

The impact of diabetic retinopathy: perspectives from patient focus groups

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Background. Diabetic retinopathy (DR) affects 50–85% of people with diabetes and may result in visual impairment or blindness.

Objective. This exploratory qualitative research was conducted to evaluate the symptom experience of DR, its impact on daily activities and health-related quality of life (HRQL), and the applicability of two vision-specific questionnaires.

Methods. Four focus groups ($n = 15$) were conducted with people with DR to explore their symptom experience and the impact on functioning and HRQL. Adults with type I or II diabetes and mild, moderate or severe non-proliferative DR (NPDR) or proliferative DR (PDR) were recruited. Content analysis and descriptive statistics were used to analyse the data.

Results. Participants described a range of symptoms and impact. Difficulty driving, especially at night, and trouble reading were noted with all levels of severity. Participants with PDR and decreased visual acuity have foregone many other important life aspects such as work, reading and sports. For the severely affected, diabetic care activities (e.g. exercising, reading nutritional labels, preparing insulin injections and glucose testing) were difficult to accomplish. Loss of independence, especially mobility and increased fear of accidents, had a profound impact on social activities. For those patients who had not experienced other complications of diabetes, the threat of vision loss was the most devastating.

Conclusion. The loss of independence and mobility associated with decreased visual functioning and visual loss were major concerns. Moderate, severe NPDR and PDR associated with visual impairment have a significant impact on HRQL, particularly in the areas of independence, mobility, leisure and self-care activities.

Keywords. Diabetic retinopathy, disease impact, health-related quality of life, patient perspective, visual function.

Introduction

Diabetes mellitus is an increasing health problem that currently affects ~150 million people worldwide and is expected to affect >200 million people by the year 2025.¹ One of the most frequent complications of diabetes is diabetic retinopathy (DR), which is estimated to account for 80% of all cases of legal blindness in persons age

20–74 years in the USA.² Initially, DR usually manifests as a gradual, painless progression of vision loss; however, visual loss may occur with vitreous haemorrhage or macular oedema (thickening of the central part of the back layer of the eye, the retina). Symptoms of DR and diabetes may include general blurred and double vision, distorted vision, floaters (spots) in the field of vision, or changes in refractive error. Symptoms may fluctuate throughout each day and from day to day.³ The mainstay of treatments for severe DR and macular oedema are laser photocoagulation for proliferative DR (PDR) and, in severe cases of PDR with vitreous haemorrhage and detachment threatening or involving the macula, vitrectomy.

Visual impairment has been shown to reduce health-related quality of life (HRQL) in people with

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cataracts^{4,5} and DR.⁶⁻⁹ Mangione *et al.*⁵ found that patients with DR reported a higher number of visual problems when compared with patients with age-related macular degeneration (ARMD), glaucoma, cataracts, cytomegalovirus retinitis or low vision from any cause. Wuslin *et al.*¹⁰ assessed the psychological effects of DR and resulting visual impairment and found moderate correlations between worsening visual acuity and worsening psychological symptoms in a sample of PDR patients. Bernbaum *et al.*¹¹ compared DR patients with stable visual impairment with those with fluctuating visual impairment (common in DR) and observed that those with fluctuating impairment experienced greater emotional distress and depression than those with stable visual impairment. These two studies focused solely on the psychosocial aspects of visual impairment and impending visual loss, but did not examine other aspects of HRQL (e.g. physical and social functioning).

The primary objective of this research was to evaluate the symptoms of DR and the impact of DR on patients' daily activities and HRQL through focus groups with clinically diagnosed DR patients to identify patient issues and concerns regarding DR. A secondary objective was to evaluate the acceptability and face validity of two vision-specific questionnaires in DR patients to ascertain if the questionnaires needed to be modified further for a DR patient population.

Methods

Recruitment

To be eligible for the focus groups, participants must have been older than 18 years of age, able to read and speak English, have a clinical diagnosis of DR (with or without macular oedema), and be willing and able to provide written informed consent. Participants were identified and screened by board-certified ophthalmologists from their clinic patient populations (Danbury Eye Clinic, Danbury, CT; University of Wisconsin, Madison WI). If eligible, potential participants were contacted by their physician or a clinic staff member to explain the purpose of the focus groups and extend an invitation to participate. If the potential participant provided verbal consent to participate, they were invited to attend scheduled focus group sessions. Institutional Review Board approval was obtained for each participating institution.

