

BMJ Open Understanding the preferences of young adults with type 2 diabetes mellitus with regard to diabetes self-management education: a qualitative study

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ABSTRACT

Aim Young-onset type 2 diabetes (YOD) is associated with poorer clinical outcomes. To support the development of more effective diabetes self-management education (DSME) programmes, this study aimed to understand the preferences of young adults with YOD in relation to the modality, content and qualities of DSME.

Methods Maximal variation sampling was employed to recruit participants of varied age, ethnicity and marital status. In-depth interviews using a semistructured questionnaire were conducted. Subsequently, thematic analysis with coding and conceptualisation of data was applied to identify the main themes regarding DSME.

Results 21 young adult participants aged 22–39 years were interviewed from three polyclinics in Singapore. The most used modalities for DSME included education from healthcare providers, information and support from family and friends and information from internet sources. Participants were most interested in information regarding diet, age-specific diabetes-related conditions and medication effects. Additionally, participants valued DSME that was credible, accessible, individualised and empathetic. Conversely, absence of the above qualities and stigma hindered participants from receiving DSME.

Conclusion Our study explored the preferences of young adults with YOD with regard to DSME, identifying the most used modalities, preferred content and qualities that were valued by young adults. Our findings will help inform the development of DSME programmes that can better meet the needs and preferences of young adults with YOD.

INTRODUCTION

Management of type 2 diabetes is complex; successful management requires masterful understanding of pathophysiological processes, as well as a careful appreciation of the art of health behaviours. Understanding the preferences of people with diabetes in relation to the modality, content and quality of their diabetes education is crucial to meeting their needs.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative approach using in-depth interviews allowed for deeper understanding of the needs and preferences of young adults with type 2 diabetes.
- ⇒ Maximal variation sampling allowed for exploration of experiences of young adults of varied age, gender, ethnicity and marital status.
- ⇒ However, this study was conducted in a multiethnic Asian population in a developed nation and may not be generalisable to more resource-deficient populations.
- ⇒ Participants were recruited during their clinic visits and may not have encapsulated the experiences of young adults who avoided clinic visits.

While traditionally regarded as a disease of older adults, over the last two decades, an increasing number of young adults have been diagnosed with type 2 diabetes.¹ These young adults fall into the category called young-onset type 2 diabetes (YOD), classically defined by an age of diagnosis less than 40 years.² Compared with usual-onset diabetes (UOD), defined by an age of diagnosis more than 40 years, prior studies have shown that control and complications of the disease are consistently poorer and more severe in YOD.^{2 3}

YOD presents an exceptional challenge to clinical care due to its unique biological, psychological and social characteristics. In terms of disease control, it was found that YOD was associated with poorer glycaemic control.^{4 5} Additionally, young adults reported poorer dietary behaviours and less physical activity, and a higher proportion of them were obese compared with people with UOD.^{6 7} Higher levels of diabetes-related distress and lower self-efficacy have also been reported.⁸ With young adults facing new challenges in

their transition to adulthood, including new responsibilities at work and in relationships, they are likely to face unique challenges when caring for their diabetes.

A systematic review evaluating self-care interventions in young adults with diabetes found no significant improvements in glycaemic levels, body mass index or self-care behaviours.⁹ Qualitative studies focus on understanding of health issues from the personal experiences of participants and employ a person-centric approach for identifying young adults' preference for diabetes self-management education (DSME) that is based on their experiences with diabetes self-care. While studies have been conducted on adults with type 2 diabetes, few studies have been conducted targeting YOD. Based on studies exploring the preferences and needs of young adults with regard to DSME, it was found that patients with YOD felt that current DSME programmes were targeted at older patients with type 2 diabetes and did not cater to their specific diabetes needs.¹⁰

With the increasing prevalence of YOD, our study aims to use a qualitative approach to better understand the preferences of young adults in receiving DSME, regarding content, modality and qualities. This will guide clinicians in developing an approach to better engage young adults under their care and aid in the development of more effective self-care interventions.

