A brief, residential peer-support retreat for trichotillomania: A mixed methods evaluation

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A brief, intensive peer-support program for trichotillomania: A mixed methods program evaluation in a community setting

Slikboer, R.[1], Rehm, I. C.[2], Lam, S.[1], Maloney, A.[1], & Nedeljkovic, M.[1]

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[1] Department of Psychology and Centre for Mental Health, Swinburne University of Technology, Melbourne, Victoria, Australia

[2] College of Science Engineering and Health, School of Health and Biomedical Sciences, RMIT University, Melbourne, Victoria, Australia

Correspondence: Reneta Slikboer, Department of Psychology and Centre for Mental Health, Swinburne University of Technology, Mail H31, PO Box 218, Hawthorn, VIC 3122, Australia. Email: rslikboer@swin.edu.au

Abstract

Evidence-based psychological treatments for trichotillomania (TTM) can be effective, however, relapse is common and consumers have indicated poor satisfaction with treatment outcomes. The aim of this study was to identify participants' perspectives of critical factors associated with short- and long-term recovery following their completion of a brief, intensive peer-support program for TTM. A mixed methods longitudinal design was used to evaluate a 3-day residential peer-support program attended by 8 women who self-referred into the program. Semi-structured interviews were conducted at post-program (*n* = 6) and 12-months follow-up (*n* = 5). Self-report measures of symptom severity, mood and quality of life were completed at baseline (n = 7), post-program (*n* = 6), 6-months follow-up (*n* = 5) and 12-months follow-up (*n* =5). An inductive thematic analysis was performed to identify themes within the interview transcripts. Quantitative outcome data was used to confirm, challenge, provide context for, and link qualitative findings within the broader literature. Quantitative outcome data demonstrated reduced TTM severity from baseline to post-program. By 6-months follow-up, symptoms had relapsed to baseline levels. Participants' perspectives of factors associated with recovery immediately after the program included group-based processes (e.g., sharing, normalisation, safety, and enhanced motivation/accountability) and individual processes (e.g., readiness for change, self-regulation skills). The qualitative and quantitative data conveyed similar outcomes at both post-program and 12-months follow-up. Brief, immersive peer-support programs for TTM may facilitate equivalent symptom reductions as longer, therapist-delivered cognitive-behavioural treatments for some individuals.

Key words: hair pulling; peer support; qualitative; recovery; treatment; trichotillomania.

Key points

What is already known about this topic

- CBT reduces TTM symptoms yet 50% of clients relapse by 6 months
- Those with TTM experience shame and isolation
- Social, cultural, spiritual and psychological change is important to recovery from TTM

What this topic adds

- Immersive peer-support programs may be used as adjuncts to traditional treatments
- Feelings of social acceptance and belonging endured 12 months after the program
- An immersive peer-support program provides therapeutic experiences not available through traditional delivery methods

Individuals with trichotillomania (TTM) repetitively pull out their own hair to the point of hair loss despite repeated attempts to decrease or stop the behaviour (American Psychiatric Association [APA], 2013). Those with TTM experience emotional distress in the form of anxiety and depression and impairment in many areas of life (Grant et al., 2017). Shame, social isolation and a belief that one is “alone” in their difficulties with hair-pulling are shared experiences among people with TTM (Rehm et al., 2016; Slikboer et al., 2018b). The effectiveness of group therapy (Diefenbach et al. 2006; Mouton & Stanley, 1996) for TTM may occur via group cohesion, social support, addressing shame and stigma, and the sharing of similar experiences within a professionally-facilitated, safe environment (Casati et al., 2000).

Group therapy also appears to have strong acceptability as a form of treatment for TTM. Among 30 women who participated in group therapies for TTM, 68% (*n* 21) perceived that group therapies were more effective than individual therapies and medications (Boughn & Holdom, 2002). To follow-up these findings, the researchers suggested that descriptive research be conducted on “non-traditional” treatments and followed longitudinally to assess long-term perceptions of treatment efficacy. One individual attributed her long-term recovery to a combination of medications, behaviour therapy and a TTM peer-support group. She reportedly considered peer-support to be helpful as she was able to share psychological experiences with others who shared similar challenges (O’Sullivan et al., 1997). Peer-support via the internet has also been important to people with TTM for obtaining information (Bruwer & Stein, 2005).

While randomised controlled trials typically exclude participants who are already receiving a similar psychological treatment or have a change in their medication (Slikboer, Nedeljkovic, Bowe, & Moulding, 2017), these studies have not excluded participants engaging in alternative psychosocial interventions such as brief residential “retreats”, peer-support groups (either online or in person), or supportive counselling (Diefenbach et al., 2006; Keijsers et al., 2006; Keuthen et al., 2012, 2011; Ninan et al., 2000; Woods et al., 2006). Given that Slikboer et al.'s (2017) meta-analysis identified that supportive counselling resulted in reduced hair pulling severity equivalent to that achieved by behaviourally-based psychological therapies (two studies), it could be beneficial to identify the change processes associated with these alternative and psychosocial interventions according to the participants' perspectives

