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Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An exploratory study from Southern India

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3 **1 Original article**
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5 **2 Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An**
6 **3 exploratory study from Southern India**
7

8 **4** *Short title: Barriers to Diabetic Retinopathy screening*
9

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27 ABSTRACT

28 **Objective:** Diabetic retinopathy (DR) is a leading cause of visual impairment and has major public health
29 implications globally and especially in countries such as India where the prevalence of diabetes is high.
30 With timely screening and intervention, the disease progression to blindness can be prevented but several
31 barriers exist to the provision of care. This study explored patient understanding of, and barriers to DR
32 screening from the perspectives of patients and health care providers (HCPs).

33 **Methods:** Using qualitative methods, 15 consenting adult patients were selected purposively from those
34 attending a large tertiary care private eye hospital in the city of Chennai in southern India to participate in
35 semi-structured interviews (SSIs). Eight SSIs were carried out with HCPs, namely ophthalmologists and
36 diabetologists, working in the same hospital. All interviews were audio-taped, transcribed verbatim and
37 analysed using the framework analytical approach.

38 **Results:** Five themes emerged following analysis, namely, recognizing and living with diabetes, care
39 seeking practices, awareness about DR, barriers to DR screening and suggestions for improvement.
40 Findings showed that patients were aware about diabetes but understanding of DR and its complications
41 was poor. Absence of symptoms, difficulties in doctor patient interactions and tedious nature of follow-up
42 care were some major deterrents to care seeking reported by patients. Difficulties communicating
43 information about DR to less literate patients, heavy work pressure and silent progression of the disease
44 were major barriers to patients coming for follow-up care as reported by HCPs.

45 **Conclusions:** Enhancing patient understanding through healthy and friendly doctor-patient interactions
46 and use of an integrated treatment approach making care seeking less cumbersome may prove more
47 effective in enhancing compliance for DR care.

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3 53 **Strength and limitations of this study:**
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- 5 54 • This study identified the barriers to diabetic retinopathy (DR) screening from the perspectives of
6 patients and health care providers (HCP).
7
8 55
9 56 • Triangulating our findings enabled a more comprehensive understanding of the phenomenon
10 and has given us good cues for development of possible intervention strategies.
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12 57
13 58 • The qualitative study looked into the following themes such as recognizing and living with
14 diabetes, care seeking practices, awareness about DR, barriers to DR screening and other
15 suggestions.
16 59
17 60
18 61 • The study could have benefited from interviews with family members, who play an important
19 role both in decision-making for care seeking and in providing support to patients.
20 62
21 63 • Inclusion of HCPs from smaller eye clinics would have provided additional perspectives further
22 enhancing understanding of the phenomena.
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79 INTRODUCTION

80 Diabetic retinopathy (DR), a microvascular complication in the eye due to uncontrolled diabetes has high
81 prevalence in Africa (33.8%) and Western Pacific (36.2%) but in contrast the highest age standardized
82 prevalence was noted in Caucasians (45.8%) followed by South Asians (19.9%) [1]. According to a study
83 [2] the disease pattern is shifting towards afflicting the older age groups, which indicates that the duration
84 of life with the disease is higher. The Wisconsin epidemiology study from Madison (US), reported that
85 26-36% of individuals diagnosed with diabetes never undergo a dilated fundus evaluation [3]. It is well
86 acknowledged that 50-70 % of DR related visual impairments could be prevented by timely screening and
87 intervention. In India, the disease has major public health implications due to two main reasons, i) an
88 estimated 57 million people in India will have diabetes by 2025 (195% increase from 1995) and ii) the
89 risk of sight threatening retinopathy is higher in adults with diabetes [4]. Previous population-based
90 studies from India have reported prevalence of diabetic retinopathy to be 10% in rural areas and 18% in
91 urban areas in population >40 years of age [5, 6]. An on-going study, SMART India study is evaluating
92 the differences in rates of diabetic retinopathy following the economic transition in several states in India.
93 The major risk factors for developing DR are attributable to the duration of diabetes [3] and lack of good
94 diabetic control [7]. Other important risk factors include hypertension [8] and elevated serum lipid levels
95 [9]. Thus, while DR is one of the leading causes of blindness, the vision loss is largely preventable
96 through regular screening and follow-up which, continues to be quite inadequate as suggested by a
97 systematic review [10-12].

98
99 Studies have identified several barriers to screening for DR which ranged from insurance issues, [13]
100 financial burden, lack of awareness about the importance of screening, [14] transportation, language
101 barriers, cultural myths, to denial, fear, and depression [15, 16]. In addition, other factors such as older
102 age, diabetes-related visual compromise associated with diabetes [17] and physical disability also act as
103 deterrents to screening. Studies from India too have highlighted several issues, which include travelling
104 long distances to access the health facility and cost of travel [18]. Patient's beliefs that their eyes are

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3 105 healthy and not having anybody to accompany them to health care facilities and financial costs of seeking
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5 106 care were among other barriers reported [19]. However, most of these findings have emerged from
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7 107 quantitative studies that by its very design are limited in terms of their ability to probe, explore and gain
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9 108 deeper insights into this. The barriers may have regional variations. There is a paucity of qualitative
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11 109 studies on this topic in India. Given that there are strategies available to manage and treat DR [20, 21] a
12
13 110 qualitative approach bringing in both patient and health care provider (HCPs) perspectives could greatly
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15 111 help to more efficiently address the problem [22]. We therefore, conducted semi-structured interviews
16
17 112 (SSIs) to explore and understand how patients with diabetes experienced and coped with their condition
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19 113 in terms of both care seeking behavior as well as life style modifications, their awareness about DR and
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21 114 their perceptions of the barriers towards DR screening. From HCPs, we explored their perceptions on
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23 115 patient understanding of diabetes and DR, the nature of information about diabetes and DR provided to
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25 116 patients and what they believed were barriers for accessing health care.
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118 **METHODS**

119 The study was carried out in a tertiary eye care center located in Chennai, capital of the state of Tamil
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121 Nadu in South India. The study was approved by the institutional review board of Vision Research
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123 Foundation and adhered to the tenets of the declaration of Helsinki.

122

123 **Patient and Public Involvement**

124 Semi structured interviews (SSIs) were purposively carried out with adult patients with diabetes mellitus
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126 (DM) aged 50 years and above who had been living with diabetes for a period of five years or more.
127
128 Using maximum variation sampling so as to obtain a wider cross-section of participants belonging to
129
130 varied socioeconomic backgrounds, we recruited 8 men and 7 women with diabetes who were attending
the out patients department for a routine eye check up. A total of eight SSIs were conducted with HCPs
comprising ophthalmologists and diabetologists. Separate interview guides, informed largely by prior
interactions with patients and provider were developed, which broadly sought to elicit information on

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3 131 patient's understanding of diabetes, perceptions on their experiences and risks of living with it, lifestyle
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5 132 modifications made, care seeking behaviours, understanding of DR, barriers to DR screening and its
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7 133 importance and suggestions on what would be helpful.
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11 135 Consenting patients who fulfilled our eligibility criteria were approached and informed about the study
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13 136 by the research team comprising two junior researchers (KG and VS) and one senior social scientist (SK).
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15 137 They were escorted to a quiet area in the hospital where the interviews were carried out. Similarly,
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17 138 ophthalmologists and diabetologists were approached and their consent obtained to participate in an
18
19 139 interview. All interviews were audio recorded after obtaining consent from the participants.
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23 24 141 **ANALYSIS**

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26 142 Each interview was transcribed verbatim and then translated into English. Analysis followed the
27
28 143 framework analytical approach, [23] which began by first gaining familiarity with each of the transcripts
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30 144 through repeated readings followed by a process of identifying a thematic framework. This included
31
32 145 indexing or sifting through data; sorting and selecting quotes and placing them under the appropriate
33
34 146 thematic category. Segments of text that were related to a common theme were pieced together and, in
35
36 147 this manner, emergent themes were identified.
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39 149 **RESULTS**

40 41 150 **Patient Sample Characteristics**

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43 151 All the 15 patients were married their average age was 63.2 ± 9.25 years. Three were non-literate; one had
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45 152 only studied till class two while another had studied till class five. Five of them had undergone between
46
47 153 10 to 11 years of schooling, three had completed graduation, one had completed post-graduation and one
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49 154 had completed his doctorate. All of them were living with diabetes for several years with an average
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51 155 duration of 15.6 ± 10.80 years.
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157 **HCP Sample Characteristics**

158 The eight HCPs, who participated in the interviews, comprised of 5 women and 3 men. Five were
159 ophthalmologists, two were diabetologist and one was a dietician. Their average age was 44.75 ± 8.19
160 years and average duration of years of experience was 17 ± 10.50 years.

162 **Themes of Analysis**

163 Five themes emerged that best explained the data and addressed our research question. These were i)
164 recognizing and living with diabetes ii) care seeking practices iii) awareness about DR iv) barriers to DR
165 screening v) any other suggestions. Both patient and HCP perspectives are presented.

167 **Patient Perspectives**

168 **Recognizing and living with diabetes**

169 Recognition of the fact that they might have diabetes came rather slowly to most participants. For the
170 most part, the diagnosis of diabetes came as a surprise and a great shock to many participants. It often
171 started with minor symptoms like a tingling feeling in the extremities, frequent urination, itching
172 sensation while passing urine, feeling unusually thirsty or hungry. These were initially ignored until other
173 symptoms started showing up like loss of weight, feeling faint and dizzy or a wound that was not healing.
174 Most patients did not even suspect that they had diabetes and it was only after they were asked to undergo
175 blood sugar tests on the instruction of the doctor, did they come to learn of their diagnosis. Others spoke
176 of not experiencing any symptoms at all and learnt of their condition when they underwent a routine
177 health check-up (DM 10). A female respondent came to know of her diabetes when she underwent
178 surgery for removal of a tumour (DM 01). Myths surrounding the disease also emerged with one
179 respondent stating that he believed he would not get the disease as he thought it only affected the first-
180 born son in the family (DM 09).

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3 182 The realization that this was a lifelong condition that could seriously spiral out of control if not carefully
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5 183 managed had begun to dawn on them. A few respondents, apart from highlighting their own concerns and
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7 184 worries, were also distressed by the stress and burden their illness would impose on their family members
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9 185 (DM 06 & DM 03). These were all typically, their first reactions to the diagnosis. But with time, regular
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11 186 medication and care provided by the doctors, their understanding of the disease improved as they came to
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13 187 terms with their disease. Some even took on a more proactive role by encouraging others who had the
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15 188 disease to be compliant while others appeared more fatalistic in accepting their situation. Some were more
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17 189 familiar with the disease as their parents, siblings or close relatives were living with it and consequently
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19 190 were emotionally better prepared when told of their diagnosis (DM 01).
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24 192 In terms of their understanding of diabetes, most respondents were aware that poor control of their blood
25
26 193 sugar level could result in a host of health problems and complications. Signs and symptoms ranging from
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28 194 becoming tired easily, losing weight, finding it difficult to work, feeling faint and dizzy to more serious
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30 195 conditions such as kidneys and liver being affected, getting paralyzed, severe pain in the feet, suffering a
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32 196 stroke or a heart attack were reported. The fact that diabetes could impair vision leading to possible loss
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34 197 of sight was also reported by many respondents (DM 04).
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39 199 For most participants their main source of information about diabetes came from their health care
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41 200 providers including doctors and nurses. A few others learnt more about the disease from books, articles
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43 201 and literature on the internet as well as from health programmes on television. They felt that doctors were
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45 202 not too forthcoming and usually did not spend time explaining in detail. Friends, neighbours and family
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47 203 members also served as another information source, more so, if they were already diagnosed with
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49 204 diabetes (DM 04).
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53 54 206 **Care Seeking Practices**

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3 207 Although many patients never thought to seek care when symptoms initially started, once diagnosed they
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5 208 became more alert to the need to seek regular health care. Based on the advice given by their doctors, they
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7 209 started attending clinics to get their blood sugar checked. One female respondent spoke of feeling
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9 210 depressed each time she underwent a blood sugar test as the test brought home to her the fact that she had
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11 211 diabetes and had to somehow “*survive with the disease*”. A few respondents emphasized the importance
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13 212 of consistently seeing the same doctor so as to avoid unnecessary confusion from varying
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15 213 recommendations. Use of alternate medicines like Ayurveda was not the preferred choice for most
16
17 214 respondents although a few reported taking it along with their regular allopathic medication as they felt
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19 215 that Ayurveda by itself would not be effective in treating them. They all spoke of the importance of eating
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21 216 a balanced diet, of exercising regularly, taking their medication as advised and of regular follow-up with a
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23 217 physician. To this end, most respondents had modified their lifestyles, although to varying degrees. They
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25 218 reported cutting down on rice-based food items and sweets and exercising to the extent possible. While
26
27 219 some indicated that they had no difficulty in changing their diet, others found it difficult. Similarly,
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29 220 regular exercise too posed a challenge with many indicating lack of time, poor motivation and complaints
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31 221 of body aches (DM 04 & DM 09).
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38 223 **Awareness about DR**

39
40 224 The findings revealed a mixed picture regarding awareness about DR. While for most, it was not a
41
42 225 familiar term, there were a few who were aware of it and of the need to undergo regular retinal screening
43
44 226 they were not fully aware of retinopathy. Most respondents, however, knew that diabetes could affect
45
46 227 their eyes and that their vision could be impaired (DM 05). In fact, they were more familiar with other eye
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48 228 problems like glaucoma and cataract but for the most part remained unaware of the details and symptom
49
50 229 manifestations of DR, and of possible preventive measures that needed to be taken to protect their eyes
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52 230 from DR. Some went on to say that they had not been informed about possible risks to their eyes on
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54 231 account of diabetes or of the precautions they needed to take to protect their eyes. On the other hand,
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232 those who had heard about DR, described it as a condition wherein the “*nerve would get affected*”. They
233 spoke of the importance of eye care, of regular eye checkup and the importance of keeping their blood
234 sugar level under control as ways and means of protecting their eyes. But for the most part, respondents
235 spoke in more general terms as regards eye care with very few expressing a modicum of awareness about
236 DR and of the need for undergoing regular eye screening (DM 04 & DM03).

237

238 **Barriers to DR**

239 Among those ignorant or less aware about DR, a host of issues were cited which according to them acted
240 as barriers to seeking eye care. These ranged from very personal ones by a female patient (DM 06). One
241 male respondent said that as he knew and understood his body and his health condition, he would go for a
242 health check-up only once in a year. The fear that they will necessarily need to take more medicines was
243 another concern expressed. Others complained about doctors being too busy and of not having the time to
244 talk to patients about all the do’s and don’ts regarding diabetic eye care. Other issues involved the
245 logistics of travelling to the health facility, costs associated with undergoing the tests, not having the time
246 to go for a check-up on account of work and family commitments. Some women respondents spoke of not
247 having anyone to accompany them to the health facility and almost all described the long hours they had
248 to spend in the hospital to undergo these tests as major deterrents. Lastly, a sense of complacency and a
249 lack of motivation were also cited as reasons for respondents failing to seek proper and regular care.
250 When patients experienced no symptoms, they tended to become complacent, assumed that all was well
251 and did not perceive the need to visit the hospital. In other cases, respondents simply lacked the
252 motivation to go for the eye test (DM03, DM 05 & DM04).

253

254 **Other suggestions**

255 The most commonly stated suggestion was for the hospital to send regular reminders to patients in the
256 form of phone calls or phone messages informing patients that they were due for a check-up. A few
257 respondents felt that the manner in which doctors communicated to patients would determine how well

258 patients would comply with their advice. They believed that doctors needed to speak gently and not
 259 frighten patients with harsh consequences. The patient would then simply go to another doctor. While
 260 they agreed that all necessary information needed to be communicated, this must be done in a friendly and
 261 non-threatening manner to instill confidence in the patient. Having health facilities that are easily
 262 accessible and did not require patients to travel long distances was also highlighted (DM06). The above
 263 mentioned patients perspectives are summarized in table 1.

265 **Table 1: Selected Quotes: Patient’s perspectives on understanding and barriers to DR screening.**

Recognizing and living with diabetes	<i>“I went abroad on work, so in that company they conducted free checkup and tested for diabetes. That time only I learnt that I have diabetes” (DM 10).</i>
	<i>“I was fat previously but gradually my weight started reducing. I felt itching sensation while passing urine. At about that time I had been advised to undergo surgery to remove a tumour in my uterus. So, I assumed that my weight loss and itching was due to the tumour. This was 7 years back, so when I consulted the doctor, he said that I had diabetes” (DM 01).</i>
	<i>“I thought I will not get it as I am the third son in my family. I was assuming that only the first son will get so I ignored it but finally I also got diabetes” (DM 09).</i>
	<i>“I was afraid at that time. It is not only difficult for me but also difficult for others in the family. So initially I was scared. (DM 06)”</i>
	<i>“I felt too upset and cried after I learnt that I have diabetes.... I was upset that I had got diabetes rather early in my life but now I am in a situation where I can counsel people”. (DM 03)</i>
	<i>“No, I have not considered it as a disease. I felt like it will go away when I take tablets. I have gone through many health problems so I didn’t think much about it. Only if we are fearful it will be a problem, so I’ll be brave. I am convinced that it is okay if I eat the right kinds of food”. (DM 01)</i>
	<i>“Few say because of diabetes, vision might get affected. There are other things that the doctors have told me which I cannot remember. Eyes will get affected that I can understand well. If we are in control (of blood sugar) then it will be fine. Main thing we need is our eyesight”. (DM 04)</i>
Care Seeking Practices	<i>“We must go to one (health care) person only. If we consult with one person then one has to believe that person only... One doctor will tell one suggestion and other doctor will say another thing”, this will confuse us, so it is best to follow only on doctor”. (DM 04)</i>

	<p>“I make efforts to go walking at least twice a day in a week for 45 minutes. Since I travel by bus to office, I feel too tired at the end of the day, so I don’t get time to go for walks everyday”. (DM 09)</p>
	<p>As this female respondent stated “If we have sugar, glaucoma will come, it will affect eyes, blurred or black spot like thing can happen. Mainly I have heard about this I do not know of any other problem” (DM 05).</p>
	<p>“No, I have not heard from anywhere the term ‘diabetic retinopathy’. I have not attended camps for eye care. They (referring to the medical team) have come for camp, but I have not attended”. (DM 04)</p>
	<p>“Diabetic retinopathy means nerve will get affected....If your vision is affected from birth then it is ok, but if you lose your vision in the middle of your life then getting back what is lost is very difficult. So, you have to control sugar and have yearly check-up. This is what is advised to us by the doctors”. (DM 03)</p>
Barriers to DR	<p>“If I have pain I think to go and meet the doctor, if not why do I need to go. If we are normal why do we need to consult the doctor they will write and give medicines so because of that I don’t go” (DM 06).</p>
	<p>“It takes a whole day to complete and come back home since it is very far... by the time I return home it is already evening. There is no one to take care of my daughter”. (DM 03)</p>
	<p>“Generally, doctors don’t have that much time to explain as they are busy. If we ask they tell they are busy which prevents patients from asking further questions”. (DM 05)</p>
	<p>“I consult with one doctor only. I know him from my childhood days. I have not gone separately for sugar specialist. I am satisfied with this doctor and there is no problem, so am continuing with him. Why do I need to see 10 doctors, where each one will tell one thing. If we consult with 10 doctors means each one will take a different decision”. (DM 04)</p>
Other suggestions	<p>“Doctors must not threaten the patient. They often tell the patient that they will lose their eyes or kidney or have heart problem, or they will not be able to walk”. Whatever information is necessary must be discussed with patient but they must not threaten the patient. If they threaten then the patient is not going to visit that doctor. My doctors are threatening me now that’s why I don’t want to consult them. They should say it gently so the patient does not get scared. If the doctor’s smiles and talk in a friendly manner, we won’t be scared”. (DM 06)</p>

266 Note: DM, diabetes mellitus

267

268 HCPs Perspectives

269 Perceptions on patient understanding of diabetes

270 The belief among the HCPs was that people were largely aware about diabetes, referred to it as “sugar
 271 disease” and understood that it required them to control their diet, restrict sweet intake and exercise
 272 regularly. Greater visibility of the disease was attributed to its high prevalence and widespread media
 273 coverage and this had contributed to considerable awareness among people. Patients who were educated

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3 274 were more aware and had access to a wide range of information sources, like the internet, medical
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5 275 literature and health-related broadcasts on radio and television. These patients also sought further
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7 276 clarifications from their doctors and even questioned them when in doubt. On the other end of the
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9 277 spectrum were the poorer, often less educated patients who were not so knowledgeable about the disease
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11 278 and who also tended to be less compliant. Explaining the nuances of the disease to such patients was often
12
13 279 difficult. The HCPs also spoke about issues concerning monitoring and controlling blood sugar levels
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15 280 which according to them was often not adequately maintained or even understood by patients (HCP 05).
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17 281 Thus, patients were generally aware about the disease, but the extent and depth of knowledge of what
18
19 282 exactly they were up against varied considerably (HCP 04).
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24 284 **Information communicated to patients**

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26 285 In terms of information communicated to patients about the disease, all HCPs uniformly said that in
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28 286 addition to telling them about the disease, its symptom manifestations and its management strategies, they
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30 287 reiterated the need to undergo periodic blood tests to monitor their blood sugar level and ensure that they
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32 288 kept it under control. The importance of seeking care from a diabetologist was also stressed as these
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34 289 doctors had the expertise to guide and appropriately advise patients. Further, they advised that as the
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36 290 disease could affect any of their internal organs and was basically a “*silent killer*”, it was imperative that
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38 291 patients underwent regular check-up. Usually the information was conveyed to patients- often with the
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40 292 use of printed pamphlets every time the patient visited the health facility. One HCP, an ophthalmologist,
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42 293 declared that he typically advised his diabetic patients to undergo an HbA1c in addition to fasting and
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44 294 post prandial blood tests. He also advised them to undergo kidney and liver function tests and check their
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46 295 cholesterol and blood pressure as their diabetes could get exacerbated by other prevailing co-morbidities.
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48 296 The HCPs thus spoke of following a fairly structured protocol which also entailed constantly emphasizing
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50 297 the importance of lifestyle modifications as being critical to maintaining health. Another HCP, a dietitian
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52 298 spoke of making efforts to understand the psyche of patients and gearing the information provided to their
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54 299 level of understanding and willingness to follow advice. The patient’s motivation levels and presence of
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3 300 social support were also assessed, based on which appropriate information on the disease was provided
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5 301 (HCP 04).

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9 303 **Understanding of DR and perceived barriers**

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11 304 The general opinion among the HCPs was that awareness about DR was still poor in patients with very
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13 305 few having heard of it. They accepted that patients knew that diabetes could affect the eyes, were familiar
14
15 306 with cataract but for the most, remained ignorant of DR. One HCP, an ophthalmologist described two
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17 307 types of diabetic patients i) those who remained unaware that the disease could affect their eyes and
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19 308 blamed their doctors for failing to educate them adequately and ii) those who despite being asked to
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21 309 attend a retinal screening failed to do so as they did not suffer any symptoms. This silent and quiet
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23 310 progression of DR where patients largely experienced no symptoms resulted in patients not perceiving the
24
25 311 need to seek care thereby seriously compromising their vision. In this context one HCP said that many
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27 312 Indian patients normally come for a check -up when there is an “*acute crises or acute problem*” and
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29 313 unless and until they experienced some difficulties, they usually did not seek care. Another barrier to
30
31 314 proper care highlighted by the HCPs was the availability of a plethora of information on social media
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33 315 sites about diabetes and related health problems. Most of this information was either inadequate or
34
35 316 incorrect and those who tended to follow it did so at great cost to themselves. Lack of motivation;
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37 317 financial problems; absence of good family/social support in terms of someone to accompany them to the
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39 318 hospital and slow improvement in vision following initiation of treatment, acted as deterrents to continued
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41 319 care seeking. Patients also tended to be complacent if their blood sugar levels were under control, little
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43 320 realizing that the longer the duration of diabetes, greater was their risk of developing DR (HCP 07 & HCP
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45 321 01).

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51 323 **Other suggestions**

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53 324 The importance of proper counselling that would educate patients about diabetes and motivate them to
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55 325 attend regular reviews to the hospital was stressed. A more friendly and caring approach so that patients

326 felt comfortable were believed to enhance trust and thereby improve follow-up compliance. A few HCPs
 327 suggested the importance of exposing patients to all the possible diabetic- related complications by
 328 showing them pictures or getting them to meet other patients. This would impress upon patients the
 329 seriousness of the problem. Use of posters and slogans educating people about the disease and
 330 emphasizing the importance of regular care were also highlighted. Use of text messages to remind
 331 patients about their forthcoming reviews was also considered to be a helpful strategy. The above
 332 mentioned HCP perspectives are mentioned in table 2.

333

334 **Table 2: Selected Quotes: HCP's perspectives on understanding and barriers to DR screening:**

Perceptions on patient understanding of diabetes	<i>"I must highlight that patients often don't understand what is meant by adequate control of diabetes. They say, 'today my blood sugar level is normal'. But the fact that this must be maintained in the long term is often not understood in many patients"</i> (HCP05).
	<i>"Patients who are well read, are more careful about their eyes, they come for regular check-u, keep a track of their own condition, ask about their previous test results etc. But there are some patients who are not educated who have extensive disease. When they come, they have no idea what they are coming for. Sometimes even if they are attending for the first time, we know the prognosis is extremely bad. They have never had a check-up or even if it was done nothing much seems to have been explained to them. Even if the doctor is saying the right thing, they are not very compliant. It's very difficult to explain to them and treat them"</i> (HCP 04).
Information communicated to patients	<i>"My way of telling them is even though nothing is a problem always have a regular annual check, you should check especially if you have strong family history. If they are diabetic then my first question will be when was the last time you had an eye check-up? Each and every patient I try and tell them that they should go to a diabetologist. I have seen that most diabetologists have a routine protocol and they have a person who will counsel patients, they also have a chart which states what tests were done and when"</i> (HCP 01).
Understanding of DR and perceived barriers	<i>"DR is mostly asymptomatic, till the end stage and they don't understand the importance...even if we tell them you have retinopathy changes, as they don't experience much of vision problems, they find it hard to accept. It is only when they have bleeding or severe vision drop or if somebody else in the family has already had this problem that they understand the seriousness of their condition... awareness is still low"</i> (HCP 07).
	<i>"Sometimes vision is not improving that much and they will say, 'we are doing all this and coming to you, but vision is not improving'. So, they need to be properly counselled and told that, 'We may not always be able to improve the vision, but we are here to stabilize the vision, in the process if the vision is improved it is good for you"</i> (HCP 01).

335 Note: HCP, Health Care Provider; DR, diabetic retinopathy

336 DISCUSSION

337 Diabetes brings with it high rates of morbidity and mortality. If left untreated or ignored, the disease can
338 cause microvascular complications, involving peripheral nerves, kidneys and eyes. According to WHO
339 (2006) the risk of some form of vision problem due to DR among persons who have lived with diabetes
340 for more than 20 years is very high with about three quarters of them likely to suffer from it [24]. In the
341 USA, research suggests that only 61% of patients with proliferative diabetic retinopathy attend their 5-
342 year follow-up visits highlighting that non-attendance is a crucial problem [25, 26]. The need for regular
343 eye tests among people with diabetes therefore, cannot be more emphasized.

