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Clinical and Psychosocial Factors Influencing Retinal Screening Uptake Among Young Adults With Type 2 Diabetes

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Abstract

Purpose of review: Young adults with type 2 diabetes (T2D, 18-39 years) experience early-onset and rapid progression of diabetic retinopathy (DR), the leading cause of vision loss for working age adults. Despite this,

uptake of retinal screening, the crucial first step in preventing vision loss from DR, is low. The aim of this review is to summarize the clinical and psychosocial factors affecting uptake of retinal screening.

Recent findings: Barriers include: lack of diabetes-related symptoms; low personal DR risk perception; high rates of depression and diabetes-related distress; fatalism about inevitability of complications; time and financial constraints; disengagement with existing diabetes self-management services; perceived stigma due to having a condition associated with older adults.

Summary: Young adults with T2D are an under-researched population who face an accumulation of barriers to retinal screening. Tailored interventions that address the needs, characteristics and priorities of young adults with T2D are warranted.

Introduction

All people with diabetes are at risk of diabetic retinopathy (DR) the leading cause of vision loss for working age adults [1-5]. While lifestyle and glycemic management are the cornerstones of preventing DR, retinal screening is the proven clinical pathway to prevention of vision loss, as risk can be significantly reduced and progression delayed by timely treatment [6-8]. Retinal screening can be conducted via a range of methods including: direct ophthalmoscopy, slit-lamp biomicroscopy, retinal photography; and more recently, via teleophthalmology [9]. Depending on the examination method, dilation drops (mydriasis) may be utilized to increase the field of view [10]. Clinical guidelines recommend retinal screening uptake at diabetes diagnosis and regular screening thereafter, with intervals dependent upon a range of factors such as healthcare system, eye health, ethnicity and clinical markers [11-13].

Despite the effectiveness of retinal screening, the relatively non-invasive modern techniques, and attempts made to reduce access barriers [9], substantial numbers of people with diabetes do not engage in this important behavior [14, 15]. Previous research has highlighted a number of demographic groups at high risk of low retinal screening uptake, including young adults with type 1 diabetes (T1D), those living in remote or socio-economically deprived areas, or from minority ethnic and Indigenous populations [14, 16-18]. Younger age is an established independent risk factor for low retinal screening uptake despite duration of diabetes being a key risk factor for DR, and young people having the greatest number of quality adjusted life years to gain [15, 16, 19-23]. However, barriers to retinal screening uptake in young adults with type 2 diabetes (T2D, aged 18-39 years) have not been reviewed previously.

Young adults with T2D are a burgeoning population who are at risk of early development of DR due to a multitude of modifiable and non-modifiable DR risk factors (e.g. aggressive phenotype, sub-optimal glycemia, hypertension, long disease duration, obesity, smoking and (for women) pregnancy) [24, 25]. This priority population is also vulnerable to low retinal screening uptake, highlighted by recent Canadian, US and UK-based analyses, with consequent 20% lifetime risk of blindness [5, 15, 26, 27]. Despite the public health implications, there is a scarcity of literature on young adults with T2D, reflected in recent reviews of factors influencing retinal screening uptake

and the broader ophthalmic literature [22, 28, 29]. Studies that have explored in-depth factors that influence (or affect) retinal screening uptake for the general diabetes population, report a range of individual-level clinical and psychosocial barriers. These include: confusion between retinal screening for DR and a standard eye check; low risk perception; lack of DR symptoms; fear of retinal screening procedure (e.g. mydriasis) or DR diagnosis; practical obstacles (e.g. cost, time, access); lack of clinician recommendation, and lack of social support [30-35]. Notably, however, average participant age (where reported) was 60 years, offering little insight into the relevance of the above barriers to young adults with T2D.

