Experiences and psychological distress of fertility treatment and employment

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Abstract

Purpose: This study examined experiences and psychological distress about fertility treatment in people combining work and treatment.

Methods: 563 participants in the UK completed an online survey asking about difficulties in combining work and treatment; workplace disclosure, support, absence and policy; and psychological distress about treatment.

Results: Absence from work and perceptions that treatment has an impact on work and career prospects were reported by the majority of participants and this was related to the psychological distress of treatment. Around three quarters of participants disclosed to their employer and colleagues. The key reason for disclosure was needing to ask for absence from work and the main reason for non-disclosure was privacy. Workplace policy relating to managing fertility treatment and support from colleagues and their employer was related to reduced psychological distress but workplace policy was reported by less than one quarter of participants.

Conclusions: Difficulties experienced in combining work and treatment suggest that support is needed. Specific workplace policy, guidance for supervisors and flexibility in fertility clinic times should help support employees during treatment and reduce psychological distress, thereby potentially influencing physical health and treatment outcomes.

Key words: assisted reproduction, infertility, psychological distress, workplace, disclosure, support, workplace policy.

Introduction

Latest statistics from the HFEA show that in the UK during 2014, 52,288 women had a total of 67,708 cycles of IVF or ICSI and these figures continue to rise [1]. Fertility treatment is a physically, psychologically and financially demanding process. Both women and men undergoing treatment have been found to experience high levels of distress worldwide, with women experiencing more distress than men [2, 3]. Although the evidence is equivocal, the distress experienced may itself affect treatment outcomes [4, 5] and psychological support may improve outcomes [6], so it is important to understand the difficulties experienced during treatment and the conditions that may create psychological distress. While there is much research exploring the experience of fertility treatment, there has been limited research examining experiences of combining treatment and employment. As the majority of men and women of child-bearing age are employed and spend much of their waking lives at work, specific difficulties and dilemmas are likely to be encountered. However, to date there has been no large-scale survey examining the extent to which combining treatment and work is perceived to be problematic. This is the aim of the present study.

A key difficulty in combining work and treatment is the need for time off work for clinic appointments. Bouwmans et al. [7] found that women in the Netherlands were absent from work for on average 23 hours during a treatment cycle. The main reason for absence reported by half the sample was clinic appointments but physical problems (27%) and emotional problems alone or combined with physical problems (23%) were also reported. Absence from work in women experiencing emotional and/or physical problems rose to on average 41 hours per cycle. Thus there is some evidence that absence is a problem but how this is managed is less clear, especially as statutory policy is lacking. For example, in the UK fertility care is not a statutory right. Time off for clinic appointments and any associated sickness is considered

the same as time off for other medical appointments or other sickness absence, although an employer must not treat a woman less favourably than a man in a similar situation, since this could amount to sex discrimination [8,9]. Once embryo implantation takes place women are protected by the Equality Act [10] and if treated unfairly this would be considered pregnancy discrimination. The Employment Statutory Code of Practice [8] suggests organizations should treat requests for absences for fertility treatment sympathetically and suggests they consider procedures in this area. Some organizations have workplace policy in this area but this is not normative and policies vary. Examples include 5 days of paid leave a year for women, or in rare cases more generous policies of up to 20 days, but fewer days or only annual leave for men, [9].

Due to a lack of research, the extent to which workplace policies supporting fertility treatment are available across organizations and the impact of these is not known. However, research on other workplace policies may serve as a basis for understanding the potential impact. For example, in countries, such as the UK, statutory policies exist to support parents and carers, as well as absence from work for pre-natal appointments and maternity and paternity leave. While workplace culture is not always supportive of expectant and existing parents or carers and discrimination has not been eliminated [11], the existence and use of policies, that for example involve flexible working, is linked to reduced distress [12 ,13]. This link may be mediated by workplace perceptions and experiences. For example, such policies are linked to perceptions of reduced conflict between work and non-work life [14] (and perceptions of increased job security, satisfaction and commitment [15]), which in turn is linked to better mental and physical health outcomes [16,17]. This raises the possibility of a similar framework for those undergoing fertility treatment, whereby workplace policy and support may help reduce difficulties in combining work and treatment and support job

security, thus reducing psychological distress. This is particularly important because theories of the stress response suggest that distress (or chronic stress), such as that associated with fertility treatment, causes prolonged activation of major systems of the body, such as the hypothalamus pituitary-adrenocortical axis, with deleterious mental and physical health consequences [18,19]. Indeed, evidence suggests that distress may affect fertility treatment outcomes [4,5]. It may also influence treatment outcomes indirectly via drop-out from treatment or using unhealthy behaviours to cope [20]. Thus, if workplace policy and support reduce distress, perhaps by lessening conflict between work and fertility treatment, this has the potential to reduce the likelihood of mental ill health and the chances of an unsuccessful treatment outcome.

