PETALS: AN ASSESSMENT OF THE OUTCOMES OF A SERVICE FOR BEREAVEMENT DURING CHILDBIRTH

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SUMMARY

Objectives: We aimed to evaluate the outcomes of Petals: a charitable organisation in Cambridgeshire. Petals provides counselling for women and couples who have suffered perinatal bereavement, or trauma during pregnancy or birth. This paper attempts to evaluate the effect of counseling interventions at this difficult time.

Methods: Outcomes were recorded in 42 patients using the CORE (Clinical Outcomes in Routine Evaluation) system. CORE was developed to assess the effectiveness of psychological therapies. CORE-OM (CORE Outcome Measure) involves a questionnaire that assesses subjective well-being, symptoms / problems, function, and risk to self and others. The CORE-OM questionnaire was completed before and after the counselling sessions.

Results: The CORE-OM scores were summated into a global representation of severity. Severity decreased in all patients. Symptoms of psychological pathology were also decreased in all cases.

Conclusion: A review of the available literature indicates that little is known about the efficacy of therapy for perinatal bereavement and trauma. These original data suggest convincing efficacy and benefits, but the numbers involved are small.Further trials with greater sample sizes are required.

Key words: *perinatal bereavement - trauma in pregnancy - counselling*

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INTRODUCTION

The perinatal loss of a child is an extremely traumatic experience for the parents. Within the UK in 2013 there were 3284 registered still births Within the UK in 2012, there were 3,558 stillbirths and 1,569 neonatal deaths (that is, within 7 days of birth), which represents a perinatal mortality rate of 7 deaths per 1,000 births (office for national statistics, 1). Poor aftercare of the parents after bereavement has been reported to lead to poor long term outcomes for the parents and family (Chebsey 2014). Petals charity was set up to support families in Cambridgeshire who have suffered loss or trauma during pregnancy or birth.

Petals offers up to six, one hour counselling sessions, free of charge. All of the counsellors are fully registered, and undergo specialist perinatal training with Petals. The sessions provide a safe environment in which clients can discuss fears and emotions, to equip them with coping strategies for everyday life. Support is invaluable to families around the difficult time of perinatal trauma. We intend to assess the outcomes of this support service.

METHODS

Measurement

Since its inception, Petals has recorded data and outcome measures using the CORE package. CORE (Clinical Outcomes in Routine Evaluation) was developed as a standardised measure that could be used to evaluate the effectiveness of the full plethora of psychological therapies, regardless of theoretical under-pinning (Evans 2002). Designed to be administered before therapy and at the end of treatment, CORE should ideally be used by every practitioner for every client (CORE System Group 1998). CORE has become increasingly popular since its inception due to its wide applicability across modalities of psychotherapy, its ease of use for clients and its licensing, which allows organisations to freely use it (Evans 2002).

CORE-OM (CORE Outcome Measure) consists of 34 items, on which the user must respond on a 5-point Likert scale ranging from 'not at all' to 'most or all of the time'. These 34 items span 4 domains as follows: subjective well-being (4 items), symptoms/problems (12 items), function (12 items) and risk to self and others (6 items). They are tuned to assess for a range of severity of problems (Evans 2002). CORE-OM may thus be used in two ways, either as a global score ranging from 0 to 136, or as 4 separate domains, although it cannot provide diagnoses of specific disorders (CORE System Group 1998).

Since its inception, CORE has been validated with samples from the general population, primary care, secondary psychiatric care and older adults (Gray & Mellor-Clark 2007). The test-retest reliability for the 4 domains varies between 0.75 and 0.95, while the external

validity is convergent with 7 other measures (Evans 2002). The risk domain is more fluctuant than the others, reflecting the high temporal variability of this aspect of patients' illnesses.

When comparing clinical and non-clinical populations, CORE shows marked and statistically significant differences, both overall and for all domains other than risk (Evans 2002). The fact that risk is once again distinct is due to the fact that the aim of the risk domain is not to distinguish clinical populations, but to help the clinician in preventing behaviour that may be dangerous to the patient or those around them. As well as statistical significance, practical significance is also demonstrated, as all domains apart from risk show a mean difference of more than 1 point on the Likert scale between the two populations (Evans 2002). To measure clinically significant change, cut-off points have been determined that specify whether a score is more characteristic of a clinical or a non-clinical population for men and women. The CORE system defines clinically significant change as movement between a clinical and a non-clinical score, whilst reliable change is considered movement of more than 5 points on the scale (Evans 2002).

We were asked to use the data as collected by CORE to evaluate the outcomes of the Petals service. We were able to assess data from 41 patients,including being able to assess symptom changes based on the symptoms recorded on CORE.

Description of client group

90% of Petals' clients are women (Figure 1). 93% are white.

Figure 2 shows the age distribution of Petals' 41 clients. 68% are in their 30s.

Figure 3 shows the employment status of clients. 78% are in paid employment (either full or part time).

The age distribution and employment status of Petals' clients may be intrinsic to the nature of the service. 30 to 39 is the age range in which many women will be having children. In the UK population the mean age of the mother at childbirth is 30 (Office for National Statistics, Birth Summary tables – England and Wales 2013). The modal age group for live births is 30 – 34 (almost 1/3 of all live births) (Office for National Statistics, Birth Summary tables – England and Wales 2013). Most births are to mothers aged between 25 and 34 (57%) (Office for National Statistics, Characteristics of Birth 2, England and Wales, 2012). The proportion of still births within this age group is also smallest, however the high number of births results in the highest total number of still births (1822 in 2012). 895 of these were within the 30-34 age group.

Neonatal mortality rates are higher for mothers over the age of 40, with a rate of 1.2% for those over 45 (Office for National Statistics, Characteristics of Birth 2, England and Wales, 2012) (Li 2014).

83% of referrals to Petals are via the NHS/doctors with only a small contribution from Social Services and voluntary organisations.

Most of the clients using Petals' service receive individual rather than marital/couple therapy (Figure 4).

The duration of therapy is very variable between clients (range = 188 days and Inter-quartile range = 28 days). The median is 70 days. This data is based on 38 clients rather than the full 41. 3 clients dropped out before treatment was completed and were thus unable to be included in the analysis.