Five mechanisms have been noted as important in the process of peer support (Watson, 2017). The mechanisms were described as: explicitly sharing and drawing on what has and hasn't worked; demonstrating emotional honesty; the position of a peer-support worker as having a role between that of a service user and service provider; a source of social and practical support; and being able to help others shift focus from one's own problems to those of others. Watson (2017) argued that the act of sharing lived experience gains its power to help due to the culture of non-disclosure in mental health services; that is, mental health care providers have more power than users and they do not share personal experiences of mental health difficulties. Peer-support programs have demonstrated equivalent outcomes to cognitive behaviour therapy for older adults with depression (Tomasion et al., 2017) and for students with symptoms of anxiety and depression (Ellis, Campbell, Seth, & O'Dea, 2011). Peer-support has also been shown to have a preventative role in the development of post-natal depression (Dennis et al., 2009). Patients with severe mental illness, such as schizophrenia and bipolar disorder, do not experience a decrease in symptoms in response to peer-support, but feelings of hope, empowerment and self-rated psychosocial recovery does improve (Lloyd-Evans et al., 2014). "Retreat" type interventions involve living in an environment designed to optimise health and wellbeing. Findings of a recent systematic review (Naidoo, Schembri, & Cohen, 2018) lead to conclusion that retreats improve quality of life, subjective wellbeing, depression and anxiety for up to 5 years through changes in psychological, cognitive, physiological, and metabolic effects. This long-term effect is aided by lifestyle changes that individuals maintain once returned home, although it is unclear how follow-up support maintains such changes (Naidoo et al., 2018).

Successful treatment for TTM has been conceptualised by some researchers as symptom remission, i.e., total abstinence of hair pulling and/or significant reductions to hair pulling urges and associated distress (Falkenstein, Rogers, Malloy, & Haaga, 2014). There is growing acknowledgement among mental health advocates that psychosocial recovery is an essential component of successful treatment (Palmer et al., 2015; Andresen et al., 2010). Psychosocial recovery can be defined as continued improvement in social, cultural, spiritual and psychological function in ways that are important to the individual (Andresen et al., 2010). For some individuals with TTM, psychosocial recovery, as opposed to symptom remission, is their preferred treatment outcome (Casati et al., 2000).

The current study evaluated the outcomes of a 3-day intensive residential peer-support retreat (“retreat”) for adults with TTM, which ran in 2014. The retreat program was developed in 2011 by peer-support volunteers with lived experience of TTM and staff at a non-profit anxiety support service in Melbourne, Australia, and has been delivered once annually since then. The aims of this study were to (a) assess the efficacy of the retreat for TTM and (b) explore the perspectives of participants of the retreat to distil the key factors associated with short-term recovery (1-week posttreatment) and long-term recovery (6 months and 1-year post-treatment). Recovery was conceptualised as both symptom remission and psychosocial recovery.

Method

Research Design

The study design was naturalistic insofar as the investigators evaluated the program as it was delivered within the community setting, i.e., the authors did not contribute to the design or delivery of the intervention. A mixed methods analysis approach was taken in this study to identify participants' experiences of the retreat, including their perspectives of critical factors associated with short- and long-term recovery and symptom changes. As recommended by Yardley and Bishop (2007), the philosophical tradition of pragmatism guided the qualitative analysis in which the aim of inquiry was not to seek the ultimate undistorted truth, but to achieve a nuanced and person-centred understanding of the perceived effectiveness and mechanisms of change of the retreat.

Based on the research question, the uniqueness of the retreat and the high likelihood that statistical analyses would not reach adequate power due to small sample size, it was decided *a priori* that the qualitative data would be given greater interpretative weight than the quantitative (symptom-focussed) data. A parallel data analysis approach was taken, in which the qualitative and quantitative data were analysed separately, then integrated during data interpretation (Ostlund et al., 2011). Quantitative data was used to (1) confirm or challenge the qualitative findings, (2) provide context for qualitative findings and (3) facilitated comparison to the wider literature, as featured in the discussion. Only the post-program and 12-month post-program interviews were qualitatively analysed and included in the current study as they were the most important time points for addressing the aims.

Participants and Procedure

Participants self-referred to the retreat and were invited to take part in the study by the service provider, verbally and in writing, when they enrolled. Eight consumers participated in the program and seven provided their informed consent to participate in the current study. Upon providing their consent, participants completed the baseline self-report paper-and-pencil measures the day prior to commencing the retreat. The study sample consisted of seven women (*M* = 35.17 years, *SD* = 17.39 years); six of whom participated in a private semi-structured 40-minute qualitative interview and diagnostic interview at the location of the service provider or authors' host institution.

Interviews were audio-recorded and transcribed to support diagnostic decision-making between Author 1, Author 2 (a doctoral-level trainee psychologist) and Author 5 (a senior clinical psychologist experienced in obsessive–compulsive-related disorders). Diagnoses were made based on consensus among all three authors. Symptoms for five of the six interviewed participants met the DSM-5 diagnostic criteria for TTM prior to the retreat. Four participants reported receiving lifetime diagnoses of depression and anxiety; one of dysthymia; and one of social anxiety disorder. One individual reported that she had not received any lifetime mental health diagnoses. Questions were also asked to determine if participants' hair pulling behaviours met DSM-5 (American Psychiatric Association, 2013) criteria for TTM.

All audio-recordings were transcribed verbatim for the qualitative analysis, see Supplementary Material S1 and S2 for interview guides. At 6- and 12-month post-retreat, participants were again invited to complete the same pencil-and-paper self-report measures and to participate in a recorded 20-min interview via telephone with (Author 1). Diagnostic interviews were not conducted at these time-points. The study was reviewed and approved by the human research ethics committee at the host institution.

