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Experiences of adults with adult-onset type 1 diabetes: a cross-sectional study

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ABSTRACT

Background. Type 1 diabetes (T1D) is a chronic, autoimmune disease where the pancreas does not produce enough insulin. T1D requires ongoing management across the lifespan through insulin regulation, monitoring of blood glucose levels, and adherence to strict diet and exercise plans. The most recent National Diabetes Services Scheme Australian Diabetes Map indicates that 129 210 Australians currently have T1D. Traditionally considered a childhood disease, more than half of all T1D diagnoses actually occur in adults aged >20 years. The aim of this study was to examine the experiences of individuals living with adult-onset T1D in relation to their diagnosis experience, access to health care, and post-diagnostic wellbeing. **Methods.** An exploratory, cross-sectional study was undertaken. Participants completed an online survey delivered via Qualtrics detailing their experiences with adult-onset T1D. The survey contained four domains: (1) demographic information; (2) diagnosis experience; (3) access to care; and (4) post-diagnostic wellbeing, including the Hospital Anxiety and Depression Scale (HADS); and the Diabetes Distress Scale (T1-DDS). Data analysis was conducted using STATA SE (v16). Descriptive statistics (means, counts) were used to describe continuous data, and frequencies and odds ratios were used to describe categorical data. **Results.** One hundred and twenty adults (mean age 49 years; 78% female) with adult-onset T1D (mean age at diagnosis 37 years) completed the survey. The most common symptoms prior to diagnosis were excess thirst, fatigue, frequent urination, and unintended weight loss. Half (50%) the sample received their T1D diagnosis from a general practitioner (GP). Several participants reported being misdiagnosed by their GP initially, representing an unadjusted odds ratio of 3.1 (95% CI 1.5, 6.2). Nearly half of all participants presented with anxiety (mean 7 (s.d. 4)) on the HADS, and most reported moderate levels of diabetes-related distress according to the T1-DDS. **Conclusions.** These findings provide a starting point to understanding the experiences of adults living with adult-onset T1D and can be used to raise awareness of their challenges and needs. These exploratory findings can also be used to inform a larger, population-based study.

Keywords: adult-onset type 1 diabetes, cross-sectional, survey, type 1 diabetes.

Introduction

Type 1 diabetes (T1D) is an autoimmune condition where the pancreas does not produce enough insulin (World Health Organization 2021). Without insulin, the body cannot turn glucose into energy. Without this energy, the body burns its own fats, releasing ketone bodies into the blood. This process can lead to diabetic ketoacidosis, a life-threatening condition that can lead to coma and death (Evans 2019). Individuals living with T1D face a lifetime of managing the disease through insulin injections or use of an insulin pump, monitoring of blood glucose levels, and following diet and exercise plans (Chiang *et al.* 2014).

According to the most recent National Health Survey data, an estimated 1.2 million Australians (4.9% of the population) had diabetes – including T1D, type 2 diabetes (T2D), and type unknown – in 2017–18 (Australian Bureau of Statistics 2018). The most recent data from the National (insulin-treated) Diabetes Register (NDR) listed 2800 new diagnoses of T1D in Australia in 2018 (Australian Institute of Health and Welfare 2018). These figures are only growing: in September 2021, there were >1.4 million people

with diabetes (5.4% of the population) registered with the Australian Government Initiative, National Diabetes Services Scheme (National Diabetes Services Scheme: An Australian Government Initiative 2021). Diabetes costs the Australian healthcare system billions of dollars each year; in 2018, diabetes expenditure reached A$2.7 billion, up from A$1.2 billion in 2009 (Australian Institute of Health and Welfare 2020*a*). Preventable diabetes-related hospitalisations and complications also cost the Australian healthcare system an extra A$32 000 per patient, each year (Diabetes NSW & ACT 2021).

There is a common misconception that T1D is a childhood disease. Although many cases do present in childhood, up to half of all T1D cases present in adulthood. In 2018, 49% of T1D diagnoses in Australia were identified in adults aged >20 years (Australian Institute of Health and Welfare 2020*b*). Emerging evidence suggests that many adults with T1D are initially misdiagnosed, increasing the risk for diabetic ketoacidosis and poorer long-term physical and mental health outcomes (Muñoz *et al.* 2019; Thomas *et al.* 2019).