In order to use policies to manage absence or to seek workplace support, employees have to disclose. However, the lack of statutory policy and thus legal protection for those having treatment may undermine the likelihood of disclosure. In Denmark, Martins et al. [21] found that 86% of women and men disclosed to close colleagues and 48% to distant colleagues. However, in the USA Finamore et al. [22] found that 57% of the employed women they surveyed did not disclose to their employer due to their or their partner's privacy, career concerns, not wanting special treatment and embarrassment. Among the 43% who disclosed, the reasons were needing absence from work, having a good relationship with their employer, having nothing to hide and needing extra support. There was some evidence of an association between disclosure and number of days off work but there was no association between disclosure and stress levels. Qualitative studies in the UK [23] and New Zealand [24] confirmed concerns about disclosure in the workplace included the personal nature of treatment and career prospects. Motives for disclosure included feeling it was necessary and shared workplace values, experiences and friendships. However, while there is some research

on reasons for workplace disclose, little is known about the extent of support that is subsequently received and the perceived impact of this.

Furthermore, little research has examined the experience of combining work and treatment more broadly. Domar et al. [25] found that 24% of their sample of women across four European countries reported that work interfered with treatment and a qualitative study of 32 women in the UK [26] found that women experienced bi-directional conflict between the demands of work and both the time and emotional demands of treatment. This was influenced by the extent to which they shifted their identity and priorities away from career to becoming a mother during treatment (a finding supported by Walker [24]). There was also evidence that conflict may worsen with more cycles of treatment and that workplace support and job flexibility were crucial for managing conflict. While this qualitative research [24,26] provides some in depth insights, it involved only a small number of women. To date, there has been no large-scale quantitative research examining the extent of these experiences and whether, for example, difficulties in combining work and treatment worsen with more cycles of treatment or are linked to levels of psychological distress. This is the contribution of the present study.

In summary, this study reports the findings of a large survey in the UK examining experiences and perceptions of combining treatment and work and the extent to which this is perceived to be problematic and linked to psychological distress. Due to the lack of research in this area, the study aimed to describe the problem and provide a background and basis for future more complex research. More specifically, the study aimed to examine:

- Absences from work and the existence of relevant policies. It was predicted that:
    - Existence of policy would be related to absence from work
    - Absence would be related to increased psychological distress of treatment

    - Existence of policy would be related to reduced psychological distress of treatment

- Disclosure and perceptions of support. It was predicted that:
    - Disclosure and perceptions of support would be related to absence from work
    - Disclosure and perceptions of support would be related to reduced psychological distress of treatment
- The perceived impact of work on fertility treatment and of treatment on work and career prospects. It was predicted that:
    - Perceived bi-directional impacts of work and treatment would be related to more cycles of treatment
    - Perceived bi-directional impacts of work and treatment would be related to absence from work
    - Perceived bi-directional impacts of work and treatment would be related to increased psychological distress of treatment

Materials and Methods

Participants

The research reported in this paper was part of a larger online survey of the impact of infertility and fertility treatment in the UK. The research was approved by the authors' University Psychology Department research ethics committee. Participants were recruited by Fertility Network UK through their social media, website, digital magazine and at events, and also shared with other professional organisations, corporate partners, clinics, and online support networks such as FertilityFriends. As is common with online surveys [27], it is not possible to know how many participants the survey reached, so a response rate is not reported, but 769 participants completed the larger survey and this paper reports on a sample

of 563 who were employed while having fertility treatment. 98% of the sample were women, 93% were in a heterosexual relationship and 95% described themselves as white. The average age of participants when they started treatment was 32.93 years (*SD* = 4.72) and the average number of treatment cycles received was 2.62 (*SD* = 2.23). While this sample is not representative of the UK population, it is similar to other samples in online research on infertility and fertility treatment, with participants tending to be white, middle class, educated, professional, older and in cohabiting relationships [28] and predominately women [5].

The survey

The larger survey covered demographic and treatment information, funding for treatment, support for fertility problems and treatment, and the impact of fertility problems and treatment on relationships and psychological distress. The psychological distress of treatment was measured by 18 items including suicidal feelings, depression, isolation, frustration, anger and guilt based on Kerr et al. [29]. Participants were asked the extent to which they had experienced each item in relation to their fertility problems and treatment. Response options ranged from 1 (not at all) to 5 (all of the time). Responses to the items were summed to form an overall measure of distress related to treatment, with possible scores ranging from 18 to 90. This measure was reliable (α = .94; *M* = 65.11, *SD* = 14.04).

