

# Views of children with diabetes from underserved communities, and their families on diabetes, glycaemic control and healthcare provision

the Diversity in Diabetes (DID) Consortium Members

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## SYSTEMATIC REVIEW

# Views of children with diabetes from underserved communities, and their families on diabetes, glycaemic control and healthcare provision: A qualitative evidence synthesis

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## Abstract

**Aims:** Children and young people with diabetes (CYPD) from socio-economically deprived and/or ethnic minority groups tend to have poorer glucose control and greater risk of diabetes-related complications. In this systematic review of qualitative evidence (qualitative evidence synthesis, QES), we aimed to explore the experiences and views of clinical encounters in diabetes care from the perspectives of CYPD and their family/carers from underserved communities and healthcare professionals in diabetes care.

**Methods:** We searched 6 databases to March 2022 with extensive search terms, and used a thematic synthesis following methods of Thomas and Harden.

**Results:** We identified 7 studies and described 11 descriptive themes based on primary and secondary constructs. From these, three “analytical themes” were developed. (1) “Alienation of CYPD” relates to their social identity and interaction with peers, family and health service practitioners in the context of diabetes self- and family/carer management and is impacted by communication in the clinical encounter. (2) “Empowerment of CYPD and family/carers” explores families’ understanding of risks and consequences of diabetes and taking responsibility for self- and family/carer management in the context of their socio-cultural background. (3) “Integration of diabetes (into self and family)” focuses on the ability to integrate diabetes self-management into the daily lives of CYPD and family/carers beyond the clinical consultation.

**Conclusions:** The analytical themes are interdependent and provide a conceptual framework from which to explore and strengthen the therapeutic alliance in clinical encounters and to foster greater concordance with treatment plans.

Complete list of Diversity in Diabetes consortium members are given in [Appendix](#) section.

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Communicating the biomedical aspects of managing diabetes in the clinical encounter is important, but should be balanced with addressing socio-emotional factors important to CYPD and family/carers.

**KEYWORDS**

adolescents, children, qualitative evidence synthesis, self-management, systematic review, type 1 diabetes mellitus, underserved communities

## 1 | INTRODUCTION

In the UK, 36,000 children and young people (CYPD) under the age of 19 are living with diabetes.<sup>1</sup> The majority, 94.6%, have Type 1 diabetes while 3% have Type 2 diabetes (29,871 0–19-year olds).<sup>2,3</sup> Good glycaemic control in CYPD is linked to optimal self- and family/carer management. Self-management is defined as “the ability of the individual in conjunction with family, community, and healthcare professionals to manage symptoms, treatments, lifestyle changes, and psychosocial, cultural, and spiritual consequences of health conditions”.<sup>4</sup> As “self and family/carer management” is not a defined concept familiar within the health service, the term is used in this context to refer to the “self-management” of children where the responsibilities fall to larger or lesser extents (depending on age) on parents/carers.

For both Type 1 and Type 2 diabetes, these self-management behaviours include healthy eating, physical activity, adherence to treatment regimens, administering insulin in the majority, and self-monitoring of blood glucose.<sup>5</sup> CYPD and their families can be supported to achieve good glycaemic control through self- and family/carer management education programmes that include: dietetic support to help in carbohydrate counting (Type 1 diabetes) for those managed with mealtime insulin; the use of diabetes technologies such as continuous glucose monitoring and continuous insulin infusion pumps; lifestyle and exercise advice; and psychological interventions that support emotional health and well-being.<sup>6</sup>

CYPD from socio-economically deprived and/or ethnic minority groups tend to have poorer outcomes in terms of glucose control, compared to CYPD from less socio-economically deprived and/or white UK populations, which puts them at greater risk of diabetes-related short- and long-term complications.<sup>7–10</sup> Evidence suggests that poorer outcomes are associated with lower levels of engagement with health services and reduced access to the technology that might assist with medication and glucose monitoring adherence.<sup>8,10,11</sup> Indeed, there is considerable variation in the delivery and uptake of diabetes care processes, engagement with structured

### What's new?

This is the first evidence synthesis of the views and experiences of children and young people with diabetes (and their families) who are from underserved communities. Descriptive themes led to the development of analytical themes that serve to better understand and strengthen the therapeutic alliance in the context of concordance with self-management of diabetes in CYPD.

