Diabetes Educators: Perceived Experiences, Supports and Barriers to Use of Common Diabetes-Related Technologies

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ABBREVIATIONS:

Australian Diabetes Educators Association (ADEA); Continuous glucose monitoring
(CGM) systems; Continuous subcutaneous insulin infusion (CSII) therapy; Diabetes
Educators (DEs); Healthcare professionals (HCPs); Smartphone and tablet applications
("apps"); Type 1 diabetes (T1D); Video-conferencing (VC).

FIGURES AND TABLE COUNT:

One table.

ABSTRACT

BACKGROUND

Various technologies are commonly used to support type 1 diabetes management (continuous subcutaneous insulin infusion therapy; continuous glucose monitoring systems; smartphone and tablet applications; and video-conferencing) and may foster self-care, communication and engagement with healthcare services. Diabetes Educators are key professional supporters of this patient group, and ideally positioned to promote and support technology use. The aim of this study was to examine Diabetes Educators' perceived experiences, supports and barriers to use of common diabetes-related technologies for people with type 1 diabetes.

METHODS

This qualitative ethnographic study recruited across metropolitan, regional and rural areas of Australia using purposive sampling of Australian Diabetes Educators Association members. Data were collected by semi-structured telephone interviews and analysed using thematic analysis.

RESULTS

Participants (n=31) overwhelmingly indicated that overall the use of technology in the care of patients with type 1 diabetes was burdensome for them. They identified three themes involving common diabetes-related technologies: access to technology, available support and technological advances. Overall, these themes demonstrated that whilst care was usually well-intentioned it was more often fragmented and inconsistent. Most often care was provided by a small number of Diabetes Educators who had technology expertise.

CONCLUSIONS

To realise the potential benefits of these relatively new but common diabetes technologies, many Diabetes Educators need to attain and retain the skills required to

deliver this essential component of care. Further, policy and strategy review is required, with reconfiguration of services to better support care delivery.

INTRODUCTION

The incidence of type 1 diabetes (T1D) is rising approximately 3% per annum internationally [1]. The substantial impact of T1D on health and disease burden has been documented, as has the importance of tight glycaemic control to avoid or defer disease complications [2, 3]. The majority of adult diabetes services are oriented towards the management of type 2 diabetes, the most common diabetes form [4, 5]; as a consequence, people with T1D may find it hard to access disease or age-specific care.

Technology can provide innovative approaches to T1D healthcare [6]. Common technologies can be broadly categorised as related to insulin delivery, blood glucose monitoring and communication, each category with multiple media. For insulin delivery, compared to injections, continuous subcutaneous insulin infusion (CSII; insulin pump) therapy has demonstrated improved quality of life, glycaemic control for some, reduced mortality and economic benefit [7-14]. With usage increasing, by 2011 in Australia approximately 10% of the T1D population were using CSII technology, with half of all users aged under 25 years [15]. Many CSII devices are obtained through a government subsidy for low income families with children with T1D, introduced in 2008 or, more commonly, private health insurance [16].

Insulin dosage calculation is reliant on blood glucose monitoring. Continuous glucose monitoring (CGM) technology overcomes the limitations of intermittent monitoring and has been associated with HbA1c reduction without increased hypoglycaemia risk, higher treatment satisfaction and improved quality of life [6, 14, 17, 18]. Software packages currently available for both CSII therapy and CGM systems enable transfer of data to a healthcare professional (HCP) via the internet [19]. However, use is limited by the requirement for personal computers, significant patient effort and time commitment [20].

Specialised program applications ('apps') downloaded on smart phones and tablets support self-care through timely provision of information on blood glucose, diet and exercise patterns; and this information can be shared electronically with healthcare providers [19, 21, 22]. Another communication modality is video-conferencing (VC), which allows simultaneous audio and visual communication between two or more locations via the internet [6]. This may involve commercial systems managed by healthcare organisations or personal communication software such as Skype^{TM}. Besides clinical care, VC can also be used for continuing education [23].

Support from a skilled multi-disciplinary team is required to achieve the potential benefits offered by common diabetes-related technologies, with Diabetes Educators (DEs) being key members of this team. When considering CSII use, for example, they may help determine insulin dosage requirements, support achievement of therapy benefits and mitigate the challenges and risks [24, 25]; reported to be common with devices, associated consumables and the user [25]. With little information how this occurs, this study aimed to examine DEs' perceived experiences, supports and barriers to use of common diabetes-related technologies for people with T1D.

METHODS

Design and data collection

This was a qualitative study undertaken June-August 2014 using an ethnographic design. Data were collected by individual semi-structured telephone interviews, allowing topics to be explored in depth, with confidentiality, providing opportunities to probe and

encourage detailed responses, and enabling participation across wide geographical distances [26].