344
345 In countries such as India, where most patients have to pay for their own healthcare, the management of
346 diabetic eye disease is influenced by cost of care, lack of screening programmes, poor public awareness
347 on diabetic eye disease, language as a barrier for communication and poor understanding of the need for
348 regular retinal screening [27-30]. Most retinal services in India that manage these patients are not public
349 funded. There is also a wide variation in provision of healthcare in India ranging from highly specialized
350 hospitals to basic facilities without trained ophthalmologists. Patients are also at liberty to seek care from
351 different centres and are often then lost to follow-up [31, 32]. Given this, the findings of this qualitative
352 study provide important insights into barriers to regular eye testing both from patient and provider
353 perspectives.

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355 There were similarities and differences between reports from patients and HCPs. Patients were largely
356 aware of diabetes, its symptoms, importance of diet and medication management and of exercise which
357 was also endorsed by the HCPs. It is evident that the management of this disease imposed a tremendous
358 burden on both HCPs and patients alike. For providers, communicating the complexities of the disease in
359 words that patients could understand and keeping them motivated to ensure good compliance proved
360 challenging. For patients the burden of constantly having to follow a healthy lifestyle, being systematic in
361 seeking care combined with a lack of depth in their understanding of the disease contributed to patients

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3 362 feeling overwhelmed and frustrated, even depressed. In this context tele-screening has been found to be
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5 363 promising in terms of improving compliance apart from being cost effective [33] for a rural population. A
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7 364 study by Li D [34] highlighted the importance of addressing depression in people with diabetes and
8
9 365 recommended the need to motivate patients to exercise and follow a healthy lifestyle. The fact that
10
11 366 diabetes can affect the eyes was reported by most participants although awareness about DR was poor, a
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13 367 fact confirmed by the HCPs. Poor understanding of DR has also been reported by patients in other studies
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15 368 wherein they expressed having no knowledge about the possibility of becoming blind on account of
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17 369 diabetes [35,36]. In another study, [37] despite most respondents being aware about the need to undergo
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19 370 eye examinations there was limited understanding about retinopathy and about the rationale behind the
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21 371 recommendation. In our study what perhaps emerged as a major deterrent to undergoing eye screening for
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23 372 DR was the absence of symptoms which created a sense of complacency among patients. Patients
24
25 373 questioned the need to undergo eye tests which were usually tedious and required them to spend long
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27 374 hours in the hospital. Further they feared having to take more medications that they thought were
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29 375 unnecessary because they were not experiencing any discomfort. The HCPs too agreed that the silent
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31 376 progression of DR was a deterrent to early care seeking and spoke of difficulties they faced in getting
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33 377 patients to understand the importance of early and regular eye screening and testing. Strategies that could
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35 378 enhance patient understanding of the disease are therefore needed. In this context, studies carried out by
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37 379 Trento et al [38, 39] showed that patients who participated in-group sessions understood DR better. These
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39 380 helped to promote learning and provided long term support to group members that served as incentives to
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41 381 remain compliant. Communication packages like conversation maps [40, 41] for people with diabetes and
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43 382 their families as well as the general population at risk of diabetes have also been found to be useful.
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45 383 Similarly, improving awareness about diabetes and its complication amongst community health workers
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47 384 such as the Accredited Social Health Activists (ASHA) in India may be a way forward. Future research
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49 385 could test the application of such strategies.
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3 387 An important point that emerged was the nature of the doctor-patient interactions. Many patients were
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5 388 critical of doctors who they felt did not explain adequately or were always in a rush. Some spoke of the
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7 389 manner in which doctors communicated to them leaving them feeling threatened and frightened, and
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9 390 therefore more likely to switch to another doctor. They felt confused when meeting different doctors on
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11 391 account of their conflicting opinions. Patients looked to their HCPs for support and encouragement that
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13 392 was often not forthcoming on account of their busy schedules. The HCP's felt that despite repeatedly
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15 393 talking to patients about the disease and its complications many patients did not appreciate the importance
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17 394 of regularly monitoring and maintaining their blood sugar levels and of coming for eye screening. They
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19 395 expressed difficulties communicating to less literate persons who were often shown to be less compliant.
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21 396 The need of patients for HCPs to be more approachable has been expressed by patients in other studies as
22
23 397 well. Peel [42] reported that respondents in her study wanted more support and information from their
24
25 398 HCPs and felt frustrated as many of their concerns had not been answered. Maddigan [43] described the
26
27 399 value of good patient-provider relationships as contributing to good exercise adherence thereby improving
28
29 400 quality of life. It is apparent that HCPs play a pivotal role in promoting understanding of the disease. Our
30
31 401 study findings showed that there is a gap between what is conveyed to patients by the HCPs, and how
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33 402 much of that is actually understood by them. Perhaps the strategy of 'one size fits all' wherein standard
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35 403 information is provided to all patients needs to be addressed. Due consideration to a patient's
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37 404 understanding capacity, self-efficacy, attitudes and health beliefs [44] which exert an influence in their
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39 405 lifestyle management would aid HCPs improve their communication skills and enhance patient
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41 406 understanding. It is important to note that doctors are often hard pressed for time which compromises
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43 407 their ability to spend quality time with patients, a feature that was highlighted by many participants in our
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45 408 study. There is therefore a need to reduce the burden on doctors, perhaps by building a comprehensive
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47 409 diabetic care team comprising of trained personnel who could work together in care delivery. Such an
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49 410 integrated approach where care of diabetes and its complications are available under one roof, literally a
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51 411 'one-stop shop', indicative of a paradigm shift compared to what is currently practiced, seems the most
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53 412 logical way going forward.
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3 413 **CONCLUSION**
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5 414 Living with and managing diabetes is a lifelong process, one that can prove overwhelming to an
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7 415 unprepared patient. It is therefore imperative that steps to ensure good patient compliance be prioritized.
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9 416 Enhancing patient understanding through friendly doctor-patient interactions will promote trust in the
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11 417 doctor and the use of an integrated treatment approach may prove more effective in the long run.
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18 420 **Declarations:**
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20 421 • **Ethics approval and consent to participant**
21

22 422 The study was approved by the Institutional Review Board (Ethics committee), Vision Research
23
24 423 Foundation and written consent was obtained from the patients as per the Declaration of Helsinki.
25

26 424 • **Consent for publication**
27

28 425 Not applicable
29

30 426 • **Availability of data and materials**
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32 427 The datasets generated during and/or analysed during the current study are not publicly available,
33
34 428 as it against the organization hospital policy. But are available from the corresponding author on
35
36 429 reasonable request.
37

38
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40

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11
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13
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15
16 442 and S.V drafted the work and S.P, P.R and S.S substantively revised it. All authors reviewed the
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24 446 **REFERENCES:**

- 25
26
27 447 1. Thomas RL, Halim S, Gurudas S, et al. IDF Diabetes Atlas: A review of studies utilising retinal
28
29 448 photography on the global prevalence of diabetes related retinopathy between 2015 and 2018.
30
31 449 *Diabetes Res Clin Pract* 2019;107840.
32
33 450 2. Flaxman SR, Bourne RR, Resnikoff S, et al. Global causes of blindness and distance vision
34
35 451 impairment 1990–2020: a systematic review and meta-analysis.
36
37 452 *Lancet Glob Health* 2017;5:e1221-34.
38
39 453 3. Klein R, Klein BE, Moss SE. The Wisconsin epidemiological study of diabetic retinopathy: a
40
41 454 review. *Diabetes Metab Res Rev* 1989;5:559-70.
42
43 455 4. Narendran V, John RK, Raghuram A, et al. Diabetic retinopathy among self reported diabetics in
44
45 456 southern India: a population based assessment. *Br J Ophthalmol* 2002;86:1014-8.
46
47 457 5. Raman R, Mahajan S, Padmaja RK, et al. Tele-health program for diabetic retinopathy in Rural
48
49 458 South India: a pilot study. *E-Health Int* 2005;2:13-8.
50
51 459 6. Raman R, Gupta A, Pal SS, et al. Prevalence of metabolic syndrome and its influence on
52
53 460 microvascular complications in the Indian population with type 2 diabetes mellitus. Sankara
54
55
56
57
58
59
60

- 1
2
3 461 Nethralaya Diabetic Retinopathy Epidemiology and Molecular Genetic Study (SN-DREAMS,
4 report 14). *Diabetol Metab Syndr* 2010;2:67.
5 462
6
7 463 7. Wong TY, Cheung N, Tay WT, et al. Prevalence and risk factors for diabetic retinopathy: the
8 Singapore Malay Eye Study. *Ophthalmol* 2008;115:1869-75.
9 464
10
11 465 8. Snow V, Weiss KB, Mottur-Pilson C. The evidence base for tight blood pressure control in the
12 management of type 2 diabetes mellitus. *Ann Intern Med* 2003;138:587-92.
13 466
14
15 467 9. Van Leiden HA, Dekker JM, Moll AC, et al. Blood pressure, lipids, and obesity are associated
16 with retinopathy: the hoorn study. *Diabetes care* 2002;25:1320-5.
17 468
18
19 469 10. Rohan TE, Frost CD, Wald NJ. Prevention of blindness by screening for diabetic retinopathy: a
20 quantitative assessment. *BMJ* 1989;299:1198-201.
21 470
22
23 471 11. Namperumalsamy P, Nirmalan PK, Ramasamy K. Developing a screening program to detect
24 sight-threatening diabetic retinopathy in South India. *Diabetes Care* 2003;26:1831-5.
25 472
26
27 473 12. Kashim RM, Newton P, Ojo O. Diabetic retinopathy screening: A systematic review on patients'
28 non-attendance. *Int J Environ Res Public Health* 2018;15:157.
29 474
30
31 475 13. Massaro L, Curry WJ, Quillen D. Screening for diabetic retinopathy: perceived barriers and
32 patient acceptability of digital scans. *J Clin Outcomes Manag* 2010;17.
33 476
34
35 477 14. Lu Y, Serpas L, Genter P, et al. Divergent Perceptions of Barriers to Diabetic Retinopathy
36 Screening Among Patients and Care Providers, Los Angeles, California, 2014-2015. *Preven*
37 *Chronic Dis* 2016;13:E140.
38 479
39
40 480 15. Bauer UE, Briss PA, Goodman RA, et al. Prevention of chronic disease in the 21st century:
41 elimination of the leading preventable causes of premature death and disability in the USA.
42 *Lancet Glob Health* 2014;384:45-52.
43 481
44
45 482 16. Pardhan S, Gilchrist J, Mahomed I. Impact of age and duration on sight-threatening retinopathy
46 in South Asians and Caucasians attending a diabetic clinic. *Eye* 2004;18:233.
47 483
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 485 17. Van Eijk KN, Blom JW, Gussekloo J, et al. Diabetic retinopathy screening in patients with
4
5 486 diabetes mellitus in primary care: Incentives and barriers to screening attendance. *Diabetes Res*
6
7 487 *Clin Pract* 2012;96:10-6.
8
9 488 18. Shukla SN, Sharma JK. Potential of mHealth to transform healthcare in India. *J Health Manag*
10
11 489 2016;18:447-59.
12
13 490 19. Venkatesan S. Barriers and facilitators in home based problem. *Indian Journal of Health and*
14
15 491 *Wellbeing* 2017;8:345-51.
16
17 492 20. Graham-Rowe E, Lorencatto F, Lawrenson JG, et al. Barriers and enablers to diabetic retinopathy
18
19 493 screening attendance: Protocol for a systematic review. *Syst Rev* 2016;5:134.
20
21 494 21. Lindenmeyer A, Sturt JA, Hipwell A, et al. Influence of primary care practices on patients'
22
23 495 uptake of diabetic retinopathy screening: a qualitative case study. *Br J Gen Pract* 2014;64:e484-
24
25 496 92.
26
27 497 22. Pooley CG, Gerrard C, Hollis S, et al. 'Oh it's a wonderful practice... you can talk to them': a
28
29 498 qualitative study of patients' and health professionals' views on the management of type 2
30
31 499 diabetes. *Health Soc Care Community* 2001;9:318-26.
32
33 500 23. Ritchie J, Lewis J, Nicholls CM, et al. Qualitative research practice: A guide for social science
34
35 501 students and researchers:: sage 2013.
36
37 502 24. World Health Organization. Prevention of blindness from diabetes mellitus: report of a WHO
38
39 503 consultation in Geneva, Switzerland:: World Health Organization 2006.
40
41 504 25. Gross JG, Glassman AR, Liu D, et al. Five-year outcomes of panretinal photocoagulation vs
42
43 505 intravitreal ranibizumab for proliferative diabetic retinopathy: a randomized clinical trial. *JAMA*
44
45 506 *Ophthalmol* 2018;136:1138-48.
46
47 507 26. Obeid A, Gao X, Ali FS, et al. Loss to follow-up in patients with proliferative diabetic
48
49 508 retinopathy after panretinal photocoagulation or intravitreal anti-VEGF injections. *Ophthalmol*
50
51 509 2018;125:1386-92.
52
53
54
55
56
57
58
59
60

- 1
2
3 510 27. Schäfer I, Pawels M, Küver C, et al. Strategies for improving participation in diabetes education.
4
5 511 A qualitative study. *PLoS One* 2014;9:e95035.
6
7 512 28. Vashist P, Singh S, Gupta N, et al. Role of early screening for diabetic retinopathy in patients
8
9 513 with diabetes mellitus: an overview. *Indian J Community Med* 2011;36:247.
10
11 514 29. Pardhan S, Nakafero G, Raman R, et al. Barriers to diabetes awareness and self-help are
12
13 515 influenced by people's demographics: perspectives of South Asians with type 2 diabetes. *Ethn*
14
15 516 *Health* 2018:1-9.
16
17
18 517 30. Liu Y, Zupan NJ, Shiyanbola OO, et al. Factors influencing patient adherence with diabetic eye
19
20 518 screening in rural communities: A qualitative study. *PloS one* 2018;13:e0206742.
21
22 519 31. Nagelkerk J, Reick K, Meengs L. Perceived barriers and effective strategies to diabetes
23
24 520 self-management. *J Adv Nurs* 2006;54:151-8.
25
26 521 32. Mtuya C, Cleland CR, Philippin H, et al. Reasons for poor follow-up of diabetic retinopathy
27
28 522 patients after screening in Tanzania: a cross-sectional study. *BMC Ophthalmol* 2016;16:115.
29
30 523 33. Rachapelle S, Legood R, Alavi Y, et al. The cost-utility of telemedicine to screen for diabetic
31
32 524 retinopathy in India. *Ophthalmol* 2013;120:566-73.
33
34 525 34. Li D, Inouye J, Davis J, et al. Associations between psychosocial and physiological factors and
35
36 526 diabetes health indicators in Asian and Pacific Islander adults with type 2 diabetes. *Res Theory*
37
38 527 *Nurs Pract* 2013;2013.
39
40 528 35. .Pasagian-Macaulay A, Basch CE, Zybert P, et al. Ophthalmic knowledge and beliefs among
41
42 529 women with diabetes. *Diabetes Educ* 1997;23:433-7.
43
44 530 36. Lewis K, Patel D, Yorston D, et al. A qualitative study in the United Kingdom of factors
45
46 531 influencing attendance by patients with diabetes at ophthalmic outpatient clinics. *Ophthalmic*
47
48 532 *Epidemiol* 2007;14:375-80.
49
50 533 37. Hartnett ME, Key IJ, Loyacano NM, et al. Perceived barriers to diabetic eye care: qualitative
51
52 534 study of patients and physicians. *Arch Ophthalmol* 2005;123:387-91.
53
54
55
56
57
58
59

- 1
2
3 535 38. Trento M, Bajardi M, Borgo E, et al. Perceptions of diabetic retinopathy and screening
4
5 536 procedures among diabetic people. *Diabet Med* 2002;19:810-3.
6
7 537 39. Trento M, Passera P, Tomalino M, et al. Group visits improve metabolic control in type 2
8
9 538 diabetes: a 2-year follow-up. *Diabetes care* 2001;24:995-1000.
10
11 539 40. Petrak F, Herpertz S, Albus C, et al. Psychosocial factors and diabetes mellitus: evidence-based
12
13 540 treatment guidelines. *Curr Diabetes Rev* 2005;1:255-70.
14
15 541 41. Kalra S, Sridhar GR, Balhara YP, et al. National recommendations: Psychosocial management of
16
17 542 diabetes in India. *Indian J Endocrinol Metab* 2013;17:376.
18
19 543 42. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of patients'
20
21 544 emotional reactions and views about information provision. *Patient Educ Couns* 2004;53:269-75.
22
23 545 43. Maddigan SL, Majumdar SR, Johnson JA. Understanding the complex associations between
24
25 546 patient-provider relationships, self-care behaviours, and health-related quality of life in type 2
26
27 547 diabetes: A structural equation modeling approach. *Qual Life Res* 2005;14:1489-500.
28
29 548 44. Peel E, Douglas M, Lawton J. Self monitoring of blood glucose in type 2 diabetes: longitudinal
30
31 549 qualitative study of patients' perspectives. *BMJ* 2007;335:493.
32
33
34
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Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An exploratory study from Southern India

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3 **1 Original article**
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5 **2 Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An**
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7 **3 exploratory study from Southern India**
8

9 **4 *Short title: Barriers to Diabetic Retinopathy screening***

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ABSTRACT

Objective: Diabetic retinopathy is a leading cause of visual impairment and has major public health implications globally and especially in countries such as India where the prevalence of diabetes is high.

With timely screening and intervention, the disease progression to blindness can be prevented but several barriers exist to the provision of care. As compliance to diabetic retinopathy screening in people with diabetes is very poor in India, this study was conducted to explore understanding of and barriers to diabetic retinopathy screening from the perspectives of patients and health care providers.

Methods: Using qualitative methods, 15 consenting adult patients were selected purposively from those attending a large tertiary care private eye hospital in the city of Chennai in southern India to participate in semi-structured interviews. Eight semi-structured interviews were carried out with health care providers working in large private hospitals. All interviews were audio-taped, transcribed verbatim and analyzed using the framework analytical approach.

Results: Four themes that best explained the data were recognizing and living with diabetes, care seeking practices, awareness about diabetic retinopathy and barriers to diabetic retinopathy screening. Findings showed that patients were aware about diabetes but understanding of diabetic retinopathy and its complications was poor. Absence of symptoms, difficulties in doctor patient interactions and tedious nature of follow-up care were some major deterrents to care seeking reported by patients. Difficulties communicating information about diabetic retinopathy to less literate patients, heavy work pressure and silent progression of the disease were major barriers to patients coming for follow-up care as reported by health care providers.

Conclusions: Enhancing patient understanding through friendly doctor-patient interactions will promote trust in the doctor. The use of an integrated treatment approach such as education by counsellors and setting up of patient support groups may prove more effective in the long run.

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3 51 **Strength and limitations of this study:**
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- 5 52 • This was a qualitative study that explored barriers to diabetic retinopathy (DR) screening from the
6 perspectives of patients and health care providers (HCP) which enabled a more comprehensive
7 53 understanding of the phenomenon.
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11 55 • Insights obtained from patients and providers have given good cues for development of
12 intervention strategies.
13 56
14 57 • The study could have benefited from interviews with family members, who play an important
15 role both in decision-making for care seeking and in providing support to patients.
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18 59 • Inclusion of HCPs from smaller eye clinics would have provided additional perspectives further
19 enhancing understanding of the phenomena.
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76 INTRODUCTION

77 Diabetic retinopathy (DR), a microvascular complication in the eye due to uncontrolled diabetes has high
78 prevalence in Africa (33.8%) and in the Western Pacific (36.2%) [1]. In another study, the highest age
79 standardized prevalence was among Caucasians at 45.8% with Asians (combined) at 19.9% [2]. Flaxman
80 et al [3] in their systematic review reported that blindness due to diabetic retinopathy has been on the rise
81 from 1990 till 2015. Shukla et al assessed the perceptions of care and challenges faced in availing care
82 among people with diabetes in India and reported that 45% of participants already had vision loss when
83 they first presented to an eye facility and before their DR was even detected [4]. Lingam et al in their
84 study on the uptake of diabetic retinopathy screening in a pyramidal model of eye health care found that
85 2% at tertiary level, 40% at secondary and 50% at primary level had undergone previous dilated eye
86 examination [5].

87
88 In India, the disease has major public health implications due to two main reasons, i) an estimated 57
89 million people will have diabetes by 2025 (195% increase from 1995) and ii) the risk of sight threatening
90 retinopathy is higher in adults with diabetes [6]. Previous population-based studies from India have
91 reported prevalence of diabetic retinopathy to be 9-10% in rural areas and 13-18% in urban areas [7].
92 Moreover sight threatening DR (STDR) affects 5%–7% of people with diabetes, i.e., 3–4.5 million, which
93 is slated to increase as the numbers of people with diabetes increases [8]. In terms of risk factors, duration
94 of diabetes, hypertension and poor diabetic control are seen as the major risk factors for developing DR
95 [2]. Mapa et al in their systematic review reported the non mydriatic two-field strategy to be a pragmatic
96 approach for starting DR screening in low income settings [9]. Sight threatening complications like
97 Diabetic Macular Edema (DME) and Proliferative diabetic retinopathy (PDR) can be effectively managed
98 through laser photo coagulation and intra-vitreous anti vascular endothelial growth factor (VEGF) injection
99 [10]. Given that 50-70 % of DR related visual impairments can be prevented by timely screening and
100 intervention [11], the importance of early identification and regular follow-up cannot be more

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3 101 emphasized. Thus, while DR is one of the leading causes of blindness, vision loss is largely preventable
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5 102 through regular screening and follow-up which, continues to be quite inadequate as suggested by previous
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7 103 research [12-15].
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11 105 In this context it is important to provide some background on the health care system in India. The
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13 106 management of diabetic eye disease in India is influenced by a lack of screening programmes, poor public
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15 107 awareness on diabetic eye disease and poor understanding of the need for regular retinal screening [16].
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17 108 Most retinal services in India that manage these patients are not public funded. There is also a wide
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19 109 variation in provision of health care ranging from highly specialized hospitals to basic facilities without
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21 110 trained ophthalmologists [4].
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26 112 Several barriers identified to screening for DR ranged from financial burden, lack of awareness about the
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28 113 importance of screening, transportation, language barriers, cultural myths, to denial, fear, and depression
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30 114 [17]. Mapa et al, found that inter-related user, family and institutional factors influenced the uptake of DR
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32 115 screening and follow-up services in the western province of Sri Lanka [18]. Factors such as older age [19]
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34 116 and physical disability have also been found to act as deterrents to screening. A Study from India
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36 117 highlighted several issues, which included travelling long distances to access the health facility and cost
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38 118 of travel [4]. Patients believe that their eyes were healthy, not having anybody to accompany them to
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40 119 health care facilities and financial costs of seeking care were among other barriers reported [20].
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42 120 However, most of these findings are from quantitative studies that by their very design are limited in
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44 121 terms of their ability to probe, explore and gain deeper insights. Furthermore, these barriers may be
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46 122 influenced by regional variations. There is thus a paucity of qualitative studies on this topic in India which
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48 123 provided the impetus for this study involving semi-structured interviews (SSIs) with both patients and
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50 124 health care providers (HCPs). We included HCPs for two reasons i) being care providers their perceptions
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52 125 and experiences would enable a more holistic understanding of this issue ii) given that HCPs are deeply
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3 126 respected in our culture they could exert a significant role in encouraging patients to get their eyes
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5 127 screened [19,21] thereby playing an important role in future interventions. From patients we explored
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7 128 their experiences of living with diabetes, how they coped with their condition in terms of both care
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9 129 seeking behaviors as well as life style modifications, their awareness about DR and their perceptions on
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11 130 barriers towards DR screening. From HCPs, we explored their perceptions on patient understanding of
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13 131 diabetes and DR, the nature of information about diabetes and DR provided to patients and what they
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15 132 believed were barriers for accessing health care.
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19 20 134 **METHODS**

21
22 135 The study was carried out in a tertiary eye care center run by a non-government organization (NGO)
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24 136 located in Chennai, capital of the state of Tamil Nadu in South India. The study was approved by the
25
26 137 institutional review board of Vision Research Foundation and adhered to the tenets of the declaration of
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28 138 Helsinki.

29 30 139 **Sampling**

31
32 140 Adult patients with type 2 diabetes mellitus (DM) aged 50 years and above who had been living with
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34 141 diabetes for a period of five years or more were purposively selected to participate in SSIs. Patients
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36 142 already diagnosed with DR were not included as the emphasis was on awareness about DR, need for eye
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38 143 screening and barriers to screening. Using maximum variation sampling we recruited 8 men and 7 women
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40 144 of different age, education and occupation which proved adequate to achieve data saturation [22]. The
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42 145 hospital maintains a computerized schedule of patient appointments with various eye specialists which
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44 146 includes the names of the patients their gender and age. As our focus was on barriers to DR care we
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46 147 reviewed the appointment schedules of the retinal specialists. On the specified dates of the appointments
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48 148 our research team (KG and VS- both trained in qualitative research methods by SK), met with patients
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50 149 aged 50 years and above, following their consult and ascertained eligibility. Those eligible were
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52 150 consented to participate in an SSI. The eight HCPs recruited had five or more years of experience
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151 working with persons with diabetes. The five ophthalmologists included three from the NGO eye hospital
152 and two from private eye hospitals. The two diabetologists and one dietician were recruited from a
153 diabetes specialty centre. All data was anonymized to maintain confidentiality.

154 Separate open ended interview guides (Supplementary file 1) for patients and HCPs informed by literature
155 and our prior interactions with patients were developed. Broadly, they elicited information on patient's
156 understanding of diabetes, perceptions on their experiences and risks of living with it, lifestyle
157 modifications made, care seeking behaviours, understanding of DR, barriers to DR screening and its
158 importance and suggestions on what would be helpful. The participants were escorted to a quiet area in
159 the hospital where the interviews were carried out. For most patients the interviews were done in Tamil,
160 the language of communication in our state while with most HCPs it was in English. All interviews were
161 audio recorded after obtaining consent from the participants. The duration of interviews varied from about
162 35-40 minutes to about 40-50 minutes. All interviews were transcribed verbatim; those in Tamil were
163 translated into English for the purpose of analysis. Every transcript was re-checked with the audio
164 recording by the team to ensure fidelity to the original audio taped interviews before analysis.

165

166 **Patients and public involvement**

167 Patients and public were not involved in the design or conduct of our study.

168

169 **ANALYSIS**

170 Analysis followed the framework analytical approach, [23] which is very suitable for data gathered
171 through SSIs [24] and began by gaining familiarity with each of the transcripts through repeated readings.
172 We carried out a systematic method of organizing our data into spreadsheets, keeping in mind our
173 research questions and listed out several categories like, 'understanding of diabetes', 'care-seeking
174 practices', 'awareness about DR', 'barriers to DR care' etc. We then began extracting relevant portions of
175 text from each interview related to these categories and went through a process of indexing or sifting

176 through the data; sorting and selecting quotes and placing them under the appropriate categories.
 177 Developing and refining our categories in this manner helped us to compare and contrast them and
 178 determine the ones that could be meaningfully combined and those that were stand alone thereby setting
 179 the stage for theme development. In developing themes we looked for patterns and made decisions on
 180 what themes best explained our data and provided important insights.

