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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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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
16
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
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 **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
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.
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19
20 59 • A larger patient sample representing a wider patient demographic could have provided wider
21
22 60 perspectives.
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24 61 • Inclusion of HCPs from smaller eye clinics would have provided additional perspectives further
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26 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
12
13 106 importance of screening, transportation, language barriers, cultural myths, denial, fear, and depression
14
15 107 [15]. Piyasena et al., found that inter-related user, family and institutional factors influenced the uptake of
16
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
20
21 110 highlighted several issues, which included travelling long distances to access the health facility and cost
22
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,
48
49 123 how they coped with their condition in terms of care seeking behaviors as well as life style modifications,
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51 124 their awareness about DR and their perceptions on barriers towards DR screening. From HCPs, we
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53 125 explored their perceptions on patient understanding of diabetes and DR, the nature of information about
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3 126 diabetes and DR provided to patients and what they believed were barriers for accessing DR care. Getting
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5 127 to understand both points of view helped to build deeper understanding of the phenomenon.
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9 129 **METHODS**

11 130 The study was carried out in a tertiary eye care center run by a non-government organization (NGO)
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13 131 located in Chennai, capital of the state of Tamil Nadu in South India. The study was approved by the
14
15 132 institutional review board of Vision Research Foundation and adhered to the tenets of the declaration of
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17
18 133 Helsinki.

20 134 **Sampling**

22 135 Adult patients with type 2 diabetes mellitus (DM) aged 50 years and above were considered, because only
23
24 136 after a few years of living with DM do patients tend to develop DR. The strongest predictor for DR is the
25
26 137 duration of diabetes [18], therefore patients who had been living with DM for a period of five years or
27
28 138 more were purposively selected to participate in SSIs. Patients already diagnosed with DR were not
29
30 139 included as the emphasis was on awareness about DR, need for eye screening and barriers to screening.
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32 140 Given that 12 interviews are sufficient to reach saturation if the objectives are fairly narrow and the
33
34 141 sample not too diverse [19] and keeping in mind feasibility, logistics and the fact that qualitative research
35
36 142 is time consuming, we decided on carrying out 15 interviews with patients. We believed this would be
37
38 143 adequate to achieve saturation. Using maximum variation sampling we recruited 8 men and 7 women of
39
40 144 different ages during the period February to June 2019. The hospital maintains a computerized schedule
41
42 145 of patient appointments with various eye specialists inclusive of names of patients, their gender and age.
43
44 146 The other details such as education levels and nature of occupation were gathered during the interview.
45
46 147 As our focus was on barriers to DR care we reviewed the appointment schedules of the retinal specialists.
47
48 148 On the specified dates of the appointments our research team (KG and VS both trained in qualitative
49
50 149 research methods by SK), met with patients aged 50 years and above, following their consult and
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52 150 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
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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
23
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
31
32 165 analysis. All data were anonymized to maintain confidentiality.
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36 166 **Patients and public involvement**

37
38 167 Patients and public were not involved in the design or conduct of our study.
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41 168

42 43 169 **ANALYSIS**

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45 170 Analysis followed the framework analytical approach, [20] which is very suitable for data gathered
46
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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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**

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2
3 199 Recognition of the fact that they might have diabetes came rather slowly to most patients. For the most
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5 200 part, the diagnosis of diabetes came as a surprise and a great shock. It often started with minor symptoms
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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
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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
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39 217 parents, siblings or close relatives were living with it and consequently were emotionally better prepared
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41 218 when told of their diagnosis.
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47 219
48 220 In terms of their understanding of diabetes, most participants were aware that poor control of their blood
49
50 221 sugar level could result in a host of health problems and complications. Signs and symptoms ranging from
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52 222 becoming tired easily, losing weight, finding it difficult to work, feeling faint and dizzy to more serious
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54 223 conditions such as kidneys and liver being affected, severe pain in the feet, suffering a stroke or a heart
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3 224 attack were reported. It is important to note, that those who had a parent or sibling living with diabetes
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5 225 reported being attuned to developing symptoms at some point and accepted the inevitability of acquiring
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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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14 229
15
16 230 The main source of information about diabetes came from their health care providers including doctors
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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.
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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
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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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3 249 doctor. While they agreed that all necessary information needed to be communicated, this needed to be
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5 250 done in a friendly and non-threatening manner so as to instill confidence.
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9 252 Use of alternate medicines like Ayurveda was not the preferred choice for most participants although a
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11 253 few reported taking it along with their regular allopathic medication as they felt that Ayurveda by itself
12
13 254 would not be effective in treating them. They all spoke of the importance of eating a balanced diet, of
14
15 255 exercising regularly, taking their medication as advised and of regular follow-up with a physician. To this
16
17 256 end, most participants had modified their lifestyles, although to varying degrees. They reported cutting
18
19 257 down on rice-based food items and sweets and exercising to the extent possible. While some indicated
20
21 258 that they had no difficulty in changing their diet, others found it difficult. Similarly, regular exercise too
22
23 259 posed a challenge with many indicating lack of time, poor motivation and complaints of body aches.
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28 261 **Awareness about DR**