Procedures

Focus group meetings were held at times and locations convenient to the participants. At Danbury, separate sessions were held for men ($n = 5$) and women ($n = 7$) to facilitate in-depth discussion and eliminate the possibility of gender bias within the groups. The three participants (two males; one female) in Madison attended the same session. Additionally, separate

sessions were held for men who have had laser surgery ($n = 2$) and those who had not ($n = 3$). The three participants (two males; one female) in Madison attended the same session. Written informed consent was obtained from all participants prior to beginning each focus group. For descriptive purposes, all participants were asked to complete a brief questionnaire of socio-demographic information (age, gender, marital status, employment and educational status). Clinical information (e.g. visual acuity levels, DR severity, years of diabetes) was obtained from the participants' medical records.

A trained moderator led the focus group sessions and all sessions were audiotaped with permission from the patients. Specific questions were designed to facilitate focused discussion, and a discussion outline served as a question and prompt guide. Participants were asked questions regarding their symptoms of DR, degree of visual impairment, and impact of DR and visual impairment on daily activities and life in general.

After the primary discussions were complete, the participants were asked to complete and review two vision-specific instruments, the Visual Function 14-Item Scale (VF-14)¹² and the National Eye Institute-Visual Function Questionnaire-25 (NEI-VFQ-25).^{5,13} After completion of the questionnaires, participants were asked in a systematic manner (cognitively debriefed) to compare the questionnaires and to identify questions or items that they felt were not applicable or that were missing from the questionnaires. The focus group discussions lasted ~90 min. Participants were reimbursed US\$50.00 for their time and travel expenses.

Data analysis

Descriptive statistics (mean, SD and frequency) were used to characterize the sample in terms of socio-demographic and clinical characteristics. Content analysis was used to evaluate the qualitative information gathered during the four focus groups.^{14,15} Two researchers systematically reviewed the transcripts and tapes to identify and quantify key and recurrent words and themes from the focus group sessions as well as time spent discussing key points.

Results

Fifteen people participated in four focus group discussions. Table 1 displays the demographic and clinical characteristics of the sample. Sixty-seven percent had type I diabetes, 60% were living with someone, 100% were Caucasian, 67% had a college degree, and 53% were retired.

Three of these discussions were gender specific (two male-only groups and one female-only group) and one was mixed gender; however, no systematic differences were noted in the group discussions. The majority of the

TABLE 1 Demographic and clinical characteristics

Characteristic	<i>n</i> = 15
Mean age (years) (SD)	61.1 (12.3)
Mean duration of visual impairment (years) (SD)	4.5 (5.5)
Gender (<i>n</i> , % male)	7 (46.7)
Marital status (<i>n</i>)	
Living alone	6
Living with someone	9
Educational attainment (<i>n</i>)	
High school or less	5
College graduate	4
Graduate degree	6
Employment status (<i>n</i>)	
Employed full time	5
Employed part time	1
Homemaker/housewife	1
Retired	8
Diabetes (<i>n</i>)	
Insulin-dependent	10
Non-insulin-dependent	5
Diabetic retinopathy severity (<i>n</i>)	
Mild non-proliferative	6
Moderate non-proliferative	4
Severe non-proliferative	1
Proliferative	4
Visual acuity (worst eye) (<i>n</i>)	
≥20/20	4
20/25–20/32	5
20/40–20/60	4
<20/60	2
Prior laser surgery (Yes)	9

participants stated that they experienced mild to moderate visual impairment which was confirmed by their clinical records. No participants were legally blind (best corrected vision 20/200 or worse), and one person had monocular blindness.

The discussions focused on the symptoms of DR and the impact of DR on various activities and HRQL. The results are organized by common themes of the discussions and are summarized in Table 2.

