on-patients/>

Fertility Network UK survey on employees undergoing fertility treatment (2021b)

<https://fertilitynetworkuk.org/over-one-third-of-employees-undergoing-fertility-treatment-consider-leaving-their-jobs/>

Frederiksen, Y., Farver-Vestergaard, I., Skovard, N. G., Ingerslev, J., & Zachariae, R. (2015). Efficacy of psychosocial interventions for psychological and pregnancy outcomes in infertile women and men: a systematic review and meta-analysis. *British Medical Journal Open*, 5:e006592


Gameiro, S., Boivin, J., Dancet, E., de Klerk, C., Emery, M., Lewis-Jones C., Thorn, P. van den Broeck, U., Venetis, C., Verhaak, C.M., Wischmann, T., & Vermeulen, N. (2015). ESHRE guideline: routine psychosocial care in infertility and medically assisted reproduction – a guide for fertility staff. *Human Reproduction*, 30(11), 2476-2485

Greil, A.L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: A review of recent literature. *Sociology of Health and Illness*, 32(1), 140-162.

HFEA (2021). Fertility Treatment 2019: Trends and Figure. <https://FertilityNetworkUK.hfea.gov.uk/about-us/publications/research-and-data/fertility-treatment-2019-trends-and-figures/>

National Institute for Health and Care Excellence (NICE) (2013). Fertility problems: assessment and treatment. <https://FertilityNetworkUK.nice.org.uk/guidance/cg156>

Payne, N., & van den Akker, O. (2022). Mental health and coping with fertility treatment cessation during the COVID19 pandemic in the UK. *Journal of Psychosomatic Obstetrics & Gynecology*. Published online first.



Payne, N., Lewis, S., & van den Akker, O. (in preparation). “Something’s got to give”: Women’s experiences of conflicts between work and fertility treatment.

Purewal, S., Chapman, S., & van den Akker, O. (2018). Depression and state anxiety scores during assisted reproduction treatment are associated with outcome: a meta-analysis. *Reproductive BioMedicine Online*, 36 (6), 646-657.

Sydsjö, G., Wadsby, M., Kjellberg, S. and Sydsjö, A. (2002). Relationship and parenthood in couples after assisted reproduction and in spontaneous primiparous couples: a prospective long-term follow-up study. *Human Reproduction*, 17, 3241–3250.