Qualitative Analysis

An inductive thematic analysis was conducted for post-retreat and 12-month follow-up interview transcripts, separately. Inductive thematic analysis produces bottom-up themes that are driven by and remain close to the data (Braun & Clarke, 2006) . The intention of inductive thematic analysis is to produce themes free of the researchers' theoretical interests, which may differ greatly from the interview questions asked. To reduce researcher bias, researcher interests were made explicit prior to the analysis (see supplemental material S3) and all authors remained unaware of activities participants had engaged in the 3-day peer-support program until thematic analysis was completed. The goal of analysis was to accurately represent as the participants' perceptions based on the explicit meanings in the transcripts, as opposed to interpreting participants' responses in the context of any therapeutic or theoretical models. The analytical procedure is described in Table 1. Data collected at 6-months follow-up was not included in the qualitative analysis as similar-term outcomes have already been investigated in the TTM literature (Falkenstein et al., 2014).

Quantitative Analysis

The mean scores for self-reported symptom and quality of life scales at all four time points were presented in a line graph to provide context for the findings of the main qualitative results. Due to the small sample sizes at each time point, statistical analyses could not be completed.

Materials

The Massachusetts General Hospital Hair Pulling Scale (MGH-HPS).

The Massachusetts General Hospital Hair Pulling Scale (MGH-HPS). The MGH-HPS (Keuthen et al., 1995) is a 7-item questionnaire assessing the frequency and intensity of hair pulling urges and behaviour, perceived control of and resistance to hair pulling, and associated distress. Symptom severity is measured over the past week. Internal consistency is good (α = 0.97) and convergent and divergent validity have been demonstrated (O'Sullivan et al., 1995)

The Australian Quality of Life Instrument AQoL. The AQoL (Hawthorne et al., 1999) is a 12-item self-report measure of five health dimensions over the last week; two of which were used in this study: relationships and mental health. Participants responded to items by choosing one of four options, for example, “Because of my health, my relationships generally: A = Are very close and warm, B = Are sometimes close and warm, C = Are seldom close and warm, and D = I have no close and warm relationships”. Unweighted summed scores were calculated, (A = 1, B = 2, C = 3 and D = 4) with higher scores reflecting poorer quality of life. Internal consistency of the AQoL is good (Chronbach’s α = 0.81) and content validity was found to be equal to or better than similar instruments. Construct validity and criterion validity has been reported as sound (Hawthorne et al., 1999).

The Depression Anxiety Stress Scales (DASS). The DASS is a 42-item questionnaire that includes three self-report scales designed to measure depression, anxiety and stress. Items are marked on a 4-point Likert scale to rate the extent to which they have experienced each state over the past week (Lovibond & Lovibond, 1995).

Interview. An in-depth semi-structured interview was developed by Authors 1 and 5 to inquire about participants' experiences of the retreat and their subjective view of their mental health. Questions about the retreat focused on: expectations for the retreat; experiences that were not part of the retreat but influenced participants' experience of it; attitudes towards the retreat facilitators and accommodation; whether and how the retreat influenced hair pulling behaviour; most and least enjoyable and effective aspects of the retreat; and previous treatment-seeking experiences. Questions regarding mental health reflected the quantitative measures used in the study; for example, participants were asked “what is your own estimate of TTM in terms of severity over the last week?” and prompted with “urges to pull,” “the behaviour of pulling,” and “distress related to pulling.” Participants were also asked about their experiences of depression, anxiety, and stress; whether they have received any other psychological diagnoses; how other areas of life are affected by TTM; and about thoughts and beliefs related to TTM (Rehm, Nedeljkovic, Thomas, & Moulding, 2015).

Intervention

The 2014 program was held over a weekend from 12.00pm Friday to 1.00pm Sunday. Prior to the program, participants received a basic activity schedule (see supplementary material S4). Three facilitators associated with the non-profit anxiety support service hosted the retreat; all of whom had experience in the mental health profession to varying degrees, with formal qualifications in education, counselling or community development. Facilitators selected and designed program activities in response to informal feedback and requests from the previous year’s attendees; all of whom experienced hair-pulling to some degree. One facilitator had lived experience of TTM and considered herself recovered from symptoms and psychosocially. The goal of the retreat program was for participants to meet others with TTM and reduce their sense of isolation; share their experiences of the impact of TTM in a safe and non-judgemental environment; learn about the disorder and therapeutic strategies from each other and the facilitators; and to engage in self-care and pleasant activities. Costs to participate in the retreat were kept low, mostly comprising of the cost of meals and of the accommodation, for which participants could choose a shared or private room to stay. The accommodation was situated in a pleasant and relaxing rural setting. In addition to structured activities, free time was also scheduled into the retreat. For more detailed information of the retreat content, please contact the non-profit anxiety support service (QSR International Pty Ltd) or see Supplementary Material S5.

Results

Quantitative findings

Improvements on the MGHHPS and DASS were reported post-retreat but not the mental health subscale of the AQoL. At 12-months follow-up, MGHHPS scores (TTM severity), AQoL subscale scores (relationship quality and mental health) were poorer than they were pre-program, however, improved symptoms of anxiety, depression and stress were maintained (Table 2).

Qualitative findings

The most important post-program qualitative finding was that participants described social elements such as sharing, normalisation and feeling safe as central to motivating individual change. While hair-pulling behaviour returned to pre-program levels at 12 months follow-up, participants described an enduring sense of social belonging. Key themes (bold text) and supportive quotes from post-program and 12 months follow-up are presented below. All themes, sub-themes and supportive quotes are presented in Tables 1S and 2S of the supplementary material.

