

Emotions towards diagnosis and impact on identity in T1DE: A qualitative exploration

Rationale

There is a significant lack of qualitative literature on type 1 diabetes (T1D) and disordered eating (T1DE), resulting in limited understanding of how T1DE is developed and maintained, and poor therapeutic interventions. Current therapy models are not adapted to T1DE and there is a high drop out rate.

Emotions towards diagnosis and identity have been identified as relevant in both T1D and eating disorder (ED) research.

This study aimed to explore how participants with T1DE feel about their T1D and ED and their impact on identity, examining their potential role in the development and maintenance of T1DE.

Method

Participants with T1DE (n=11, mean age 37.73, SD=12.79, all female) were asked to write one letter to their T1D and one to their ED, expressing their emotions towards each diagnosis and how their identity had been impacted.

Results

Qualitative analysis identified five themes: (1) Resentment, (2) Relentlessness, (3) Identity, (4) Something Needed and (5) Dictator. The first three from T1DM letters and the final two from ED letters.

Emotions towards T1D and its impact on identity, and how these factors differed in ED, suggests that T1DE may initially develop to counterbalance the impact of T1D, but result in an individual becoming stuck under the power of the ED.

Conclusion

These findings support and expand upon existing literature in the conceptualisation of T1DE, calling for further considerations on how clinical practice can adapt to meet need.

This study highlights the value of qualitative research in exploring participant experiences and the uniqueness of T1DE.

Resentment

"...this resentment I had for you began to morph into resentment for everyone else around me...Resentment towards strangers who seemed to take for granted having lives without you in it. Having freedom when I was feeling suffocated by you."

Relentlessness

"I pushed you aside...it wasn't until I was a teenager that you truly hit me, that you was still with me, and you wasn't going to go away...No matter how many times I would hide from the diabetes nurses when they came to my house. No matter how many times I said my bloods were ok, when they were not, no matter how many times I faked it, I had no control over you T1D. I couldn't escape you."

Identity

"Why did my teachers refer to me as 'the diabetic one'?...Why did you become my whole identity before I had the chance to figure out who I wanted to be...?"

Something needed

"...after years of never feeling good enough, like I didn't fit in, that there was something wrong with me and like I didn't matter... you help me belong and that people accept me when you're with me."

Dictator

"Birthdays, social events, holidays, work duties, pet owner duties, health duties all come into practice after I have pleased you ... from the moment I wake up the first thing on my mind is how I plan on organising my day so you are happy...I feel I must please you."

"You also reminded me that I am strong. That your voice is loud, but I am louder. I deserve a life with joy and excitement. I am a good person."

"you must do diabetes, or you die"

"I feel like a slave to a master"