Although there is some academic literature that examines adult-onset T1D, the majority of the research literature has focused on childhood onset of T1D (Fourlanos *et al.* 2005; Davis *et al.* 2018). Although the needs of adults with T1D were first added to the Australian Evidence-Based Clinical Guidelines for Diabetes in 2011 (Craig *et al.* 2011), the information primarily focuses on the transition from paediatric to adult care. Given that T1D is a lifelong disease and burdensome on both the patient and the healthcare system, it is essential that the Australian health system is appropriately resourced to provide best practice care to adults presenting with T1D. Therefore, the aim of this study was to examine the experiences of individuals living with adult-onset T1D in relation to their diagnosis experience, access to health care, and post-diagnostic wellbeing.

Methods

Study design

A cross-sectional study was undertaken and consisted of an online survey based on existing literature and consumer input. Ethics was approved by the Monash University Human Research Ethics Committee (Project ID 24990).

Participant eligibility and recruitment

Individuals were eligible to participate in this study if they were: Australian citizens or permanent residents, aged ≥18 years, with a self-reported diagnosis of T1D in adulthood (≥18 years of age). Individuals were not eligible to participate if they reported a paediatric T1D diagnosis.

Potential participants were recruited via social media (e.g. Facebook, Twitter, LinkedIn), diabetes online forums (e.g. 'DiabetesDaily' and 'TuDiabetes'), and national and state-specific diabetes associations (e.g. Diabetes Australia, Diabetes New South Wales).

Survey development

The survey was developed based on existing T1D literature and input from one of the researchers based on their lived experience as an adult diagnosed with T1D. The survey was piloted by two individuals also living with adult-onset T1D and further refined based on feedback from this pilot process. Based on the feedback received, two validated patient-reported outcome measures (PROMs) were included in the survey: the Type 1 Diabetes Distress Scale (T1-DDS) (Fisher *et al.* 2015) and the Hospital and Anxiety Depression Scale (HADS) (Herrmann 1997).

The T1-DDS is a self-rating measure of diabetes-specific distress in adults with T1D. The scale consists of 28 questions divided into seven subscales: eating distress, friend/family distress, hypoglycaemia distress, management distress, negative social perceptions, physician distress, and powerlessness. Each subscale is measured on a six-point response scale: (1) not a problem, (2) a slight problem, (3) a moderate problem, (4) a somewhat serious problem, (5) a serious problem, and (6) a very serious problem. The T1-DDS yields an overall distress score based on average responses along the 1–6 scale for all 28 items, and a score for each of the seven subscales based on the average response on all of the items in that subscale (range = 1–6). An overall score is generated indicating the severity of distress: ≥3 = high distress, 2–2.9 = moderate distress, 0–1.9 = little or no distress (Diabetes Distress Assessment and Resource Centre 2017).

The HADS is a self-rating measure of anxiety and depression. The HADS contains 14 questions, which are divided into two subscales for anxiety and depression. Responses to each question are measured on a four-point scale ranging from zero to three. The total derived score is the sum of the 14 items: 0–7 = normal and likely to be without depression or anxiety, 8–10 = borderline and potential presence of depression or anxiety, ≥11 = case and probable presence of clinical depression or anxiety (Zeltzer and Kloda 2008).

This survey was distributed during the coronavirus disease 2019 (COVID-19) pandemic from July 2020 to August 2020. As such, two questions were also included about changes and barriers to accessing T1D-related health care and medications.

Data collection

The survey was delivered electronically via the online survey platform, Qualtrics (Provo, Utah, USA) and was open for 7 weeks. The survey contained four domains:

1. Demographic information, including individual characteristics and family and personal health history;
2. Diagnosis experience, including symptoms pre-and-post diagnosis, diagnosis experiences, and perceptions of available information and support;

3. Access to care, including the types of services accessed, frequency of diabetes-related appointments, and COVID-19 impacts on care;
4. Post-diagnostic wellbeing, in particular mental health (measured via T1-DDS and HADS).

Data analysis

Surveys with a completion rate of ≥30% were included. This means that participants had to complete at least one of the survey domains in full to be included in the analysis. This guide is in line with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES), which states that the specific completeness rate is not essential in the reporting of Electronic surveys (Eysenbach 2004), but should be selected nonetheless. Data analysis was conducted using STATA SE (v16; Stata Corp., College Station, TX, USA). Descriptive statistics (means, counts) were used to describe continuous data, and frequencies were used to describe categorical data.

Results

Over the 7-week data collection period, 150 potential participants expressed interest in the survey. Eleven did not complete the eligibility criteria questions, nine did not meet inclusion criteria, five recorded responses were removed based on duplicate IP addresses, and five had >30% missing data. Overall, data from 120 participants were included in the final analysis.

