Comprehensive Overview of Quality of Life Instruments Used in Studies of Children with Diabetes: A Systematic Mapping Review

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Background. Quality of life (QoL) is extensively used as an outcome in the studies of children with diabetes. The interest in measuring QoL in relation to clinical treatment and interventions has led to an increase in the development and use of QoL measures. The vast number of available instruments can be a barrier for establishing evidence and can be overwhelming for clinicians and researchers who are interested in measuring QoL of children with diabetes.

Aim. A first step for reaching consensus, we aimed to provide a comprehensive overview of the application of QoL instruments used in children (2–18 years old) with diabetes.

Method. A literature search for studies published from inception to January 2022 was conducted in the databases MEDLINE (Ovid), Embase (Ovid), PsycINFO (EBSCO), CINAHL (EBSCO), and ERIC (EBSCO). The search strategy combined the key concepts of “quality of life”, “diabetes”, and “children or adolescents”. Studies were found eligible if (1) the population was below 19 years of age; (2) had diabetes mellitus; and (3) a quantitative measure of QoL was used.

Results. 3,775 unique articles were retrieved in the literature search and, across 503 articles included for synthesis, 67 QoL instruments were identified. The instruments were classified by i.a. population age, continent, use of pre–post measure, self-report or proxy, and type of diabetes.

Conclusion. The extensive number of QoL instruments that are used for children with diabetes constitutes a substantial barrier for establishing evidence in relation to QoL in this research area.

1. Introduction

Quality of life (QoL) is widely recognized as an important health outcome in the treatment of pediatric diabetes [1, 2]. The complex and constant illness management required during childhood and adolescence places a significant burden on children with diabetes and their families. This heavy burden can lead to serious psychosocial problems, which may affect diabetes management, and ultimately lead to dysregulated blood glucose in the children [3, 4]. Systematic monitoring of QoL has been shown to improve adolescents’ well-being and satisfaction with care [5] and, if used appropriately, regular measures of QoL can identify children with reduced QoL, and hence guide timely interventions to help the children enhance their QoL [6]. It has been suggested that regular assessment of the family’s psychosocial needs, and subsequent interventions addressing potential challenges, may be as important to diabetes management as insulin, diet, and physical activity [7]. Furthermore, The International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines state that pediatric diabetes teams should routinely assess the QoL of their patients [8] and that the shared goal of care should be: “to optimize health outcomes and health related quality of life” [8]. Regular measures of the QoL in children with diabetes can be critical for decision-making in the pediatric diabetes clinic as a valuable supplement to clinical and biological measures, for example, when
deciding which treatment option is best for the child and his/her family [9, 10].

In studies of children and adolescents with diabetes, QoL is extensively used as a primary and secondary outcome [11]. More than 20 years ago, Polonsky [12] pointed out that interest in measuring QoL grew at a phenomenal rate during the 80s and 90s. He further stressed that poor definitions of QoL and the number of instruments purporting to measure the concept were overwhelming [12]. Since then, continued use of QoL as a primary or secondary outcome has led to a further increase in the development and use of QoL measures [10]. For those who do not have a good understanding of how to select an appropriate QoL measure, the vast number of available questionnaires claiming to measure QoL in children with diabetes may be overwhelming [2] and become a barrier for clinicians and researchers interested in acquiring knowledge about QoL in children with diabetes [13]. For example, in a recent review on health-related QoL in children with diabetes using insulin infusion systems, Rosner and Roman-Urestarazu [14] identified eight different instruments across the 15 included studies. The authors claimed that the large heterogeneity in assessment of QoL and differences in how it was reported limited their meta-analysis [14].

