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Multidisciplinary diabetes team care: the experiences of young adults with Type 1 diabetes

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Abstract

Background This research examined whether young adults with Type 1 diabetes engage with the multidisciplinary consultation process and if not, then why.

Methods We designed a web-based self-reported survey, available online from February to May 2011, for Australian adults 18–35 years with Type 1 diabetes. Respondents were asked about which clinicians they consulted to assist with self-management. To expand on the results of the survey, we interviewed 33 respondents.

Results Survey: Respondents (n = 150) consulted with the following clinicians: endocrinologist and diabetes educators: 23.3%; endocrinologist only: 18.0%; endocrinologist, diabetes educators and dieticians: 14.6%; endocrinologist, diabetes educators, dietician and general practitioners (GP): 11.3%; endocrinologist and GP: 10.6%; GP only: 4.6%; all clinicians recommended to assist with self-management: 1.3%; 2.7% did not consult any clinician. Interview: Participants (n = 33) reported eight key disincentives to consultation with multidisciplinary clinicians. These were time constraints; provision of conflicting advice; inaccessibility of health services; variation in service standards; cost constraints; failure of clinicians to refer to other clinicians; lack of opportunity to build a therapeutic relationship; and failure of clinicians to engage in shared decision making.

Conclusion Our results indicate that high attrition rates of young adults with Type 1 diabetes from recommended diabetes health services is linked to the failure of those services to meet the needs and preferences of their patients. The identified needs and preferences included joint consultation with multi-disciplinary team clinicians; flexible access to advice by email or telephone consultation; and shared decision making. Patient engagement in health-service re-design has implications for improved health-service delivery and enhanced treatment outcomes.

Introduction

Type 1 diabetes is the quintessential self-managed chronic disease, requiring lifelong intensive treatment. Effective self-management involves balancing a complex array of interactive physiological parameters with algorithms for insulin dose treatment options. Due to the complexity of treatment, many patients fail to reach recommended treatment target levels of glycaemic control and suffer concomitant poor health outcomes.[1] This is particularly true for young adults.[2,3] As well as suffering poor health outcomes there is a high attrition rate of young adults from diabetes health-related services.[2,3] It has been hypothesized that this may be related to their emerging independence from parental guidance for disease self-management; the transition process into adult health services; and the competing priorities that social, educational and vocational activities place on diabetes self-management.[2,4,5] The impact of chronic illness on the development of social and personal identity may also be relevant.[6] Yet, few studies have examined the reasons as to why young adults with Type 1 diabetes fail to take up recommended health services.

The widely recommended diabetes health service delivery mode is via multi-disciplinary clinician consultation.[7–9] The rationale for such an approach is based on the multi-dimensional, multifaceted requirements of diabetes management.[8] The consultation process is recommended to promote and assist patients with the day-to-day self-management of Type 1 diabetes by availing the patient of specialized assistance. The multidisciplinary consultation approach is not a standard model of care, and is subject to wide variation. Whilst some clinical practice guidelines only broadly recommend the multidisciplinary consultation process,[8] others explicitly recommend which clinicians of the multidisciplinary team patients should consult. In Australia, the clinicians that young adults with Type 1 diabetes are recommended to consult are the endocrinologist/specialist physician; the diabetes educator (a specialist nurse with an accredited post-graduate certificate or diploma in diabetes education); the dietician; and the psychologist/social worker. The general practitioner (GP) (family physician) is recommended to be involved in the patient's ancillary care.[9]

The modes of delivery and consultation costs of multidisciplinary consultation vary. Service delivery can range from accessing multidisciplinary clinicians at the same geographical location at minimum expense to the patient, such as in a diabetes clinic, to a series of separate patient–clinician encounters at different times and geographical locations, with each encounter incurring a separate consultation fee if outside of the public hospital setting.

As well as multidisciplinary diabetes consultations to assist with self-management, recommended Type 1 diabetes care also requires patients to consult with other specialist clinicians for the surveillance and treatment of diabetes-related complications. With increasing numbers of clinicians involved, care may become poorly co-ordinated, fragmented and time consuming for the patient. The number of clinical encounters and the burden of recommended health-service requirements may overwhelm patients. This has led to a call for more minimally disruptive medicine.[10] Yet simultaneously, the burden that the increasing incidence that chronic disease places on western health systems, coupled with the increasing specialization of clinician skills, has necessitated the dispersion of responsibilities for patient care across multi-disciplinary groups of clinicians, whether or not there is evidence to support this style of care and whether or not it is responsive to patient needs.