The majority of clients receive 6 sessions over the therapy period (Figure 5). This is the target number of sessions as stated on Petals' website (Petals charity 2014).

64% of referrals are seen and assessed (wait time) within 10 days of referral and this increases to 74% within 15 days (2 weeks) (Figure 6). The mode and median wait time are both approximately 1 week. If no first assessment data is recorded then the last assessment date is used. If neither is present then the wait cannot be calculated and the client is omitted from the chart. The data for 2 clients is unknown and thus not included in these statistics.

The frequency of therapy varies between individual clients. 39% attend therapy sessions less than once a week, 24% once or more a week and 32% with no fixed frequency (Figure 7). The frequency of sessions is decided on between the client and counsellor dependent on initial assessment and clients' lifestyles (Petals charity 2014).
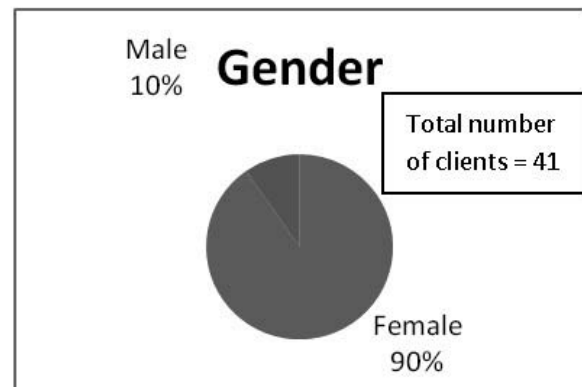

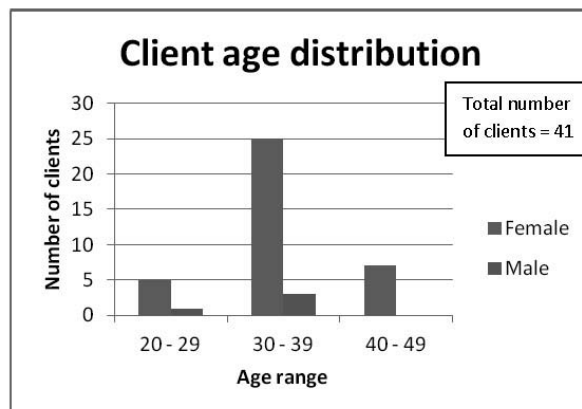**Figure 1.** Gender distribution of Petals' clients
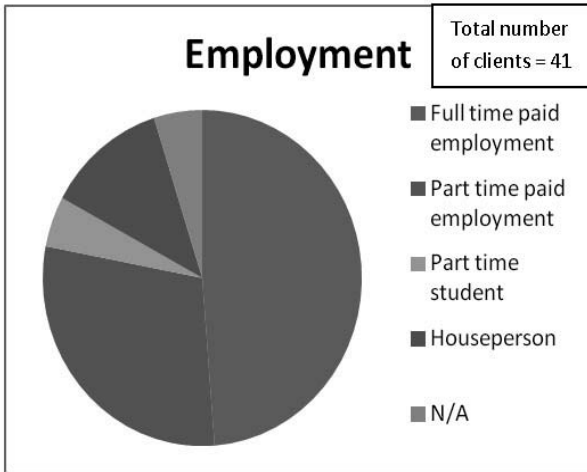

Figure 2. Age of Petals' clients

Figure 3. Employment distribution of Petals' clients
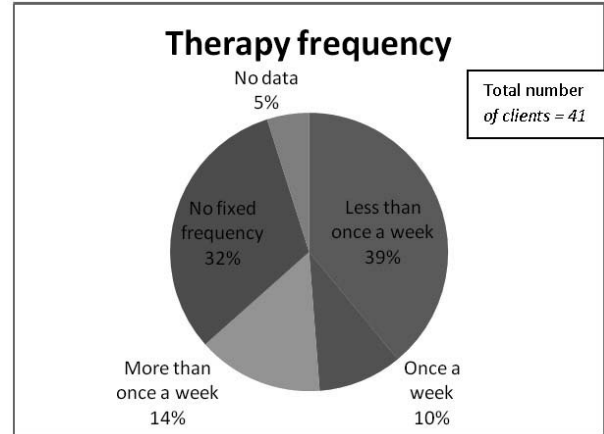
Figure 4. Type of therapy received

Figure 5. Number of sessions attended by clients

Figure 6. Wait for assessment

Figure 7. Frequency of therapy sessions

Series 1: number of clients

Figure 8. Clients who consulted GP

Series 1: number of clients

Figure 9. Number of clients given a diagnosis

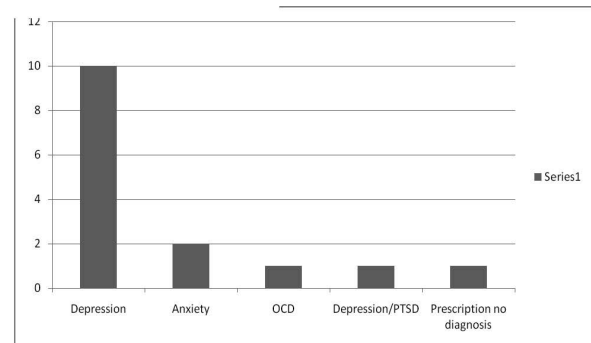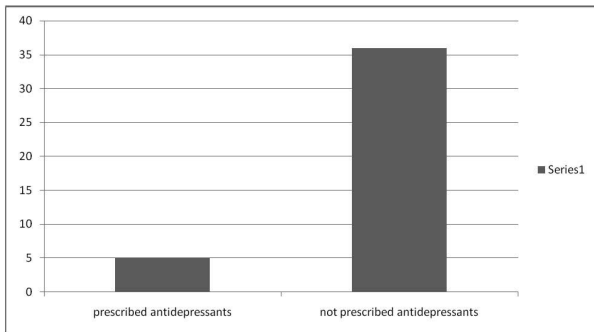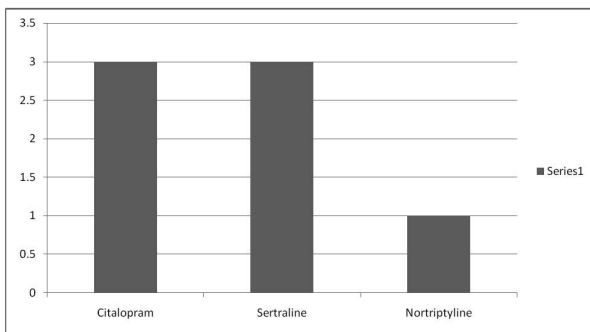Series 1: number of clients