### What is already known?

- Ethnicity and low socio-economic status are associated with poor glycaemic control and long-term outcomes for children with diabetes
- Little published data exist regarding the views and experiences of children and young people with diabetes from underserved communities (and their families and their healthcare providers) on their health care, their glycaemic control and managing their diabetes

### What this study has found?

- Themes identified included self-perception, identity, understanding of diabetes and its treatments, relevance of healthcare services, children taking on responsibility and support for families
- An exploration of how the analytical themes interact reveals how concordance with treatment may be affected in underserved communities.

### What are the implications of the study?

- The findings can be used to inform the development of diabetes services for children and young people from underserved communities.

education, diabetes technologies and achievement of diabetes-related health targets in underserved communities.<sup>2</sup> Underserved communities, for the purpose of this evidence synthesis, are defined as young people living in the UK or Europe from non-white ethnicities and/or people in the UK or Europe living with poverty or living in disadvantaged areas. Where an area is referred to as deprived, it can mean that people have a lower income but it can also mean they have fewer resources or opportunities. In the UK, for example, health services will refer to the national indices of deprivation and each consider seven domains which might contribute to deprivation: income, employment, education, health, housing and services, crime and living environment.<sup>12–15</sup> Health inequalities are defined by the NHS as “unfair and avoidable differences in health across the population, and between different groups within society”.<sup>16</sup> To improve the outcomes of the most disadvantaged CYPD, it is important to address the challenges of health inequalities and the impact of a range of socio-cultural and economic factors.

Interventions to improve glycaemic control, and reduce anxiety for parents for both adults and children have been developed, they include Diabetes Self-Management Education advice and instruction, psychological counselling, self-monitoring, specialised (tailored) clinical care, occupational health one-to-ones with young adults with goals and aims, telecare (health-specific responsive feedback), parental mentoring, assistance with parenting and behaviour and interventions may use a combination of approaches.<sup>17</sup> However, there are vanishingly few studies of these interventions aimed at children from underserved communities, and the majority have recruited and enrolled homogeneous adolescent samples from lower or the lowest risk groups. It has, therefore, been suggested that such interventions may actually widen inequalities in diabetes outcomes due to lack of cultural specificity and low rates of participation of target groups in these interventions.<sup>18–22</sup>

In the past, approaches to improving diabetes self-management have focused the attention and attributed blame on the behaviour of CYPD and their careers, rather than on the nature of the therapeutic relationship. This approach may be disempowering or hamper the integration of diabetes into daily life.<sup>23,24</sup> Patient-centred approaches with a focus on the patient as a whole person, recognising the importance of individual preferences, social context and empowerment have been called for.<sup>25</sup> Enabling the sharing of power and decision-making about the interventions could enable CYPD and their parents to develop capacity for self-responsibility for their diabetes, tailored to fit the context of their lives. A review of knowledge and awareness of empowerment processes between

patients and HCPs have shown equality, trust and respect are crucial in healthcare services to avoid judgemental attitudes and paternalism.<sup>26</sup>

Concordance is an evolving concept in health care in which the consultation is characterised by a partnership approach in which patients and HCPs work together to make decisions about treatment that align with patients' preferences, lifestyle and health beliefs.<sup>23</sup> The aim of concordance in the context of diabetes management is to elicit a trusting relationship in the clinical encounter that supports self- and family/carers through facilitating a personalised treatment approach for the CYPD including discussion and mutual agreement between the HCP and the CYPD.<sup>27</sup> These patient-centred factors should continue to be considered as the child develops and adopts responsibility for self-management of diabetes.<sup>28</sup>

The aim of this qualitative evidence synthesis (QES) is to identify and synthesise existing primary qualitative research exploring the experiences, beliefs, and views of CYPD from underserved communities, their family/carers and those who deliver diabetes healthcare services. We will look into CYPD and family/carers' experiences of the clinical encounter. This work will inform the development of the diabetes self-management interventions within the “Diversity in Diabetes” study (NIHR202358) which has an over-arching goal of co-designing a bespoke programme of support more sensitive to the needs and preferences of this patient group to better understand and strengthen the therapeutic alliance in the clinical encounter and to foster greater self- and family/carer management of diabetes in underserved communities.

## 2 | METHODS

We registered the protocol for this evidence synthesis on the PROSPERO database (CRD42022316028)<sup>29</sup> and followed ENTREQ reporting guidance.<sup>30</sup>

### 2.1 | Research aim and inclusion criteria

We used the PERSPECTIF framework (Perspective, Setting, Phenomenon of Interest, Environment, Comparison, Timing) to frame the research question (see Table 1)<sup>31</sup> which was: To examine, experiences, views, beliefs of, and attitudes to the factors influencing self-management of diabetes by CYPD from underserved communities, their family/carers and those who deliver diabetes healthcare services (doctors, specialist diabetes nurses, psychologists, nutritionists). Setting was paediatric diabetes healthcare services within “free at point

TABLE 1 Inclusion criteria based on the PerSPEcTiF framework.

