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Browne, J. L., Scibilia, R. and Speight, J. 2013, The needs, concerns and characteristics of younger Australian adults with Type 2 diabetes, *Diabetic Medicine*, vol. 30, no. 5, pp. 620-626.

This is the accepted manuscript.

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The needs, concerns, and characteristics of younger Australian adults with type 2 diabetes

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Word count: *Abstract:* 250 *Main text:* 3,290

Article type: Original research

Running title: Younger adults with type 2 diabetes

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Abstract

Aims: The mean age of onset of type 2 diabetes (T2DM) is decreasing in Australia and internationally. We conducted an internet-based survey to improve our understanding of the emotional well-being and unmet needs of younger adults with T2DM, and to inform service provision for this group.

Methods: A random sample of National Diabetes Services Scheme registrants (n=1,417) with T2DM, aged 18-39, living in the Australian state of Victoria received an invitation to complete the online survey. The study was also advertised state-wide. The survey included validated scales (e.g. PAID-5: diabetes-related distress; WHO-5: general emotional wellbeing) and study-specific items. A total of 149 eligible respondents participated.

Results: Almost two-thirds (63%) of respondents reported severe-diabetes related distress; more than a quarter (27%) had impaired general emotional wellbeing. Most (82%) were overweight or obese (BMI \geq 25); most (77%) had at least one other co-morbidity. Lack of motivation, feeling burned out, and being time poor were identified as top barriers to self-management. More than half (59%) of respondents had not participated in structured diabetes education. Respondents perceived that younger adults with T2DM had different healthcare needs than their older counterparts (68%), and that most T2DM information/services were aimed at older adults (62%). Of a range of potential new services, respondents indicated greatest interest in an online forum specifically for younger adults with T2DM.

Conclusions: Younger adults with T2DM have impaired emotional wellbeing and physical health. Population-based research is needed to confirm the current findings, to further inform service delivery and optimise outcomes for this group.

Keywords: type 2 diabetes, young adult, wellbeing, self-management, healthcare access

List of abbreviations:

DES-SF:	Diabetes Empowerment Scale – Short Form
GP:	General practitioner
NDSS:	National Diabetes Services Scheme
OHAs:	oral hypoglycaemic agents
PAID-5:	5-item Problem Areas In Diabetes scale
T2DM:	type 2 diabetes mellitus
US:	United States of America
WHO-5:	WHO-5 Wellbeing Index

Abstract reference: Browne JL, Scibilia R, Speight J. The needs, concerns, and characteristics of younger Australian adults with type 2 diabetes. Proceedings of *The Annual Scientific Meeting of the Australian Diabetes Society and the Australian Diabetes Educators Association* (p.150), August 2012, Gold Coast, Australia.

Introduction

Of the one million people with diagnosed diabetes in Australia, 85-90% have type 2 diabetes (T2DM) and its incidence is rising at an alarming rate (1), with 700,000 estimated to have undiagnosed T2DM and a further two million at high risk. T2DM was once thought of as a condition of older age, but the average age of onset has declined in recent years. In the US, the mean age of T2DM diagnosis has dropped significantly from 52 years in 1988 to 46 years in 2000 (2). Population-based studies in Finland and Australia have found increasing numbers of younger adults with T2DM (1, 3, 4). Furthermore, T2DM is now evident in paediatric populations (5).

We cannot assume that the needs of younger adults with T2DM are the same or similar to those of younger adults with type 1 diabetes, or older adults (e.g. those aged ≥ 40 years) with T2DM. We have much to learn about how to help younger adults manage this unrelenting condition, how to support them emotionally and how to help them effect the behavioural changes that are, undoubtedly, warranted. Unsurprisingly, in T2DM older adults have been the focus of research and clinical care efforts, which means 1) many T2DM services are designed for and aimed at older adults, and may not meet the needs of the younger adults; 2) there is a limited evidence base from which to draw when developing clinical services and interventions targeting younger people with T2DM. Interestingly, while paediatric T2DM has received relatively substantial research attention (5), the needs, concerns and characteristics of younger adults (those under age 40) with T2DM remain under-investigated and poorly understood. Even studies that include adults with T2DM of all ages rarely have large numbers of younger adults, and usually control for age variation or exclude younger participants as outliers (6).

