

CGM for children and young people with type 1 diabetes: NICE criteria and effects of decision fatigue and alarm fatigue

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Research has shown that use of continuous glucose monitoring (CGM) is associated with improved time in range, improved HbA_{1c}, and decreased risk of long-term complications secondary to type 1 diabetes. There are, however, several barriers that can lead to discontinuation of CGM, including pain, skin reactions, concerns around accuracy, sensor loss, interference with daily activity, and alarm fatigue. This review paper will outline the impact of decision fatigue and alarm fatigue in children and young people using CGM.

Type 1 diabetes (T1D) is a chronic condition that requires life-long treatment with insulin multiple times each day in order to maintain glucose levels within an optimum target range and prevent long-term complications. To optimise the management of their condition, people with T1D undertake self-monitoring of blood glucose (SMBG) by performing fingerprick checks 6–10 times per day (Marks and Wolfsdorf, 2020). For young people, carrying out these checks can be frustrating and inconvenient. An alternative to SMBG, continuous glucose monitoring (CGM) is a small sensor inserted under the skin that measures the glucose levels in the interstitial fluid and sends readings to a reader or phone application every few minutes (Health Quality Ontario, 2018). This system can help to reduce the number of fingerprick checks required.

Changes in policy

In March 2022, NICE guidelines for children and young people (CYP) with T1D were updated to include new guidance for CGM (NICE, 2022). The guidelines state:

“Offer real-time continuous glucose monitoring (rtCGM) to all children and young people with type 1 diabetes, alongside education to support children and young people and their families and carers to use it.”

Benefits and challenges of CGM

Research has shown that use of CGM is associated with improved time in range (TIR), improved HbA_{1c}, and decreased risk of long-term complications secondary to T1D (Zimmerman et al, 2019). Deeb et al (2018), however, recognises that there are several barriers that can lead to discontinuation of CGM, including pain, skin reactions, concerns around accuracy, sensor loss, interference with daily activity, and alarm fatigue.

Implications for practice

While the advantages of CGM are well recognised, as practitioners it is important to be aware of the implications of CGM use. Decision and alarm fatigue will present specific challenges for children and young people (CYP) and their families.

Decision fatigue

Everyday, people make thousands of decisions as part of their daily life. Every decision takes up mental energy (Pignatiello et al, 2018), making the decisions at the end of the day harder than those at the beginning. It has been estimated that people with T1D make an additional 180 health-related decisions each day (Tack et al, 2018). Consequently, it is important as practitioners who support CYP with T1D to recognise this concept and where possible provide them with tools to help them to minimise this problem (Sherr et al, 2018).

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Article points

1. While the advantages of continuous glucose monitoring (CGM) are well recognised, as practitioners it is important to be aware of the implications of CGM use.
2. People with diabetes can never have a day without checking and responding to ever-changing glucose levels, which puts them at an increased risk of developing decision fatigue.
3. It is important for practitioners to support patients in creating balance between setting alarm limits that are narrow enough to ensure patient safety, but not so narrow that alarms will be repeatedly triggered can lead to the risk of alarms being ignored.

Key words

- Alarm fatigue
- Continuous glucose monitoring
- Decision fatigue
- Type 1 diabetes

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What is decision fatigue and why it is a problem?

Decision fatigue is a concept described as “the impaired ability to make decisions and control behavior as a consequence of repeated acts of decision-making” (Pignatiello et al, 2018). People with T1D report that it is a long-term condition that you can never take a day off from, describing it as similar to a full-time job (Abdoli et al, 2021). People with diabetes can never have a day without checking and responding to ever-changing glucose levels, which puts them at an increased risk of developing decision fatigue. This is relevant in managing T1D, as it has been shown that when people are experiencing decision fatigue they may act impulsively, delay action, or even not act at all (Pignatiello et al, 2018).

Kalra and Sahay (2018) define fatigue as “physical and/or mental exhaustion” with various triggers, and they discuss the implications and management of Diabetes Fatigue Syndrome (DFS). They highlight that DFS can be reduced by effective management of diabetes distress, lifestyle optimisation and effective glucose control; however, these may be difficult for someone who is experiencing DFS/burnout. The experience of people using CGM could go either way - increasing levels of diabetes distress (for example, causing increased anxiety from alarms), or minimising it (for example, people finding reassurance from alarms). This further highlights the importance of the multidisciplinary team (MDT) providing education around interpreting CGM data and improving an individual’s tools for decision making.