Figure 10. Diagnosis given

Series 1: number of clients

Figure 11. Clients prescribed antidepressants


Series 1: number of clients

Figure 12. Antidepressants prescribed

Out of 41 patients, Of 41 Patients,27 Saw a GP, 14 did not.As a consequence, of 41 Patients 14 were given a diagnosis, 27 were not. Hence, of the 27 patients who saw a GP we have no record of a diagnosis in 14 cases. The diagnoses given included depression (10 patients), Anxiety (2 patients), obsessive compulsive disorder (1 patient), depression and post-traumatic stress disorder (1 patient), and one person was given antidepressants without a diagnosis being recorded. Hence Petals was dealing with a variety of diagnoses. Of the 41 Patients, 5 were prescribed antidepressants and 36 were not prescribed antidepressants. Of the antidepressants prescribed, 3 were prescribed citalopram, 3 were prescribed sertraline, and one was prescribed nortriptyline.In one there was a change of medication, so that both citalopram and sertraline were used.

Regarding the benefits of therapy, the following parameters were assessed; Anxiety/Stress, Bereavement/loss, Depression, Eating Disorder, Interpersonal/ Relationship, Personality Problems, Physical Problems, Self Esteem, Trauma/Abuse as recorded in CORE for 41 patients. This data was gathered by the counsellor during the last session of therapy. The data (Figure 13) show that all of these symptoms were reduced in all patients where the symptoms were relevant.

Therapy Benefit
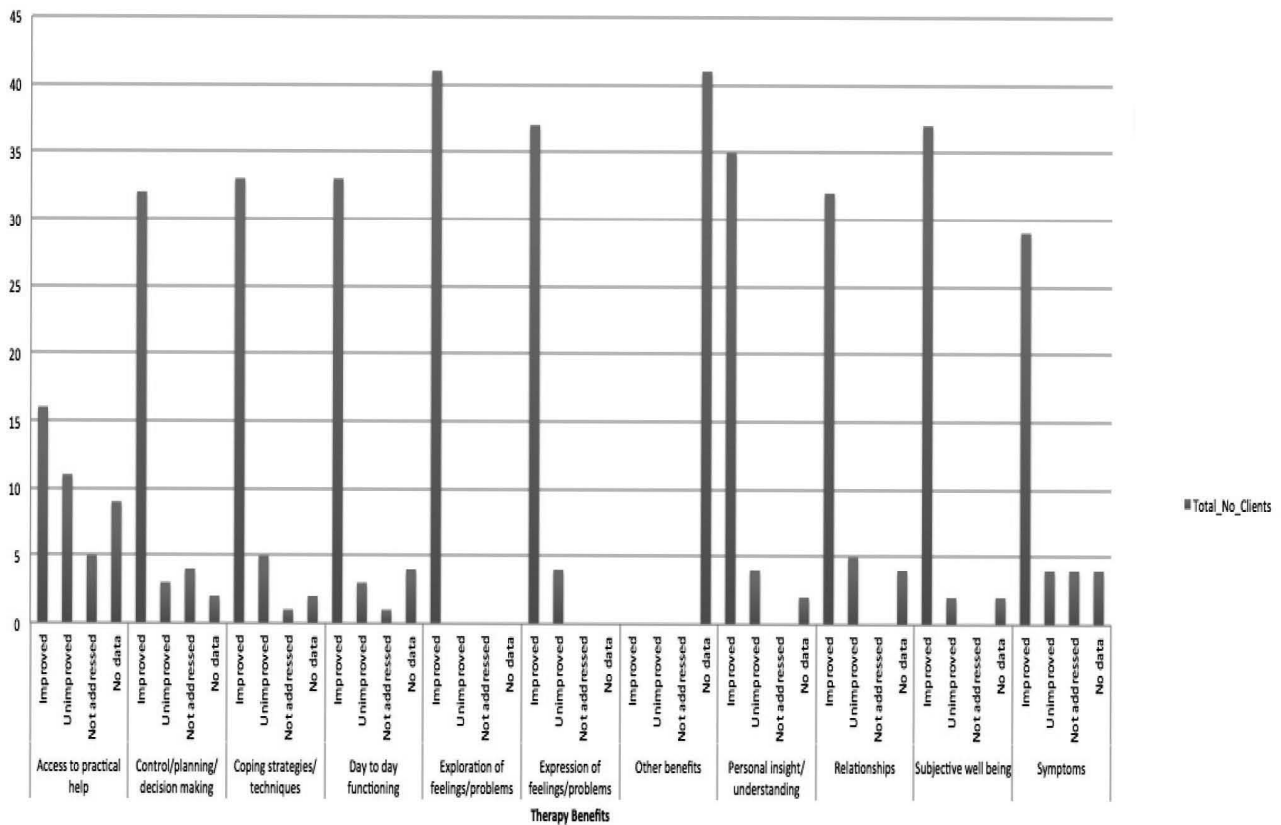
Figure 13. Benefits of therapy

The Average OM score across all 4 assessed domains reduces post-treatment. This is shown in both non-medicated (Figure 14) and medicated patients (Figure 15). Patients' medication may change across the treatment period. The change in medication may then account for any reduction in OM score observed rather than Petals' therapy itself. The data excluding medicated patients removes this variable. This however biases the data – patients with more severe symptoms are likely to be medicated. Both data are thus summarised above. There is little difference between the 2 populations. This suggests counselling is effective in non-medicated clients. Counselling is effective in isolation or complementary to medication. However the number of medicated clients is currently too small to draw significant conclusions. Both populations show an average reduction in OM score after treatment.