181

182 FINDINGS

183 Patient and HCP Characteristics

184 All the 15 patients were married and their average age was 63.2 ± 9.2 years. All of them were living with
 185 diabetes for several years with an average duration of 15.6 ± 10.8 years and had not received any
 186 treatment for diabetic eye disease. The eight HCPs, who participated in the interviews, comprised of 5
 187 women and 3 men. Their average age was 44.7 ± 8.1 years and average duration of years of experience
 188 was 17 ± 10.5 years. (Table 1)

189

190 **Table 1: Patient and HCP characteristics**

Characteristics of Patients	n(%)	Characteristics of HCPs	n(%)
Gender		Gender	
Male	8(53.3)	Male	3(37.5)
Female	7(46.7)	Female	5(62.5)
Age (years)		Age (years)	
50-60	6(40)	30-40	2(25)
61-70	4(26.7)	41-50	5(62.5)
71-80	5(33.3)	51-60	-
Marital status		61-70	1(12.5)
Married	15(100)	Marital status	
Single	-	Married	7(87.5)
Education level		Single	1(12.5)
Non-literate	3(20)	Professional status	
5 yrs of school th	2(13.3)	Ophthalmologists	5(62.5)
6 to 12yrs of school	5(33.3)	Diabetologist	2(25)
College and above	5(33.3)	Dietician	1(12.5)

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192

193 **Themes of Analysis**

194 The four themes that best explained the data and addressed our research questions were i) recognizing
195 and living with diabetes ii) care seeking practices iii) awareness about DR iv) barriers to DR screening.
196 Both patient and HCP perspectives are presented.

197

198 **Patient Perspectives**

199 **Recognizing and living with diabetes**

200 Recognition of the fact that they might have diabetes came rather slowly to most patients. For the most
201 part, the diagnosis of diabetes came as a surprise and a great shock. It often started with minor symptoms
202 like a tingling feeling in the extremities, frequent urination, itching sensation while passing urine, feeling
203 unusually thirsty or hungry. These were initially ignored until other symptoms started showing up like
204 loss of weight, feeling faint and dizzy or a wound that was not healing. Most patients did not even suspect
205 that they had diabetes and it was only after they were asked to undergo blood sugar tests on the
206 instruction of the doctor, did they come to learn of their diagnosis. Others spoke of not experiencing any
207 symptoms at all and learnt of their condition when they underwent a routine health check-up. A female
208 participant came to know of her diabetes when she underwent surgery for removal of a tumour. Myths
209 surrounding the disease also emerged with one participant stating that he believed he would not get the
210 disease as he thought it only affected the first-born son in the family. The realization that this was a
211 lifelong condition that could seriously spiral out of control if not carefully managed had begun to dawn on
212 them. A few participants, apart from highlighting their own concerns and worries, were also distressed by
213 the stress and burden their illness would impose on their family members. These were all typically, their
214 first reactions to the diagnosis. But with time, regular medication and care provided at their health
215 facilities their understanding of the disease improved as they came to terms with their disease. Some even
216 took on a more proactive role by encouraging others who had the disease to be compliant while others
217 appeared more fatalistic in accepting their situation. Some were more familiar with the disease as their

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3 218 parents, siblings or close relatives were living with it and consequently were emotionally better prepared
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5 219 when told of their diagnosis.
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9 221 In terms of their understanding of diabetes, most participants were aware that poor control of their blood
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11 222 sugar level could result in a host of health problems and complications. Signs and symptoms ranging from
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13 223 becoming tired easily, losing weight, finding it difficult to work, feeling faint and dizzy to more serious
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15 224 conditions such as kidneys and liver being affected, severe pain in the feet, suffering a stroke or a heart
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17 225 attack were reported. Important to note, that those who had a parent or sibling living with diabetes
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19 226 reported being attuned to developing symptoms at some point and accepted the inevitability of acquiring
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21 227 the disease on account of its genetic nature. They were also more aware of the consequences of improper
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23 228 management and spoke of the risks to their health in terms of developing a stroke. The fact that diabetes
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25 229 could impair vision leading to possible loss of sight was also reported by many participants.
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30 230
31 231 The main source of information about diabetes came from their health care providers including doctors
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33 232 and nurses. A few others learnt more about the disease from books, articles and literature on the internet
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35 233 as well as from health programmes on television. They felt that doctors were not too forthcoming and
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37 234 usually did not spend time explaining in detail. Friends, neighbours and family members also served as
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39 235 another information source, more so, if they were already diagnosed with diabetes.
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43 237 **Care Seeking Practices**
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45 238 Although many patients never thought to seek care when symptoms initially started, once diagnosed they
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47 239 became more alert to the need to seek regular health care. Based on the advice given by their doctors, they
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49 240 started attending clinics to get their blood sugar checked. One female participant spoke of feeling
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51 241 depressed each time she underwent a blood sugar test as the test brought home to her the fact that she had
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53 242 diabetes and had to somehow “*survive with the disease*”. While participants appreciated the necessity of
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243 these periodic visits to test their blood sugars, they nevertheless found them to be tedious. Therefore,
244 recommendations by doctors to undergo further tests like an eye test for example was seen as an added
245 burden both in time and cost and was often resisted. A few participants emphasized the importance of
246 consistently seeing the same doctor so as to avoid unnecessary confusion from varying recommendations.
247 In this context, the manner in which doctors communicated to patients influenced trust levels and how
248 well patients would comply with their advice. Participants believed that doctors needed to speak gently
249 and not frighten them with harsh consequences which would only result in them going to another doctor.
250 While they agreed that all necessary information needed to be communicated, this needed to be done in a
251 friendly and non-threatening manner so as to instill confidence.

252
253 Use of alternate medicines like Ayurveda was not the preferred choice for most participants although a
254 few reported taking it along with their regular allopathic medication as they felt that Ayurveda by itself
255 would not be effective in treating them. They all spoke of the importance of eating a balanced diet, of
256 exercising regularly, taking their medication as advised and of regular follow-up with a physician. To this
257 end, most participants had modified their lifestyles, although to varying degrees. They reported cutting
258 down on rice-based food items and sweets and exercising to the extent possible. While some indicated
259 that they had no difficulty in changing their diet, others found it difficult. Similarly, regular exercise too
260 posed a challenge with many indicating lack of time, poor motivation and complaints of body aches.

261
262 **Awareness about DR**
263 The findings revealed a mixed picture regarding awareness about DR. For most, it was not a familiar term
264 while a few were aware of it and of the need to undergo regular retinal screening. The understanding that
265 diabetes could affect their eyes and that their vision could be impaired had been gleaned through
266 interactions with doctors, other health staff they came into contact with and through posters on diabetes
267 on display in the hospitals they had been to. Issues, about the potential threat to their eyes on account of

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3 268 diabetes were often reiterated during these visits. Participants were more familiar with other eye problems
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5 269 like glaucoma and cataract but for the most part remained unaware of the details and symptom
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7 270 manifestations of DR, and of possible preventive measures that needed to be taken to protect their eyes
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9 271 from DR. Only a couple of participants indicated that they had not been informed about possible risks to
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11 272 their eyes on account of diabetes or of the precautions they needed to take to protect their eyes. The few
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13 273 who had heard about DR, described it as a condition wherein the “*nerve would get affected*”. They spoke
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15 274 of the importance of eye care, of regular eye checkup and the importance of keeping their blood sugar
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17 275 level under control as ways and means of protecting their eyes. Such participants were generally better
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19 276 educated, tended to discuss their health issues with their doctors and were more compliant.
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24 278 **Barriers to DR**

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26 279 Among those unfamiliar or less aware about DR, several issues emerged which acted as barriers to
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28 280 seeking eye care. A typical one related to consulting a doctor only if there was pain or some discomfort in
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30 281 the eye. In the absence of any symptoms it was deemed unnecessary to seek such eye care. Participants
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32 282 also feared that undergoing eye screenings and tests could result in more medicines being prescribed.
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34 283 Apart from concerns about cost and managing the dosage, they believed that these medicines meant a
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36 284 more chemicals being ingested which was perceived as harmful as it contributed to excessive “heat”,
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38 285 Others complained about doctors being too busy and of not having the time to talk to patients about all the
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40 286 do’s and don’ts regarding diabetic eye care. If the doctor appeared to be too curt or busy patients felt
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42 287 dissatisfied. But, patients who indicated that they were doing well were generally satisfied with the care
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44 288 received and also tended to be more adherent to the doctor’s advice. Other issues involved the logistics of
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46 289 travelling to the health facility, costs associated with undergoing the tests, not having the time to go for a
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48 290 check-up on account of work and family commitments. Some women participants spoke of not having
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50 291 anyone to accompany them to the health facility and almost all described the long hours they had to spend
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52 292 in the hospital to undergo these tests as major deterrents. Lastly, a sense of complacency and a lack of
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293 motivation were also cited as reasons for participants failing to seek regular care. In this context one
 294 suggestion was for the hospital to send regular reminders to patients in the form of phone calls or phone
 295 messages informing patients that they were due for a check-up and encouraging them to visit the hospital.
 296 The above mentioned patients perspectives are summarized in table 2.

297

298 **Table 2: Selected Quotes: Patient's perspectives**

Recognizing and living with diabetes	<i>"I went abroad on work, so in that company they conducted free checkup and tested for diabetes. That time only I learnt that I have diabetes."</i> (DM 10, 59 years, M)
	<i>"I was fat previously but gradually my weight started reducing. I felt itching sensation while passing urine. During that time I had been advised to undergo surgery to remove a tumour in my uterus. So, I assumed that my weight loss and itching was due to the tumour. This was 7 years back, when I consulted the doctor, he said that I had diabetes."</i> (DM 01, 50 years, F)
	<i>"I thought I will not get diabetes, as I am the third son in my family. I was assuming that only the first son will get so I ignored it but finally I also got diabetes."</i> (DM 09, 58 years, M)
	<i>"I was afraid at that time. It is not only difficult for me but also difficult for others in the family. So initially I was scared."</i> (DM 06, 65 years, F)
	<i>"I felt too upset and cried when I came to learn that I have got diabetes.... I was upset that I had got it rather early in my life but now I am in a situation where I can even counsel people."</i> (DM 03, 48 years, F)
	<i>"I took it lightly, I didn't consider it as a disease only. Because my father, grandfather, my mother and father in law, my wife everyone is diabetic, that's why I didn't worry too much."</i> (DM 09, 58 years, M)
	<i>"The reason for keeping my sugar under control these 20 years is due to self-control. I do not touch sweets, have to cheat my tongue. I have completely avoided taking tea, coffee while attending functions also. I have changed my life style. Along with that I do exercise, yoga and walking thereby keeping sugar under control."</i> (DM 10, 59 years, M)
Care Seeking Practices	<i>"I consult with one doctor only. I know him from my childhood days. I have not gone separately to a sugar specialist. I am satisfied with this doctor and there is no problem, so am continuing with him. Why do I need to see 10 doctors, where each on one will take a different decision."</i> (DM 04, 67 years, M)
	<i>"I have consulted with 15 doctors but still did not recover. I even tried "naatu vaithiyam" (traditional medicines) for 1.5 months, that to did not help. Every night I will be crying because of this pain and pricking sensation. On seeing this, my so has taken me to so many hospitals, nearly 15 doctors he has taken met to see in just one month. Wherever he advised I have gone there."</i> (DM 02, 55 years, F)
	<i>"Doctors must not threaten the patient. They often tell the patient that they will lose their eyes or kidney or have heart problem, or they will not be able to</i>

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	<p>walk". Whatever information is necessary must be discussed with patient but they must not threaten the patient. If they threaten then the patient is no more going to visit that doctor. My doctors are threatening me now that's why I don't want to consult them. They should say it gently so the patient must not get scared. If the doctor's smiles and talk in a friendly manner, we won't be scared." (DM 06, 65 years, F)</p> <p>"Doctor always advises me to reduce the sugar level and the level must not be high at all. He used to ask whether am I am walking or not? If I say no then he will insist that I walk Regarding food intake also they have told me. Dietician has given suggestions to change my food intake pattern." (DM 03, 48 years, F)</p>
Awareness about DR	<p>"Diabetic Retinopathy means eye will get affected and vision will be lost. Nerve surrounding the eye will get weaker; this is called as "Fundus Retinopathy". Because of diabetes cataract problem will come. Known diabetic patients must take care of eye from getting more affected due to cataract." (DM 13,76 years, M)</p> <p>"I heard that directly the vision will get affected, but I don't know which part of eye gets affected. Sometimes it can lead to glaucoma, but am not sure." (DM 10, 59 years, M)</p> <p>"If we have sugar, glaucoma will come, it will affect eyes, blurred or black spots can happen. Mainly I have heard about this I do not know of any other problem." (DM 05, 66 years, M)</p> <p>"No, I have not heard from anywhere the term 'diabetic retinopathy'. I have not attended camps for eye care. They (referring to the medical team) have come for camp, but I have not attended." (DM 04, 67 years, M)</p> <p>"Diabetic retinopathy means nerve will get affected....If your vision is affected from birth then it is ok, but if you lose your vision in the middle of your life then getting back what is lost is very difficult. So, you have to control sugar and have yearly check-up. This is what is advised to us by the doctors." (DM 03, 48 years, F)</p>
Barriers to DR	<p>"If I have pain I think to go and meet the doctor, if not why do I need to go. If we are normal why do we need to consult the doctor they will write and give more medicines which will only create more heat in my body because of that I do not go." (DM 06, 65 years, F)</p> <p>"Eye is fine only so they won't come back. Only when they attain severe stage they will consult, till then they won't know. Financial problem may be the reason. If a person is retired there won't be earning or dependent on a small pension or on the son who may not give money. So 90% is due to financial constraint." (DM 08, 72 years, M)</p> <p>"Generally, doctors don't have that much time to explain as they are busy. If we ask they tell they are busy which prevents patients from asking further questions." (DM 05, 66 years, M)</p> <p>"It takes a whole day to complete and come back home since it is very far... by the time I return home it will be evening. There is no one to take care of my daughter." (DM 03, 48 years, F)</p> <p>"If it is nearby then it will be good. This much distance is far for me I don't come alone, my neighbour only took me here. While going back home my younger son will come to pick up. Since I am diabetic, my family members are scared to send me alone to hospital." (DM 07, 50 years, F)</p>

	<i>“Work is there at home so I won’t be able to go. There is also no one to accompany me, like while going for blood test or for any other tests.” (DM 06, 65 years, F)</i>
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299 Note: DM, diabetes mellitus; M, Male; F, Female

300

301 **HCPs Perspectives**

302 **Perceptions on patient understanding of diabetes**

303 The HCPs believed that people were largely aware about diabetes, referred to it as “*sugar disease*” and
304 understood that it required them to control their diet, restrict sweet intake and exercise regularly. Greater
305 visibility of the disease was attributed to its high prevalence and widespread media coverage which had
306 contributed to considerable awareness among people. Patients who were educated were more aware and
307 had access to a wide range of information sources, like the internet, medical literature and health-related
308 broadcasts on radio and television. These patients also sought further clarifications from their doctors and
309 even questioned them when in doubt. On the other end of the spectrum were the poorer, often less
310 educated patients who were not so knowledgeable about the disease and who also tended to be less
311 compliant. The HCPs also spoke about issues concerning monitoring and controlling blood sugar levels
312 which according to them was often not adequately maintained or even understood by patients. Thus,
313 patients were generally aware about the disease, but the extent and depth of knowledge of what exactly
314 they were up against varied considerably. In this context, the importance of proper counselling that would
315 educate patients about diabetes and motivate them to attend regular reviews to the hospital was stressed.
316 A few HCPs suggested the importance of exposing patients to all the possible diabetic- related
317 complications by showing them pictures or getting them to meet other patients. This would impress upon
318 patients the seriousness of the problem.

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320 **Information communicated to patients**

321 In terms of information communicated to patients about the disease, all HCPs uniformly said that in
322 addition to telling them about the disease, its symptom manifestations and its management strategies, they

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3 323 reiterated the need to undergo periodic blood tests to monitor their blood sugar level and ensure that they
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5 324 kept it under control. The importance of seeking care from a diabetologist was also stressed as these
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7 325 doctors had the expertise to guide and appropriately advise patients. Further, they advised that as the
8
9 326 disease could affect any of their internal organs and was basically a “*silent killer*”, it was imperative that
10
11 327 patients underwent regular check-up. Usually the information was conveyed to patients- often with the
12
13 328 use of printed pamphlets every time the patient visited the health facility. One HCP, an ophthalmologist,
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15 329 declared that he typically advised his diabetic patients to undergo an HbA1c in addition to fasting and
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17 330 post prandial blood tests. He also advised them to undergo kidney and liver function tests and check their
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19 331 cholesterol and blood pressure as their diabetes could get exacerbated by other prevailing co-morbidities.
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22 332 The HCPs thus spoke of following a fairly structured protocol which also entailed constantly emphasizing
23
24 333 the importance of lifestyle modifications as being critical to maintaining health. Use of posters and
25
26 334 slogans educating people about the disease and emphasizing the importance of regular care were also
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28 335 highlighted. Another HCP, a dietitian spoke of gearing the information to the patient’s level of
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30 336 understanding, breaking it down to simple do’s and don’ts which she felt was easier for the patient to
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32 337 follow. This was feasible for her to do as she had more time with the patient unlike the doctors. Patient’s
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34 338 motivation levels and presence of good family support were also seen as aids to good compliance.
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37 339

39 340 **Understanding of DR and perceived barriers**

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41 341 The general opinion among the HCPs was that awareness about DR was still poor in patients with very
42
43 342 few having heard of it. They accepted that patients knew that diabetes could affect the eyes, were familiar
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45 343 with cataract but for the most, remained unaware of DR. One HCP, an ophthalmologist described two
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47 344 types of diabetic patients i) those who remained unaware that the disease could affect their eyes and
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49 345 blamed their doctors for failing to educate them adequately and ii) those who despite being asked to
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51 346 attend a retinal screening failed to do so as they did not suffer any symptoms. This silent and quiet
52
53 347 progression of DR where patients largely experienced no symptoms resulted in patients not perceiving the

348 need to seek care thereby seriously compromising their vision. In this context one HCP said that many
 349 Indian patients normally come for a check-up when there is an “acute crisis or acute problem” and unless
 350 and until they experienced some difficulties, they usually did not seek care. Cost and lack of time were
 351 other issues particularly for poorer persons and those working on daily wages resulting in delays in
 352 seeking care. Explaining the nuances of the disease to such patients who often tended to have low
 353 literacy was found to be quite a challenge. Another barrier to proper care highlighted by the HCPs was the
 354 availability of a plethora of information on social media sites about diabetes and related health problems.
 355 Most of this information was either inadequate or incorrect and those who tended to follow it did so at
 356 great cost to themselves. Lack of motivation; financial problems; absence of good family/social support in
 357 terms of someone to accompany them to the hospital and slow improvement in vision following initiation
 358 of treatment, acted as deterrents to continued care seeking. Patients also tended to be complacent if their
 359 blood sugar levels were under control, little realizing that the longer the duration of diabetes, greater was
 360 their risk of developing DR. The above mentioned HCP perspectives are mentioned in table 3.

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362 **Table 3: Selected Quotes: HCP’s perspectives**

Perceptions on patient understanding of diabetes	<i>“I must highlight that patients often don’t understand what is meant by adequate control of diabetes. They say, ‘today my blood sugar level is normal’. But the fact that this must be maintained in the long term is often not understood by many patients.” (HCP05 Ophthalmologist, 43 years, M)</i>
	<i>“Patients who are well read, are more careful about their eyes, they come for regular check-up, keep a track of their own condition, ask about their previous test results etc. But there are some patients who are not educated who have extensive disease. When they come, they have no idea what they are coming for. Sometimes even if they are attending for the first time, we know the prognosis is extremely bad. They have never had a check-up or even if it was done nothing much seems to have been explained to them. Even if the doctor is saying the right thing, they are not very compliant. It’s very difficult to explain to them and treat them.” (HCP 04_ Ophthalmologist, 33 years, F)</i>
	<i>“Patients with diabetes for 10-15 years or more have an assumption that if HbA1c is normal then they will not develop diabetic retinopathy. Because they presume that they do not have eye complaints and the sugar level is under control. Few patients understand cataract better than diabetic retinopathy, where they mistook the treatment procedure many times when advised.” (HCP</i>

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	07_Ophthalmologist, 47 years, F)
Information communicated to patients	<i>“My way of telling them is even though nothing is a problem always have a regular annual check, you should check especially if you have strong family history. If they are diabetic then my first question will be when was the last time you had an eye check-up? Each and every patient I try and tell them that they should go to a diabetologist. I have seen that most diabetologists have a routine protocol and they have a person who will counsel patients, they also have a chart which states what when tests were done and other details.” (HCP 01_Ophthalmologist, 48 years, F)</i>
	<i>“We have put up some posters on which is written, “the world is beautiful; don't let diabetic retinopathy prevent you from seeing it, so have your eyes checked today” like that we have some posters put up also. Even the patient waiting area also we have posters. On world diabetes day we run camps and distribute pamphlets which explain about diabetes and retinopathy. There are pamphlets which say “Have your eyes checked early and yearly” like that we have posters, put up. We also conduct slogan contests for our staff and give a small reward, for the best ones.” (HCP 07_Ophthalmologist, 47 years, F)</i>
Understanding of DR and perceived barriers	<i>“DR is mostly asymptomatic, till the end stage and they don't understand the importance...even if we tell them you have retinopathy changes, as they don't experience much of vision problems, they find it hard to accept. It is only when they have bleeding or severe vision drop or if somebody else in the family has already had this problem that they understand the seriousness of their condition... awareness is still low.” (HCP 07_Ophthalmologist,47 years, F).</i>
	<i>“The patient, Indian patient normally reports when there is an acute crises or acute problem. So this type of slow going process they are not bothered. Unless and until they have some co-morbidity like some difficulties then only they come for consultation.” (HCP 05_Ophthalmologist,43 years, M)</i>
	<i>“They have multiple reasons to say (for delaying the follow-up). I just now completed my daughter's marriage, I don't have money, to build a new house, financial problem, daughter delivered a baby, I am out of station that's why I didn't come, and I thought I will come here but my husband was not well or my daughter was not well they have all lame explanations and excuses.” (HCP 03_Diabetologist, 61 years, M)</i>
	<i>“I think the media has a major role to play. They should not send out wrong messages or incorrect information that should be avoided. The right kind of messages only should go through social media.” (HCP 07_Ophthalmologist, 47 years, F)</i>
	<i>“We spend lot of timing in educating the patients, so it's not one time. Every time when they come in some sort of information will be given to the patient. For that we have a different education method one is interactive lecture section are available. During one to one counselling we have, conversation, map section, group therapies, support group, various mode of education are</i>

	<i>there.</i> ” (HCP08_Dietician, 43 Years, F)
	<i>“Sometimes vision is not improving that much and they will say, ‘we are doing all this and coming to you, but vision is not improving’. So, they need to be properly counselled and told that, ‘We may not always be able to improve the vision, but we are here to stabilize the vision, in the process if the vision is improved it is good for you.’”</i> (HCP 01_Ophthalmologist, 48 years, F)

363 Note: HCP, Health Care Provider; DR, diabetic retinopathy; M, Male; F, Female

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365 DISCUSSION

366 This qualitative study has provided important insights into barriers to regular screening for DR from the
 367 perspectives of patient and providers across four themes, i) recognizing and living with diabetes, ii) care
 368 seeking practices, iii) awareness about DR and iv) barriers to DR screening. There were similarities and
 369 differences between reports from patients and HCPs. Patients were largely aware of diabetes, its
 370 symptoms, importance of diet and medication management and of exercise which were also endorsed by
 371 the HCPs. It was also evident that the management of this disease imposed a tremendous burden on both
 372 HCPs and patients alike. For providers, communicating the complexities of the disease in words that
 373 patients could understand and keeping them motivated to ensure good compliance proved challenging.
 374 For patients the burden of constantly having to follow a healthy lifestyle, being systematic in seeking care
 375 combined with a lack of depth in their understanding of the disease contributed to patients feeling
 376 overwhelmed and frustrated, even depressed. In this context tele-screening has been found to be
 377 promising in terms of improving compliance apart from being cost effective [25] for a rural population. A
 378 study by Li D [26] highlighted the importance of addressing depression in people with diabetes and
 379 recommended the need to motivate patients to exercise and follow a healthy lifestyle. The fact that
 380 diabetes can affect the eyes was reported by most although awareness about DR was poor, a fact
 381 confirmed by the HCPs. Poor understanding of DR has also been reported by patients in other studies
 382 wherein they expressed having no knowledge about the possibility of becoming blind on account of
 383 diabetes [27,28]. In another study, [29] despite most participants being aware about the need to undergo

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3 384 eye examinations there was limited understanding about retinopathy and about the rationale behind the
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5 385 recommendation. In our study what perhaps emerged as a major deterrent to undergoing eye screening for
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7 386 DR was the absence of symptoms which created a sense of complacency among patients. Patients
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9 387 questioned the need to undergo eye tests which were usually tedious and required them to spend long
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11 388 hours in the hospital Further they feared having to take more medications that they thought were
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13 389 unnecessary as they experienced no symptoms. Besides it meant ingesting more chemicals contributing to
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15 390 excessive heat in their bodies. This cultural belief in the concept of excessive heat and cold attributed to
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17 391 both modern medicines and foods dates back to the Charaka Samhita, a Sanskrit text on Ayurveda (Indian
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19 392 traditional medicine) and has deep roots in the minds of people[30,31]. The HCPs agreed that the silent
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21 393 progression of DR was a deterrent to early care seeking and spoke of difficulties they faced in getting
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23 394 patients to understand the importance of early and regular eye screening and testing. Strategies that could
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25 395 enhance patient understanding of the disease are therefore needed. In this context, studies carried out by
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27 396 Trento et al [32] showed that patients who participated in-group sessions understood DR better. The
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29 397 recent trial in Kenya showed the effectiveness of peer support groups in increasing uptake of DR
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31 398 screening [33] as they helped to promote learning and provided long term support to group members
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33 399 which acted as an incentives to remain compliant. In our setting educating patients about diabetes is
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35 400 mostly didactic, and happens during the brief consultation sessions with the doctors and subsequently
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37 401 during their interaction with other health care staff. Communication packages like conversation maps [34]
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39 402 for people with diabetes and their families as well as the general population at risk of diabetes have also
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41 403 been found to be useful. Similarly, improving awareness about diabetes and its complications among
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43 404 community health workers such as the Accredited Social Health Activists (ASHA) in India, which has
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45 405 worked well for other health issues like maternal and child health and infectious diseases like HIV [35,
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47 406 36] may be a way forward. Future research could test the application of such strategies.
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3 408 An important point that emerged was the nature of the doctor-patient interactions. Many patients were
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5 409 critical of doctors who they felt did not explain adequately or were always in a rush. Some spoke of the
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7 410 manner in which doctors communicated to them leaving them feeling threatened and frightened, and
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9 411 therefore more likely to switch to another doctor. They felt confused when meeting different doctors on
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11 412 account of their conflicting opinions. Patients looked to their HCPs for support and encouragement that
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13 413 was often not forthcoming on account of their busy schedules. The HCP's felt that despite repeatedly
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15 414 talking to patients about the disease and its complications many patients did not appreciate the importance
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17 415 of regularly monitoring and maintaining their blood sugar levels and of coming for eye screening. They
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19 416 expressed difficulties communicating to less literate persons who were often shown to be less compliant.
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21 417 The need of patients for HCPs to be more approachable has been expressed by patients in other studies as
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23 418 well. Peel [37] reported that participants in her study wanted more support and information from their
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25 419 HCPs and felt frustrated as many of their concerns had not been answered. Maddigan [38] described the
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27 420 value of good patient-provider relationships as contributing to good exercise adherence thereby improving
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29 421 quality of life. It is apparent that HCPs play a pivotal role in promoting understanding of the disease given
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31 422 the almost reverential position they occupy in our culture. Patient's expectations from doctors are also
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33 423 very high and if they feel that they are not improving to their satisfaction, an element of distrust and
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35 424 unhappiness tends to creep in which in turn colours their opinion. Our study findings further showed that
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37 425 there is a gap between what is conveyed to patients by the HCPs, and how much of that is actually
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39 426 understood by them. Perhaps the strategy of 'one size fits all' wherein standard information is provided to
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41 427 all patients needs to be addressed in the form of health care awareness and education by counsellors [39,
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43 428 40]. Due consideration to a patient's understanding capacity, self-efficacy, attitudes and health beliefs
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45 429 [41] which exert an influence in their lifestyle management would aid HCPs improve their
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47 430 communication skills and enhance patient understanding. It is important to note that doctors are often
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49 431 hard pressed for time which compromises their ability to spend quality time with patients, a feature that
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51 432 was highlighted by many in our study. There is therefore a need to reduce the burden on doctors, perhaps

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3 433 by building a comprehensive diabetic care team comprising of trained personnel who could work together
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5 434 in care delivery. Educating people about the skill sets and roles of each member of the team will also be
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7 435 essential to promote acceptance. Such an integrated approach where care of diabetes and its complications
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9 436 are available under one roof, literally a 'one-stop shop', indicative of a paradigm shift compared to what
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11 437 is currently practiced, seems the most logical way going forward.
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15 439 This qualitative study by exploring perspectives of both patients and HCPs has provided useful insights
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17 440 which have the potential for guiding future intervention development. The study could have benefited
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19 441 from interviews with family members, who play an important role in decision-making for care seeking
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21 442 and in providing support to patients. Inclusion of HCPs from smaller eye clinics would have provided
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23 443 additional perspectives further enhancing understanding of the phenomena.
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26 444 27 28 445 **CONCLUSION**

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30 446 Living with and managing diabetes is a lifelong process, one that can prove overwhelming to an
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32 447 unprepared patient. It is therefore imperative that steps to ensure good patient compliance be prioritized.
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34 448 Enhancing patient understanding through healthy and friendly doctor-patient interactions and use of an
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36 449 integrated treatment approach including education by counsellors and setting up patient support groups
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38 450 may prove more effective in enhancing compliance for DR care.
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43 452 **Declarations:**
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- **Ethics approval and consent to participant**
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47 454 The study was approved by the Institutional Review Board (Ethics committee), Vision Research
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49 455 Foundation and written consent was obtained from the patients as per the Declaration of Helsinki.