Another aspect to consider in reviewing a person’s CGM data and encouraging them to make independent dose adjustments is that there are often multiple ways to achieve the same outcome, and flexibility is important in care approaches for CYP. Clinicians may look at the same CGM data, but disagree on the treatment decision. For example, when presented with glucose levels that are outside the target range, one clinician may want to change the basal dose, and another might want to change the meal insulin dose. Both courses of treatment could be considered acceptable and correct decisions (Mahmoudi et al, 2015). This becomes relevant to the concept of decision fatigue, because it further highlights the number of important decisions that people with T1D are required to make.

What can be done?

One way of supporting people with diabetes struggling with decision fatigue is to provide them with decision-making tools, for example, the use of a bolus calculator has been shown to reduce burden (Sherr et al, 2018). Recently, phone applications have become a popular way of supporting daily T1D management and decision making (Katz et al, 2018), and research has shown that bolus calculators on phone applications have the potential to decrease fatigue; although, further in-depth research needs to be done to provide more substantial evidence (Tack et al, 2018).

Alarm fatigue

The frequency of alarms from CGM is reported as a reason some individuals choose to discontinue treatment (Shivers et al, 2013). While the advantages of these alarms can alert patients to a blood glucose level that may need intervention, it is important to consider when alarms or alerts might be inconvenient or unwanted.

What is alarm fatigue?

Shivers et al, (2013) describes alarm fatigue as “when the user of a device is frequently exposed to alarms (in particular, false or unnecessary ones) and, over time, becomes less likely to respond appropriately to true alarms.”

Why is alarm fatigue a problem?

As well as hyperglycaemia and hypoglycaemia alarms, CGM also provides 24-hour data, which is advantageous as a tool for practitioners and families when making dose changes. Although, having data constantly available can be overwhelming for patients and in some cases can increase anxiety levels (Messer et al, 2017). This can be due to the feeling of being unable to switch off and CGM sensors linked to phone applications will likely increase screen time for patients. Evidence has shown that increased screen time can be addictive and can lead to negative physical and psychological effects (Lissak, 2018). International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines highlight that the education provided by the MDT will be a key part of supporting patients with the use of their device (Phelan et al, 2018).

What can be done?

To reduce the burden of CGM alarms, it is important for practitioners to support patients in creating balance between setting alarm limits that are narrow enough to ensure patient safety and support positive health outcomes, but not so narrow that alarms will be repeatedly triggered can lead to the risk of alarms being ignored due to the frequency of them (Sherr et al, 2018). Research has shown that people respond to fewer alarms if they feel that the “false alarm” rate is too high, which can lead to the user ignoring important alarms, causing potentially negative outcomes (Shivers et al, 2013). It can be equally argued that alarm limits set too widely may lead to less frequent intervention, which might increase the risk of larger swings in glucose levels and poorer control overall. Hirsch (2009) discusses alarm options and suggests initially starting with wider alarm limits and narrowing them as the patient adjusts to the device.

This highlights our need in practice to appropriately manage expectations when starting new technologies (Sherr et al., 2018).

How do decision fatigue and alarm fatigue link together in CGM use?

One of the key stages of decision making is perceiving new information (Katz et al, 2018), which becomes relevant to CGM use as the individual is presented with continuous data. Data 24 hours per day provides more information, but this potential benefit is likely to lead to more decision making, which in the longer term can cause fatigue and burnout. For example, CYP who have previously monitored their blood glucose by finger pricks would be familiar reading a number only, and the number of possible decisions from one reading are limited. With CGM, CYP are provided with predictive trend arrows and alarms, which may lead to different interpretation of their glucose level and this, in turn, can create a cascade of decisions to be made. As CGM is continuous, these decisions can become infinite with no endpoint, which further requires practitioners to be educated in how to personalise the CGM experience for CYP given the life-long nature of T1D.

A study by Burckhardt et al (2019) looked at the experience of parents of children under 12 years using CGM, and found that in some cases parents

reported feeling overwhelmed by the increased quantity of information and reported increased anxiety; whereas others found that it reduced their anxiety. Burckhardt et al (2019) go on to explain that in most cases, parents who initially experienced increased anxiety when their children started CGM adjusted to the amount of information over time. This further highlights the importance of expectation management when starting CGM for both the patient and relatives, and the need for ongoing education to support families (Burckhardt et al, 2019).

