



Fertility Network UK Survey on the Impact of Fertility Problems

Final Report

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Nicky Payne and Olga van den Akker

With thanks to Emma Hughes

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Executive Summary

Fertility problems 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 relatively few work environments have formal policies in place to support people having treatment. 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. In order to examine the impact of fertility problems and treatment, an online survey was conducted to examine the psychological, emotional and relationship impacts of treatment, funding and support issues, and experiences of combining treatment and work. The survey aimed to update and extend upon a survey conducted by Fertility Network UK in 1997. There were 865 responses to the current survey of which 780 completed the entire survey. Respondents were mainly white, heterosexual women.

Key findings

- 54% of respondents had to pay for at least part of their treatment.
- 81% in N. Ireland were offered only one cycle of NHS treatment, whereas in Scotland and Wales 87% and 85% respectively were offered more than one cycle and in England 62% were offered more than one cycle.
- 10% had spent more than £30,000 on treatment and 31% of those having NHS treatment had to pay for additional treatments or tests.
- 44% received counselling and 54% of these had to fund some of it themselves, yet 75% would like to have counselling if it were free.
- 17% attended a support group, yet 52% would like to attend had there been one nearby.
- 52% fully understood the nature of their fertility problem and only 26% felt their GP provided sufficient information.
- Respondents felt on average sad, frustrated and worried nearly all of the time and 42% experienced suicidal feelings as a result of fertility problems and/or treatment
- 70% reported some detrimental impact of fertility problems and/or treatment on their relationship.
- Those most in danger of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment, who spent longer trying to conceive, who experienced some relationship strains and who had less support from friends and family and their employer.
- 50% 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 23% reported the existence of supportive workplace policy and only 41% received really good support from their employer.
- 50% of respondents needed more than a week off work during a treatment cycle.



Key recommendations

- Regional differences in availability of funded treatment and guidelines for individual eligibility need to be reconsidered and more NHS treatment cycles offered.
- 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.
- Funded counselling is needed at appropriate times and with an appropriate focus, including supporting people with unsuccessful treatment outcomes or relationship difficulties.
- Workplace policy for fertility treatment is needed and this should be combined with guidance to support employers who may have limited understanding of the needs of someone having treatment.

Background

Latest reported statistics show that during 2013, 49,636 women had a total of 64,600 cycles of IVF and 2,379 women had a total of 4,611 cycles of donor insemination (DI) and these figures continue to rise (HFEA, 2013). Fertility problems are an ongoing issue, and treatment is an incredibly physically, psychologically and financially demanding process (van den Akker, 2012).

Both women and men having treatment have been found to experience high levels of distress (Greil et al., 2010) with women experiencing more distress than men (Slade et al., 2007). For example, themes extracted from interviews with women experiencing fertility problems included grief and depression, anxiety and stress, anger and resentment and experiencing an 'emotional rollercoaster' (Williams, 1997). It is not clear whether levels of stress are related to the length of time having treatment, but stress levels vary with stage of treatment (Greil et al., 2010). A survey conducted by I N UK in 1997 (Kerr et al., 1999) also found a wide range of negative emotions were experienced by 980 respondents, with one in five reporting they experienced suicidal feelings and one in three reporting that fertility problems had strained their relationship. The stress experienced from diagnosis and treatment may even affect treatment outcomes (Boivin and Schmidt, 2005) and later adjustment to parenting (Sydsjo et al., 2002).

The financial impacts of treatment are also highly problematic. The 1997 I N UK survey found that about 75% of respondents had been forced to pay for some or all of their treatments and investigations, whereas 18% had their treatments fully funded by the National Health Service (NHS). Furthermore, 71% of respondents said that they would request counselling if it were offered free, but only 12% had been provided with free counselling on the NHS. The funding situation has changed since 1997 and current national guidance recommends that up to three full cycles be provided to those eligible. However in practice many individuals are unable to access this level of treatment, particularly across England where NHS funding is patchy and limited in places to one or two part cycles and in some areas there is currently no funding.

Another issue, which has been recognised more recently, is difficulties experienced in combining treatment with work. In the UK, employees have a right to absences for pre-natal and for post-natal care and the right to request flexible working but pre conception care is not a statutory right, so relatively few work environments have formal policies in place to support people having treatment. Our recent research (Payne et al., 2014a,b, 2016) using in depth interviews found that women and men having treatment experience conflict between the demands of work and the time and emotional demands of treatment. Workplace support and job flexibility were found to be crucial for managing this conflict but experiences of support varied considerably and people also had concerns about having to disclose to request support. Findings from our own research (van den Akker et al., submitted) and a survey (Finamore et al., 2007) have confirmed these disclosure concerns with 57% of the women surveyed not disclosing to their employer due to protecting

their privacy, career concerns, not wanting special treatment and embarrassment.

The project brief

Fertility Network UK commissioned us to conduct a survey to examine the impact of failing to conceive and of subsequent fertility treatment to extend the survey conducted in 1997 but with more of a focus on accessing funding for treatment, the impacts of treatment for friends, family and employment and support for treatment and understanding from employers. Specifically Fertility Network UK hoped to gather information on:

- Emotional and psychological impact of experiencing fertility problems and of treatment
- How it affects their relationships with friends and family
- Whether there was any impact on their work/career
- How supportive or otherwise their employer was
- Whether they were able to access counselling as part of their treatment
- Ability or otherwise of people to access NHS treatment and the impact of that
- Whether they had to access other NHS services following a diagnosis of fertility issues

Fertility Network UK wished the survey to be applicable to a broad range of individuals including those who have a diagnosis, those who have had or are having treatment or who are planning or awaiting fertility treatment and also including those who have completed their fertility journey whether they have been successful or have had to accept involuntary childlessness

The Survey

Initial questions were provided by Chief Executive Susan Seenan and some comments were also provided by members of the Board of Trustees. We developed the questions further and prepared the survey using Qualtrics survey software. The survey was piloted on several individuals, including some Fertility Network UK staff. Final changes were made and the survey was launched during the second week of October 2015 and ran until the end of March 2016.

The survey was divided into five sections:

Section 1: Demographic and treatment information

Section 2: Funding for past, present or future treatment

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

Section 4: Impact of fertility problems and treatment, including on relationships and on a variety of indicators of well-being and mental health such as depression, anxiety and suicidal feelings

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

Data collection

There were 865 responses to the survey, of which 780 completed the entire survey (a completion rate of 90%). It is not possible to calculate the response rate, as with mass electronic distribution it is not possible to know the number of potential participants who have seen the survey link. The number of responses is slightly less than the 980 who completed the first survey in 1997. However, the climate in 2016 is quite different from that in 1997; busy modern lives and being bombarded with online content means that people are now less willing to complete such surveys. The 1997 survey would have been a postal survey and was sent to the membership of two organisations and a 50% response rate was achieved. However, postal surveys are costly and not so far reaching (e.g. many of the responses to the current survey are from people using online forums such as Fertility Friends who would not be reached by a postal survey).

Fertility Network UK promoted the survey to their service users through social media, website and digital magazine/newsletter. It was also promoted extensively at events including The Fertility Show and the British Fertility Society annual conference, sent to all clinics, shared with all sister organisations and other professional organisations including the British Fertility Society and Association of Clinical Embryologists. Staff shared the survey link directly with all their individual contacts, with all fundraising volunteers as well as general volunteers and board members, all of whom were asked to cascade the dissemination in turn to their contacts. Fertility Network UK corporate partners were also asked to help disseminate the survey and links have appeared on blogs written by our volunteers and contacts including Kate Brian (Fertility Matters) and Jessica Hepburn (In Pursuit of Motherhood)

We have promoted the survey via DCN, BICA, Fertility Friends, Brilliant Beginnings, a variety of contacts and colleagues with large twitter followings and several bloggers on the topic of fertility problems who have previously participated in research we have conducted. Other organizations who were asked to promote the survey include: NGDT, Male Fertility UK, Care Fertility, COTS, Surrogacy UK and The Baby Centre.

Findings

There are some limitations to these 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 having fertility treatment. The sample is limited in terms of diversity, so the views of men, same sex couples and black and minority ethnic people are not sufficiently represented. Additionally, surveys rely on self-reports, which 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.

Demographic and treatment information

98% of respondents were women. 93% were in a heterosexual relationship (with 3% in a same sex relationship, 3% single and 1% defining themselves as 'other'). 77% were living in England (with 10% in Scotland, 8% in N. Ireland and 5% in Wales). 94% were white (with 2% mixed heritage, 2% Asian and 2% black). The average current age of respondents was 35.54 years (*SD* 6.10) and the average age when they started treatment was 32.54 years (*SD* 4.77) with the oldest being 50 years of age at the start of treatment.