Symptom experience

Overall, 14 participants had experienced visual symptoms either before or after diagnosis with DR, while one participant has never experienced any visual symptoms. Only five participants experienced subtle visual symptoms that led them to see an ophthalmologist; however, no one attributed his or her visual symptoms to DR. Seven participants were diagnosed with DR by routine clinical exam as opposed to seeking out an exam in response to experiencing visual symptoms (how this was diagnosed is not known in three participants). Comments such as: “I was having trouble in the sun and stuff and figured I needed better

TABLE 2 Summary of key concepts of focus groups

Symptoms
Wavy distortion (<i>n</i> = 2)
Blurred vision (<i>n</i> = 1)
Floaters (<i>n</i> = 3)
Flashes of light (<i>n</i> = 3)
Haemorrhage with vision loss (<i>n</i> = 3)
Decreased acuity (<i>n</i> = 3)
Sensitivity to brightness (<i>n</i> = 3)
Life impact
Inability to drive/driving restrictions (<i>n</i> = 8)
Decreased mobility (<i>n</i> = 2)
Loss of independence (<i>n</i> = 2)
Decreased social activities (<i>n</i> = 2)
General day-to-day impact on all tasks (<i>n</i> = 1)
Inability or difficulties in reading (<i>n</i> = 6)
Difficulties in maintaining diabetes care activities (<i>n</i> = 2)
Difficulties recognizing faces (<i>n</i> = 4)
Loss of vision
Very real perceived threat (<i>n</i> = 4)
Causes apprehension and feelings of vulnerability (<i>n</i> = 8)
Vision-high priority
Loss of vision—worst complication of diabetes (<i>n</i> = 6)
Maintenance of vision highly valued (<i>n</i> = 5)
Link between glucose level and visual symptoms
Notice visual symptoms when glucose is elevated (<i>n</i> = 7)

glasses . . .” and “My vision was blurry, just not clear, . . . I went to the eye doctor, who saw that I was hemorrhaging . . .” demonstrate the vague nature of the initial symptoms experienced by a few of the participants.

Symptoms that participants attributed to DR varied from overall vision blurring, wavy vision, flashes of light, floaters in the visual field, trouble with bright lights and difficulty reading small print, to total visual distortion and temporary loss of sight. For most, visual symptoms were transient, varying from minutes to months. Almost half of the participants were able to link high blood sugar levels with a worsening in visual symptoms: “I knew that when my vision started to get distorted, my sugar was too high” and “usually if I have problems with my blood sugar in the morning, then I know I’m going to have [visual] problems all day . . .” and “. . . as soon as I was on the tablets, it’s a better connection; the DR symptoms went as soon as I got my diabetes in control.” Participants stated that close monitoring, tight control of blood glucose levels and regular examinations by their physicians currently were their only way of trying to control the progression of DR.

Knowledge and concern about DR

Twelve participants specifically stated that they were very surprised when diagnosed with DR as they had either not experienced symptoms or had thought that the visual changes they had experienced were due to getting older. The knowledge about DR varied among the participants, from very knowledgeable (*n* = 3) to knowing nothing about DR or that it was a potential

complication of diabetes. Four participants knew that diabetes and eye problems were related, but did not know the cause or even the term ‘retinopathy’. A few participants had previous experience with DR, as a parent or friend had gone blind with DR, as noted by one participant: “I was really concerned from what I knew happened to my mother when she went blind, and all of that.” The majority of the participants realized that DR could lead to visual loss or blindness; however, the actual threat of visual loss was perceived differently among the participants. Participants with milder forms of DR viewed the likelihood of blindness as a more remote possibility than those with moderate or severe DR who were already experiencing varying degrees of visual impairment.

Most participants found the diagnosis of DR somewhat frightening and disconcerting which led to feelings of vulnerability: “I was very scared. I didn’t know if I was going to lose my sight in a few days. I had no idea what the process was. The whole thing was very scary . . .” and “Complete shock and not knowing, not knowing what will happen because they can’t tell you.” Two participants specifically stated that they were thankful for each day with no further vision loss: “I think about it every day. Every day I get up, open my eyes and see something, I’m a happy man.” Others, however, said that they do not think about their vision very often at all. “I don’t really think that much about it, at least not while I have my blood sugars under control—then it doesn’t bother me.”

For six participants, the loss of vision was perceived as the worst complication of diabetes. Much apprehension and fear of severe visual impairment with subsequent loss of independence was voiced by these individuals:

“I could lose my hearing, I could lose talking, but . . . it’s frightening to lose my eyesight.”

“I’m mostly concerned about my sight too. At one point I spent about three years on crutches, so I’m fairly confident that I could do okay if for some reason I lost a leg, but I don’t think I could handle losing my sight.”