Because the concept of QoL is complex, subjective, and thus not directly observable, it is undisputedly difficult to quantify. Unfortunately, application of different terms to describe one concept or of one term to describe different concepts, is a contributing factor to the continued development of questionnaires claiming to measure QoL in children [6]. Furthermore, many questionnaires have been developed without the use of appropriate methods or best practices [15]. There is still no consensus in the definition or measurement of QoL among children with diabetes, and few research papers have stated their definition of QoL or their rationale for choosing a specific questionnaire [12]. This lack of attention regarding the choice of QoL instrument may have huge implications for the research community [15], meaning that the instrument defines the data on which the analyses will be based. This may imply that the data collected through inappropriate instruments are not reproducible or, in the worst case, fail to measure the essence of the concept the researchers expect the instrument to capture [15]. Ultimately, these issues can impact the reliability and validity of survey data, making it difficult to trust any conclusions drawn.

As a necessary first step for establishing evidence on QoL for children with diabetes, this systematic mapping review will serve as a comprehensive starting point for future consensus on the QoL instruments. By conducting a thorough literature search, screening, and classification of journal articles reporting on QoL in children with diabetes, the present systematic mapping review aims to provide a comprehensive overview of the instruments used for measuring QoL in children (2–18 years old) with diabetes.

2. Methods

Because the aim of this present paper was to create an overview of scientific literature measuring QoL among children and adolescents with diabetes, a systematic mapping approach was used. Booth [16] explains that mapping reviews are especially useful for areas in which a large volume of literature exists. Furthermore, that systematic mapping reviews are useful to conduct prior to more narrow systematic reviews since they can be used to identify knowledge gaps. Mapping reviews can thus be used to code and categorize an extensive body of literature, at a more general level, and subsequently be used for guidance when selecting more narrow themes for detailed systematic reviews [17].

The reporting in the present systematic mapping review follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for scoping reviews (PRISMA-ScR) adapted to a mapping review [16, 18]. The reporting of the literature search follows the PRISMA Statement for Reporting Literature Searches in Systematic Reviews (PRISMA-S) [19].

2.1. Eligibility Criteria. Studies were found eligible if (1) the population (or a major part of the population) was below 19 years of age; (2) had diabetes mellitus; and (3) a quantitative measure of QoL was used.

There is substantial debate around the construct of QoL and the conceptual approach across the included studies and instruments is most likely to vary. However, we wanted to include all studies adding to the evidence on QoL for children with diabetes and thus did not limit our search to a specific conceptual approach. Because of the indiscriminate use of QoL and health-related quality of life (HRQoL), we included both terms to avoid missing important studies.

Studies were excluded if they were not journal articles including primary research data, for example, reviews, editorials, discussion points, conference abstracts, and book chapters.

2.2. Search Strategy. An electronic literature search for studies published from inception to 13 February 2020 was conducted in the databases MEDLINE (Ovid), Embase (Ovid), PsycInfo (EBSCO), CINAHL (EBSCO), and ERIC (EBSCO) (Supplementary 1). The search was updated in all five databases on January 18, 2022. The search strategy combined the key concepts of “quality of life,” “diabetes,” and “children or adolescents.” We searched all concepts using both relevant medical subject headings, multiple free text words, and keywords where possible.

We applied a validated filter removing animal studies in MEDLINE and Embase. Because no validated filter was available for PsycInfo, CINAHL, and ERIC, we decided not to take the risk of applying filters in those databases. An “exclude MEDLINE journals” limit was applied in Embase and CINAHL to remove references already captured in the MEDLINE search.

The search strategy was developed and tested in MEDLINE to evaluate if the search string retrieved known key articles of interest. Subsequently, we translated the search strategy to the other databases.

All identified records were uploaded to and organized in EPPI Reviewer Web, a web application developed to conduct systematic reviews [20]. Two information specialists conducted
the literature search, and the entire search strategy is documented in Supplementary 1.

2.3. Study Selection. Deduplication was performed in EPPI Reviewer Web in two steps. First, an automatic function identified possible duplicates, and one author verified and accepted all true duplicates ($n = 616$). Second, all remaining records were manually examined by one author to detect duplicates not already identified by the automatic duplicate function ($n = 54$).

All records were screened independently by title and abstract by two researchers according to the eligibility criteria. Disagreements were solved by consensus and, if not possible, subsequently by a third researcher. Full-text reports of all included records were first sought for retrieval electronically. Second, we attempted to retrieve the records physically from the Danish Royal Library. Third, an e-mail was sent to the first author of the record. If no answer was received after 1 month, then the record was excluded.