A relatively small body of research indicates that having T2DM at a younger age is associated with higher levels of diabetes-related distress and depressive mood, lower levels of self-efficacy, poorer health status, more life stressors, higher HbA1c, higher BMI, more cardiovascular disease risk factors, higher rates of nephropathy and microalbuminuria, poorer diet, lower levels of physical activity, ethnicity, lower socioeconomic backgrounds, and being a woman (6-17).

Despite indicating some of the challenges associated with having diabetes at a younger age, existing studies have not addressed key issues such as barriers to self-management and perceptions of and engagement with healthcare services. In Australia, research with younger adults with T2DM is scarce, with only two published studies identified in our search, each of which involved very small sample sizes. A study with detailed quantitative data from only nine Australian young adults with T2DM indicated that obesity and impaired quality of life were common (14), and a qualitative study (n=13) found that young adults with T2DM thought that existing diabetes education and services did not meet their needs (18).

Our aim in the current online questionnaire study was to build on the available evidence about the needs, concerns, and characteristics of younger adults with type 2 diabetes for the purposes of informing clinical practice and policy locally and abroad.

Method

Questionnaire

The study consisted of an online questionnaire for younger Australian adults with T2DM, and was initiated by Diabetes Australia – Vic (Victorian branch of Diabetes Australia, the national consumer diabetes organisation) for the purpose of informing service provision by this organisation. The questionnaire was constructed and made available to participants using Survey Monkey®. The questionnaire included validated scales to assess the psychosocial issues of diabetes-related distress (5-item Problem Areas in Diabetes (PAID-5) scale (19)), general emotional wellbeing (WHO-5 Wellbeing Index (WHO-5) (20)), and diabetes-specific self-efficacy (Diabetes Empowerment Scale – Short Form (DES-SF) (21)). The PAID-5 is scored on a five-point Likert scale (0=Not a problem, 4=Serious problem), and the WHO-5 is scored on a six-point Likert scale (5=All the time, 0=At no time). Total scores for both measured are computed by summing the item scores. The DES-SF is scored on a five-point Likert scale (1=Strongly disagree, 5=Strongly agree), and a composite score is computed by taking the mean of the item scores.

The questionnaire also included several study-specific items. Eleven items assessed the extent to which various environmental and individual factors acted as barriers to optimal self-management (scored on a five-point Likert scale: 0=Not at all, 4=Completely). Participants were asked to indicate their main sources of information about diabetes from a list of 11 options (multiple responses were possible). Five items assessed perceptions of the healthcare needs (scored on a five-point Likert scale: 1=Strongly disagree, 5=Strongly agree). Two questions addressed participation in structured diabetes education.

Self-reported demographics and clinical data (e.g. diabetes duration, treatment, HbA1c, co-morbidities, height and weight to facilitate BMI calculation) were also collected. The survey was pilot-tested with four younger adults with diabetes (age range: 23-38 years), with feedback resulting in minor edits to language and response options but not to the substantive content of the survey.

Due to the fact that Diabetes Australia – Vic initiated this project originally for service development (non-research) purposes, the study and associated publication was deemed exempt from ethical review by the Deakin University Human Research Ethics Committee (reference: 2012-065).

Data Collection and Participants

Personnel with authorised access to the National Diabetes Services Scheme (NDSS) database obtained a random sample of around one quarter of all registrants meeting the inclusion criteria: living with T2DM, aged 18-39, and living in Victoria (n=1,417). This random sample received an email (if available) or postal invitation to complete the online survey. The study was also advertised state-wide through diabetes-related e-newsletters and social media. The questionnaire was available online throughout September and October 2011. A total of 173 people responded to the questionnaire, representing a maximum response rate of 12%. Of those, 149 were eligible for inclusion in the study sample (meeting the criteria: T2DM, aged 18-39 years, living in Victoria). All subsequent analyses refer to the final sample of 149 eligible respondents.

Statistical Analyses

Statistical analyses were performed using IBM SPSS 20.0 (New York, USA). Mean±standard deviations are reported for continuous variables, and categorical data are expressed as a percentage. Chi square tests were used to examine relationships between categorical variables, and Pearson's *r* or partial correlations were used to examine relationships between continuous variables. Independent samples *t* tests were used for between-group comparisons. A *p* value of <0.05 was considered statistically significant.