PerSPEcTiF	Include	Exclude
Perspective	<ul style="list-style-type: none"> <li>Children and young people with diabetes (CYPD: T1 or T2) at any stage of disease, for example at diagnosis or with established diabetes in <i>underserved communities</i></li> <li>For example living in a disadvantaged area, or from a migrant population similar to that encountered in the UK. For example migrant populations found in the UK that are also found in mainland Europe or the Republic of Ireland or other European islands</li> <li>The carers of the CYPD or those healthcare professionals delivering diabetes care to the CYPD</li> </ul>	<p>Studies that included people likely to encounter different challenges to those to be found in the UK for example first nation populations, indigenous or aboriginal peoples in Australia, Canada, New Zealand or US were excluded</p> <p>Studies in the US that included African American and Latino populations were also excluded as although they are likely to be underserved are likely to experience different issues to ethnic minority populations in the UK</p>
Setting	<ul style="list-style-type: none"> <li>Free at point-of-care healthcare systems</li> <li>Paediatric diabetes healthcare service</li> <li>The home and community</li> </ul>	Healthcare where payment is required for services
Phenomenon of Interest	<p>Primary focus of the included papers should be:</p> <ul style="list-style-type: none"> <li>The experiences, views, beliefs, and attitudes of:</li> <li>CYPD with T1 or T2 diabetes from underserved communities (including migrant communities)</li> </ul> <p>Iteration—we will broaden the respondents to:</p> <ul style="list-style-type: none"> <li>Parents (caregivers) of CYPD with T1 or T2 diabetes from underserved communities</li> <li>HCPs that deliver diabetes care to CYPD (from underserved communities) with T1 or T2 diabetes (doctors, specialist diabetes nurses, psychologists, nutritionists) on the factors influencing self-management of CYPD.</li> </ul>	Studies looking at views about prevention of Type 2 diabetes in children
Environment	Diabetes health care delivered in high-income countries to children and young people	Health care delivered which must be paid for at the point of care for children
Timing	At any time point in their experience of diabetes from diagnosis onwards but not before diagnosis	Studies looking at prevention of diabetes
Findings	Attitudes, experiences, beliefs, perceptions, and views related to delivery of the health service and self-management of diabetes as it affects CYPD and their families	Surveys or numerical analysis of qualitative research

Note: Perspective, Setting, Phenomenon of Interest, Environment, Comparison, Timing to frame the research question and inclusion criteria.

of care” healthcare systems in high-income countries as defined by the World Bank.<sup>32</sup> Factors of interest included, but were not limited to: engagement, acceptability of the healthcare system, aspects that help or hinder good self-management, aspects of specific interventions delivered to improve self- and family/carer management (e.g., introduction of additional support such as education programmes), acceptability of/or access to treatment regimens to improve glycaemic control, for example, insulin pump (continuous subcutaneous insulin

infusion CSII), continuous glucose monitoring systems (CGMS). We included primary research using qualitative methods and systematic reviews for the purposes of citation searching. Determination of some inclusion criteria was an iterative process<sup>33</sup> and studies where the underserved communities were not representative of, and therefore likely to encounter different challenges to those to be found in the UK; for example, first nation populations, indigenous or aboriginal peoples in Australia, Canada, New Zealand or US, were excluded.



Studies from countries that had recruited from an underserved population similar to the UK were included, for example, people migrating from Iran, Syria, Turkey and Sudan. Furthermore, we only included studies from countries where health care is free at the point of delivery through a government-funded system such as found in many countries in mainland Europe.

## 2.2 | Search methods

We ran Search strategies developed by an information specialist (SD) (February to March 2022) in MEDLINE, CINAHL, PsycINFO, Embase, Web of Science, International Bibliography of the Social Sciences (IBSS), Social Services Abstracts, Social Care Online and Sociological Abstracts. Terms for <children and young people>, <diabetes> and <underserved communities> were used together with a filter for qualitative evidence.<sup>34</sup> Full details are in Data S1. We limited the search to English language from the year 2000 onwards to ensure relevance to current health systems. Forwards and backwards citation searches were run on all included studies and relevant systematic reviews.

## 2.3 | Selection of studies

Titles and abstracts were screened to remove irrelevant records using Rayyan software.<sup>35</sup> Relevant records were retrieved for full-text screening. Screening was done independently and in duplicate by two reviewers (TM, AS) using pre-stated inclusion criteria with disagreements solved by discussion.