Figure 16 shows Petal's therapy is effective overall (OM score averaged across all 4 domains) on an individual basis in almost all cases (1 client showed no change in OM score over the treatment period). Therapy is effective irrespective of whether the client has visited their GP, is diagnosed with a psychiatric disorder and/or on medication. There is individual variation in the degree of effectiveness but there appears to be little correlation between effectiveness and diagnosis or medication being taken. GPs are likely to diagnose and medicate the most serious cases. This data therefore suggests that Petal's therapy can be effective in even the most severe cases and alongside other forms of therapy.

Figure 17 shows the average change in OM score over the treatment period. Again, all 4 population groups show a decrease in OM score. A one-way ANOVA showed that there was no statistically significant difference in the change in score between the 4 groups (F=0.44, p=0.72). Thus, whether the client has a diagnosis or is on medication seems to make little difference to the effectiveness of Petal's therapy.
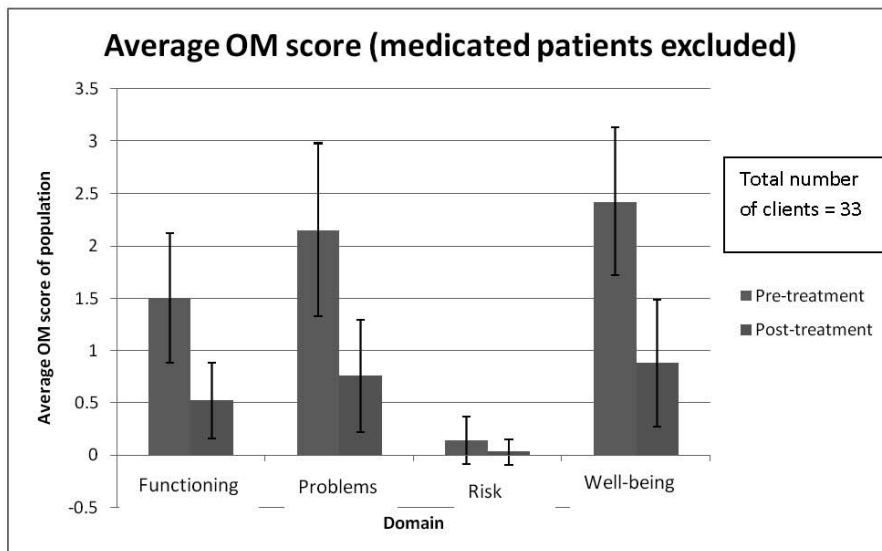
Figure 14. Average OM score in population not including medicated patients
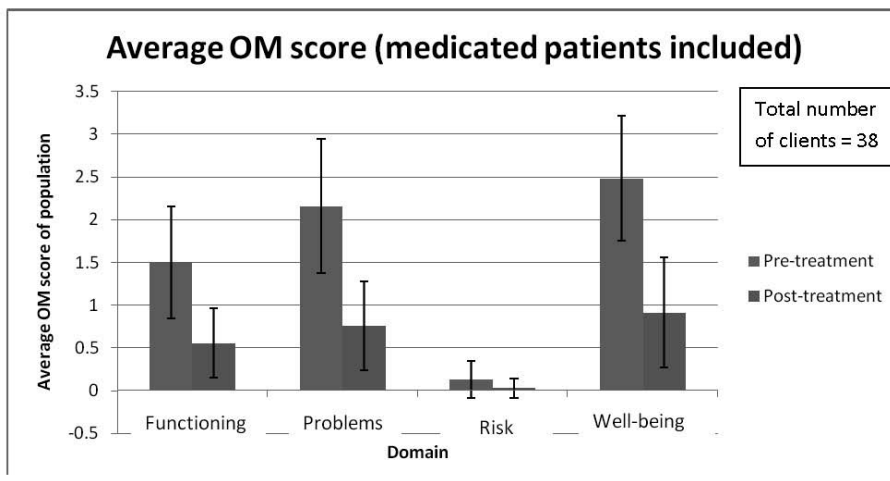
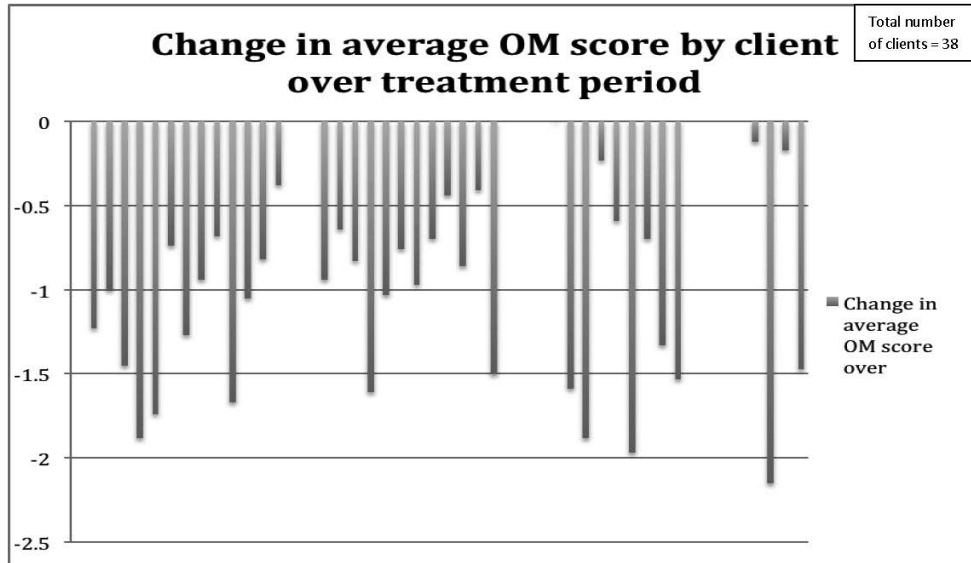**Figure 15.** Average OM score in population including medicated patients