The interview schedule was developed by research team members, and piloted with two Canadian based DEs. Topics included participants' experience of working with each type of technology; the impact of supporting these technologies on workload; perceived supports and barriers to their use; and the influence of work environments on uptake and capacity. Participants were asked to briefly describe their professional background and geographical location.

Sample

A purposive sample was collected from members of the Australian Diabetes Educators Association (ADEA); the leading Australian organisation for multidisciplinary HCPs who provide diabetes education and care. This sampling technique was chosen to obtain a wide cross-section of participants with collective experience with the four technologies. Participants were eligible for the study if they had current ADEA membership, current or past experience as a DE in Australia and in use of CSII, CGM, apps and/or VC. They were required to be able to converse in the English language, have access to a telephone and an email address. Recruitment ceased when data saturation had been reached and it was deemed there were no new data to gather.

Procedure

Two hundred and thirteen members who responded to advertisements in the ADEA newsletter and completed an anonymous web-based survey (published elsewhere [6]), were supplied with study information and invited to participate; interested participants provided their contact details. Interviews were conducted by the first author, whose

professional standing as a DE facilitated development of the trust necessary to share private, sensitive or controversial details [27, 28]. It also enabled understanding of participants' frame of reference, and potential exploration of contextual points or ideas raised. Personal preconceptions and biases were addressed through maintenance of a reflexive journal, peer debriefing and triangulation [29]. Field notes were collected during and after each interview, which was audio recorded after an introduction where confidentiality principles were reinforced. Approval was obtained from the University of Technology Sydney Human Research Ethics Committee.

Data analyses

Audio data and field notes were transcribed verbatim into Microsoft Office Word 2010™, de-identified and imported into NVivo 10™ software. Data were analysed using Gibb's [30] framework, which entailed transcription and familiarisation, code building, theme development, and data consolidation and interpretation. Transcripts were available to participants for comment. They were read by all authors; the first author initiated coding and theme organisation which was developed and discussed with all authors to reach consensus.

RESULTS

Interviews were conducted with DEs (n = 31) who worked across metropolitan, regional and rural areas (Table 1). Most were female (90.3%) and Registered Nurses (96.8%), although working at differing levels of expertise and responsibility. Interviews lasted mean (SD) 35 (8.75) minutes.

Participants overwhelmingly perceived technology use as personally burdensome, when considering the increased demands that this placed on themselves and the need to occasionally use personal resources. Many wanted help, particularly to support patients with CSII. Three themes detailed perceived supports and barriers to involvement with common diabetes-related technologies in the care of patients with T1D: access to technology; availability of support; and technological advances.

Access to technology

Access to technology was often difficult, both for patients and DEs. Patient access to CSII was limited by device costs, seen as prohibitive for many. The current Australian government subsidy, whilst considered beneficial, was not available to young adults, many of whom were unable to self-fund these devices. The absence of government CSII device support after age 18 years resulted in some patients being unable to replace and so continuing to use old and defective equipment. Participants felt obliged to support patients with minimally functioning devices, even though it was not seen as in their best interests:

> "*I had a chap the other week that didn't even have a face on his pump*
>
> *[CSII]....he's still using it six months after I asked him not to.*" (DE23:Metro)

Another barrier to access was the lack of systematic processes for determining the balance of benefit and risk from device use for individual patients. Often DEs were expected to take responsibility to gate keep this technology without formal organisational policy or professional guidance. As one DE stated:

"It's generally up to the DE who will see the patient first. They will deem if they think it [CSII] is suitable." (DE-53:Metro)

Similar access difficulties were described in relation to CGM technology. Participants, especially those working in hospitals, expressed frustration with their lack or limited access to CGM devices, transmitters and sensors, and that they often did not have adequate software and computer access to download CGM or CSII data direct from devices. They also perceived the cost of CGM technology as prohibitive to consumers, and appreciated when diabetes centres could fund CGM sensors. This occurred where DEs judged there was clinical need, a decision seldom underpinned by any formal policy or guidance. Where hospitals, and sometimes private DE practitioners, loaned CGM devices and/or transmitters to patients, this was seldom covered by a specific organisational infection control policy; devices were however routinely cleansed upon return. Highlighting co-operation between paediatric and adult diabetes services to increase CGM access in a regional setting, one DE stated:

"The paediatric unit actually paid for the device [CGM]....I get the adults to pay for their sensors." (DE-92)

Difficulties with access were also described in relation to apps. Participants expressed their frustration that apps were not available across all brands and models of smartphones and tablets. They highlighted that many patients lack access to this technology and Wi-Fi coverage. However, this was also not provided to many DEs by their employers, and consequently they resorted to using their personal smartphones and Wi-Fi accounts.

