Experiences of involuntary childlessness and treatment in the UK: what has changed in 20 years?

Accepted for publication in Human Fertility

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Acknowledgements

We wish to thank Emma Hughes for her support with data analysis.

Funding

This work was supported by Fertility Network UK.

Disclosure of interest

Susan Seenan is retired Chief Executive of Fertility Network UK. She contributed to designing and promoting the survey and commented on the draft manuscript but was not involved in data analysis and interpretation which was conducted independently by the other authors.

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Abstract

This study examined the financial, emotional and relationship impacts of involuntary childlessness and treatment, and satisfaction with support from professionals. 796 participants in the UK completed an online survey based on a survey conducted in 1997. 55% of participants had to pay for at least part of their treatment. High levels of distress were experienced and 42% experienced suicidal feelings at least occasionally. Those most at risk of suffering distress and suicidal feelings at some point had only experienced unsuccessful treatment outcomes, spent longer trying to conceive and experienced some relationship strains. 75% would like to have counselling if it were free but 45% received counselling and 54% of these had to fund some of it themselves. Thus although advances have been made in the availability of funded treatment and psychological support, involuntary childlessness and treatment continue to have financial, emotional and relationship consequences for many people. While counselling was generally reported to be useful, a whole clinic approach involving all fertility clinic staff in the psychosocial care of clients is advisable.

Key words: involuntary childlessness, fertility treatment, distress, counselling, support, funding

Introduction

In 1997 a National Infertility Awareness Campaign (NIAC) survey of 980 people in the UK (Kerr et al., 1999) found a wide range of negative emotions were experienced by people having fertility treatment, with one in five reporting they experienced suicidal feelings and one in three reporting that fertility problems had strained the relationship with their partner. More recently, Domar et al., (2012) obtained similar findings, and strain in the relationship with a partner is reported particularly by women (Tao et al., 2012). Women and men having difficulty conceiving and those who choose to pursue treatment (Greil et al., 2010) are likely to experience mental ill health. For example, Volgsten et al. (2008) found that 31% of women undergoing treatment and 10% of men had one or more diagnosed mental health conditions, such as depression or anxiety, and depression is related to fertility-related distress (Peterson et al., 2014). There is also evidence that anxiety and depression may affect treatment outcomes resulting in lower pregnancy rates (Matthisen et al., 2011; Purewal et al., 2017, 2018). Depression is particularly common in women following unsuccessful treatment (Lund et al., 2009) as well as suicidal feelings and a greater risk of suicide (Cousineau & Domar, 2007; Kjaer et al., 2011). For example, women, showed an increase in depression and anxiety after unsuccessful treatment and a decrease after successful treatment resulting in a pregnancy. Six months later women showed no recovery after unsuccessful treatment (Verhaak et al., 2005). Prior depression has been found to predict depression among women and men following unsuccessful treatment, so assessment and support prior to treatment is needed (Holley et al., 2015).

It is a requirement that counselling is offered to patients seeking fertility treatment in the UK (HFEA, 2019; NICE, 2013). This is especially important given that a review of research evidence found that psychological intervention is associated with higher pregnancy rates

(Frederiksen et al., 2015). However, psychological care is often insufficiently geared towards dealing with the severe and long term emotional impacts, counselling practices vary dramatically across counsellors and clinics (Visser et al., 2018) and take-up of counselling, due to barriers such as the cost of counselling, is poor (Boivin et al., 1999). The NIAC survey in the UK in 1997 (Kerr et al., 1999) found that 71% of respondents reported they would request counselling if it were offered free, but 31% had received counselling and only 12% had been provided with National Health Service (NHS) funded counselling.

Furthermore, although involuntary childlessness and the use of assisted conception are increasing (HFEA, 2018), and the WHO (2009) refers to infertility as a disease and a disability, access to funded treatment is often limited (Fertility Fairness, 2017). The NIAC survey (Kerr et al., 1999) found that about 75% of respondents had to pay for some or all of their treatments (with 45% spending more than £4,000), and only 18% had their treatments fully funded by the NHS. The national funding situation has changed since 1997, and NICE recommends that the NHS provides up to three full cycles to those eligible. However, in practice, the number of treatment cycles offered and eligibility criteria differ across the four countries of the UK, leaving many individuals unable to access this level of treatment (NICE, 2013; Kennedy, Kingsland, Rutherford, Hamilton & Ledger, 2006; Fertility Fairness, 2017).

