




A Qualitative Study Exploring International Experiences of Seeking Treatment for Adults With Trichotillomania: A Story of Frustration and Unmet Need

Journal of Patient Experience
Volume 8: 1-5
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DOI: 10.1177/23743735211060792
journals.sagepub.com/home/jpx


Chane Anne Roodt, BSc Hons, MSc, PhD¹ ,
Mary Turner, RGN, PhD, FHEA²,
Amanda Edmondson, BSc, MSc, PhD, CPsychol³,
Philip Keeley, PhD, RN⁴, and Sarah Kendal, RMN, BA, MHSc, PhD⁵ 

Abstract

Trichotillomania (TTM) is a poorly understood disorder with no consensus on aetiology or epidemiology; often overlooked due to high comorbidity rates. Cross-cultural qualitative research is sparse; therefore, an international qualitative study was conducted. A generic qualitative approach with thematic analysis was used to explore data from asynchronous email interviews. The aim of this article is to report participant experiences of seeking treatment. Using a sample of 20 adults (18–55 years) from 15 different countries, this article highlights lack of access and unmet healthcare needs signifying an inadequate supply of TTM expertise globally and the need for more robust clinical guidance.

Keywords

trichotillomania, psychiatric, access to treatment, asynchronous email interview, thematic analysis, qualitative research

Introduction

Trichotillomania (TTM) is a poorly understood disorder (1) commonly resulting in clinically significant distress and impairment across all aspects of life, with subsequent hair loss not attributable to another medical condition or mental health disorder (2). Secrecy and non-disclosure tendencies of people with TTM and lack of awareness by healthcare professionals (3) all contribute towards diagnostic under-recognition in the general population. Prevalence was largely unknown for decades; the first large epidemiological survey examining prevalence in a USA general population sample (4) revealed 1.7% of participants as having current TTM, with the lifetime TTM rate at 2.5%. There is a dearth of qualitative enquiry around TTM with cross-cultural research being limited (5).

TTM impacts health and wellbeing in numerous ways; physical complications including skin infections, bleeding, irritation and inflammation from excessive hair-pulling (3). Trichophagia (ingesting hair) is associated with risk of trichobezoar (mass of ingested hair) which can prove fatal without surgical intervention. Functional outcomes associated with TTM include impairment in social, occupational, academic

and psychological functioning (1). Chronic hair-pullers often experience depression, anxiety, embarrassment, feelings of unattractiveness and low self-esteem (6). TTM is known to be a distressing disorder commonly linked to secrecy and shame; a lack of understanding about the availability and efficacy of interventions further contributes toward poor prognosis and routine outcomes (7). Little is known about the experience of people living with TTM from a qualitative perspective and despite several reviews (3,7), little is known about the cause,

¹ School of Human and Health Sciences, University of Huddersfield, Huddersfield, UK

² Department of Nursing & Midwifery, School of Human and Health Sciences, University of Huddersfield, Huddersfield, UK

³ Division of Psychology, Nottingham Trent University, Nottingham, UK

⁴ Faculty of Medicine and Health Sciences, School of Nursing and Midwifery, Keele University, Keele, UK

⁵ School of Healthcare, University of Leeds, Leeds, UK

Corresponding Author:

Chane Anne Roodt, BSc Hons, MSc, PhD, School of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield, HD1 3DH, UK.

Email: Chane.Roodt@hud.ac.uk



epidemiology or aetiology of TTM, with treatment yielding mixed results at best (3). This article reports participant access to and experiences of seeking treatment for TTM.

Method

A generic qualitative approach was utilised (8). Data originated from an international sample and comprised in-depth asynchronous email interviews. Ethical approval was granted by a university research ethics panel. Participants provided informed consent, were notified of their rights to anonymity, confidentiality and rights of withdrawal from the study. Participants were debriefed and provided with support measures at the end of participation. A purposive sampling strategy was utilised to specifically recruit individuals with a common experience of having TTM. Semi-structured asynchronous email interviews (9) were flexible and took place over 8–10 email exchanges. Inclusion criteria contained screening questions guided by the DSM-5 criteria for TTM (2). Exclusion criteria included a screening question which aimed to identify anyone who considered themselves to be at risk. Within the international sample, the ability to speak and write in English was not a pre-defined criterion; the general message seeking participants was written in English and only participants who could respond in English volunteered their participation. Data were analysed using the six-phase thematic analysis process by Braun and Clarke (10); a method that is largely independent of theory and offers a flexible process of analysing data. The thematic analysis was developed inductively to locate semantic level themes, aiming to facilitate data driven findings. Nested within a larger study, participants were asked questions related to their experiences of seeking treatment for TTM.