29
30 262 The findings revealed a mixed picture regarding awareness about DR. For most, it was not a familiar term
31
32 263 while a few were aware of it and of the need to undergo regular retinal screening. The understanding that
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34 264 diabetes could affect their eyes and that their vision could be impaired had been gleaned through
35
36 265 interactions with doctors, other health staff they came into contact with and through posters on diabetes
37
38 266 on display in the hospitals they had been to. Issues about the potential threat to their eyes on account of
39
40 267 diabetes were often reiterated during these visits. Participants were more familiar with other eye problems
41
42 268 like glaucoma and cataract but for the most part remained unaware of the details and symptom
43
44 269 manifestations of DR, and of possible preventive measures that needed to be taken to protect their eyes
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46 270 from DR. Only a couple of participants indicated that they had been informed about possible risks to their
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48 271 eyes on account of diabetes or of the precautions they needed to take to protect their eyes. The few who
49
50 272 had heard about DR, described it as a condition wherein the “*nerve would get affected*”. They spoke of
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52 273 the importance of eye care, of regular eye checkup and the importance of keeping their blood sugar level
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3 274 under control as ways and means of protecting their eyes. Such participants were generally better
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5 275 educated, tended to discuss their health issues with their doctors and were more compliant.
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9 277 **Barriers to DR Screening**

11 278 Among those unfamiliar or less aware about DR, several issues emerged which acted as barriers to
12
13 279 seeking eye care. A typical one related to consulting a doctor only if there was pain or some discomfort in
14
15 280 the eye. In the absence of any symptoms it was deemed unnecessary to seek such eye care. Participants
16
17 281 also feared that undergoing eye screenings and tests could result in more medicines being prescribed.
18
19 282 Apart from concerns about cost and managing the dosage, they believed that these medicines meant more
20
21 283 chemicals being ingested which was perceived as harmful as it contributed to excessive “heat”. Others
22
23 284 complained about doctors being too busy and of not having the time to talk to patients about all the dos
24
25 285 and don’ts regarding diabetic eye care. If the doctor appeared too curt or busy, patients felt dissatisfied.
26
27 286 But, patients who indicated that they were doing well were generally satisfied with the care received and
28
29 287 also tended to be more adherent to the doctor’s advice. Other issues involved the logistics of travelling to
30
31 288 the health facility, costs associated with undergoing the tests, not having the time to go for a check-up on
32
33 289 account of work and family commitments. Some women participants spoke of not having anyone to
34
35 290 accompany them to the health facility and almost all described the long hours they had to spend in the
36
37 291 hospital to undergo these tests as major deterrents. Lastly, a sense of complacency and a lack of
38
39 292 motivation were also cited as reasons for participants failing to seek regular care. In this context, one
40
41 293 suggestion was for the hospital to send regular reminders to patients in the form of phone calls or phone
42
43 294 messages informing patients that they were due for a check-up and encouraging them to visit the hospital.
44
45 295 The above mentioned patient’s perspectives are summarized in supplementary table 2.
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50 296