As the health system moves towards more patient-centred systems of care, patient input becomes an important resource for improving both health-service delivery and the health outcomes of patients.[11,12] Due to high attrition rates from diabetes health services, there is a strong imperative to understand, from the patients' experiences, whether recommended diabetes health-service delivery suits the needs and preferences of patients. Consideration of these issues in health-service re-design may result in a higher uptake by patients and, in particular, young adults of recommended health services. We hypothesized that the high attrition rates of young adults from recommended health services might be due to the fact that diabetes health-service delivery did not meet the needs and preferences of the patient; that is, that the mode of health-service delivery was too disruptive to young adult lifestyles and not patient-centred.

The aim of this study was to investigate the extent to which young adults with Type 1 diabetes engaged with the multidisciplinary consultation process. We wanted to determine the patterns of consultation with endocrinologists; diabetes educators; dieticians and GPs. We set out to identify the other clinicians that young Australian adults with Type 1 diabetes consulted to assist them with their diabetes management. We wanted to understand from patients' perspectives what factors acted as disincentives to the uptake of the multidisciplinary team consultation process.

Methods

Participants

The study population was a sample of Australian adults aged 18–35 years with Type 1 diabetes. Participants were recruited from February to May 2011 from Australian diabetes consumer support organizations via advertisements on websites, e-newsletters, Facebook and print journals. To obtain qualitative data, interviews were conducted in all state capital cities excepting Hobart, with some participants travelling from regional areas. The University of NSW granted ethics approval: HREC 10395. All participants gave individual informed consent before involvement.

Age-limited inclusion criteria for the study were established for the following reasons. First, there is a paucity of research that examines the self-management practices of young adults with Type 1 diabetes. Second, attrition rates from diabetes health services are known to be high in this age group.[2,3] Third, this age group is known to suffer comparatively worse health outcomes.[2] Exclusion criteria were people with Type 1 diabetes outside of the set age limits, people with Type 1 diabetes not living in Australia and carers of those with Type 1 diabetes.

Survey

The quantitative component of the study consisted of a web-based, self-reported, cross-sectional survey of methods of diabetes self-management. A paper version of the survey was available but not utilised by any respondent. The survey consisted of 96 questions that covered a comprehensive assessment of factors relevant to Type 1 diabetes self-management although not all questions were relevant to every respondent. (For example questions related to the use of continuous insulin infusion devices were not relevant to respondents who used multiple daily injections.) Respondents were informed that the survey would take approximately forty minutes to complete. Following assessment of respondent demographic characteristics, the survey addressed questions related to modes, frequency and evaluation of insulin delivery systems and blood glucose monitoring systems. The survey also explored respondents' record keeping, dietary management, insulin adjustment and blood glucose target levels (including exercise, sick days, alcohol consumption); identification and evaluation of health services and diabetes education accessed. The survey was piloted on a sample of four young adults with Type 1 diabetes and 10 health-service workers and researchers. Recommended improvements were incorporated into the final version of the survey.

Respondents were asked whether they consulted with the following clinicians to assist with their diabetes self-management: endocrinologist/diabetes specialist physician; diabetes educator; dietician; GP. Respondents were further asked to nominate whether they consulted with any other health practitioner about their diabetes care. If they responded in the affirmative, they were asked to record whether they consulted with any of the following clinicians: psychologist and/or counsellor; social worker; psychiatrist; cardiologist; renal physician; ophthalmologist; neurologist; podiatrist; alternate medical practitioner; or other clinician. The survey format then provided opportunity for the respondent to record the profession or nature of the consultation relevant to the other category.

Respondents were further asked to record which member of the health-care team they relied on the most to assist them with their diabetes management. The options provided were: endocrinologist/diabetes specialist physician; diabetes educator; dietician; GP; psychologist; psychiatrist; alternative medical practitioner; 'I do not rely on one member of the health-care team the most'; or other. The survey format again provided opportunity for the respondent to record the 'other' person.