The final section of the survey covered whether participants reduced their hours or left their job during treatment and questions about the effect of treatment on the job (e.g. lack of concentration), fears of treatment affecting career prospects, effects of treatment on career, and effects of the job on treatment (e.g. hard to go to appointments) (all with response options: yes definitely, yes a bit, not sure and no). Participants were also asked about the

amount of time taken off work, what policies or practices they used to take time off, and whether their workplace had a specific policy for people having fertility treatment (with response options: yes, not sure and no). They were asked whether they disclosed to their employer and colleagues and, if they disclosed, whether they received support from their employer and colleagues (with response options: a great deal, a bit and none). Finally, they were asked about reasons for disclosure or non-disclosure to their employer, and whether their employer would benefit from education to help them understand the needs of people having treatment (with response options: yes, not sure and no). The survey is available from the authors upon request.

Data analysis

Frequency counts were calculated for categorical variables and means and standard deviations for continuous variables. Bivariate analyses were conducted using ANOVA to examine group differences where one variable was categorical and the other continuous, such as whether there was a difference in levels of treatment distress between people who did and not did disclose. Pearson's correlations were used where both variables were continuous, such as whether there was a relationship between absence from work and levels of treatment distress. Finally, a multiple regression analysis was used to examine the predictors of distress.

Results

Absence from work and policy

The average number of days taken off work during a treatment cycle was 8.74 (SD 9.32). 50% of participants took up to a week off work, 24% took up to two weeks, 15% took up to three weeks, 3% took a month and 8% took more than this and in some cases up to several months. Taking more days off was associated with greater psychological distress ($r = .14$, $p =$

.002). Absence from work for treatment was managed in various ways, as shown in Figure I. 'Other' methods include special leave, swapping shifts or reducing hours or quitting work.

Figure I near here

23% of participants reported their workplace had some policy relating to treatment (19% were not sure and 58% said it did not). The available policies varied greatly. In some cases policies stated that IVF is elective so no absence from work was 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 (paid or unpaid) days of absence (generally between 2 and 10 days) but often restricted the number of treatment cycles that would be supported (generally between 1 and 3). As shown at the top of table 1, levels of psychological distress (but not absences from work) were lower among those who reported the existence of policy compared to those who reported no policy.

Table 1 near here

Disclosure and support

74% of participants disclosed to at least some colleagues. Of those who disclosed 35% received a great deal of support, 47% received a bit of support and 18% received no support. 72% disclosed to their employer. Of those who disclosed 42% received a great deal of support, 48% received a bit of support and 10% received no support. As shown in Table 1, those who disclosed to their employer and colleagues had more days off (but did not report lower levels of psychological distress) and those who received the most employer and

colleague support reported the lowest levels of psychological distress (but did not report more absence from work).

Reasons for non-disclosure to their employer are shown in Figure II. 'Other' reasons include 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 III. '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 had IVF policy.

More than half of participants (60%) reported their employer would benefit from education/support to help them better understand the needs of employees having treatment (20% were not sure and 21% felt this was not necessary), suggesting that employers were generally seen as unaware of the unique needs of employees undergoing fertility treatment.

Figures II and III near here

Combining work and treatment

Fifty-eight percent of participants reported work affected their treatment 'definitely' or 'a bit' (e.g. it was difficult to make clinic appointments) and 87% reported treatment affected their work (e.g. it was difficult to concentrate). 51% were concerned it would affect their career prospects and 35% felt it actually affected their career. Furthermore, 13% reduced their hours and 6% left their job due to treatment. As shown in Figures IV and V, those who reported work affected treatment and that treatment affected work, career prospects and had actually affected their career reported greater psychological distress ($F = 4.76$, $p = .003$; $F = 26.38$, p

< .001; F = 11.95, p <.001; F = 6.76, p < .001 respectively) and had more cycles of treatment (F = 2.70, p = .04; F = 4.98, p = .002; F = 3.91, p = .009; F = 4.86, p < .001 respectively) than those who did not think there was an affect or were not sure. Additionally, those who reported that treatment affected work reported more absence from work (F = 2.85, p = .04).

Figures IV and V near here

Finally, a multiple linear regression analysis was conducted to predict the psychological distress of treatment from the seven predictors that were significant in the analyses discussed so far: perceptions that work affected treatment and that treatment affected work, career prospects and their career, employer and colleague support and number of days of absence from work. As the first six of these variables are categorical, they were dummy coded. After controlling for the the number of treatment cycles received, 18% of the variance in treatment distress was explained (R^2 = .18, F = 4.74, p < .001). Perceptions that work definitely affected treatment (ß = .54, p <.001) and affected treatment a bit (ß = .36, p <.001) compared to perceptions that work did not affect treatment were the only significant predictors of psychological distress.