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- **Consent for publication**
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53 457 Not applicable

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3 458 • **Availability of data and materials**

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5 459 The datasets generated during and/or analysed during the current study are not publicly available,
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7 460 as it against the organization hospital policy. But are available from the corresponding author on
8
9 461 reasonable request.

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11 462 • **Competing interests**

12
13 463 The authors declared that they have no competing interests.

14
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28
29 471 • **Authors contributions:**

30
31 472 R.R and S.K; contributed to the conception and design of the study. S.K wrote the main
32
33 473 manuscript text. G.K and S.V assisted with data collection and statistical analyses. R.R, S.K, G.K
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35 474 and S.V drafted the work and S.P, P.R and S.S substantively revised it. All authors reviewed the
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37 475 manuscript.
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44 **REFERENCES:**

- 45
46 478 1. Thomas RL, Halim S, Gurudas S, et al. IDF Diabetes Atlas: A review of studies utilising retinal
47
48 479 photography on the global prevalence of diabetes related retinopathy between 2015 and 2018.
49
50 480 *Diabetes Res Clin Pract* 2019;157:107840.
- 51
52 481 2. Yau JW, Rogers SL, Kawasaki R, et al. Global prevalence and major risk factors of diabetic
53
54 482 retinopathy. *Diabetes care* 2012;35:556-64.

- 3 483 3. Flaxman SR, Bourne RR, Resnikoff S, et al. Global causes of blindness and distance vision
4 484 impairment 1990–2020: a systematic review and meta-analysis. *Lancet Glob Health*
5 485 2017;5:e1221-34.
- 9 486 4. Shukla R, Gudlavalleti MV, Bandyopadhyay S, et al. Perception of care and barriers to treatment
11 487 in individuals with diabetic retinopathy in India: 11-city 9-state study. *Indian J Endocrinol Metab*
13 488 2016;20(Suppl 1):S33-S41. doi:10.4103/2230-8210.179772.
- 16 489 5. Lingam S, Rani PK, Sheeladevi S, et al. Knowledge, attitude and practices on diabetes,
17 490 hypertension and diabetic retinopathy and the factors that motivate screening for diabetes and
19 491 diabetic retinopathy in a pyramidal model of eye health care. *Rural Remote Health* 2018;18:4304.
21 492 <https://doi.org/10.22605/RRH4304>.
- 24 493 6. Narendran V, John RK, Raghuram A, et al. Diabetic retinopathy among self reported diabetics in
25 494 455 southern India: a population based assessment. *Br J Ophthalmol* 2002;86:1014-8.
- 28 495 7. Raman R, Gella L, Srinivasan S, et al. Diabetic retinopathy: An epidemic at home and around the
29 496 world. *Indian J Ophthalmol* 2016;64:69-.
- 32 497 8. Gilbert C, Gordon I, Mukherjee CR, et al. Guidelines for the prevention and management of
34 498 diabetic retinopathy and diabetic eye disease in India: A synopsis. *Indian Journal of*
36 499 *Ophthalmology*. *Indian J Ophthalmol* 2020;68(Suppl 1):S63.
- 39 500 9. Piyasena MM, Murthy GV, Yip JL, et al. Systematic review and meta-analysis of
40 501 diagnostic accuracy of detection of any level of diabetic retinopathy using digital retinal
43 502 imaging. *Sys Rev* 2018;7:182.
- 46 503 10. Ciulla TA, Amador AG, Zinman B. Diabetic retinopathy and diabetic macular edema:
47 504 pathophysiology, screening, and novel therapies. *Diabetes care* 2003;26:2653-64.
- 50 505 11. Coney JM. Addressing unmet needs in diabetic retinopathy. *Am J Manag Care* 2019;25(16
51 506 Suppl):S311-6.

- 1
2
3 507 12. Vengadesan N, Ahmad M, Sindal MD, et al. Delayed follow-up in patients with diabetic
4
5 508 retinopathy in South India: social factors and impact on disease progression. *Indian J Ophthalmol*
6
7 509 2017;65:376-84.
8
9 510 13. Rohan TE, Frost CD, Wald NJ. Prevention of blindness by screening for diabetic retinopathy: a
10
11 511 quantitative assessment. *BMJ* 1989;299:1198-201.
12
13 512 14. Namperumalsamy P, Nirmalan PK, Ramasamy K. Developing a screening program to detect sight-
14
15 513 threatening diabetic retinopathy in South India. *Diabetes Care* 2003;26:1831-5.
16
17 514 15. Kashim RM, Newton P, Ojo O. Diabetic retinopathy screening: A systematic review on patients'
18
19 515 non-attendance. *Int J Environ Res Public Health* 2018;15:157.
20
21
22
23 516 16. Ramasamy K, Raman R, Tandon M. Current state of care for diabetic retinopathy in India.
24
25 517 *Curr Diab Rep* 2013;13:460-8.
26
27
28
29 518 17. Lu Y, Serpas L, Genter P, et al. Divergent Perceptions of Barriers to Diabetic Retinopathy
30
31 519 Screening Among Patients and Care Providers, Los Angeles, California, 2014–2015. *Prev Chronic*
32
33 520 *Dis* 2016;13:160193. DOI: <http://dx.doi.org/10.5888/pcd13.160193>
34
35
36 521 18. Piyasena MM, Murthy GV, Yip JL, et al. A qualitative study on barriers and enablers to
37
38 522 uptake of diabetic retinopathy screening by people with diabetes in the Western Province
39
40 523 of Sri Lanka. *Trop Med Health* 2019;47:34.
41
42
43
44 524 19. Van Eijk KN, Blom JW, Gussekloo J, et al. Diabetic retinopathy screening in patients with
45
46 525 diabetes mellitus in primary care: Incentives and barriers to screening attendance. *Diabetes Res*
47
48 526 *Clin Pract* 2012;96:10-6.
49
50
51 527 20. Peng PH, Laditka SB, Lin HS, et al. Factors associated with retinal screening among patients with
52
53 528 diabetes in Taiwan. *Taiwan J Ophthalmol.* 2019;9:185.
54
55

- 1
2
3 529 21. Graham-Rowe E, Lorencatto F, Lawrenson JG, et al. Barriers to and enablers of diabetic
4
5 530 retinopathy screening attendance: a systematic review of published and grey literature. *Diabet Med*
6
7 531 2018;35:1308-19.
8
9 532 22. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data
10
11 533 saturation and variability. *Field Methods* 2006;18:59-82.
12
13 534 23. Ritchie J, Lewis J, Nicholls CM, et al. Qualitative research practice: A guide for social science
14
15 535 students and researchers:: sage 2013.
16
17 536 24. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative
18
19 537 data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:1-8.
20
21 538 25. Rachapelle S, Legood R, Alavi Y, et al. The cost-utility of telemedicine to screen for diabetic
22
23 539 retinopathy in India. *Ophthalmol* 2013;120:566-73.
24
25 540 26. Li D, Inouye J, Davis J, et al. Associations between psychosocial and physiological factors and
26
27 541 diabetes health indicators in Asian and Pacific Islander adults with type 2 diabetes. *Res Theory*
28
29 542 *Nurs Pract* 2013;2013.
30
31 543 27. Pasagian-Macaulay A, Basch CE, Zybert P, et al. Ophthalmic knowledge and beliefs among
32
33 544 women with diabetes. *Diabetes Educ* 1997;23:433-7.
34
35 545 28. Lewis K, Patel D, Yorston D, et al. A qualitative study in the United Kingdom of factors
36
37 546 influencing attendance by patients with diabetes at ophthalmic outpatient clinics. *Ophthalmic*
38
39 547 *Epidemiol* 2007;14:375-80.
40
41 548 29. Hartnett ME, Key IJ, Loyacano NM, et al. Perceived barriers to diabetic eye care: qualitative study
42
43 549 of patients and physicians. *Arch Ophthalmol* 2005;123:387-91.
44
45 550 30. Selin H. A History of Indian Medical Literature; 2002.
46
47 551 31. Satyavati GV. The Legacy of Caraka; 2003.
48
49 552 32. Trento M, Bajardi M, Borgo E, et al. Perceptions of diabetic retinopathy and screening procedures
50
51 553 among diabetic people. *Diabet Med* 2002;19:810-3.
52
53
54
55
56
57
58
59
60

- 1
2
3 554 33. Mwangi N, Gakuo E, Gichuhi S, et al. Effectiveness of peer support to increase uptake of retinal
4
5 555 examination for diabetic retinopathy: study protocol for the DURE pragmatic cluster randomized
6
7 556 clinical trial in Kirinyaga, Kenya. *BMC Public Health* 2018;18:871.
8
9 557 34. Kewming S, D'Amore A, Mitchell EK. Conversation maps and diabetes education groups: an
10
11 558 evaluation at an Australian rural health service. *Diabetes Spectr* 2016;29:32-6.
12
13 559 35. Lassi ZS, Bhutta ZA. Community-based intervention packages for reducing maternal and neonatal
14
15 560 morbidity and mortality and improving neonatal outcomes. *Cochrane Database Syst Rev* 2015.
16
17 561 Art. No.: CD007754. DOI: 10.1002/14651858.CD007754.pub3.
18
19 562 36. Busza J, Dauya E, Bandason T, et al. The role of community health workers in improving HIV
20
21 563 treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health*
22
23 564 *Policy Plann* 2018;33:328-34.
24
25 565 37. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of
26
27 566 patients' emotional reactions and views about information provision. *Patient Educ Couns*
28
29 567 2004;53:269-75.
30
31 568 38. Maddigan SL, Majumdar SR, Johnson JA. Understanding the complex associations between
32
33 569 patient-provider relationships, self-care behaviours, and health-related quality of life in type
34
35 570 2diabetes: A structural equation modeling approach. *Qual Life Res* 2005;14:1489-500.
36
37 571 39. Malathy R, Narmadha MP, Jose MA, et al. Effect of a diabetes counseling programme on
38
39 572 knowledge, attitude and practice among diabetic patients in Erode district of South India. *J Young*
40
41 573 *Pharm* 2011;3:65-72.
42
43 574 40. Adepu R, Rasheed A, Nagavi BG. Effect of patient counseling on quality of life in type-2 diabetes
44
45 575 mellitus patients in two selected South Indian community pharmacies: A study. *Indian J Pharm*
46
47 576 *Sci* 2007;69:519.
48
49 577 41. Peel E, Douglas M, Lawton J. Self monitoring of blood glucose in type 2 diabetes: longitudinal
50
51 578 qualitative study of patients' perspectives. *BMJ* 2007;335:493.
52
53
54
55
56
57
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For peer review only

Patient and provider perspectives on barriers to screening for Diabetic Retinopathy:

An exploratory study from Southern India

Semi Structured Interview Guide

Patients

1. Can you describe how you found out about the fact that you had diabetes?
(Probe: what symptoms had been noticed, what was patient's age, what was his/her reaction to the diagnosis)
2. Please describe what all you did in terms of seeking care once you found out about your illness.
(Probe: where and when he/she sought care, whether care sought from places other than SN, any home management done and for how long)
3. How long have you been suffering from diabetes and what have you learnt about its effects on your health?
(Probe: is he/she aware about importance of controlling blood sugar, healthy diet, exercise, regular health checks, the potential negative consequences of diabetes, and impacts on lifestyle)
4. From whom/where have you learnt about your disease and how useful has this been?
(Probe: what he/she thinks about the nature of information given, was it easy to understand, difficult to follow, who provided the information, any reading material given, how useful was it)
5. Can you describe how your health is now and what steps you are taking to protect yourself?
(Probe: how he/she feels about his/her health status, whether he/she comes for regular health checks, how often, any medication being taken, any changes in life style)
6. Are there any specific health problems that you are facing as a result of diabetes?
(Probe: specifically any vision related problems, how/he she is managing this, what advice if any has been given by the health care professionals)
7. What do you know about diabetic retinopathy?
(Probe: what information has been given, what has he/she understood from the information given about what all need to be done to protect his/her eyes, how important does he/she believe this is)
8. Have you ever undergone screening for diabetic retinopathy, when was your last screen?
(Probe: regularity of screening, whether he/she comes regularly as required, what difficulties he she faces in undergoing this, what has been helpful in undergoing screening)
9. What suggestions do you have to get patients to come regularly for diabetic retinopathy screening?
(Probe: how often is acceptable, where would be ideal, what could encourage patients to come regularly)

Semi Structured Interview Guide

Health Care Providers

1. What categories of health professionals are available to care for patient with diabetes at your institution?
(Probe: Primary care, physician/dietician, endocrinologist/Ophthalmologist, Ophthalmic trained nurse)
2. What health promotion and patient education strategies you use for diabetes patients?
(Probe: Clinical services, supportive services at community level)
3. What will be your primary prevention and screening process you follow for Diabetic retinopathy?
(Probe: Primary prevention: change in life style, diet, use of home monitoring like glucometer)
(Probe: Screening for other conditions like nephropathy, neuropathy)
4. What type of informations are taken for DR patients?
(Probe: Do you take history about other complications, about other treatment for eye and diabetes)
5. What will be the understanding about patient's behavior towards diabetes and DR?
(Probe: patient understanding and acceptance of their illness poor compliance fear)
6. What information about individual patients are recorded specifically for DR patients?
(Probe: Risk factors, complications, previous examination, treatments and follow-up)
7. What communication methods are followed currently to have follow-up eye examination?
(Probe: Personal record books, text message such as reminders)
8. How are the interventions for people with DR financed?
(Probe: Funds by govt, private insurance, out of pocket/NGO)
9. What is your opinion about follow-up of Diabetic retinopathy patient?
(Probe: Are they coming regularly as advised, Do they come only if they have symptoms)
10. What reasons usually patient reports for the poor follow-up?
(Probe: Financial problem, Travel, Long waiting time, have they taken any steps to reschedule it)
11. What strategies you feel would make a better follow-up for DR patients?
(Probe: Concession, travel expense, reschedule appointments, free top up)

Standards for Reporting Qualitative Research (SRQR Checklist)

No	Topic	Item
Title and abstract		
S1	Title	Page 1 (Line 2 &3)
S2	Abstract	Page 2 (Line 28-49)
Introduction		
S3	Problem formulation	Page 4-6 (Line 77 to 127)
S4	Purpose or research question	Page 6 (Line 127-132)
Methods		
S5	Qualitative approach and research paradigm	Page 6-7 (Line 135-164)
S6	Researcher characteristics and reflexivity	Page 6 (147-149) & Page 7(158-164)
S7	Context	Page 6 (Line 135-136)
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S9	Ethical issues pertaining to human subjects	Page 6-7 (Line 135-138)
S10	Data collection methods	Page 6-7 (Line 149-153)
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S13	Data processing	Page 7-8 (Line 173-179)
S14	Data analysis	Page 7 (Line 169-173)
S15	Techniques to enhance trustworthiness	Page 7 (Line 163)
Results/findings		
S16	Synthesis and interpretation	Page 8-13 (Line 181-259) & Page 15-17 (Line 301-360)
S17	Links to empirical data	Page 13-15 & Page 17-19
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Page 19-22 (Line 365-450)
S19	Limitations	Page 22 (Line 440-443)
Other		
S20	Conflicts of interest	Page 23 (Line 463)
S21	Funding	Page 23 (Line 465)

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Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An exploratory study from Southern India

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3 **1 Original article**
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5 **2 Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An**
6 **3 exploratory study from Southern India**
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8 **4** *Short title: Barriers to Diabetic Retinopathy screening*
9

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3 26 **ABSTRACT**
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5 27 **Objective:** Diabetic retinopathy is one of the leading causes of visual impairment after cataract and
6
7 28 uncorrected refractive error. It has major public health implications globally, especially in countries such
8
9 29 as India where the prevalence of diabetes is high. With timely screening and intervention, the disease
10
11 30 progression to blindness can be prevented, but several barriers exist. As compliance to diabetic
12
13 31 retinopathy screening in people with diabetes is very poor in India, this study was conducted to explore
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15 32 understanding of and barriers to diabetic retinopathy screening from the perspectives of patients and
16
17 33 health care providers.

18
19
20 34 **Methods:** Using qualitative methods, 15 consenting adult patients with diabetes were selected
21
22 35 purposively from those attending a large tertiary care private eye hospital in southern India. Eight semi-
23
24 36 structured interviews were carried out with health care providers working in large private hospitals. All
25
26 37 interviews were audio-taped, transcribed verbatim and analyzed using the framework analytical approach.

27
28 38 **Results:** Four themes that best explained the data were recognizing and living with diabetes, care seeking
29
30 39 practices, awareness about diabetic retinopathy and barriers to diabetic retinopathy screening. Findings
31
32 40 showed that patients were aware about diabetes but understanding of diabetic retinopathy and its
33
34 41 complications was poor. Absence of symptoms, difficulties in doctor patient interactions and tedious
35
36 42 nature of follow-up care were some major deterrents to care seeking reported by patients. Difficulties in
37
38 43 communicating information about diabetic retinopathy to less literate patients, heavy work pressure and
39
40 44 silent progression of the disease were major barriers to patients coming for follow-up care as reported by
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42 45 health care providers.

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44
45 46 **Conclusions:** Enhancing patient understanding through friendly doctor-patient interactions will promote
46
47 47 trust in the doctor. The use of an integrated treatment approach including education by counsellors,
48
49 48 setting up of patient support groups, tele-screening approaches and use of conversation maps may prove
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51 49 more effective in the long run.
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3 51 **Strength and limitations of this study:**
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- 5 52 • This was a qualitative study that explored barriers to diabetic retinopathy (DR) screening from the
6
7 53 perspectives of patients and health care providers (HCP) which enabled a more comprehensive
8
9 54 understanding of the phenomenon.
10
11 55 • Insights obtained from patients and providers have given good cues for development of
12
13 56 intervention strategies.
14
15 57 • The study could have benefited from interviews with family members, who play an important
16
17 58 role both in decision-making for care seeking and in providing support to patients. A larger
18
19 59 patient sample representing a wider patient demographic could have provided wider perspectives.
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21 60 • Inclusion of HCPs from smaller eye clinics would have provided additional perspectives further
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23 61 enhancing understanding of the phenomena.
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76 INTRODUCTION

77 Diabetic retinopathy (DR), a microvascular complication in the eye due to uncontrolled diabetes has high
78 prevalence in Africa (33.8%) and in the Western Pacific (36.2%) [1]. In another study, the highest age
79 standardized prevalence was among Caucasians at 45.8% with Asians (combined) at 19.9% [2]. Flaxman
80 et al [3] in their systematic review reported that blindness due to diabetic retinopathy has been on the rise
81 from 1990 till 2015. In India, the disease has major public health implications due to two main reasons, i)
82 an estimated 57 million people will have diabetes by 2025 (195% increase from 1995) and ii) the risk of
83 sight threatening retinopathy is higher in adults with diabetes [4]. Previous population-based studies from
84 India have reported prevalence of diabetic retinopathy to be 10% in rural areas and 18% in urban areas
85 [5]. Moreover sight threatening DR (STDR) affects 5% of people with diabetes, i.e., 4.5 million, which is
86 stated to increase as the numbers of people with diabetes increases [6].

87 The management of diabetic eye disease in India (Supplementary file 1) is influenced by a lack of
88 screening programmes, poor public awareness on diabetic eye disease and poor understanding of the need
89 for regular retinal screening [7]. Most retinal services in India that manage these patients are not public
90 funded. There is also a wide variation in provision of health care ranging from highly specialized
91 hospitals to basic facilities without trained ophthalmologists [8].

92 Shukla et al assessed the perceptions of care and challenges faced in availing care among people with
93 diabetes in India and reported that 45% of participants already had vision loss when they first presented to
94 an eye facility and before their DR was even detected [8]. Lingam et al in their study on the uptake of
95 diabetic retinopathy screening in a pyramidal model of eye health care found that 2% at tertiary level,
96 40% at secondary and 50% at primary level had never undergone previous dilated eye examination [9].
97 Given that 50-70% of DR related visual impairments can be prevented by timely screening and
98 intervention [10], the importance of early identification and regular follow-up cannot be overemphasized.
99 Thus, while DR is one of the leading causes of blindness, vision loss is largely preventable through

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3 100 regular screening and follow-up which, continues to be quite inadequate as suggested by previous
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5 101 research [11-14].
6

7 102 Several barriers identified to screening for DR ranged from financial burden, lack of awareness about the
8
9 103 importance of screening, transportation, language barriers, cultural myths, denial, fear, and depression
10
11 104 [15]. Piyasena et al, found that inter-related user, family and institutional factors influenced the uptake of
12
13 105 DR screening and follow-up services in the Western Province of Sri Lanka [16]. Factors such as older age
14
15 106 and physical disability have also been found to act as barriers to screening. A study from India
16
17 107 highlighted several issues, which included travelling long distances to access the health facility and cost
18
19 108 of travel [8]. Patient's belief that their eyes were healthy, not having anybody to accompany them to
20
21 109 health care facilities and financial costs of seeking care were among other barriers reported [17].
22
23 110 However, most of these findings are from quantitative studies [10,12,15] that by their very design are
24
25 111 limited in terms of their ability to probe, explore and gain deeper insights. Furthermore, these barriers
26
27 112 may be influenced by regional variations. There is thus a paucity of qualitative studies on this topic in
28
29 113 India [18,19] which provided the impetus for this study involving semi-structured interviews (SSIs) with
30
31 114 both patients and health care providers (HCPs).
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33

34 115 We included HCPs for two reasons, i) being care providers their perceptions and experiences would
35
36 116 enable a more holistic understanding of this issue ii) given that HCPs are deeply respected in our culture
37
38 117 they could exert a significant role in encouraging patients to get their eyes screened thereby playing an
39
40 118 important role in future interventions. From patients we explored their experiences of living with diabetes,
41
42 119 how they coped with their condition in terms of care seeking behaviors as well as life style modifications,
43
44 120 their awareness about DR and their perceptions on barriers towards DR screening. From HCPs, we
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46 121 explored their perceptions on patient understanding of diabetes and DR, the nature of information about
47
48 122 diabetes and DR provided to patients and what they believed were barriers for accessing DR care. Getting
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50 123 to understand both points of view helped to build deeper understanding of the phenomenon.
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125 **METHODS**

126 The study was carried out in a tertiary eye care center run by a non-government organization (NGO)
127 located in Chennai, capital of the state of Tamil Nadu in South India. The study was approved by the
128 institutional review board of Vision Research Foundation and adhered to the tenets of the declaration of
129 Helsinki.

130 **Sampling**

131 Adult patients with type 2 diabetes mellitus (DM) aged 50 years and above were considered, because it is
132 only after a few years of living with DM do patients tend to develop DR. The strongest predictor for DR
133 is the duration of diabetes [20], therefore patients who had been living with DM for a period of five years
134 or more were purposively selected to participate in SSIs. Patients already diagnosed with DR were not
135 included as the emphasis was on awareness about DR, need for eye screening and barriers to screening.
136 Given that 12 interviews are sufficient to reach saturation if the objectives are fairly narrow and the
137 sample not too diverse [21] and keeping in mind feasibility, logistics and the fact that qualitative research
138 is time consuming, we decided on carrying out 15 interviews with patients. We believed this would be
139 adequate to achieve saturation. Using maximum variation sampling we recruited 8 men and 7 women of
140 different ages during the period February to June 2019. The hospital maintains a computerized schedule
141 of patient appointments with various eye specialists inclusive of names of patients, their gender and age.
142 The other details such as education levels and nature of occupation were gathered during the interview.
143 As our focus was on barriers to DR care we reviewed the appointment schedules of the retinal specialists.
144 On the specified dates of the appointments our research team (KG and VS both trained in qualitative
145 research methods by SK), met with patients aged 50 years and above, following their consult and
146 ascertained eligibility. Those eligible were consented to participate in an SSI. The eight HCPs recruited
147 had five or more years of experience working with persons with diabetes. Five ophthalmologists were
148 recruited, three worked at the NGO eye hospital and two were from another private eye hospital. The
149 remaining HCPs included two diabetologists and one dietician recruited from a diabetes speciality centre.