Themes from the post-retreat thematic analysis

Retreat Structure. Participants described the type of accommodation as "*peaceful*" and "*natural*", which was further noted as being important for their experience of recovery during the retreat. Some participants recommended a longer retreat duration. There were no concerns about the facilitator-to-participant ratio. The intensive presence of others at the retreat inhibited some participants' hair pulling, but was challenging for one individual. Participants who stayed in private rooms noted that this facilitated their hair pulling in between scheduled activities with the group. Limitations were raised about the need for more information about program content prior to enrolling into the retreat, and increased follow-up after the retreat (e.g., support with finding ongoing treatment).

"Um, you know, it was a very relaxed environment and I think that the eight people and the three facilitators was a really good amount. I think that if it was a lot more than that it would have been really overwhelming."

"I liked the quietness of it and the surroundings being away from the city"

Benefits of the Retreat. Participants generally experienced the retreat as valuable. Many reported symptom changes, such as being less anxious and reduced hair pulling. However, one participant did not feel the retreat changed the severity of her hair pulling.

"I was reflecting on the weekend I felt like it was, um – I just felt like it was really beneficial and I just felt really thankful."

Therapeutic Processes – Group Processes. Participants found peer-support to be meaningful and helpful. Through the process of sharing, participants were able to gain a sense of community connection and normalisation. Participants also felt a sense of safety and motivation within the non-judgemental environment created by their peers and facilitators.

"I suppose the cathartic effect of just being able to share um openly or share your story for the first time and - - - it's quite liberating or healing …"

"Yeah, um I think it was the activities where people got to share their experience with trich, because it sort of made me feel like oh, other people have these thoughts that I thought I was really weird for having [this] sort of thing, like it normalised it a bit more."

"… also being given that very, very peaceful and very safe space helped me as well."

Therapeutic Processes – Individual Processes. Individual processes broadly centred around two sub-themes of readiness for change and self-regulation. Readiness for change consisted of taking on personal accountability, gaining a sense of hope for recovery, and recognising the impact TTM had on the individual's life. In addition, participants reported improved self-regulation skills learned during the retreat, such as acknowledging and expressing their emotions, and focussing on self-care through relaxing and pleasant activities (e.g., mindfulness, singing bowl meditation). For one participant, self-care activities had the effect of positively improving the relationship she had with her hair.

"It was also perhaps my feeling of responsibility to the – the retreat, where I knew on Friday it was difficult but I knew that you only get out what you put in and that I'm responsible to everybody else there as well, so I make more of an effort to, um, really engage with the relaxation process and that I – and that's the kind of thing I struggle to do outside."

Influence of Retreat Facilitators. Retreat facilitators were described as empathetic, flexible, knowledgeable and experienced in helping people with TTM. The lived experience of one facilitator was highly respected and motivational for participants; an element that many participants commented was lacking in their other treatment experiences.

"Well, she'd [peer facilitator] experienced it herself for five years, so she wasn't reading out of a book."

Engagement Barriers. Challenges to engaging in the retreat activities were expressed by one participant, in particular. Challenges included anxiety about sharing information about her experiences, doubt that change was truly possible, and ambivalence that her TTM was truly problematic.

"But maybe there's - there's probably an underlying belief that it's not possible for me, you know"

Themes from the 12-month follow-up thematic analysis

Satisfaction with retreat. Twelve months on, recollections of the retreat remained satisfactory. Most participants reported that they would like to attend another retreat in the future; several perceived the retreat to have been effective and that it at least met, if not exceeded, their expectations. One participant expressed ambivalence about the effectiveness of the retreat, acknowledging that it was personally beneficial, but did not result in a complete remission of TTM symptoms as she had hoped.

"I wasn't expecting to be cured and I wasn't you know, all those things. But I think it definitely did meet my expectations, beyond"

Symptom changes. All participants perceived their hairpulling urges and behaviour had remained unchanged or stayed consistent since being interviewed at 6-months post-retreat. Two participants reported that, while their symptoms had improved immediately after the retreat, they experienced a relapse shortly thereafter. One participant reported that her increased resolve to resist hairpulling urges after attending the retreat was maintained at 12-months.

"Whatever they did, it, it, it worked for a certain amount of time for me"

Therapeutic processes – Group processes. Acceptance, belonging and shared experience were identified as being particularly important to participant's positive experiences at the retreat. Several participants reported a reduced sense of isolation, knowing that they are not alone in their experiences of TTM; that they were allowed and encouraged to be vulnerable; and they also felt radically accepted as a person and valued group member. In other words, participants reported a strong sense of belonging, understanding and validation. Engaging in group activities and discussions about shared experiences was identified as influencing their sense of acceptance and belonging. One participant commented that hearing the lived experience of her peers supported her in a way not possible in individual therapy with psychologists who themselves had no personal experience of TTM.

"It was pow- it was powerful in that you know, it was in that, it, it was a shared experience. And that it, and that experience is making yourself vulnerable and, and being you know, accepted and not judged on those sorts of things, which I think um, yeah, there's something about the group experience that I think is, is different than just like one-on-one counselling. But um, yeah, that was really, um, a very you know, memorable experience"

Therapeutic processes – Individual processes. Some participants reported that attending the retreat helped them to start their recovery from TTM and/or instilled a sense of hope that recovery was possible. One participant linked her hope of recovery to gaining a greater knowledge of TTM, and she was also reassured to learn of the existence of a community of professionals and peers with knowledge or lived experience of TTM. Several participants identified that one of the helpful aspects of the retreat was the "safe space" it provided for quiet introspection, reflection, and peace from responsibilities and distractions in life outside the retreat.