Since the NIAC survey is now twenty years old, Fertility Network UK commissioned an updated survey with a new sample, the findings of which are reported in this paper. The survey aimed to examine:

- the emotional and relationship impacts of fertility problems and treatment, including which groups experience the highest levels of distress,

- how treatment is funded and how much is spent by participants, including differences across the four countries of the UK,
- access to, use of and satisfaction with support from professionals

Materials and methods

Following University ethics committee approval, an online survey was promoted by Fertility Network UK in 2016 through their social media, website, digital magazine and at events (The Fertility Show and the British Fertility Society Annual Conference). Other organizations were also asked to promote the survey (e.g. British Fertility Society, Association of Clinical Embryologists, British Infertility Counselling Association, Donor Conception Network, Brilliant Beginnings), HFEA licensed clinics and online support networks such as FertilityFriends. 769 participants provided consent and completed the anonymous survey.

The online survey was based on the 1997 NIAC survey (Kerr et al., 1999) so that comparisons were possible. Section 1 covered sociodemographic and treatment information. Section 2 covered treatment funding (NHS or private) and country, number of cycles of NHS treatment offered, reasons for not being able to access NHS treatment (open ended question), how many treatment cycles were received, and how much money had been spent. Section 3 covered whether participants received counselling, how this was funded (NHS funded or paid for) and whether and why this was helpful (open ended question), as well as whether support was received online from fertility organizations or forums, and from support groups. Section 4 covered the impact of fertility problems and//or treatment on relationships with friends, family and partner. Emotional distress was measured by 18 emotions such as suicidal feelings, depression, isolation, frustration, and anger from Kerr et al. (1999). Participants were asked to respond regarding the extent to which they had experienced each in relation to their fertility problems and/or treatment. Response options were 1 = not at all, 2 = occasionally, 3 = sometimes, 4 = often, 5 = all of the time. Responses were summed to form an overall measure of distress, which was statistically reliable (α = .94).

Statistical analyses

Descriptive statistics (frequency counts or means and standard deviations) were generated for all variables. ANOVA was used to examine group differences where one variable was categorical and the other continuous. Pearson's correlations were used to determine the relationship between two continuous variables. Statistical significance was set at $p < .05$. Responses to open ended questions were analysed using content analysis with codes agreed by the first author and a research assistant.

Results

Participant characteristics

Of the 769 participants, 98% were women, 93% were in a heterosexual relationship and 94% described themselves as white. The average age of participants when they started treatment was 32.59 years (*SD* = 4.78). Participants had on average been trying to conceive for 4.47 years (*SD* = 3.10), with 64% trying for less than 5 years, 27% for 5-9 years and 9% for 10 years or more.

Treatment outcomes

In total 18% of the sample had not received any treatment at the time of the survey, 23% were currently having treatment but may also have previously experienced unsuccessful attempts (i.e. no pregnancy or a pregnancy but no live birth), 26% achieved a successful pregnancy (i.e. a live birth) but may also have previously experienced unsuccessful attempts and 33% had only unsuccessful attempts and did not intend to have further treatment or were undecided. Of the 554 participants who had been through treatment at least once, 36% had a successful pregnancy (i.e. a live birth), 68% experienced treatment resulting in no pregnancy at least once and 31% experienced a pregnancy but no live birth at least once.

Funding for treatment

41% of participants had or planned to have NHS funded treatment, 31% private treatment, 24% a mix of both and 4% were not sure yet, so at least 55% had to pay/were going to have to pay for some or all of their treatment. 81% of participants had or planned to have treatment in the UK, 4% abroad, 9% in both and 6% were unsure. Among participants who were having or had already received treatment, there were no significant differences in levels of distress between those who paid for treatment and those who did not or between those who had treatment in the UK and those who went abroad. Key reasons for not being able to access NHS treatment are shown in Table I.

