

Only so many hours in a day!

The question of how much time diabetes management actually takes each day is often asked. It sounds a very simple question; however, as is often the case, the answer is more complex than it might appear to be. Hidden behind the question is a plethora of definitions of what it means to either personally self-manage or support the self-management of type 1 diabetes, and it is extremely difficult to quantify in hours and minutes exactly what this means in the context of everyday life. One could ask whether it is even possible to reduce diabetes self-management to a unit of time and, if it is, what aspects of care should be measured. Should physical tasks, such as self-monitoring of blood glucose, insulin injections and cannula set changes, be measured alone? Or should the time spent “thinking” about diabetes also be included? If so, is it possible to capture this in any meaningful way?

In the STAR 3 (Sensor-Augmented Pump Therapy for A1C Reduction 3) study, Kamble et al (2013) attempted to do just that and compare the “patient time costs” associated with sensor-augmented insulin pump (SAP) and multiple daily injection (MDI) therapy in people with type 1 diabetes. They explored the time costs of 483 people aged 7–70 years in a 52-week clinical trial. After the 8-week initiation period, participants in the SAP group were found to spend an average of 4.4 hours per week on diabetes-related care, while the MDI group spent 3.4 hours. The authors acknowledge that they did not record the time spent on specific activities, and that their estimates did not explicitly account for caregivers’ and family members’ time. Such a quantification remains useful, however, as it recognises individuals’ ongoing time demands specific to diabetes management. The authors concluded that participants receiving SAP therapy spent approximately 1 hour more per week on diabetes-related care than MDI recipients, resulting in higher personal time costs.

This opens up an interesting debate. Diabetes-related technologies are increasingly being prescribed and are widely reported to reduce diabetes-related burden and improve biomedical and psychosocial outcomes, including quality of life, for users and their family members (Barnard et al, 2014a). These technologies include insulin pumps, continuous glucose monitoring (CGM) devices and, ultimately, new closed-loop automated insulin delivery systems, which will soon be available (Food and Drug Administration, 2016). However, according to the STAR 3 results, these devices require more time, not less, than older therapies such as MDI. This raises the question, are they worth it?

Richard Rubin’s powerful article about diabetes and quality of life was published in *Diabetes Spectrum* 16 years ago (Rubin, 2000). Professor Rubin started with the statement, “Diabetes is a demanding disease.” Instead of listing the demands of diabetes in terms of self-management tasks, he presented a quote from his son, who had lived with diabetes for more than 20 years, since being diagnosed at the age of 7 years. His son said:

“At least once every 15 minutes, I have to deal with my diabetes. I have to stop what I’m doing, think about how I’m feeling, try to remember when and what I last ate, think about what I’ll be doing next, and decide whether to test my blood. Then, depending on the results of the test (or my guess as to my sugar level), I’ll plan when to eat or take my next insulin bolus.”

Could anything so ubiquitous as diabetes and its management, asked Rubin, not affect a person’s quality of life, their ability to function and their ability to derive satisfaction from doing so?

Rubin’s article clearly shifts the focus from the “mechanics” of diabetes self-management to a “lived experience” perspective, which adds depth and context far beyond glycaemic control. As we strive to constantly improve the treatments and



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technologies available to support optimal diabetes self-management, it is crucial that we don’t lose sight of their potential impact on the end user. Bradley and Speight (2002) point out that both diabetes and its treatment have a potential negative impact on quality of life. The balancing act to ensure that both medical and psychosocial outcomes are optimised is, arguably, akin to the balancing act that is daily self-management itself: the constant challenge faced by families all day, every day.

So perhaps a better question to ask is whether new technologies have broadly reduced the burden of diabetes self-management for individuals and their families? The biomedical benefits of devices are well reported, yet national audit data show that suboptimal glycaemic control remains a reality for the majority of children and young people with type 1 diabetes (Royal College of Paediatrics and Child Health, 2016). How can it be that, with the very latest expertise and advances in medical devices from an engineering and medical perspective, it is not possible to achieve optimal glycaemic control – particularly when all of the variables can, allegedly, be controlled?

We continue to argue that the traditional medical model of healthcare is inadequate to effectively support chronic conditions such as type 1 diabetes and that a more holistic approach is required (Barnard et al, 2014b). The factors directly impacting an individual’s ability to maintain an optimal glycaemic range lie both within and beyond the biological factors associated with disease management. A model of care that encompasses the environment, intrinsic thought and therapy regimens to provide tailored, personalised healthcare supporting enhanced self-management for optimal biomedical and quality-of-life outcomes is required. We need to help each individual to understand their own barriers to and facilitators of optimal diabetes self-management, in the context of their own life across their entire lifespan. That’s the challenge. The Kaleidoscope model of care (Figure 1) proposes such an approach.

The Kaleidoscope model takes existing philosophies of diabetes care and self-management, combining them into a holistic, wide-reaching model to address all aspects of living with diabetes (Barnard et al, 2014b). The model incorporates