"I guess I still feel like it was um, a start on the road towards recovery even though I feel like I've barely made any progress, but I feel like I am on the road. Somehow, I'm more, um, in terms of a bit more focussed and hopeful um, about recovery and sort of more, um, making more effort towards it"

Post-retreat treatment seeking. Most participants reported that after the retreat, they had engaged in individual psychotherapy with psychologists, counsellors or continued attending peer-support groups at the organisation that delivered the retreat. It was unclear whether engaging in psychotherapy was done for the first time for some participants due to their positive experience at the retreat or if this was a continuation of prior treatment.

"I've started seeing a, a psychologist, but it's sort of [inaudible]. Trich is sort of in the mix there with it, but it's sort of not the, the main focus"

Comparison of qualitative and quantitative findings over time

Most participants described substantial improvement in TTM symptoms and/or associated psychological symptoms post-program (Table 2), which was largely supported by the quantitative results (Figures 1 to 3). Participants each entered the retreat harbouring different expectations, and with varying levels of support from family and friends. Group therapeutic processes that were reported as helpful in reducing symptoms were; ‘sharing’, ‘normalisation’, ‘safety’, and ‘enhanced motivation’. The presence of others inhibited hair pulling behaviour, yet participants felt that some time to themselves was still necessary to test the strategies they had learned from retreat facilitators. Individual therapeutic processes that contributed to symptom reduction were; ‘readiness for change’, which included taking personal accountability for change, gaining a sense of hope for recovery, and becoming aware of the impact of their TTM. Another aspect to the individual change process was ‘self-regulation’, which involved developing emotional awareness and expression, learning about self-care, and changing the relationship one has with their hair.

At 12-months post-retreat, TTM relapse was common and this was reflected in the quantitative data (Figure 2). Even so, participants maintained that feelings of acceptance and belonging were important group processes that had influenced their initially positive symptom improvements. For individual processes one year on, the specific skills mentioned at post-program were no longer salient. However, a sense of hope and reflective introspection was maintained, and most participants had engaged in further activities aimed at addressing hair pulling. These enduring elements of hope and introspection were supported by lowered anxiety, depression and stress as measured by the DASS compared to pre-retreat levels. The DASS results did not reflect those of the AQoL, as the 12-month follow-up AQoL measures of mental health and relationships indicated poorer quality of life in these domains than at pre-retreat.

Discussion

The aims of the study were to assess the efficacy of the retreat and explore the key factors participants’ reported as leading to treatment outcomes. One week post-retreat TTM symptom reductions were of a similar magnitude to more conventional psychological treatments of longer duration (e.g., Moritz & Rufer, 2011; Woods et al., 2006). However, like the findings associated with such conventional treatment, gains from the current program were not maintained long-term at the 6-months or one year follow-up. According to participants, the factors most strongly associated with immediate symptom improvement were, at a group level: the sharing of lived experiences, community connection, normalisation, feelings of safety and motivation. Individual factors were: personal accountability, gaining hope for recovery, recognising the impact TTM has on one's life, and improved self-regulation skills (e.g., self-care, emotion regulation). By 12-months follow-up, psychosocial factors associated with the group processes were viewed as contributing to a sense of belonging not previously experienced in the course of receiving other treatments. Even though TTM symptom severity returned to baseline levels by 6-months post-program, participants expressed a sense of enduring hope and motivation for recovery, which grew out of improved understanding of their TTM (e.g., hairpulling cues, impact) and awareness of the existing local community of professionals and peers with knowledge or lived experience of the disorder.

The retreat program differed substantially from evidence-based cognitive-behavioural therapies (CBT) for TTM, which typically include a series of weekly sessions (as reviewed in Slikboer et al., 2017). At the retreat, participants were immersed into a therapeutic environment over three days, limiting their ability to engage in behavioural social avoidance and self-concealment, possible maintaining factors in TTM (Slikboer et al. 2018a). It has been suggested that a group format could have a diluting effect on behavioural treatment for TTM when compared to supportive therapy (Diefenbach et al., 2006). Our results point to the idea that supportive group therapy could be more effective than originally anticipated through the group-based processes of change described by the participants in this study. Quantitative measures of TTM symptoms in the current study are comparable to those found in more rigorous treatment trials that have demonstrated decreases in symptom severity post-treatment (see supplemental material, Table 3S, for a summary) (e.g., Diefenbach et al., 2006; Keuthen et al., 2012; Moritz & Rufer, 2011; van Minnen, Hoogduin, Keijsers, Hellenbrand, & Hendriks, 2003; Woods et al., 2006). CBT does have some effect on reducing symptoms long-term (Falkenstein et al., 2014), however, the 3-day retreat did not demonstrate this same effect.