Table I near here

Of the participants who were having or had already received treatment, the number of cycles they had received is shown in Figure 1. Across NHS and private treatment, 32% of participants received one cycle of treatment 30% received two, 19% received three and 19% received more than three cycles. Of the 530 participants who had or were considering NHS treatment, 39% were told they could have one cycle, 25% were told two, 19% were told three and 17% did not know.

Figure 1 near here

Participants who were having or had received treatment had spent on average £11,378 (*SD* = 13,872) on treatment, with 32% spending less than £5,000, 22% spending £5-9,000, 23% spending £10-19,000, 12% spending £20-29,000 and 11% spending more than £30,000.

Geographic variation in access to NHS funded treatment

77% of the sample lived in England, with 9% in Scotland, 9% in Northern Ireland (NI) and 5% in Wales. Of those who were having or had received treatment, those living in NI received fewer NHS cycles compared to those in Scotland, England and Wales and those in England had received fewer than those in Scotland (F = 5.59, p = .001). 97% of participants in NI were told they were entitled to only one cycle, compared to 42% in England, 21% in Wales and 15% in Scotland. This is consistent with current NHS provision whereby three treatment cycles are offered in Scotland, two in Wales, one in NI and between zero and three (although rarely three) in England, depending on the Clinical Commissioning Group (CCG), to eligible women aged under 40. Additionally, Scotland and Wales and some CCGs in England offer one treatment cycle to women aged 40-42 (Fertility Fairness, 2017).

Relationship and emotional difficulties

Involuntary childlessness and treatment had an impact on some relationships, as shown in Figure 2. The majority of relationships with friends or family were unchanged or mixed (sometimes difficult, sometimes fine), although a number of friendships ended. Impact on their relationship with a partner also varied; 29% of participants reported their relationship with their partner was improved or unchanged, 15% said it was strained or ended and 56% said it was strained initially, now improved or was mixed (sometimes difficult, sometimes fine).

Figure 2 near here

Figure 3 shows on average the frequency with which various emotional impacts of involuntary childlessness and treatment were experienced. The average score for sadness (4.28) means that this was experienced the most (almost ‘all the time’) and 99% experienced this at least ‘occasionally’, whereas suicidal feelings were experienced the least (1.82) but 42% still experienced suicidal feelings at least ‘occasionally’.

Figure 3 near here

Analyses were conducted to examine which participants were most at risk of experiencing overall distress (*M* = 65.11, *SD* = 14.04). Those who had only unsuccessful outcomes (who had either decided not to have more treatment or were undecided) reported greater distress (F = 5.42, p < .001) compared to those who had not received treatment, were currently having treatment or had successful treatment resulting in a live birth. Additionally, those who had only unsuccessful outcomes had spent longer trying to conceive, including prior to treatment (F = 14.80, p < .001), and spending longer trying was associated with greater distress (r = .17, p < .001). Furthermore, as shown in Figure 4, there was an association between the relationship with a partner and distress (F = 17.79, p < .001), where having a strained relationship or even a mix of it being sometime difficult, sometimes fine were problematic.

Figure 4 near here

Support from professionals

59% of participants sought online support from a fertility organization or forum. Only 17% attended a support group but 50% of those who did not would definitely have liked to attend had there been one nearby. 75% of participants reported they would like counselling if they did not have to pay for it. Overall 45% actually received counselling, with 46% of these 346 participants having received free NHS counselling, 17% having to top this up with counselling they paid for themselves and 37% having to pay for all the counselling they received, so 54% of those who received counselling had to fund some of it themselves. Thus 28% of the total sample received some NHS funded counselling. There was no difference in distress between those who did and did not attend counselling. However, 75% of participants who had received counselling said they found it useful. Reasons that counselling was useful or not are reported in Table II.

Table II near here

Discussion

Advances have been made in the availability of funded treatment and psychological support since a survey 20 years ago. However, distress levels remain high and there remains a lack of appropriate, funded support from, for example, counsellors.