METHODS

Study design

In-depth interviews were conducted with participants using a semistructured interview guide. To address the study aims, an interpretive and inductive approach was used. This study was reported according to the Standards for Reporting Qualitative Research.¹¹

Inclusion criteria included individuals between 21 and 39 years with type 2 diabetes receiving care from National Healthcare Group polyclinics. Exclusion criteria included the presence of mental disabilities or untreated psychosis because issues faced by individuals with these conditions will be unique and should be explored separately. Eligible participants were identified through their medical records and invited to participate by members of their healthcare team when they visited the clinic for a doctor consultation. All participants gave written consent before participation. Maximal variation sampling was employed to recruit participants of varied age (21–29 years and 30–39 years), gender (male and female), ethnicity (Chinese, Malay and Indian) and marital status (single and married), to capture a broad spectrum of perspectives. This will allow for data analysis to consider the influence from contextual factors such as cultural background and social support. All participants were reimbursed with S\$40 grocery vouchers for their participation in the study.

A patient information questionnaire was used to collect participants' demographic data. A semistructured interview guide was used to conduct the in-depth interviews, which lasted between 45 and 90 min each. The

semistructured interview guide was developed by the study team to address the study aims. The study team consisted of two family physicians (SKWW: MBBS, PhD and WS: MBBS), an academic family physician (HES: PhD), an academic psychologist (KG: PhD), a research assistant (EC: MPH) and a medical student (RRJS: MBBS). The interview guide was pilot tested with three participants to ensure that it effectively captured participants' experiences and preferences and was further revised before use in the study. This study is the second part of a larger qualitative study that explored the barriers and facilitators to self-care behaviours in young adults with YOD.¹² Responses to the second section of the interview guide were analysed for this study (see Appendixonline supplemental appendix). The interviews were conducted either in person at the polyclinic or via a video-conferencing platform (Zoom). Prior to the interviews, rapport was established through introduction of interview's profession and their aims in conducting this study. A reflexive iterative approach was used, and additional questions were added based on responses provided by previous participants. Field notes were taken by interviewers. Recruitment ceased when data reached saturation, defined as when no new preferences were identified; a previous systematic review showed that between 9 and 17 interviews are typically required to attain data saturation.¹³ Interviews were conducted by a female research assistant with prior experience in qualitative research, or by a female family physician (SKWW: MBBS, PhD and WS: MBBS) with experience in qualitative interviews with no other persons present. Physician interviewers did not interview participants who were directly under their care and no repeat interviews were conducted. Participant responses were compared between both researchers and no differences were noted with regard to willingness of participants to share about experiences and challenges.

Patient and public involvement

The study was designed in responses to issues brought up by patients under the care of SKWW and WS and from literature review. However, patients or the public were not formally involved in the design, conduct, reporting or dissemination plans of this research.

Data collection and data analysis

Interviews were conducted from April 2019 to April 2021. Audio recordings were done for every interview and were transcribed verbatim by a research assistant. Transcripts were verified by a member of the study team for accuracy and completeness and were not returned to participants for verification. Audio recordings and transcripts were stored in password-protected laptops and were only available to assigned study team members. Pseudonyms were used to protect personal data. Patient identifiers were removed from the questionnaires and transcripts. Reflexive thematic analysis was performed using an inductive approach to identify participants' experiences and preferences for DSME.¹⁴ An initial open coding

was conducted by two study team members (SKWW, RS) independently, breaking down the data and identifying similarities, differences and relationships between codes. Discussion of codes was done with five members of the study team. Lower-order themes were first identified. Higher-order themes were subsequently identified by examining the relationships between lower-order themes as well as grouping and analysing similar overarching concepts. The themes were refined through iterative analysis and triangulation of data within the research team. NVivo V.12 (QSR International, 2018) was used for data analysis.

RESULTS

Participant characteristics

A total of 22 participants were recruited. 1 participant dropped out and did not complete the interview due to its length, and 21 interviews were completed. 5 participants (23.8%) were aged between 21 and 29 years and 16 (76.2%) were aged between 30 and 39 years. 13 (61.9%) participants were men, while 8 (38.1%) were women. There were nine (42.9%) Chinese participants, eight (38.1%) Malay participants, two (9.5%) Indian participants and two (9.5%) participants from other ethnicities. 6 (42.9%) participants had up to secondary education, 11 participants (42.4%) had a diploma and 4 (19.0%) participants received university education. Table 1 provides a description of participant characteristics.

Summary of findings

Participants' experiences and preferences for DSME were related to modality, informational content and DSME qualities. A summary of the findings related to these themes are presented in figure 1.

Used DSME modalities

The frequently used modalities for DSME included education from healthcare providers (HCPs) (100%), information and support from family and friends (95.2%) and information from internet sources (85.7%).

DSME information of interest

Participants were most interested in information regarding diet, age-specific diabetes-related conditions and medication effects.