51 297 **HCPs Perspectives**

52 298 **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
6
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
12
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
30
31 313 complications by showing them pictures or getting them to meet other patients. This would impress upon
32
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
42
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
8
9 327 pressure as their diabetes could get exacerbated by other prevailing co-morbidities. The HCPs thus spoke
10
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
26
27 336 more time with the patient unlike the doctors. Patient's motivation levels and presence of good family
28
29 337 support were also seen as aids to good compliance.
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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
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39 341 few having heard of it. They accepted that patients knew that diabetes could affect the eyes, were familiar
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41 342 with cataract but for the most, remained unaware of DR. One HCP, an ophthalmologist described two
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43 343 types of diabetic patients: i) those who remained unaware that the disease could affect their eyes and
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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
6
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
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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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20 357 in supplementary table 3.
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22 358

24 359 **DISCUSSION**

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
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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
50
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

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3 374 confirmed by the HCPs. Poor understanding of DR has also been reported by patients in other studies
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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
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18 381 more than half a day at the hospital, as health facilities here are mostly very crowded, was another major
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20 382 deterrent to care seeking for DR. Patients therefore tended to delay seeking care and clung to the belief
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22 383 that as they were feeling alright there was no requirement to go to the hospital. This absence of symptoms
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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
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28 386 for DR in our study. Patients questioned the need to undergo eye tests which were usually tedious and
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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
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40 392 people [27,28]. The HCPs agreed that the silent progression of DR was a deterrent to early care seeking
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42 393 and spoke of difficulties they faced in getting patients to understand the importance of early and regular
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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
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51 397 carried out by Trento et al. [29], showed that patients who participated in group sessions understood DR
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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
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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
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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
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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
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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
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25 410 the application of such strategies.
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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
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37 415 therefore more likely to switch to another doctor. They felt confused when meeting different doctors on
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39 416 account of their conflicting opinions. Patients looked to their HCPs for support and encouragement that
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41 417 was often not forthcoming on account of their busy schedules. Doctors are often hard pressed for time
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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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11 428 It is apparent that HCPs play a pivotal role in promoting understanding of the disease given the almost
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13 429 reverential position they occupy in our culture. At the same time, patient's expectations of doctors are
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15 430 also very high and if they feel that they are not improving to their satisfaction, an element of distrust and
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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
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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,
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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
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31 438 building a comprehensive diabetic care team comprising of trained personnel, some of whom could take
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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
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39 442 are available under one roof, literally a 'one-stop shop', indicative of a paradigm shift compared to what
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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
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51 447 interviews with family members, who play an important role in decision-making for care seeking and in
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53 448 providing support to patients. Inclusion of HCPs from smaller eye clinics would have provided additional
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3 449 perspectives further enhancing understanding of the phenomena. A larger patient sample representative of
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5 450 a wider patient demographic could perhaps have brought in more perspectives.
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8 9 452 **CONCLUSION**

11 453 Living with and managing diabetes is a lifelong process, one that can prove overwhelming to an
12
13 454 unprepared patient. It is therefore imperative that steps to ensure good patient compliance be prioritized.
14
15 455 Enhancing patient understanding through healthy and friendly doctor-patient interactions and use of an
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17 456 integrated treatment approach including education by counsellors, setting up patient support groups, tele-
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19 457 screening approaches and use of conversation maps are some strategies that may prove more effective in
20
21 458 enhancing compliance for DR care.
22
23

24 459 25 26 460 **Declarations:**

27 28 461 • **Ethics approval and consent to participant**

29
30 462 The study was approved by the Institutional Review Board (Ethics committee), Vision Research
31
32 463 Foundation and written consent was obtained from the patients as per the Declaration of Helsinki.
33
34

35 464 • **Consent for publication**

36
37 465 Not applicable
38

39 466 • **Availability of data and materials**

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41 467 The datasets generated during and/or analysed during the current study are not publicly available,
42
43 468 as it is against the organization hospital policy. They can however, be made available from the
44
45 469 corresponding author on reasonable request.
46

47 48 470 • **Competing interests**

49
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51

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10

11
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13
14 479 R.R and S.K; contributed to the conception and design of the study. S.K wrote the main
15
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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.
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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 love 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”.</i>(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> (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>(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> (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 26-49)
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S3	Problem formulation	Page 4-5 (Line 77 to 112)
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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)