

Information needs of young adults with type 2 diabetes: a literature review

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ABSTRACT

Background Type 2 diabetes (T2DM) is increasingly prevalent in young adults but there is very little information about what information they need to undertake diabetes self-management.

Aim To undertake a structured literature review to identify what information people with type 2 diabetes aged 25 to 45 years need to manage their diabetes and how they would like to receive it.

Methods A structured literature search was conducted. The MEDLINE, CINAHL, AMI, APAIS-Health databases were searched for articles published between 1980 and 2011. The reference list of journals and relevant websites were searched. Inclusion criteria were: literature about T2DM in young adults and literature about education and information needs of young adults with T2DM.

Results Only one article specifically focussed on the information needs of young people with T2DM and two reports included some information about T2DM and young adults. The limited data available suggested young adults with T2DM have specific information needs that are not sufficiently addressed in current resources, and have some needs different from young people with type 1 diabetes. Young people with T2DM want clear, consistent information from credible sources, delivered in a range of formats. They also want psychological support and counselling, age-specific education groups, after hours access to health professionals and education provided to family members and the community about T2DM in young people and about how to support people with T2DM.

Conclusion With the prevalence of T2DM in young adults continuing to increase, the need to address the specific information needs and

learning styles of people with T2DM aged 25 to 45 is increasingly important.

Key words Young adults; type 2 diabetes; information; education; literature review

INTRODUCTION

Type 2 diabetes (T2DM) is a serious global health problem. Current Australian prevalence data suggests 7.1% of the population aged 25 years and older have type 2 diabetes and the prevalence is rising.¹ Young Indigenous Australians are three times as likely as young non-Indigenous Australians to have diabetes.¹ However, although the prevalence of type 2 (T2DM) increases with age, young people are increasingly developing type 2 diabetes.¹ Effective self-care is essential to reduce the morbidity and mortality associated with diabetes, however, people need appropriate information to undertake self-care.

Young people with T2DM may have different information needs from older people and from those with type 1 diabetes (T1DM). For example, young people are more likely to be in the paid workforce. The Australian Bureau of Statistics fertility rates for 2009 indicate the birth rate is highest in women aged 30 to 34 (124 babies per 1,000 women).² An increasing number of young women develop gestational diabetes (GDM) and T2DM.^{3,5} Significantly, GDM increases the woman's risk of developing T2DM at a later time.⁶ Information needs of people with diabetes also change over time.⁷

Furthermore, several researchers report differences between health professionals' (HPs) perceptions of the issues that concern people with diabetes and their actual concerns.⁸⁻¹⁰ Therefore, it is important to identify the areas of concern of specific age groups to

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assist HPs to provide appropriate support to people with diabetes.

The majority of people aged 25 to 45 are categorised as ‘Generation X’ and were born in the early 1960s and 1970s. Although generation categories are generalisations and may not apply to all individuals within the generation,¹¹ certain generational characteristics distinguish Generation X from other generations (Table 1).¹²⁻¹⁴ These traits reflect ‘Generation X’ learning styles, which are different from other generations, and need to be considered when developing and delivering diabetes education. However, most current information was developed for other generations and T1DM. Therefore, the Australian Diabetes Educators Association (ADEA) commissioned a comprehensive literature review to identify the type of information people with T2DM aged 25–45 years require and how they would like to receive such information, which is the subject of this paper.

SEARCH STRATEGY

The MEDLINE, CINAHL, AMI (Australian Medical Index), APAIS-Health databases and the Cochrane Database of Systematic Reviews were searched for papers published between 1980 and 2011. The search terms used were type 2 diabetes combined with young adults, younger, or young people and education or information and various combinations of these terms. In addition, the content lists of specific diabetes journals, the reference lists of articles were hand searched to identify relevant articles that may not have been identified in the electronic search. Australian and international diabetes-related websites were searched to

identify relevant reports or materials.

Inclusion criteria were: literature about T2DM in young adults and literature about education and information needs of young adults with T2DM. Literature was excluded if it was about T1DM, adolescents or older people with diabetes, or did not refer to education and information needs. Two researchers independently searched the databases and screened titles and abstracts to determine whether the articles met the inclusion criteria. The same two researchers reviewed the full texts of articles that met the inclusion criteria to decide whether to include them in the review.