Access to NHS funded treatment

Although 55% of the participants were having to pay for at least part of their treatment, this was an improvement since the 1997 NIAC survey, where 75% had to pay (Kerr et al., 1999). However, only 19% were told they were entitled to three NHS funded treatment cycles, as recommended by NICE (2013). While NHS CCGs in England have difficult decisions to make, patchy funding in England and geographical differences across the countries of the UK

(Fertility Fairness, 2017), and reports of no funding at all by some participants in this survey should be addressed in future policy and practice. It has been argued that involuntary childlessness should be viewed in the same light as other chronic non life-threatening conditions; a disease and a disability (WHO, 2009). Past research (e.g. Volgsten et al., 2008) and the findings of the present study also suggest involuntary childlessness has significant mental health implications. Furthermore, for those not receiving (sufficient) NHS funded treatment, the financial costs can be great, which may in part drive the decision by some to seek more affordable treatment aboard. These costs appear to have increased since the 1997 NIAC survey when 45% spent over £4,000, compared to 68% spending over £5,000 in the current study.

Emotional impact of involuntary childlessness and treatment

Compared to the 1997 NIAC survey, negative emotional impacts of fertility problems and treatment remained high. For example, those who responded to the current survey reported feeling on average sad, frustrated and worried almost ‘all of the time’ and 42% had experienced suicidal feelings at least ‘occasionally’, compared to 20% reporting suicidal feelings in the NIAC survey. There was no difference here between those who had not received treatment and those who were currently having treatment. Thus in the present study involuntary childlessness itself was distressing and receiving treatment did not appear to improve or reduce this. However, those most at risk of experiencing high levels of distress had only experienced unsuccessful outcomes, had spent longer trying to conceive, and had experienced some relationship strains. Previous research (Lund et al., 2009; Verhaak et al., 2005) has also found that unsuccessful treatment creates particular emotional distress. In the present study 68% of those who had received treatment experienced unsuccessful treatment (i.e. no pregnancy) at least once and 31% achieved a pregnancy but no live birth at least once. The high levels of emotional distress and suicidal feelings reported suggest a need for access to sources of psychological support, such as funded counselling. Furthermore, while fewer participants in current study reported their relationship with their partner to be strained compared to the 1997 NIAC survey (11% v 31% respectively), relationship strains (including a mix of it being sometime difficult, sometimes fine) were linked to greater emotional distress. Thus, as there may be relationship consequences of involuntary childlessness and treatment, couples may benefit from accessing psychological supports, such as relationship counselling, together.

Support from professionals

Despite HFEA (2019) mandatory requirements to offer counselling, it was received by 45% of the participants, and 54% of these had to fund at least some of it themselves. Thus of the total sample, 28% received some NHS funded counselling. Although this is an improvement from the NIAC survey in 1997, where 31% received counselling and 12% received NHS funded counselling, this is still problematic as financial cost has been found to be a barrier to take-up of counselling (Boivin et al., 1999). However, in the present study there was no difference in levels of distress between those who attended counselling and those who did not attend, which might suggest that counselling is not a crucial factor in easing distress. In contrast, other research has obtained more positive findings, as well as finding that psychological intervention is associated with higher pregnancy rates (e.g. Frederiksen et al., 2015). This contrast with previous research may be explained by differences in the sources or nature of the counselling received, but a limitation of this study is that we do not have this information. For example, in the present study we do not know details of the source of counselling; those receiving NHS counselling may have accessed this through their G.P. or their fertility specialist and those who paid may have received this through their private fertility clinic or from various other private sources. Additionally, we do not know whether the counselling took account of European

Society of Human Reproduction and Embryology (ESHRE) guidelines for fertility counselling (Boivin et al., 2011), such as using appropriate assessment tools, choosing the most appropriate form of counselling for the individual/couple and their situation, and understanding differing experiences for heterosexual couples, lesbian couples and single women, as well as gender differences, problems in the marital or sexual relationship and decisions regarding third-party reproduction. Nevertheless, while there was no difference in levels of distress between those who did and did not receive counselling in the present study, 75% of those who received counselling found it useful. In addition to the potential utility of support from counsellors, ESHRE guidelines (Gameiro et al., 2015) call for a fully integrated approach to psychosocial support involving all fertility clinic staff. This approach involves all staff understanding patient preferences regarding support and being able to detect and address the needs of patients, by referring them for counselling where appropriate, before, during and after treatment. This includes patients' behavioural (e.g. lifestyle), relationship, emotional and cognitive (e.g. information) needs.