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Access to VC was mixed. Participants employed within hospitals, particularly in metropolitan areas, largely reported access to commercial VC systems, usually shared across health disciplines. However, the cost of such systems was prohibitive for smaller diabetes services, general practices and private DE practitioners. Instead, many participants in regional and rural localities used free personal communication software such as Skype™. Originally banned, Skype™ use was now often approved. However, network coverage in non-metropolitan areas was often erratic, especially outside of school hours, resulting in inconsistent visual and sound quality, and outages. This often deterred use.

Availability of support

Time constraints were a barrier to participants' involvement with all technologies; CSII and CGM, particularly, were perceived to negatively impact workload. Recognising the number of interactions required to commence a patient on CSII, one DE stated:

> *"We've got [small number] educators so if a person wants to go on a pump [CSII] you've got one educator out (i.e. solely preoccupied with that patient) for a day and a half."* (DE-22:Metro)

Participants expressed their frustrations at insufficient DE staffing for their patient numbers and lack of staff skilled in CSII and CGM, in particular. Considering the increasing uptake, they were anxious how they would cope into the future, especially within paediatric settings. However they valued the support received from DE colleagues.

Participants also expressed their discomfort working with patients who had commenced CSII elsewhere, for the demands this placed on themselves and their already strained

diabetes service. Many in regional and rural localities were suspicious that funding incentives from CSII companies, rather than patient needs, drove decisions to commence patients on this method of insulin delivery in metropolitan centres. Their concern was that these patients later sought follow-up, and in the event of related ill-health, presented to their local diabetes service or hospital, which was often under-staffed and under-skilled for this.

> "*Multiple metropolitan centres….would be happy to take a referral to initiate a pump [CSII], but that's the end of the service provided.*" (DE-11:Rural)

Limitations to Australian government Medicare rebates meant that many private DE practitioners were unpaid for much of the work they undertook. This acted as a barrier towards further involvement with CSII, CGM and VC. One DE stated:

> "*The patients have to pay to see me or they had EPCs [enhanced primary care plans – government funding] that they could put through. I put in a lot of time and effort that I was never reimbursed for.*" (DE-9:Regional)

Managers and physicians could be supportive towards technology use, for example, by advocating for and securing related funding. However they could also act as barriers to involvement. Medical staff who had qualified from medical school years earlier were viewed particularly negatively when considering their views towards use of apps and CSII. Especially in community and general practice settings, little hands-on support was available to DEs for CSII and CGM use. General practitioners were perceived to have limited involvement in the care of patients using these technologies, referring any issues

to DEs. Participants also highlighted endocrinologists' under-use and occasional unwillingness to use VC.

There was concern at lack of funding for on-call DE staffed services to provide advice in emergencies for CSII and CGM users outside of office hours: device failure, acute diabetes-related complications and sick-day management, for example. In rare instances where on-call services were available, these were staffed by physicians with limited knowledge of these technologies. As a consequence, many participants provided selected patients with their personal contact details; criteria for such decisions were unclear:

> "*There's no point in them going to hospital because….They are not upskilled with using the pump [CSII]….If we can avoid an admission, I prefer to give them my personal mobile number.*" (DE-12:Regional)

Support was available from the manufacturers of CSII and CGM technologies through telephone help-lines for patients and HCPs. These were deemed very helpful by DEs, though concerns were raised at calls being diverted to agents in other countries and the sometimes "textbook" advice provided. Companies also loaned devices and transmitters, and provided consumables, trial sensors and ongoing education. However, for VC, participants identified very limited and sometimes complete absence of organisational training. They also had concerns about the support and facilities at connecting sites. Information technology departments were seen as both supportive and barriers to involvement with this technology.

Technological advances

Participants had difficulty keeping up to date with advances in design and programming of CSII and CGM devices. They relied almost exclusively on information from companies. They struggled to maintain the regular software updates required for full functioning, in the face of barriers to downloading, organisational hurdles and computer firewalls.

Similar difficulties were reported in keeping up to date with apps, especially because of their increasing numbers and the workload burden this represented. Participants primarily relied on obtaining information at conferences, but also from DE colleagues, companies, patients and professional magazines:

> "*Everybody's so busy rowing the boat that they don't have time. Our flow through is not dropping, it's getting bigger…. and you get less funding, less resources.*" (DE-27:Metro)

DEs were unable to make best use of data collected through apps and CGM systems. They highlighted concerns regarding the formats in which data were provided, based on programming deficiencies and the difficulties experienced interpreting such data. Patients were also not always good at providing complete information, with records omitting important details such as carbohydrate consumption and exercise undertaken.