Records in other languages than English, Danish, Swedish, and Norwegian (languages spoken in the review team) were not included in the synthesis, but are listed in supplementary materials for others to analyze (see Supplementary 2).

2.4. Quality Assessment. In accordance with guidelines on systematic mapping reviews [16], no quality assessment of the 503 included studies was conducted.

2.5. Data Extraction and Synthesis. Data extraction was conducted according to a mapping strategy aiming to classify included studies under the following themes: “instrument(s) used”, “use of pre–post measure,” “continent,” “population age,” “population size,” “telephone, internet or off-line,” “interview or self-complete,” “self-report or proxy,” and “type of diabetes.” Furthermore, we extracted information on the title, author, and year of publication. All data were extracted by one researcher and subsequently verified by another. Disagreements were discussed, if needed with a third researcher, and consensus was reached. The synthesis was conducted with a visualization and mapping function in EPPI Reviewer Web to create an evidence gap map [21].

3. Results

Interrater reliability (IRR) for the title and abstract screening was 92.776% and for full-text screening IRR was 92.780%.

The literature search returned a total of 4,445 papers, which were reduced to 3,775 after checking for duplicates. After screening the papers’ titles and abstracts, 620 papers were included in the review. Additional screening of the full-text papers excluded 117 papers from the synthesis (Supplementary 2). Thirty-seven were written in a language other than English, Danish, Swedish, or Norwegian, 63 did not include a quantitative measure of QoL in children or adolescents with diabetes and 17 were excluded because we could not access the full-text article after electronic search, library search, and direct contact to the first author. The flow diagram in Figure 1 illustrates the selection of articles.

To create transparency, visualize research available, illustrate gaps in the literature, and allow readers to further explore the data extracted in the present mapping review, an interactive evidence gap map with all included studies was created and made accessible at: https://gapmap.danishdiabetesknowledgecenter.dk/qolchildren. A screenshot of a selected area of the evidence gap map is shown in Figure 2.

As illustrated in Figure 3, the articles were published between 1989 and 2022, with a steady rise in frequency from 1996 to 2021. Because the search was conducted in January 2022, only 3 articles from 2022 were included.

A total of 445 (88.5%) of the included articles targeted children with type-1 diabetes exclusively. Only 10 articles (2.0%) targeted children with type-2 diabetes exclusively, whereas 18 (3.6%) articles included children with type-1 or type-2 diabetes. Studies including other types of diabetes were coded as type-1 or type-2 according to which of those two types was the dominant.

Across the 503 included articles, a total of 67 different QoL instruments were identified. The 67 instruments include different versions of the same core questionnaire (e.g., versions for children, adolescents, or parent proxy).

A list of all included instruments is presented in Table 1. Where slightly different names were used to apparently describe the same instrument, the paper and references were scrutinized to confirm which instrument was used, to ensure that the correct instruments were registered in the review. An important finding was that, in 30 examples (6.0%), reports on QoL in children with diabetes were based on a questionnaire that we were not able to identify with certainty. In these instances, the instrument was coded as “self-constructed/unclear.” To highlight the instruments currently in use, instruments in Table 1 are written in italics if they have not been referred to in publications since 2016.

To illustrate the use of instruments in different age groups, the age of the target population was categorized into three groups: <6 years, 6–12 years, and 13–18 years. If the target population included, for example, 8- to 15-year-olds, both groups (6–12 years, and 13–18 years) were selected. In some articles, age of the target group was indicated by mean and standard deviation (SD), but without indication of the age range. In other studies, age range was mentioned among the inclusion criteria, but not reported for the actual study population. In these instances, and where no age was reported, age was coded as “unclear.” The distribution of age groups is illustrated in Figure 4, showing that most research on QoL in children with diabetes is conducted within the age range of 13- to 18-year-olds, whereas studies on QoL in the youngest children are sparse, with fewer than 100 studies in total. In 25 articles, we were not able to identify the precise age range of the target population.