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3 150 Separate open-ended interview guides (Supplementary file 2) for patients and HCPs, informed by
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5 151 literature and our prior interactions with patients were developed. Broadly, they elicited information on
6
7 152 patient's understanding of diabetes, perceptions on their experiences and risks of living with it, lifestyle
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9 153 modifications made, care seeking behaviours, understanding of DR, barriers to DR screening and its
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11 154 importance and suggestions on what would be helpful. The participants were escorted to a quiet area in
12
13 155 the hospital where the interviews were carried out. For most patients the interviews were done in Tamil,
14
15 156 the language of communication in our state, while with most HCPs it was in English. Informed consent
16
17 157 was obtained from all participants following which interviews were conducted and audio recorded. The
18
19 158 duration of interviews varied from about 35 to 50 minutes. All interviews were transcribed verbatim;
20
21 159 those in Tamil were translated into English for the purpose of analysis. Every transcript was re-checked
22
23 160 with the audio recording by the team to ensure fidelity to the original audio taped interviews before
24
25 161 analysis. All data were anonymized to maintain confidentiality.
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29 162 **Patients and public involvement**

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31 163 Patients and public were not involved in the design or conduct of our study.
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35 165 **ANALYSIS**

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37 166 Analysis followed the framework analytical approach, [22] which is very suitable for data gathered
38
39 167 through SSIs [23] and began by gaining familiarity with each of the transcripts through repeated readings.
40
41 168 We carried out a systematic method of organizing our data into spreadsheets, keeping in mind our
42
43 169 research questions and listed out several categories like, 'understanding of diabetes', 'care-seeking
44
45 170 practices', 'awareness about DR', 'barriers to DR screening' etc. We then began extracting relevant
46
47 171 portions of text from each interview related to these categories and went through a process of indexing or
48
49 172 sifting through the data; sorting and selecting quotes and placing them under the appropriate categories.
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51 173 Developing and refining our categories in this manner helped us to compare and contrast them and
52
53 174 determine the ones that could be meaningfully combined and those that were standalone thereby setting
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175 the stage for theme development. In developing themes, we looked for patterns and made decisions on
176 what themes best explained our data and provided important insights.

177

178 **FINDINGS**

179 **Patient and HCP Characteristics**

180 All the 15 patients were married and their average age was 63.2 ± 9.2 years. All of them were living with
181 diabetes for several years with an average duration of 15.6 ± 10.8 years and had not received any
182 treatment for diabetic eye disease. The eight HCPs, who participated in the interviews, comprised of 5
183 women and 3 men. Their average age was 44.7 ± 8.1 years and average duration of years of experience
184 was 17 ± 10.5 years (Supplementary table 1).

185

186 **Themes of Analysis**

187 The four themes that best explained the data and addressed our research questions were, i) recognizing
188 and living with diabetes ii) care seeking practices iii) awareness about DR iv) barriers to DR screening.
189 These were explored from the perspectives of both patients and providers. However, the last two themes
190 have been combined and presented for the HCPs so as to succinctly reflect the manner in which they best
191 described the themes.

192

193 **Patient Perspectives**

194 **Recognizing and living with diabetes**

195 Recognition of the fact that they might have diabetes came rather slowly to most patients. For the most
196 part, the diagnosis of diabetes came as a surprise and a great shock. It often started with minor symptoms
197 like a tingling feeling in the extremities, frequent urination, itching sensation while passing urine, feeling
198 unusually thirsty or hungry. These were initially ignored until other symptoms started showing up like
199 loss of weight, feeling faint and dizzy or a wound that was not healing. Most patients did not even suspect

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3 200 that they had diabetes and it was only after they were asked to undergo blood sugar tests on the
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5 201 instruction of the doctor, did they come to learn of their diagnosis. Others spoke of not experiencing any
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7 202 symptoms at all and learnt of their condition when they underwent a routine health check-up. A female
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9 203 participant came to know of her diabetes when she underwent surgery for removal of a tumour. Myths
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11 204 surrounding the disease also emerged with one participant stating that he believed he would not get the
12
13 205 disease as he thought it only affected the first-born son in the family. The realization that this was a
14
15 206 lifelong condition that could seriously spiral out of control if not carefully managed had begun to dawn on
16
17 207 them. A few participants, apart from highlighting their own concerns and worries, were also distressed by
18
19 208 the stress and burden their illness would impose on their family members. These were all typically, their
20
21 209 first reactions to the diagnosis. But with time, regular medication and care provided at their health
22
23 210 facilities their understanding of the disease improved as they came to terms with their disease. Some even
24
25 211 took on a more proactive role by encouraging others who had the disease to be compliant while others
26
27 212 appeared more fatalistic in accepting their situation. Some were more familiar with the disease as their
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29 213 parents, siblings or close relatives were living with it and consequently were emotionally better prepared
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31 214 when told of their diagnosis.
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37 215
38 216 In terms of their understanding of diabetes, most participants were aware that poor control of their blood
39
40 217 sugar level could result in a host of health problems and complications. Signs and symptoms ranging from
41
42 218 becoming tired easily, losing weight, finding it difficult to work, feeling faint and dizzy to more serious
43
44 219 conditions such as kidneys and liver being affected, severe pain in the feet, suffering a stroke or a heart
45
46 220 attack were reported. It is important to note, that those who had a parent or sibling living with diabetes
47
48 221 reported being attuned to developing symptoms at some point and accepted the inevitability of acquiring
49
50 222 the disease on account of its genetic nature. They were also more aware of the consequences of improper
51
52 223 management and spoke of the risks to their health in terms of developing a stroke. The fact that diabetes
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54 224 could impair vision leading to possible loss of sight was also reported by many participants.
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5 226 The main source of information about diabetes came from their health care providers including doctors
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7 227 and nurses. A few others learnt more about the disease from books, articles and literature on the internet
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9 228 as well as from health programmes on television. They felt that doctors were not too forthcoming and
10
11 229 usually did not spend time explaining in detail. Friends, neighbours and family members also served as
12
13 230 another information source, more so, if they were already diagnosed with diabetes.
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17 18 232 **Care Seeking Practices**

19
20 233 Although many patients never thought to seek care when symptoms initially started, once diagnosed they
21
22 234 became more alert to the need to seek regular health care. Based on the advice given by their doctors, they
23
24 235 started attending clinics to get their blood sugar checked. One female participant spoke of feeling
25
26 236 depressed each time she underwent a blood sugar test as the test brought home to her the fact that she had
27
28 237 diabetes and had to somehow "*survive with the disease*". While participants appreciated the necessity of
29
30 238 these periodic visits to test their blood sugars, they nevertheless found them to be tedious. Therefore,
31
32 239 recommendations by doctors to undergo further tests like an eye test for example was seen as an added
33
34 240 burden both in time and cost and was often resisted. A few participants emphasized the importance of
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36 241 consistently seeing the same doctor so as to avoid unnecessary confusion from varying recommendations.
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38 242 In this context, the manner in which doctors communicated to patients influenced the level of trust and
39
40 243 how well patients would comply with their advice. Participants believed that doctors needed to speak
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42 244 gently and not frighten them with harsh consequences which would only result in them going to another
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44 245 doctor. While they agreed that all necessary information needed to be communicated, this needed to be
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46 246 done in a friendly and non-threatening manner so as to instill confidence.
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51 248 Use of alternate medicines like Ayurveda was not the preferred choice for most participants although a
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53 249 few reported taking it along with their regular allopathic medication as they felt that Ayurveda by itself

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3 250 would not be effective in treating them. They all spoke of the importance of eating a balanced diet, of
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5 251 exercising regularly, taking their medication as advised and of regular follow-up with a physician. To this
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7 252 end, most participants had modified their lifestyles, although to varying degrees. They reported cutting
8
9 253 down on rice-based food items and sweets and exercising to the extent possible. While some indicated
10
11 254 that they had no difficulty in changing their diet, others found it difficult. Similarly, regular exercise too
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13 255 posed a challenge with many indicating lack of time, poor motivation and complaints of body aches.
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17 18 257 **Awareness about DR**

19
20 258 The findings revealed a mixed picture regarding awareness about DR. For most, it was not a familiar term
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22 259 while a few were aware of it and of the need to undergo regular retinal screening. The understanding that
23
24 260 diabetes could affect their eyes and that their vision could be impaired had been gleaned through
25
26 261 interactions with doctors, other health staff they came into contact with and through posters on diabetes
27
28 262 on display in the hospitals they had been to. Issues about the potential threat to their eyes on account of
29
30 263 diabetes were often reiterated during these visits. Participants were more familiar with other eye problems
31
32 264 like glaucoma and cataract but for the most part remained unaware of the details and symptom
33
34 265 manifestations of DR, and of possible preventive measures that needed to be taken to protect their eyes
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36 266 from DR. Only a couple of participants indicated that they had been informed about possible risks to their
37
38 267 eyes on account of diabetes or of the precautions they needed to take to protect their eyes. The few who
39
40 268 had heard about DR, described it as a condition wherein the “*nerve would get affected*”. They spoke of
41
42 269 the importance of eye care, of regular eye checkup and the importance of keeping their blood sugar level
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44 270 under control as ways and means of protecting their eyes. Such participants were generally better
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46 271 educated, tended to discuss their health issues with their doctors and were more compliant.
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50 51 273 **Barriers to DR Screening**

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3 274 Among those unfamiliar or less aware about DR, several issues emerged which acted as barriers to
4
5 275 seeking eye care. A typical one related to consulting a doctor only if there was pain or some discomfort in
6
7 276 the eye. In the absence of any symptoms it was deemed unnecessary to seek such eye care. Participants
8
9 277 also feared that undergoing eye screenings and tests could result in more medicines being prescribed.
10
11 278 Apart from concerns about cost and managing the dosage, they believed that these medicines meant more
12
13 279 chemicals being ingested which was perceived as harmful as it contributed to excessive “heat”. Others
14
15 280 complained about doctors being too busy and of not having the time to talk to patients about all the dos
16
17 281 and don’ts regarding diabetic eye care. If the doctor appeared too curt or busy, patients felt dissatisfied.
18
19 282 But, patients who indicated that they were doing well were generally satisfied with the care received and
20
21 283 also tended to be more adherent to the doctor’s advice. Other issues involved the logistics of travelling to
22
23 284 the health facility, costs associated with undergoing the tests, not having the time to go for a check-up on
24
25 285 account of work and family commitments. Some women participants spoke of not having anyone to
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27 286 accompany them to the health facility and almost all described the long hours they had to spend in the
28
29 287 hospital to undergo these tests as major deterrents. Lastly, a sense of complacency and a lack of
30
31 288 motivation were also cited as reasons for participants failing to seek regular care. In this context, one
32
33 289 suggestion was for the hospital to send regular reminders to patients in the form of phone calls or phone
34
35 290 messages informing patients that they were due for a check-up and encouraging them to visit the hospital.
36
37 291 The above mentioned patient’s perspectives are summarized in supplementary table 2.
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43 293 **HCPs Perspectives**

44 294 **Recognizing and living with diabetes**

45 295 The HCPs believed that people were largely aware about diabetes, referred to it as “*sugar disease*” and
46
47 296 understood that it required them to control their diet, restrict sweet intake and exercise regularly. Greater
48
49 297 visibility of the disease was attributed to its high prevalence and widespread media coverage which had
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51 298 contributed to considerable awareness among people. Patients who were educated were more aware and
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3 299 had access to a wide range of information sources, like the internet, medical literature and health-related
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5 300 broadcasts on radio and television. These patients also sought further clarifications from their doctors and
6
7 301 even questioned them when in doubt. On the other end of the spectrum were the poorer, often less
8
9 302 educated patients who were not so knowledgeable about the disease and who also tended to be less
10
11 303 compliant. The HCPs also spoke about issues concerning monitoring and controlling blood sugar levels
12
13 304 which according to them was often not adequately maintained or even understood by patients. Thus,
14
15 305 patients were generally aware about the disease, but the extent and depth of knowledge of what exactly
16
17 306 they were up against varied considerably. In this context, the importance of proper counselling that would
18
19 307 educate patients about diabetes and motivate them to attend regular reviews to the hospital was stressed.
20
21
22 308 A few HCPs suggested the importance of exposing patients to all the possible diabetes - related
23
24 309 complications by showing them pictures or getting them to meet other patients. This would impress upon
25
26 310 patients the seriousness of the problem.
27

28 311

312 **Care Seeking Practices**

313 In terms of issues related to care seeking, all HCPs uniformly said that in addition to telling patients about
314 the disease, its symptom manifestations and its management strategies, they reiterated the need to undergo
315 periodic blood tests to monitor their blood sugar level and ensure that they kept it under control. The
316 importance of seeking care from a diabetologist was also stressed as these doctors had the expertise to
317 guide and appropriately advise patients. Further, they advised that as the disease could affect any of their
318 internal organs and was basically a “*silent killer*”, it was imperative that patients underwent regular
319 check-up. Usually the information was conveyed to patients often with the use of printed pamphlets every
320 time the patient visited the health facility. One HCP, an ophthalmologist, declared that he typically
321 advised his diabetic patients to undergo an HbA1c in addition to fasting and post prandial blood tests. He
322 also advised them to undergo kidney and liver function tests and check their cholesterol and blood
323 pressure as their diabetes could get exacerbated by other prevailing co-morbidities. The HCPs thus spoke

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3 324 of following a fairly structured protocol which also entailed constantly emphasizing the importance of
4
5 325 lifestyle modifications as being critical to maintaining health. Use of posters and slogans educating people
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7 326 about the disease and emphasizing the importance of regular care were also highlighted. A barrier to
8
9 327 proper care highlighted by the HCPs was the availability of a plethora of information on social media
10
11 328 sites about diabetes and related health problems. Most of this information was either inadequate or
12
13 329 incorrect and those who tended to follow it did so at great cost to themselves. Another HCP, a dietician
14
15 330 spoke of gearing the information to the patient's level of understanding, breaking it down to simple do's
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17 331 and don'ts which she felt was easier for the patient to follow. This was feasible for her to do as she had
18
19 332 more time with the patient unlike the doctors. Patient's motivation levels and presence of good family
20
21 333 support were also seen as aids to good compliance.
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26 335 **Awareness about DR and Barrier to DR screening**

28 336 The general opinion among the HCPs was that awareness about DR was still poor in patients with very
29
30 337 few having heard of it. They accepted that patients knew that diabetes could affect the eyes, were familiar
31
32 338 with cataract but for the most, remained unaware of DR. One HCP, an ophthalmologist described two
33
34 339 types of diabetic patients: i) those who remained unaware that the disease could affect their eyes and
35
36 340 blamed their doctors for failing to educate them adequately and ii) those who despite being asked to
37
38 341 attend a retinal screening failed to do so as they did not suffer any symptoms. This silent and quiet
39
40 342 progression of DR where patients largely experienced no symptoms resulted in patients not perceiving the
41
42 343 need to seek care thereby seriously compromising their vision. In this context, one HCP said that many
43
44 344 Indian patients normally come for a check-up when there is an "*acute crisis or acute problem*" and unless
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46 345 and until they experienced some difficulties, they usually did not seek care. Cost and lack of time were
47
48 346 other issues particularly for poorer persons and those working on daily wages resulting in delays in
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50 347 seeking care. Explaining the nuances of the disease to such patients who often tended to have low literacy
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52 348 was found to be quite a challenge. Lack of motivation; financial problems; absence of good family/social
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3 349 support in terms of someone to accompany them to the hospital and slow improvement in vision
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5 350 following initiation of treatment, acted as deterrents to continued care seeking. Patients also tended to be
6
7 351 complacent if their blood sugar levels were under control, little realizing that the longer the duration of
8
9 352 diabetes, greater was their risk of developing DR. The above mentioned HCP perspectives are mentioned
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11 353 in supplementary table 3.
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15 355 **DISCUSSION**

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18 356 This qualitative study has provided important insights into barriers to regular screening for DR from the
19
20 357 perspectives of patient and providers across four themes, i) recognizing and living with diabetes, ii) care
21
22 358 seeking practices, iii) awareness about DR and iv) barriers to DR screening. Patients were largely aware
23
24 359 of diabetes, its symptoms, importance of diet and medication management and of exercise which were
25
26 360 also endorsed by the HCPs. It was also evident that the management of this disease imposed a tremendous
27
28 361 burden on both HCPs and patients alike. For providers, communicating the complexities of the disease in
29
30 362 words that patients could understand and keeping them motivated to ensure good compliance proved
31
32 363 challenging. For patients the burden of constantly having to follow a healthy lifestyle, being systematic in
33
34 364 seeking care combined with a lack of depth in their understanding of the disease contributed to them
35
36 365 feeling overwhelmed and frustrated, even depressed.
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41 367 A study by Li D [24], highlighted the importance of addressing depression in people with diabetes and
42
43 368 recommended the need to motivate patients to exercise and follow a healthy lifestyle. The fact that
44
45 369 diabetes can affect the eyes was reported by most although awareness about DR was poor, a fact
46
47 370 confirmed by the HCPs. Poor understanding of DR has also been reported by patients in other studies
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49 371 wherein they expressed having no knowledge about the possibility of becoming blind on account of
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51 372 diabetes [25,26]. In another study [27], despite most participants being aware about the need to undergo
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373 eye examinations there was limited understanding about retinopathy and about the rationale behind the
374 recommendation.

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376 Apart from feeling overwhelmed and frustrated with the care routines, the prospect of having to spend a
377 whole day or more than half a day at the hospital, as health facilities here are mostly very crowded was
378 another major deterrent to care seeking for DR. Patients therefore tended to delay seeking care and clung
379 to the belief that as they were feeling alright there was no requirement to go to the hospital. This absence
380 of symptoms which created a sense of complacency among patients similar to the findings reported in the
381 systematic review by Graham-Rowe et al [28], emerged as a major deterrent to undergoing eye screening
382 for DR in our study. Patients questioned the need to undergo eye tests which were usually tedious and
383 required them to spend long hours in the hospital. Further they feared having to take more medications
384 that they thought were unnecessary as they experienced no symptoms. Besides it meant ingesting more
385 chemicals contributing to excessive heat in their bodies. This cultural belief in the concept of excessive
386 heat and cold attributed to both modern medicines and foods dates back to the Charaka
387 Samhita, a Sanskrit text on Ayurveda (Indian traditional medicine) and has deep roots in the minds of
388 people [29,30]. The HCPs agreed that the silent progression of DR was a deterrent to early care seeking
389 and spoke of difficulties they faced in getting patients to understand the importance of early and regular
390 eye screening and testing.

391
392 Thus, strategies that enhance patient understanding of the disease are needed. In this context, a study
393 carried out by Trento et al [31], showed that patients who participated in-group sessions understood DR
394 better. The recent trial in Kenya showed the effectiveness of peer support groups in increasing uptake of
395 DR screening [32]. These helped to promote learning and provided long term support to group members
396 which acted as an incentive to remain compliant. In our setting, educating patients about diabetes is
397 mostly didactic, and happens during the brief consultation sessions with the doctors and subsequently

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3 398 during their interaction with other health care staff. Communication packages like conversation maps
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5 399 which are interactive illustrations have been found to be helpful by HCPS in better educating DM patients
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7 400 about the importance of self-care, as a means to prevent/delay the onset of related complications [33].
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9 401 Tele-screening has been found to be promising in terms of improving compliance apart from being cost
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11 402 effective [34] for a rural population. Improving awareness about diabetes and its complications among
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13 403 community health workers such as the Accredited Social Health Activists (ASHA) in India, which has
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15 404 worked well for other health issues like maternal and child health and infectious diseases like HIV [35,
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17 405 36] may be a way forward. Future research could test the application of such strategies.
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23 407 Another important point that emerged was the nature of the doctor-patient interactions. Many patients
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25 408 were critical of doctors who they felt did not explain adequately or were always in a rush. Some spoke of
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27 409 the manner in which doctors communicated to them leaving them feeling threatened and frightened, and
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29 410 therefore more likely to switch to another doctor. They felt confused when meeting different doctors on
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31 411 account of their conflicting opinions. Patients looked to their HCPs for support and encouragement that
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33 412 was often not forthcoming on account of their busy schedules. Doctors are often hard pressed for time
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35 413 which compromises their ability to spend quality time with patients, a feature that was highlighted by
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37 414 many in our study. The HCP's felt that despite repeatedly talking to patients about the disease and its
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39 415 complications many patients did not appreciate the importance of regularly monitoring and maintaining
40
41 416 their blood sugar levels and of coming for eye screening. They expressed difficulties communicating to
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43 417 less literate persons who were often shown to be less compliant. The need of patients for HCPs to be more
44
45 418 approachable has been expressed by patients in other studies as well. Peel [37], reported that participants
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47 419 in her study wanted more support and information from their HCPs and felt frustrated as many of their
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49 420 concerns had not been answered. Maddigan [38], described the value of good patient-provider
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51 421 relationships as contributing to good exercise adherence thereby improving quality of life.
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3 423 It is apparent that HCPs play a pivotal role in promoting understanding of the disease given the almost
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5 424 reverential position they occupy in our culture. At the same time, patient's expectations from doctors are
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7 425 also very high and if they feel that they are not improving to their satisfaction, an element of distrust and
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9 426 unhappiness tends to creep in which in turn colours their opinions. Our study findings further showed that
10
11 427 there is a gap between what is conveyed to patients by the HCPs, and how much of that is actually
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13 428 understood by them. Perhaps the strategy of 'one size fits all' wherein standard information is provided to
14
15 429 all patients needs to be addressed in the form of health care awareness and education by counsellors [39,
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17 430 40]. Due consideration to a patient's understanding capacity, self-efficacy, attitudes and health beliefs
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19 431 [41] which exert an influence on their lifestyle management would aid HCPs improve their
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21 432 communication skills and enhance patient understanding. Reducing the burden on doctors, perhaps by
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23 433 building a comprehensive diabetic care team comprising of trained personnel, some of whom could take
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25 434 on the role of educating, and counselling patients while doctors could focus on care delivery could be a
26
27 435 possible strategy. Educating people about the skill sets and roles of each member of the team will also be
28
29 436 essential to promote acceptance. Such an integrated approach where care of diabetes and its complications
30
31 437 are available under one roof, literally a 'one-stop shop', indicative of a paradigm shift compared to what
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33 438 is currently practiced, seems the most logical way going forward (Supplementary file 3).
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39 440 This qualitative study by exploring perspectives of both patients and HCPs has provided useful insights
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41 441 which have the potential for guiding future intervention development. The study could have benefited
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43 442 from interviews with family members, who play an important role in decision-making for care seeking
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45 443 and in providing support to patients. Inclusion of HCPs from smaller eye clinics would have provided
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47 444 additional perspectives further enhancing understanding of the phenomena. A larger patient sample
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49 445 representative of a wider patient demographic could perhaps have brought in more perspectives.
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53 447 **CONCLUSION**

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3 448 Living with and managing diabetes is a lifelong process, one that can prove overwhelming to an
4
5 449 unprepared patient. It is therefore imperative that steps to ensure good patient compliance be prioritized.
6
7 450 Enhancing patient understanding through healthy and friendly doctor-patient interactions and use of an
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9 451 integrated treatment approach including education by counsellors, setting up patient support groups, tele-
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11 452 screening approaches and use of conversation maps are some strategies that may prove more effective in
12
13 453 enhancing compliance for DR care.
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17
18 455 **Declarations:**

19
20 456 • **Ethics approval and consent to participant**

21
22 457 The study was approved by the Institutional Review Board (Ethics committee), Vision Research
23
24 458 Foundation and written consent was obtained from the patients as per the Declaration of Helsinki.

25
26 459 • **Consent for publication**

27
28 460 Not applicable

29
30 461 • **Availability of data and materials**

31
32 462 The datasets generated during and/or analysed during the current study are not publicly available,
33
34 463 as it is against the organization hospital policy. They can however, be made available from the
35
36 464 corresponding author on reasonable request.

37
38 465 • **Competing interests**

39
40 466 None declared

41
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43
44 468 Not applicable

45
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474 • **Authors contributions:**

475 R.R and S.K; contributed to the conception and design of the study. S.K wrote the main
476 manuscript text and guided the analyses. G.K and S.V assisted with data collection and analyses.
477 R.R, S.K, G.K and S.V drafted the work and S.P, P.R and S.S substantively revised it. All authors
478 reviewed the manuscript.

480 **REFERENCES:**

- 481 1. Thomas RL, Halim S, Gurudas S, et al. IDF Diabetes Atlas: A review of studies utilising retinal
482 photography on the global prevalence of diabetes related retinopathy between 2015 and 2018.
483 *Diabetes Res Clin Pract* 2019;157:107840.
- 484 2. Yau JW, Rogers SL, Kawasaki R, et al. Global prevalence and major risk factors of diabetic
485 retinopathy. *Diabetes care* 2012;35:556-64.
- 486 3. Flaxman SR, Bourne RR, Resnikoff S, et al. Global causes of blindness and distance vision
487 impairment 1990–2020: a systematic review and meta-analysis. *Lancet Glob Health*
488 2017;5:e1221-34.
- 489 4. King H, Aubert RE, Herman WH. Global burden of diabetes, 1995–2025: prevalence, numerical
490 estimates, and projections. *Diabetes care* 1998;21:1414-31.
- 491 5. Raman R, Gella L, Srinivasan S, et al. Diabetic retinopathy: An epidemic at home and around the
492 world. *Indian J Ophthalmol* 2016;64:69-75.
- 493 6. Gilbert C, Gordon I, Mukherjee CR, et al. Guidelines for the prevention and management of
494 diabetic retinopathy and diabetic eye disease in India: A synopsis. *Indian Journal of*
495 *Ophthalmology*. *Indian J Ophthalmol* 2020;68(Suppl 1):S63.