A greater understanding of young adults with T2D is needed as previous research has established that they differ clinically, physiologically and psychosocially, and have worse health outcomes, than their counterparts with older-onset T2D, or younger adults with T1D [24, 36, 37]. Contributing to this are a range of clinical and psychosocial barriers to diabetes self-management including high rates of physical comorbidity (e.g. obesity, high blood pressure, high blood cholesterol); delay in diagnosis of T2D (estimated twice that of young adults with T1D), and misdiagnosis, due to the clinical complexity of younger-onset T2D [38, 39]. Psychosocial barriers to diabetes self-management include lack of engagement with existing diabetes support programs and services; high levels of diabetes-related distress, depression and anxiety; impaired quality of life, low self-efficacy and unmet psychosocial and information needs [39-41]. Identification of the needs, characteristics and factors affecting the health behaviors of a specific population is important if they are to be properly addressed via clinical, policy and educational intervention [42] - this applies to retinal screening uptake for young adults with T2D.

Thus, the purpose of this review is to summarize the clinical and psychosocial barriers to DR screening uptake impacting young adults with T2D (Table 1). Facilitators of retinal screening are conceptualized as the converse of the barriers (e.g. engagement, as opposed to lack of engagement, with diabetes self-care). Facilitators that are unrelated to a concomitant barrier are specified and addressed separately. Finally, we acknowledge the existence of barriers beyond the remit of this review, such as: environmental (e.g. lack of transport, remote location/lack of access), systemic (e.g. health insurance, practice management, lack of care pathways) and demographic (e.g. delays in diabetes diagnosis, ethnic and linguistic diversity, social deprivation, smoking, level of education) [9, 21, 22, 26, 35, 43-49].

Clinical factors influencing retinal screening uptake.

Clinical characteristics of young adults with T2D. Retrospective analyses of medical databases have provided a picture of the clinical characteristics of young adults with T2D which include obesity, sub-optimal glycemia, hypertension and dyslipidaemia, polycystic ovarian syndrome (for women) and non-alcoholic fatty liver. Three of the characteristics that define young adults with T2D (i.e. age <39 years, sub-optimal glycemic and blood pressure control) are also demonstrated risk factors for low retinal screening uptake, highlighting the vulnerability of this population to both DR and low retinal screening rates [16, 21, 22, 24].

Asymptomatic nature of DR. T2D is typically characterized by an early, asymptomatic period, with clinically important complications manifesting themselves after many years. Similarly, DR has an early, asymptomatic period, resulting in a lack of connection between the individual's physical experience and the clinical imperative to screen for DR, reducing prioritization of the behavior [60, 67, 68]. Although younger-onset T2D is a more aggressive phenotype, with higher complication risk and worse mortality when compared with similar age adults with T1D or older-onset T2D, major complications typically manifest after 10 years duration [38, 51, 54]. Where presence of DR symptoms, such as experience of vision loss, is a key retinal screening facilitator, lack of symptoms is an acknowledge barrier [33, 34, 50, 69]. Notably, in the recent Diabetic Retinopathy Barometer Study, a large-scale survey of 4,340 adults with diabetes and 2,329 health professionals from 41 countries, 65% of optometrists who participated, reported that most individuals presented for retinal screening when visual problems had already occurred [45].

Competing health demands. Diabetes is a chronic condition and the presence of other, often chronic, medical comorbidities can complicate and take precedence over diabetes self-care, including therapeutics and complications screening [44, 70]. Despite often being unaffected by diabetes-related complications in the early stages, young adults with T2D are characterized by health comorbidities and complex healthcare needs [51, 53, 54, 71]. For example, in their qualitative exploration of barriers to diabetes self-management for US adolescents with T2D (aged 14-19 years) and their parents, Auslander and colleagues reported that all participants had at least one health comorbidity, and that both parents and adolescents cited health comorbidities as a key barrier to optimal self-care [53]. More recently, Koelmeyer and colleagues reported a range of statistically significant physical and health-related comorbidities correlated with diabetes diagnosis in their young adult male cohort, including obesity, depression, anxiety, high cholesterol and high blood pressure [52]. The latter is particularly noteworthy, as hypertension is both an independent risk factor for DR and negatively associated with retinal screening uptake [21, 72]. Finally, self-management of T2D can take a back seat to other factors affecting the lives of young adults with T2D, such as obesity, which is commonly cited as the most important health issue by this priority population [40, 54].