ISPAD guidelines for technology highlight the importance of expectation management when starting patients on new technologies, as this links directly to the how successfully patients and families are able to adopt them (Sherr et al, 2018). Further to this, IPSAD guidelines for diabetes education highlight the importance of high-quality structured education in order to improve clinical outcomes and patient experience (Phelan et al, 2018).

Implications for practice

It is important to provide specific education around decision making and responding to alarms to both manage expectations and improve patient outcomes. It is well recognised that improved glycaemic control decreases the risk of long-term complications and in doing so improves quality of life (Keller et al, 2016). Equally, practitioners must keep in mind the concept of alarm burden and decision fatigue so that we can recognise when patients are risk and where it would be beneficial to adjust alarm settings or alter a treatment plan altogether. The MDT will be able to support patients with altering settings and supporting them with tools to make decisions. Individual teams will have tools that can be used to support patients in decision making, for example, handbooks or flowcharts which can help to simplify the decision process.

Griggs and Morris (2018) state that fatigue is directly linked with an individual’s ability to manage their condition. Although this was not directly in relation to decision fatigue, it could be argued that the same would apply, particularly with T1D, and therefore by supporting patients experiencing fatigue, it will help them self-manage their condition.

NICE guidelines recommend that practitioners

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“As technology is constantly being upgraded, it is important for practitioners to be aware of and understand the differences between different CGM systems.”

support patients with making informed decisions about treatment options (NICE, 2022). The balance of patient input to their treatment options and the availability of data could provide the support clinicians need to drive improved patient outcomes and simultaneously understand the origin of alarm and decision fatigue in CGM. Although the availability of 24-hour data from CGM may increase the number of decisions to be made, other studies have found that with appropriate education in understanding CGM data, the continuous data could lead to an increase in the efficiency and clinical safety of decisions (Vettorini et al, 2015).

As technology is constantly being upgraded, it is important for practitioners to be aware of and understand the differences between different CGM systems. This is key to providing patients and their families with the most up-to-date knowledge to support them with use of these devices. For example, each CGM will have different usability, alarm features, and compatible technologies. The National CYP Diabetes Network have written comparison charts of current CGM options, which educate practitioners in the features of the available systems (National CYPD Network, 2021). This encourages practitioners to advocate for their patient’s individual needs, enhancing family-centred care.

Regular communication with patients enables practitioners to build rapport and pick up on areas where the patient might be struggling (Patel et al, 2018). In some cases, this will be through general conversation between the MDT and the family; however, at times it might be necessary to use formal tools to help identify key areas where the patient requires more support, for example, managing hypoglycaemia, coping with T1D, or burden of technology. While there are tools that have been shown to be reliable to assess burnout (Abdoli et al. 2021), there are not yet specific tools to assess decision fatigue or alarm burden. This highlights an area for further research as to whether such a tool would be useful in practice. Other tools such as questionnaires could be useful to assess patients’ experience of CGM. A study by Messer et al (2019) showed these questionnaires to be valid in the adolescent population (12–19 years); however, further research is needed to assess the reliability of these questionnaires in the younger paediatric population.

Conclusion

Decision and alarm fatigue in T1D is an area that requires more research. They will likely overlap in practice, because most alarms will lead to a decision needing to be made by the patient or their carer. Reducing alarm burden will hopefully also lead to a reduction in decision fatigue. Failure to recognise decision and alarm fatigue in patients would cause a departure from family-centred care, resulting in poorer outcomes for patients, both physically and mentally. It is important to empower patients to put boundaries in place if they are showing signs of decision fatigue or alarm burden, for instance by working through decision fatigue tools together, or changing to a different CGM where the notifications are changeable respectively.

The right approach will be different for each individual, which supports the principle that knowing your patient and recognising what will best benefit them is so important. This will partly be learned over time as relationships with patients take time to develop, which is why regular contact is essential, especially when starting new technologies. Guidelines are a useful tool, and this change to the management of T1D is an exciting advance in care, but it should not override an in-depth knowledge of your patient and their idiosyncrasies. ■

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