Discussion

This study explored the experiences of people combining work and fertility treatment. More than half of the participants reported that work affected their treatment, but the impact of treatment on work was worse; the vast majority of participants felt that having treatment affected their day-to-day work, half were concerned that treatment would affect their career prospects, one third felt their career was actually damaged as a result, and one fifth had to reduce their work hours or quit their job. These concerns increased with more cycles of

treatment and were all related to greater levels of psychological distress about treatment. This supports a qualitative study [26] which suggests that both the time demands of treatment and the strain of treatment conflict with the demands of work, with difficulties relating to 'body time' (that is, waiting for when the body is ready for egg collection) further compounding the unpredictability of planning absences from work. Furthermore, bodily and associated emotional symptoms must also be managed in the workplace to conform to gendered ideal worker norms of prioritizing work over personal life and not bringing emotions to work [11].

Difficulties in combining day-to-day work and treatment were also related to greater absence from work. The average number of days of absence from work during a treatment cycle (8.74) was significantly more than the average 23 hours reported by Bouwmans et al. [7]. However, Bouwmans et al. also reported an average of 41 hours of absence for those experiencing greater emotional and physical problems relating to treatment and half of their sample reported these problems as the main reason for their absence. In the present study, more days of absence were associated with greater psychological distress about treatment, so emotional problems associated with treatment are likely to be part of the explanation. However, physical problems such as side-effects or complications of treatment are also likely to be linked to absences from work and future research should examine specific reasons for absences. Not only do physical problems such as side-effects or complications of treatment increase psychological distress and treatment drop-out [30] but distress in turn may exacerbate physical problems. Thus emotional and physical problems associated with treatment interact and are likely to be compounded by difficulties of combining work and treatment and associated job insecurity.

While the impact of treatment on work and career was the biggest concern for participants (supported by the results of the multiple regression analysis), more than half also reported that work affected their treatment (which is almost twice as many as reported by Domar et al. [25]) and this was related to greater psychological distress about treatment. Payne et al. [26] found that women undergoing fertility treatment felt that work interfered with treatment by affecting their ability to make clinic appointments and focus on treatment. They also feared that work demands would undermine treatment outcomes; once again emphasizing the potential psychosomatic implications. Since there is evidence to support a link between distress and treatment outcomes [4, 5], employer support and understanding to enable employees to make treatment a priority, while also maintaining their career trajectory, is crucial. However, only one quarter of participants reported the existence of workplace policy and less than half of the participants received good support from their employer (although 90% received at least some support). Workplace policy and support were linked to reduced psychological distress about treatment, which highlights the importance of both. Payne et al. [26] also highlight the importance of line manager support, especially if more absence from work is needed during a cycle and if many cycles of treatment are required. However, in order to seek support it is necessary to disclose. In the present study 72% of participants disclosed to their employer, which is more than the 43% reported by Finamore et al [22], although the main reasons for disclosing (or not) were similar. Although disclosure was not related to reduced psychological distress about treatment, the main reasons for non-disclose were a desire for privacy and the fear that their employer would not understand. Similarly to Finamore et al. [22], disclosure was related to more absence from work.

There are a number of factors that were not explored in the present study that may influence the experience of combining work and treatment. In particular, identity centrality in relation

to career and to becoming a parent may shift from the former to the latter during treatment [24,26]. For some women the drive to achieve parenthood may lead them to forgo their career. In contrast, for other women it may be crucial to maintain their career in case treatment is unsuccessful, so work may provide a focus and an important role in maintaining self-identity (24,26). Especially for these employees, damage to career prospects may be a particular concern.

The influence of factors outside of work should also be taken into account in future research. For example, being able to attend a *local* clinic that offers out of hours appointments, and benefiting from a high level of support outside of work, especially from a partner, may also help reduce time off work and conflicts between work and treatment. Greater social support is linked to better mental health in involuntary childless women [31] and the benefits of psychological support are also well recognized [6]. However, the fears associated with disclosure of treatment to those outside of the immediate personal network, as well as feelings of psychological distress, may be compounded in employed men and women, making them more vulnerable to the potential impacts of distress on treatment outcomes [4,5] and increasing their need for psychological support.

Overall the findings suggest that workplace policy is needed. This may reduce the obstacles of disclosing the personal in the public domain of work and reduce psychological distress of treatment (as suggested by the findings of this study). This may in turn have implications for physical health as evidence suggests that psychological distress may affect fertility treatment outcomes directly [4] or indirectly [20], as well as physical health more generally [32]. Workplace policy should incorporate flexibility, so that, for example, time can be made up later or shifts swapped. Guidance for supervisors, who may have limited understanding of the

needs of someone having treatment should also be incorporated. Indeed, in the present study fears that employers would not understand was the second most commonly reported reason for non-disclosure and more than half felt that their employer would benefit from guidance. Ideally this would be combined with clinical practice changes in flexibility of clinic appointments to allow at least some of these to take place outside of working hours. This would help reduce the amount of absence needed and may also lessen the need for workplace disclosure. Finally, psychological intervention to support those having fertility treatment is needed and should incorporate discussion of work-related difficulties and dilemmas.