As shown in Figure 5, the vast majority of studies on QoL in children with diabetes were conducted in Europe (207) and North America (195), whereas only 30, 14, and 12 studies were conducted in Oceania, Africa, and South America, respectively. Studies conducted in Turkey or Russia were coded as both “Asia” and “Europe.”

Furthermore, we found that some instruments tended to be used exclusively on the continent in which they were
originally developed (data can be retrieved from the Evidence Gap Map). For example, the DISABKIDS, which was developed based on a sample from seven European countries [40], was reported a total of 50 times, but only three of the cases were from studies conducted outside Europe. The only instruments that have been used across all continents were DQOLY [32] and PedsQL [72].

Of the 67 identified instruments, 43 (64.2%) have been used, across 206 articles, to measure change in QoL by comparing measures before and after a treatment procedure or intervention. Especially DQOLY [32] and PedsQL [72] were popular choices for measuring change in children’s QoL.

Although most of the articles used instruments to measure QoL as experienced by the children themselves (self-report), 35.4% included both a self-report and a proxy measure, whereas 6.4% used only a proxy measure to quantify the children’s QoL.

The ten instruments most frequently used to measure QoL among children with diabetes are: PedsQL (nonspecific), PedsQL Generic Core Scale, PedsQL Diabetes Module, DQOL, DQOLY, DQOLY-SF, DISABKIDS, DISABKIDS Generic Module Short Form, DISABKIDS Disease-Specific Module for Diabetes, and KINDL. A table with key characteristics of the instruments most frequently used was made to illustrate differences and similarities (Table 2). Since the

![Flow diagram of the selection of articles on quality of life in children with diabetes.](image-url)
FIGURE 2: Screenshot of a selected area of the interactive evidence gap map available online.

FIGURE 3: Distribution of included articles by publication year.
**Table 1:** Instruments identified in the systematic mapping review (instruments in italics have not been referred to in publications since 2016).

<table>
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<th>Instrument</th>
<th>Code ID</th>
<th>Count</th>
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<td><em>Audit of diabetes-dependent QoL for teenagers (ADDQoL-Teen)</em> [23]</td>
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<td>Check your health [24]</td>
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<td>Health-related quality of life questionnaire for diabetics NA</td>
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<td>Smiley faces questionnaire [47]</td>
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<td>Pediatric quality of life inventory (PedsQL) generic core scale [58]</td>
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TABLE 1: Continued.

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<td>Schedule for the evaluation of individual quality of life: a direct weighting procedure for quality of life domains (SEIQoL-DW) [65]</td>
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<td>The 5-item world health organization well-being index (WHO-5) [71]</td>
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<td>Self-constructed/unclear</td>
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FIGURE 4: Distribution of articles by age of the target group.