Interviews

To expand on the results of the survey, participants were invited by email to attend focus groups. There were 68 affirmative responses. Due to logistical venue and date availability, we interviewed a total of 33 respondents. All participants came from major or regional cities. Interviews were conducted using a semi-structured format of open-ended questions. The open-ended questions were developed based on emergent themes arising from the results of the survey and were designed to validate the survey results by triangulation.[13] Interview discussion continued until content saturation was achieved. Interviews were electronically recorded and transcribed verbatim. The interviewer (JW) wrote notes after each meeting, reflecting on the principal matters discussed and recording the perceived feelings, emotions and personal interactions of the participants.

Data processing and analyses

Of 167 commenced survey responses, 150 respondents completed all survey questions relevant to their self-management practices. Only completed responses were incorporated into the data analyses. Quantitative analysis was undertaken using SPSS 20.0. Sections of the survey also provided for free-text responses. These responses were analysed with the aid of the qualitative data analysis program QRS Nvivo 9 and triangulated with the qualitative data generated by interview. The interview data were analyzed for thematic content using a constant comparative method for emerging themes.[13] Data were coded into recurring themes and subthemes with the aid of QRS Nvivo 9. Emerging qualitative themes and subthemes were compared to quantitative results for consistency. A second researcher (JL) analysed the quantitative data to check thematic consistency and interpretative analysis. Quotations of transcripts that reflected recurring themes were chosen on the basis that they were appropriate examples of consensual opinion. Further discussion between researchers (JW and JL) continued until there was agreement that both the quotations and text were an accurate representation of participants' views. A third health services researcher (MW) analysed the quantitative and qualitative data to check for thematic consistency and interpretative analysis.

Results

Survey results

Demographic characteristics of sample

The sample participants had the following characteristics: 30.5% were aged 18–24 years, 34.4% were 25–29 years and 35.1% were 30–35 years. Eighty percent of respondents were female; 80.0% came from eastern seaboard states (reflecting Australian population demographics); 68.0% were living in major cities; 79.0% had attained an education level of tertiary or higher, 64.0% were working full time, 10.0% were working part time, 13.0% were studying, 5.0% were not employed and 8.0% combined a variety of roles. Eighty-four percent had private health insurance.

Diabetes characteristics of sample

Clinical diabetes characteristics were self-reported. As shown in Table 1, 34.0% reported that their last HbA1c was less than 7.0%; 44.7% reported that their BMI was in the normal range; 25.3% had a duration of diabetes of less than 5 years; and 39.3% had a duration of diabetes of >15 years.

Consultation characteristics of sample

The number of respondents who currently consulted with recommended clinicians was: endocrinologists, 135 (90.0%); diabetes educators, 89 (59.3%); dieticians, 50 (33.3%); psychologist/psychiatrist/social worker 34 (22.7%); GPs, 56 (37.3%). Four respondents (2.7%) did not currently consult any clinician. The average number of clinicians that respondents consulted to assist with self-management was 2.3.

One hundred and five respondents (70.0%) consulted health-care practitioners other than an endocrinologist, diabetes educator, dietician or GP. The number of respondents who consulted with other health-care practitioners is shown in Table 2. Seventy-five respondents (49.9%) consulted an ophthalmologist or optometrist; 66 (44.0%) a podiatrist; 34 (22.6%) a psychologist/psychiatrist/ social worker; 5 (3.3%) a renal physician and 3 (2.0%) a cardiologist. Three respondents (2.0%) consulted an alternate health practitioner.

Table 1 Clinical characteristics of the 150 survey participants

Duration of diabetes	
<5 years	38 (25.3%)
5–10 years	30 (20.0%)
11–15 years	23 (15.3%)
16–20 years	26 (17.3%)
>20 years	33 (22.0%)
Last HbA1c	
Don't know	6 (4.0%)
<7%	51 (34.0%)
7.1–7.5%	30 (20.0%)
7.6–8%	18 (12.0%)
8.1–8.5%	21 (14.0%)
8.6–9%	9 (6.0%)
>9%	15 (10.0%)
HbA1c performed in the last 6 months	
Yes	135 (90.0%)
No	15 (10.0%)
BMI	
Don't know	34 (22.7%)
<19	5 (3.3%)
19–25	67 (44.7%)
>25–30	33 (22.0%)
>30+	11 (7.3%)

Sixty-eight respondents (45.3%) nominated endocrinologists as the health-care professional that they relied on the most, followed by 44 (29.3%) for diabetes educators; 17 (11.3%) for GPs and 2 (1.3%) for dieticians. Nine respondents (6.0%) reported that they did not rely on one member of the health-care team the most. Ten respondents nominated the 'other' category. Of those 10, six respondents nominated themselves and three provided responses that included two or three practitioners. The final respondent provided an explanation as to why they relied on one practitioner the most.