Recent diabetes diagnosis and clinician role. Adding to the confluence of clinical factors noted above, considerable psychological and lifestyle adjustments are needed when T2D is diagnosed [73]. As the primary source of healthcare advice for people living with T2D, the general practitioner (GP) plays a key role in facilitating retinal screening uptake [69]. Survey findings from the Diabetic Retinopathy Barometer Study found that although people knew about DR, a large proportion were “insufficiently motivated” to visit an eye health professional [45], highlighting the role of the GP in informing and motivating newly diagnosed adults to initiate retinal screening for DR. Despite this, only 50% of adults who participated in the study reported receiving information about DR from their GP. Two recent cross-sectional surveys indicate that lack of GP knowledge or confidence may underlie lack of encouragement to initiate retinal screening with only 29% of GPs reporting they had read national guidelines on management of DR, and 75% not routinely conducting retinal screening themselves, citing lack of confidence in their ability to detect DR [55].

Psychosocial factors influencing retinal screening uptake.

Knowledge. In general, most people living with diabetes are aware of a connection between diabetes and vision loss, and that eyes need to be examined regularly [45]. However, knowledge of the mechanism by which this happens (i.e., DR as a condition or complication of diabetes and of the role of retinal screening in prevention and early detection of DR) is often lacking [31, 45, 60]. Additional barriers include lack of knowledge of the asymptomatic nature of early DR, confusion between screening for DR and a standard vision-related eye examination, and lack of awareness of DR status [9, 30, 67-69]. Unsurprisingly, young adults with T2D are also impacted by lack of knowledge, with results from a recent cross-sectional study comparing young Australian adults with T2D who had screened for DR, with those who had not, confirming significant differences between the two groups. Key differences included when to initiate DR screening, recommended screening duration for low-risk eyes, and modifiable DR risk factors [56].

Health literacy. An individual's ability to seek, understand and act appropriately on health information is important, due to the many activities required for optimal self-care of T2D. These include (daily) attention to general health behaviours (e.g. diet, physical activity, alcohol intake, smoking cessation) and diabetes-specific health behaviours (e.g. taking medications as recommended, daily glucose monitoring (if indicated), and foot care) [74]. In addition, it is important for people with T2D to understand the critical role of clinical markers (such as HbA1c and blood pressure) and regular DR screening, with respect to prevention and management of DR [75]. Young adults with T2D (and those young adults at high risk of T2D) are characterized by low general and health literacy [37, 57], which has been associated with negative diabetes self-management outcomes, including for retinal screening [76].

Diabetes self-management education. Participation in diabetes self-management education is an important predictor of retinal screening uptake [32, 47, 50, 67]. Despite this, participation is low overall for people with diabetes, across countries and healthcare systems, and has been identified as significantly lower for younger adults [42, 77]. These low rates of participation in structured diabetes education by young adults with T2D may be due to participants feeling they have "different" healthcare needs from "older" adults, and that current education programs were not age-appropriate and did not meet their needs [39, 40, 58]. However, a predominant factor appears to be the view by young adults with T2D that their needs are different to older adults, for which the majority of existing T2D support and services are designed [39, 58].

Life stage demands. Practical obstacles, such as lack of time, cost and competing commitments, are commonly cited barriers to retinal screening uptake in the general diabetes population [30-34]. These obstacles are of particular relevance to young adults with T2D due to their stage of life, which typically includes time and resource-demanding commitments such as work/study and childcare [40, 59]. For example, Moss and colleagues compared 1,298 people with diabetes (type not defined) stratified by age at diagnosis ($n=765 <30$ years, $n=533 \geq 30$ years). They reported that a higher proportion of the younger-onset group cited time and cost as reasons for no retinal screening uptake, compared to those with older-onset diabetes (23% vs 11% for lack of time, 30% vs 12% for cost) [60].

