What is health-related quality of life? Perspectives from diabetes care providers

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ABSTRACT

Background
While health-related quality of life (HRQOL) is gaining recognition as an important patient-reported outcome, little is known about how diabetes care providers define or apply HRQOL in practice. The purpose of this study was to identify how diabetes care providers conceptualize HRQOL for youth and adults with type 1 diabetes (T1D) to help guide efforts to more routinely assess and intervene to improve HRQOL.

Methods
As part of a larger qualitative study on T1D-specific HRQOL, semi-structured qualitative interviews were conducted with 8 diabetes care providers (5 pediatric providers, 3 adult providers, 62.5% male) via focus groups or individually. Sessions were audio-recorded, transcribed, and coded to derive common themes.

Results

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Percent (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, % female</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Medical discipline</td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>87.5% (7)</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>12.5% (1)</td>
</tr>
<tr>
<td>Years in T1D practice</td>
<td></td>
</tr>
<tr>
<td>1-4 years</td>
<td>12.5% (1)</td>
</tr>
<tr>
<td>5-10 years</td>
<td>50% (4)</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>37.5% (3)</td>
</tr>
<tr>
<td>Proportion of current T1D caseload</td>
<td></td>
</tr>
<tr>
<td>&lt;50%</td>
<td>50% (4)</td>
</tr>
<tr>
<td>50% or more</td>
<td>50% (4)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
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<tr>
<td>Non-Hispanic White</td>
<td>75% (6)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0% (0)</td>
</tr>
<tr>
<td>Other</td>
<td>25% (2)</td>
</tr>
</tbody>
</table>

Interview topics included:
- Areas of patients’ diabetes HRQOL
- Providers want to be aware of how providers typically assess their patients’ diabetes HRQOL.
- Interviews were recorded and transcribed verbatim before coding.
- Three psychologists and three research staff reviewed transcripts to develop thematic codes, which were applied using NVivo software (25% double-coded).

Day-to-Day Functioning
Degree to which diabetes influences their ability to carry out everyday activities, including its impact on their general emotional well-being

“T I think a number of my patients feel like it’s very unfair, like they have to do way more than their peers.” – Pediatric Provider

“T I also try to gauge how intrusive the diabetes is on their lifestyle.” – Adult Provider

“I sort of try to talk to people about what limits their daily activities.” – Adult Provider

“I think the mismatch of what their lifestyle is and what they need versus what their regimen is can be a big quality of life disruptor.” – Pediatric Provider

Medical Management
Engagement in diabetes self-management behaviors, presence of hypo/hyperglycemia and health complications

“If you’re in DKA continuously, that objectively is going to impact your quality of life.” – Pediatric Provider

“It takes a lot of time and effort to take care of type 1 diabetes. Full-time job.” – Adult Provider

“So many report how hyperglycemia affects everything.” – Pediatric Provider

“You ask them about hypoglycemia, exercise, if they’re fatigued—tired.” – Adult Provider

Personal Relationships
Impact of their diabetes on social and family relationships, including its impact on the HRQOL of their parents or partners

“The biggest problem with diabetes, is it takes over…your family’s life.” – Pediatric Provider

“If it’s a young person and they’re married—the person who didn’t have diabetes their whole life has suddenly inherited diabetes.” – Adult Provider

“Sometimes other siblings feel left out and the parents feel like they can’t do everything.” – Pediatric Provider

“For the patients of the child with diabetes, oftentimes that can change the dynamics of the relationship after they are diagnosed.” – Pediatric Provider

RESULTS

CONCLUSIONS

- Providers characterized three aspects of HRQOL in youth and adults with type 1 diabetes: everyday activities, medical/clinical considerations, and interpersonal/family relationships.
- This extends the HRQOL literature from other populations with chronic conditions, which has not emphasized provider perceptions of HRQOL, has primarily identified medical domains such as disease-specific symptoms/complications, and provides little information about the HRQOL of other family members.
- The purpose of this study was to identify diabetes care providers characteristics as the key components of HRQOL for youth and adults with type 1 diabetes.
- Clarification of this construct will help guide efforts to more accurately measure diabetes-specific HRQOL and integrate HRQOL assessment and intervention into routine clinical care.

REFERENCES


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