Respondent consultation patterns for recommended clinicians to assist with self-management

Excluding consultation for psychologist/psychiatrist/social worker support, the most common multidisciplinary consultation patterns were: endocrinologist and educator (23.3%), endocrinologist only (18.0%), endocrinologist, educator and dietician (14.6%), endocrinologist, educator, dietician and GP (11.3%) and endocrinologist

Table 2 Other clinician groups consulted by respondents

Health-care practitioner	*n* (%) consulted
Ophthalmologist	68 (45.3)
Podiatrist	66 (44.0)
Psychologist	26 (17.3)
Optometrist	7 (4.6)
Psychiatrist	6 (4.0)
Renal physician	5 (3.3)
Neurologist	3 (2.0)
Cardiologist	3 (2.0)
Alternate medical practitioner	3 (2.0)
Exercise physiologist	2 (1.3)
Social worker	2 (1.3)
Chiropractor	1 (0.6)
Pharmacist	1 (0.6)
Rheumatologist	1 (0.6)
Orthopaedic surgeon	1 (0.6)
Health fund nurse	1 (0.6)

and GP (10.6%). Two respondents (1.3%) consulted all recommended multidisciplinary team members including a psychologist/psychiatrist/social worker; two respondents (1.3%) consulted an endocrinologist, educator, dietician and psychologist/psychiatrist/social worker; and four respondents (2.7%) did not consult with any clinicians to assist with diabetes self-management. A breakdown of respondent consultation patterns for clinicians recommended to assist with self-management is shown in Table 3. When the consultation patterns of respondents were analysed without inclusion of GP or psychologist/psychiatrist/social worker consultations, the most common team-care consultation patterns were: endocrinologist and educator (32.0%), endocrinologist only (31.0%), endocrinologist, educator and dietician (24.0%).

Interview results

Demographic characteristics of the interview participants

These were a subset of the survey participants. Twenty-seven females (81.8%) and six males

Table 3 Respondent consultation patterns with five recommended clinician groups

Clinicians consulted	Other clinicians consulted	No. of respondents consulting	Percentage of total	Mental Health Consultation*	No. of respondents consulting	Percentage of total
Endocrinologist	No other clinicians	27	18.0	Yes	3	2.0
				No	24	16.0
	Diabetes educator	35	23.3	Yes	3	2.0
				No	32	21.3
	General practitioner	16	10.6	Yes	0	0.0
				No	16	10.6
	Dietician	2	1.3	Yes	1	0.7
				No	1	0.7
	Diabetes educator Dietician	22	14.6	Yes	2	1.3
				No	20	13.3
	Diabetes Educator General practitioner	11	7.3	Yes	5	3.3
				No	6	4.0
	Dietician General practitioner	5	3.3	Yes	0	0.0
				No	5	3.3
	Diabetes educator Dietician General practitioner	17	11.3	Yes	2	1.3
				No	15	10.0
Diabetes educator (Endocrinologist not consulted)		1	0.7	Yes	1	0.7
				No	0	0.0
	Dietician	2	1.3	Yes	0	0.0
				No	2	1.3
	Dietician General practitioner	1	0.7	Yes	0	0.0
				No	1	0.7
General Practitioner (Endocrinologist or educator not consulted)		7	4.6	Yes	0	0.0
				No	7	4.7
No clinicians consulted		4	2.7			2.7
Total		150	100		150	100

*Psychologist/Psychiatrist/Social worker.

(18.1%) attended the focus groups. All participants came from major or regional cities. Their mean age was 25.1 years old with a range from 20 to 33 years. The mean duration of Type 1 diabetes was 10.5 years with a range of duration from 0.5 to 25 years.

Most participants reported that they were not engaging with the recommended multidisciplinary consultation process. Following thematic analysis of the qualitative data, eight key experiences emerged that reflected disincentives to accessing multidisciplinary consultation of diabetes clinicians. They were time constraints; provision of conflicting advice by different clinicians in the recommended multidisciplinary team; inaccessibility of health services; the variation in the standard of services provided; cost constraints; the failure of clinicians to refer to other recommended multidisciplinary clinicians; a lack of opportunity for participants to build a therapeutic-relationship with clinicians; and the failure of clinicians to engage in shared decision making. We also found that disincentives to access multidisciplinary diabetes consultations differed depending upon whether the patient attended a specialised diabetes hospital's outpatient clinic or whether they consulted clinicians privately. Each of these disincentives is discussed below.