“I think I could much better handle the loss of limbs than I could eyesight; it would be pretty tough to go on without sight.”

“If you can’t see, there’s not much you can do about anything.”

“I consider visual abilities to be really high on the list of things you need to function and maintain your independence.”

Interestingly, the participants who perceived DR to be the most devastating complication had not experienced other complications of diabetes. For the

seven participants who had experienced other diabetic complications (primarily cardiac and renal complications), DR was “just one more thing”: “You carry them all to the end. They’re all areas of concern, I don’t look back as one scaring me more than another; they all scare me . . .” Others remarked on the additional impact of DR and visual impairment on their lives in conjunction with their other diabetic complications: “It’s all inter-related, it’s not just the eyes, but maybe I am aware of the eyes on a more day-to-day basis” and “When I was diagnosed with this [DR], the whole body was falling apart. I’m on dialysis, I had cancer at the time, but to be losing my eyesight too—that scared me.”

Impact on daily activities

The impact of visual impairment was prominent in the participants’ thoughts, activities and lives. Several poignant stories regarding the impact of DR were heard:

“I was planning on doing a lot of reading, some fishing and some referral work, and maybe surgery after I retired, but now I cannot see to do surgery. I can’t read unless it’s large print books with three power reading glasses. I can’t drive, and I can’t fish because I can’t see to tie the knots. You’re not able to do the things you thought you’d be able to do.”

“I used to love to cook, but now I hate it. You’re looking for something, but you can’t find it. You drop something and you can’t see to pick it up. I’m just totally dependent on other people now. I used to love to go visiting, but now I can’t. I’m dependent on people now. Everything is difficult. Since you’re dependent, you’re restricted in what you can do.”

“When I lost the vision in the left eye I stopped driving all together. It’s been about 2 months now. It’s terrible—the worst thing in the world to have happen to me.”

Losing one’s independence as a result of visual impairment was devastating for those who experienced it and a great concern for others in the focus groups. While most participants were not as affected as the above participants, they did have negative experiences from visual impairment associated with DR on their daily activities.

Driving a car was the most frequently affected activity. Night driving was raised as particularly problematic. Several participants admitted to having trouble driving at night; a few stopped driving at night; others stayed on well-lit roads, familiar routes, or “hoped for the best.” Although the participants knew that their vision was impaired and that they had “problems seeing at night”, they did not seem to express feelings of guilt about driving despite these visual limitations. Mobility and depending on others for transportation was the most bothersome change faced

by participants, and profoundly impacted social activities for the most severely affected. For previously independent participants, the need to call a friend or family member for transportation to the store or social function was very demoralizing—so much so that they would avoid doing the activity.

The inability to see well enough to read or the need for special glasses to assist in reading was mentioned by several participants: “I used to read a lot, I love to read, but now for about six weeks the only thing I’ve been able to do is get these books on tape. I even canceled my newspaper subscription.” In addition to reading difficulties, participants noted difficulties in everyday general activities: “Anything I try to do, I can’t do it. All the normal things around the house, like tightening a screw, I just can’t see to do it. They all bother me a lot—there’s nothing specific. Anything I want to do that requires seeing anything with any slight detail, I can’t do.”

A few participants described the impact of DR and visual impairment on their diabetic care activities to include interference with exercise, diet, insulin injections and blood testing. One participant shared a particular fear of not being able to “continue what I have to do to treat the diabetes.” Currently, she prepares her insulin shots 2 days ahead of time “just in case I have a day where my sight is so bad I can’t prepare a shot.” Others mentioned difficulties in seeing to test their blood: “for a while, I couldn’t see the numbers . . . I have a problem getting the blood on the spot [on the glucometer].” Other participants mentioned the negative impact on their exercise routines, which included not being able to drive to the gym, being unable to see the ball while playing racquetball, and not performing aerobics due to fear of further retinal detachment. Additionally, DR affected grocery shopping, not only in terms of getting to the supermarket, but also in terms of reading labels regarding the nutritional content of food: “Shopping for food can be difficult sometimes. Since I’m diabetic I have to watch real carefully what I’m eating, but reading those nutrition labels with the small print can sometimes be a real pain.” Visual impairment has a significant negative impact on diabetic care activities.