- 1
2
3 496 7. Ramasamy K, Raman R, Tandon M. Current state of care for diabetic retinopathy in India. *Curr*
4
5 497 *Diab Rep* 2013;13:460-8.
6
7
8 498 8. Shukla R, Gudlavalleti MV, Bandyopadhyay S, et al. Perception of care and barriers to treatment
9
10 499 in individuals with diabetic retinopathy in India: 11-city 9-state study. *Indian J Endocrinol Metab*
11
12 500 2016;20(Suppl 1):S33-S41. doi:10.4103/2230-8210.179772.
13
14
15 501 9. Lingam S, Rani PK, Sheeladevi S, et al. Knowledge, attitude and practices on diabetes,
16
17 502 hypertension and diabetic retinopathy and the factors that motivate screening for diabetes and
18
19 503 diabetic retinopathy in a pyramidal model of eye health care. *Rural Remote Health* 2018;18:4304.
20
21 504 <https://doi.org/10.22605/RRH4304>.
22
23 505 10. Coney JM. Addressing unmet needs in diabetic retinopathy. *Am J Manag Care* 2019;25(16
24
25 506 Suppl):S311-6.
26
27 507 11. Vengadesan N, Ahmad M, Sindal MD, et al. Delayed follow-up in patients with diabetic
28
29 508 retinopathy in South India: social factors and impact on disease progression. *Indian J Ophthalmol*
30
31 509 2017;65:376-84.
32
33
34 510 12. Rohan TE, Frost CD, Wald NJ. Prevention of blindness by screening for diabetic retinopathy: a
35
36 511 quantitative assessment. *BMJ* 1989;299:1198-201.
37
38 512 13. Namperumalsamy P, Nirmalan PK, Ramasamy K. Developing a screening program to detect sight-
39
40 513 threatening diabetic retinopathy in South India. *Diabetes Care* 2003;26:1831-5.
41
42 514 14. Kashim RM, Newton P, Ojo O. Diabetic retinopathy screening: A systematic review on patients'
43
44 515 non-attendance. *Int J Environ Res Public Health* 2018;15:157.
45
46
47 516 15. Lu Y, Serpas L, Genter P, et al. Divergent Perceptions of Barriers to Diabetic Retinopathy
48
49 517 Screening Among Patients and Care Providers, Los Angeles, California, 2014–2015. *Prev Chronic*
50
51 518 *Dis* 2016;13:160193. DOI: <http://dx.doi.org/10.5888/pcd13.160193>

- 1
2
3 519 16. Piyasena MM, Murthy GV, Yip JL, et al. A qualitative study on barriers and enablers to uptake of
4
5 520 diabetic retinopathy screening by people with diabetes in the Western Province of Sri Lanka. *Trop*
6
7 521 *Med Health* 2019;47:34.
8
9
10 522 17. Peng PH, Laditka SB, Lin HS, et al. Factors associated with retinal screening among patients with
11
12 523 diabetes in Taiwan. *Taiwan J Ophthalmol*. 2019;9:185-93.
13
14 524 18. Lindenmeyer A, Sturt JA, Hipwell A, et al. Influence of primary care practices on patients' uptake
15
16 525 of diabetic retinopathy screening: a qualitative case study. *Br J Gen Pract* 2014;64:e484-92.
17
18 526 19. Khan FN, Agne AA, Buttan S, et al. Assessing diabetes knowledge and barriers to health services
19
20 527 among patients with diabetes: a qualitative study in Delhi, India. *Int J Health Promot Educ*
21
22 528 2013;51:290-9.
23
24 529 20. Raman R, Rani PK, Racheppalle SR, et al. Prevalence of diabetic retinopathy in India: Sankara
25
26 530 Nethralaya diabetic retinopathy epidemiology and molecular genetics study report 2. *Ophthalmol*
27
28 531 2009;116:311-8.
29
30 532 21. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data
31
32 533 saturation and variability. *Field Methods* 2006;18:59-82.
33
34 534 22. Ritchie J, Lewis J, Nicholls CM, et al. Qualitative research practice: A guide for social science
35
36 535 students and researchers:: sage 2013.
37
38 536 23. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative
39
40 537 data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:1-8.
41
42 538 24. Li D, Inouye J, Davis J, et al. Associations between psychosocial and physiological factors and
43
44 539 diabetes health indicators in Asian and Pacific Islander adults with type 2 diabetes. *Res Theory*
45
46 540 *Nurs Pract* 2013;2013.
47
48 541 25. Pasagian-Macaulay A, Basch CE, Zybert P, et al. Ophthalmic knowledge and beliefs among
49
50 542 women with diabetes. *Diabetes Educ* 1997;23:433-7.
51
52
53
54
55
56
57
58
59
60

- 1
2
3 543 26. Lewis K, Patel D, Yorston D, et al. A qualitative study in the United Kingdom of factors
4
5 544 influencing attendance by patients with diabetes at ophthalmic outpatient clinics. *Ophthalmic*
6
7 545 *Epidemiol* 2007;14:375-80.
8
9 546 27. Hartnett ME, Key IJ, Loyacano NM, et al. Perceived barriers to diabetic eye care: qualitative study
10
11 547 of patients and physicians. *Arch Ophthalmol* 2005;123:387-91.
12
13 548 28. Graham-Rowe E, Lorencatto F, Lawrenson JG, et al. Barriers to and enablers of diabetic
14
15 549 retinopathy screening attendance: a systematic review of published and grey literature. *Diabet Med*
16
17 550 2018;35:1308-19.
18
19 551 29. Selin H. A History of Indian Medical Literature; 2002.
20
21 552 30. Satyavati GV. The Legacy of Caraka; 2003.
22
23 553 31. Trento M, Bajardi M, Borgo E, et al. Perceptions of diabetic retinopathy and screening procedures
24
25 554 among diabetic people. *Diabet Med* 2002;19:810-3.
26
27 555 32. Mwangi N, Gakuo E, Gichuhi S, et al. Effectiveness of peer support to increase uptake of retinal
28
29 556 examination for diabetic retinopathy: study protocol for the DURE pragmatic cluster randomized
30
31 557 clinical trial in Kirinyaga, Kenya. *BMC Public Health* 2018;18:871.
32
33 558 33. Carvalho SL, Ferreira MA, Medeiros JM, et al. Conversation map: an educational strategy in the
34
35 559 care of elderly people with diabetes mellitus. *Revista brasileira de enfermagem*. 2018;71:925-9.
36
37 560 34. Rachapelle S, Legood R, Alavi Y, et al. The cost-utility of telemedicine to screen for diabetic
38
39 561 retinopathy in India. *Ophthalmol* 2013;120:566-73.
40
41 562 35. Lassi ZS, Bhutta ZA. Community-based intervention packages for reducing maternal and neonatal
42
43 563 morbidity and mortality and improving neonatal outcomes. *Cochrane Database Syst Rev* 2015.
44
45 564 Art. No.: CD007754. DOI: 10.1002/14651858.CD007754.pub3.
46
47 565 36. Busza J, Dauya E, Bandason T, et al. The role of community health workers in improving HIV
48
49 566 treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health*
50
51 567 *Policy Plann* 2018;33:328-34.
52
53
54
55
56
57
58
59
60

- 1
2
3 568 37. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of
4
5 569 patients' emotional reactions and views about information provision. *Patient Educ Couns*
6
7 570 2004;53:269-75.
8
9 571 38. Maddigan SL, Majumdar SR, Johnson JA. Understanding the complex associations between
10
11 572 patient-provider relationships, self-care behaviours, and health-related quality of life in type
12
13 573 2diabetes: A structural equation modeling approach. *Qual Life Res* 2005;14:1489-500.
14
15 574 39. Malathy R, Narmadha MP, Jose MA, et al. Effect of a diabetes counseling programme on
16
17 575 knowledge, attitude and practice among diabetic patients in Erode district of South India. *J Young*
18
19 576 *Pharm* 2011;3:65-72.
20
21 577 40. Adepu R, Rasheed A, Nagavi BG. Effect of patient counseling on quality of life in type-2 diabetes
22
23 578 mellitus patients in two selected South Indian community pharmacies: A study. *Indian J Pharm*
24
25 579 *Sci* 2007;69:519.
26
27 580 41. Peel E, Douglas M, Lawton J. Self monitoring of blood glucose in type 2 diabetes: longitudinal
28
29 581 qualitative study of patients' perspectives. *BMJ* 2007;335:493.
30
31 582
32
33 583
34
35 584
36
37 585
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39 586
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Supplementary file 1: DR screening in India

- There is no national screening program for DR in India and the retinal services for the patients are not funded.
- In hospitals annual retinal check-up system is initiated to monitor the retinal complications among diabetic patients. Based on the severity of DR the follow-up will be advised by Ophthalmologists and the corresponding treatment will be given.
- In India, retinal screening is carried out in camps, Telemedicine and opportunistic screening. With telemedicine, retinal screening camps are managed by ophthalmologists and local community workers.
- With help of mobile van facilities, retinal images are obtained and transmitted to an expert who reads them remotely. The patient then receives the diagnosis and is counselled for further treatment and follow-up.
- In case of opportunistic screening, diabetic patients will be screened when they visit a physician or diabetologist.
- Trained technicians take fundus images and direct the patient to the ophthalmologist who advises on treatment and follow-up.
- Patients usually visits diabetologist to monitor the glucose level and few of them examine the fundus status. If they suspect for DR findings, patients will be referred to ophthalmologist.

Supplementary file 2

Semi Structured Interview Guide

Patients

1. Can you describe how you found out about the fact that you had diabetes?
(Probe: what symptoms had been noticed, what was patient's age, what was his/her reaction to the diagnosis)
2. Please describe what all you did in terms of seeking care once you found out about your illness.
(Probe: where and when he/she sought care, whether care sought from places other than SN, any home management done and for how long)
3. How long have you been suffering from diabetes and what have you learnt about its effects on your health?
(Probe: is he/she aware about importance of controlling blood sugar, healthy diet, exercise, regular health checks, the potential negative consequences of diabetes, and impacts on lifestyle)
4. From whom/where have you learnt about your disease and how useful has this been?
(Probe: what he/she thinks about the nature of information given, was it easy to understand, difficult to follow, who provided the information, any reading material given, how useful was it)
5. Can you describe how your health is now and what steps you are taking to protect yourself?
(Probe: how he/she feels about his/her health status, whether he/she comes for regular health checks, how often, any medication being taken, any changes in life style)
6. Are there any specific health problems that you are facing as a result of diabetes?
(Probe: specifically any vision related problems, how/he she is managing this, what advice if any has been given by the health care professionals)
7. What do you know about diabetic retinopathy?
(Probe: what information has been given, what has he/she understood from the information given about what all need to be done to protect his/her eyes, how important does he/she believe this is)
8. Have you ever undergone screening for diabetic retinopathy, when was your last screen?
(Probe: regularity of screening, whether he/she comes regularly as required, what difficulties he she faces in undergoing this, what has been helpful in undergoing screening)
9. What suggestions do you have to get patients to come regularly for diabetic retinopathy screening?
(Probe: how often is acceptable, where would be ideal, what could encourage patients to come regularly)

Semi Structured Interview Guide

Health Care Providers

1. What categories of health professionals are available to care for patient with diabetes at your institution?
(Probe: Primary care, physician/dietician, endocrinologist/Ophthalmologist, Ophthalmic trained nurse)
2. What health promotion and patient education strategies you use for diabetes patients?
(Probe: Clinical services, supportive services at community level)
3. What will be your primary prevention and screening process you follow for Diabetic retinopathy?
(Probe: Primary prevention: change in life style, diet, use of home monitoring like glucometer)
(Probe: Screening for other conditions like nephropathy, neuropathy)
4. What type of informations are taken for DR patients?
(Probe: Do you take history about other complications, about other treatment for eye and diabetes)
5. What will be the understanding about patient's behavior towards diabetes and DR?
(Probe: patient understanding and acceptance of their illness poor compliance fear)
6. What information about individual patients are recorded specifically for DR patients?
(Probe: Risk factors, complications, previous examination, treatments and follow-up)
7. What communication methods are followed currently to have follow-up eye examination?
(Probe: Personal record books, text message such as reminders)
8. How are the interventions for people with DR financed?
(Probe: Funds by govt, private insurance, out of pocket/NGO)
9. What is your opinion about follow-up of Diabetic retinopathy patient?
(Probe: Are they coming regularly as advised, Do they come only if they have symptoms)
10. What reasons usually patient reports for the poor follow-up?
(Probe: Financial problem, Travel, Long waiting time, have they taken any steps to reschedule it)
11. What strategies you feel would make a better follow-up for DR patients?
(Probe: Concession, travel expense, reschedule appointments, free top up)

Supplementary file 3: Integrated approach for DR care

- Currently patients do receive reminders about their next visit. In terms of enhancing access, currently eye care is provided only in specialty hospitals or exclusive eye clinics.
- Government run eye hospitals are also available but most are located in urban areas. Therefore, for people in rural or outlying areas to take the time off to come to the eye hospital is time consuming and would mean a loss of a day's wages.
- However, both government and private run eye hospitals do run outreach camps which help to bring eye care virtually to the door step. Screening for DR also happens in these camps.

Supplementary Table 1: Patient and HCP characteristics

Characteristics of Patients	n(%)	Characteristics of HCPs	n(%)
Gender		Gender	
Male	8(53.3)	Male	3(37.5)
Female	7(46.7)	Female	5(62.5)
Age (years)		Age (years)	
50-60	6(40)	30-40	2(25)
61-70	4(26.7)	41-50	5(62.5)
71-80	5(33.3)	51-60	-
Marital status		61-70	1(12.5)
Married	15(100)	Marital status	
Single	-	Married	7(87.5)
Education level		Single	1(12.5)
Non-literate	3(20)	Professional status	
5 yrs of school	2(13.3)	Ophthalmologist	5(62.5)
6 to 12 yrs of school	5(33.3)	Diabetologist	2(25)
College and above	5(33.3)	Dietician	1(12.5)
Occupation			
House wife	3(20)		
Goldsmith	1(6.6)		
Weaver	2(13.3)		
Self employed	1(6.6)		
Retired	6(40)		
Security guard	1(6.6)		
Household worker	1(6.6)		

Note: HCP, Health Care Provider

Supplementary Table 2: Selected Quotes: Patient's perspectives

Recognizing and living with diabetes	<i>"I went abroad on work, so in that company they conducted free checkup and tested for diabetes. That time only I learnt that I have diabetes". (DM 10, 59 years, M)</i>
	<i>"I was fat previously but gradually my weight started reducing. I felt itching sensation while passing urine. During that time, I had been advised to undergo surgery to remove a tumour in my uterus. So, I assumed that my weight loss and itching was due to the tumour. This was 7 years back, when I consulted the doctor, he said that I had diabetes". (DM 01, 50 years, F)</i>
	<i>"I thought I will not get diabetes, as I am the third son in my family. I was assuming that only the first son will get so I ignored it but finally I also got diabetes". (DM 09, 58 years, M)</i>
	<i>"I was afraid at that time. It is not only difficult for me but also difficult for others in the family. So initially I was scared". (DM 06, 65 years, F)</i>
	<i>"I felt too upset and cried when I came to learn that I have got diabetes.... I was upset that I had got it rather early in my life but now I am in a situation where I can even counsel people". (DM 03, 48 years, F)</i>
	<i>"I took it lightly, I didn't consider it as a disease only. Because my father, grandfather, my mother and father in law, my wife everyone is diabetic, that's why I didn't worry too much". (DM 09, 58 years, M)</i>
	<i>"The reason for keeping my sugar under control these 20 years is due to self-control. I do not touch sweets, have to cheat my tongue. I have completely avoided taking tea, coffee while attending functions also. I have changed my life style. Along with that I do exercise, yoga and walking thereby keeping sugar under control". (DM 10, 59 years, M)</i>
Care Seeking Practices	<i>"When i plan to go for check-up that time only i use to do blood test. Mind is going depressed if i check the blood test frequently. I have prepared my mind like i have come know that i have diabetes and i have to "survive" also".(DM03,48 years, F)</i>
	<i>"I consult with one doctor only. I know him from my childhood days. I have not gone separately to a sugar specialist. I am satisfied with this doctor and there is no problem, so am continuing with him. Why do I need to see 10 doctors, where each one will take a different decision". (DM 04, 67 years, M)</i>
	<i>"I have consulted with 15 doctors but still did not recover. I even tried "naatu vaithiyam" (traditional medicines) for 1.5 months, that to did not help. Every night I will be crying because of this pain and pricking sensation. On seeing this, my son has taken me to so many hospitals, nearly 15 doctors he has taken me to see in just one month. Wherever he advised I have gone there". (DM 02, 55 years, F)</i>
	<i>"Doctors must not threaten the patient. They often tell the patient that they will lose their eyes or kidney or have heart problem, or they will not be able to walk. Whatever information is necessary must be discussed with patient but they must not threaten the patient. If they threaten then the patient is no more going to visit that doctor. My doctors are threatening me now that's why I don't want to consult them. They should say it gently so the patient must not get scared. If the doctor's smiles and talk in a friendly manner, we won't be scared". (DM 06, 65 years, F)</i>
	<i>"Doctor always advises me to reduce the sugar level and the level must not be high at all. He used to ask whether am I walking or not? If I say no then he will insist that I walk. Regarding food intake also they have told me. Dietician has given suggestions to change my food intake pattern". (DM 03, 48 years, F)</i>
Awareness about DR	<i>"Diabetic Retinopathy means eye will get affected and vision will be lost. Nerve surrounding the eye will get weaker; this is called as "Fundus</i>

	<p><i>Retinopathy". Because of diabetes cataract problem will come. Known diabetic patients must take care of eye from getting more affected due to cataract". (DM 13, 76 years, M)</i></p> <p><i>"I heard that directly the vision will get affected, but I don't know which part of eye gets affected. Sometimes it can lead to glaucoma, but am not sure". (DM 10, 59 years, M)</i></p> <p><i>"If we have sugar, glaucoma will come, it will affect eyes, blurred or black spots can happen. Mainly I have heard about this I do not know of any other problem". (DM 05, 66 years, M)</i></p> <p><i>"No, I have not heard from anywhere the term 'diabetic retinopathy'. I have not attended camps for eye care. They (referring to the medical team) have come for camp, but I have not attended". (DM 04, 67 years, M)</i></p> <p><i>"Diabetic retinopathy means nerve will get affected....If your vision is affected from birth then it is ok, but if you lose your vision in the middle of your life then getting back what is lost is very difficult. So, you have to control sugar and have yearly check-up. This is what is advised to us by the doctors". (DM 03, 48 years, F)</i></p>
Barriers to DR Screening	<p><i>"If I have pain I think to go and meet the doctor, if not why do I need to go. If we are normal why do we need to consult the doctor? They will write and give more medicines which will only create more heat in my body because of that I do not go". (DM 06, 65 years, F)</i></p> <p><i>"Eye is fine, so they won't come back. Only when they attain severe stage they will consult, till then they won't know. Financial problem may be the reason. If a person is retired there won't be earning or dependent on a small pension or on the son who may not give money. So 90% is due to financial constraint". (DM 08, 72 years, M)</i></p> <p><i>"Generally, doctors don't have that much time to explain as they are busy. If we ask they tell that they are busy which makes the patient hesitant to ask further questions". (DM 05, 66 years, M)</i></p> <p><i>"It takes a whole day to complete and come back home since it is very far... by the time I return home it will be evening. There is no one to take care of my daughter". (DM 03, 48 years, F)</i></p> <p><i>"If it is nearby then it will be good. This much distance is far for me. I don't come alone, my neighbour only took me here. While going back home my younger son will come to pick up. Since I am diabetic, my family members are scared to send me alone to hospital". (DM 07, 50 years, F)</i></p> <p><i>"Work is there at home so I won't be able to go. There is also no one to accompany me, like while going for blood test or for any other tests". (DM 06, 65 years, F)</i></p>

Note: DM, diabetes mellitus; M, Male; F, Female

Supplementary Table 3: Selected Quotes: HCP's perspectives

<p>Recognizing and living with diabetes</p>	<p><i>"I must highlight that patients often don't understand what is meant by adequate control of diabetes. They say, 'today my blood sugar level is normal'. But the fact that this must be maintained in the long term is often not understood by many patients". (HCP05_Ophthalmologist, 43 years, M)</i></p>
	<p><i>"Patients who are well read, are more careful about their eyes, they come for regular check-up, keep a track of their own condition, ask about their previous test results etc. But there are some patients who are not educated who have extensive disease. When they come, they have no idea what they are coming for. Sometimes even if they are attending for the first time, we know the prognosis is extremely bad. They have never had a check-up or even if it was done nothing much seems to have been explained to them. Even if the doctor is saying the right thing, they are not very compliant. It's very difficult to explain to them and treat them". (HCP 04_Ophthalmologist, 33 years, F)</i></p>
<p>Care Seeking Practices</p>	<p><i>"My way of telling them is even though nothing is a problem always have a regular annual check, you should check especially if you have strong family history. If they are diabetic then my first question will be when was the last time you had an eye check-up? Each and every patient I try and tell them that they should go to a diabetologist. I have seen that most diabetologists have a routine protocol and they have a person who will counsel patients, they also have a chart which states what when tests were done and other details". (HCP 01_ Ophthalmologist, 48 years, F)</i></p>
	<p><i>"We have put up some posters on which is written, "the world is beautiful; don't let diabetic retinopathy prevent you from seeing it, so have your eyes checked today" like that we have some posters put up also. Even the patient waiting area also we have posters. On world diabetes day we run camps and distribute pamphlets which explain about diabetes and retinopathy. There are pamphlets which say "Have your eyes checked early and yearly" like that we have posters, put up. We also conduct slogan contests for our staff and give a small reward, for the best ones". (HCP 07_ Ophthalmologist, 47 years, F)</i></p>
	<p><i>"I think the media has a major role to play. They should not send out wrong messages or incorrect information that should be avoided. The right kind of messages only should go through social media". (HCP 07_ Ophthalmologist, 47 years, F)</i></p>
<p>Awareness about DR and Barrier to DR screening</p>	<p><i>"DR is mostly asymptomatic, till the end stage and they don't understand the importance...even if we tell them you have retinopathy changes, as they don't experience much of vision problems, they find it hard to accept. It is only when they have bleeding or severe vision drop or if somebody else in the family has already had this problem that they understand the seriousness of their condition... awareness is still low"(HCP 07_ Ophthalmologist,47 years, F).</i></p>
	<p><i>"Patients with diabetes for 10-15 years or more have an assumption that if HbA1c is normal then they will not develop diabetic retinopathy. Because they presume that they do not have eye complaints and the sugar level is under control. Few patients got confused diabetic retinopathy treatment (Laser photocoagulation) with cataract surgery (Phaco emulsification). Advice for retinal laser, is often considered as an advice of phaco. (HCP 07_ Ophthalmologist, 47 years, F)</i></p>

	<p><i>“The patient, Indian patient normally reports when there is an acute crisis or acute problem. So this type of slow going process they are not bothered. Unless and until they have some co-morbidity like some difficulties then only they come for consultation”.</i>(HCP 05_Ophthalmologist,43 years, M)</p>
	<p><i>“They have multiple reasons to say (for delaying the follow-up). I just now completed my daughter’s marriage, I don’t have money, to build a new house, financial problem, daughter delivered a baby, I am out of station that’s why I didn’t come, and I thought I will come here but my husband was not well or my daughter was not well they have all lame explanations and excuses”.</i> (HCP 03_Diabetologist, 61 years, M)</p>
	<p><i>“We spend lot of timing in educating the patients, so it’s not one time. Every time when they come in some sort of information will be given to the patient. For that we have a different education method one is interactive lecture section are available. During one to one counselling we have, conversation, map section, group therapies, support group, various mode of education are there”.</i>(HCP08_Dietician, 43 Years, F)</p>
	<p><i>“Sometimes vision is not improving that much and they will say, ‘we are doing all this and coming to you, but vision is not improving’. So, they need to be properly counselled and told that, we may not always be able to improve the vision, but we are here to stabilize the vision, in the process if the vision is improved it is good for you.”</i> (HCP 01_Ophthalmologist, 48 years, F)</p>

Note: HCP, Health Care Provider; DR, diabetic retinopathy; M, Male; F, Female

Standards for Reporting Qualitative Research (SRQR Checklist)

No	Topic	Item
Title and abstract		
S1	Title	Page 1 (Line 2 &3)
S2	Abstract	Page 2 (Line 27-50)
Introduction		
S3	Problem formulation	Page 4-5 (Line 77 to 109)
S4	Purpose or research question	Page 5 (Line 110-114)
Methods		
S5	Qualitative approach and research paradigm	Page 6-7 (Line 126-161)
S6	Researcher characteristics and reflexivity	Page 6 (143-146) & Page 7(155-161)
S7	Context	Page 6 (Line 126-127)
S8	Sampling strategy	Page 6 (Line 139)
S9	Ethical issues pertaining to human subjects	Page 6(Line 127-129)
S10	Data collection methods	Page 6-7 (Line 146-150)
S11	Data collection instruments and technologies	Page 7 (Line 150-151, 156-157)
S12	Units of study	Page 6-7 (Line 139, 147-149)
S13	Data processing	Page 7-8 (Line 170-176)
S14	Data analysis	Page 7 (Line 166-172)
S15	Techniques to enhance trustworthiness	Page 7 (Line 159)
Results/findings		
S16	Synthesis and interpretation	Page 8-15 (Line 178-353)
S17	Links to empirical data	Supplementary table 1,2,3
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Page 15-18 (Line 355-438)
S19	Limitations	Page 18 (Line 441-445)
Other		
S20	Conflicts of interest	Page 19 (Line 466)
S21	Funding	Page 19 (Line 468)

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Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An exploratory study from Southern India

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3 **1 Original article**
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5 **2 Patient and provider perspectives on barriers to screening for Diabetic Retinopathy: An**
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7 **3 exploratory study from Southern India**
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9 **4 *Short title: Barriers to Diabetic Retinopathy screening***

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3 26 **ABSTRACT**
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5 27 **Objective:** Diabetic retinopathy is one of the leading causes of visual impairment after cataract and
6
7 28 uncorrected refractive error. It has major public health implications globally, especially in countries such
8
9 29 as India where the prevalence of diabetes is high. With timely screening and intervention, the disease
10
11 30 progression to blindness can be prevented, but several barriers exist. As compliance to diabetic
12
13 31 retinopathy screening in people with diabetes is very poor in India, this study was conducted to explore
14
15 32 understanding of and barriers to diabetic retinopathy screening from the perspectives of patients and
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17 33 health care providers.

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19
20 34 **Methods:** Using qualitative methods, 15 consenting adult patients with diabetes were selected
21
22 35 purposively from those attending a large tertiary care private eye hospital in southern India. Eight semi-
23
24 36 structured interviews were carried out with health care providers working in large private hospitals. All
25
26 37 interviews were audio-taped, transcribed verbatim and analyzed using the framework analytical approach.

27
28 38 **Results:** Four themes that best explained the data were recognizing and living with diabetes, care seeking
29
30 39 practices, awareness about diabetic retinopathy and barriers to diabetic retinopathy screening. Findings
31
32 40 showed that patients were aware of diabetes but understanding of diabetic retinopathy and its
33
34 41 complications was poor. Absence of symptoms, difficulties in doctor patient interactions and tedious
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36 42 nature of follow-up care were some major deterrents to care seeking reported by patients. Difficulties in
37
38 43 communicating information about diabetic retinopathy to less literate patients, heavy work pressure and
39
40 44 silent progression of the disease were major barriers to patients coming for follow-up care as reported by
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42 45 health care providers.

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45 46 **Conclusions:** Enhancing patient understanding through friendly doctor-patient interactions will promote
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47 47 trust in the doctor. The use of an integrated treatment approach including education by counsellors,
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49 48 setting up of patient support groups, tele-screening approaches and use of conversation maps may prove
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51 49 more effective in the long run.
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3 51 **Strengths and limitations of this study:**
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- 5 52 • This was a qualitative study that explored barriers to diabetic retinopathy (DR) screening from the
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7 53 perspectives of patients and health care providers (HCP) which enabled a more comprehensive
8
9 54 understanding of the phenomenon.
10
11 55 • Insights obtained from patients and providers have given good cues for development of
12
13 56 intervention strategies.
14
15 57 • The study could have benefited from interviews with family members, who play an important
16
17 58 role both in decision-making for care seeking and in providing support to patients.
18
19 59 • A larger patient sample representing a wider patient demographic could have provided wider
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21 60 perspectives.
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23 61 • Inclusion of HCPs from smaller eye clinics would have provided additional perspectives further
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25 62 enhancing understanding of the phenomena.
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76 INTRODUCTION

77 Diabetic retinopathy (DR), a microvascular complication in the eye due to uncontrolled diabetes, has high
78 prevalence in Africa (33.8%) and in the Western Pacific (36.2%) [1]. In another study, the highest age
79 standardized prevalence was among Caucasians at 45.8% with Asians (combined) at 19.9% [2]. Flaxman
80 et al. [3] in their systematic review reported that blindness due to diabetic retinopathy has been on the rise
81 from 1990 till 2015. In India, the disease has major public health implications due to two main reasons, i)
82 an estimated 57 million people will have diabetes by 2025 (195% increase from 1995) and ii) the risk of
83 sight threatening retinopathy is higher in adults with diabetes [4]. Previous population-based studies from
84 India have reported prevalence of diabetic retinopathy to be 10% in rural areas and 18% in urban areas
85 [5]. Moreover sight threatening DR (STDR) affects 5% of people with diabetes, i.e., 4.5 million, which is
86 stated to increase as the number of people with diabetes increases [6].

87
88 The management of diabetic eye disease in India (Supplementary file 1) is influenced by a lack of
89 screening programmes, poor public awareness on diabetic eye disease and poor understanding of the need
90 for regular retinal screening [7]. Most retinal services in India that manage these patients are not publicly
91 funded. There is also a wide variation in provision of health care ranging from highly specialized
92 hospitals to basic facilities without trained ophthalmologists [8].