Disincentives to the multidisciplinary diabetes consultation process

Time constraints. A common factor that affected participants' decisions not to consult with a multidisciplinary team was that they were constrained by the time that it took to do so. Participants reported that even though they perceived that there might be benefits from consultation with multidisciplinary clinicians, the fact that each consultation represented a separate entity regardless of whether it was at a diabetes clinic or in private premises, meant that the interference with their other life activities was too great.

> Managing my diabetes already takes up a lot of my time. Trying to squeeze more in, even though it is beneficial is just too difficult on a short-term basis. If you line up all these appointments and try to squeeze them in, then you stifle your life.

Respondents spoke of the need to prioritize the clinicians that they consulted due to time constraints.

> I guess I would prioritize … I only have time to see this amount of people and the most important for me is the endocrinologist and the educator.

Time constraints were compounded when hospital-based diabetes clinic consultations were not running to time or were cancelled.

> I started at [hospital name], but I found it an inconvenience because the bookings get cancelled or you are sent for and then sit there the whole half a day and you are just waiting … you can't do that … when you are working. So now I go privately.

Provision of conflicting advice by multidisciplinary clinicians. For the majority of participants, the multidisciplinary consultation process involved separate consultations with individual members of the multidisciplinary health-care team. Under such circumstances, participants reported that the provision of inconsistent advice between the clinicians consulted was a common experience. Some participants indicated that the stress of dealing with the divergent views of the multidisciplinary clinicians became the reason why they limited the number of recommended multidisciplinary clinicians that they consulted.

> It's frustrating because you go to the educator and they will tell you one thing, and then you go to the endocrinologist and they will tell you something else.

Nonetheless, some participants expressed that there was value in obtaining the divergent views provided in the consultation process and that the lack of consensus by the clinicians improved the participant's ability to believe in their own expertise.

> I definitely get mixed messages…. She thinks this and he thinks that and I take it all in and go well what do I think and what would work for me and I trial and error all of them.

Participants that attended one inner-city diabetes clinic reported that their model of care involved all of the multidisciplinary clinicians in joint consultation simultaneously with the patient. In this way, divergent views were discussed and consensus reached. Participants who attended that clinic expressed strong support for that model of care. Many participants who attended that focus group who had not experienced that model of care indicated they could see inherent benefits in this mode of health-service delivery.

Inaccessibility of services. Lack of accessibility to health services acted as a barrier to partaking in multidisciplinary clinician consultations. The majority of participants could only access consultation with clinicians in standard workforce hours. The competition of workforce commitments with scheduled consultation times, acted as a barrier to accessing the multidisciplinary consultation process.

> There are benefits (of the clinic), but you can't get an appointment when you want which can be a problem. And if you cancel … you can't get in anyway.

Geographical barriers or barriers created by clinicians' referral habits were also reported. Some participants called for a database of diabetes clinicians to overcome such network barriers.

> My endocrinologist is in Blacktown and he is trying to find someone for me on the North Shore, but it is just hard because he doesn't know anyone in that network.

Participant's frustration over accessibility was compounded by participant's perceptions that clinicians lacked understanding about access barriers to health services and instead blamed patients for not making the effort to prioritise their health.

> A lot of people think that we can just leave our job whenever we want to and consult them at their discretion, and it's not the case. They think: How important is your health? But how important is reality?

The standard of services. Participants indicated that in some instances poor standards of care was a reason why they had ceased to access the multidisciplinary consultation process. There were three expressed reasons for perceived poor standards of care. Participants perceived that their clinician: lacked relevant expertise; failed to impart new knowledge; or, if in the private sector, failed to have access to required technology.

Participants reported that they did not consult with the multidisciplinary team when they perceived that the level of expertise within certain groups of clinicians that they had consulted was substandard. Often, a negative experience with the perceived level of expertise of a specific clinician would lead to a discontinuation of consultation with that particular multidisciplinary group of clinicians.

> I only see an endocrinologist, as he was the only person who could answer my questions to a level of satisfaction.