> "*They send me information and you just can't work out what time it was and all sorts of things…it's not set out in a manner that is friendly for us.*" (DE-23:Metro)

DISCUSSION

Our research provides important insights into DEs' experiences and perceptions of what supports and limits the use of common diabetes-related technologies for patients with T1D in Australia. Overall, themes demonstrated that whilst care was usually well-intentioned it was more often fragmented and inconsistent, and not often enough delivered with appropriate technology expertise. Change is clearly needed at multiple levels of the Australian healthcare system to facilitate DEs' technology adoption and realisation of the potential of these technologies for improved patient outcomes and support.

Firstly, findings reveal that DEs need support to attain and retain the skills required to deliver these essential components of care. They mesh with findings from the anonymous web-based survey from which the sample derived (published elsewhere [6]), which highlighted the need for DEs' ongoing education to promote technology adoption. Though the support need around skills may lessen in the future with the generational ages of participants predominantly not indicative of 'digital natives' [31], in the meantime organisational and managerial support in the form of funding and time allowance (both study time to gain the skills and time to use them) would assist, as would rotating placements across and between paediatric and adult diabetes care settings. Besides increasing DEs' technology exposure, this may better align the norms of practice in different settings for greater consistency of patient experience [6]. Mentorship schemes should also be established and promoted; external stakeholders such as the ADEA may be able to assist [32]. They could also assist by providing periodic detailed summaries of evolving CSII and CGM systems and apps, in view of participants' difficulties keeping up to date. However whilst education is a necessary pre-requisite, it is not a panacea.

Support for DEs in providing technology-based care delivery could involve service reconfiguration. In some areas this may necessitate reallocation of staffing and resources and improved infrastructure. Cross-coverage from areas where technology-based expertise exists would also assist, enabled by maximisation of VC use. Besides facilitating DE peer support and professional development, VC could also be the medium to provide support directly for patients, to make communication more flexible and care more efficient [23]. Information technology departments have an important role in this, and access to such support should be maximised.

A review of policy and strategy is also required of the allocation of devices to patients, of the role of patients in choosing insulin delivery and glucose monitoring systems, and the processes for ensuring support from healthcare providers. The absence of consistent policies relating to CSII and CGM compounded the confusion reported both within and between services. Recent Australian CSII clinical guidelines feature assessment of patient suitability for CSII use [33, 34], and state guidelines make recommendations for in-hospital CSII care [35]. These should be promoted and adopted, and local policies formulated from these documents to translate guidelines into practice.

Australian government policy for access to common diabetes-related technologies, especially CSII, requires review. The current government CSII device subsidy ceases once a child reaches age 18 years [16]. However, considering the importance of optimal glycaemic control to minimise diabetes complications, and hence their associated costs [7, 36], there is a case to extend the subsidy to enable CSII use to continue safely through the often impoverished early adult years when glycaemic control often deteriorates.

Review is also required of the Australian government Medicare rebates available to private DE practitioners; lack of reimbursement was reported as a barrier to DEs involvement with CSII, CGM and VC. Existing rebates do not take full account of the time required to commence a patient on CSII, reported as median 18.6 hours and 14.1 interactions over 11.8 weeks [33]. Rebates only cover five 'face-to-face' visits and do not fund consultations undertaken via VC although HCPs other than DEs are able to utilise this technology [37].

Study limitations include that recruitment methods targeted only members of ADEA, and participants self-selected; findings may not be representative of all DEs [38]. There was no quantification of participants' experience with the technologies; limited exposure may have influenced perceptions. Nonetheless, strengths derive from the number of interviews undertaken, recruitment across diverse and wide sociological and geographical areas, and the depth and detail of data obtained on this little explored topic.

CONCLUSIONS

This research provides important insights into the perceptions of an essential professional group in the care of patients with T1D, in relation to what supports and deters use of common diabetes-related technologies. Difficult access to technology; limited availability of support; and relentless but inaccessible technological advances influenced DEs' involvement. Findings suggest that to maximise technology adoption and support many DEs need to attain and retain the skills required to deliver this essential component of care. Further, there is a need for review of policy and strategies, followed by reconfiguration of services to support care delivery and realise the potential benefits of these new but now common diabetes technologies.

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Table 1: Interviewee characteristics

	n	Male	RN	APD	Age (mean (SD))*
Rural	6	2	6	0	48 (10.6)
Regional	9	0	9	0	53 (4.7)
Metro	16	1	15	1	49.6 (5)
Total	**31**	**3**	**30**	**1**	**50 (6.4)**

n=Number.   RN=Registered Nurse.   APD=Accredited Practising Dietician.
*=in years.   Metro=Metropolitan