Impact on relationships

None of the participants felt that their relationships with friends and family had been negatively affected by DR, although a few admitted that their “family gets a bit fed up after a while.” Conversely, many participants noticed that people, even strangers, were ‘more kind’ and more helpful. Family members would ask more frequently as to how they were doing and assist in necessary tasks; strangers would assist with reading labels or prices when asked. This additional assistance was appreciated by most participants, although a few felt that it sometimes “drives them crazy.”

Impact on work

For the six participants who were employed either full- or part-time, work productivity was not perceived to be affected. A few participants stated that they had difficulty reading the computer sometimes or reading small numbers, but they did not feel it had reduced their productivity.

Financial impact

Other than medical expenses which were covered mostly by insurance, purchasing eyeglasses, brighter light bulbs and large print or books on tape were the primary additional expenses stated by the participants. The participants generally agreed that the financial impact of diabetes in general was far greater than that of DR in particular.

Laser surgery

Nine participants had laser surgery to treat their DR (all with moderate or severe NPDR, PDR or macular oedema). Most participants stated that the laser surgery would not cure the DR, but would prevent progression of the disease (“It didn’t fix my eyes, but they haven’t gotten any worse”) and perhaps regain some visual loss. The participants largely appreciated that there were no other treatment options available for severe DR and that without laser therapy they could lose their vision. Two participants who had laser surgery in the 1980s claimed that their surgeries were physically painful, but the others did not echo this experience. (Both participants had significant visual symptoms prior to photocoagulation and had considerable improvement in their symptoms after photocoagulation.)

Questionnaire review

All participants completed the VF-14 and NEI-VFQ-25 questionnaires by self-administration, with both questionnaires being well-received. The time required to complete the questionnaires and the number of questions were considered appropriate: “No problem. Very quick.” “The questions are simple and short.” All participants understood the directions and which questions to answer in the case of skip patterns.

When asked if there were issues or concerns which should be addressed in either questionnaire that were not currently addressed, one participant stated: “in one of the questions, it asks about brightness, but it’s not just the brightness, it’s also color.” Another concurred, “and especially with printed material, contrast is a big thing. Like, I at least have a shot at things that are black and white, but, like black and gray, I have no chance at reading stuff like that.” Two other participants suggested adding questions regarding diabetes-specific daily activities such as testing blood sugar levels (being able to see the glucometer) and preparing insulin syringes. One participant suggested that questions

regarding satisfaction with disease management should be added.

Some participants expressed confusion about an NEI-VFQ-25 response option: “Stopped doing this for other reasons or not interested in doing this.” The participants were asked to explain that option in their own words. Some thought it meant they did not want to say they were blind; some thought it meant an indirect result of loss of eyesight (the respondent stopped doing the activity because he/she did not enjoy the activity because he/she couldn’t see to do it). Additionally, they thought this option was not always appropriate for the questions (e.g. reading street signs or cooking if one does not drive or cook).

When asked if there were questions on the VF-14 that should be changed to make them more clear or more applicable, one participant stated that the tasks in the question “Do you have difficulty writing checks or filling out forms?” should be separated. She stated that writing checks is significantly easier because the format is always the same; forms are more difficult to complete because the format of the questions and answers are unknown to the recipient and constantly differ.

The cooking questions in both the NEI-VFQ-25 and VF-14 were raised by participants as being somewhat problematic. One participant was unsure what the VF-14 was asking about “do you have any difficulty cooking?” “Do they mean cooking like reading the labels or actually with the cooking process?” Another participant suggested that the question in the VFQ-25 regarding “doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools” was confusing. He thought that activities associated with cooking were not ‘up close’ and, therefore, the reference to cooking should be removed from that question.

Although three participants specifically stated that they preferred the VF-14, the remaining participants thought that the NEI-VFQ-25 was more comprehensive and applicable to their lives and experiences.

