

A qualitative study exploring international experiences of seeking treatment for adults with Trichotillomania: a story of frustration and unmet need.

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9 **Abstract**

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12 epidemiology; often overlooked due to high comorbidity rates. Cross-cultural qualitative research is
13 sparse; therefore, an international qualitative study was conducted. A generic qualitative approach
14 with thematic analysis was used to explore data from asynchronous email interviews. The aim of this
15 article is to report participant experiences of seeking treatment. Using a sample of 20 adults (18-55
16 years) from 15 different countries, this article highlights lack of access and unmet healthcare needs
17 signifying an inadequate supply of TTM expertise globally and the need for more robust clinical
18 guidance.
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28 **Keywords**

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30 trichotillomania, psychiatric, access to treatment, asynchronous email interview, thematic analysis,
31 qualitative research
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37 **Introduction**

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39 Trichotillomania (TTM) is a poorly understood disorder¹ commonly resulting in clinically significant
40 distress and impairment across all aspects of life, with subsequent hair loss not attributable to another
41 medical condition or mental health disorder.² Secrecy and non-disclosure tendencies of people with
42 TTM and lack of awareness by healthcare professionals³ all contribute towards diagnostic under-
43 recognition in the general population. Prevalence was largely unknown for decades; the first large
44 epidemiological survey examining prevalence in a USA general population sample⁴ revealed 1.7% of
45 participants as having current TTM, with the lifetime TTM rate at 2.5%. There is a dearth of qualitative
46 enquiry around TTM with cross-cultural research being limited.⁵
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56 TTM impacts health and wellbeing in numerous ways; physical complications including skin infections,
57 bleeding, irritation and inflammation from excessive hair-pulling.³ Trichophagia (ingesting hair) is
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3 associated with risk of trichobezoar (mass of ingested hair) which can prove fatal without surgical
4 intervention. Functional outcomes associated with TTM include impairment in social, occupational,
5 academic and psychological functioning.¹ Chronic hair-pullers often experience depression, anxiety,
6 embarrassment, feelings of unattractiveness and low self-esteem.⁶ TTM is known to be a distressing
7 disorder commonly linked to secrecy and shame; a lack of understanding about the availability and
8 efficacy of interventions further contributes toward poor prognosis and routine outcomes.⁷ Little is
9 known about the experience of people living with TTM from a qualitative perspective and despite
10 several reviews^{3,7}, little is known about the cause, epidemiology or aetiology of TTM, with treatment
11 yielding mixed results at best.³ This article reports participant access to and experiences of treatment
12 for TTM.

23 **Method**

24 A generic qualitative approach was utilised.⁸ Data originated from an international sample and
25 comprised in-depth asynchronous email interviews. Ethical approval was granted by a university
26 research ethics panel. Participants provided informed consent, were notified of their rights to
27 anonymity, confidentiality and rights of withdrawal from the study. Participants were debriefed and
28 provided with support measures at the end of participation. A purposive sampling strategy was utilised
29 to specifically recruit individuals with a common experience of having TTM. Semi-structured
30 asynchronous email interviews⁹ were flexible and took place over 8 – 10 email exchanges. Inclusion
31 criteria contained screening questions guided by the DSM-5 criteria for TTM.² Exclusion criteria
32 included a screening question which aimed to identify anyone who considered themselves to be at risk.
33 Within the international sample, the ability to speak and write in English was not a pre-defined
34 criterion; the general message seeking participants was written in English and only participants who
35 could read/speak English volunteered their participation. Data were analysed using the six-phase
36 thematic analysis process by Braun and Clarke¹⁰; a method that is largely independent of theory and
37 offers a flexible process of analysing data. The thematic analysis was developed inductively to locate
38 semantic level themes, aiming to facilitate data driven findings. Nested within a larger study,
39 participants were asked questions related to their experiences of seeking treatment for TTM.
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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.

(Table 1)

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 described how some 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)

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3 There were expressions of frustration at the lack of understanding healthcare professionals have
4 about TTM, with claims of knowing 'bare essential' information about the disorder:
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7 *'In a total of 30 years trying to seek help, and only ONE person knew the bare essential information*
8 *about Trichotillomania. (...) most times when I tell a healthcare "professional" I have Trichotillomania,*
9 *they will say something such as 'you can just stop if you try hard enough' (P3 – Male, 54, Germany)*

10 Participant experiences suggest a lack of sensitivity training among healthcare professionals; this
11 ranged from general misunderstanding of the disorder, perceptions of repulsion and descriptions of
12 how healthcare professionals 'gave up' too easily:
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16 *'I don't feel they ever quite understood. They gave up on me too easily, or tried to push drugs at me.*
17 *With some, I even got a sense that they were repulsed by it' (P1 – Female, 49, Massachusetts)*