Paradoxically, participants reported that the acknowledgement by the clinician that their expertise was limited was a positive clinical interaction that built trust and enhanced the therapeutic relationship.

> I have a really good one (GP) … they don't pretend to know everything about it. They have a baseline, and if they can't answer it, they know who to refer you to, and if they can answer it, they do.

The failure by clinicians to impart new knowledge to assist with self-management was cited by some participants as a reason to cease consultation with that clinician group.

> I have not been seeing an educator. I felt like I had reached the ceiling of what they could actually teach me … they were really searching for stuff to teach me, and it was frustrating and not worth it.

Some participants who consulted with clinicians in the private sector reported the lack of appropriate technology as a reason why they ceased consultation with that clinician or group of clinicians. A commonly reported issue was the failure of private endocrinologists to have point-of-care testing for HbA1c levels.

> I went private … but they did not even have a meter to check out your HbA1c!

Cost constraints. Most participants reported that the cost of private health services, particularly allied health services, was a significant factor in the decision not to consult with multidisciplinary clinicians.

> I went private. It was really frustrating. I had to pay separately to see an educator or a dietician.

The three participants (2%) who had accessed the government-sponsored financial assistance programme aimed at encouraging patient uptake of the multidisciplinary consultation process did not have a positive experience with the programme's implementation. Their experiences included loathness on the part of the GP, the gatekeeper of the system, to instigate the programme and a concomitant consultation fee increase on the part of the clinician to offset the subsidy.

> The GP made me make a double appointment with her to fill out the paperwork. She then charged outrageously for the appointment. … She gave me a referral to the dietician, and I went, and was charged a huge amount even though I was supposed to get a rebate. … She wasn't even helpful. … It was a really bad experience. I was out of pocket $80. … The whole idea of the plan was to open up access to non-Medicare refundable services like podiatry. I haven't been to see the podiatrist after that. I figured the best way was to access one through a clinic.

Not referred by other clinicians. Some participants reported that the clinician that they primarily consulted did not refer them to other members of a diabetes health-care team. On that basis, they had not instigated consultation with other clinicians.

> He is my endocrinologist, and I don't refer to anyone else. He doesn't ask me to see an educator or a dietician. I figured that if I needed to seek other opinions, then I would do it on my own, but I haven't felt that need. It is a time factor as well.

Lack of opportunity to develop a therapeutic relationship. Participants reported that the development of a therapeutic relationship with a clinician was an important factor in sustaining consultation with that clinician. Alternately, failure to develop a therapeutic relationship increased the likelihood that the participant would cease consultation with the clinician.

Two main themes emerged that acted to destabilize the therapeutic relationship: First was the consultation time constraints of clinicians. Consultation with a time-compromised clinician fuelled participant perception that the consultation outcome was not worthwhile. Second, participants reported that the rotation of clinicians, especially training clinicians, through hospital diabetes outpatient-clinics meant that there was no continuity of service provision, thereby creating little opportunity to build a therapeutic relationship. Such experiences were reported as a significant driver of participants to the private sector or to cease health-service uptake altogether.

> It is really great to have the same doctor. It is really difficult when you have to change between doctors, as it takes a while to build rapport with them. At the clinic, you don't necessarily get the same doctor. One doctor who I had twice, I was really unhappy with. I spoke to the clinic to say I felt really uncomfortable with him. … I mentioned to my GP that I was really upset about seeing this horrible doctor so she referred me to a specialist.

Lack of shared decision making. Participants' exposure to different members of the multidisciplinary team coincided with their growing awareness of differing consultation styles by clinicians. Many participants reported that they would cease consultation with clinicians or a group of clinicians when they encountered negative experiences with clinicians that failed to acknowledge and respect their own expertise in managing the day-to-day therapeutic challenges of glycaemic control or who failed to incorporate the their input into a clinician-directed regimen.

> I have a discussion. Like it's a bit more of an open table. I don't just go, I don't pay someone to tell me what I'm doing wrong, because I wouldn't go anymore. I wouldn't go if that were the case

Incentives to continue with the multidisciplinary consultation process

Participants identified that certain circumstances acted as an incentive to the continuance of the multidisciplinary consultation process. These were when clinicians undertook joint consultations with other multidisciplinary team clinicians; provided flexible access to advice by email or telephone consultation; or practiced shared decision making.