There are some limitations to this study which should be considered in planning future research. This self-selected sample was limited in terms of diversity, thus limiting the generalizability of the findings. The focus on the UK and the lack of ethnic, and likely lack of socioeconomic diversity (although this was not measured) in the sample means that differing cultural and socioeconomic attitudes to infertility or childlessness were not included. For example, in some countries childlessness is viewed as a personal failure and parenthood is considered a necessary part of adulthood and especially womanhood [33]. The focus on one country or a sample lacking in diversity is unfortunately common to much research on infertile populations [e.g. 5,28]. Therefore, future research should aim to examine the experiences of a diverse range of participants. Furthermore, as many participants were asked to retrospectively recall their experiences, which could have led to recall bias, it would be useful to adopt a longitudinal approach during the course of treatment and beyond, to gain greater understanding of the experience of combining work and treatment as it unfolds. This would also enable examination of a model predicting psychological distress, physical health, and treatment complications and outcomes. The findings of this study suggest that such research would be a worthwhile endeavor.

In conclusion, research on combining employment and fertility treatment is limited but the findings of the present study suggest that psychological distress is compounded by the effects of work and provide a basis for future research. Reports that treatment affects work, and career and vice versa, and the subsequent link to psychological distress, suggest that workplace policy, guidance for supervisors, flexibility in fertility clinic times and psychological support are needed to support employees having fertility treatment. If such supports help to reduce psychological distress and conflicts between work and treatment, this has implications for employee retention, and may have implications for physical health and successful treatment outcomes or at the very least for an improved treatment experience.

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Table 1: The association between policy and psychological distress, disclosure and psychological distress, and support and days off work

Variable	**M (SD) Psychological distress**			**F**	**p**
Workplace policy	No policy	Not sure	Policy		
	66.12 (14.11)	65.04 (13.25)	61.95 (14.93)	3.53	.03
Employer support	No support	A bit of support	A great deal		
	69.22 (14.61)	66.56 (13.25)	62.43 (13.79)	5.78	.003
Colleague support	No support	A bit of support	A great deal		
	71.57 (12.06)	65.21 (12.83)	63.08 (14.76)	10.32	< .001
	M (SD) Number of days off work				
Disclosed to employer	Disclosure	Non-disclosure			
	9.82 (5.23)	5.89 (4.29)		17.92	<.001
Disclosed to colleagues	Disclosure	Non-disclosure			
	9.34 (9.73)	7.04 (7.77)		5.85	.02