Demographic information

The average age of participants was 49 years (range 19–79), and the mean age at diagnosis was 37 years (range 18–70). The majority of participants were female (n = 93, 78%) and born in Australia (n = 98, 82%). Half of all participants lived in either Victoria or Queensland (n = 60, 50%), and over one-third of participants lived in New South Wales (n = 44, 37%). Just over one-third of participants were employed part time (35%). Participant characteristics and family and personal health history is outlined in Table 1. Of note, 30% (n = 36) reported a family history of autoimmune disease and 30% (n = 36) indicated they had more than one autoimmune condition.

Diagnosis of T1D experience

Participants reported on their symptoms and glucose and ketone levels prior to diagnosis. Participants also provided data on the original diagnosis they received, perceptions of their diagnosis experience, and what types of support they were aware of and/or chose to access. The most common symptoms that participants experienced prior to diagnosis were excess thirst (n = 94, 78%), fatigue (n = 84, 70%), frequent urination (n = 83, 69%), and unintended weight loss (n = 73, 61%).

Two-thirds of participants reported their blood glucose levels at diagnosis, which averaged 23.43 mmol/L (s.d. 7.98 mmol/L). A blood glucose reading of ≥7.0 mmol/L indicates presence of diabetes. A further 25 participants reported their ketone levels at diagnosis, which averaged 2.3 mmol/L (s.d. 2.36 mmol/L). Ketone levels >1.5 mmol/L indicate high risk of diabetic ketoacidosis (American Diabetes Association 2005).

Table 1. Participant characteristics and family/personal health history.

Characteristic	n = 120	%
Current age, mean (s.d.) (years)	48.98 (16.19)	
Age at diagnosis, mean (s.d.) (years)	37.51 (13.90)	
Female	93	77.5
County of birth		
Australia	98	81.7
United Kingdom	12	10.0
Other	10	8.3
State		
New South Wales	44	36.7
Queensland	31	25.8
Victoria	29	24.2
Not reported	8	6.7
Australian Capital Territory	6	5.0
South Australia	2	1.6
Employment status		
Full-time work	43	35.8
Part-time or casual work	24	20.0
Retired	36	30.0
Unemployed	11	9.2
Student	6	5.0
Insulin used		
Manual injection	86	71.7
Pump	34	28.3
Comorbid autoimmune conditions		
Yes	36	30.0
No	84	70.0
Family history of autoimmune disease		
Yes	36	30.0
No	76	63.3
Unsure	8	6.7
Family history of diabetes		
Yes – T1D	18	28.6
Yes – T2D	22	34.9
Yes – T1D & T2D	23	36.5

Half (n = 60, 50%) of all participants received their T1D diagnosis from a general practitioner (GP), and almost all remaining participants (n = 58, 48%) were diagnosed by an endocrinologist. More than one-third of participants (n = 47, 39%) reported being misdiagnosed prior to being correctly diagnosed with T1D. Of those misdiagnosed, 75% (n = 35) were misdiagnosed with T2D, 21% (n = 10) were misdiagnosed with 'other' conditions (including pre-diabetes, exhaustion, food poisoning), 6% (n = 3) were misdiagnosed with stress and/or anxiety, and 4% were misdiagnosed with gestational diabetes (n = 2). The majority of misdiagnosed participants received their initial misdiagnosis from a GP (n = 41, 87%), representing an unadjusted odds ratio of 3.1 (95% CI 1.5, 6.2). The most common presenting symptoms for misdiagnosed participants were fatigue (n = 33, 70%), excess thirst (n = 31, 66%), unintended weight loss (n = 29, 62%), and frequent urination (n = 28, 60%). Misdiagnosed participants were also more likely to report less traditional T1D symptoms, including weakness (n = 20, 43%) and irritability and mood changes (n = 18, 39%), compared to those who were not misdiagnosed (weakness: n = 14, 29%; irritability and mood changes: n = 10, 21%).

Importantly, one-third of participants (n = 40, 33%) reported being dissatisfied with the perceived T1D knowledge of their diagnosing health professional. Close to one-third of participants (n = 35, 29%) also reported being dissatisfied with their diagnosis experience.

Access to care

T1D management requires multidisciplinary care and collaboration between a range of specialists. In the past 12 months, the majority of participants sought care from an endocrinologist (n = 113, 95%), optometrist (n = 101, 85%), and a diabetes educator (n = 75, 63%). Podiatrists (n = 54, 45%) and dietitians (n = 46, 39%) were the least accessed healthcare professional in the past 12 months by participants with T1D. In contrast, access to mental health support services, including psychologists, psychiatrists, counsellors, and/or social workers was low. The majority of participants (n = 91, 76%) had never accessed mental health support for T1D, and only one-fifth (n = 20, 20%) had visited a psychologist.