Beliefs about consequences. Belief constructs related to retinal screening uptake include outcome expectancies and anticipated regret. Negative outcome expectancies (such as fear of discomfort or visual disturbance from mydriasis) are commonly cited screening barriers, particularly for working age people who express concern about inability to resume normal workday activities and the need to take time off work [30, 33, 44, 61]. Similarly, expectations of DR diagnosis and subsequent treatment (particularly laser treatment) have been shown to deter screening attendance [32, 33, 44, 47, 61]. More recently, positive expectations such as an “all-clear” outcome and associated relief and feelings of reassurance have been shown to sustain regular retinal screening behaviour [61]. Further, as vision loss from DR is the most commonly cited concern for those living with diabetes, anticipated regret (the belief about whether feelings of guilt or regret will result from inaction) is an important retinal screening facilitator [78]. This appears to be a particularly salient for young adults with T2D, due to concerns they express about the impact that vision loss would have on their ability to support the family unit [61].

Perception of personal risk. In a recent systematic review of how people living with T2D perceive their risk of diabetes-related complications, the authors reported mixed findings, including overestimation or underestimation of risk, or absence of correlation between perceived and actual risk, dependent upon population and diabetes-related complications. When limited to the studies that included eye complications, the authors reported under-estimation of risk and greater optimistic bias [79]. As both of these characteristics are represented during young adulthood, there is strong likelihood that low perception of personal DR risk is a key barrier to retinal screening uptake for young adults with T2D [59, 80]. This is supported by studies highlighting the lack of appreciation shown by young adults with T2D of the implications of having diabetes at a young age, including the expressed views that eye health is an issue only for “older people” and that eye examinations would be necessary only “if symptoms appeared” [20, 47, 61-63].

Two additional factors are also likely to influence perception of personal risk for young adults with T2D. The first is clinical inertia, defined as “health professional’s failure to act, or intensify treatment, when clinically indicated” [81, p.267]. This concept, which is related to lack of clinician recommendation and consequent lack of knowledge of personal susceptibility, has been demonstrated to disproportionately impact the management of young adults with T2D [2]. Second, fatalism about the inevitability of diabetes complications may also play a part in young adults with T2D attitudes towards retinal screening uptake. Young adults with T2D are more likely than older adults to have a family history of T2D, and recent qualitative research with youth with T2D suggested that family history may contribute to a sense of fatalism regarding the inevitability of diabetes complications [63, 82].

Depression and diabetes-specific distress. Prevalence of depression among adults with T2D is almost twice as high as in the general population, and is associated with low participation in diabetes self-care, of which DR screening is one aspect [83]. Diabetes-specific distress, a separate psychological construct which entails a range of negative emotions specific to living with and managing diabetes (e.g. feeling overwhelmed by diabetes, fear for the future and risk of complications, feelings of guilt or anxiety about getting ‘off-track’ with diabetes self-care), also impacts upon diabetes self-management and is associated with sub-optimal HbA1c [84]. Among adults with T2D, younger age is independently associated with high rates of both depressive symptoms and diabetes-specific distress

and has been linked to greater emotional distress at diabetes diagnosis, when compared to older adults [36, 39]. Despite this, only a small proportion of those with younger-onset T2D receive appropriate therapeutic intervention, indicating that these (untreated) factors are likely to negatively impact diabetes self-management, and retinal screening behavior [64].

Social support, opportunity for social comparison. Perceptions of negative judgement are common in people living with T2D [85]. These are salient issues for young adults with T2D who report reluctance to disclose their T2D diagnosis and additional psychological burden for having a condition commonly associated with obesity and older adulthood [39, 40, 65, 66]. As a relatively small population, many young adults with T2D do not know others of similar age with the same condition, and are likely to be socially isolated and have limited opportunity for social comparison [61, 86]. Viewed together, a consequence of these factors represents a lost opportunity to seek or receive peer and family support, self-management education, and adequate healthcare support, including social normative factors, such as knowing whether other young adults with T2D screen for DR [40, 65, 66].