## 2.4 | Data extraction and assessment of study quality

One author extracted study details using a standardised data extraction form and a second author (AS) checked them. The CASP (Critical Appraisal Skills Programme) tool was used to assess study rigour by one author (TM) and a second (AS) checking.<sup>36</sup>

## 2.5 | Thematic analysis

Inductive thematic synthesis was undertaken following the three-stage process developed by Thomas and Harden.<sup>33,37,38</sup> Stage 1: Data coding. Open, line-by-line coding of the first-order (verbatim quotes from respondents) and second-order (authors' views) constructs was done

by two reviewers (AS, TM) in duplicate using NVivo.12.<sup>39</sup> Stage 2: Development of descriptive themes: TM, AS met to discuss and consolidate the meaning of the codes. Stage 3: Development of analytical themes: As the development of descriptive themes “remains” close to the primary studies and in accordance with Thomas and Harden,<sup>38</sup> the reviewers endeavoured to generate “new interpretive constructs explanations or hypotheses”. This notion of “going beyond” the descriptive themes generated from the synthesis of primary study findings is what distinguishes it from other types of literature review and informs the development of subsequent research and intervention.

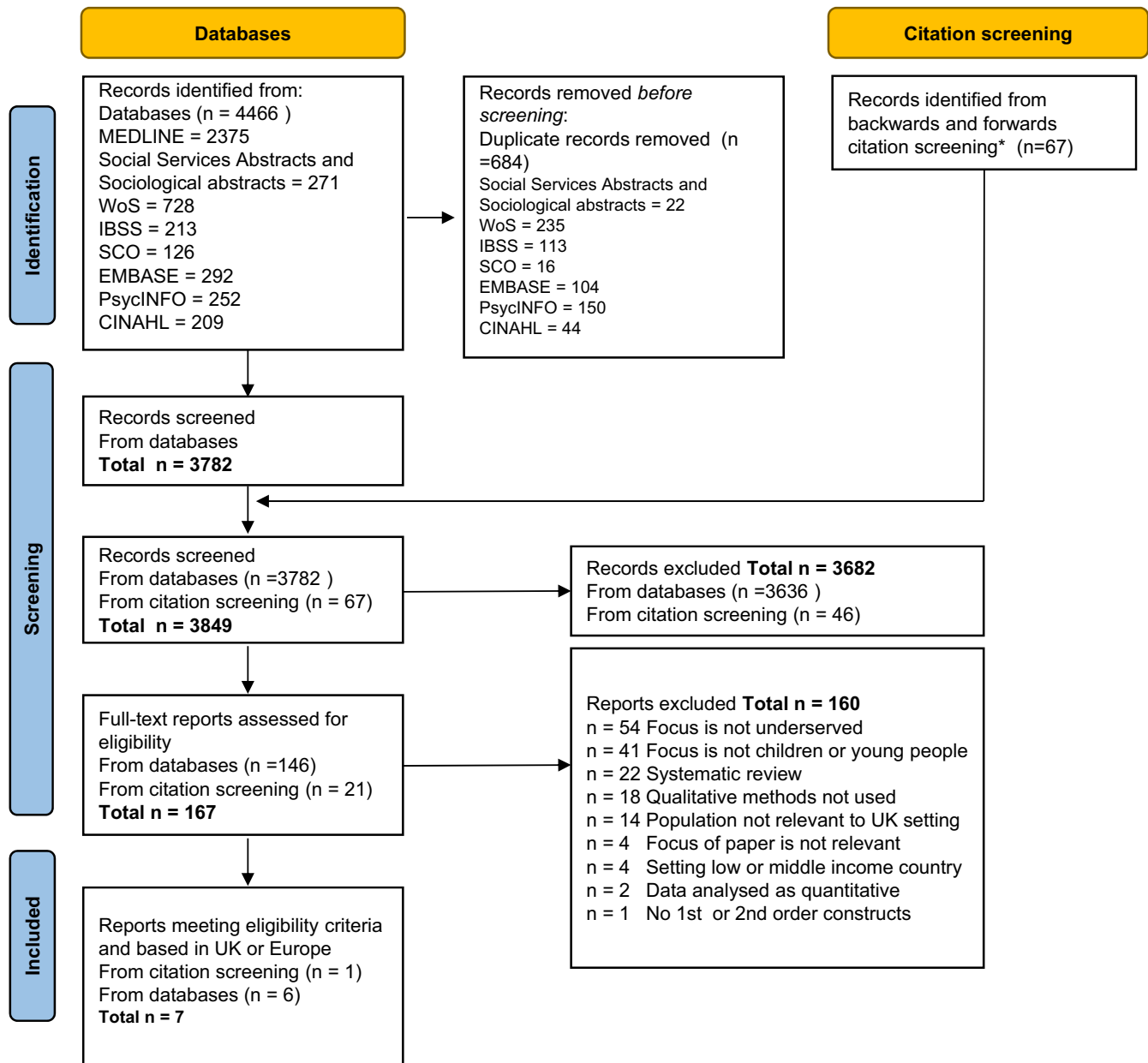
## 2.6 | Grade of evidence

The certainty of the descriptive themes was assessed with the application of GRADE CERQual (See Table 3 and Data S1).<sup>40,41</sup>

## 3 | RESULTS

### 3.1 | Description of studies

We found 3782 records after removing duplicates (see Figure 1) and a further 67 from citation searching of included studies and systematic reviews. From these, we assessed 167 full-text papers from which 7 were included in the review.<sup>42–48</sup> Reasons for exclusion are listed in Figure 1. All included studies were based in northern Europe, (Denmark, Sweden and the UK), see Table 2. Respondents were children and young people aged 4–19 years ( $n = 67$ ) with Type 1 diabetes,<sup>44,45,47,48</sup> Type 2 diabetes<sup>42</sup> or a mixture of Type 1 and Type 2 diabetes.<sup>43,46</sup> Two studies included parents ( $n = 16$ ),<sup>44,45</sup> one study included healthcare professionals (specialist nurses and endocrinologists [n not reported]).<sup>45</sup> The families and CYPD included in the studies were selected because they lived in areas of known deprivation<sup>42,43,46</sup> or because of their immigration status.<sup>44,45,47,48</sup> Ethnicities included South Asian heritage<sup>43</sup>; Black Caribbean heritage<sup>42,43</sup>; Black African heritage<sup>43</sup>; parents who had immigrated from Somalia, Morocco, Iraq, Lebanon, or were Turkish or Kurdish or had a “non-Nordic” background<sup>44,45,47,48</sup> or white British.<sup>42,43</sup> Socio-economic status (SES) was specifically described as separate from ethnicity in three studies, all from the UK, which recruited in socio-economically deprived areas.