Results

Sample Characteristics

Sample characteristics are displayed in Table 1. Most respondents were women, managed their diabetes using oral hypoglycaemic agents (OHAs), had an HbA1c above the recommended target of 7.0% or 53mmol/mol, had a family history of T2DM, lived in metropolitan areas of Victoria, resided with a partner (with or without children), and had paid employment. Of those who provided weight and height measurements ($n=125$), 82% ($n=103$) were overweight or obese. People from culturally and linguistically diverse backgrounds, including those from an Aboriginal or Torres Strait Islander (ATSI) background, were under-represented.

-----insert Table 1 here-----

Co-Morbidities

Almost a quarter of respondents ($n=35$; 23%) indicated that they did not have any of the listed co-morbidities, while 28% ($n=42$) reported one co-morbidity, 24% ($n=36$) two co-morbidities, and 12% ($n=18$) reported three or more co-morbidities. Most common were high cholesterol ($n=57$; 38%), high blood pressure ($n=55$; 37%) and depression ($n=49$; 33%). Other co-morbidities were reported in very low numbers: neuropathy ($n=7$); peripheral vascular disease ($n=6$); and retinopathy, heart disease, and kidney damage ($n<5$ each). Number of co-morbidities was not associated with diabetes duration ($r=0.04$, $p>0.05$).

General well-being and diabetes-related distress

Descriptive statistics and gender comparisons for the WHO-5 and PAID-5 are displayed in Table 2. No gender differences were observed. There was no association between age and either WHO-5 score or PAID-5 score ($r=0.03$ and $r=-0.01$, both $p>0.05$). However, general emotional wellbeing and diabetes-related distress were significantly correlated, $r=-0.30$, $p<0.001$. Higher BMI was weakly but significantly associated with poorer general emotional wellbeing ($r=0.18$, $p<0.05$), but there was no significant association between BMI and diabetes-related distress ($r=0.08$, $p>0.05$). Number of co-morbidities was not associated with general emotional wellbeing ($r=-0.15$, $p>0.05$) or diabetes-related distress ($r=-0.04$, $p>0.05$). Diabetes-related distress did not differ between those using insulin to manage their diabetes (mean±standard deviation= $4.15±.80$) and those not using insulin ($5.03±.47$; $t(137)=-.18$, $p>0.05$). Based on a PAID-5 cut-off of ≥ 8 , 63% ($n=88$) of respondents experienced severe diabetes-related distress. The PAID-5 item that assesses 'worry about the future and the possibility of serious complications' had the highest mean score of all five items on this scale ($2.53±1.17$). More than a quarter of all respondents (27%, $n=37$) indicated impaired general emotional wellbeing (based on a WHO-5 cut-off score <13), and 23% of these ($n=7$) had a score of ≤ 7 , indicating depressed mood.

Self-Efficacy

Descriptive statistics and gender comparisons for the DES-SF are displayed in Table 2. There were no gender differences, and diabetes-specific self-efficacy was not related to age ($r=0.11$, $p>0.05$) or diabetes duration ($r=0.09$, $p>0.05$). Diabetes-related distress and diabetes-specific self-efficacy were negatively correlated ($r=-0.26$, $p<0.01$), however this relationship did not remain after controlling for general emotional wellbeing ($r=-0.16$, $p>0.05$). Diabetes-specific self-efficacy was associated with

higher levels of general emotional wellbeing, even after controlling for diabetes-related distress ($r=0.21, p<0.05$).

-----insert Table 2 here-----

Barriers to Optimal Self-care

Descriptive statistics and gender comparisons for each of the 11 items about barriers to optimal self-care are displayed in Table 3. Based on mean item scores, the top barriers to optimal self-care for this group were lack of motivation, feeling burned out, and being time poor. Barriers to self-care did not differ by gender.

-----insert Table 3 here-----

Health Care and Support Services

Most respondents (59%, $n=116$) had not participated in any formal or structured diabetes education. Only a very small proportion of respondents indicated that they had attended a diabetes support group (9%, $n=12$), however a somewhat larger number of respondents had engaged with online support groups or forums (16%, $n=22$).