Another avenue of support is ensuring there is sufficient availability of support groups. In the present study 59% sought online support from a fertility organization or forum. Online support groups provide anonymity and are a convenient and cost-effective way to access support, although one potential disadvantage is encountering misleading information (Coulson, 2019). There is evidence suggesting that participation in health-related online support groups is beneficial but robust evidence is still lacking (Coulson, 2019). However, online support is not necessarily a substitute for face-to-face support groups and in the present study 17% of participants attended a support group but 50% would like to had there been one nearby. This suggests support groups are valued by many people and they have been found to be an important adjunct to psychological support (Worrall et al., 2018).

Limitations of this study

The sample was self-selected and lacking in diversity, thus limiting the generalizability of the findings. In particular, the findings do not necessarily reflect the experiences of men, same sex couples, non-white people and those from differing cultural backgrounds. For example, involuntary childlessness and treatment have more of an influence on women’s mental health (Lund et al., 2009; Verhaak et al., 2005), so this study may have found less of an impact if more men had been included. Similarly, in some cultures childlessness is viewed as a personal failure and parenthood is considered a necessary part of adulthood and especially womanhood (van den Akker, 2012), but such issues would not be reflected here due to the lack of ethnic diversity. This lack of diversity is unfortunately common to much research on involuntary childless populations (e.g. Frederiksen et al., 2015). Future research could focus recruitment more on targeting organizations, groups and forums specifically supporting these particular groups. Furthermore, many participants were asked to retrospectively recall their experiences of treatment, which could have led to recall bias. This is compounded by the fact that the length of time between treatment ending and completion of the survey is not known. Additionally, almost one-fifth of the sample had not received treatment so were reporting on the impacts of involuntary childlessness, and not also on the treatment. Nevertheless, they did not differ in reported levels of distress from those who were currently having treatment. Finally, our measure of distress was based on the 1997 NIAC survey. It was not possible to use pre-existing measures of, for example, anxiety or depression, as these measures generally address how someone is feeling now or has felt recently and would have made comparisons with the 1997 survey difficult. However, the measure used was found to statistically highly reliable in the present study.

Conclusion

The findings suggest that involuntary childlessness and treatment continue to have financial, emotional and relationship consequences for many people. Yet despite some advances in the availability of funded treatment and psychological support, treatment funding remains patchy across the UK and this inequity needs to be reduced. There also remains a lack of appropriate, funded psychological support. While counselling was generally reported to be useful, a whole clinic approach involving all fertility clinic staff in the psychosocial care of patients may be advisable. This approach involves staff being able to detect the behavioural, relationship, emotional and cognitive needs of patients before, during and after treatment, and address these needs by referring patients for counselling where appropriate.

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Table I Key reasons for not being able to access NHS treatment

	% of the 297 participants 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%

Table II Key reasons counselling was helpful or was not helpful

	% of the 257 participants 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/normalized feelings	17%
Helped to accept the situation/face the future	11%
Helped relationship with partner	9%
Someone who was non-judgmental	6%
Reasons counselling was not helpful	
Wrong focus or timing	39%
It was a tick box exercise	25%
Counsellor was unsupportive	24%
Other reason (e.g. it was only one session)	16%
Counsellor lacked facts/knowledge of fertility	12%

Figure 1 Number of treatment cycles received by participants who received NHS or private treatment or both