<sup>42,43,46</sup> The studies were set in paediatric diabetes outpatient clinics<sup>43,45,47,48</sup> or in the community<sup>42,46</sup> or special educational sessions organised by paediatric diabetes outpatient clinics.<sup>44</sup> One study reported views of adults and children with diabetes and we extracted only constructs attributed specifically to



\* Citation screening was done for relevant systematic reviews, and for included studies and primary research addressing the diabetes and underserved communities based in the UK

FIGURE 1 PRISMA Flow chart of study selection.

CYPD.<sup>46</sup> Some included measures to facilitate communication and relevance of the research such as interpreters,<sup>47</sup> and used CYPD co-investigators.<sup>43</sup>

### 3.2 | Stages 1 and 2: Development of descriptive themes

The iterative coding and synthesis process led to the development of 11 descriptive themes that ranged from aspects of self-perception and identity, understanding of diabetes

and its treatments, to how the families felt supported by each other, their caregivers and schools (Table 3). Most themes were graded as “moderate certainty” because of combinations of being drawn from relatively few studies or participants, availability of primary and secondary constructs and reasonable alignment of the aim of the papers to that of our research aim. The themes “Family finances” and “Diabetes self-care in a school setting” were graded as low certainty because there were few studies with thin data (fewer than 10 constructs) contributing to them. The theme “Perception of diabetes and glycaemic control”

was graded high certainty because there were a reasonable number of studies, and many constructs. (Table 3 and Data S1).

### 3.3 | Stage 3: Development of analytical themes

In the final stage, analytical themes were developed by AS, TM and JW who were involved in the process of identifying and interpreting concepts found within and across the dataset and going beyond the content of the original studies. Through further interpretation of the inter-relationships between the descriptive themes, the analysts (AS TM JW) developed three analytical themes that are considered to be integral to engaging with the “diabetes discourse” and strengthening the therapeutic alliance. The “diabetes discourse” is considered the salient knowledge on what diabetes is and how it should be managed in the context of the biomedical model.<sup>47</sup> The themes are 1. Alienation of CYPD; 2. Empowerment of CYPD and family; 3. Integration of diabetes (into self and daily life).

*Theme 1: Alienation of CYPD* (this theme was drawn from descriptive themes: self-perception and identity, HCP delivery, faith and culture, perception of the clinical consultation, social interaction and peer support, taking responsibility and family support).