Relevant quantitative articles were graded using the Joanna Briggs Institute (JBI) criteria, which comprise four levels of evidence: ‘I’ represents the most reliable evidence.¹⁵ Qualitative articles were graded using the Critical Appraisal Skills Programme (CASP) criteria, which ask ten questions about rigour and credibility: a score of ten indicates the study is rigorous and methodologically sound.¹⁶

FINDINGS

The search of citations produced 189 articles and five reports. However, when abstracts and full texts were examined only one article and two reports met the inclusion criteria. Only one article specifically focussed on the information needs of young people with T2DM: an Australian study where 14 young adults with T2DM participated in a focus group discussion or a telephone interview.¹⁷

Two reports discussed T2DM and young adults. One was an online survey undertaken to “document concerns and issues young adults with diabetes face, and identify areas of need in relation to information, health services and other types of support.” Forty-nine of 414 participants had T2DM age range 16 to 35.¹⁸

The other report presented data from focus groups about the information needs of 31 people with T1DM, T2DM or gestational diabetes.¹⁹ The level of evidence of the quantitative report¹⁸ was Level 3 using the JBI criteria.¹⁵ One qualitative study was rated 8 out of 10¹⁷ and the other 6 out of 10¹⁹ using the CASP criteria (Table 2).¹⁶ In the absence of specific information about young adults with T2DM, relevant articles about the information needs of people with diabetes in general

Table 1. Characteristics of Generation X

Generation X typically:

- scan information rather than read it in-depth
- dislike being lectured to, especially by ‘baby boomers’
- make autonomous decisions
- want to be heard
- solve problems independently and value autonomy and flexibility
- desire personal interaction and constant feedback
- expect immediate answers
- prefer concrete, specific information
- are interested in new technologies and are technologically literate
- engage in parallel thinking
- crave stimulation (Brown, 1997; Collins & Tilson, 1999; Kerr & Gascoigne, 1996; Ryan, Romanelli, Smith & Johnson, 2003).

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were considered to inform the discussion.

INFORMATION REQUIRED

Table 2 presents details of the information needs and issues that concern young people with diabetes identified in the literature. Interestingly, the authors of the report about information needs of young people with T1DM and T2DM noted that young people with T1DM reported different challenges, used different medicines, received different support from health professionals (HPs) and visited different HPs from respondents with T2DM.¹⁸

Some topics young people mentioned are consistent with those topics older people with T2DM diabetes describe in the general literature – for example, making appropriate food choices, dietary restrictions and concerns about diabetes complications.⁹⁻¹⁰ Some issues are unique to young people. These include new developments in medicines and technology, travel advice, drug and alcohol use, pregnancy and information about managing diabetes during medical procedures (Table 2).

Other areas identified included the need to increase community awareness about diabetes.¹⁷⁻¹⁸ Focus group participants comprising a range of people with either T1DM or T2DM of varying ages, and parents of children with diabetes suggested the immediate family should be included in diabetes education programs and provided with relevant information.^{17,19} In

addition, participants indicated the extended family, teachers and classmates, friends, baby sitters, employers and airlines also require accurate information about diabetes.¹⁹

Psychological support and counselling emerged as key needs in the literature.^{17,19} Significantly, 25% of 414 young people with diabetes in the Diabetes Australia (DA) needs analysis reported having long term depression.¹⁸

SUITABILITY OF INFORMATION

People with diabetes want clear, reliable information based on research from credible sources, that is, in language they understand and that encompasses real life experiences.^{17,19} Some people with diabetes report the information they receive is too basic or ‘dumbed down’,¹⁹ others find it too complex or difficult to apply to their diabetes type (T1DM, T2DM or gestational diabetes).

INFORMATION SOURCES

Diabetes Australia¹⁸ reported 31% of 49 young people with T2DM rated parents or family as very useful information sources and support, and 73% cited HPs, specifically GPs (27%), endocrinologist (24%) or diabetes educators (22%). In addition 24% found DA a useful resource.¹⁸ Colagiuri and Goodall¹⁹ also found people with diabetes and parents of children with diabetes regarded HPs and diabetes organisations and centres as useful sources of information. Two studies reported people with diabetes regarded peer support as desirable.^{17,19} Twenty per cent of Colagiuri & Goodall’s¹⁸ participants rated Internet websites as very useful.