Diet

Participants were interested in the nutritional content and suitability of food for people with diabetes, as well as finding healthy yet delicious recipes. Participants perceived that diet had the greatest impact on glycaemic levels and wanted to know what types of food were beneficial for their diabetes.

Useful information. It will be probably more for the diet, because I mean our diet is totally linked to our blood sugar. (Participant 007, female)

Table 1 Participant characteristics

Characteristics	N	%
Age		
21–29 years	5	23.8
30–39 years	16	76.2
Gender		
Male	13	61.9
Female	8	38.1
Ethnicity		
Chinese	9	42.9
Malay	8	38.1
Indian	2	9.5
Others	2	9.5
Educational level		
Up to secondary	6	28.6
Diploma	11	42.4
University	4	19.0
Marital status		
Single	8	38.1
Married	13	61.9
Diabetes duration		
0–5 years	15	71.4
6–10 years	6	28.6
HbA1c		
<7%	4	19.0
≥7%	14	66.7
Did not know	3	14.3
HbA1c, haemoglobin A1C.		

They generally understood the concept of carbohydrates contributing to glycaemic levels. Additionally, they valued specific information instead of generic advice, such as whether people with type 2 diabetes should abstain from certain sweeter fruits like mangos.

Age-specific diabetes-related conditions

Both female and male participants expressed concerns about the effects diabetes will have on their fertility. This concern was raised by participants who did not have children because of their desire to have children in the future.

My concern is... will it affect my ability to have kids... How it will affect your future life in terms of... causing you to be less fertile... I think that is quite important for young people. (Participant 011, male)

A female participant shared that she was diagnosed with polycystic ovarian disease, which was associated with type 2 diabetes and could potentially reduce fertility. She was surprised because it was not mentioned by her doctor who provided care for diabetes.

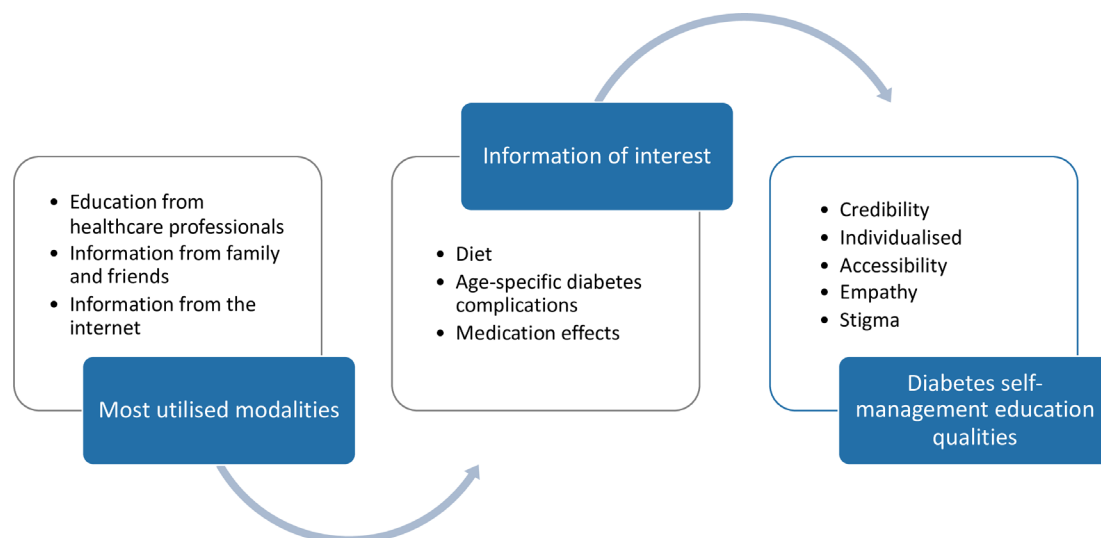


Figure 1 Summary of findings.

Medication effects

Participants wanted to better understand how diabetes medications worked and their side effects. They knew that these were long-term medications, and given their young age, they were concerned about potential side effects.

Like medicine, I ask [my nursing friend], I ask him a lot. Like, how does this help me. (Participant 004, male)

When participants were not convinced about the benefits of medications or were concerned about side effects, they would either not take the medication or lower the dosage on their own. Frequently, participants shared that they would not volunteer medication adherence behaviours to doctors.

DSME qualities valued

Five main qualities valued when receiving DSME were identified: credibility, individualised, accessibility, empathy and avoidance of stigma.