Qualitative themes identified in the current study closely reflect the recovery-based approaches typically used to guide the development and delivery of mental health services for severe and chronic psychological disorders (e.g., schizophrenia, bipolar disorder). Such recovery-based approaches emphasise that, even with the experience of mental illness, quality of life is possible through fostering one's sense of connectedness; hope and optimism about the future; identity; meaning in life; and empowerment (Leamy et al., 2011; Watson, 2017). TTM is a chronic and distressing disorder, which has a significant adverse impact upon one's sense of self and belonging (Rehm et al., 2015, 2016). Our findings support the use of immersive, structured peer-support interventions for TTM to instil connectedness with a community of accepting others, challenging beliefs about the impossibility of change, and expanding clients' own definitions of what it means to "recover" from TTM; all of which has the potential to broaden one's identity beyond their appearance and improve self-esteem. While the inability to control one's own behaviour and consequent hair loss are undeniably deserving targets of intervention, the strong focus on symptom-based definitions of recovery evident in TTM treatment outcome studies may inadvertently minimise or distract from the importance of psychosocial recovery. As highlighted by our participants, even though TTM symptom severity returned to baseline, their sense of belonging to a valued community and of personal hope was maintained 12-months post-retreat.

Important elements to consider for future therapeutic advances ought to leverage the themes of psychosocial recovery and group-based processes identified in the present study. The presence of a role model (i.e., someone who considers themselves recovered from TTM) could promote the development of hope, model the possibility of and pathways to change, and may enhance motivation for longer-term application of newly learned self-regulation skills. Accessible but limited time alone during treatment may heighten accountability and suppress hairpulling, which may be possible by engaging trusted, supportive others (e.g., friends, family) to help clients use treatment strategies between therapy sessions. Indeed, accessing social support is already a component of CBT for TTM (e.g., Keuthen et al., 2011, 2012). A participant described pleasant sensory experiences during self-care activities (e.g., massage) as important to improve her relationship with her hair. As such facilitating pleasant sensory experiences focused on the hair, scalp, and hands could be helpful treatment strategies to foster self-compassion. Other activities featured in the retreat, such as the empty chair technique, journaling, and group discussions facilitated the identification, questioning and confrontation of long-standing beliefs around the role TTM had in participants' lives. Our findings demonstrate that deep cognitive work can occur outside the traditional therapeutic settings for those with TTM and supports recent research emphasising the importance of addressing cognitions and beliefs in TTM (Keijsers et al., 2016; Rehm et al., 2015; Shareh, 2018). Interestingly, such intervention techniques resemble those of compassion-focussed therapy, which has shown some efficacy for treating anxiety and depression (Finlay-Jones, 2017). Compassion-focussed therapy promotes mindfulness, self-care practices and adopting a mindset of “common humanity” (i.e., that distress and difficulty are common human experiences with potential to connect communities rather than isolate individuals) (Finlay-Jones, 2017). Compassion-focussed therapy may offer a complementary foundation from which to ground CBT for TTM.

Researchers were not privy to the decision-making and rational underlying retreat content, limiting the analysis of content to that described by participants. A potential limitation of the study is that the longitudinal design with followup at 6 and 12 months may have inadvertently triggered participants' reports that more follow-up after the retreat was needed. Repeated contact may also have increased the likelihood of social desirability influencing participants responses to self-report measures and interview questions, with a bias towards positive feedback. Another limitation of the longitudinal nature was that of memory and recall biases which were considered part of the participants' perceptions and interpreted on face value during the thematic analysis. The small sample size and self-selection into both the peer-support retreat and the study may limit generalisability of the findings. For instance, it is likely that this was a highly motivated group of participants who were actively seeking recovery from TTM, and open to engage in alternative therapeutic experiences.

The longitudinal, mixed-methods design of the study is nevertheless unique and a strength within the TTM treatment literature. The current study detailed what treatment users perceived as important, retrospectively, highlighting therapeutic elements that could be used to extend treatment gains from evidence-based CBT approaches. Participants were interviewed in isolation to reduce the influence of in-group biases and facilitate discussion of emotionally sensitive topics. The use of standard quantitative measures of symptom severity facilitated the relevance of the current study's findings in comparison with outcomes reported in previous treatment trials (e.g., Diefenbach et al., 2006; Keuthen et al., 2012; van Minnen et al., 2003; Woods et al., 2006). Another strength was the researchers being blind to the therapeutic content and strategies included in the retreat (except for what participants revealed in interviews) until finalisation of the qualitative analysis. The 3-day residential peer-support retreat under investigation is the only retreat of its type for TTM in Australia and this is the first time it has been formally evaluated.

This exploratory research indicates that a treatment trial using an immersive retreat delivery mode with a larger sample, clearly defined treatment content, and an emphasis on quantitative data rather than qualitative data is warranted. Such a trial would move our knowledge in this area from descriptive to directional. Our findings highlight the potential usefulness of an immersive retreat program for women with TTM, and indicates that factors thought to be important in the recovery of TTM such as emotional regulation (Shusterman, Feld, Baer, & Keuthen, 2009), maladaptive beliefs (Rehm et al., 2015), and avoidance (Slikboer, Castle, et al., 2018) can be addressed within a compassionate peer-support environment. Although the retreat was a brief experience that lead to only short-term symptom improvements, participants described outcomes critical to psychosocial recovery (Leamy et al., 2011), such as a sense of acceptance, belonging and shared experience, which they valued 12 months later.

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Conflict of interest

I.C.R. is a serving, volunteer member of the ARCVic committee of management. R.S. was a volunteer support group facilitator at commencement of this project.