PREFERRED MODES OF RECEIVING INFORMATION

Approximately 50% of 49 young people with T2DM who participated in an online survey listed DA, the Internet, magazines/journals/newsletters, and other people with diabetes as their preferred diabetes information sources.¹⁸ When asked how they wanted to receive information, young people with T2DM indicated they wanted a range of options including printed, web-based and telephone-based information; but stressed they wanted a centralised approach to information.¹⁷ Interestingly, some participants in Savage et al’s study were ambivalent about using the Internet because of the huge amount of information and the difficulty locating specific information.¹⁷

Australian HPs used the following **PAGE 22►**

Table 3. Implications for DE practice

Young people with T2DM are likely to have different information and support needs from older people with T2DM and to young people with T1DM. Thus DEs could:

- Identify and address any specific information needs young people with T2DM have as a group and individually.
- Provide consistent and evidence-based information in sufficient detail to enable young people with T2DM to be informed, collaborative and active participants in their diabetes care and management decisions.
- Identify the young person with T2DM’s preferred format for receiving information.
- Provide age appropriate and diabetes specific accurate resources whenever possible.
- Provide information about reliable information sources including Internet sources.
- Consider providing information in a range of formats and ensure it is appropriate for people with time constraints.
- Consider providing after hours services for people in employment or with family and other commitments.
- Consider and address the young person with T2DM’s need for emotional or psychological support, particularly at diagnosis.

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delivery modes: individual education sessions, group programs, printed materials and telephone advice.¹⁹ Delivering information either individually or in group sessions is consistent with people with diabetes' preference.¹⁹ Young people in Savage et al's study wanted to be educated in age-specific groups because they felt their experiences and views were different from older peoples.¹⁷

INDIGENOUS AUSTRALIANS AND PEOPLE OF CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS

The Diabetes Australia report about the information needs of young people with diabetes reported 14% of respondents to a national online survey were indigenous people with T2DM and 24% were born overseas.¹⁸ However, the data for these groups was not separated from other respondents' data in the report and was not discussed as a separate finding in the current review. A Diabetes Australia consultation report identified the importance of ensuring materials and dissemination approaches are culturally appropriate for Indigenous Australians.²⁰ Traditional Indigenous communication involves 'having a yarn,' thus, verbal or written stories are an appropriate way to provide diabetes education for some Indigenous community members. Other approaches such as dance or role plays may also be appropriate. Strategies specifically for young Indigenous adults were not discussed. Similarly, people from culturally and linguistically diverse (CALD) backgrounds require culturally appropriate resources and approaches to education.²⁰

BARRIERS TO USING INFORMATION

Four main barriers to obtaining or using available information consistently appear in the literature: inconsistent information, accessing information and health services, time and cost.

1. Receiving inconsistent information. Three Australian studies indicated people with diabetes often become confused when they receive conflicting advice or inconsistent information from HPs.¹⁷⁻¹⁹ Importantly, 78% of 49 young people with T2DM in one study reported they frequently received conflicting advice from HPs.¹⁸
2. Accessing information and health services. People with diabetes want information about where and how to access diabetes services and advice about the information they need to ask for.¹⁹ Long waiting lists

and GP practices not accepting new patients were significant service access barriers. Consequently, young people with diabetes did not attend appointments with some HPs as often as they would like,¹⁸ which could compromise their diabetes management and health.

3. Time. The need for after hours access to HPs emerged in discussions with young people with T2DM¹⁷ and in focus groups with people with diabetes and parents of children with diabetes.¹⁹ Difficulty getting time away from work or study to keep appointments with HPs was a problem for young people with diabetes.¹⁷⁻¹⁸ In addition, access to specialist diabetes services is limited in regional and remote areas.¹⁸⁻¹⁹
4. Cost. The cost of diabetes services and products is a major problem for some people with diabetes, particularly the cost of counselling services,¹⁹ diabetes supplies, and medication despite NDSS and Medicare subsidies.¹⁸

DISCUSSION

There is a paucity of literature about the particular information needs of people aged 25 to 45 years with T2DM. However, there is some pertinent information about the topics young people with T2DM need information about, how they want information delivered and the reasons they do not use available information. Importantly, despite some similarities in the information young people with T1DM and T2DM require, there is evidence that the needs and concerns of young people with T2DM differs significantly from people with T1DM.¹⁸ Therefore, education and information should be specially tailored for each group.