Credibility

Credibility of information was important. Participants generally deemed that information from HCPs was reliable. However, there were instances where information on the internet contrasted with information provided by HCPs; their doctors advised taking medications but internet sources who claimed to be doctors said that medications were not necessary and that HCPs were advising them for monetary gain. In such situations, trust in their own doctor would determine the level of credibility placed on the advice. Participants frequently sought information and advice from friends and family, especially if they worked in the healthcare industry, or had first-hand experience dealing with diabetes. Participants trusted these friends and family members and believed they had adequate expertise or experience for reliable information.

Some of my friends [are] in the body-building line... some of them even nutritionists... so I gather info from them. They even give me some booklets, books or some tips. (Participant 016, male)

Conversely, participants deemed internet sources generally unreliable and lacking credibility. Many participants expressed that they would not trust internet sources of information unless it is personally experienced or verified by HCPs, trusted friends and family members.

No, [I don't trust everything I read online]. Until I experience it myself. If I suffer the same thing. (Participant 011, male)

Individualised

Participants valued DSME that was tailored to their individualised needs. Prior negative experiences included receiving education that was too generic, lacking consideration for the lifestyles of young adults or appreciation of the real-life challenges of heeding such advice.

Don't like generalise all your patients... as a young adult patient, I don't think that makes any sense... it's not motivating at all. (Participant 007, female)

Additionally, consideration for racial and cultural differences was important. This was especially so for participants who belonged to minority ethnic groups, when dietary education was perceived to focus on the diet of the most common ethnic group.

What Indians eat, what Malays eat, and what Chinese eat? So if they actually like, ask them what they eat on a daily basis... then from there... they can suggest the alternatives... I mean we all don't eat the same food... because of the cultural differences. (Participant 020, female)

Accessibility

Participants had multiple commitments and faced conflicting demands on their time; therefore, they preferred DSME that was highly accessible and provided information whenever needed, like through mobile applications. They mentioned that the national HealthHub application, where they could access their own laboratory test results, was useful. Most participants also searched the internet for information, despite concerns about credibility, and shared that they would like to be able to easily access information that was credible and individualised to their own needs.

It's the HealthHub app that actually helped me a lot... It helps me track my appointments... It shows my previous test results. (Participant 008, male)

Some participants perceived that their doctors were not an accessible source of DSME, because doctors were unable to spend time to answer many of their questions due to consultation time constraints.

At the polyclinic, [doctors won't be able to answer my questions] because I understand that there's a lot of people so they can't entertain a lot of questions. (Participant 001, female)

Empathy

Participants valued DSME that was delivered with empathy and considered their feelings and challenges. In particular, emotional support was valued, and some participants preferred group programmes because they could relate to others' shared experiences of living with diabetes, exchange practical advice and provide psychological support to one another, fostering a sense of community.

Knowledge wise, we get that every time from our doctors, from the nurses, even from the internet... But support is very different... like you don't actually get to find it online, or anywhere else. (Participant 007, female)

Avoidance of stigma

The stigma of having type 2 diabetes at a young age was experienced by many participants. This was encountered even in their consultations with healthcare professionals, who made comments such as "you're too young to have diabetes." Many participants described avoiding DSME because they perceived judgement by others.

Some people may feel that it's a body image issue because if you walk into a room full of people who have diabetes – it's usually people who are overweight... I'm a young person there and I can feel that eyes are on me and people are questioning: why does this person have [diabetes]. (Participant 005, male)

DISCUSSION

This qualitative study explored the preferences of young adults with type 2 diabetes with regard to DSME. Findings were categorised by DSME modality, informational content and DSME qualities that were valued. Young adults accessed multiple modalities for DSME, and gaps were identified in diabetes education topics, which included the impact of diabetes on fertility and long-term medication effects. In addition, qualities of DSME that were valued included being credible, individualised, accessible, empathetic and avoiding stigmatisation. These important areas should be addressed when developing DSME programmes in YOD.

Some of the educational topics preferred by participants were unique to the young adult population. For example, the impact of type 2 diabetes on fertility was highlighted as an important topic but was often omitted in existing DSME. A systematic review found that up to 20% of adolescent girls with type 2 diabetes had co-existing polycystic ovarian disease.¹⁵ Yet, female participants shared they were unaware and would have preferred to have been told by their healthcare professionals. DSME for YOD should incorporate discussion regarding fertility issues and this could also include pre-pregnancy counselling in eligible patients. Another educational topic was sharing the indication for diabetes medications and its potential long-term side effects. This was of importance to participants given young adults' longer lifetime exposure to drug treatment. Medication-related education requires individualisation due to different medications being prescribed and may not be well covered in group-based DSME programmes. Doctors and pharmacists who provide care for YOD should actively seek to identify and address any medication concerns because participants who doubted the efficacy of their medications tended to reduce the dose or avoid the medication entirely.