18 Participants expressed frustration at attempting to seek help for TTM but not being taken seriously,
19 with suggestions that some healthcare professionals do not perceive TTM to be a life impacting
20 disorder:
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24 *'I have been pulling on & off for 26 years now and was only diagnosed about 8 years ago. My doctor has*
25 *been very hesitant to try me on any medicine, he doesn't think the trichotillomania causes much of a*
26 *distruption [disruption] in my life. I have asked for help, and he says it should be manageable without*
27 *medicine...talk about frustrating! Sometimes doctors don't know best.'* (P17 – Male, 52, Cape Town)

28 There were other descriptions detailing minimal clinician effort alongside the assumption that TTM is
29 not viewed as a serious enough disorder; this may subconsciously affect the level at which clinicians
30 provide support:
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34 *'He didn't offer me help, and he has never made any effort to read up about treatments for me. That is*
35 *the most frustrating thing... they are not willing to learn about it to try and help because in their view it's*
36 *not an important or serious condition' (P10 – Female, 32, Mauritius)*

37 **Discussion**

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39 TTM impairment appears to worsen over time; mild to moderate social and interpersonal impairment
40 is evident in childhood¹¹ which often progresses to moderate to severe impairment in later life.¹

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42 Participants' accounts of their unmet healthcare needs suggest early intervention may impact
43 positively on health and social outcomes. Often the first point of contact, GP's face a formidable
44 challenge when dealing with patients who have complex symptoms¹² of disorders with no known
45 aetiology. People with TTM may benefit from improved access to psychological therapies, especially
46 those with chronic symptoms as they often experience comorbidity and make heavy demand on
47 multiple healthcare services, with generally unsatisfactory outcomes.¹³ TTM symptoms may often
48 exacerbate comorbid disorders and vice versa; there is a tendency within specialist services to keep
49 things separated, this can result in people with comorbidity falling through the cracks¹⁴ and signals a
50 need for partnership across healthcare departments.
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3 Treatment seeking behaviours are low within the TTM population; in one study, just over 61% of
4 survey participants sought treatment, but only 14.8% reported a moderate to large reduction in TTM
5 symptoms.¹ Current findings suggest treatment seeking commonly results in unmet healthcare needs;
6 this finding can be used to inform how clinicians better understand and support people with TTM.
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8 Previous research^{3,15} highlighted an inadequate supply of healthcare providers trained to treat TTM
9 and called for more information and training to address the global shortage of therapist expertise.
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11 Unfortunately, based on the current findings, this has remained the same a decade later. Participant
12 accounts of perceived repulsion on the part of the clinicians suggests professional support could in
13 some cases be adversely influenced by clinicians' personal feelings about TTM; relevant training for
14 clinicians could therefore include an examination of conscious and unconscious bias. To compare
15 current findings, future research may investigate healthcare professional perceptions and experiences
16 of supporting patients with TTM. Previous research noted low clinician ratings of impairment for TTM
17 patients¹⁶; this contradicts accumulating evidence which highlights the negative consequences
18 associated with TTM and further emphasises that TTM is a misunderstood disorder.
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31 As comorbidity is common with TTM, clinical services should aim to utilise an inclusive approach
32 whereby provisions should be needs-led rather than service-led.¹⁴ Arguably, study findings emphasise
33 the importance of patient-centred support that offers an appropriate response to people with TTM
34 experiencing distress. Further, coupled with the need for TTM training in the healthcare field, there
35 should be a move toward development and pilot of a novel, accessible specialist service for people
36 with TTM. The asynchronous email interview method provided an acceptable and feasible way to
37 access an international sample of people with TTM, while eliminating the need to travel. Long-term
38 email engagement facilitated rapport. The method was effective in highlighting participants' shared
39 experience of misunderstandings on the part of clinicians, delayed diagnosis and difficulty accessing
40 appropriate TTM treatment.
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51 **Limitations**

52 Interviews that take longer to complete may result in a higher possibility of dropouts.¹⁷ Given the
53 sample size; it was not a specific aim to produce generalisable findings. Despite reported limitations
54 of internet recruitment, internet sampling procedures can provide results consistent with traditional
55 methods.¹⁸ Limited clinical and demographic information was gathered, though the inclusion of
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3 screening questions guided by the DSM-5 criteria for TTM² may have mitigated the absence of
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5 verified participant diagnoses.
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8 9 **Conclusion**

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