Respondents had on average been trying to conceive for 4.4 years (*SD* 3.1), with 65% trying for less than 5 years, 27% for 5-9 years and 8% 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). For the purpose of later analyses all respondents were also separated into four discrete groups shown in Figure 2. Of those who had or were due to begin treatment, 82% had IVF/ICSI, 19% IUI and 30% were prescribed Clomid. 11% used donor eggs, 9% donor sperm and 2% donor embryos.

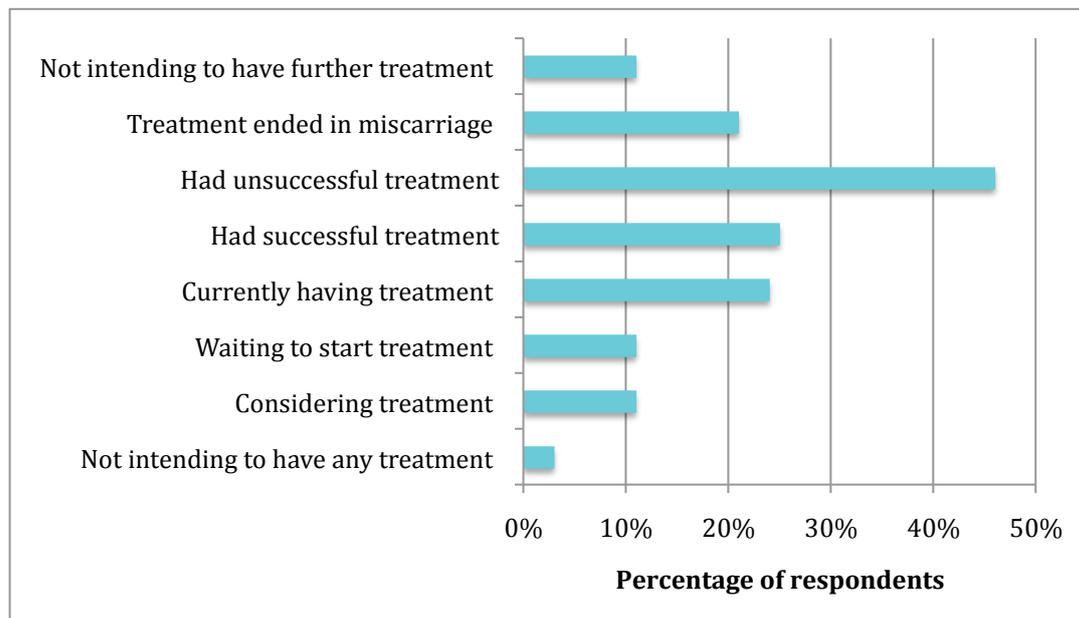


Figure 1: Treatment status

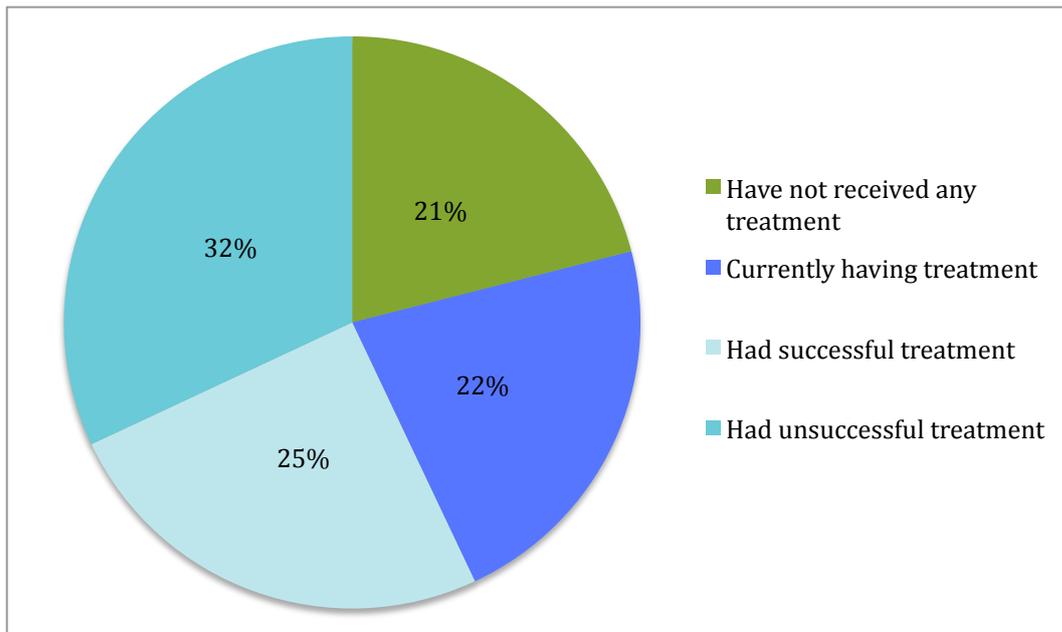


Figure 2: Groups based on treatment status

(NB. The four 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. 'Had successful treatment' comprises those with a successful treatment outcome, some of whom also had one or more previously unsuccessful outcomes. 'Had unsuccessful treatment' comprises those who had one or more unsuccessful outcomes and were either not intending to pursue further treatment or were undecided.)

Funding for past, present or future treatment

41% of respondents had or planned to have NHS funded treatment, 30% private treatment, 24% a mix of both and 5% were not sure yet. Key reasons for not being able to access NHS treatment are shown in Table 1.

Table 1: Key reasons for not being able to access NHS treatment

	% of the 313 respondents who answered this question
Have a child/partner has child	27%
Too old or young	23%
Already had a round of IVF on the NHS	15%
BMI too high or low (self or partner)	10%
Other reason (e.g. low chance of success)	10%
Waiting list too long	8%
No NHS funds available	7%
Specialist treatment is needed	6%
Single status	5%

81% of respondents had or planned to have treatment in the UK only, 4% abroad, 9% in both and 6% were not sure yet. The most popular locations abroad were Spain, Greece, and the Czech Republic, but many other countries such as Poland, Belgium, Norway, Tunisia, Cyprus, Hong Kong, USA and Canada were also listed. Key reasons for going abroad are shown in Table 2.

Table 2: Key reasons for going abroad for treatment

	% of the 105 respondents who answered this question
Cheaper	58%
Donor availability	27%
Faster	18%
More professional/personal care	15%
Have lived/will live there	13%
More advanced Technology	11%
Better success rates	11%

Of those who had or were considering NHS treatment, 39% were told they could have one cycle, 24% were told two, 18% were told three and 19% did not know. Of those who had already had IVF/ICSI, the number of cycles they received is shown in Figure 3. On average respondents had received 2.66 (*SD* 2.47) cycles of private IVF and 1.53 (*SD* .77) cycles of NHS IVF. The average total number of cycles across NHS and private was 2.62 (*SD* 2.21) with 32% of respondents receiving one cycle, 30% receiving two, 18% receiving three and 20% receiving more than three cycles.