Discussion

DR with visual loss has a profound impact on patients’ lives. Our focus groups contained a range of patients with mild to severe DR and PDR, 60% who had been treated with retinal photocoagulation, who were with and without visual impairment. As expected, the impact of severe DR and PDR with resulting vision loss on HRQL was much more profound than the impact of mild DR without visual impairment; however, the impact of mild DR on HRQL is not negligible. Although this patient sample consisted primarily of participants without visual impairment (60% \geq 20/32), a negative impact on everyday activities and HRQL was voiced by the participants. Klein *et al.*⁷ found poorer vision to be

strongly associated with the subscale scores of the NEI-VFQ-25, with decreases in scores noted with best corrected visual acuity worse than 20/25. Although multivariate models of the data of Klein *et al.* showed that the degree of visual impairment was found to have a greater impact on HRQL than DR severity level, the focus group participants did not qualitatively discriminate between vision impairment and DR, as DR and vision impairment were perceived to be one and the same.

Additionally, participants with mild DR experienced fear of the unknown and feelings of vulnerability to vision loss. Williams *et al.*¹⁶ noted similar findings in a sample of macular degeneration patients in whom levels of emotional distress were higher in those with unilateral blindness and a shorter period of vision loss than patients who were bilaterally blind for a longer period of time. The fear of losing sight and independence created emotional distress for our focus group participants and, for some, this fear was greater than the fear of losing limbs or having cardiac or renal complications of diabetes.

For those individuals who were already experiencing significant visual impairment, the impact on their HRQL was profound and manifested in all facets of their lives. Physical, social and leisure activities were curtailed as a result of their visual impairment. Additionally, daily activities such as reading, hobbies, diabetes care activities, cooking, housekeeping and getting dressed were impacted by their visual impairment. The emotional distress of such impairments was communicated by the participants, and this finding is consistent with the research from Karlsson¹⁷ in patients with various visual impairments. Although participants with severe NPDR and PDR experienced the greatest impact on the above activities, all participants but one had experienced vague, often transient, visual symptoms that impacted some aspect of their functioning or HRQL.

In our focus group discussions, participants felt that there was no negative effect on their current work productivity or finances. Although Baker *et al.*¹⁸ found that visually impaired persons faced significant extra costs in meeting daily living needs such as cleaning, cooking, shopping and getting around, participants in our focus groups felt that the only financial impact from DR was for small assistive devices such as glasses, stronger light bulbs and books on tape. However, it should be noted that a group discussion may not have been the best setting for financial discussions as some participants may have felt uncomfortable with such interactions in this setting.

DR patients differ from most other patients with ophthalmological conditions that cause visual impairment in that they have an underlying chronic condition, diabetes, for which DR is a complication. Diabetes, independent of DR, has been shown to negatively

impact HRQL,¹⁹ and the addition of DR with its negative consequences may exacerbate this effect, resulting in further HRQL decrements. Certainly, controlling diabetes is more challenging for some DR patients due to the inability to read labels, exercise, test glucose levels or even administer insulin. This additional challenge complicates maintaining adequate glycaemic control which can further impair vision and also increase the likelihood of suffering from other diabetic complications. Interestingly, almost half of the participants were able to correlate visual changes with glucose levels, as evidenced by comments such as, “I knew that when my vision started to get distorted, my sugar was too high”, and “I know when I’m lax, and my blood sugar is elevated, I get blurriness.”

Reviewing the existing vision-specific questionnaires provided useful information regarding the appropriateness and applicability of the VF-14 and NEI-VFQ-25. Respondent burden is always a concern when administering patient questionnaires; however, the majority of the participants preferred the longer questionnaire (NEI-VFQ-25) as they felt it was more comprehensive in terms of evaluating areas of DR’s impact. Participants were also able to identify gaps in the questionnaire—specifically the need for diabetes-specific questions and questions regarding colour and contrast. Adding such additional items may increase the sensitivity of the questionnaire in DR patients as these may be items where changes of particular importance to the patient may occur. This approach of getting patients to review and comment on in a standardized manner (cognitive debriefing) existing patient questionnaires that are being considered for use can be particularly useful when administering a questionnaire to patient populations slightly different from those for whom the questionnaire was originally developed.

Patient insight can not only greatly enhance the appropriateness and applicability of the questionnaire, but can assist in improving the format of the questionnaire to facilitate its administration.

This study was not designed to quantify or correlate patient-related issues with disease severity, visual impairment fluctuations or psychosocial impact. Although the sample size of this study is small, this exploratory and qualitative study illustrates the thoughts and concerns of people with DR regarding their diagnosis, vision, daily activities and treatment. In summary, the impact of DR on HRQL cannot be undervalued.

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