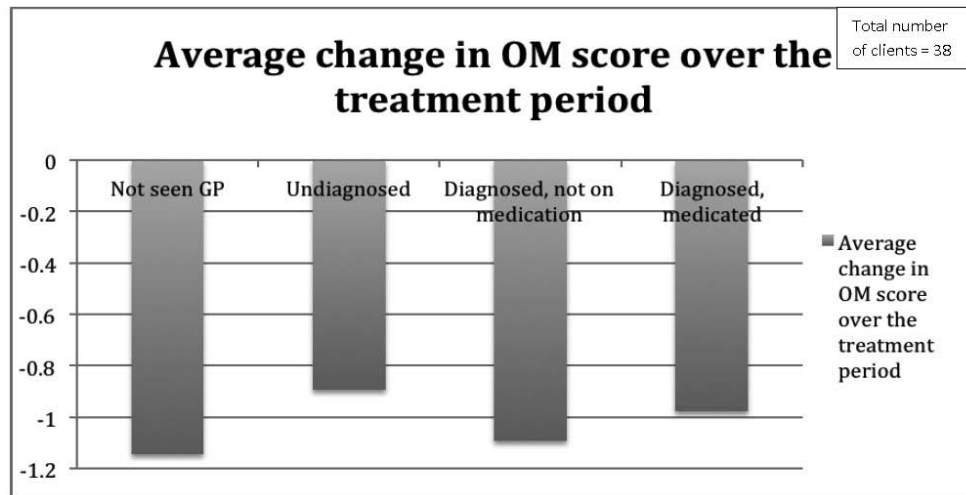**Figure 16.** Change in average OM score by individual client

Figure 17. Average change in OM score in different client categories

Figures 16 and 17 are based on data from 38 clients. We are unable to include in the final analysis 3 of the 41 clients as they dropped out of therapy and therefore no post-treatment OM score could be obtained1. We have examined whether the clients who dropped out were clients who had been diagnosed and were receiving other forms of therapy (such as medication) via other services. This does not seem to be the case:

- Client 1: Not seen their GP (and hence not diagnosed or medicated) at the time of drop-out;
- Client 2: Seen GP but not diagnosed or been prescribed medication;
- Client 3: Had seen their GP and received a diagnosis of Depression. This was being treated by the GP by a prescription for Sertraline.

The 3 clients who dropped out of Petal's therapy therefore had very different situations with regards to medication and psychiatric illness. We have no further information with regards to the reason for discontinuing

therapy. This would be useful information to try and gather with regards to future patients.

We present multiple graphs showing differences in symptom severity at assessment versus the end of therapy for each 'problem'.

The severity scores for each 'problem' were totalled to attain a summed severity score for each individual client.

Figure 18 plots the total severity score for each individual client. For almost every client the severity score was reduced post treatment, as shown by a downwards shift in the data.

Figure 19 plots the change in symptom severity. For almost every client the change in symptom severity is negative. This suggests that the therapy is effective for the vast majority of clients (and does not worsen the severity of problems for any clients).

Regarding risk, this was assessed in terms of Risk to self by self harm, risk to others, risk of suicide, and legal or forensic risk. None of the 41 patients assessed

appeared to pose a risk in these terms at the beginning of treatment, nor have they done so at the end of treatment. Hence we could not show any change in risk to the patients before or after treatment.

Overall: Therapy seems to be effective for almost all clients. Looking at specific risk factors reflects this general trend showing reductions in severity of every risk factor individually (Figure 20). As these data demonstrate, across all risk factors severity reduces over the treatment period.
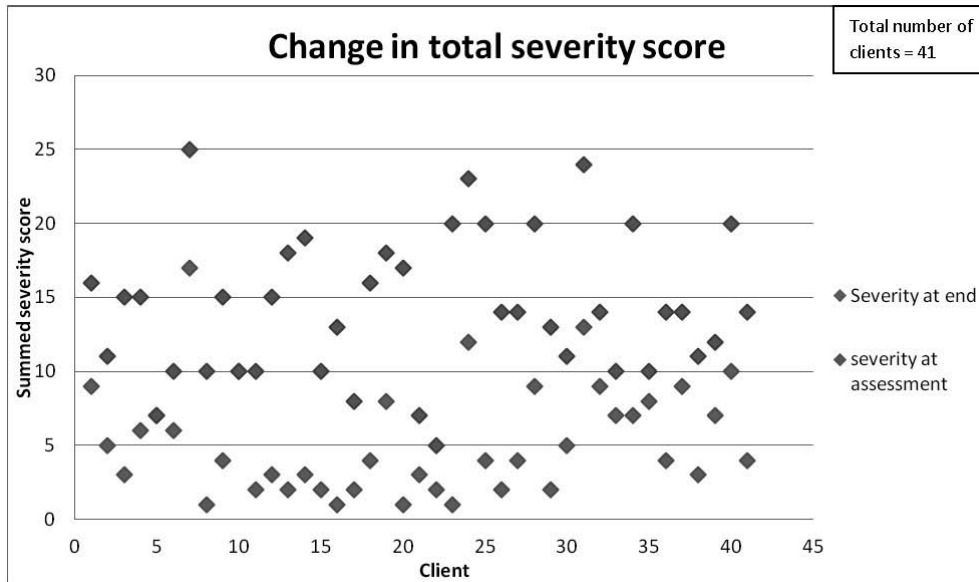