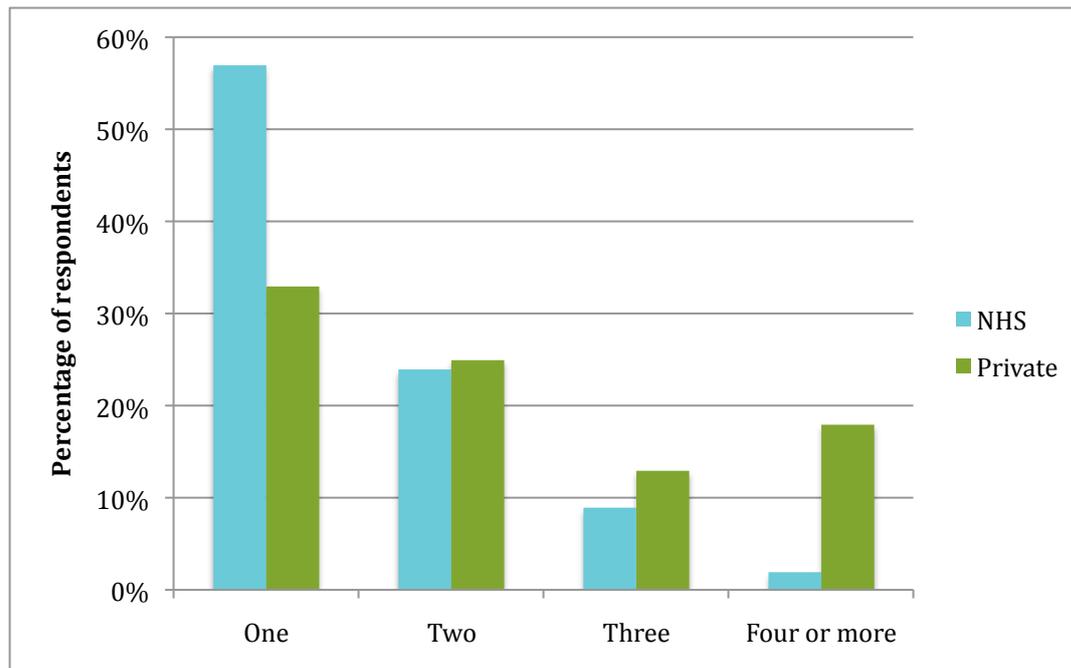


Figure 3: Number of IVF/ICSI cycles received

Further analyses in Figure 4 show that those living in N. Ireland had received fewer NHS cycles compared to those in Scotland and England and those in England had received fewer than those in Scotland ($F = 3.12$, $p = .03$). This is likely to be due to a difference in the number of cycles allowed; 81% of respondents in N. Ireland reported being told they were allowed only one cycle, compared to 38% in England, 15% in Wales and 13% in Scotland ($\chi^2 = 123.17$, $p < .001$). However, it should be noted that only a small number (8%) of respondents live in N. Ireland.

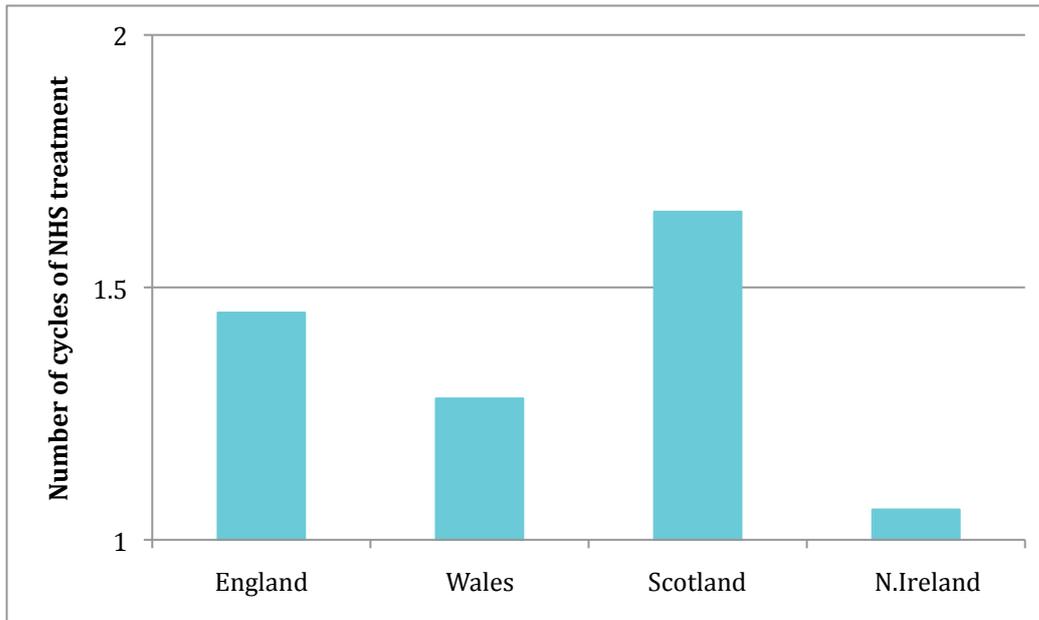


Figure 4: The association between location and average number of NHS IVF/ICSI cycles

Of those who paid for additional tests or treatments 69% were requested as part of private treatment, 20% as part of NHS treatment and 11% as part of both. The main additional tests or treatments are shown in Figure 5.

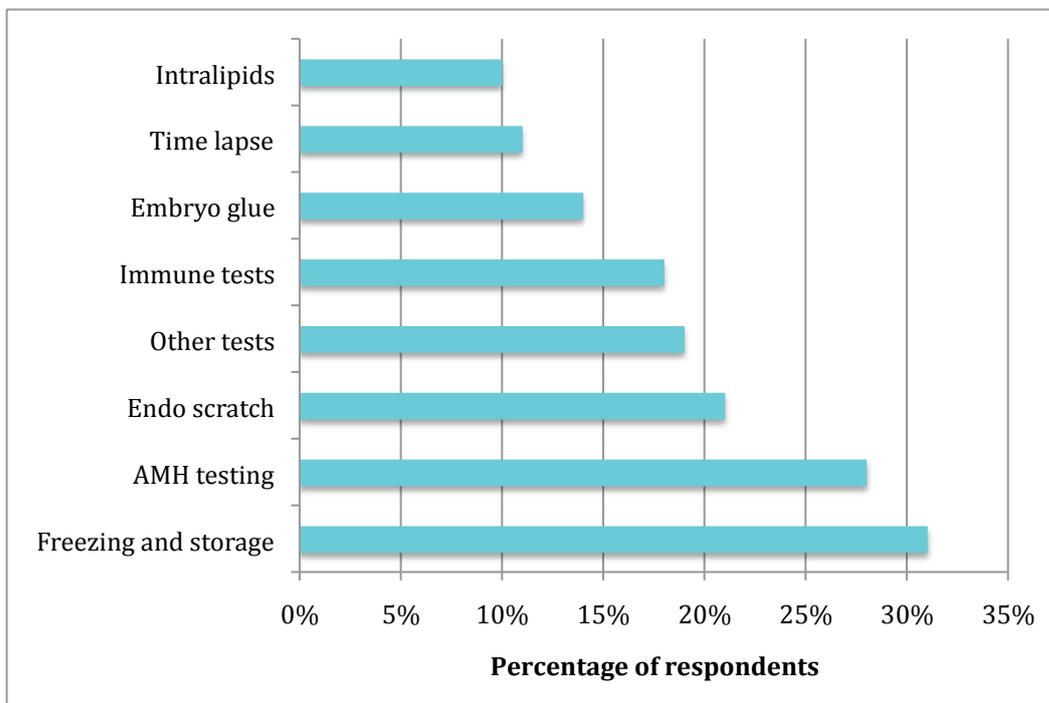


Figure 5: Additional tests or treatments requiring payment

Respondents had spent on average £11,378 (*SD* 13,872) on investigations and treatment, with 38% spending less than £5,000, 27% spending £5-9,000, 14% spending £10-19,000, 11% spending £20-29,000 and 10% spending more than £30,000 and in a few cases up to £100,000.

Support for fertility problems and/or treatment

73% of respondents reported they would like counselling if they did not have to pay for it (20% were not sure and only 7% said they would not want counselling). However, only 44% actually received counselling. 46% of these had free NHS counselling, a further 17% had to top this up with additional private counselling and 36% had private counselling only. Therefore, 27% of the total sample had to pay for some or all of their counselling. 75% of these found the counselling useful. Reasons the counselling was useful or not are reported in Table 3.

Table 3: Key reasons counselling was helpful or was not helpful

	% of the 288 respondents who answered this question
Reasons counselling was helpful	
Helped understand facts	31%
Helped to explore/deal with feelings	26%
Someone impartial to talk to	20%
Someone who understood/normalised feelings	17%
Helped to accept the situation/face the future	11%
Helped relationship with partner	9%
Someone who was non-judgmental	6%
It was a requirement to get to treatment	2%
Reasons counselling was not helpful	
Wrong focus or timing	39%
It was a ticking boxes exercise	25%
Counsellor was unsupportive	24%
Other reason (e.g. it was only one session)	16%
Counsellor lacked facts/knowledge of fertility	12%

52% of respondents felt they understood the nature of their fertility problem and only 26% reported that their GP provided sufficient information about fertility problems and treatment. However, 70% felt they received positive help and support from their fertility specialist and clinic staff. Additional support or information respondents would like to receive from their GP or clinic is shown in Table 4. 'Other' support includes wanting to be seen by the same staff, better communication between GP and clinic staff, a more individualized approach to treatment, an equal focus on men and women and more awareness of same sex couples.