Nearly one-quarter (n = 28, 23%) of participants reported intentionally avoiding medical appointments. The most common reason for avoiding appointments was because of perceived judgement from their healthcare provider, feelings of shame and fear, and difficulty making time for an appointment.

Over one-third of participants (n = 41, 34%) reported that the COVID-19 pandemic impacted on their ability to access their regular healthcare provider, and one-fifth of participants reported difficulty accessing a new insulin pump when required (n = 23, 19%). Over half of participants (n = 62, 52%) engaged with telehealth, which mitigated some of the difficulty scheduling face-to-face appointments. A low number of participants (n = 6, 5%) also reported using home medicine delivery services during the pandemic, none of whom had accessed the service prior to the COVID-19 pandemic.

Post-diagnostic wellbeing

Two validated mental health scales were embedded into the survey: the Hospital Anxiety and Depression Scale (HADS); and the Diabetes Distress Scale (T1-DDS). The mean anxiety and depression scores for the cohort overall were 'normal' (anxiety: mean 7 (s.d. 4); depression: mean 5 (s.d. 4)), where ≥0–7 indicates 'normal'. However, nearly half (45%) of all participants presented with borderline-case (8–10) or case (≥11) score anxiety, and one-quarter (24%) presented with borderline-case or case score depression. The results of the HADS are outlined in Table 2.

Based on the T1-DDS, the cohort experienced moderate levels of total distress, where <2 indicates little or no distress, ≥2–2.9 indicates moderate distress, and ≥3 indicates high distress. The results of each T1-DDS category are outlined in Table 3.

Discussion

Traditionally considered a childhood disease, half of all T1D diagnoses occur in adults aged ≥20 years (Thomas *et al.* 2019).

Table 2. HADS Scores.

HADS Subscale		n = 119	%	Mean ± s.d.
Anxiety	Case	33	27.7	7 ± 4
	Borderline case	20	16.8	
	Normal	66	55.5	
Depression	Case	15	12.6	5 ± 4
	Borderline case	13	10.9	
	Normal	91	76.5	

≥0–7, normal; ≥8–10, borderline case; ≥11, case.

Table 3. T1-DDS Scores.

T1-DDS Category	Mean ± s.d.	Interpretation of score
Total Distress	2.2 ± 1.0	Moderate distress
Powerlessness	2.2 ± 1.0	Moderate distress
Management Distress	3.0 ± 1.3	High distress
Hypoglycaemia Distress	2.3 ± 1.2	Moderate distress
Negative Social Perceptions	1.9 ± 1.2	Little or no distress
Eating Distress	2.5 ± 1.3	Moderate distress
Physician Distress	1.8 ± 1.1	Little or no distress
Friend and Family Distress	1.7 ± 0.9	Little or no distress

This study aimed to examine the experiences of individuals diagnosed with T1D in adulthood, with particular focus on individual characteristics and family and personal health history, diagnosis experience, access to care, and post-diagnostic wellbeing. High misdiagnosis rates, and moderate-to-high levels of anxiety and diabetes-related distress, were prominent in this sample.

Among the participants there were several cases of polyautoimmunity, which is the presence of two or more autoimmune conditions in a single patient (Anaya 2014). One-third of the sample had an additional autoimmune disease to their T1D. These findings contribute an adult perspective to the well-researched comorbidity of autoimmune conditions among children with T1D. For example, out of a cohort of 25 759 children and adults on the US T1D Exchange Clinical Network Registry, it was found that >25% of individuals had at least one additional autoimmune condition (Hughes *et al.* 2016). A separate study of 491 children in the US with T1D found that one-third had an additional autoimmune condition (Triolo *et al.* 2011). In Australia, research with 102 Australians diagnosed with T1D in adulthood found that one-quarter had polyautoimmunity (Fourlanos *et al.* 2006). In addition to living with a comorbid autoimmune condition, one-third of our participants reported a family history of autoimmune disease. The presence of both polyautoimmunity, and a family history of autoimmune conditions, is well established in the paediatric T1D literature (Alhonen *et al.* 2011; Parkkola *et al.* 2013; Turtinen *et al.* 2019). Our findings suggest that the same diagnostic criteria may be applicable to adults presenting with T1D symptoms.

