

A study of letters written to glucose monitors by individuals living with type 1 diabetes and with experience of disordered eating

Jennifer Heath, Emily Williams & Christian Koebbel

Introduction

In recent years, diabetes technologies have advanced significantly; flash and continuous glucose monitors (FGM/CGM) are more widely accessible. To date, little research has explored the specific benefits or pitfalls that FGM/CGM use may come with for individuals with type 1 diabetes and disordered eating (T1DE). Previous research has explored the utility and acceptability of devices. Instead, this research explored users' relationships to their device to provide insights that could be of use to clinicians within diabetes and eating disorder services, and even technology developers.

Aim

This qualitative study aimed to explore the relationship that those living with type 1 diabetes and experience of disordered eating have with their FGM/CGM.

Method

Participants were asked to write letters addressed to their FGM/CGM. The letters were analysed using reflexive thematic analysis (Braun & Clarke, 2022) to construct themes capturing relationships individuals with T1DE had to their device.

Results

16 letters were received and 4 themes were constructed during analysis. The themes demonstrate how FGM/CGM can be supportive and life changing but the relationship is one of necessity rather than choice: **"I don't always like or want you...I NEED you...but I wish I didn't"**. Constant monitoring and **"facing the facts"** can feel overwhelming, leading to some participants taking steps to ensure they could get a break from the device. Continuous monitoring can lead to the device forming a relationship with the user's thoughts and disordered eating behaviours: **"You are intertwined with disordered eating"**. These become hard to separate; sometimes they conflict, sometimes they work together with disordered eating taking the leading role. FGM/CGM can promote unreachable targets reinforced by discourses such as the importance of being 'a good diabetic' or the societal thin ideal. Devices also act to **"communicate with others"** a person's identity as a diabetic, inviting others in; an experience that can be either positive or negative.

Conclusions

Whilst FGM/CGM had unintended negative consequences due to the constant and consuming nature of the data, users did not want to be without their device, acknowledging an overall improvement in quality of life.

Data from devices could be used to achieve better health and diabetes management but, at other times, had been used to support development and maintenance of disordered eating behaviour.

It is vital that healthcare professionals and technology developers better understand this relationship to encourage healthy use of devices designed to support self-care and management of diabetes.

Recommendations

Technology Developers: Consider in-app messages or questions that could encourage self-reflection, supporting users to develop more positive relationships to their data.

Clinicians: Person-centred care, exploring individuals' relationship to their FGM/CGM, and how they respond to constant monitoring by their device, should be prioritised with personalised diabetes management plans that include input from the whole multidisciplinary care team.

Policy: Psychological support should be available to individuals with T1DE. Specific T1DE guidelines should be developed and published, including clear information regarding FGM/CGM use.

Key References

Braun, V., & Clarke, V. (2022). Thematic Analysis: A Practical Guide. Sage.

Williams, E. (2024). A study of letters written to glucose monitors by individuals living with type 1 diabetes and with experience of disordered eating. Available from <https://uhra.herts.ac.uk>