93
94 Shukla et al. assessed the perceptions of care and challenges faced in availing care among people with
95 diabetes in India and reported that 45% of participants already had vision loss when they first presented to
96 an eye facility and before their DR was even detected [8]. Lingam et al. in their study on the uptake of
97 diabetic retinopathy screening in a pyramidal model of eye health care found that 2% at tertiary level,
98 40% at secondary and 50% at primary level had never undergone previous dilated eye examination [9].
99 Given that 50-70% of DR related visual impairments can be prevented by timely screening and
100 intervention [10], the importance of early identification and regular follow-up cannot be overemphasized.

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3 101 Thus, while DR is one of the leading causes of blindness, vision loss is largely preventable through
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5 102 regular screening and follow-up which continues to be quite inadequate as suggested by previous research
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7 103 [11-14].
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11 105 Several barriers identified to screening for DR ranged from financial burden, lack of awareness about the
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13 106 importance of screening, transportation, language barriers, cultural myths, denial, fear, and depression
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15 107 [15]. Piyasena et al., found that inter-related user, family and institutional factors influenced the uptake of
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17 108 DR screening and follow-up services in the Western Province of Sri Lanka [16]. Factors such as older age
18
19 109 and physical disability have also been found to act as barriers to screening. A study from India
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21 110 highlighted several issues, which included travelling long distances to access the health facility and cost
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23 111 of travel [8]. Patient's belief that their eyes were healthy, not having anybody to accompany them to
24
25 112 health care facilities and financial costs of seeking care were among other barriers reported [17].
26
27 113 However, most of these findings are from quantitative study [15] that by their very design are limited in
28
29 114 terms of their ability to probe, explore and gain deeper insights. Furthermore, these barriers may be
30
31 115 influenced by regional variations. There is thus a paucity of qualitative studies on this topic in India
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33 116 which provided the impetus for this study involving semi-structured interviews (SSIs) with both patients
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35 117 and health care providers (HCPs).
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41 119 We included HCPs for two reasons, i) being care providers their perceptions and experiences would
42
43 120 enable a more holistic understanding of this issue ii) given that HCPs are deeply respected in our culture
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45 121 they could exert a significant role in encouraging patients to get their eyes screened thereby playing an
46
47 122 important role in future interventions. From patients we explored their experiences of living with diabetes,
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49 123 how they coped with their condition in terms of care seeking behaviors as well as life style modifications,
50
51 124 their awareness about DR and their perceptions on barriers towards DR screening. From HCPs, we
52
53 125 explored their perceptions on patient understanding of diabetes and DR, the nature of information about
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126 diabetes and DR provided to patients and what they believed were barriers for accessing DR care. Getting
127 to understand both points of view helped to build deeper understanding of the phenomenon.

128

129 **METHODS**

130 The study was carried out in a tertiary eye care center run by a non-government organization (NGO)
131 located in Chennai, capital of the state of Tamil Nadu in South India. The study was approved by the
132 institutional review board of Vision Research Foundation and adhered to the tenets of the declaration of
133 Helsinki.

134 **Sampling**

135 Adult patients with type 2 diabetes mellitus (DM) aged 50 years and above were considered, because only
136 after a few years of living with DM do patients tend to develop DR. The strongest predictor for DR is the
137 duration of diabetes [18], therefore patients who had been living with DM for a period of five years or
138 more were purposively selected to participate in SSIs. Patients already diagnosed with DR were not
139 included as the emphasis was on awareness about DR, need for eye screening and barriers to screening.
140 Given that 12 interviews are sufficient to reach saturation if the objectives are fairly narrow and the
141 sample not too diverse [19] and keeping in mind feasibility, logistics and the fact that qualitative research
142 is time consuming, we decided on carrying out 15 interviews with patients. We believed this would be
143 adequate to achieve saturation. Using maximum variation sampling we recruited 8 men and 7 women of
144 different ages during the period February to June 2019. The hospital maintains a computerized schedule
145 of patient appointments with various eye specialists inclusive of names of patients, their gender and age.
146 The other details such as education levels and nature of occupation were gathered during the interview.
147 As our focus was on barriers to DR care we reviewed the appointment schedules of the retinal specialists.
148 On the specified dates of the appointments our research team (KG and VS both trained in qualitative
149 research methods by SK), met with patients aged 50 years and above, following their consult and
150 ascertained eligibility. Those eligible were consented to participate in an SSI. The eight HCPs recruited

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3 151 had five or more years of experience working with persons with diabetes. Five ophthalmologists were
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5 152 recruited, three worked at the NGO eye hospital and two were from another private eye hospital. The
6
7 153 remaining HCPs included two diabetologists and one dietician recruited from a diabetes speciality centre.
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10 154 Separate open-ended interview guides (Supplementary file 2) for patients and HCPs, informed by
11
12 155 literature and our prior interactions with patients were developed. Broadly, they elicited information on
13
14 156 patient's understanding of diabetes, perceptions on their experiences and risks of living with it, lifestyle
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16 157 modifications made, care seeking behaviours, understanding of DR, barriers to DR screening and its
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18 158 importance and suggestions on what would be helpful. The participants were escorted to a quiet area in
19
20 159 the hospital where the interviews were carried out. For most patients the interviews were done in Tamil,
21
22 160 the language of communication in our state, while with most HCPs it was in English. Informed consent
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24 161 was obtained from all participants following which interviews were conducted and audio recorded. The
25
26 162 duration of interviews varied from about 35 to 50 minutes. All interviews were transcribed verbatim;
27
28 163 those in Tamil were translated into English for the purpose of analysis. Every transcript was re-checked
29
30 164 with the audio recording by the team to ensure fidelity to the original audio taped interviews before
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32 165 analysis. All data were anonymized to maintain confidentiality.
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36 166 **Patients and public involvement**

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38 167 Patients and public were not involved in the design or conduct of our study.
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42 43 169 **ANALYSIS**

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45 170 Analysis followed the framework analytical approach, [20] which is very suitable for data gathered
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47 171 through SSIs [21] and began by gaining familiarity with each of the transcripts through repeated readings.
48
49 172 We carried out a systematic method of organizing our data into spreadsheets, keeping in mind our
50
51 173 research questions and listed out several categories like, 'understanding of diabetes', 'care-seeking
52
53 174 practices', 'awareness about DR', 'barriers to DR screening' etc. We then began extracting relevant
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55

175 portions of text from each interview related to these categories and went through a process of indexing or
176 sifting through the data; sorting and selecting quotes and placing them under the appropriate categories.
177 Developing and refining our categories in this manner helped us to compare and contrast them and
178 determine the ones that could be meaningfully combined and those that were standalone thereby setting
179 the stage for theme development. In developing themes, we looked for patterns and made decisions on
180 what themes best explained our data and provided important insights.

181

182 **FINDINGS**

183 **Patient and HCP Characteristics**

184 All 15 patients were married and their average age was 63.2 ± 9.2 years. All of them were living with
185 diabetes for several years with an average duration of 15.6 ± 10.8 years and had not received any
186 treatment for diabetic eye disease. The eight HCPs, who participated in the interviews, comprised of 5
187 women and 3 men. Their average age was 44.7 ± 8.1 years and average duration of years of experience
188 was 17 ± 10.5 years (Supplementary table 1).

189

190 **Themes of Analysis**

191 The four themes that best explained the data and addressed our research questions were, i) recognizing
192 and living with diabetes ii) care seeking practices iii) awareness about DR iv) barriers to DR screening.
193 These were explored from the perspectives of both patients and providers. However, the last two themes
194 have been combined and presented for the HCPs so as to succinctly reflect the manner in which they best
195 described the themes.

196

197 **Patient Perspectives**

198 **Recognizing and living with diabetes**

1
2
3 199 Recognition of the fact that they might have diabetes came rather slowly to most patients. For the most
4
5 200 part, the diagnosis of diabetes came as a surprise and a great shock. It often started with minor symptoms
6
7 201 like a tingling feeling in the extremities, frequent urination, itching sensation while passing urine, feeling
8
9 202 unusually thirsty or hungry. These were initially ignored until other symptoms started showing up like
10
11 203 loss of weight, feeling faint and dizzy or a wound that was not healing. Most patients did not even suspect
12
13 204 that they had diabetes and it was only after they were asked to undergo blood sugar tests on the
14
15 205 instruction of the doctor, did they come to learn of their diagnosis. Others spoke of not experiencing any
16
17 206 symptoms at all and learnt of their condition when they underwent a routine health check-up. A female
18
19 207 participant came to know of her diabetes when she underwent surgery for removal of a tumour. Myths
20
21 208 surrounding the disease also emerged with one participant stating that he believed he would not get the
22
23 209 disease as he thought it only affected the first-born son in the family. The realization that this was a
24
25 210 lifelong condition that could seriously spiral out of control if not carefully managed had begun to dawn on
26
27 211 them. A few participants, apart from highlighting their own concerns and worries, were also distressed by
28
29 212 the stress and burden their illness would impose on their family members. These were all typically, their
30
31 213 first reactions to the diagnosis. But with time, regular medication and care provided at their health
32
33 214 facilities their understanding of the disease improved as they came to terms with their disease. Some even
34
35 215 took on a more proactive role by encouraging others who had the disease to be compliant while others
36
37 216 appeared more fatalistic in accepting their situation. Some were more familiar with the disease as their
38
39 217 parents, siblings or close relatives were living with it and consequently were emotionally better prepared
40
41 218 when told of their diagnosis.
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45 219
46
47 220 In terms of their understanding of diabetes, most participants were aware that poor control of their blood
48
49 221 sugar level could result in a host of health problems and complications. Signs and symptoms ranging from
50
51 222 becoming tired easily, losing weight, finding it difficult to work, feeling faint and dizzy to more serious
52
53 223 conditions such as kidneys and liver being affected, severe pain in the feet, suffering a stroke or a heart
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1
2
3 224 attack were reported. It is important to note, that those who had a parent or sibling living with diabetes
4
5 225 reported being attuned to developing symptoms at some point and accepted the inevitability of acquiring
6
7 226 the disease on account of its genetic nature. They were also more aware of the consequences of improper
8
9 227 management and spoke of the risks to their health in terms of developing a stroke. The fact that diabetes
10
11 228 could impair vision leading to possible loss of sight was also reported by many participants.
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15
16 230 The main source of information about diabetes came from their health care providers including doctors
17
18 231 and nurses. A few others learnt more about the disease from books, articles and literature on the internet
19
20 232 as well as from health programmes on television. They felt that doctors were not too forthcoming and
21
22 233 usually did not spend time explaining in detail. Friends, neighbours and family members also served as
23
24 234 another information source, more so, if they were already diagnosed with diabetes.
25
26
27 235

28 236 **Care Seeking Practices**

29
30 237 Although many patients never thought to seek care when symptoms initially started, once diagnosed they
31
32 238 became more alert to the need to seek regular health care. Based on the advice given by their doctors, they
33
34 239 started attending clinics to get their blood sugar checked. One female participant spoke of feeling
35
36 240 depressed each time she underwent a blood sugar test as the test brought home to her the fact that she had
37
38 241 diabetes and had to somehow "*survive with the disease*". While participants appreciated the necessity of
39
40 242 these periodic visits to test their blood sugars, they nevertheless found them to be tedious. Therefore,
41
42 243 recommendations by doctors to undergo further tests like an eye test for example was seen as an added
43
44 244 burden both in time and cost and was often resisted. A few participants emphasized the importance of
45
46 245 consistently seeing the same doctor so as to avoid unnecessary confusion from varying recommendations.
47
48 246 In this context, the manner in which doctors communicated to patients influenced the level of trust and
49
50 247 how well patients would comply with their advice. Participants believed that doctors needed to speak
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52 248 gently and not frighten them with harsh consequences which would only result in them going to another
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249 doctor. While they agreed that all necessary information needed to be communicated, this needed to be
250 done in a friendly and non-threatening manner so as to instill confidence.

251
252 Use of alternate medicines like Ayurveda was not the preferred choice for most participants although a
253 few reported taking it along with their regular allopathic medication as they felt that Ayurveda by itself
254 would not be effective in treating them. They all spoke of the importance of eating a balanced diet, of
255 exercising regularly, taking their medication as advised and of regular follow-up with a physician. To this
256 end, most participants had modified their lifestyles, although to varying degrees. They reported cutting
257 down on rice-based food items and sweets and exercising to the extent possible. While some indicated
258 that they had no difficulty in changing their diet, others found it difficult. Similarly, regular exercise too
259 posed a challenge with many indicating lack of time, poor motivation and complaints of body aches.

260

261 **Awareness about DR**

262 The findings revealed a mixed picture regarding awareness about DR. For most, it was not a familiar term
263 while a few were aware of it and of the need to undergo regular retinal screening. The understanding that
264 diabetes could affect their eyes and that their vision could be impaired had been gleaned through
265 interactions with doctors, other health staff they came into contact with and through posters on diabetes
266 on display in the hospitals they had been to. Issues about the potential threat to their eyes on account of
267 diabetes were often reiterated during these visits. Participants were more familiar with other eye problems
268 like glaucoma and cataract but for the most part remained unaware of the details and symptom
269 manifestations of DR, and of possible preventive measures that needed to be taken to protect their eyes
270 from DR. Only a couple of participants indicated that they had been informed about possible risks to their
271 eyes on account of diabetes or of the precautions they needed to take to protect their eyes. The few who
272 had heard about DR, described it as a condition wherein the “*nerve would get affected*”. They spoke of
273 the importance of eye care, of regular eye checkup and the importance of keeping their blood sugar level

274 under control as ways and means of protecting their eyes. Such participants were generally better
275 educated, tended to discuss their health issues with their doctors and were more compliant.

276

277 **Barriers to DR Screening**

278 Among those unfamiliar or less aware about DR, several issues emerged which acted as barriers to
279 seeking eye care. A typical one related to consulting a doctor only if there was pain or some discomfort in
280 the eye. In the absence of any symptoms it was deemed unnecessary to seek such eye care. Participants
281 also feared that undergoing eye screenings and tests could result in more medicines being prescribed.
282 Apart from concerns about cost and managing the dosage, they believed that these medicines meant more
283 chemicals being ingested which was perceived as harmful as it contributed to excessive “heat”. Others
284 complained about doctors being too busy and of not having the time to talk to patients about all the dos
285 and don’ts regarding diabetic eye care. If the doctor appeared too curt or busy, patients felt dissatisfied.
286 But, patients who indicated that they were doing well were generally satisfied with the care received and
287 also tended to be more adherent to the doctor’s advice. Other issues involved the logistics of travelling to
288 the health facility, costs associated with undergoing the tests, not having the time to go for a check-up on
289 account of work and family commitments. Some women participants spoke of not having anyone to
290 accompany them to the health facility and almost all described the long hours they had to spend in the
291 hospital to undergo these tests as major deterrents. Lastly, a sense of complacency and a lack of
292 motivation were also cited as reasons for participants failing to seek regular care. In this context, one
293 suggestion was for the hospital to send regular reminders to patients in the form of phone calls or phone
294 messages informing patients that they were due for a check-up and encouraging them to visit the hospital.
295 The above mentioned patient’s perspectives are summarized in supplementary table 2.

296

297 **HCPs Perspectives**

298 **Recognizing and living with diabetes**

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2
3 299 The HCPs believed that people were largely aware about diabetes, referred to it as “*sugar disease*” and
4
5 300 understood that it required them to control their diet, restrict sweet intake and exercise regularly. Greater
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7 301 visibility of the disease was attributed to its high prevalence and widespread media coverage which had
8
9 302 contributed to considerable awareness among people. Patients who were educated were more aware and
10
11 303 had access to a wide range of information sources, like the internet, medical literature and health-related
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13 304 broadcasts on radio and television. These patients also sought further clarifications from their doctors and
14
15 305 even questioned them when in doubt. On the other end of the spectrum were the poorer, often less
16
17 306 educated patients who were not so knowledgeable about the disease and who also tended to be less
18
19 307 compliant. The HCPs also spoke about issues concerning monitoring and controlling blood sugar levels
20
21 308 which according to them was often not adequately maintained or even understood by patients. Thus,
22
23 309 patients were generally aware about the disease, but the extent and depth of knowledge of what exactly
24
25 310 they were up against varied considerably. In this context, the importance of proper counselling that would
26
27 311 educate patients about diabetes and motivate them to attend regular reviews to the hospital was stressed.
28
29 312 A few HCPs suggested the importance of exposing patients to all the possible diabetes - related
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31 313 complications by showing them pictures or getting them to meet other patients. This would impress upon
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33 314 patients the seriousness of the problem.
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39 316 **Care Seeking Practices**

40
41 317 In terms of issues related to care seeking, all HCPs uniformly said that in addition to telling patients about
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43 318 the disease, its symptom manifestations and its management strategies, they reiterated the need to undergo
44
45 319 periodic blood tests to monitor their blood sugar level and ensure that they kept it under control. The
46
47 320 importance of seeking care from a diabetologist was also stressed as these doctors had the expertise to
48
49 321 guide and appropriately advise patients. Further, they advised that as the disease could affect any of their
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51 322 internal organs and was basically a “*silent killer*”, it was imperative that patients underwent regular
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53 323 check-up. Usually the information was conveyed to patients often with the use of printed pamphlets every
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3 324 time the patient visited the health facility. One HCP, an ophthalmologist, declared that he typically
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5 325 advised his diabetic patients to undergo an HbA1c in addition to fasting and post prandial blood tests. He
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7 326 also advised them to undergo kidney and liver function tests and check their cholesterol and blood
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9 327 pressure as their diabetes could get exacerbated by other prevailing co-morbidities. The HCPs thus spoke
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11 328 of following a fairly structured protocol which also entailed constantly emphasizing the importance of
12
13 329 lifestyle modifications as being critical to maintaining health. Use of posters and slogans educating people
14
15 330 about the disease and emphasizing the importance of regular care were also highlighted. A barrier to
16
17 331 proper care highlighted by the HCPs was the availability of a plethora of information on social media
18
19 332 sites about diabetes and related health problems. Most of this information was either inadequate or
20
21 333 incorrect and those who tended to follow it did so at great cost to themselves. Another HCP, a dietician
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23 334 spoke of gearing the information to the patient's level of understanding, breaking it down to simple dos
24
25 335 and don'ts which she felt was easier for the patient to follow. This was feasible for her to do as she had
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27 336 more time with the patient unlike the doctors. Patient's motivation levels and presence of good family
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29 337 support were also seen as aids to good compliance.
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35 339 **Awareness about DR and Barrier to DR screening**

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37 340 The general opinion among the HCPs was that awareness about DR was still poor in patients with very
38
39 341 few having heard of it. They accepted that patients knew that diabetes could affect the eyes, were familiar
40
41 342 with cataract but for the most, remained unaware of DR. One HCP, an ophthalmologist described two
42
43 343 types of diabetic patients: i) those who remained unaware that the disease could affect their eyes and
44
45 344 blamed their doctors for failing to educate them adequately and ii) those who despite being asked to
46
47 345 attend a retinal screening failed to do so as they did not suffer any symptoms. This silent and quiet
48
49 346 progression of DR where patients largely experienced no symptoms resulted in patients not perceiving the
50
51 347 need to seek care thereby seriously compromising their vision. In this context, one HCP said that many
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53 348 Indian patients normally come for a check-up when there is an "*acute crisis or acute problem*" and unless
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3 349 and until they experienced some difficulties, they usually did not seek care. Cost and lack of time were
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5 350 other issues particularly for poorer persons and those working on daily wages resulting in delays in
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7 351 seeking care. Explaining the nuances of the disease to such patients who often tended to have low literacy
8
9 352 was found to be quite a challenge. Lack of motivation; financial problems; absence of good family/social
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11 353 support in terms of someone to accompany them to the hospital and slow improvement in vision
12
13 354 following initiation of treatment, acted as deterrents to continued care seeking. Patients also tended to be
14
15 355 complacent if their blood sugar levels were under control, little realizing that the longer the duration of
16
17 356 diabetes, greater was their risk of developing DR. The above mentioned HCP perspectives are mentioned
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19 357 in supplementary table 3.
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23 24 359 **DISCUSSION**

25
26 360 This qualitative study has provided important insights into barriers to regular screening for DR from the
27
28 361 perspectives of patient and providers across four themes, i) recognizing and living with diabetes, ii) care
29
30 362 seeking practices, iii) awareness about DR and iv) barriers to DR screening. Patients were largely aware
31
32 363 of diabetes, its symptoms, importance of diet and medication management and of exercise which were
33
34 364 also endorsed by the HCPs. It was also evident that the management of this disease imposed a tremendous
35
36 365 burden on both HCPs and patients alike. For providers, communicating the complexities of the disease in
37
38 366 words that patients could understand and keeping them motivated to ensure good compliance proved
39
40 367 challenging. For patients the burden of constantly having to follow a healthy lifestyle, being systematic in
41
42 368 seeking care combined with a lack of depth in their understanding of the disease contributed to them
43
44 369 feeling overwhelmed and frustrated, even depressed.
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49 371 A study by Li D [22], highlighted the importance of addressing depression in people with diabetes and
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51 372 recommended the need to motivate patients to exercise and follow a healthy lifestyle. The fact that
52
53 373 diabetes can affect the eyes was reported by most although awareness about DR was poor, a fact

1
2
3 374 confirmed by the HCPs. Poor understanding of DR has also been reported by patients in other studies
4
5 375 wherein they expressed having no knowledge about the possibility of becoming blind on account of
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7 376 diabetes [23,24]. In another study [25], despite most participants being aware about the need to undergo
8
9 377 eye examinations there was limited understanding about retinopathy and about the rationale behind the
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11 378 recommendation.
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16 380 Apart from feeling overwhelmed and frustrated with the care routines, the prospect of having to spend a
17
18 381 more than half a day at the hospital, as health facilities here are mostly very crowded, was another major
19
20 382 deterrent to care seeking for DR. Patients therefore tended to delay seeking care and clung to the belief
21
22 383 that as they were feeling alright there was no requirement to go to the hospital. This absence of symptoms
23
24 384 which created a sense of complacency among patients, which was also a theme reported in the
25
26 385 systematic review by Graham-Rowe et al. [26], emerged as a major deterrent to undergoing eye screening
27
28 386 for DR in our study. Patients questioned the need to undergo eye tests which were usually tedious and
29
30 387 required them to spend long hours in the hospital. Further, they feared having to take more medications
31
32 388 that they thought were unnecessary as they experienced no symptoms. Besides, it meant ingesting more
33
34 389 chemicals contributing to excessive heat in their bodies. This cultural belief in the concept of excessive
35
36 390 heat and cold attributed to both modern medicines and foods dates back to the Charaka
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38 391 Samhita, a Sanskrit text on Ayurveda (Indian traditional medicine) and has deep roots in the minds of
39
40 392 people [27,28]. The HCPs agreed that the silent progression of DR was a deterrent to early care seeking
41
42 393 and spoke of difficulties they faced in getting patients to understand the importance of early and regular
43
44 394 eye screening and testing.
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49 396 Thus, strategies that enhance patient understanding of the disease are needed. In this context, a study
50
51 397 carried out by Trento et al. [29], showed that patients who participated in group sessions understood DR
52
53 398 better. The effectiveness of peer support as a method of increasing uptake of DR screening is a concept
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3 399 that is to be tested in a proposed trial in Kenya [30]. Such studies will help to prove whether being part of
4
5 400 a peer groups enhances long term support to group members thereby acting as an incentive to remain
6
7 401 compliant. In our setting, educating patients about diabetes is mostly didactic, and happens during the
8
9 402 brief consultation sessions with the doctors and subsequently during their interaction with other health
10
11 403 care staff. HCPs have found communication packages like conversation maps, which are interactive
12
13 404 illustrations, helpful to educate patients with DM about the importance of self-care, as a means to
14
15 405 prevent/delay the onset of related complications [31]. Tele-screening has been found to be promising in
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17 406 terms of improving compliance apart from being cost effective [32] for a rural population. Improving
18
19 407 awareness about diabetes and its complications among community health workers such as the Accredited
20
21 408 Social Health Activists (ASHA) in India, which has worked well for other health issues like maternal and
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23 409 child health and infectious diseases like HIV [33, 34] may be a way forward. Future research could test
24
25 410 the application of such strategies.
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30
31 412 Another important point that emerged was the nature of the doctor-patient interactions. Many patients
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33 413 were critical of doctors who they felt did not explain adequately or were always in a rush. Some spoke of
34
35 414 the manner in which doctors communicated to them leaving them feeling threatened and frightened, and
36
37 415 therefore more likely to switch to another doctor. They felt confused when meeting different doctors on
38
39 416 account of their conflicting opinions. Patients looked to their HCPs for support and encouragement that
40
41 417 was often not forthcoming on account of their busy schedules. Doctors are often hard pressed for time
42
43 418 which compromises their ability to spend quality time with patients, a feature that was highlighted by
44
45 419 many in our study. The HCPs felt that despite repeatedly talking to patients about the disease and its
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47 420 complications many patients did not appreciate the importance of regularly monitoring and maintaining
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49 421 their blood sugar levels and attending for eye screening. They expressed difficulties communicating to
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51 422 less literate persons who were often shown to be less compliant. The need of patients for HCPs to be more
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53 423 approachable has been expressed by patients in other studies as well. Peel [35], reported that participants
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3 424 in her study wanted more support and information from their HCPs and felt frustrated as many of their
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5 425 concerns had not been answered. Maddigan [36], described the value of good patient-provider
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7 426 relationships as contributing to good exercise adherence thereby improving quality of life.
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10 427

11 428 It is apparent that HCPs play a pivotal role in promoting understanding of the disease given the almost
12
13 429 reverential position they occupy in our culture. At the same time, patient's expectations of doctors are
14
15 430 also very high and if they feel that they are not improving to their satisfaction, an element of distrust and
16
17 431 unhappiness tends to creep in which in turn colours their opinions. Our study findings further showed that
18
19 432 there is a gap between what is conveyed to patients by the HCPs, and how much of that is actually
20
21 433 understood by them. Perhaps the strategy of 'one size fits all' wherein standard information is provided to
22
23 434 all patients needs to be addressed in the form of health care awareness and education by counsellors [37,
24
25 435 38]. Due consideration to a patient's understanding capacity, self-efficacy, attitudes and health beliefs
26
27 436 [39] which exert an influence on their lifestyle management would aid HCPs improve their
28
29 437 communication skills and enhance patient understanding. Reducing the burden on doctors, perhaps by
30
31 438 building a comprehensive diabetic care team comprising of trained personnel, some of whom could take
32
33 439 on the role of educating, and counselling patients while doctors could focus on care delivery could be a
34
35 440 possible strategy. Educating people about the skill sets and roles of each member of the team will also be
36
37 441 essential to promote acceptance. Such an integrated approach where care of diabetes and its complications
38
39 442 are available under one roof, literally a 'one-stop shop', indicative of a paradigm shift compared to what
40
41 443 is currently practiced (Supplementary file 1), seems the most logical way going forward.
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47 445 This qualitative study by exploring perspectives of both patients and HCPs has provided useful insights
48
49 446 which have the potential to guide future intervention development. The study could have benefited from
50
51 447 interviews with family members, who play an important role in decision-making for care seeking and in
52
53 448 providing support to patients. Inclusion of HCPs from smaller eye clinics would have provided additional
54
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449 perspectives further enhancing understanding of the phenomena. A larger patient sample representative of
450 a wider patient demographic could perhaps have brought in more perspectives.