FIGURE 5: Distribution of articles by continent.
<table>
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<tr>
<th>Instrument</th>
<th>Developed to measure</th>
<th>Year of development</th>
<th>Items</th>
<th>Domains</th>
<th>Response</th>
<th>Generic or specific</th>
<th>Available versions for children</th>
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<td>Health-related quality of life</td>
<td>1998</td>
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<td>Physical functioning, Emotional functioning, Social functioning, School functioning</td>
<td>5-point Likert scale</td>
<td>Generic</td>
<td>Self-report 5–7 years, 8–12 years, 13–18 years, Proxy 2–4 years, 5–7 years, 8–12 years, 13–18 years</td>
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<td>Pediatric quality of life inventory (PedsQL) diabetes module [68]</td>
<td>Diabetes-specific quality of life</td>
<td>2003</td>
<td>28 (3.0) 33 (3.2)</td>
<td>Diabetes, Treatment, Worry, Communication</td>
<td>5-point Likert scale</td>
<td>Diabetes specific</td>
<td>Self-report 5–7 years, 8–12 years, 13–18 years, Proxy 2–4 years, 5–7 years, 8–12 years, 13–18 years</td>
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<td>Diabetes quality of life for youth scale (DQOLY) [23]</td>
<td>Self-perceived quality of life</td>
<td>1991</td>
<td>52</td>
<td>Diabetes life satisfaction, Disease impact, Disease-related worries</td>
<td>5-point Likert scale</td>
<td>Diabetes specific</td>
<td>Self-report 11–22 years</td>
</tr>
<tr>
<td>Diabetes quality of life for youth scale—short form (DQOLY-SF) [44]</td>
<td>General satisfaction with life and concerns over social and vocational issues related to diabetes</td>
<td>2006</td>
<td>18</td>
<td>Disease impact, Disease-related worries</td>
<td>5-point Likert scale</td>
<td>Diabetes specific</td>
<td>Self-report 10–18 years</td>
</tr>
<tr>
<td>DISABKIDS [49]</td>
<td>Health-related quality of life of children and adolescents with chronic medical conditions</td>
<td>2006</td>
<td>37</td>
<td>Mental, Independence, Emotion, Social, Inclusion, Exclusion, Physical, Physical limitation, Medical treatment</td>
<td>5-point Likert scale</td>
<td>Chronic-generic</td>
<td>Self-report 4–7 years (6-item version), 8–16 years, Proxy 8–16 years, 4–7 years (6-item version)</td>
</tr>
<tr>
<td>DISABKIDS, chronic generic module, short form (DCGM-12) [50]</td>
<td>General subjective chronic generic quality of life</td>
<td>2006</td>
<td>12</td>
<td>Mental, Independence, Emotion, Social, Inclusion, Exclusion, Physical, Physical limitation, Medical treatment</td>
<td>5-point Likert scale</td>
<td>Chronic-generic</td>
<td>Self-report 4–7 years (6-item version), 8–16 years, Proxy 8–16 years, 4–7 years (6-item version)</td>
</tr>
<tr>
<td>Instrument</td>
<td>Developed to measure</td>
<td>Year of development</td>
<td>Items</td>
<td>Domains</td>
<td>Response</td>
<td>Generic or specific</td>
<td>Available versions for children</td>
</tr>
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<td>------------</td>
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<td>--------------------------------</td>
</tr>
<tr>
<td>DISABKIDS, disease-specific module for diabetes (DM) [22]</td>
<td>Diabetes-specific quality of life</td>
<td>2006</td>
<td>13</td>
<td>Impact (acceptance) Treatment</td>
<td>5-point Likert scale</td>
<td>Diabetes specific</td>
<td>Self-report 8–16 years Proxy 8–16 years</td>
</tr>
<tr>
<td>KINDL questionnaire [59]</td>
<td>Health-related quality of life</td>
<td>1994</td>
<td>24+ 6 item &quot;disease module&quot;</td>
<td>Psychological well-being Social relationships Physical function Everyday life activities</td>
<td>5-point Likert scale</td>
<td>Generic</td>
<td>Self-report 4–6 years (interview based) 7–13 years 14–17 years Proxy 3–6 years 7–17 years</td>
</tr>
</tbody>
</table>
nonspecific PEDSQL must be either the Generic Core Scale or the Diabetes Module, only nine measures were included in the table.

4. Discussion

Across the 503 papers included in the present systematic mapping review, we identified 67 different instruments that have been used to measure QoL in children with diabetes. For an additional 30 instruments we were not able to identify the instrument with certainty, and in 25 of the included articles, we could not identify the precise age range of the target group. These findings emphasize the importance of precise reporting of the target population and the instruments used. In accordance with previous research [12], it seemed as though rationales for selecting a particular questionnaire were often missing and that the most frequently used rationales were that it was: (1) widely used and (2) validated (data not shown).

Because different research questions call for different characteristics in a QoL instrument, selection of such an instrument should always be guided by the research question being investigated [12]. However, the large number of available instruments identified in this review may add to the challenge faced by researchers and clinicians, in that limited time and resources may cause them to choose a measure that is less than optimal [73]. While recognizing that “the single best” QoL instrument for children with diabetes does not exist in an absolute sense, there are instruments that are better choices for specific purposes [74], and there are several things to consider when searching for the most suitable instrument for measuring QoL in children with diabetes.