Table 1. The six phases of thematic analysis Braun and Clarke (2006) and how they were operationalised in the study

Phase	Description
1.Familiarising yourself with the data	The first author conducted all interviews and transcribed half of them. The first, second, and third authors all read transcripts numerous times.
2. Generating the initial codes	The first, second and third authors participated in coding (as a team and individually) using NVivo 11 (https://www.qsrinternational.com/) and frequently met to discuss code content at intermittent points throughout the coding process.
3. Searching for themes	Codes were printed on to slips of paper and arranged into themes during team discussion between the first, second and third authors. All codes were included.
4. Reviewing themes	Through team discussion, codes were removed, changed or added to initial themes and relationships between the themes and codes proposed.
5. Defining and naming themes	Themes were further refined and named to reflect content. Disagreements about theme content and names were resolved by the fifth author who analysed theme content, definitions and supportive quotes.
6. Producing the report	The first draft of the report was written by the first author with selected extracts and themes integrated into a table by the second author. Subsequent drafts included feedback from all authors.

Table 2. The means and standard deviations of included measures before and after the retreat program and at 6-month follow-up

	Pre-retreat n= 6 Mean (SD)	1 week post-retreat n=6 Mean (SD)	Six months post retreat n=5 Mean (SD)	One year post retreat n=5 Mean (SD)
MGH-HPS	18.28 (3.90)	10.00 (2.97)	18.2 (5.16)	19.20 (5.50)
DASS-S	14.28 (13.94)	16.17 (14.14)	21.60 (10.60)	16.20 (14.14)
DASS-A	12.86 (7.80)	5.17 (4.31)	8.60 (5.31)	6 .00(4.67)
DASS-D	17.28 (9.60)	10.33 (4.63)	10.33 (6.24)	13.60 (7.28)
SOC-AQoL	6.28 (1.60)	6.00 (1.41)	6.60 (0.89)	7.20 (1.30)
PSYCH-AQoL	6.23 (1.72)	6.5 (1.76)	7.00 (1.87)	7.20 (1.79)

Abbreviations: DASS = depression Anxiety and Stress Scale, DASS-S = stress subscale of DASS; DASS-A = anxiety subscale of DASS; DASS-D = Depression subscale of DASS; MGH-HPS = Massachusetts General Hospital Hair Pulling Scale; PSYCH-AQoL = psychological subscale of the Australian quality of life Instrument; SOC-AQoL = social subscale of the Australian Quality of Life Instrument.

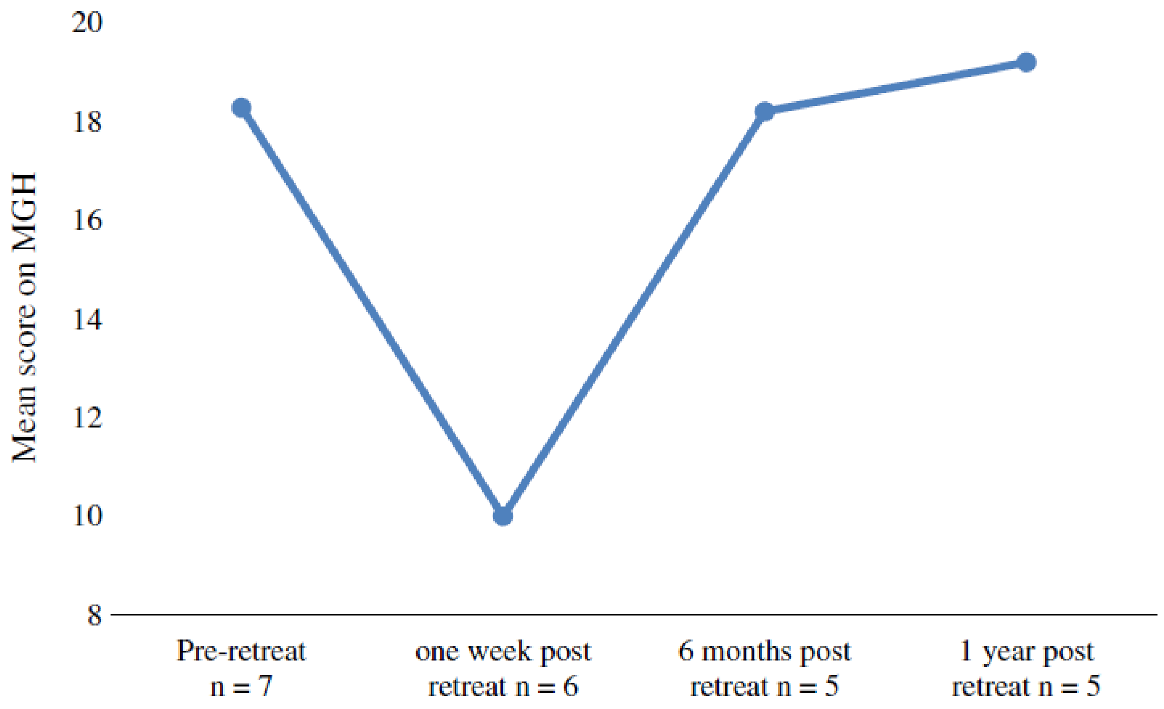

Figure 1. Mean MGH scores over the four time-points.