The most common source of diabetes information was a general practitioner (GP) (68%, $n=102$), followed by the internet (46%, $n=69$). However, most respondents (88%, $n=128$) had used the internet to access diabetes-related information at least once in the past 12 months.

More than two thirds of respondents (68%, $n=91$) agreed or strongly agreed with the statement that younger adults with T2DM have different healthcare needs and concerns from their older counterparts, while 62% ($n=83$) thought that most T2DM information and services seem to be aimed at people much older than them. A total of 66% ($n=88$) perceived that most people thought T2DM was a condition experienced only by older people, while 37% ($n=49$) agreed or strongly agreed with the statement that health professionals do not understand the needs and concerns of younger adults with T2DM.

When asked what tailored services (if any) they would be interested in receiving/participating in, the most popular was an online forum designed for and populated by younger adults with T2DM (55%, $n=75$), followed by a mentoring program (49%, $n=66$), and information (44%, $n=60$) and social (41%, $n=56$) events.

Discussion

This study provides important insights into the needs, concerns and characteristics of younger adults with T2DM in Victoria, Australia. To our knowledge, this is the first Australian study to assess a breadth of psychosocial, behavioural, and healthcare issues in a substantial sample of younger adults with T2DM and adds to the limited international literature in this field. The findings and implications of this study can be considered across a number of themes.

1. Psychosocial Aspects

In this sample of younger adults with T2DM, the prevalence of severe diabetes-related distress was very high, at 63%. Studies of diabetes-related distress among the general or older adult population with T2DM indicate the prevalence to be much lower (22, 23). Previous studies have shown that diabetes-related distress is negatively associated with age (24, 25), meaning that younger cohorts are likely to display higher rates of distress than older groups. While differences in measures (e.g. 20-item PAID scale versus the 5-item PAID scale as used in the current study) may introduce some variance in the observed rates of severe diabetes-related distress, it is unlikely that the high prevalence observed here, up to three times that found in other studies, can be explained as a measurement artifact alone. Given the low rate of participation in structured diabetes education, high incidence of cardiovascular risk factors, and short mean diabetes duration for this sample (shorter diabetes duration has been shown to be associated with higher levels of distress in non-insulin-treated T2DM, (24)), the observed high rates of severe diabetes-related distress are perhaps unsurprising. Inconsistent with previous research, distress scores did not differ significantly between those using insulin and those not using insulin (24). This suggests that in this sub-group, diabetes-related distress is less the result of a specific treatment regimen, and may instead be determined by other factors, such as those outlined above. Regardless, severely impaired diabetes-specific wellbeing is a prominent issue in this group.

Almost one third of respondents indicated impaired general emotional wellbeing, and around one-third self-reported a diagnosis of depression. Our findings are consistent with previous research that found high rates of depression in younger people taking OHAs, either alone or in combination with insulin (7). However, it is somewhat counter-intuitive that severe diabetes-related distress was more common in this sample than depressed mood. Given the high incidence of obesity and other co-morbidities, high rates of unemployment, and young age of the sample, it might be expected that depressed mood would be more common, and that diabetes would not be the primary concern in their lives. Future research needs to investigate this issue in younger adults with T2DM using a measure designed specifically to detect depression (e.g. the Patient Health Questionnaire (PHQ9)).

Additional population-based studies are required to confirm the patterns observed in this sample. Clinicians working with younger adults with T2DM need to consider them an 'at-risk' group for psychological or emotional distress, and also consider screening for distress as part of routine practice.

2. Physical Health and Self-Management

Poor physical health was observed in the current sample, with the majority being overweight or obese, and many respondents also reporting the presence of cardiovascular disease risk factors, consistent with previous research with this population (12). Despite the short mean diabetes

duration of the sample, most respondents reported at least one co-morbidity associated with diabetes. Rates of micro- and macro-vascular co-morbidities were quite low. The number of co-morbidities reported was not associated with diabetes duration, possibly because it is often the development of diabetes-related signs and complications that prompt people to seek the assistance of healthcare professionals, which in turn leads to the diagnosis of T2DM (26).