Literature about young people with T2DM indicates this group needs information about new developments in diabetes care and education, travel, medicines, alcohol and illicit drugs, and pregnancy, in addition to the usual information about diet, exercise, medicines and diabetes complications. Young people with T2DM also want information to be available to the people they associate with and the community to help these people understand T2DM in young people to reduce the stigma associated with T2DM and so they can provide appropriate support.¹⁷⁻¹⁹ The broader literature reflects the importance of having other people informed about diabe-

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tes; people with T1DM and T2DM noted they need support from colleagues to enable them to manage events such as hypoglycaemia whilst at work.⁸

Young people with T2DM described the emotional impact of diabetes and need access to affordable psychological support and counseling.^{17,19} A large proportion of young people with diabetes reported having depression in the literature reviewed,¹⁸ which is consistent with the literature.²¹ Young people with T2DM could be given information about how to access emotional support and develop life skills.

Information needs change according to life stages and disease progression. Diabetes information provided to people diagnosed with T2DM in previous generations and older people is not necessarily appropriate for young adults with T2DM because they are in a different life stage when they are diagnosed with diabetes. As young adults move through adult transitions their needs will continue to change.²² T2DM is associated with progressive beta cell loss and consequently, treatment changes, therefore, people's information needs are likely to change. HP's acknowledged the progressive nature of T2DM, but may not change the information they provide or their teaching style.¹⁹

The literature suggests real life descriptions in information resources is helpful to young people.¹⁹ In addition, studies about the learning styles of people aged 25 to 45 years, "Generation X", indicated their learning style is different from other generations. Thus, diabetes educators need to identify the content and preferred information delivery modes of young people with T2DM in order to provide information in a style that meets their needs. Many people with diabetes feel overwhelmed by the amount of information they receive and that is available in the public domain and find it difficult to determine whether the information is accurate and to identify credible information sources.^{17,19} Muhlhauser and Berger²³ stated people with diabetes need unbiased information about the benefits of specific aspects of their treatment to enable them to participate in decisions about their diabetes treatment and undertake self-care, but indicated such information is usually not provided. The challenge for HPs is to provide consistent, evidence-based information in sufficient detail that meets readability crite-

ria to enable young people with T2DM to be informed, collaborative and active participants in their diabetes care and management decisions. Some strategies that could reduce the confusion young people with T2DM experience include collaboration among HPs from different disciplines and with people with diabetes to develop relevant information, as well as agreeing on and consistently using evidence-based management guidelines.

Time emerged as a barrier to optimal diabetes self-management in two of the studies reviewed.¹⁷⁻¹⁸ Information about how to manage multiple commitments and still manage their diabetes, for example, time management skills would help young people with T2DM. Difficulty accessing services and HPs due to time constraints¹⁷ and the costs associated with taking time off work or study¹⁹ were other barriers that emerged. There is clearly a need for greater flexibility in the hours DE and HP services are provided and/or in the service delivery modes to enable young people to more effectively balance diabetes self-care, work and family commitments.

STRENGTHS AND LIMITATIONS

The subject of the review is novel and of increasing importance. The review highlighted some specific information young people with T2DM need to help them accept and manage their diabetes. Implications of the findings for DE practice are presented in Table 3. The limitations of the review need to be acknowledged. There was a paucity of published literature. There may be relevant unpublished reports from other countries that the authors were unable to identify in the literature search.

The three studies included in the review had a small number of young people with T2DM included in the sample and used different methodologies. Thus, the representativeness of the findings is reduced.

CONCLUSION

There is a paucity of literature about the information needs and preferences for the delivery of information to young people, specifically those aged 25 to 45 years with T2DM. Although some of the information young people with T1 and T2DM need is similar, the review suggests that there are some specific differences in information needs between young adults with T1DM and T2DM.

The information needs of young

Table 2. Concerns/information needs of young people with T2DM listed in alphabetical order and associated level of evidence using Joanna Briggs Institute (JBI) or Critical Appraisal Skills Program (CASP) levels of evidence.