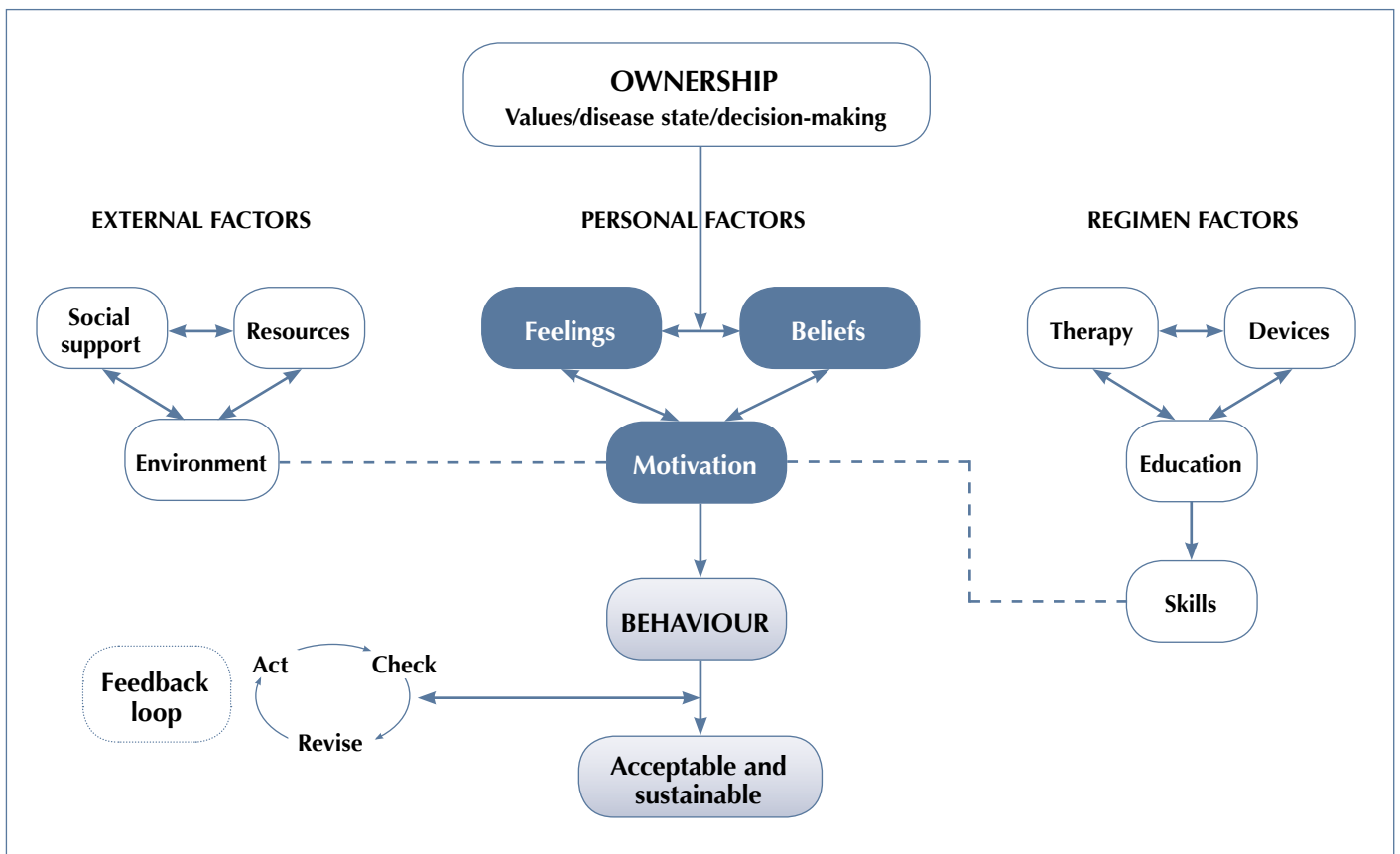


Figure 1. The Kaleidoscope model of care.

external factors (e.g. social support), treatment regimens and intrinsic personal drivers. These are separated into distinct but linked core components, or “cogs”, which interact to reflect individuals’ experience and priorities for their specific treatment needs. The model supports healthcare professionals to provide care pathways that are tailored to an individual’s priorities and needs. Research is currently underway to evaluate the clinical outcomes and cost-effectiveness of this novel model.

One would hope that new technologies would reduce this burden for individuals and their families; however, if you assess purely from a time perspective, it would seem from the STAR 3 study that this is not the case. There is a growing number of individuals, often calling themselves hackers, who are willing to take a do-it-yourself approach to diabetes devices, building home-made artificial pancreas systems and posting instructions on the internet for others to follow. The so-called rights and wrongs of these actions become somewhat irrelevant when we look from the perspective of families who are simply seeking relief from the relentless and frightening reality of a life with type 1 diabetes. Beyond the daily self-management lies the constant threat of diabetes-related complications and premature death. For parents, part of the hope associated with novel closed-loop automated insulin delivery systems is the reduction of this risk.

When one examines the qualitative data derived from research into use of new diabetes technologies, insulin pumps are associated with increased flexibility, freedom, reduced fear of hypoglycaemia and reduced daily hassle (Pouwer and Hermanns, 2009). However, increased visibility of disease state remains an important issue. CGM has received mixed reports in the field of research. Improvements in glycaemic control are dependent on regular use, but alarm fatigue, technical failure and accuracy problems limit ongoing engagement, with lack of trust cited as the primary reason (Ramchandani et al, 2011). A negative psychosocial impact of CGM has been described (Markowitz et al, 2012), and, despite a high rate of insulin pump use, the rate of CGM use in the T1D Exchange cohort remains low at around 9%, with half of those on CGM stopping it within 1 year (Wong et al, 2014). The latest generation of sensors have addressed some of these issues; however, it takes time to rebuild confidence, and not everybody wants to be constantly reminded of his or her blood glucose levels.

As we move forward into the era of closed-loop automated insulin delivery systems and all that they promise, it is perhaps timely to take stock and reflect on not only how we will best support use of these devices, but also how we can provide the required care. By working collaboratively and addressing both the biomedical and psychosocial aspects of these new devices, as well as realistically managing the expectations of both healthcare professionals and families living with type 1 diabetes, hopefully we will realise the potential of these devices and reduce the burden on families. ■

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