Discussion

Our findings were that in a sample of motivated people with Type 1 diabetes, the recommended multidisciplinary consultation process is rare. We hypothesize that it is even less frequent for less motivated people. That the majority of young Australian adults with type 1 diabetes do not access the recommended multidisciplinary consultation process, questions the suitability of this style of recommended care for this age group. The social, educational and vocational challenges faced by this cohort may necessitate a more accessible, less time-consuming approach to health-service delivery.[2,14,15]

Participants who wanted to continue to engage with the multidisciplinary consultation process were faced with the dilemma of either attending a hospital clinic where they had rigid appointment times and little opportunity to develop sustained therapeutic relationships with their clinicians or otherwise accept the cost burden of multiple private consultations. Either way, the issues of inconsistent clinician advice and time constraints were problematic. These disincentives to the adoption of the multidisciplinary consultation have been reported previously.[14,16,17]

Models of care that promote divisions of responsibility for patient education and support or for incorporating shared decision making into the management plan may be based on health system organizational and structural limitations, an increasing tendency to clinician skills specialization or the preferences of clinicians rather than the preferences of patients.[18] If the result of such models is that there is poor care co-ordination and high attrition rates from health services, then, irrespective of the inherent system limitations and difficulties involved, the factors that lead to those high attrition rates from health services need to be addressed.

Given the key disincentives identified by participants as to why they do not engage with the multidisciplinary consultation process, a single consultation encounter with a team would mitigate many of those concerns. The report by some participants of a preference for a model of care whereby joint consultation with multidisciplinary team members occurred simultaneously is consistent with such a premise. Under such a model, the time spent by patients in consultation would be reduced, as would the capacity for clinicians to give conflicting advice. A model of care that amongst other interventions sought to improve care co-ordination by holding team meetings for each individual patient has previously been shown to significantly improve glycaemic control.[16] Advancements in telemedicine may make the implementation of such a model of care a practical reality.[19] It should also be considered that the needs of patients to require multidisciplinary team care might evolve with duration of disease. The value of multidisciplinary team expertise may wane as the patients become more experienced in their own self-management.

Our sample was biased in favour of participants who were female, more highly educated, had health insurance and better glycaemic control than national averages. Our attrition rate from all services was 2.7%, whereas attrition rates in Australia have been reported in this age group as high as 50%.[3] The demographic and clinical characteristics of our sample might indicate a bias towards patients that were more motivated to maintain glycaemic control and actively sought out health services. Yet, even though our study group was biased towards a group that does attend services, our results indicate that they do not engage with the recommended multidisciplinary consultation process.

Australian citizens do not incur charges for hospital-based diabetes clinic consultations. In the private sector, the Medicare system provides rebates for doctors' and some nurse practitioners' fees, but patients may incur a gap fee. To offset the cost of private allied health services, patients with a chronic disease who have a GP-administered Chronic Disease Management Plan are entitled to access Government funded rebates for allied health services. A Team Care Arrangement (TCA) is also required to access this rebate.[20] But the system has not been widely implemented by GPs.[21] Our findings also reinforce that this system has not been widely adopted and raises a question as to whether clinicians may be boosting their consultation fees in response to the programme. Further research is warranted into the dynamics of these funding arrangements and their impact on allied-health-care accessibility.

According to the clinical guidelines, the anticipated role of the GP in the multidisciplinary team is to assist with care co-ordination, ancillary care and transitions of care.[9] However, only 37.0% of respondents consulted a GP for their diabetes care. If the multidisciplinary consultation process is to be promoted, then diabetes clinicians should ensure that referral options include the promotion of the role of the GP. An increase in the number of young adults who consult their GP might also lead to increased referrals to TCA's. Moreover, the role of the GP to assist with self-management was greater than would be predicted, given the clinical guidelines: Even though only 37.0% consulted GP's, 11.3% percent of respondents nominated that they relied on the GP the most to assist them with their self-management.