Results

During 2016, email interviews were conducted with 20 participants (13 female) from 15 countries; mean age 34.3 years; age range 18–55 years; reported onset of TTM range was 5–26 years; TTM had been experienced for an average of 20.05 years. Sample demographics are noted in Table 1. Four people dropped out of the interview citing various reasons (e.g. change of mind, time constraints) and six people began the interview but stopped responding; dropout and non-responder data were not used. Thematic analysis highlighted one theme; lapse in duty of care, and one sub-theme; inadequate training of healthcare professionals.

Lapse in Duty of Care

Most participants reported unmet needs in relation to support, referral, or treatment options for their TTM:

‘My doctor cant [can’t] even say the word ‘trichotillomania’ he offered no help and he is unwilling to even read about it’ (P10 – Female, 32, Mauritius)

Some participants described instances where healthcare professionals failed to offer any treatment and seemed to place the responsibility of stopping hair-pulling behaviours directly onto the participant:

‘I have not tried any treatment because no treatments have been offered to me by doctors. They have just said I should control it myself’ (P6 – Male, 30, Brazil)

This seemed to resonate with other participants who suggested they were told to ‘just live’ with TTM, resulting in some participants feeling alone in their diagnosis:

‘I have tried no treatment, no treatment was offered! I was told it is incurable and I should just live with the problem. I am alone in this battle with Trichotillomania and there is no help’ (P7 – Female, 22, China)

Inadequate Training of Healthcare Professionals

Participants described their difficulties in dealing with healthcare professionals; all 20 participants expressed that many primary healthcare providers had a lack of training around TTM:

‘My mum took me to see 4 doctors (2 GP’s, 1 Dermatologist, and 1 Psychiatrist). The first 3 knew nothing about Trich [Trichotillomania], would tell my mum I’d grow out of it and I should just stop (...) It was frustrating (...) 3 out of 4 were not educated enough to diagnose Trichotillomania.... That’s 75%. Just ludicrous’ (P9 – Male, 26, Australia)

Coupled with the perception that healthcare providers lack understanding and adequate training when facing a patient with TTM, participants experienced significant delays in receiving a formal diagnosis:

‘I have been pulling for 12 years there about, but I was only diagnosed 2 years ago (...) doctors don’t understand that it’s a real problem. 3 GP’s did not diagnose me, the diagnosis was made with psychiatrist’ (P4 – Male, 29, India)

There were expressions of frustration at the lack of understanding healthcare professionals have about TTM, with claims of knowing ‘bare essential’ information about the disorder:

‘In a total of 30 years trying to seek help, and only ONE person knew the bare essential information about Trichotillomania. (...) most times when I tell a healthcare “professional” I have Trichotillomania, they will say something such as ‘you can just stop if you try hard enough’ (P3 – Male, 54, Germany)

Participant experiences suggest a lack of sensitivity training among healthcare professionals; this ranged from general

Table 1. Demographic Information of the Asynchronous Email Interview Sample.

Participant	Gender	Location	Age	Reported age of onset	Participant	Gender	Location	Age	Reported age of onset
P1	Female	Massachusetts	49	10	P11	Female	Abu Dhabi	24	9
P2	Female	New Zealand	44	12	P12	Male	Johannesburg	35	20
P3	Male	Germany	54	24	P13	Female	Jamaica	18	14
P4	Male	India	29	17	P14	Female	Ireland	28	5
P5	Male	Canada	46	5	P15	Female	Switzerland	55	25
P6	Male	Brazil	30	12	P16	Female	Illinois	42	24
P7	Female	China	22	10	P17	Male	Cape Town	52	26
P8	Female	Morocco	20	7	P18	Female	England	31	13
P9	Male	Australia	26	16	P19	Female	Ohio	27	16
P10	Female	Mauritius	32	9	P20	Female	Wales	22	11

misunderstanding of the disorder, perceptions of repulsion and descriptions of how healthcare professionals ‘gave up’ too easily:

‘I don’t feel they ever quite understood. They gave up on me too easily, or tried to push drugs at me. With some, I even got a sense that they were repulsed by it’ (P1 – Female, 49, Massachusetts)

Participants expressed frustration at attempting to seek help for TTM but not being taken seriously, with suggestions that some healthcare professionals do not perceive TTM to be a life impacting disorder:

‘I have been pulling on & off for 26 years now and was only diagnosed about 8 years ago. My doctor has been very hesitant to try me on any medicine, he doesn’t think the trichotillomania causes much of a disruption [disruption] in my life. I have asked for help, and he says it should be manageable without medicine...talk about frustrating! Sometimes doctors don’t know best.’ (P17 – Male, 52, Cape Town)

There were other descriptions detailing minimal clinician effort alongside the assumption that TTM is not viewed as a serious enough disorder; this may subconsciously affect the level at which clinicians provide support:

‘He didn’t offer me help, and he has never made any effort to read up about treatments for me. That is the most frustrating thing... they are not willing to learn about it to try and help because in their view it’s not an important or serious condition’ (P10 – Female, 32, Mauritius)

Discussion

TTM impairment appears to worsen over time; mild to moderate social and interpersonal impairment is evident in childhood (11) which often progresses to moderate to severe impairment in later life (1). Participants’ accounts of their unmet healthcare needs suggest early intervention may impact positively on health and social outcomes. Often the first point of contact,

GP’s face a formidable challenge when dealing with patients who have complex symptoms (12) of disorders with no known aetiology. People with TTM may benefit from improved access to psychological therapies, especially those with chronic symptoms as they often experience comorbidity and make heavy demand on multiple healthcare services, with generally unsatisfactory outcomes (13). TTM symptoms may often exacerbate comorbid disorders and vice versa; there is a tendency within specialist services to keep things separated, this can result in people with comorbidity falling through the cracks (14) and signals a need for partnership across healthcare departments.

Treatment seeking behaviours are low within the TTM population; in one study, just over 61% of survey participants sought treatment, but only 14.8% reported a moderate to large reduction in TTM symptoms (1). Current findings suggest treatment seeking commonly results in unmet healthcare needs; this finding can be used to inform how clinicians better understand and support people with TTM. Previous research (3,15) highlighted an inadequate supply of healthcare providers trained to treat TTM and called for more information and training to address the global shortage of therapist expertise. Unfortunately, based on the current findings, this has remained the same a decade later. Participant accounts of perceived repulsion on the part of the clinicians suggests professional support could in some cases be adversely influenced by clinicians’ personal feelings about TTM; relevant training for clinicians could therefore include an examination of conscious and unconscious bias. To compare current findings, future research may investigate healthcare professional perceptions and experiences of supporting patients with TTM. Previous research noted low clinician ratings of impairment for TTM patients (16); this contradicts accumulating evidence which highlights the negative consequences associated with TTM and further emphasises that TTM is a misunderstood disorder.

As comorbidity is common with TTM, clinical services should aim to utilise an inclusive approach whereby provisions should be needs-led rather than service-led (14). Arguably, study findings emphasise the importance of patient-centred support that offers an appropriate response

to people with TTM experiencing distress. Further, coupled with the need for TTM training in the healthcare field, there should be a move toward development and pilot of a novel, accessible specialist service for people with TTM. The asynchronous email interview method provided an acceptable and feasible way to access an international sample of people with TTM, while eliminating the need to travel. Long-term email engagement facilitated rapport. The method was effective in highlighting participants' shared experience of misunderstandings on the part of clinicians, delayed diagnosis and difficulty accessing appropriate TTM treatment.

Limitations

Interviews that take longer to complete may result in a higher possibility of dropouts (17). Given the sample size; it was not a specific aim to produce generalisable findings. Despite reported limitations of internet recruitment, internet sampling procedures can provide results consistent with traditional methods (18). Limited clinical and demographic information was gathered, though the inclusion of screening questions guided by the DSM-5 criteria for TTM () (2) may have mitigated the absence of verified participant diagnoses.

Conclusion

TTM remains a misunderstood disorder with poor prognosis. The wide-ranging impairments and comorbidities associated with TTM imply high societal costs, highlighting a need for greater knowledge and understanding of the condition. Many people with TTM are underserved and have unmet healthcare needs; guidance for practitioners on this subject is generally sparse, changes to policy and practice are warranted and provision of education for clinicians is needed. These findings can inform how clinicians support people with TTM and suggest avenues for further research.

Ethical Approval

Ethical approval was obtained from University of Huddersfield's School of Human and Health Sciences Research Ethics Panel (SREP/2015/118)

Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the University of Huddersfield's School of Human and Health Sciences Research Ethics Panel (SREP/2015/118) approved protocols.

Statement of Informed Consent

Written informed consent was obtained from the patient(s) for their anonymized information to be published in this article.



Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

ORCID iDs

Chane Anne Roodt  <https://orcid.org/0000-0001-5822-2958>
Sarah Kendal  <https://orcid.org/0000-0001-8557-5716>

References

1. Woods DW, Flessner C, Franklin ME, Keuthen NJ, Goodwin RD, Stein DJ, et al. The trichotillomania impact project (TIP): exploring phenomenology, functional impairment, and treatment utilization. *J Clin Psychiatry*. 2006;67(12):1877-88. DOI: 10.4088/jcp.v67n1207
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Fifth Edition. Arlington VA, American Psychiatric Association, 2013
3. Duke DC, Keeley ML, Geffken GR, Storch EA. Trichotillomania: a current review. *Clinical Psychology Review*. 2010;30(2):181-93. DOI: 10.1016/j.cpr.2009.10.008
4. Grant JE, Dougherty DD, Chamberlain SR. Prevalence, gender correlates, and co-morbidity of trichotillomania. *Psychiatry Res*. 2020;288:112948. DOI: 10.1016/j.psychres.2020.112948
5. Walther M, Ricketts E, Conelea C, Woods DW. Recent advances in the understanding and treatment of trichotillomania. *J Cogn Psychother*. 2010;24(1):46-64. DOI: 10.1891/0889-8391.24.1.46
6. Townsley-Stemberger RMT, Thomas AM, Mansueto CS, Carter JG. Personal toll of trichotillomania: behavioral and interpersonal sequelae. *J Anxiety Disord*. 2000;14(1):97-104. DOI: 10.1016/S0887-6185(99)00028-6
7. Slikboer R, Nedeljkovic M, Bowe SJ, Moulding R. A systematic review and meta-analysis of behaviourally based psychological interventions and pharmacological interventions for trichotillomania. *Clinical Psychologist*. 2015 (Australian Psychological Society);21(1):20-32. DOI: 10.1111/cp.12074
8. Percy WH, Kostere K, Kostere S. Generic qualitative research in psychology. *The Qualitative Report*. 2015;20(2):76-85. DOI:10.46743/2160-3715/2015.2097
9. McCoyd J, Kerson T. Conducting intensive interviews using email: a serendipitous comparative opportunity. *Qual Soc Work*. 2006;5(3):389-406. DOI: 10.1177/1473325006067367
10. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. DOI: 10.1191/1478088706qp063oa
11. Franklin ME, Flessner CA, Woods DW, Keuthen NJ, Piacentini JC, Moore P, et al. The child and adolescent trichotillomania impact project: descriptive psychopathology, comorbidity, functional impairment, and treatment utilization. *Journal of Developmental and Behavioral Pediatrics*. 2008;29(6):493-500. DOI: 10.1097/DBP.0b013e31818d4328
12. Eriksen TE, Kirkengen AL, Vetlesen AJ. The medically unexplained revisited. *Med Health Care and Philos*. 2013;16(3):587-600. DOI: 10.1007/s11019-012-9436-2
13. McCrae N, Correa A, Chan T, Jones S, de Lusignan S. Long-term conditions and medically-unexplained symptoms:

- feasibility of cognitive behavioural interventions within the improving access to psychological therapies programme. *Journal of Mental Health*. 2015;24(6):379-84. DOI: 10.3109/09638237.2015.1022254
14. Baldacchino A. Co-morbid substance misuse and mental health problems: policy and practice in Scotland. *American Journal of Addictions*. 2007;16(3):147-59. DOI: 10.1080/08982100701375209
 15. Franklin ME, Zgrabke K, Benavides K. Trichotillomania and its treatment: a review and recommendations. *Expert Rev Neurother*. 2011;11(8):1165-74, DOI: 10.1586/em.11.93
 16. Stanley MA, Prather RC, Wagner AL, Davis ML, Swann AC. Can the yale-brown obsessive-compulsive scale be used to assess trichotillomania? A preliminary report. *Behav Res Ther*. 1993;31(2):171-7. DOI: 10.1016/0005-7967(93)90068-6
 17. Hodgson S. Cutting through the silence: a sociological construction of self-injury. *Sociol Inq*. 2004;74(2):162-79. DOI: 10.1111/j.1475-682X.2004.00085.x
 18. Gosling SD, Vazire S, Srivastava S, John OP. Should we trust web-based studies? A comparative of six preconceptions about internet questionnaires. *American Psychologist*. 2004;59(2):93-104. DOI: 10.1037/0003-066X.59.2.93