Table 4: Additional support or information respondents would like to receive from their GP or clinic

	% of the 484 respondents who answered this question
Better knowledge of investigation process/clear explanation of treatment options	26%
Better knowledge of fertility problems/basic advice on things to try	23%
Better emotional support/counselling	22%
Empathic approach	18%
Other	17%
Full/clear information about the condition	13%
Provide more tests	12%
Follow-up appointments and care	7%
Faster referral times	6%
Shorter waiting times	5%
Help with weight loss/nutritional advice	4%
More time during appointments	2%

28% of respondents sought support from Fertility Network UK and 45% from another organization or online support. Many examples were provided but the most common were Fertility Friends, Fertility Zone, NGDT, DCN, HFEA, Mindful Mums to be/Embrace Fertility, The Miscarriage Association, Gateway Women, The Dove Cote, Mumsnet, NetMumsHealthUnlocked, as well as general Facebook groups, twitter, and fertility blogs and forums. Only 17% attended a support group but 52% would have liked to attend had there been one nearby (36% were not sure and only 12% said they would not want to attend). Figure 6 provides details of when counselling and support were sought.

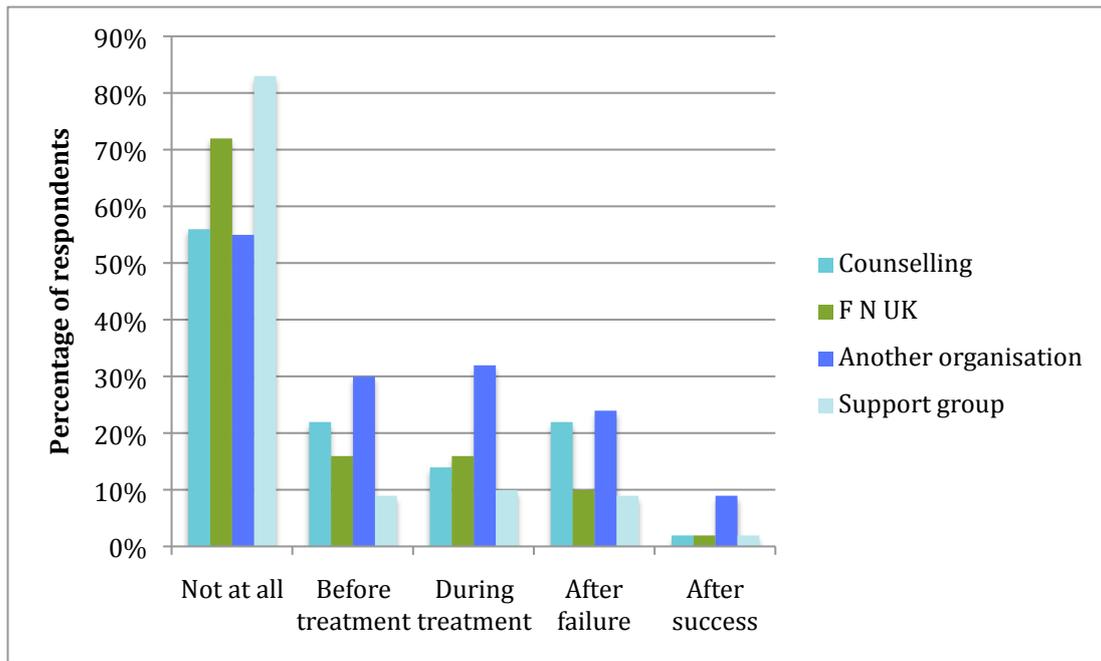


Figure 6: When counselling and support are sought

In addition to seeking support from organisations, 52% of respondents sought advice on changing aspects of their lifestyle and 93% actually made lifestyle changes. Key lifestyle changes shown in Figure 7 are dietary changes and reducing alcohol and coffee consumption. The most common 'other' lifestyle change was taking vitamins and supplements. 64% also used alternative therapies, with acupuncture the most popular (see Figure 8). The most common 'other' therapies were massage and reiki.

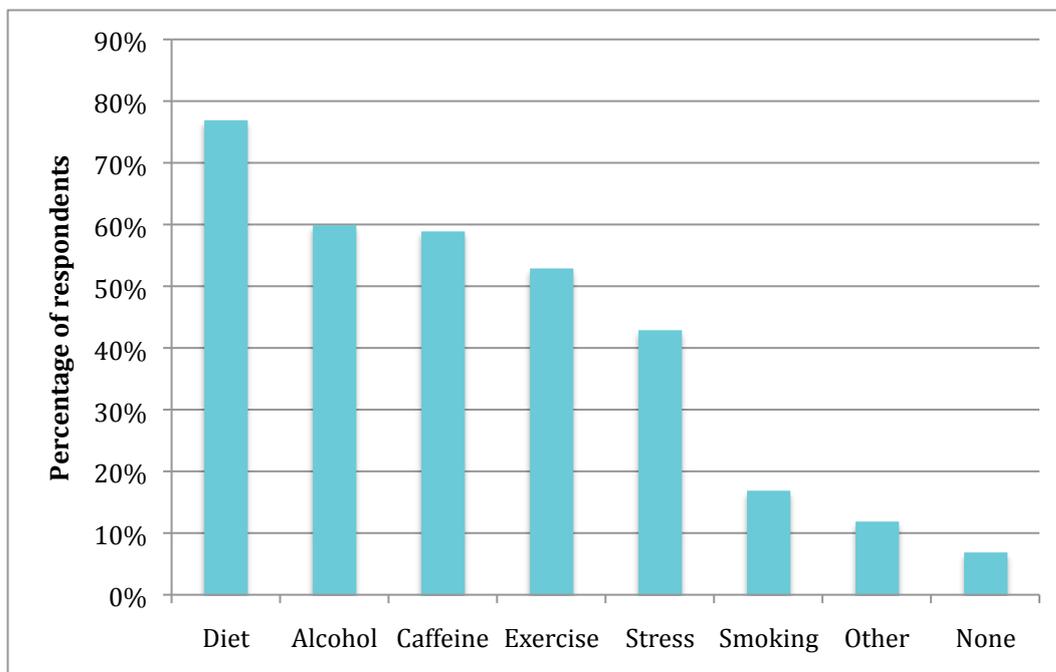


Figure 7: Lifestyle changes made

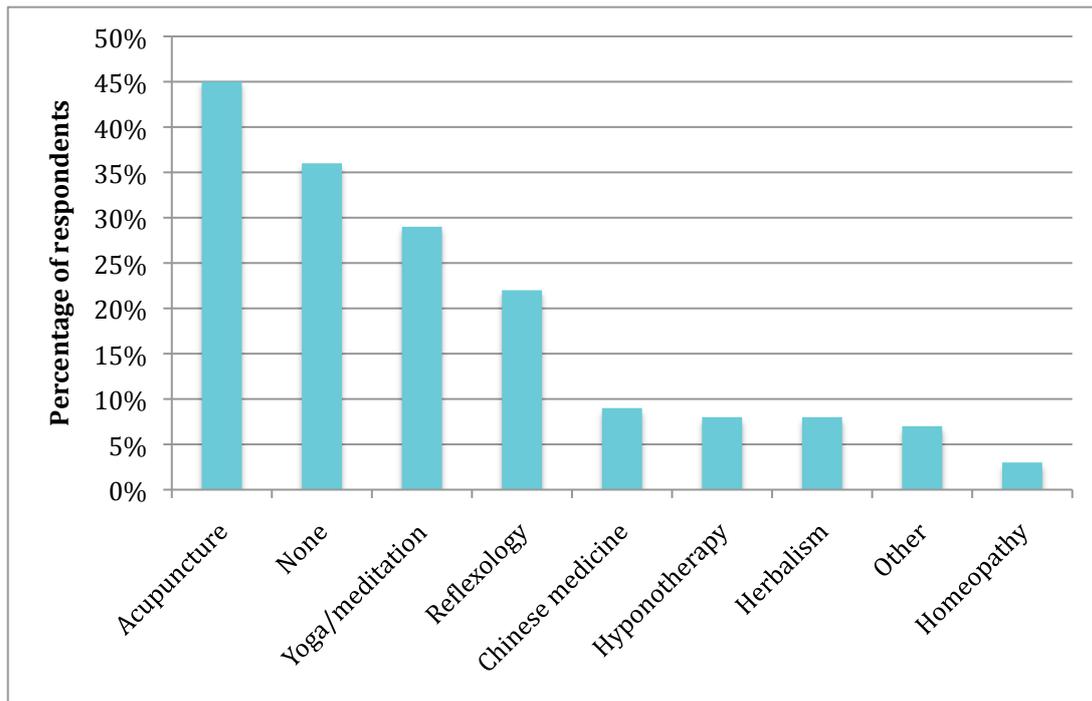


Figure 8: Alternative therapies used

Impact of fertility problems and treatment

94% of respondents disclosed to at least some of their friends and family. 46% received a great deal of support from friends and 48% a bit of support. 53% received a great deal of support from family and 41% a bit of support. However, fertility problems and/or treatment had an impact on some relationships. Figure 9 shows that the majority of relationships with friends or family were unchanged or mixed, although a number of friendships ended. Relationships with a partner were also mixed but were often improved as a result of the experience even after some initial strain. For example, 30% of respondents reported their relationship with their partner was improved or unchanged, 15% said it was strained or ended and 55% said it was only strained initially or was mixed. Therefore, for 70% of respondents fertility problems and/or treatment had some detrimental impact on their relationship.