Figure 18. Clients' severity scores pre- and post- treatment
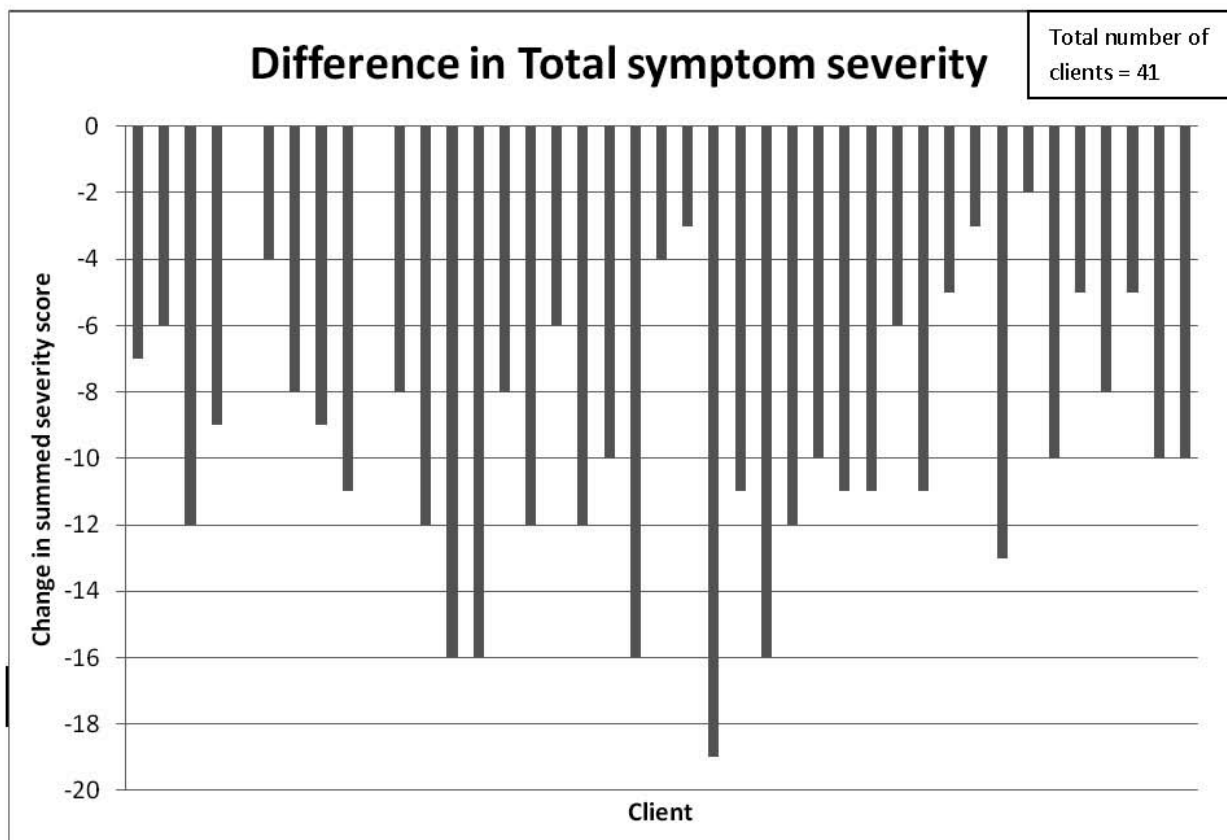

Figure 19. Change in total severity score by client over the treatment period

Change in severity score by parameter

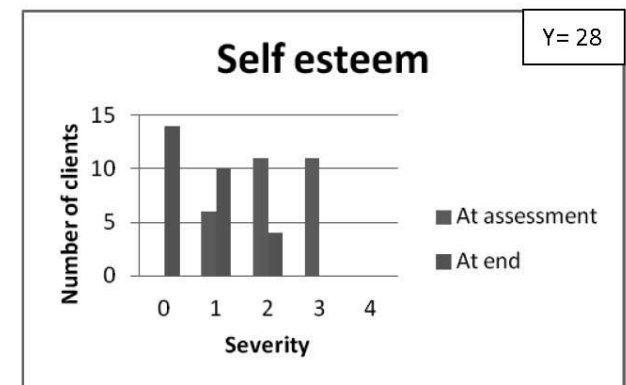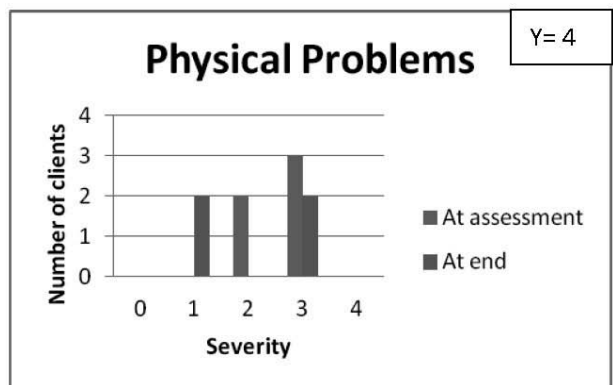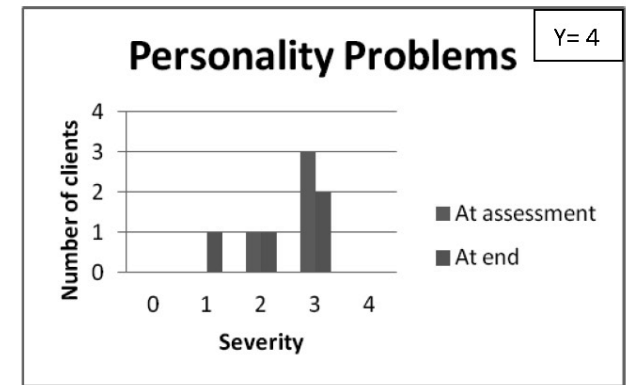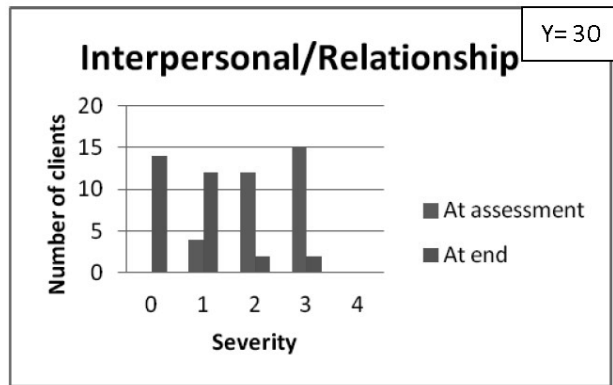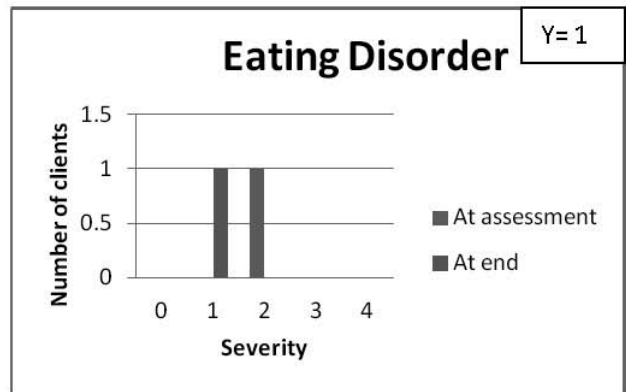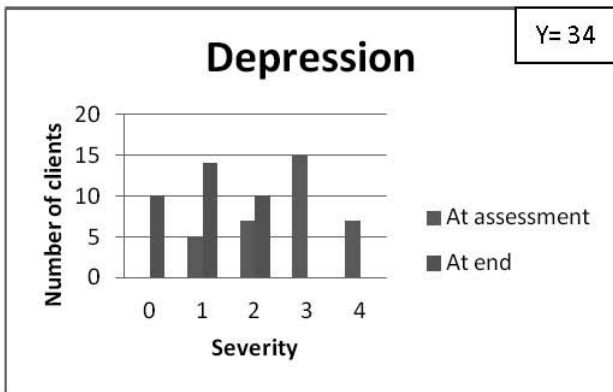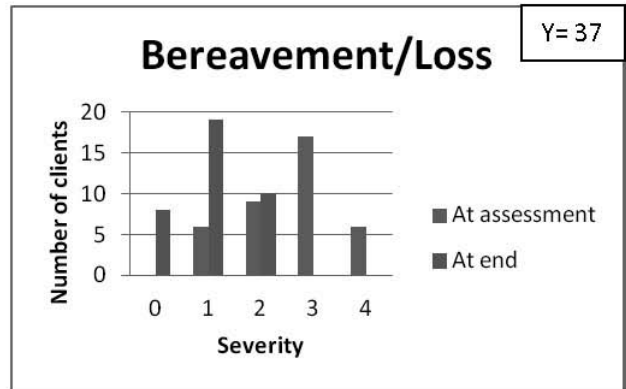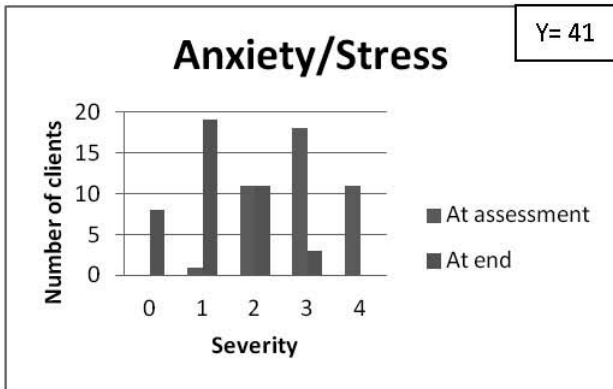Y = total number of clients
complying with parameter