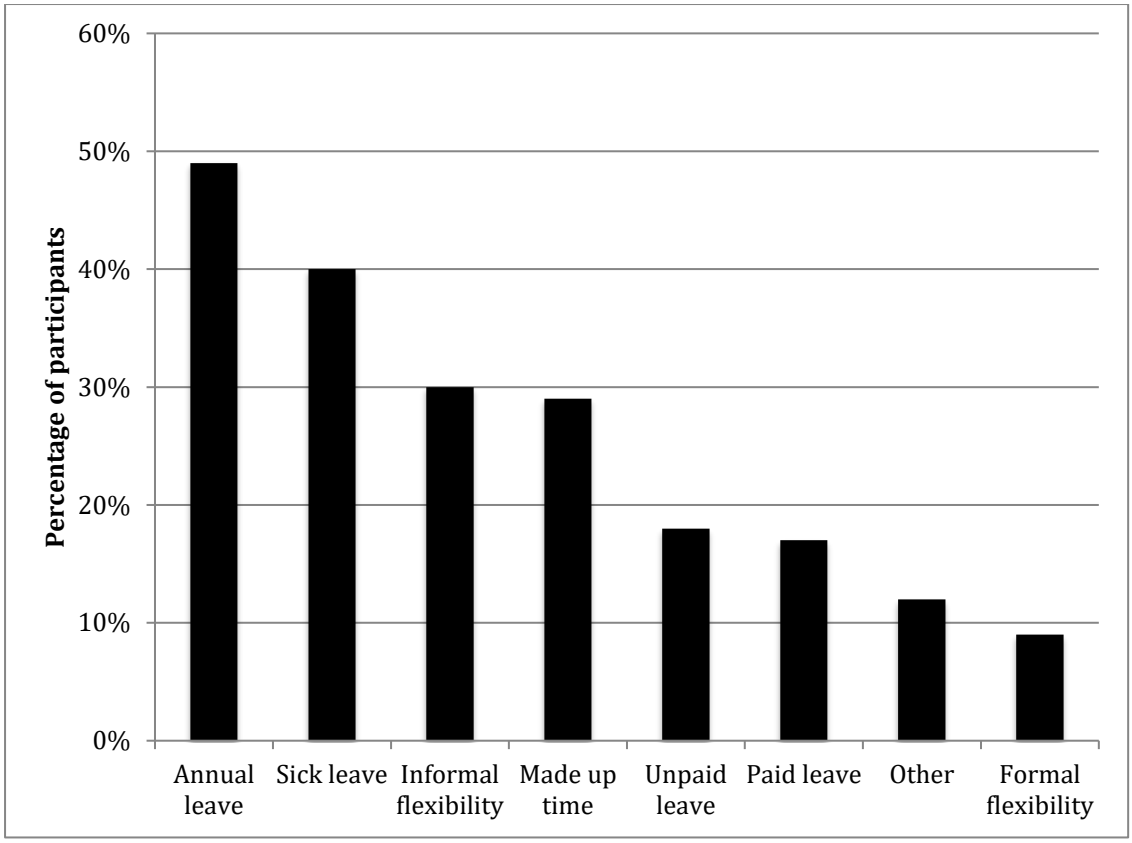

Figure I: Methods used to manage absence from work

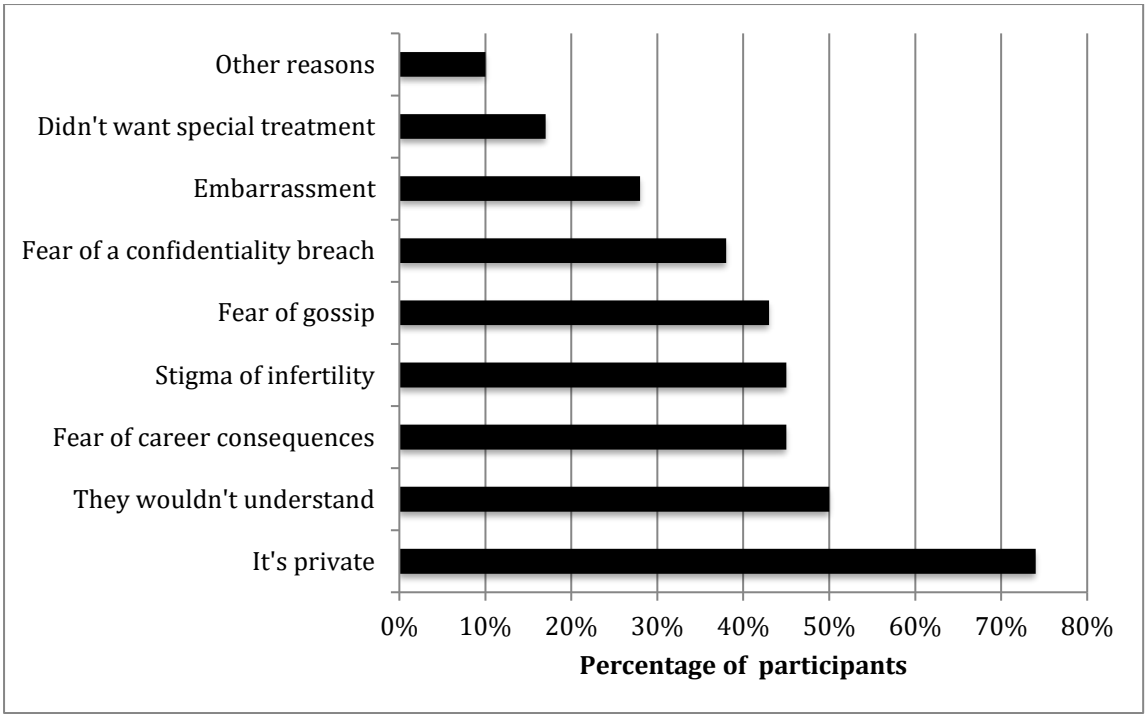

Figure II: Reasons for non-disclosure to an employer

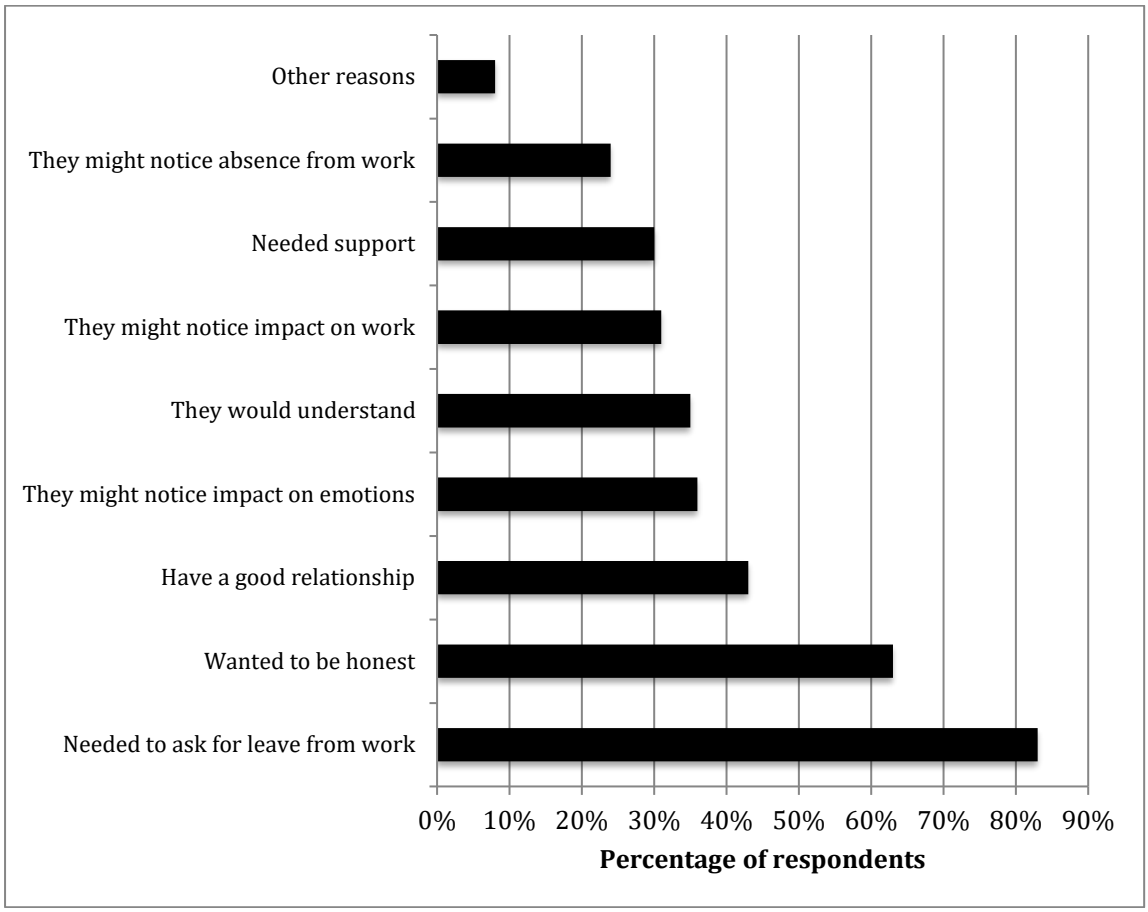