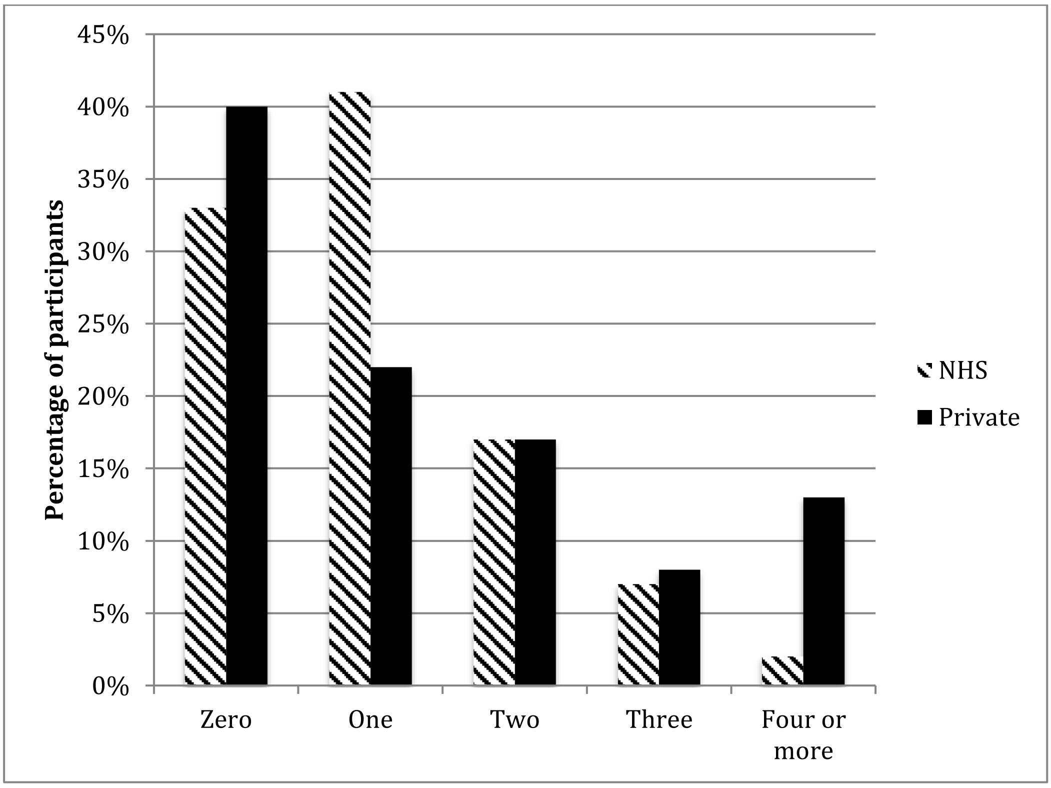

Figure 2 Impact of involuntary childlessness and treatment on relationships

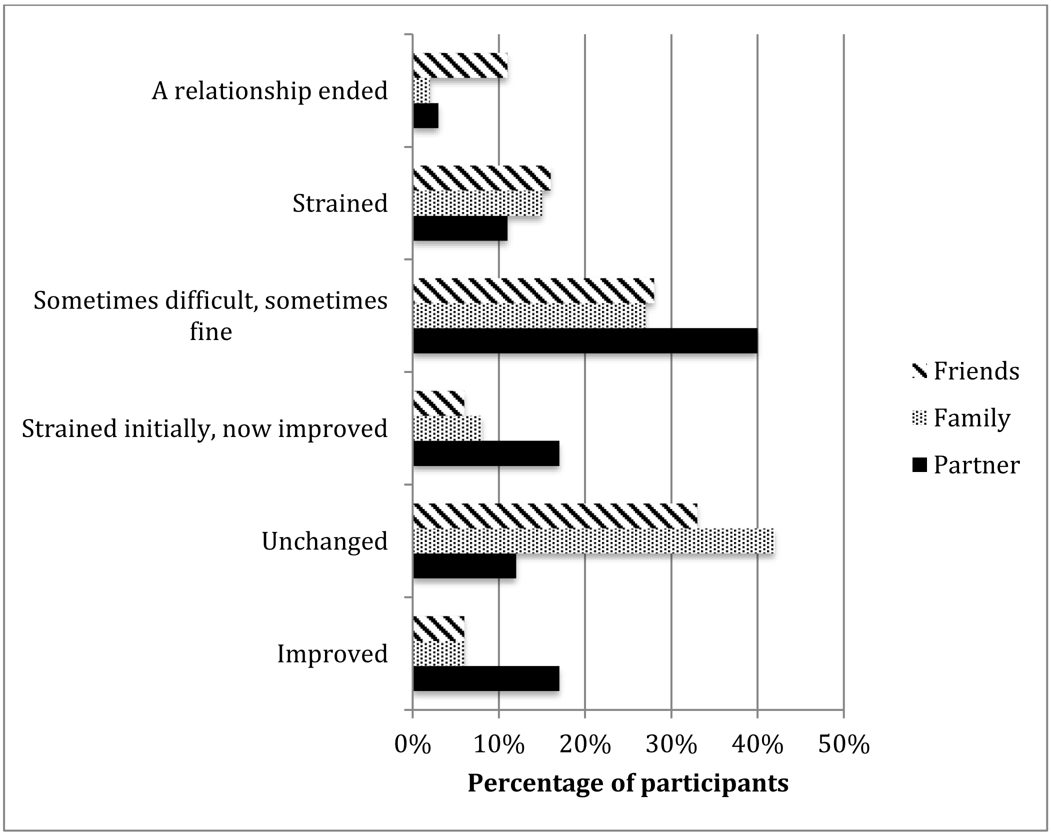

Figure 3 The emotional impacts of involuntary childlessness and treatment