Reported consultations with clinicians other than the endocrinologist/diabetes educator/dietician/GP would suggest that referral to psychological or mental health support services is low; 22.8% of respondents reported attending a psychologist/psychiatrist/social worker. The low rate of respondents attending clinicians to assist with mental health support is concerning, given that the co-occurrence of psychological disorders is common.[2,7–9] Whilst the GP or other clinicians may have an important role in psychosocial support, the inclusion of a psychologist or social worker in the specialist multidisciplinary team is recommended. Such specialist expertise may assist to facilitate the empowerment process through the use of narrative.[6] Our finding that only 49.9% of respondents consulted with either an ophthalmologist or an optometrist, suggests that many young Australian adults may not be accessing the recommended diabetes complications screening procedures. Our findings suggest that pharmaceutical consultation is rare. It may be that the age group of our sample was such that their interaction with pharmacists was minimal. However, the opportunity to talk about insulin from a pharmaceutical point of view and to support the patient with other pharmaceutical questions and issues would still be valuable.

A patient-centred approach to health-service delivery gives consideration to the needs and preferences of the patient, particularly in relation to health-service accessibility. It promotes shared decision making between patients and their clinicians, and aims to improve patients' health literacy.[22–25] Our research provides evidence that many of the facets that define patient-centred care are not being realized in health services for young adults with Type 1 diabetes.

Type 1 diabetes is one of only a few chronic diseases that require the patient to make therapeutic decisions on a daily basis, outside of clinician control.[26] The importance of incorporating the expertise of the patient into decision making for diabetes regimen formulation is now recognized and incorporated into clinical practice guidelines.[7–9] Although there is evidence that there is some uptake of shared decision making by clinicians,[27] implementation is still in its infancy.[26] These results suggest that young adults with Type 1 diabetes support the paradigm shift of shared decision making and may fail to take up recommended health services when that consultation style is not available. However, further research needs to be undertaken to confirm these results in less motivated patients whose needs could differ. Nonetheless, these results provide impetus for the further engagement with shared decision making by clinicians.

Our findings regarding the disincentives to uptake of the multidisciplinary consultation process highlight the value of giving consideration to the perspectives of patients regarding the health services that they experience. The importance of patients' perspectives to improve the quality and safety of health services is well recognized.[11,12,22] Patients' and providers' opinions on health-service standards can differ.[11] The benefits inherent in a mixed-methods approach to the assessment of patients' health-service experiences has been established.[28] Yet, the use of qualitative data collection of patients' perspectives as a driver for improvement in health-service delivery is underdeveloped.[12] This is particularly true in relation to Type 1 diabetes.[29]

By giving consideration to the perspectives of young adults with diabetes as to the disincentives to uptake of the multidisciplinary consultation process, we can appreciate and address the challenges and constraints that they face in their patient journey. We would then be on the road to more patient-centred systems of care, and the benefits for both patients and clinicians that such systems provide which include improved glycaemic control,[30,31] greater patient satisfaction,[31,32] higher levels of patient well being,[32,33] increased patient engagement[31–33] and more provider satisfaction.[33]

Limitations

Recruitment of the study group by self-selection and through advertisements in diabetes-related support organizations introduced a potential for bias. The characteristics of that bias were towards a patient that does attend diabetes services and has already been discussed. Therefore, the uptake of health services by young Australian adults may not be as high as our study indicates. As the needs and preferences of patients who are less motivated to access health services may differ, further research needs to explore their requirements. The clinical indicators recorded in our survey were self-reported and therefore results may be subject to recall and reporting bias.

Qualitative studies such as this one collect large amounts of data from a small number of informants or study sites. They are not designed to estimate proportions in a wider population, quantify relationships between predetermined variables, or provide a single representative or average view or opinion. Instead, they seek to document and explain the variation in a wide range of views, needs, values, practices and beliefs.

Conclusion

Our results indicate that high attrition rates of young adults with Type 1 diabetes from recommended diabetes health services is linked to the failure of those services to meet the needs and preferences of their patients. Given the low health-service uptake and poor health outcomes of young adults with Type 1 diabetes, our results provide evidence for the potential value of patient engagement in health-service re-design. The study has implications for improved health-service delivery and improved treatment outcomes.

Overall, there is a paucity of literature regarding the self-management practices of young adults with Type 1 diabetes. This study provides pointers to ways that may assist in improving health-service delivery and health outcomes for these young adults.

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Competing interests

The authors declare that they have no competing interests.

Authors' contributions

JW conducted the study, analysed the data, contributed to discussions and wrote, reviewed and edited the manuscript. MW analysed data, contributed to discussions and reviewed and edited the manuscript. JL supported the data analysis, contributed to discussions and reviewed and edited the manuscript. JG, RD and JB contributed to discussions and reviewed and edited the manuscript. JW is the guarantor of this work, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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