Figure III: Reasons for disclosure to an employer

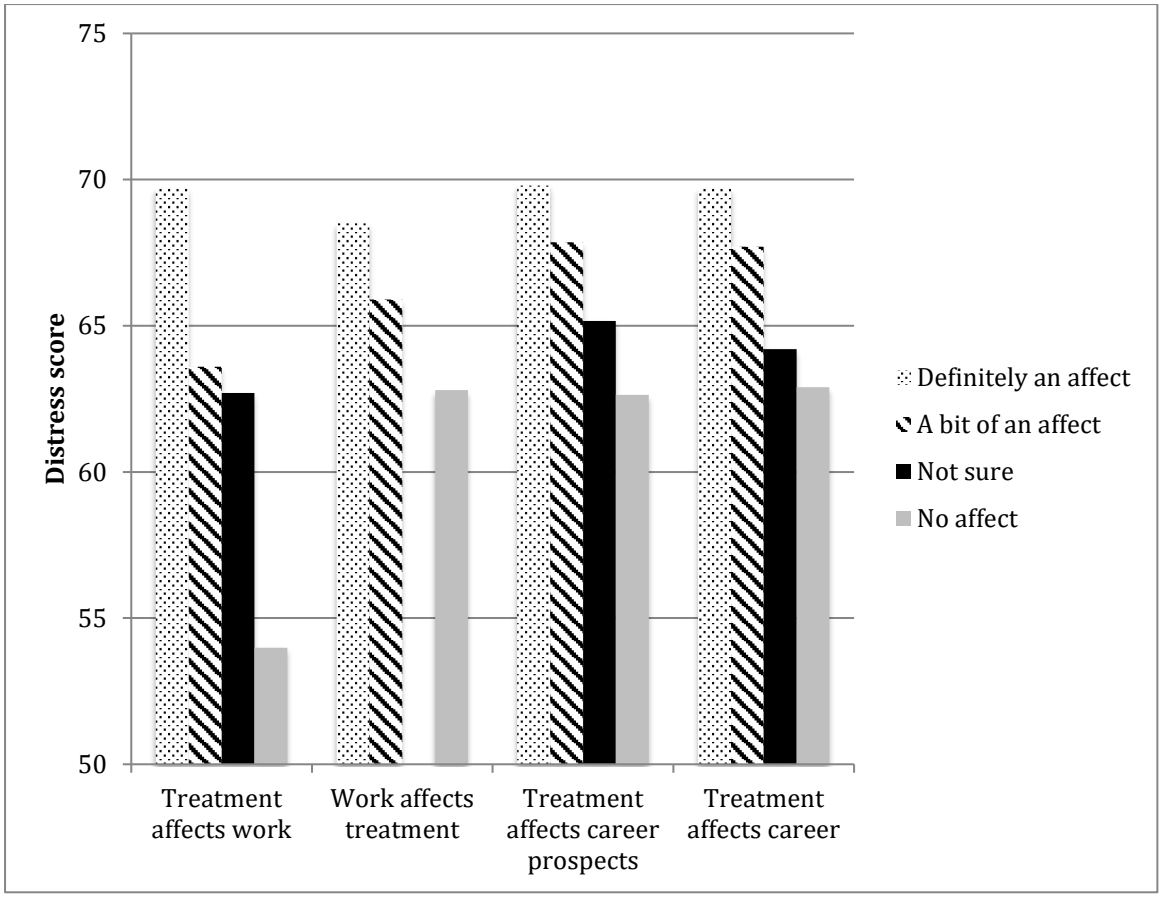

Figure IV: The association between average levels of psychological distress and experience of work affecting