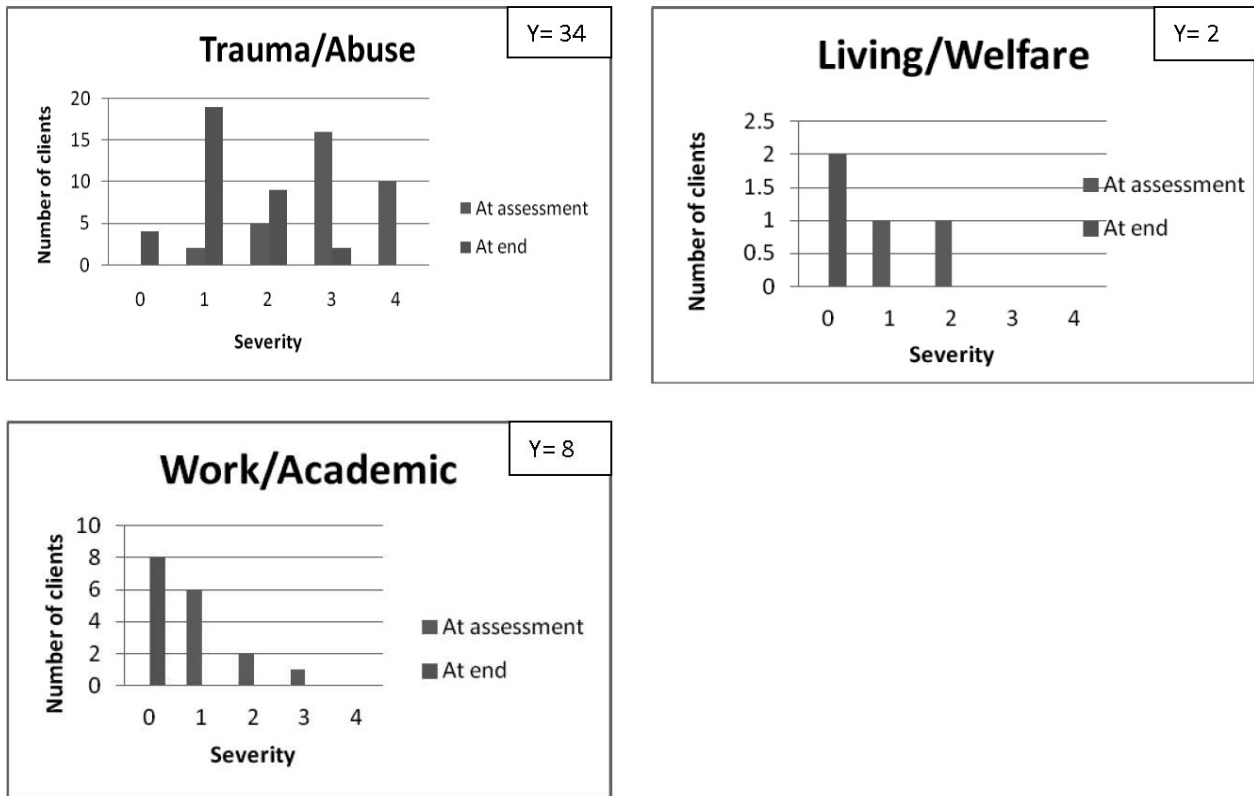**Figure 20.** Every risk factor individually

Figure 20. Every risk factor individually (Continues)