Engagement in diabetes self-care. Unsurprisingly, engagement in diabetes self-care is a key retinal screening facilitator [33]. A recent UK study by Strutton and colleagues highlighted disengagement with diabetes self-care as a key factor in low retinal screening uptake [44]. Young adults with T2D have been demonstrated to engage in less self-care activities than their older adult with T2D and equivalent age T1D counterparts, including taking medication as recommended, eating healthily and physical activity [36]. The reasons behind disengagement are complex and embody many of the factors cited above, including impaired emotional well-being, health comorbidities, stage of life demands and lack of symptoms from diabetes-related complications. Additional factors unique to young adults with T2D which may impact acknowledgement of diabetes diagnosis and self-care behaviors include perceived stigma due to having a condition typically associated with older adults [24, 39, 66].

Summary

Young adults with T2D are vulnerable to a range of clinical and psychosocial risk factors for low retinal screening uptake. There is a clear imperative to promote uptake of this important preventative behavior at diabetes diagnosis for this priority population, particularly as once initiated, retinal screening is generally sustained [87]. The individual-level clinical and psychosocial factors summarized in this review should not be viewed in isolation. Previous research has suggested that an accumulation of barriers, rather than any specific barrier, may explain lower screening uptake for people living with diabetes [21, 43, 44, 48]. This hypothesis appears to be supported with regard to young adults with T2D, both by the factors cited in this review and in the only qualitative study which has explored this issue [61]. In that study, young adults with T2D made a considerably higher number of barrier references compared with older adults with T2D, *irrespective* of retinal screening behavior. These findings highlight the confluence of barriers influencing retinal screening uptake for young adults with T2D and suggest that those young adults with T2D who *had* engaged in retinal screening for DR, had overcome more barriers to do so. Finally, it is important to note that retinal screening uptake for young adults with T2D is also impacted by the environmental, systemic and demographic barriers noted earlier, which are beyond the remit of this review.

Recommendations for research and clinical practice

Health policy and clinical practice.

- Retinal screening for the early detection of DR satisfies the criteria for a screening program outlined by the World Health Organization [88]. Despite the challenges associated with establishing systematic nationwide retinal screening programs, they are effective in increasing screening rates and in decreasing the frequency of vision-threatening DR, and have significant economic benefits [23, 89, 90]. These programs are also a valuable tool for contacting and recruiting both newly diagnosed and hard-to-reach populations into retinal screening uptake [23, 91]. We propose that policymakers consider implementation of coordinated, national DR screening programs wherever possible, in order to identify and recruit young adults with T2D into retinal screening, in order to replicate the UK experience, where DR is no longer the leading cause of vision loss in working age adults [90].
- In the absence of a nationally coordinated retinal screening program, GPs (the healthcare professionals most commonly seen by young adults with T2D), are important gatekeepers to retinal screening for this priority population. Given the low numbers of GPs conducting retinal screening, we recommend increased clinician training in this area, to improve GP confidence in their ability to screen young adults with T2D for DR at diabetes diagnosis and to address psychosocial barriers to screening, including negative outcomes expectancies and low perception of personal risk. Addressing GP-related barriers (e.g. such as confusion about the management of younger-onset T2D and confidence) via targeted training is also warranted.
- We recommend development of age-appropriate care pathways for this priority population and support the recommendations of leading clinicians in the area who have called for health policy to focus on coordinated clinical service provision [24, 69, 71, 92, 93]. Recommendations include coordinated lifestyle (including bariatric support), therapeutic management, and emotional and psychological support initiatives to promote engagement with all aspects of diabetes management for this priority population. Based on the DR risk, we also recommend that retinal screening referral is included in a comprehensive clinical service for this priority population and that additional effort be made to address and minimize the barriers cited in this review, many of which are modifiable.
- Comprehensive, age-appropriate educational and psychosocial support is required to assist this priority population to both cope with, and appreciate, the complication risk associated with younger-onset T2D [20, 36, 63, 93]. Young adults with T2D identify as different to their older adult with T2D counterparts, and report disengagement with existing resources and services, which appear targeted at older adults with T2D. Further, members of this priority population are characterized by low health literacy, which is likely to exacerbate disengagement as many existing retinal screening and DR information resources are written at literacy levels well above the skills of the general population [94]. Health education resources that do not suit the characteristics and literacy levels of the target population risk loss of engagement and unmet information needs, or worse, elicit feelings of stigma or shame in the reader [95]. Thus, we recommend development of tailored