treatment/treatment affecting work.

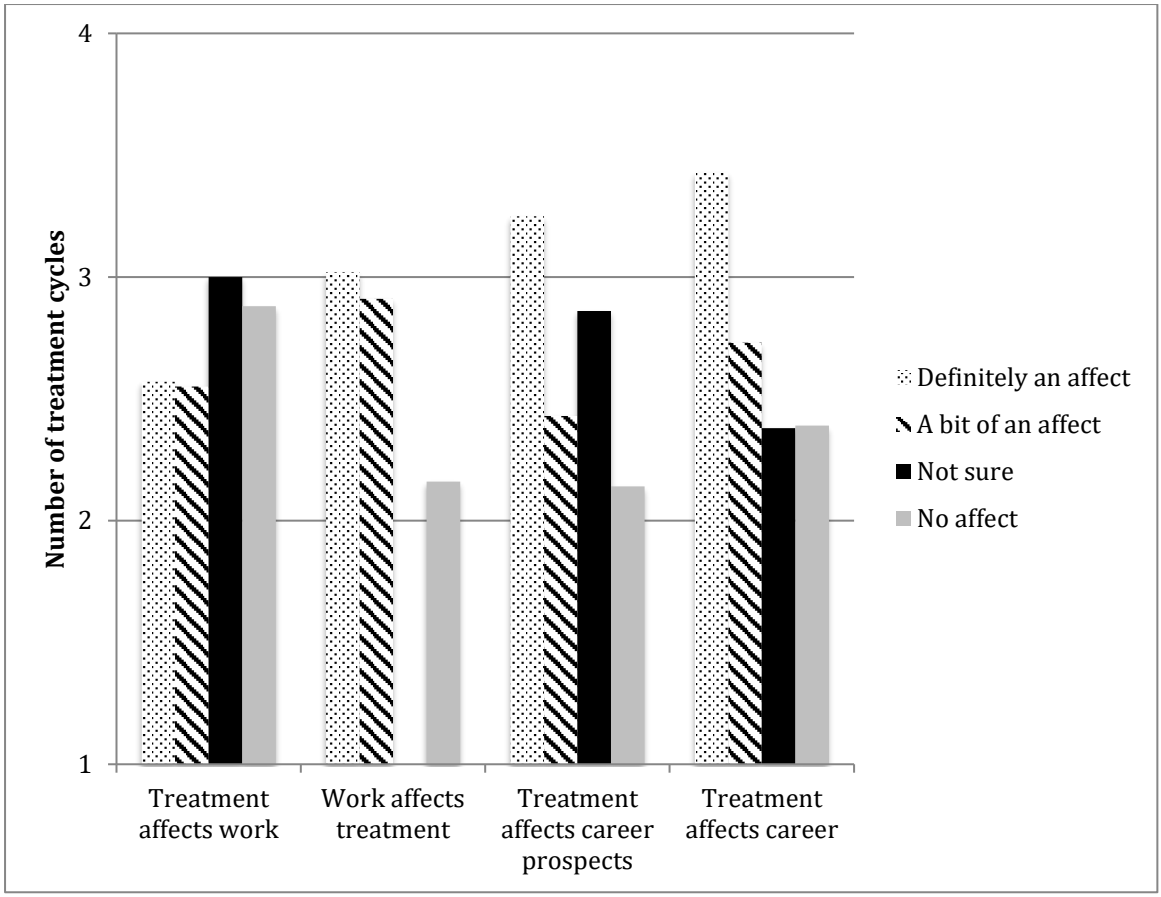

Figure V: The association between number of cycles of treatment and experience of work affecting treatment/treatment affecting work.