For more than one-third of participants, misdiagnosis was a key part of their T1D diagnosis experience. Of those misdiagnosed, the majority received an incorrect T2D diagnosis. This finding is remarkably consistent with two other cross-sectional studies involving adults with T1D. A US study involving 856 participants with adult-onset T1D found that 39% had been initially misdiagnosed; of the 39%, over three-quarters were misdiagnosed with T2D (Muñoz *et al.* 2019). Similarly, a UK study with 583 adults with T1D (age of onset <30 years) found that 38% did not start insulin therapy at diagnosis, and were treated as T2D patients (Thomas *et al.* 2019). Our findings contribute to a small, but growing body of literature characterising misdiagnosis rates among adults with T1D (Leslie *et al.* 2021), and is the first demonstrating this phenomenon in Australia. Misdiagnosis has implications for patient wellbeing: it can create a sense of distrust towards health professionals and healthcare systems, leading to delays in treatment and long-term physical and psychological complications (Shepherd 2008; Bao *et al.* 2019). This was also evident among our sample, some of whom reported intentionally avoiding T1D medical appointments due to dissatisfaction with past healthcare experiences.

In the past 12 months, the majority of participants reported visiting an endocrinologist, optometrist, and diabetes educator. Fewer participants reported seeing other types of allied health services, such as a podiatrist, dietitian, or mental health professional. T1D management requires a multidisciplinary care team, and evidence suggests that consistently accessing allied health services, in addition to medical appointments, optimises outcomes in this patient population (Wiley *et al.* 2015). The most recent National Evidence-Based Clinical Care Guidelines for Type 1 Diabetes in Children, Adolescents and Adults states that people with T1D should be seeing a dietitian for comprehensive education in accurate carbohydrate counting and matching insulin to carbohydrates, and that podiatrists play an important role in preventing T1D-attributable foot complications (Craig *et al.* 2011). Evidence suggests that the absence of allied health services as part of routine T1D care can result in generally poorer diabetes management, and can lead to long-term T1D complications such as retinopathy, neuropathy, and cardiovascular disease (Saleh 2015; Litchfield *et al.* 2019). This also places financial strain on the Australian healthcare system: the average annual cost per T1D patient increases from A$3468 for individuals without complications, to AUD 32 000 for individuals with micro and macrovascular complications (Diabetes NSW & ACT 2021).

Participants overall reported elevated levels of distress on the T1-DDS. These findings complement US-based cross-sectional studies utilising the T1-DDS, demonstrating the global impact of T1D (Polonsky *et al.* 2016; Abdoli *et al.* 2020). The T1-DDS includes seven subscales, one of which is management distress: a sense of disappointment in one's effort to control their diabetes (Fisher *et al.* 2015). In the current study, participants scored highest (3.0) for the management distress category. Some management techniques have been shown to reduce T1D distress, including use of insulin pumps as an alternative to manual injections. The most recent Australian data (albeit from 2014) states that only 12% of adults with T1D are insulin pump users, with cost being the biggest barrier to higher uptake (Diabetes Australia 2014). Further, there are currently no specific recommendations for screening and treatment of diabetes distress under T1D clinical care guidelines. Based on our findings, this presents a clear gap in care, which should be filled as part of routine clinical care for T1D.

This study's main strength is in its novelty, by exploring the experiences of Australians diagnosed with T1D as an adult. The multipronged recruitment strategy allowed for the recruitment of diverse participants across Australia. Although only descriptive, these findings provide a starting point for future research to improve the patient experience and delivery of health care to adults with T1D. Still, we acknowledge the research limitations. Our sample may not be representative of the broader Australian population with T1D: our sample was predominantly female, even though more males are diagnosed with T1D in adulthood than females. The self-reported nature of the survey also introduces potential recall and response bias; however, given

participant anonymity, we expect that the effect of participants' response bias was minimised. This survey was administered during the COVID-19 pandemic, which may have contributed excess diabetes-related distress, anxiety, and depression among participants. Although we did include COVID-19-related questions in our survey, we acknowledge that the pandemic itself may confound our findings. Finally, we were unable to calculate the participation rate of the survey, as the anonymous link was distributed among an unknown number of individuals through our diverse recruitment strategy.

Conclusion

This study has explored the experiences of adults diagnosed with T1D in Australia. Our findings contribute to a small, but growing body of literature focusing on adult diagnoses of T1D, which historically has been considered a childhood disease only. A number of areas of improvement in healthcare delivery were identified for this population, including improving patients' diagnosis experience, and the introduction of regular screening for T1D-related distress. This research should be used as a starting point for more targeted research in the diabetes sphere.

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