Alienation is a recurrent theme for CYPD and their families. Alienation in the context of diabetes self- and family/carer management is affected by communication in the clinical encounter. Alienation of CYPD is also impacted by the extent of perceived family support and in relation to the extent of peer support, acceptance and identity validation for CYPD. During the clinical encounter, these factors contributing to alienation could be reinforced as a result of the CYPDs' / family carers' perception that HCPs followed a narrow diabetes discourse such that factors related to the family and socio-cultural and emotional context of the CYPD were not adequately addressed.

The responsibility for self-management behaviours was negotiated with family/carers who may either be reluctant to cede responsibility for self-management to the CYPD, or CYPD may perceive family/carers to be over-involved in their care which makes it difficult to elicit an environment, supportive of self-management. There are also social pressures that may undermine the CYPD in taking responsibility for self-care. For example, the data from CYPD across the studies suggested that self-management behaviours such as insulin injection, blood testing and having to be continually attached to an insulin pump can disrupt self-identity and social activities with peers and serve in alienating the CYPD. This alienation is also contingent on the extent of CYPDs' adaptation to

social norms, and the influence of their families' cultural and religious background. For example, CYPD were reluctant to disclose their diabetes to others due to perceived shame and stigma that was culturally and socially based, which in turn made support seeking from peers and family difficult to negotiate. In addition, there are implications regarding the school environment such that a lack of awareness and prompting from staff, provision of suitable rooms offering privacy for insulin injection may also instil a sense of alienation in CYPD.

*Theme 2: Empowerment of CYPD and family* (this theme was drawn from descriptive themes: taking responsibility, family support, social interaction and peer support, perception of diabetes and treatments and faith and culture).

Patient empowerment is defined as helping patients discover and develop their inherent capacity to be responsible for their own health.<sup>25</sup> Empowerment may be contingent on the extent to which the CYPD feel supported in taking responsibility for managing their diabetes and the extent to which their families' perception of diabetes and its treatment aligns with the “diabetes discourse”. For example, there were data pertaining to the descriptive themes to suggest that CYPD from minoritised backgrounds were subject to culturally determined discourses where disease perceptions sometimes differ from the dominant discourse of the host country. Such data highlight the tension that some CYPD experienced between the dominant diabetes discourse of the clinical encounter and cultural perceptions of sickness and treatment relating to their own background. Furthermore, some families, despite having long-term experience of managing a child with diabetes and receiving educational support, still seemed to experience conflicts between their perception of “being a good parent” and diabetes management. These conflicts illustrate the emotional challenges families experienced with accepting the condition and its management. Review data also suggested that families were anxious about perceived social consequences and resulted in feelings of shame and stigma. For example, there were fears about how diabetes would affect CYPD's marriage or employment prospects which sometimes dominated over concerns about the potential for long-term health complications. Finally, empowerment of CYPD and family/carers was unlikely to develop if the responsibility for managing diabetes was seen to lie solely with the HCP and health service. This was affected by HCP's communication style which sometimes negatively affected motivation to learn about and take responsibility for self-management. Indeed, despite expressing satisfaction with the health-care professionals, some parents described doubts about whether their children were given the best treatment, and some felt a need to consult social media and/or HCPs from



TABLE 2 Characteristics of included studies.