Based on the screening of articles for the present systematic mapping review, we recognized a need for emphasizing the importance of including a section on the applied instruments in all research articles. To select the most appropriate instrument, awareness of the reason for measuring QoL is crucial. Therefore, a deliberate rationale for wanting to measure QoL should be considered before deciding on an instrument; and the rationale for using the selected instrument should always be provided in research articles to help readers evaluate the validity of the results [75]. The fact that the instrument is widely used and/or validated is not a sufficient argument. Furthermore, the section should include a thorough description of the instruments on which the results are based. Sometimes the instrument is mentioned using a slightly modified name or simply just described as “a quality of life questionnaire,” which makes it impossible for the readers to identify the instrument used [75]. It is crucial to provide the precise name and details and to include a correct reference, so that the original instrument can be identified.

In the following, we will expand on the common “widely used” and “validated” arguments by accompanying our results with some general considerations about QoL instrument selection for children with diabetes.

4.1. The Developing Concept of QoL. Because the time since development of the instrument may partially explain its frequency of use, appropriateness for the target population should always be considered—even if the instrument is widely used and validated. Obviously, the dissemination and validation of more recently developed instruments do not compare with instruments developed decades ago. Nevertheless, newer instruments may be based on a more updated approach to QoL and thus provide a more contemporary reflection of the concept. The most frequently used instruments in the present review were originally developed 17–30 years ago [32, 72, 76], and although our results illustrate how the original instruments have been adapted and adjusted to suit different needs, for example, a version specifically suitable for children and adolescents with diabetes [59], the rationale behind some of the most frequently used QoL assessments may not be in accordance with the most recent conceptual understanding. For example, a review of QoL measures for adults with diabetes (2020) underlined the importance of considering the surrounding environment and society as part of a QoL assessment, and the authors described how failing to do so may entail missing information on perceptions of QoL related to, for example, a supportive health care system and societal attitude toward illness [10]. This more recent approach to QoL measurement suggests that QoL should not only be reduced to a measure of the absence of negative aspects related to the illness, but also include aspects of psychological coping and acceptance [10]. Whereas many illness-specific instruments address potential negative aspects of life, few address aspects such as acceptance, hope, and having a positive attitude toward the illness [10].

4.2. Applicability to Other Target Groups. Another aspect to keep in mind, before deciding on an instrument, is the applicability of an existing instrument to a different target group. Results from the present mapping review showed that some instruments were mainly used on the continent where they were developed [76], whereas others have been used across all continents [32]. Some instruments were developed across a number of countries [40], whereas others were developed in a specific cultural setting [32]. When instruments are applied in a different cultural setting than they were originally developed for, investigation of their cultural applicability and adaptation to the new context is necessary. Adaptation to a different context is often reduced to a translation from the source language to a target language [77]. The quality of such an instrument translation varies, but even when a careful forward–backward translation procedure is conducted, a linguistic translation does not guarantee that the instrument is culturally relevant [77]. Therefore, the original target group, for example, age and type of illness, cultural context, and what purpose the instrument was originally developed for should always be investigated and considered before deciding on an instrument. If using the instrument in a different target group or for a different purpose, feasibility tests should be conducted to ensure that the instrument is relevant to the new context [77].

4.3. Awareness of the Properties of Instruments. The present mapping review identified 206 articles using 43 different instruments used to measure change in QoL. When aiming
to measure the impact of an intervention or treatment pro-
cedure on QoL in children with diabetes, an impact is more
likely to be captured by a diabetes-specific measure rather
than by a generic measure [12], because some of the items in
a generic measure may be perceived as insignificant to chil-
dren with diabetes. Insignificant items are known to be less
 sensitive to change because responses tend to cluster at the
ends of the response scale [74]. Instruments are more likely
to detect change in QoL if the responses of the target popu-
lation are distributed around the middle of the response
options. Thus, an instrument’s ability to detect changes
depends on the target population [74]. Unfortunately, the
ability of instruments to detect chance over time (responsible-
ness to change) is often not properly investigated [78]. This
means that changes in QoL can be difficult to detect, leading
to erroneous conclusions.