Lack of motivation and feeling 'burned out' from managing diabetes were the most commonly reported barriers to optimal self-management. Many factors can influence motivation such as self-efficacy, normative beliefs, beliefs about the illness and associated management behaviours, and communication and support from health care providers (27, 28). Further research is required to understand the motivating and de-motivating forces specifically for younger adults with T2DM.

Lack of time was also identified as a barrier to self-management. Younger adults, by virtue of life stage, are likely to be balancing additional priorities (e.g. study/work, finances, relationships, and family), which compete with the demands of managing T2DM, such as self-care and healthcare appointments. Consideration needs to be given to ways in which younger adults with T2DM can become more engaged in self-care and healthcare without adding substantial burden to already busy lives.

3. Diabetes Information and Services

One of the main aims of this study was to inform service delivery for younger adults with T2DM in Victoria. Most participants indicated that they did not feel that available T2DM services or resources were tailored to the needs and concerns of younger adults, which may explain the low rates of structured education and support group participation observed in this sample.

While participants in this study primarily indicated that their GP was their main source of diabetes information, many also indicated a reliance on the internet for diabetes-related information. Of a range of potential services tailored for younger adults with T2DM, there was most interest in an online support group or forum designed for and populated by younger adults with T2DM. Such a service might cater well to this group who regularly use the internet to access diabetes information but who also feel time-poor. Younger adults are likely to be technology-literate, and therefore identifying and accessing relevant resources online may not require a large time investment. Furthermore, online peer support and information can be accessed flexibly, at a time that suits the individual. There is some evidence to suggest that online support groups for those with diabetes have a positive impact on perceived support, which may in turn impact emotional wellbeing (another primary concern for younger adults with T2DM) and self-care behaviours (29).

Limitations

The response rate observed in this study was very low (12% at best). Other Australian surveys of the general population of adults with diabetes have attracted higher response rates, using similar recruitment methods (30). There are a number of reasons why younger adults with T2DM might be less likely to engage in research. First, the findings of the current study indicate some level of dissatisfaction with T2DM programs and services amongst this group, which may result in disengagement and serve as a deterrent to involvement in other unknown initiatives, such as this survey. Second, this group may be reluctant to self-identify and engage with others about their T2DM given the perceived stigma associated with the condition (31), especially as they are living

with what they believe is perceived to be a condition of older adulthood. Third, younger adults with T2DM have poor physical health, impaired emotional wellbeing, and overweight/obesity are common. It may be that that T2DM is not a high priority health concern in this context or even a condition with which they identify strongly, resulting in disinterest in taking part in research.

People from culturally and linguistically diverse backgrounds, including those from of ATSI origin, were under-represented in the sample. However, it is known that with ATSI origin are at higher risk of developing T2DM than the general population, and that the condition is often developed at a younger age in this group (32). Therefore, it is likely that issues of access, engagement, and health literacy may have been barriers to study participation.

The generalisability of our findings may be limited by the small sample size, participant self-selection, and the limited geographical region from which participants were drawn. Furthermore, although the current study focused on younger adults with T2DM, respondents ranged from 18-39 years, and the mean age was at upper end of this range. Future studies need to be population-based, and attempt to focus on a younger cohort of adults with T2DM (e.g. 18-29 years).

Finally, all data are self-report. While this is an appropriate method for measuring for attitudes and well-being outcomes, this is a limitation regarding the collection and interpretation of clinical data (e.g. HbA1c and co-morbidities).

Summary and Conclusions

With the mean age of onset of T2DM decreasing across the world, improving our understanding of the well-being and unmet needs of younger adults with T2DM is an important first step in research focused on this group. Respondents in the current study had impaired emotional wellbeing and physical health. Many had not taken part in structured diabetes education and perceived that available T2DM services and resources did not cater to their needs. The development of online services, such as forums and support groups, tailored specifically for this population may be one way to cater effectively to their needs and potentially improve their overall wellbeing. The development of research programs with younger adults with T2DM is an urgent priority in order to inform service delivery and optimise outcomes for this group.

Declaration of competing interests

Nothing to declare.

Funding

The Australian Centre for Behavioural Research in Diabetes is a partnership for better health between Diabetes Australia - Vic and Deakin University. Both bodies provide core funding for the Centre, which enabled this work to be undertaken.

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