Source paper country setting CASP score	Participant type	Socio-economic status and cultural background	Diabetes type setting
Boman 2015 <sup>47</sup> Sweden <i>Setting:</i> Paediatric diabetes outpatient clinic CASP=10/10	Adolescents: <i>n</i> = 13 age: 13–18 years. Female <i>n</i> = not stated. Male <i>n</i> = not stated	First or second-generation immigrants to Sweden Born in Sweden <i>n</i> = 9, born in Iraq <i>n</i> = 3, born in Somalia <i>n</i> = 1	Diabetes: Type 1 <i>Setting:</i> Paediatric diabetes outpatient clinic
Boman 2017 <sup>48</sup> Sweden <i>Setting:</i> Paediatric diabetes outpatient clinic CASP = 9/10	Adolescents: <i>n</i> = 9 age: 13–18 years. Mean age 15 years. Female <i>n</i> = 6. Male <i>n</i> = 35 Participants used continuous insulin infusion and 4 used multiple daily injections Healthcare professionals <i>n</i> = 4	Non-Nordic background. All could speak Swedish	Diabetes: Type 1 <i>Setting:</i> Paediatric diabetes outpatient clinic
Povlsen 2008 <sup>45</sup> Denmark <i>Setting:</i> Additional education sessions from the diabetes healthcare teams directed at immigrant families with Arabic speaking parents CASP = 5/10	Children: <i>n</i> = 11 age: 4–17 years. Female <i>n</i> = 6 Male <i>n</i> = 5 Parents: <i>n</i> = 8 parents of the children. Healthcare professionals (specialist nurses and endocrinologist) Interpreter	Turkish or Kurdish immigrants to Denmark 1 of 11 of the mothers was 2nd generation. Children were therefore mostly second-generation immigrants with 1 third generation	Diabetes: Type 1 Diagnosed for 1–9 years Paediatric diabetes outpatient clinic
Povlsen 2009 <sup>44</sup> Denmark <i>Setting:</i> Additional education sessions from the diabetes healthcare teams directed at immigrant families with Arabic speaking parents. CASP = 9/10	Arabic speaking parents ( <i>n</i> = 4 mothers and <i>n</i> = 4 fathers) of children with Type 1 diabetes Children were not interviewed but were: aged 7 to 16 <i>n</i> = 4 boys and <i>n</i> = 3 girls. Children aged 7–16 years	<i>Immigrant population:</i> Parents of children with Type 1 diabetes who immigrated to Denmark from Iraq ( <i>n</i> = 4, Morocco <i>n</i> = 1, Lebanon <i>n</i> = 1). At least one parent from each family needed an interpreter	Diabetes: Type 1 The children were diagnosed after they immigrated to Denmark. <i>Setting:</i> Additional education sessions from the diabetes healthcare teams directed at immigrant families with Arabic speaking parents. Glostrup, Denmark
Hinder 2012 <sup>46</sup> <i>Setting:</i> Home, school or work UK Four counties in the North of England CASP 10/10	Children and Adults <i>N</i> = 30) (Aged 5 to 88 years). Children: <i>n</i> = 5 aged 5 to 16 years	Specifically regions of high social deprivation in the UK. Ethnicity: White: <i>n</i> = 22, South Asian <i>n</i> = 7, African <i>n</i> = 1 Ethnicities not specified for children	Diabetes: Type 1 <i>n</i> = 15 Type 2 <i>n</i> = 15 The type of diabetes was not specified for the children. <i>Setting:</i> Home, school or work
Sharpe 2021 <sup>43</sup> UK North London and East London <i>Setting:</i> Paediatric outpatient clinic CASP = 9/10	Children and adolescents <i>n</i> = 22 age 10–19 years. 10–13 years <i>n</i> = 9 14–17 years <i>n</i> = 4 18 and over <i>n</i> = 9	Black African <i>n</i> = 2 Black Caribbean <i>n</i> = 2 Dual heritage <i>n</i> = 4 South Asian <i>n</i> = 7 White British <i>n</i> = 6 White other = 1	Diabetes: Type 1 <i>n</i> = 20 Type 2 <i>n</i> = 2 <i>Setting:</i> Paediatric outpatient clinic
Turner 2015 <sup>42</sup> UK <i>Setting:</i> Healthcare, home, and school. CASP = 9/10	Adolescents: <i>n</i> = 12 Age 14–17 years <i>n</i> = 4 Age 16–17 years <i>n</i> = 4 Age 18–19 years <i>n</i> = 4	White British <i>n</i> = 8 Asian <i>n</i> = 3 Black Caribbean <i>n</i> = 1 Parental unemployment: Living with one parent unemployed <i>n</i> = 4 Living with two parents unemployed <i>n</i> = 4 Living with two employed parents <i>n</i> = 3	Diabetes: Type 2 diabetes diagnosed for 2 years. <i>Setting:</i> Healthcare, home, and school