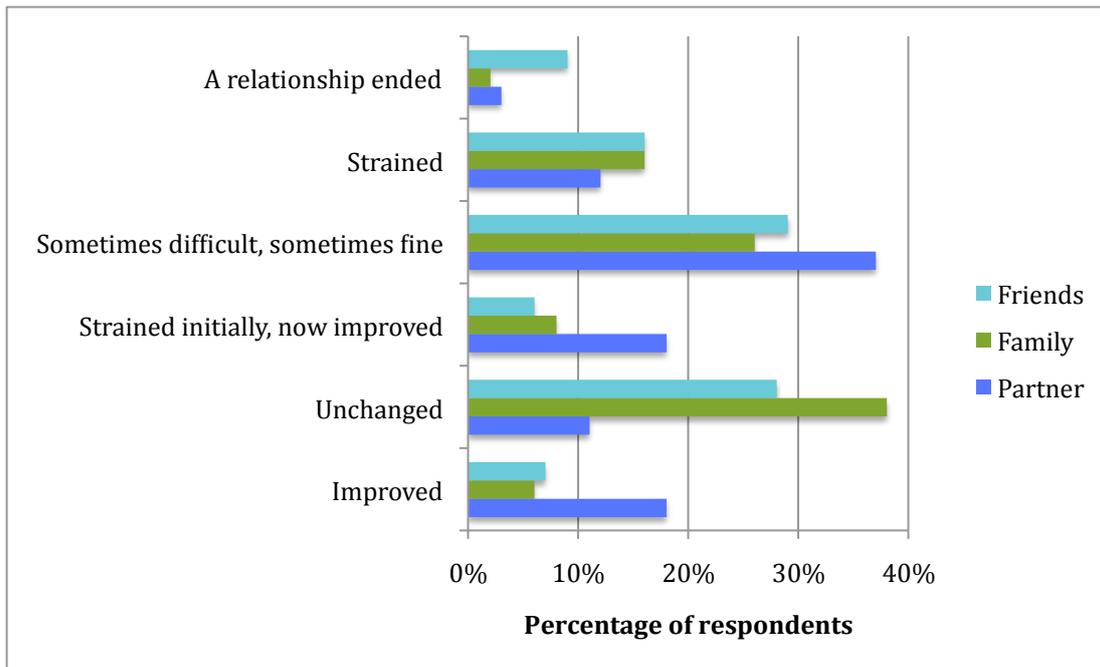


Figure 9: Impact of fertility problems and/or treatment on relationships

Key worries and the percentage of respondents reporting these are shown in Figure 10. Treatment uncertainty followed by concerns about funding and impact on work were most often reported.

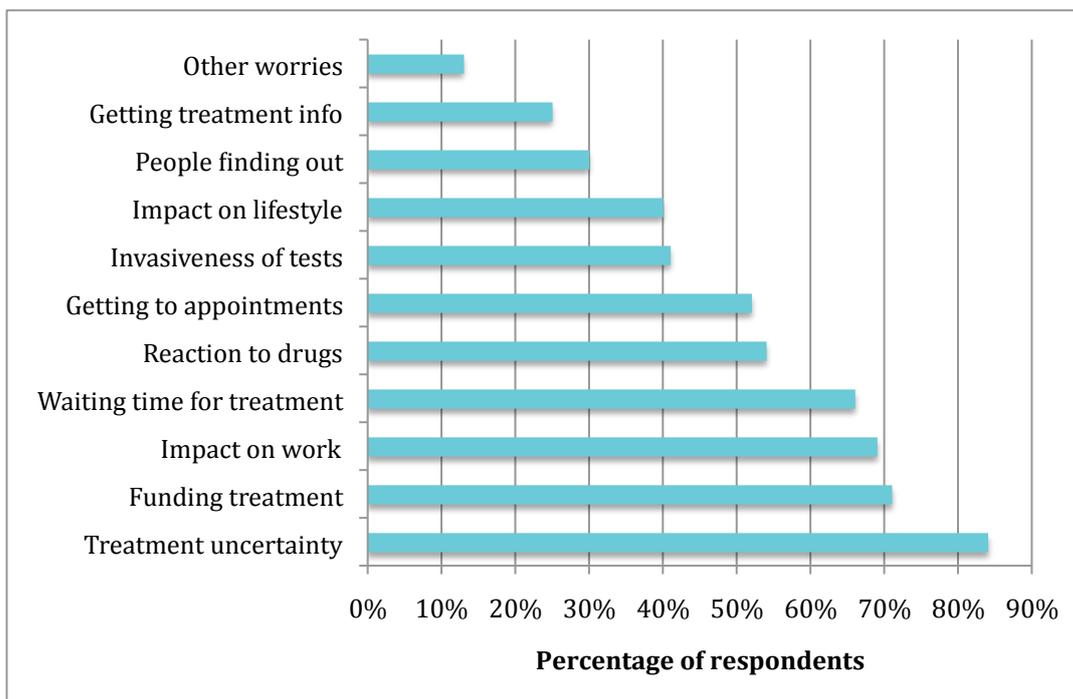


Figure 10: Worries about treatment

Figure 11 shows on average the frequency with which various psychological impacts of fertility problems and 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 sadness (4.28) means that this was experienced the most (almost all the

time), whereas suicidal feelings were experienced the least (1.82). However, this still means that on average suicidal feeling were experienced occasionally and 42% of respondents experienced such feelings occasionally, sometimes, often or all the time.

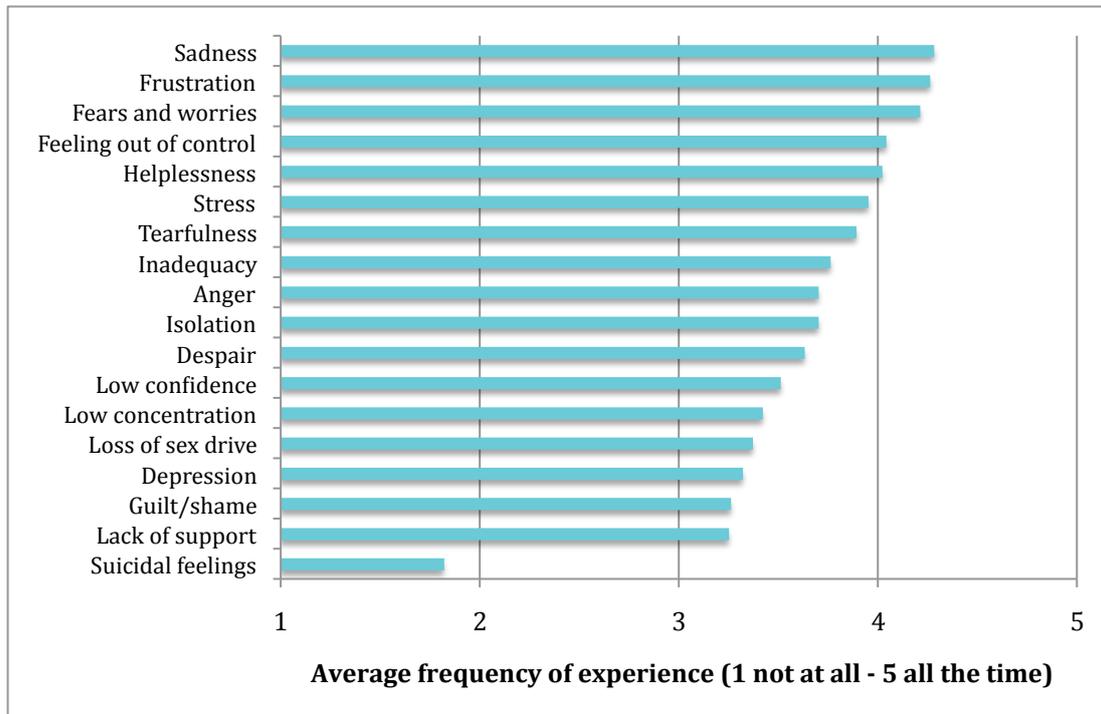


Figure 11: The psychological impacts of fertility problems and treatment

Individual responses to the psychological impacts items shown in Figure 11 were summed to form an overall measure of distress, with possible scores ranging from 18 to 90. Analyses were conducted to examine which respondents were most in danger of experiencing distress and suicidal feelings. Unsurprisingly, as shown in Figure 12, those who had unsuccessful treatment (who had either decided not to have more treatment or were undecided) reported greater distress as well as more frequent suicidal feelings ($F = 6.24, p < .001$; $F = 2.70, p = .05$). Additionally those who had unsuccessful treatment had spent longer trying to conceive ($F = 22.48, p < .001$). Spending longer trying was in turn associated with greater distress and more frequent suicidal feelings ($r = .17, p < .001$; $r = .11, p = .002$). Those who had successful treatment had more treatment cycles ($F = 3.39, p = .03$) and spent more money on treatment ($F = 13.19, p < .001$).