Author / Country	Sampling Population and sample	Methods	Concerns / information needs of people with type 2 diabetes	Strength of evidence
Colagiuri & Goodall (2004) Australia Purpose: To consult people with diabetes, or people directly affected by diabetes, about what information they need.	Purposive sample obtained from DA, Juvenile Diabetes Research Foundation (JDRF) and various diabetes centres. 31 people with types 1 and 2 or gestational diabetes, and parents of children with diabetes. 25 senior volunteers from JDRF aged 18 years. Number of participants with T2DM not stated.	Focus groups: several small groups which included a variety of ages, stages and types of diabetes. Semi – structured. Topics covered: Information needed for the person with diabetes. Information needed for others. Changes in need over time. Delivery modes. Sources of information.	Participants wanted information about : Lifestyle issues – diet and nutrition, sport and exercise. Understanding ‘why me’ and ‘where do I go from here’. The serious nature of diabetes. How to navigate the health system. Hypoglycaemia Hyperglycaemia Complications Managing diabetes Pregnancy Up-to-date information. Also wanted: Psychosocial – counselling, peer support, help with coping. Education and information about diabetes for family members.	CASP score 6
Diabetes Australia (DA) (2006) Australia Purpose: To understand the key issues young people with diabetes encounter and identify areas of need including information.	Sampling population – all people aged 16 to 35 with diabetes who accessed the DA website between July 13 and August 31 2006 were eligible to take part. Sample was self-selected by completing the DA website on-line questionnaire. 414 people participated, 49 had T2DM. Mean age of participants with T2DM = 29 yrs. Number of questionnaires distributed to those who did not have internet access was not stated.	On-line survey using a self – completed questionnaire. Did not state if it was anonymous. Questionnaire was developed from an initial series of 10 group discussions and six one-on-one interviews with people aged 16-35 with diabetes. Three group discussions were with women recently diagnosed with Gestational Diabetes – some have since been diagnosed with T2DM diabetes. No males with T2DM diabetes were recruited to the group sessions.	Respondents indicated they would like more information about: Appropriate food choices (69%) Exercise appropriately (65%) Minimising chances of developing complications (53%) Care for feet (41%) When to test blood glucose (27%) How to take medicines (16%) Discounts and services available through NDSS (51%) New developments in medicines / technology (47%) Diabetes complications (41%) Travel advice (39%) Support groups / activities for young people who have diabetes (37%) Managing pregnancy or planning a baby (31%) Impact of diabetes on the baby (31%) Issues relating to drugs/alcohol (31%) Managing hypoglycaemia (24%)	Level 3b, JBI
Savage, Dabkowski & Dunning (2009) Australia Purpose: To identify the preferred content and delivery mode of information for people aged 25 to 45 with T2DM to enable them to effectively self-manage their diabetes.	Sampling population: people with T2DM aged 25-45 living in Melbourne or Geelong, Victoria. Sample: 13 people aged 25-45 participated in the study. 9 people (6 female, 3 males) participated in the focus group and 4 of the 5 people (3 females, 1 male) unable to attend the focus group participated in a telephone interview.	One focus group and (n = 13) and 4 individual interviews with people with T2DM aged 25-45.	Information needs to be easy to find and not conflicting. <ul style="list-style-type: none"> • Content of information needs to be: • Easy to understand • Brief • Cover a range of additional topics specific to the age groups’ stage of life and lifestyle needs such as; planning pregnancy, travel, the effects of alcohol and diabetes, diabetes medicines and interactions with other medicines, diabetes and other health issues or diabetes and the need for surgery or medical procedures/anaesthetics etc. Participants preferred information to be: <ul style="list-style-type: none"> • Consistent • Accessed via a centralised peak diabetes organisation • Available with a national telephone number for advice • Provided to family members and other support people. Participants also wanted: Age appropriate peer support Psychological support Education for the community.	CASP score 8

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adults with T2DM are different from those of older people with T2DM for whom most information about T2DM was developed. With the prevalence of T2DM in young adults continuing to increase, the need to address the specific information needs and learning styles of people with T2DM aged 25 to 45 is increasingly important.

The current literature highlighted the need for further study to determine the most efficient and effective ways to meet the specific information needs of young adults with T2DM. Further research is also needed to clarify appropriate content and delivery modes to meet the information needs of Indigenous Australian young adults and other cultural groups with T2DM.

AUTHOR CONTRIBUTION:

Trisha Dunning identified and reviewed the literature, contributed to discussion and writing manuscript, reviewed/edited manuscript. Sally Savage identified and reviewed the literature, contributed to the discussion, contributed to writing the manuscript. Susan Streat identified the literature, contributed to writing the manuscript.

ACKNOWLEDGEMENTS

The literature review was conducted as part of a larger study funded by the Australian Diabetes Educators Association.

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