Two overarching approaches, “generic” and “specific,”
can be employed when assessing QoL among children with
diabetes. For comparison of children with other illnesses, a
chronic generic approach (i.e., including different chronic
conditions) can be considered [41]. If a study aims to com-
pare the QoL of children with diabetes to that of children
without any chronic condition, a generic instrument should
be used. Diabetes-specific instruments are not appropriate
for comparison across target groups without diabetes because
they address dimensions that are specifically relevant
to the lives of children with diabetes, but may be irrelevant
to children without diabetes (e.g., issues related to pain and
stigma). Because of their different assessment of QoL, it is
often suggested that both generic and diabetes-specific
aspects of QoL should be included in studies of children
with diabetes.

4.4. Implications for Research. Considering the challenges
described in the present systematic mapping review, we
should use due caution when (1) selecting an instrument;
(2) citing an instrument; as well as (3) reporting and reading
conclusions based on an instrument. Which concept is actu-
ally being measured? Is the applied instrument appropriate
for the target group? Which properties do the applied instru-
ment have? Despite this complexity, we should continue to
strive to select sound and informative measures of QoL in
children with diabetes.

Based on the overview created in this present study, nar-
row themes for detailed systematic reviews can be identified.
Such reviews could for example focus on studies used within
a specific age range, studies including a pre–post measure or
studies using a specific QoL-instrument (data can be
retrieved from the evidence gap map).

4.5. Implications for Practice. The present mapping review
provides an overview of instruments used to measure QoL in
children with diabetes. The overview and descriptions may
increase awareness of the importance of selecting an appro-
priate QoL instrument and facilitate the process of selecting
appropriate measures for use in pediatric diabetes clinics.

Due to the limited time resources, on the part of both
professionals and children with diabetes, instruments with
few items are often favored. Although this is understandable,
our review underlines the importance of selecting an instru-
ment suitable for addressing the question of interest. For
example, applying an instrument that is not able to measure
change over time can lead to the conclusion that an inter-
vention had no effect on the children’s QoL—disregarding
the actual impact.

5. Conclusion

In conclusion, the present mapping review identifies and
describes the extensive number of QoL instruments used
for children with diabetes. The vast number of available
instruments is a challenge when searching for the most
appropriate instrument to include in a study, which further
complicates comparison across studies. This disparity con-
stitutes a substantial barrier for establishing evidence in rela-
tion to QoL in this research area.

Data Availability

The present mapping review is registered with the Research
Registry and the unique identifying number is: researchreg-
istry890. The review protocol can be accessed online at
Research Registry [79]. Louise Norman Jespersen, Tue
Helms Andersen, and Dan Grabowski conducted the system-
atic mapping review since the time of registration of the
protocol, and the list of authors has therefore been updated.
Data extraction for all included articles is available at: https://
gapmap.danishdiabetesknowledgecenter.dk/qolchildren.

Additional Points

A strength of our study is the extensive review of the litera-
ture and the systematic identification and presentation of
QoL instruments used for children with diabetes. To be
able to fully guide the readers in selection of measures, we
are aware that a necessary next step is to conduct a quality
assessment of a selection of the included studies. This is
beyond the scope of this current paper, but will be initiated
in the immediate future.

Disclosure

The funders had no role in any part of this review.

Conflicts of Interest

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hausen, a public hospital and research institution under the
Capital Region of Denmark, which is partly funded by a
grant from the Novo Nordisk Foundation. No conflicts of
interest exist.

Authors’ Contributions

L. N. J. conceived the idea, L. N. J., T. H. A., and D. G.
designed the study, T. H. A. conducted the literature search,
L. N. J. conducted the screening and data extraction. L. N. J.
and T. H. A. synthesized the data, L. N. J. took the lead in
writing the manuscript, with input from T. H. A. and D. G. All authors have read and approved the final manuscript.

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Supplementary Materials

Supplementary 1: search documentation. Supplementary 2: excluded articles. (Supplementary Materials)

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