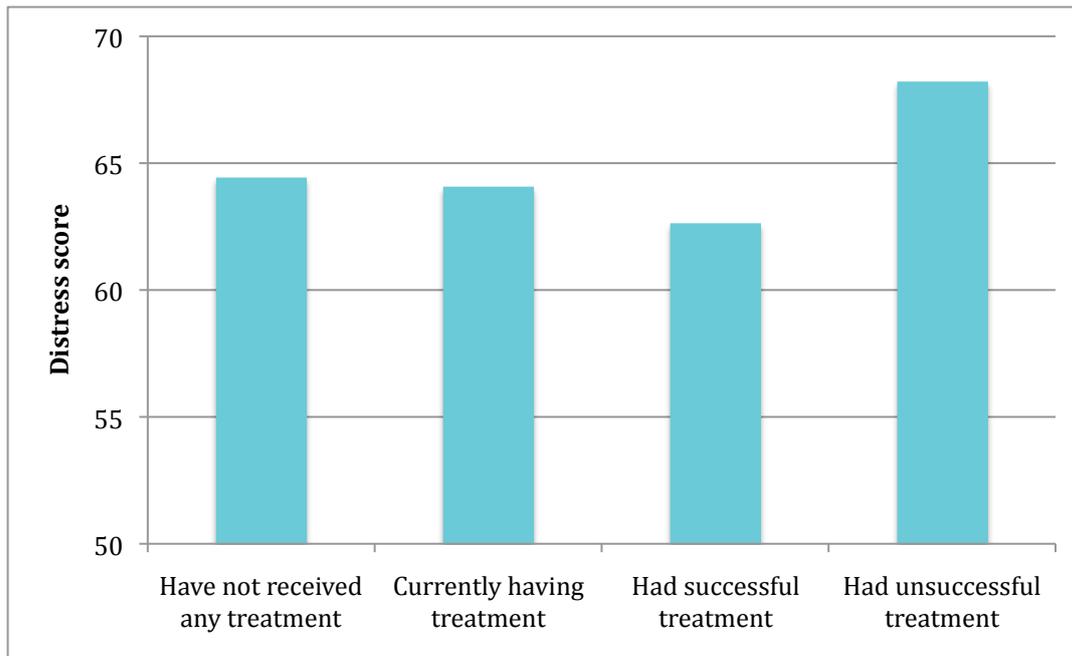


Figure 12: The association between treatment status and average level of distress

There were no differences in distress between those who did and did not attend counseling and support groups or contact organisations such as Fertility Network UK. However, those who received counselling and said they found it helpful reported lower distress and reduced suicidal feelings compared to those who said it was not helpful ($F = 5.13, p = .02$; $F = 4.11, p = .04$). Reporting greater levels of overall support (including from friends, family and colleagues) was associated with lower distress and reduced suicidal feelings ($r = -.13, p < .001$; $r = -.14, p < .001$). Furthermore, as shown in Figure 13, there was an association between the impact of fertility problems and/or treatment on the relationship with a partner and distress and suicidal feelings ($F = 18.29, p < .001$; $F = 11.06, p < .001$), such that having a strained relationship or even a mix of it being strained and fine were problematic.

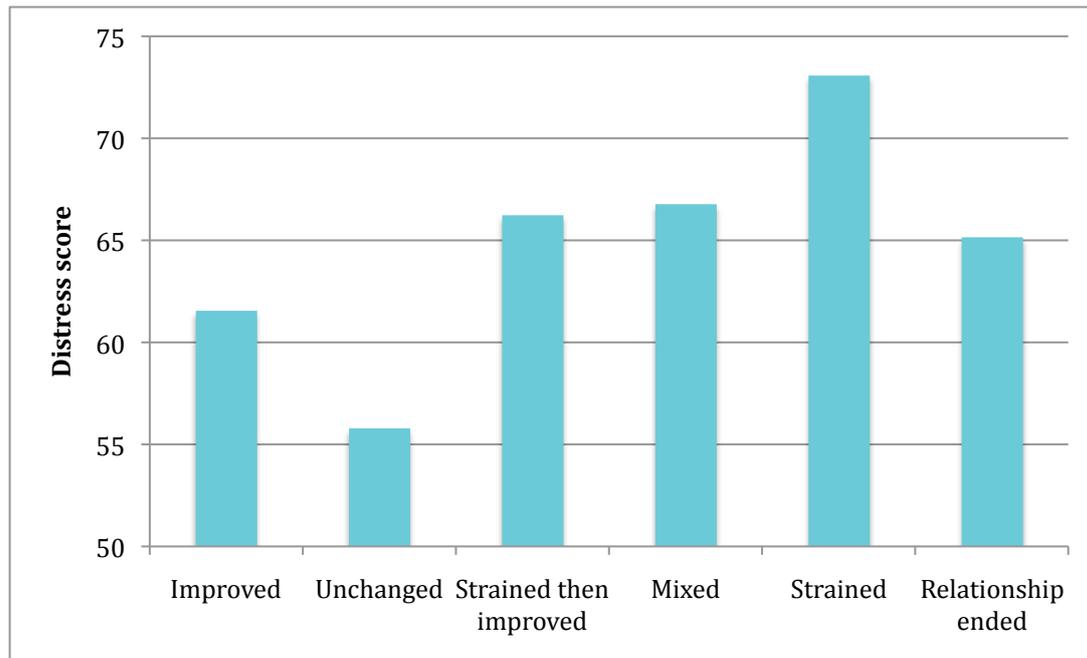


Figure 13: The association between the impact of fertility problems and/or treatment on the relationship with a partner and average level of distress

Work and treatment

Of those who worked at the start of treatment, 80% worked full-time, 13% part-time and 7% were self-employed. 13% of respondents reduced their hours and 6% left their job due to treatment.

58% of respondents reported work affected their treatment (e.g. it was difficult to make appointments) and 85% reported treatment affected their work (e.g. it was difficult to concentrate). 50% were concerned it would affect their career prospects and 35% felt it did actually affect their career. As shown in Figure 14, those who felt work affected treatment and that treatment affected work and career reported greater distress ($F = 5.68, p < .001$; $F = 32.72, p < .001$; $F = 12.30, p < .001$), as well as more frequent suicidal feelings ($F = 4.19, p = .006$; $F = 8.63, p < .001$; $F = 4.09, p = .007$). Furthermore, those who felt treatment affected work had more days off work ($F = 2.92, p = .03$) and those who felt treatment affected their career and that work affected treatment had more cycles of treatment ($F = 4.12, p = .007$; $F = 5.25, p < .001$).