DISCUSSION

Perinatal mortality has decreased in high income countries but often the cause of death, especially for stillbirths, is unexplained (Corcoran 2014). In a recent national study from Ireland, the common causes of death in stillbirth were congenital anomaly (26%), placental conditions (17%) and ante/intrapartum haemorrhage (11%), 20% were unexplained (Corcoran 2014). On the other hand, early neonatal deaths were usually due to congenital anomaly (51%) or respiratory disorder (33%), while just 4% were unexplained (Corcoran 2014). Low birthweight was common, being below normal range for 53% of stillbirths and 40% of early neonatal deaths (Corcoran 2014). In most cases of early neonatal death, spontaneous respiratory activity was absent or ineffective within five minutes following delivery (63%) and death occurred within 24h (62%). Similar lists of causes of stillbirth or perinatal death have been reported from England (Birthplace in England Collaborative Group 2011). Such diverse causes of still birth and perinatal death, especially when there is the unexplained death of a child previously considered healthy will put important stress on both carers and parents, and hence implies important challenges for a service like Petals. Recent studies have identified that research into bereavement care for families who experience perinatal death should be considered a priority by healthcare organisations, as poor bereavement care is associated with poor long-term outcomes for the parents and families (Chebsey 2014). Our study helps contribute to this need. Communication and decision making is challenging for staff and parents at such a difficult time (Chebsey 2014). Chebsey et al point out that parents and maternity staff differed in their approach after the event of stillbirth; staff appeared to automatically shift care priorities to the mother and their potential future pregnancies, whilst parents continued to focus their concerns on their baby (Chebsey 2014). A service such as Petals should help to redress this balance.

The fact that the vast majority of clients are white could reflect the distribution of the wider population (92% of the Cambridge population are white (Office for National Statistics, 2011 census: KS201UK Ethnic Group, Local Authorities in the UK)) or could suggest biases in the referral system. The ethnic distribution amongst clients would be expected to reflect that of the population if there is fair access to the service. The 93% of Petals' clients who are white is very close to the 92% of the Cambridgeshire population suggesting access is fair. However it could also reflect differences in culture between ethnic groups. To assess the reasons for such a bias further, data on the ethnic structure of the population and on those who are aware of the service but do not make use of it is needed. 83% of referrals are via the NHS/doctors with only a small contribution from Social Services and voluntary organisations. An implication is that because the NHS is accessible to all UK citizens, the Petals service should have similarly inclusive access.

Most of the clients using Petals' service receive individual rather than marital/couple therapy (Figure 4). It may be useful to investigate whether one type of therapy is more/less effective under different circumstances. This would allow targeted therapy to achieve the best results for clients.

The duration of therapy is very variable between clients (range = 188 days and Inter-quartile range = 28 days). Petals provides a service aiming to work with clients to improve their psychological health. It follows that Petals must offer a very personalised service. However, such a large range of therapy durations may not be practical. Further information is needed as to why the length of therapy received by some clients is so much greater/less than by others. It may be that these clients are 'special cases'. The median is 70 days. The majority of clients receive 6 sessions over the therapy period (Figure 5). More information would be useful with respect to the clients who received only 2, 3 or 4 sessions to explain these data (which appear to be anomalous).

64% of referrals are seen and assessed (wait time) within 10 days of referral and this increases to 74% within 15 days (2 weeks) (Figure 6). This is in keeping with the aims set out on Petals' website (Petals charity 2014). The mode and median wait time are both approximately 1 week. There is no data to suggest whether this is an appropriate time frame. It would be useful to know how and if wait time relates to outcome. The frequency of therapy varies between individual clients. This may be by personal choice of the client and therapist, further highlighting the flexibility of the service offered. Again more data would be useful to guide decisions on therapy frequency.

Most of Petals' clients live with their partner (88%). Again this likely reflects the target population, the majority of live births still occur within marriage (Office for National Statistics, Birth Summary Tables – England and Wales 2013). The data could also be used to suggest the best options for the type of therapy offered. Since over half (54%) of clients are carers for children it may be worth considering whether whole family therapy would be a useful service to offer.

The data relating to the clients using Petals is useful in both directing the therapy and identifying services which will best meet the needs of the population. It also suggests the best ways to target the population to ensure all those who may benefit have the opportunity to engage with it and that the best outcomes are achieved.

The data shows that in the patients assessed, therapy from the Petals service does appear to reduce symptoms reported from clients.

The issue that many patients did mot go to their GP requires comment. Petals is a councelling service and therefore can be described as being part of primary care. Primary care often deals with distress rather than a diagnosed mental illness, and it is evident that many of Petals clients did not feel it necessary to go to Primary care, and , indeed did not feel the need to be prescribed antidepressants. However depressive and anxiety symptoms were present in many patients. The therapy received from Petals is effective irrespective of whether the client has visited their GP, is diagnosed with a psychiatric disorder and/or on medication. There is individual variation in the degree of effectiveness but there appears to be no correlation between effectiveness and diagnosis or medication being taken. GPs are likely to diagnose and medicate the most serious cases. This data therefore suggests that Petal's therapy can be effective in even the most severe cases and alongside other forms of therapy. Also there appears no statistical difference between the improvement of patients given medication and those not given medication, hence it may be argued that the use of antidepressants does not appear to have contributed greatly to the improvement of the patients.

A review of the literature,particularly systematic reviews in the Cochrane Database (Flenady & Wilson 2008, Koopmans 2013), suggests that little is known about the efficacy of counselling services for patients who suffer bereavement in childbirth. Encouraging involvement in trials of such a target population is very sensitive. In addition obtaining reliable, objective data is difficult for such personal therapies. We come to a similar conclusion as others – that more trials are required (Flenady & Wilson 2008, Koopmans 2013). The original data used to compose this review will hopefully contribute to reducing the current gap in data, although larger and many more trials are required.

There are a number of limitations to our assessment.

Firstly, numbers are small, and a further assessment with greater numbers would be useful.

Secondly, CORE does not record diagnoses, so we cannot say that particular syndromes/illnesses as defined by ICD (e.g. a depressive Episode F32) have been treated, but only that symptoms have been alliviated.

Thirdly, while all patients appear to have improved, we cannot say that this is due to therapy alone, as the CORE data do not give us information as to whether medication, such as antidepressants have been used concomitantly. As we do not have a control group, other factors such as regression towards the mean cannot be excluded either.

CONCLUSION

The Petals service aims to address a gap in the current services offered by the NHS and other voluntary organisations. It is therefore difficult to analyse the service – client numbers are small and detailed data cannot be collected in such small populations. As more data continues to be collected more correlations may emerge and improvements and refinements to the service can be made. The data collection would benefit from becoming more specific and defined. Current data suggests efficacy but poses important questions. Further data collection may enable some of these to be answered.

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