451

452 CONCLUSION

453 Living with and managing diabetes is a lifelong process, one that can prove overwhelming to an
454 unprepared patient. It is therefore imperative that steps to ensure good patient compliance be prioritized.
455 Enhancing patient understanding through healthy and friendly doctor-patient interactions and use of an
456 integrated treatment approach including education by counsellors, setting up patient support groups, tele-
457 screening approaches and use of conversation maps are some strategies that may prove more effective in
458 enhancing compliance for DR care.

459

460 Declarations:

- 461 • **Ethics approval and consent to participant**

462 The study was approved by the Institutional Review Board (Ethics committee), Vision Research
463 Foundation and written consent was obtained from the patients as per the Declaration of Helsinki.

- 464 • **Consent for publication**

465 Not applicable

- 466 • **Availability of data and materials**

467 The datasets generated during and/or analysed during the current study are not publicly available,
468 as it is against the organization hospital policy. They can however, be made available from the
469 corresponding author on reasonable request.

- 470 • **Competing interests**

471 None declared

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2
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10
11
12 478 • **Authors contributions:**

13
14 479 R.R and S.K; contributed to the conception and design of the study. S.K wrote the main
15
16 480 manuscript text and guided the analyses. G.K and S.V assisted with data collection and analyses.
17
18 481 R.R, S.K, G.K and S.V drafted the work and S.P, P.R and S.S substantively revised it. All authors
19
20 482 reviewed the manuscript.
21
22 483

23
24 484 **REFERENCES:**

- 25
26 485 1. Thomas RL, Halim S, Gurudas S, et al. IDF Diabetes Atlas: A review of studies utilising retinal
27
28 486 photography on the global prevalence of diabetes related retinopathy between 2015 and 2018.
29
30 487 *Diabetes Res Clin Pract* 2019;157:107840.
31
32 488 2. Yau JW, Rogers SL, Kawasaki R, et al. Global prevalence and major risk factors of diabetic
33
34 489 retinopathy. *Diabetes care* 2012;35:556-64.
35
36 490 3. Flaxman SR, Bourne RR, Resnikoff S, et al. Global causes of blindness and distance vision
37
38 491 impairment 1990–2020: a systematic review and meta-analysis. *Lancet Glob Health*
39
40 492 2017;5:e1221-34.
41
42 493 4. King H, Aubert RE, Herman WH. Global burden of diabetes, 1995–2025: prevalence, numerical
43
44 494 estimates, and projections. *Diabetes care* 1998;21:1414-31.
45
46 495 5. Raman R, Gella L, Srinivasan S, et al. Diabetic retinopathy: An epidemic at home and around the
47
48 496 world. *Indian J Ophthalmol* 2016;64:69-75.
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 497 6. Gilbert C, Gordon I, Mukherjee CR, et al. Guidelines for the prevention and management of
4
5 498 diabetic retinopathy and diabetic eye disease in India: A synopsis. *Indian Journal of*
6
7 499 *Ophthalmology*. *Indian J Ophthalmol* 2020;68(Suppl 1):S63.
8
9 500 7. Ramasamy K, Raman R, Tandon M. Current state of care for diabetic retinopathy in India. *Curr*
10
11 501 *Diab Rep* 2013;13:460-8.
12
13
14 502 8. Shukla R, Gudlavalleti MV, Bandyopadhyay S, et al. Perception of care and barriers to treatment
15
16 503 in individuals with diabetic retinopathy in India: 11-city 9-state study. *Indian J Endocrinol Metab*
17
18 504 2016;20(Suppl 1):S33-S41. doi:10.4103/2230-8210.179772.
19
20 505 9. Lingam S, Rani PK, Sheeladevi S, et al. Knowledge, attitude and practices on diabetes,
21
22 506 hypertension and diabetic retinopathy and the factors that motivate screening for diabetes and
23
24 507 diabetic retinopathy in a pyramidal model of eye health care. *Rural Remote Health* 2018;18:4304.
25
26 508 <https://doi.org/10.22605/RRH4304>.
27
28 509 10. Coney JM. Addressing unmet needs in diabetic retinopathy. *Am J Manag Care* 2019;25(16
29
30 510 Suppl):S311-6.
31
32 511 11. Vengadesan N, Ahmad M, Sindal MD, et al. Delayed follow-up in patients with diabetic
33
34 512 retinopathy in South India: social factors and impact on disease progression. *Indian J Ophthalmol*
35
36 513 2017;65:376-84.
37
38 514 12. Rohan TE, Frost CD, Wald NJ. Prevention of blindness by screening for diabetic retinopathy: a
39
40 515 quantitative assessment. *BMJ* 1989;299:1198-201.
41
42 516 13. Namperumalsamy P, Nirmalan PK, Ramasamy K. Developing a screening program to detect sight-
43
44 517 threatening diabetic retinopathy in South India. *Diabetes Care* 2003;26:1831-5.
45
46 518 14. Kashim RM, Newton P, Ojo O. Diabetic retinopathy screening: A systematic review on patients'
47
48 519 non-attendance. *Int J Environ Res Public Health* 2018;15:157.
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 520 15. Lu Y, Serpas L, Genter P, et al. Divergent Perceptions of Barriers to Diabetic Retinopathy
4
5 521 Screening Among Patients and Care Providers, Los Angeles, California, 2014–2015. *Prev Chronic*
6
7 522 *Dis* 2016;13:160193. DOI: <http://dx.doi.org/10.5888/pcd13.160193>
8
9
10 523 16. Piyasena MM, Murthy GV, Yip JL, et al. A qualitative study on barriers and enablers to uptake of
11
12 524 diabetic retinopathy screening by people with diabetes in the Western Province of Sri Lanka. *Trop*
13
14 525 *Med Health* 2019;47:34.
15
16
17 526 17. Peng PH, Laditka SB, Lin HS, et al. Factors associated with retinal screening among patients with
18
19 527 diabetes in Taiwan. *Taiwan J Ophthalmol*. 2019;9:185-93.
20
21 528 18. Raman R, Rani PK, Racheppalle SR, et al. Prevalence of diabetic retinopathy in India: Sankara
22
23 529 Nethralaya diabetic retinopathy epidemiology and molecular genetics study report 2. *Ophthalmol*
24
25 530 2009;116:311-8.
26
27 531 19. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data
28
29 532 saturation and variability. *Field Methods* 2006;18:59-82.
30
31 533 20. Ritchie J, Lewis J, Nicholls CM, et al. Qualitative research practice: A guide for social science
32
33 534 students and researchers:: sage 2013.
34
35 535 21. Gale NK, Heath G, Cameron E, et al. Using the framework method for the analysis of qualitative
36
37 536 data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:1-8.
38
39 537 22. Li D, Inouye J, Davis J, et al. Associations between psychosocial and physiological factors and
40
41 538 diabetes health indicators in Asian and Pacific Islander adults with type 2 diabetes. *Res Theory*
42
43 539 *Nurs Pract* 2013;2013.
44
45 540 23. Pasagian-Macaulay A, Basch CE, Zybert P, et al. Ophthalmic knowledge and beliefs among
46
47 541 women with diabetes. *Diabetes Educ* 1997;23:433-7.
48
49
50
51
52
53
54
55
56
57
58
59
60

- 1
2
3 542 24. Lewis K, Patel D, Yorston D, et al. A qualitative study in the United Kingdom of factors
4
5 543 influencing attendance by patients with diabetes at ophthalmic outpatient clinics. *Ophthalmic*
6
7 544 *Epidemiol* 2007;14:375-80.
- 8
9 545 25. Hartnett ME, Key IJ, Loyacano NM, et al. Perceived barriers to diabetic eye care: qualitative study
10
11 546 of patients and physicians. *Arch Ophthalmol* 2005;123:387-91.
- 12
13 547 26. Graham-Rowe E, Lorencatto F, Lawrenson JG, et al. Barriers to and enablers of diabetic
14
15 548 retinopathy screening attendance: a systematic review of published and grey literature. *Diabet Med*
16
17 549 2018;35:1308-19.
- 18
19 550 27. Selin H. A History of Indian Medical Literature; 2002.
- 20
21 551 28. Satyavati GV. The Legacy of Caraka; 2003.
- 22
23 552 29. Trento M, Bajardi M, Borgo E, et al. Perceptions of diabetic retinopathy and screening procedures
24
25 553 among diabetic people. *Diabet Med* 2002;19:810-3.
- 26
27 554 30. Mwangi N, Gakuo E, Gichuhi S, et al. Effectiveness of peer support to increase uptake of retinal
28
29 555 examination for diabetic retinopathy: study protocol for the DURE pragmatic cluster randomized
30
31 556 clinical trial in Kirinyaga, Kenya. *BMC Public Health* 2018;18:871.
- 32
33 557 31. Carvalho SL, Ferreira MA, Medeiros JM, et al. Conversation map: an educational strategy in the
34
35 558 care of elderly people with diabetes mellitus. *Revista brasileira de enfermagem*. 2018;71:925-9.
- 36
37 559 32. Rachapelle S, Legood R, Alavi Y, et al. The cost-utility of telemedicine to screen for diabetic
38
39 560 retinopathy in India. *Ophthalmol* 2013;120:566-73.
- 40
41 561 33. Lassi ZS, Bhutta ZA. Community-based intervention packages for reducing maternal and neonatal
42
43 562 morbidity and mortality and improving neonatal outcomes. *Cochrane Database Syst Rev* 2015.
44
45 563 Art. No.: CD007754. DOI: 10.1002/14651858.CD007754.pub3.
- 46
47 564 34. Busza J, Dauya E, Bandason T, et al. The role of community health workers in improving HIV
48
49 565 treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. *Health*
50
51 566 *Policy Plann* 2018;33:328-34.

- 1
2
3 567 35. Peel E, Parry O, Douglas M, et al. Diagnosis of type 2 diabetes: a qualitative analysis of
4
5 568 patients' emotional reactions and views about information provision. *Patient Educ Couns*
6
7 569 2004;53:269-75.
8
9 570 36. Maddigan SL, Majumdar SR, Johnson JA. Understanding the complex associations between
10
11 571 patient-provider relationships, self-care behaviours, and health-related quality of life in type
12
13 572 2diabetes: A structural equation modeling approach. *Qual Life Res* 2005;14:1489-500.
14
15 573 37. Malathy R, Narmadha MP, Jose MA, et al. Effect of a diabetes counseling programme on
16
17 574 knowledge, attitude and practice among diabetic patients in Erode district of South India. *J Young*
18
19 575 *Pharm* 2011;3:65-72.
20
21 576 38. Adepu R, Rasheed A, Nagavi BG. Effect of patient counseling on quality of life in type-2 diabetes
22
23 577 mellitus patients in two selected South Indian community pharmacies: A study. *Indian J Pharm*
24
25 578 *Sci* 2007;69:519.
26
27 579 39. Peel E, Douglas M, Lawton J. Self monitoring of blood glucose in type 2 diabetes: longitudinal
28
29 580 qualitative study of patients' perspectives. *BMJ* 2007;335:493.
30
31 581
32
33 582
34
35 583
36
37 584
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39 585
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Supplementary file 1

DR screening in India

- There is no national screening programme for DR in India and the retinal services for patients are not funded.
- In hospitals annual retinal check-up system is initiated to monitor the retinal complications among diabetic patients. Based on the severity of DR follow-up is advised by an ophthalmologist and corresponding treatment is given.
- In India, retinal screening is carried out in camps, telemedicine and opportunistic screening. With telemedicine, retinal screening camps are managed by ophthalmologists and local community workers.
- With help of mobile van facilities, retinal images are obtained and transmitted to an expert who reads them remotely. The patient then receives the diagnosis and is counselled for further treatment and follow-up.
- In case of opportunistic screening, diabetic patients are screened when they visit a physician or diabetologist.
- Trained technicians take fundus images and direct the patient to the ophthalmologist who advises on treatment and follow-up.
- Patients usually visit a diabetologist to monitor the glucose level and few of them examine the fundus status. If they suspect DR, patients are referred to an ophthalmologist.

Integrated approach for DR care

- Currently patients do receive reminders about their next visit. In terms of enhancing access, currently eye care is provided only in specialty hospitals or exclusive eye clinics.
- Government run eye hospitals are also available but most are located in urban areas. For people in rural or outlying areas to take time off to come to the eye hospital, is time consuming and would mean loss of a day's wages.
- However, both government and private run eye hospitals do run outreach camps which help to bring eye care virtually to the door step. Screening for DR also happens in these camps.

Supplementary file 2

Semi Structured Interview Guide

Patients

1. Can you describe how you found out about the fact that you had diabetes?
(Probe: what symptoms had been noticed, what was patient's age, what was his/her reaction to the diagnosis)
2. Please describe what all you did in terms of seeking care once you found out about your illness.
(Probe: where and when he/she sought care, whether care sought from places other than SN, any home management done and for how long)
3. How long have you been suffering from diabetes and what have you learnt about its effects on your health?
(Probe: is he/she aware about importance of controlling blood sugar, healthy diet, exercise, regular health checks, the potential negative consequences of diabetes, and impacts on lifestyle)
4. From whom/where have you learnt about your disease and how useful has this been?
(Probe: what he/she thinks about the nature of information given, was it easy to understand, difficult to follow, who provided the information, any reading material given, how useful was it)
5. Can you describe how your health is now and what steps you are taking to protect yourself?
(Probe: how he/she feels about his/her health status, whether he/she comes for regular health checks, how often, any medication being taken, any changes in life style)
6. Are there any specific health problems that you are facing as a result of diabetes?
(Probe: specifically any vision related problems, how/he she is managing this, what advice if any has been given by the health care professionals)
7. What do you know about diabetic retinopathy?
(Probe: what information has been given, what has he/she understood from the information given about what all need to be done to protect his/her eyes, how important does he/she believe this is)
8. Have you ever undergone screening for diabetic retinopathy, when was your last screen?
(Probe: regularity of screening, whether he/she comes regularly as required, what difficulties he she faces in undergoing this, what has been helpful in undergoing screening)
9. What suggestions do you have to get patients to come regularly for diabetic retinopathy screening?
(Probe: how often is acceptable, where would be ideal, what could encourage patients to come regularly)

Semi Structured Interview Guide

Health Care Providers

1. What categories of health professionals are available to care for patient with diabetes at your institution?
(Probe: Primary care, physician/dietician, endocrinologist/Ophthalmologist, Ophthalmic trained nurse)
2. What health promotion and patient education strategies you use for diabetes patients?
(Probe: Clinical services, supportive services at community level)
3. What will be your primary prevention and screening process you follow for Diabetic retinopathy?
(Probe: Primary prevention: change in life style, diet, use of home monitoring like glucometer)
(Probe: Screening for other conditions like nephropathy, neuropathy)
4. What type of informations are taken for DR patients?
(Probe: Do you take history about other complications, about other treatment for eye and diabetes)
5. What will be the understanding about patient's behavior towards diabetes and DR?
(Probe: patient understanding and acceptance of their illness poor compliance fear)
6. What information about individual patients are recorded specifically for DR patients?
(Probe: Risk factors, complications, previous examination, treatments and follow-up)
7. What communication methods are followed currently to have follow-up eye examination?
(Probe: Personal record books, text message such as reminders)
8. How are the interventions for people with DR financed?
(Probe: Funds by govt, private insurance, out of pocket/NGO)
9. What is your opinion about follow-up of Diabetic retinopathy patient?
(Probe: Are they coming regularly as advised, Do they come only if they have symptoms)
10. What reasons usually patient reports for the poor follow-up?
(Probe: Financial problem, Travel, Long waiting time, have they taken any steps to reschedule it)
11. What strategies you feel would make a better follow-up for DR patients?
(Probe: Concession, travel expense, reschedule appointments, free top up)

Supplementary table 1

Patient and HCP characteristics

Characteristics of Patients	n(%)	Characteristics of HCPs	n(%)
Gender		Gender	
Male	8(53.3)	Male	3(37.5)
Female	7(46.7)	Female	5(62.5)
Age (years)		Age (years)	
50-60	6(40)	30-40	2(25)
61-70	4(26.7)	41-50	5(62.5)
71-80	5(33.3)	51-60	-
Marital status		61-70	1(12.5)
Married	15(100)	Marital status	
Single	-	Married	7(87.5)
Education level		Single	1(12.5)
Non-literate	3(20)	Professional status	
5 yrs of school	2(13.3)	Ophthalmologist	5(62.5)
6 to 12 yrs of school	5(33.3)	Diabetologist	2(25)
College and above	5(33.3)	Dietician	1(12.5)
Occupation			
House wife	3(20)		
Goldsmith	1(6.6)		
Weaver	2(13.3)		
Self employed	1(6.6)		
Retired	6(40)		
Security guard	1(6.6)		
Household worker	1(6.6)		

Note: HCP, Health Care Provider

Supplementary table 2: Selected Quotes: Patient's perspectives

Recognizing and living with diabetes	<i>"I went abroad on work, so in that company they conducted free checkup and tested for diabetes. That time only I learnt that I have diabetes". (59 years, M)</i>
	<i>"I was fat previously but gradually my weight started reducing. I felt itching sensation while passing urine. During that time, I had been advised to undergo surgery to remove a tumour in my uterus. So, I assumed that my weight loss and itching was due to the tumour. This was 7 years back, when I consulted the doctor, he said that I had diabetes". (50 years, F)</i>
	<i>"I thought I will not get diabetes, as I am the third son in my family. I was assuming that only the first son will get so I ignored it but finally I also got diabetes". (58 years, M)</i>
	<i>"I was afraid at that time. It is not only difficult for me but also difficult for others in the family. So initially I was scared". (65 years, F)</i>
	<i>"I felt too upset and cried when I came to learn that I have got diabetes.... I was upset that I had got it rather early in my life but now I am in a situation where I can even counsel people". (48 years, F)</i>
	<i>"I took it lightly, I didn't consider it as a disease only. Because my father, grandfather, my mother and father in law, my wife everyone is diabetic, that's why I didn't worry too much". (58 years, M)</i>
	<i>"The reason for keeping my sugar under control these 20 years is due to self-control. I do not touch sweets, have to cheat my tongue. I have completely avoided taking tea, coffee while attending functions also. I have changed my life style. Along with that I do exercise, yoga and walking thereby keeping sugar under control". (59 years, M)</i>
Care Seeking Practices	<i>"I used to undergo blood test, only when I intend to go for consultation. I am getting depressed just thinking about these frequent blood tests. But I have been diagnosed with diabetes and have to survive with the disease". (48 years, F)</i>
	<i>"I consult with one doctor only. I know him from my childhood days. I have not gone separately to a sugar specialist. I am satisfied with this doctor and there is no problem, so am continuing with him. Why do I need to see 10 doctors, where each one will take a different decision". (67 years, M)</i>
	<i>"I have consulted with 15 doctors but still did not recover. I even tried "naatu vaithiyam" (traditional medicines) for 1.5 months, that to did not help. Every night I will be crying because of this pain and pricking sensation. On seeing this, my son has taken me to so many hospitals, nearly 15 doctors he has taken me to see in just one month. Wherever he advised I have gone there". (55 years, F)</i>
	<i>"Doctors must not threaten the patient. They often tell the patient that they will lose their eyes or kidney or have heart problem, or they will not be able to walk. Whatever information is necessary must be discussed with patient but they must not threaten the patient. If they threaten then the patient is no more going to visit that doctor. My doctors are threatening me now that's why I don't want to consult them. They should say it gently so the patient must not get scared. If the doctor's smiles and talk in a friendly manner, we won't be scared". (65 years, F)</i>
	<i>"Doctor always advises me to reduce the sugar level and the level must not be high at all. He used to ask whether am I walking or not? If I say no then he will insist that I walk. Regarding food intake also they have told me. Dietician has given suggestions to change my food intake pattern". (48 years, F)</i>

Awareness about DR	<p><i>“Diabetic Retinopathy means eye will get affected and vision will be lost. Nerve surrounding the eye will get weaker; this is called as “Fundus Retinopathy”. Because of diabetes cataract problem will come. Known diabetic patients must take care of eye from getting more affected due to cataract”.</i> (76 years, M)</p>
	<p><i>“I heard that directly the vision will get affected, but I don’t know which part of eye gets affected. Sometimes it can lead to glaucoma, but am not sure”.</i> (59 years, M)</p>
	<p><i>“If we have sugar, glaucoma will come, it will affect eyes, blurred or black spots can happen. Mainly I have heard about this I do not know of any other problem”.</i> (66 years, M)</p>
	<p><i>“No, I have not heard from anywhere the term ‘diabetic retinopathy’. I have not attended camps for eye care. They (referring to the medical team) have come for camp, but I have not attended”.</i> (67 years, M)</p>
	<p><i>“Diabetic retinopathy means nerve will get affected....If your vision is affected from birth then it is ok, but if you lose your vision in the middle of your life then getting back what is lost is very difficult. So, you have to control sugar and have yearly check-up. This is what is advised to us by the doctors”.</i> (48 years, F)</p>
Barriers to DR Screening	<p><i>“If I have pain I think to go and meet the doctor, if not why do I need to go. If we are normal why do we need to consult the doctor? They will write and give more medicines which will only create more heat in my body because of that I do not go”.</i> (65 years, F)</p>
	<p><i>“Eye is fine, so they won’t come back. Only when they attain severe stage they will consult, till then they won’t know. Financial problem may be the reason. If a person is retired there won’t be earning or dependent on a small pension or on the son who may not give money. So 90% is due to financial constraint”.</i> (72 years, M)</p>
	<p><i>“Generally, doctors don’t have that much time to explain as they are busy. If we ask they tell that they are busy which makes the patient hesitant to ask further questions”.</i> (66 years, M)</p>
	<p><i>“It takes a whole day to complete and come back home since it is very far... by the time I return home it will be evening. There is no one to take care of my daughter”.</i> (48 years, F)</p>
	<p><i>“If it is nearby then it will be good. This much distance is far for me. I don’t come alone, my neighbour only took me here. While going back home my younger son will come to pick up. Since I am diabetic, my family members are scared to send me alone to hospital”.</i> (50 years, F)</p>
<p><i>“Work is there at home so I won’t be able to go. There is also no one to accompany me, like while going for blood test or for any other tests”.</i> (65 years, F)</p>	

Note: DM, diabetes mellitus; M, Male; F, Female

Supplementary table 3

Selected Quotes: HCPs perspectives

<p>Recognizing and living with diabetes</p>	<p><i>"I must highlight that patients often don't understand what is meant by adequate control of diabetes. They say, 'today my blood sugar level is normal'. But the fact that this must be maintained in the long term is often not understood by many patients". (43 years, M)</i></p>
	<p><i>"Patients who are well read, are more careful about their eyes, they come for regular check-up, keep a track of their own condition, ask about their previous test results etc. But there are some patients who are not educated who have extensive disease. When they come, they have no idea what they are coming for. Sometimes even if they are attending for the first time, we know the prognosis is extremely bad. They have never had a check-up or even if it was done nothing much seems to have been explained to them. Even if the doctor is saying the right thing, they are not very compliant. It's very difficult to explain to them and treat them". (33 years, F)</i></p>
<p>Care Seeking Practices</p>	<p><i>"My way of telling them is even though nothing is a problem always have a regular annual check, you should check especially if you have strong family history. If they are diabetic then my first question will be when was the last time you had an eye check-up? Each and every patient I try and tell them that they should go to a diabetologist. I have seen that most diabetologists have a routine protocol and they have a person who will counsel patients, they also have a chart which states what when tests were done and other details". (48 years, F)</i></p>
	<p><i>"We have put up some posters on which is written, "the world is beautiful; don't let diabetic retinopathy prevent you from seeing it, so have your eyes checked today" like that we have some posters put up also. Even the patient waiting area also we have posters. On world diabetes day we run camps and distribute pamphlets which explain about diabetes and retinopathy. There are pamphlets which say "Have your eyes checked early and yearly" like that we have posters, put up. We also conduct slogan contests for our staff and give a small reward, for the best ones". (47 years, F)</i></p>
	<p><i>"I think the media has a major role to play. They should not send out wrong messages or incorrect information that should be avoided. The right kind of messages only should go through social media". (47 years, F)</i></p>
<p>Awareness about DR and Barrier to DR screening</p>	<p><i>"DR is mostly asymptomatic, till the end stage and they don't understand the importance...even if we tell them you have retinopathy changes, as they don't experience much of vision problems, they find it hard to accept. It is only when they have bleeding or severe vision drop or if somebody else in the family has already had this problem that they understand the seriousness of their condition... awareness is still low"(47 years, F).</i></p>
	<p><i>"Patients with diabetes for 10-15 years or more have an assumption that if HbA1c is normal then they will not develop diabetic retinopathy. Because they presume that they do not have eye complaints and the sugar level is under control. Few patients got confused diabetic retinopathy treatment (Laser photocoagulation) with cataract surgery (Phaco emulsification). Advice for retinal laser, is often considered as an advice of phaco. (47 years, F)</i></p>

	<p><i>"The patient, Indian patient normally reports when there is an acute crisis or acute problem. So this type of slow going process they are not bothered. Unless and until they have some co-morbidity like some difficulties then only they come for consultation".(43 years, M)</i></p>
	<p><i>"They have multiple reasons to say (for delaying the follow-up). I just now completed my daughter's marriage, I don't have money, to build a new house, financial problem, daughter delivered a baby, I am out of station that's why I didn't come, and I thought I will come here but my husband was not well or my daughter was not well they have all lame explanations and excuses". (61 years, M)</i></p>
	<p><i>"We spend lot of timing in educating the patients, so it's not one time. Every time when they come in some sort of information will be given to the patient. For that we have a different education method one is interactive lecture section are available. During one to one counselling we have, conversation, map section, group therapies, support group, various mode of education are there".(43 Years, F)</i></p>
	<p><i>"Sometimes vision is not improving that much and they will say, 'we are doing all this and coming to you, but vision is not improving'. So, they need to be properly counselled and told that, we may not always be able to improve the vision, but we are here to stabilize the vision, in the process if the vision is improved it is good for you." (48 years, F)</i></p>

Note: HCP, Health Care Provider; DR, diabetic retinopathy; M, Male; F, Female

Standards for Reporting Qualitative Research (SRQR Checklist)

No	Topic	Item
Title and abstract		
S1	Title	Page 1 (Line 2 &3)
S2	Abstract	Page 2 (Line 26-49)
Introduction		
S3	Problem formulation	Page 4-5 (Line 77 to 112)
S4	Purpose or research question	Page 5 (Line 113-117)
Methods		
S5	Qualitative approach and research paradigm	Page 6-7 (Line 130-165)
S6	Researcher characteristics and reflexivity	Page 6 (147-150) & Page 7(159-165)
S7	Context	Page 6 (Line 130-131)
S8	Sampling strategy	Page 6 (Line 140-144)
S9	Ethical issues pertaining to human subjects	Page 6(Line 131-133)
S10	Data collection methods	Page 6-7 (Line 150-155)
S11	Data collection instruments and technologies	Page 7 (Line 154-155, 161)
S12	Units of study	Page 6-7 (Line 143, 151-153)
S13	Data processing	Page 7-8 (Line 174-180)
S14	Data analysis	Page 7 (Line 170-174)
S15	Techniques to enhance trustworthiness	Page 7 (Line 163)
Results/findings		
S16	Synthesis and interpretation	Page 8-15 (Line 182-357)
S17	Links to empirical data	Supplementary table 1,2,3
Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Page 15-18 (Line 359-443)
S19	Limitations	Page 18-19 (Line 446-450)
Other		
S20	Conflicts of interest	Page 19 (Line 471)
S21	Funding	Page 19 (Line 473)