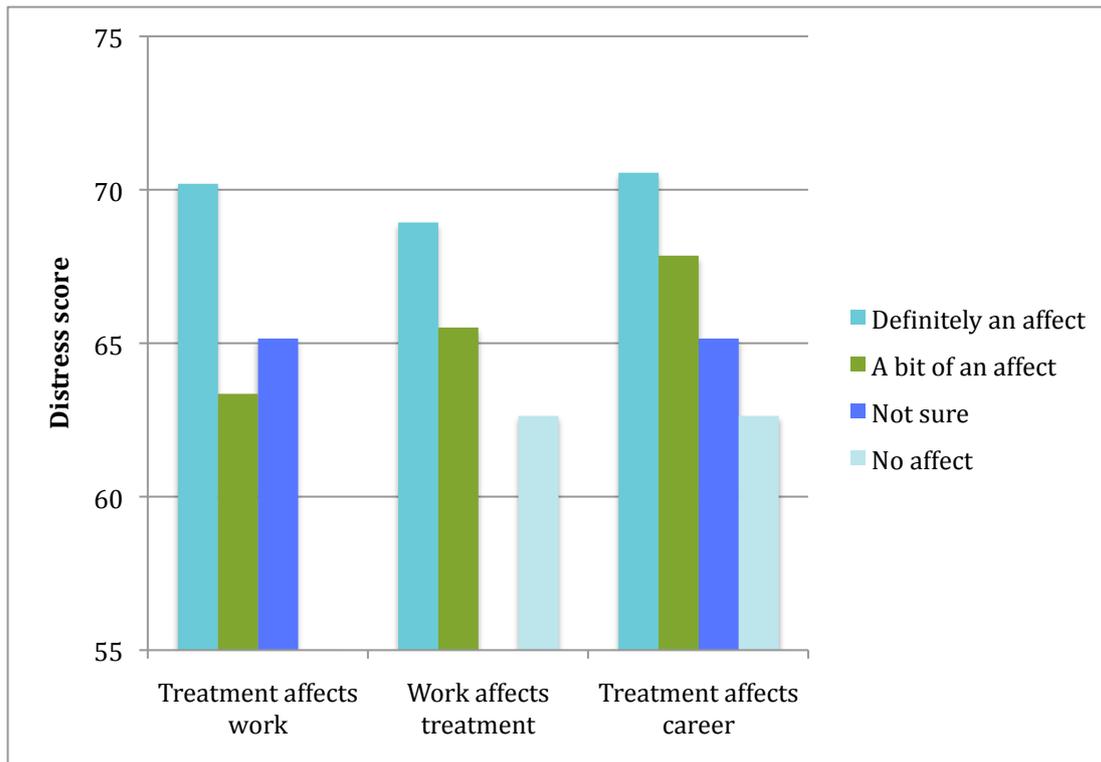


Figure 14: The association between average levels of distress and experience of work affecting treatment/treatment affecting work

(NB. No one selected 'not sure' for 'work affects treatment')

70% of respondents disclosed to at least some colleagues; 33% received a great deal of support and 47% received a bit of support. 72% disclosed to their employer; 41% received a great deal of support and 49% received a bit of support. Those who disclosed had more days off ($F = 18.96, p < .001$) and those who received more employer support reported lower levels of distress and less frequent suicidal feelings ($F = 7.12, p < .001$; $F = 4.77, p = .009$). Reasons for non-disclosure to their employer are shown in Figure 15. 'Other' reasons include being self-employed, wanting to maintain some normality, not wanting advice and sympathy, and knowing their organisation would not be supportive/did not have an IVF policy. Reasons for disclosure to their employer are shown in Figure 16. 'Other' reasons include having to explain the amount of sick leave taken, being unable to do an aspect of the job (due to e.g. safety) and knowing the organisation has IVF policy.

59% of respondents felt their employer would benefit from education/support to help them better understand the needs of someone having treatment (21% were not sure and 20% felt this was not necessary).

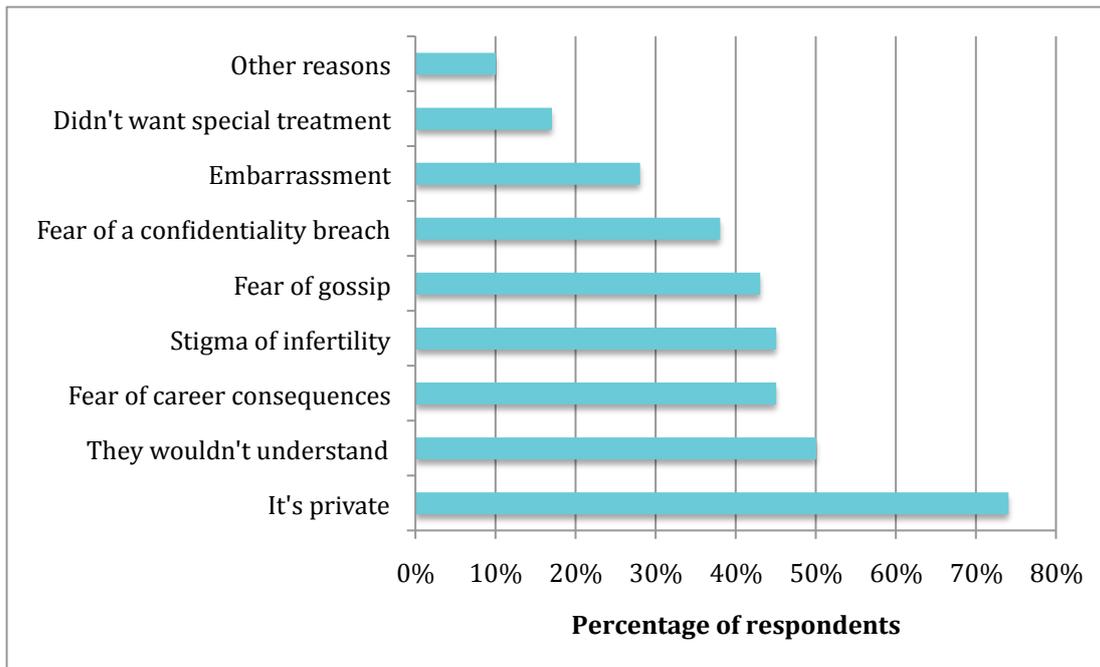
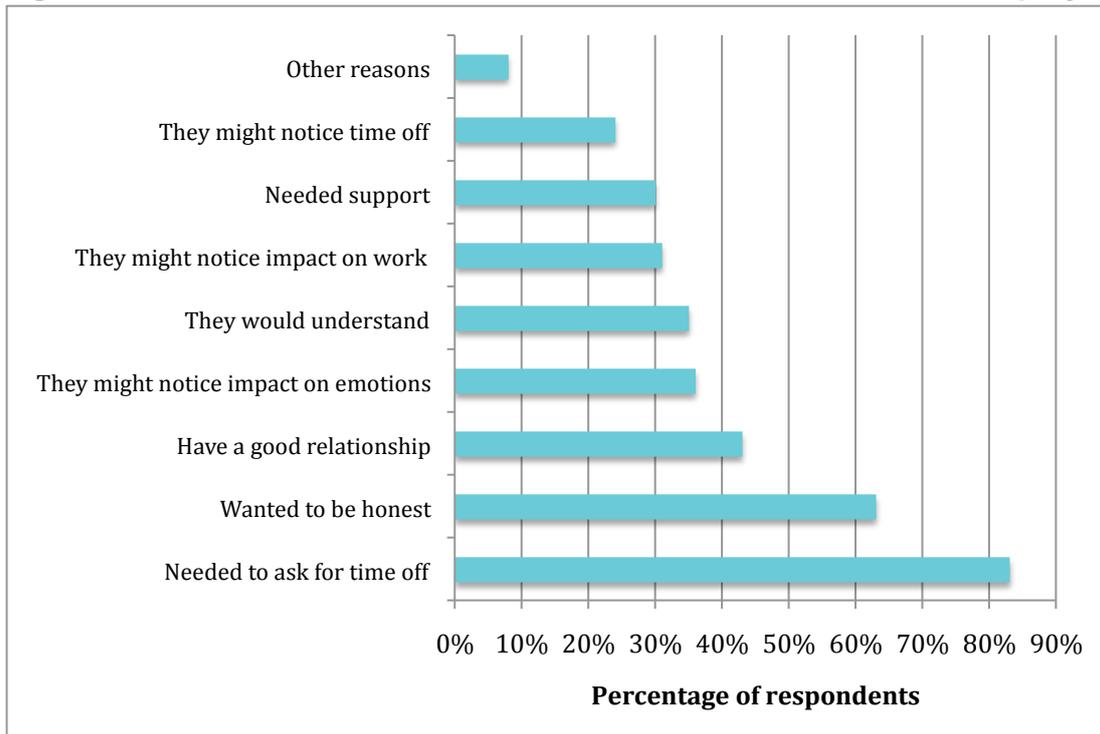


Figure 15: Reasons for non-disclosure to their employer

Figure 16: Reasons for disclosure to their employer



The average number of days taken off work during a treatment cycle was 8.74 (SD 9.32). 50% of respondents took up to a week off work, 24% took up to two weeks, 15% took up to three weeks, 4% took a month and 7% took more than this and in some cases up to several months. Taking more days off was associated with greater distress ($r = .15, p < .001$). Time off work for treatment was managed in various ways, as shown in Figure 17, with annual leave and sick leave being most commonly used. 'Other' methods include using specific

IVF policy, special leave, swapping shifts, being self-employed or working part-time and quitting work.