Five DSME qualities were valued by participants: credibility, individualised, accessibility, empathy and avoidance of stigma. However, participants shared that the DSME they experienced frequently did not encapsulate all the valued qualities. For example, DSME from HCPs was perceived to be credible, but information was frequently not individualised to their culture and preferences and sometimes lacked empathy, perpetuating stereotypes and worsening stigma. The role of physician communication is more critical in YOD: a previous study showed that physician communication was more strongly associated with adherence in YOD, compared with middle-aged adult populations.¹⁶ Therefore, training in communication techniques, especially young adult-focused communication styles, may be an important strategy to improve engagement and avoid further stigmatisation.

Interestingly, participants perceived that information from friends and family with experience in diabetes care was very credible, highlighting the influence of vicarious experiences. In our study, many participants preferred to consult friends rather than family members, which appeared to reflect the assertion of identity and

development of independence that characterises the transition to adulthood.¹⁷ Studies have mainly evaluated the effectiveness of family-based interventions, showing significant improvements in knowledge and glycaemic levels; however, few studies have explored the effectiveness of friends based intervention.¹⁸ Therefore, a novel DSME approach in YOD could include study into the feasibility and effectiveness of engaging young adults and their friends in diabetes care.

Technology-based DSME was preferred by participants for its accessibility, anonymity and provision of additional services. For example, health apps integrated with clinic systems helped co-ordinate appointments and provided access to health records. Previous studies similarly identified accessibility as a key reason for preferring technology-based DSME.^{19 20} Our study also found that anonymity was important with young adult participants, due to concerns about stigmatisation. Encountering stigma was common and many participants avoided certain forms of DSME due to perceived stigma, such as being in group programmes where majority of participants were older adults. There is an urgent need to increase awareness of the stigma associated with YOD among HCPs and the public. This is important to ensure adequate psychosocial support and to foster increased participation in DSME.

The many gaps in DSME identified in our study highlighted the urgent need for review of DSME programmes for YOD. Clinicians providing care for YOD should also actively address fertility issues, individualise and contextualise dietary recommendations and explain the mechanism of action for medications and their potential adverse effects. In developing DSME programmes, novel approaches may be needed that are able to incorporate the valued characteristics of DSME (credible, individualised, accessible, empathetic and avoidance of stigma). These values are aligned with the guiding principles for DSME development from the American Association of Diabetes Educators 7 Self-Care Behaviours framework, which encompassed information sharing, psychosocial and behavioural support, engagement and co-ordination of care.^{21 22} Approaches could include community-based programmes that engage young adults and their peers and leveraging on digital health innovations. Future research should focus on developing effective DSME interventions in YOD and to understand the mechanisms by which they are able to effectively improve self-management in young adults.

Limitations

Our study contributed to the growing literature regarding the unique needs and preferences of young adults with type 2 diabetes. However, our study findings should be interpreted in the context of our study population. The study was conducted among a multiethnic Asian population in a developed nation and hence may not be generalisable to more resource-deficient populations. Participants who consented to participate were recruited during their clinic visits; consequently, this study may not

have encapsulated the experiences of young adults who avoided clinic visits leading to an undercoverage bias. Social desirability bias could also lead to participants only providing socially desirable responses. Two out of the three interviewers were practising clinicians, and this may potentially add to social desirability bias. Steps taken to mitigate this included assurance of confidentiality, use of pseudonyms and consciously applying neutral wording during the interviews. This supported participants especially when providing negative responses, such as negative experiences with HCPs.

Conclusion

Our study found that young adults with type 2 diabetes accessed multiple modalities for DSME, and DSME that was valued was credible, accessible, individualised, empathetic and without inherent stigma. These findings may guide the development of more effective DSME programmes that have a greater reach.

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Contributors SKWW, WS, HES and KG were involved in the development of the study methodology. SKWW and WS conducted the interviews with a research assistant (EC). SKWW and RRJS coded the interview transcripts. All authors discussed and identified the themes. RRJS and SKWW drafted the manuscript, and WS, HES and KG reviewed the manuscript. SKWW is the guarantor.

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Patient consent for publication Not applicable.

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