self-management services and resources for this priority population to both ensure relevance and address the unmet needs of this population.

- Finally, given the negative impact of depression and diabetes-related distress on optimal diabetes self-management, we recommend routine screening of emotional well-being in clinical practice. Brief screening tools (such as the WHO-5 and PAID or DDS [96-98]) are freely available. Moreover, practical, evidence-based and clinically informed strategies, enabling the clinician to rapidly assess and address emotional health issues with the person living with diabetes have also been made freely available [99].

Future research.

- Recommendations for early and aggressive therapeutic management and tailored educational and psychological support must be underpinned by an evidence base. Young adults with T2D are a small but burgeoning population, with acknowledged barriers to recruitment and retention in research [54, 82]. For these reasons, there is currently a paucity of research focusing on this priority population, including on barriers to retinal screening uptake. Many of the factors listed above have been selected because they have been demonstrated to impact self-management for young adults with T2D more broadly, and retinal screening uptake for the general diabetes population. However, we recommend a greater focus on research to confirm their likely salience for young adults with T2D.
- In addition to DR, young adults with T2D are at increased risk of progression of a range of diabetes-related complications including peripheral neuropathy, albuminuria (an indicator of chronic kidney disease), and cardiovascular disease [2, 100-102]. This vulnerability highlights a dual imperative for increased research focus on this group overall and development of a range of diabetes evidence-based self-management resources tailored to young adults with T2D, in order to engage them in the range of diabetes self-care activities.

Conclusions

The aim of this review was to synthesize available evidence on those factors likely to impact retinal screening for young adults with T2D in response to a paucity of literature on this issue, despite acknowledged risk of DR. We have presented evidence that young adults with T2D face unique clinical and psychosocial barriers to this crucial screening behavior, including lack of knowledge, clinician recommendation, and lack of DR symptoms, low health literacy and low engagement in diabetes self-management. While more research is needed in young adults with T2D, it is clear that a range of policy, clinical and behavioral strategies is needed to improve the health outcomes for this priority population. Fortunately, as noted in this review, many of the individual-level barriers are modifiable and there is much opportunity to improve the long-term health and quality of life of this population.

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Compliance with Ethical Standards

Conflict of Interest

A. J. Lake, G. Rees, and J. Speight declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

The studies involving human participants, which were conducted by the authors and which are contained in this review, were conducted in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the studies. The authors declare that they have no competing interests.

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Table 1. Summary of barriers to retinal screening uptake among young adults with T2D

Clinical
Clinical characteristics of young adults with T2D ^[16, 21, 22, 24]
Asymptomatic nature of DR ^[45, 50, 51]
Competing health demands ^[52-54]
Recent diabetes diagnosis and clinician role ^[45, 55]
Psychosocial
Knowledge ^[45, 56]
Health literacy ^[37, 42, 57]
Diabetes self-management education ^[39, 40, 58]
Life stage demands ^[40, 59, 60]
Beliefs about consequences ^[44, 61]
Perception of personal risk ^[20, 61-63]
Depression and diabetes-specific distress ^[36, 39, 64]
Social support, opportunity for social comparison ^[40, 65, 66]
Engagement in diabetes self-care ^[36, 44]

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