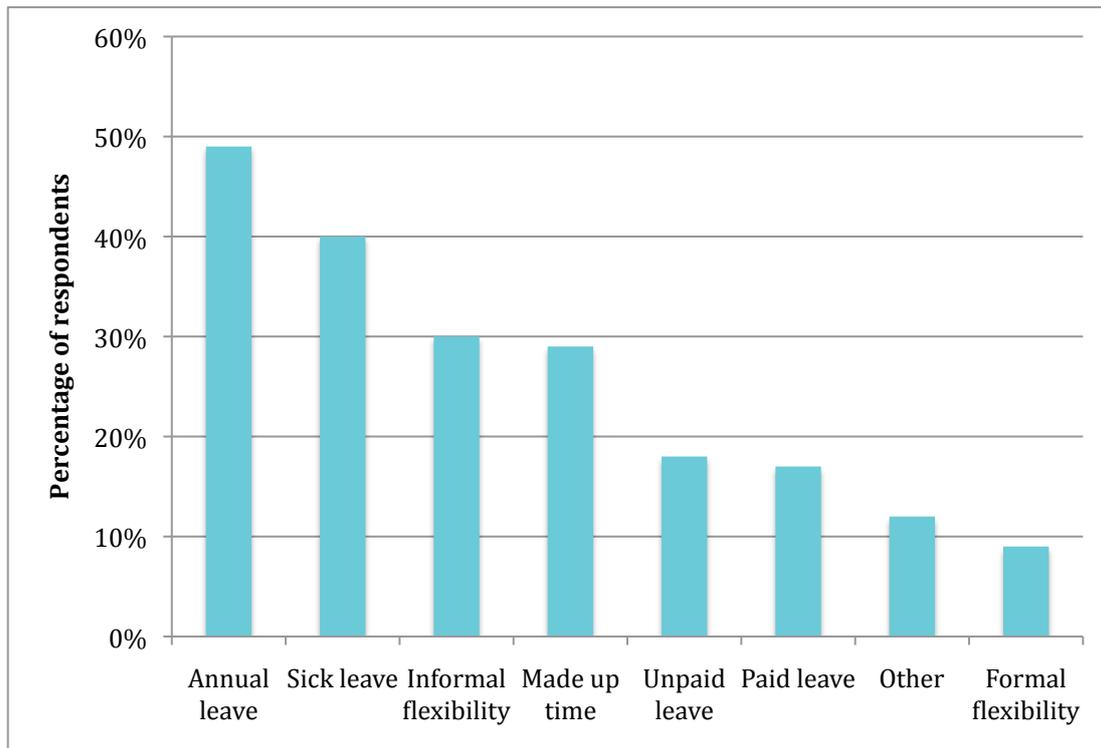


Figure 17: Methods used to manage time off work

23% of respondents reported their workplace had some policy relating to treatment (19% were not sure and 58% said it did not). Those who reported no policy reported greater distress ($F = 3.31, p = .04$) and those who reported there was policy were more likely to disclose than those who reported no policy or that they did not know ($\chi^2 = 13.47, p < .001$). The available policies varied greatly. In some cases policies stated that IVF is elective so no time off is allowed. In other cases the policies were vague or left decisions to the discretion of the line manager. Some policies allowed a specific number of days of leave (generally between 2 and 10 days), which in some cases was unpaid leave and in others was paid leave for either one cycle of IVF or in some cases up to 3 cycles.

Conclusions

Funding for past, present or future treatment

The findings suggest that lack of NHS funding may be an issue as 54% of respondents were having to pay for at least part of their treatment. However, things have improved since the 1997 survey where 82% were having to pay for at least some part of their treatment. Key reasons given for being denied NHS treatment, which could be reconsidered in future guidelines, include already having a child/partner having a child (especially when this child is not a child the couple has conceived together), such stringent body weight criteria and the absence of a partner for those who are single.

Although most respondents live in England, so the following should be interpreted with some caution, 81% of respondents in N. Ireland said they were offered only 1 cycle of NHS treatment and consequently they received the fewest NHS cycles. In contrast those in Scotland fare the best with 87% reporting they were offered more than one cycle. Thus regional differences are another issue which may need some 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 as much as £100,000 on treatment. Almost one-third of those having NHS treatment still reported having to pay for some additional treatments or tests. Although only 13% were seeking treatment outside of the UK, key reasons for doing so related to better quality, choice and cost.

Support for fertility problems and/or treatment

Access to psychological support may also be an issue as less than half (44%) of respondents received counselling (and more than half of these had to fund some of it themselves). Yet three quarters would like to have counselling if it were free. However, again this has improved since the 1997 survey where fewer people received counselling and received it free. Three-quarters of those who received counseling found it useful. However, the rest did not find it helpful mainly due to the wrong focus or timing, or because it was seen as a tick box exercise or something they had to do to receive treatment.

Only one fifth of respondents attended a support group but one half would like to had there been one nearby, suggesting that availability of such groups needs further consideration. Support networks such as Fertility Network UK and Fertility Friends were used by many respondents but some preferred more specialized networks such as Gateway Women (for those who had decided to no longer pursue treatment and try to adjust to being childless).

Only half of respondents reported that they fully understood the nature of their fertility problem and only one quarter felt their GP provided sufficient information, suggesting that more work is needed to educate and inform GPs so they are more able to support their patients. Key areas in which there could be improvements include GPs having better knowledge of fertility problems and of investigation processes and treatment options, as well as providing more empathy and emotional support and access to counselling. 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 the 1997 survey the number of people experiencing relationship difficulties and negative psychological impacts of fertility problems and treatment appears to have increased. For example, those who responded to

the current survey reported feeling on average sad, frustrated and worried nearly all of the time and 42% had experienced suicidal feelings compared to 20% in the 1997 survey. Those most in danger of experiencing high levels of distress and suicidal feelings were those who had unsuccessful treatment, who spent longer trying to conceive, who experienced some relationship strains, and who had less support from friends and family and from their employer. This suggests that additional counselling beyond IVF counselling may be needed for some couples, especially as 70% reported some detrimental impact on the relationship with their partner. However, although fertility problems and/or treatment took its toll on relationships, with many respondents reporting strained and mixed relationships with friends, family and their partner, the vast majority (94%) reported receiving at least some support from family and friends. Surprisingly, attending counselling, support groups or contacting organisations such as Fertility Network UK did not seem to be related to reduced distress. However, it is possible that the counselling drawn upon by some respondents was non-specific and not carried out by an accredited BICA counsellor.

Work and treatment

Key worries about treatment include its uncertainty, funding, waiting times and the impact of treatment on work. Certainly difficulties combining treatment and work were apparent. The vast majority of respondents (85%) felt that having treatment affected their day-to-day work, half felt concerned that treatment would affect their career prospects, a third felt their career was actually damaged as a result, and 19% had to reduce their work hours or quit their job. These concerns about work and career increased with more cycles of treatment and were all related to greater levels of distress and suicidal feelings. Yet only one quarter of respondents reported the existence of supportive workplace policy and less than half received really good support from their employer (although 90% received at least some support).

Where policy was reported it sometimes specified 5 days of leave, but half of the respondents needed more than 5 days and the average number of days off per cycle was 9 (although this varied considerably). In some cases policy specified a more generous 10-12 days of leave, but one quarter of respondents needed more than this. Having policy was associated with lower levels of distress and respondents were more likely to disclose where it existed. This could mean that the existence of policy makes requesting time off for IVF an entitlement and more normative. However, this relationship between policy and disclosure is more likely to be because people have to disclose (whether they want to or not) to use the policy. In fact 70% of respondents disclosed to their employer and the main reason for disclosing was necessity in order to request time off. The outcome of disclosure, in terms of the extent of support received, and not merely the act of disclosure, was related to reduced distress. Where respondents did not disclose this was mainly due to a desire for privacy and the fear that their employer would not understand. Thus it is clear that workplace policy is needed but this must be combined with guidance to support both employers, who may have limited

understanding of the needs of someone having treatment, and those having treatment.

Key Recommendations

Due to difficulties in accessing funded treatment for some people, regional differences in availability and guidelines for individual eligibility need to be reconsidered and more NHS treatment cycles offered.

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, especially among those who have unsuccessful treatment outcomes, access to funded counselling is crucial. It is vital that such support is available at an appropriate time and has an appropriate focus in order to maximize effectiveness. For example, those who have unsuccessful treatment outcomes need specific support, as well as couples experiencing relationship strains.

As work affects treatment and treatment affects work, including damage to career prospects, a new focus on workplace policy for fertility treatment is necessary, particularly to improve the current gender disadvantage for employed women having treatment. Policy should be combined with guidance to support employers who may have limited understanding of the needs of someone having treatment. Policy and support have the potential to reduce levels of psychological distress.

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