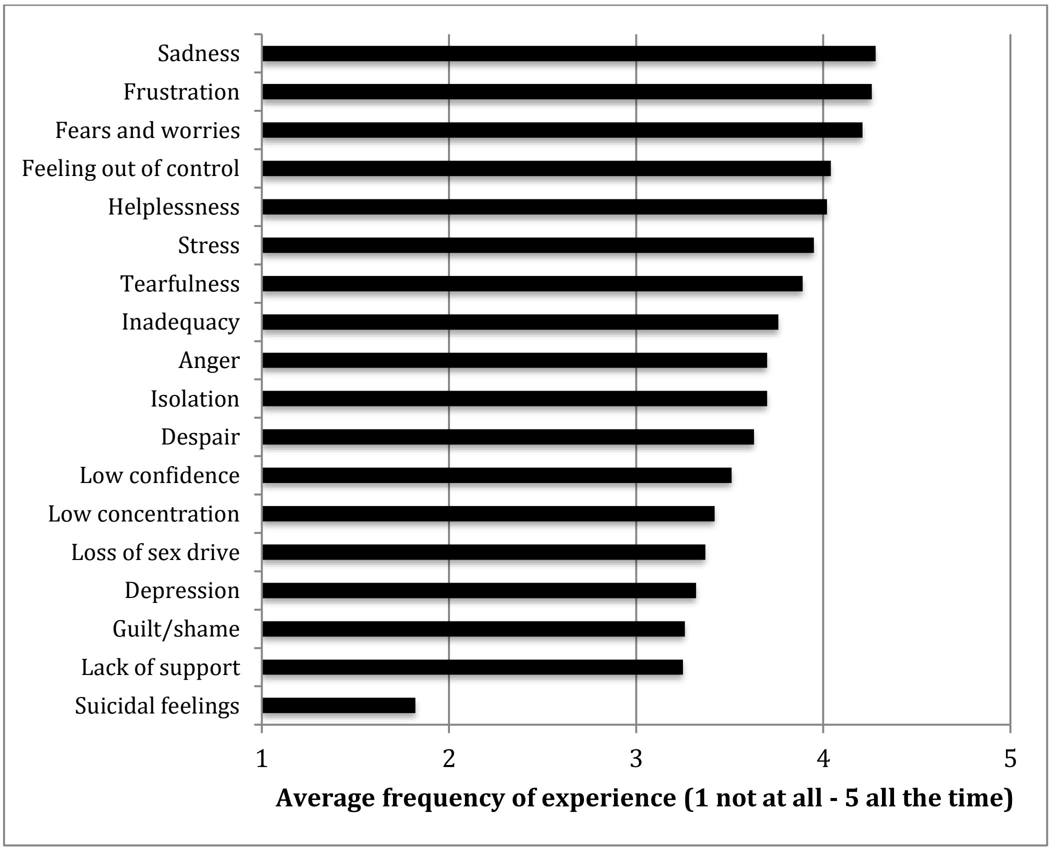

Figure 4 The association between the impact of involuntary childlessness and treatment on the relationship with a partner and level of distress