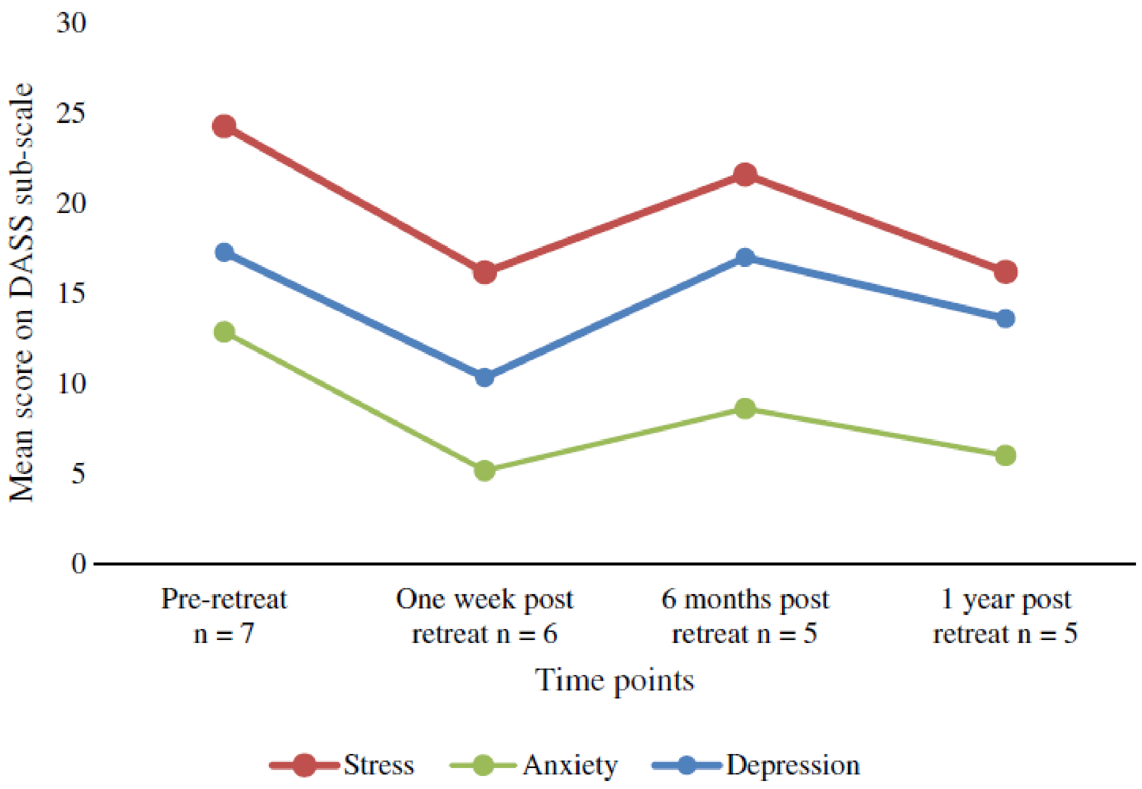

Figure 2. Mean DASS subscales over the four time-points.

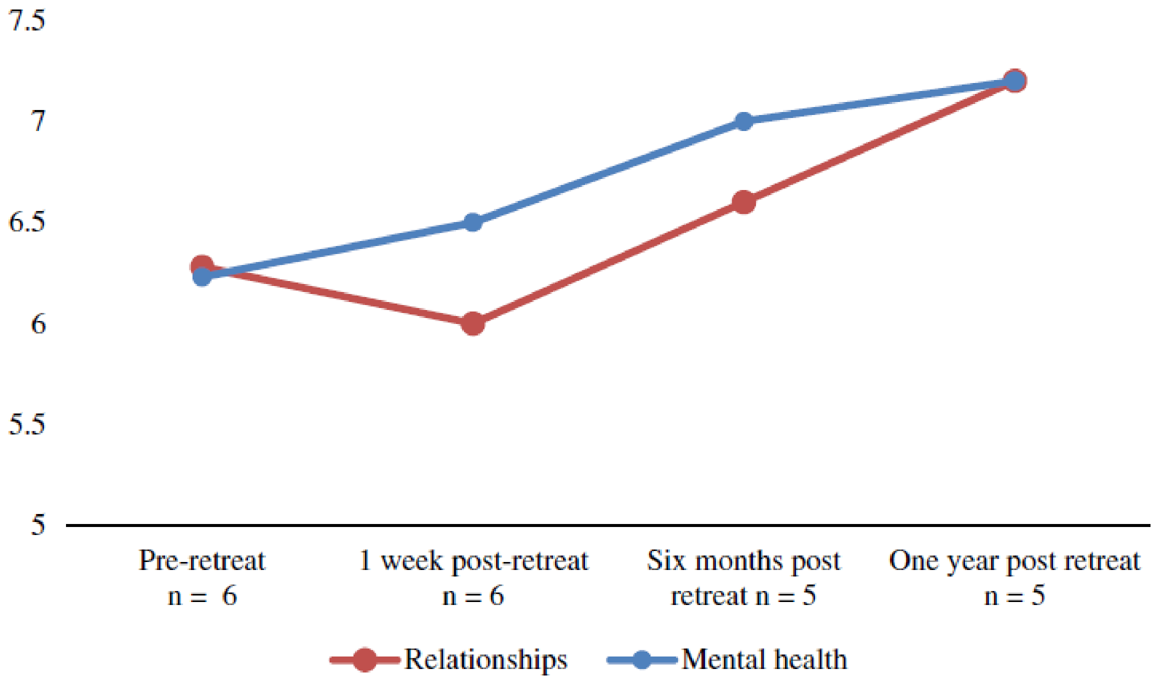

Figure 3. Mean AQoL mental health subscale score and AQoL relationship subscale mean scores. Lower scores indicate better quality of life.