Sample size and strategy	Data collection methods	Method of analysis/ theoretical approach	Measures in place to address cultural variation	Aim
Approached $n = 24$ 13 agreed	Semi-structured interviews	Phenomenology. Analysed using the meso, micro and macro model.	None reported. All adolescents spoke Swedish.	To identify factors important for adolescents to take responsibility for self-care.
Approached $n = 24$ 9 agreed	Participant observation: Audio and video recordings of scheduled appointments between adolescents and physicians	Phenomenology. Observation of video and audiotapes identified similarities and differences in the statements made and 5 themes were identified: Hope, forgetfulness, personality, attitude to disease and autonomy	None reported. All adolescents spoke Swedish	To identify aspects of the paediatric diabetes outpatient clinic that affect empowerment of adolescents and integration
	Observation of the paediatric clinic appointments with children and medical professionals. Assessment of medical records of the children. Semi-structured interviews with the parents	Interviews and medical records were analysed by layered reading and content analysis using constant comparison		
8 families approached (14 parents and 7 children) 7 parents were interviewed	Semi-structured interviews in small Groups. One group for parents with children aged 7–9 and a second for parents with children aged 13–16 years. Interviews held Nov–Dec 2005 Interviews in Arabic/Danish with the use of an Arabic interpreter. Interviews were taped and translation verified by independent translator. A thematic guide was used	Phenomenological approach.	Arabic interpreter was used for the interviews with parents. All children could speak English.	“to explore variations in how parents living as immigrants in Denmark and in their native country had perceived learning to live with a child with diabetes. This was done in order to identify potential problems related to immigration and cross-cultural care which should be considered in the provision of diabetes care to immigrant families”. This intervention is described in Povlsen 2005
A sample of 30 people with a range of age, type of diabetes, ethnicity, health literacy, family support and socio-economic status. Participants were sampled from primary and secondary diabetes care clinics, community contacts, and ethnic organisations in four counties in the North of England	Participant observation. The participants were observed for 2 to 4 periods of several hours. Participants were taken out for a meal. Detailed field notes were taken. Interviews (sometimes with a family member or caregiver present) about self-management efforts	Data analysis was informed by structuration theory, with the assumption that actions and choices depend on their disposition and capabilities and mediated by wider social structures	Lay family members interpreted for two people with limited English (these participants were unlikely to be the children in the sample)	To produce a richer understanding of how people live with diabetes and why self-management is challenging for some
CYP characterised as “Disengaged” were identified from registers at two paediatric outpatient clinics in North and East London	Semi-structured interview	Thematic analysis	Young co-investigators aged 16–25 and helped to develop the topic guide and the participant information sheets	To understand the factors affecting disengagement from services from ethnically diverse communities and socially deprived communities
Participants with Type 2 diabetes were sampled from a longitudinal cohort of children. From 100 approached 15 agreed	In depth interviews by telephone using a topic guide	Thematic analysis	None	To explore the views and experiences of adolescents about different treatment options for Type 2 diabetes and concordance with those treatments

TABLE 3 Descriptive themes and certainty GRADE CERQual.

Theme and description	Example (primary and secondary constructs)	Papers contributing to this Theme GRADE CERQual level of certainty
<p><b>1 Diabetes self-care in school setting</b></p> <p>Aspects of school organisation that affect the ability of CYPD to carry out self-management behaviours at school.</p>	<p>Adolescents pointed out that too little time was scheduled for lunch to allow them to take the test, queue up, be served, and eat: "I do not have time to eat, and I also have to queue; terribly boring" (G, 17)<sup>47</sup></p>	<p>Boman 2015<sup>47</sup></p> <p>Hinder 2012<sup>46</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p><b>Low</b></p>
<p><b>2 Faith and culture</b></p> <p>How faith and culturally based factors affect self- and family/carer management of diabetes such as acceptance of diabetes and trust and dialogue with health services</p>	<p>Despite their expressed satisfaction with the Danish healthcare professionals, immigrant parents described insecurity and worry as to whether their children were given the best treatment and a need to consult media, doctors and others from their own background.<sup>45</sup></p>	<p>Boman 2015<sup>47</sup></p> <p>Povlsen 2008<sup>45</sup></p>
<p><b>3 Family finances</b></p> <p>Factors relating to the financial and social position of the family in relation to providing resources for self- and family/carer management of diabetes</p>	<p>"I had a DKA [diabetic ketoacidosis] over Ramadan. My mother was away and I was at home with my older sister. I wanted to experience fasting and the feast at the end. However, I ended up in hospital" (P11, aged 18, T2).<sup>43</sup></p> <p>The impacts of poverty and family disruption were sometimes multiple and mutually reinforcing. Karl, for example, lived with his mother in a 2-bedroomed council house (IMD score 58); his brother lived with his father. "I ask if Karl goes to any activities outside school. He says he used to go to boxing but his dad lost his driving licence and they had to stop for three months and did not start again". Field notes from visit to Karl, age 11,<sup>46</sup></p>	<p>Povlsen 2009<sup>44</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p>Turner 2015<sup>42</sup></p> <p><b>Moderate</b></p> <p>Hinder 2012<sup>46</sup></p>
<p><b>4 Family support</b></p> <p>Practical and emotional support from parents and other family members to the CYPD, and support for the parents of CYPD receive in relation to self- and family/carer management of diabetes.</p>	<p>"You're better off here with this disease, because of the chances of getting insulin and all that; the material things are available here. But down there (in Iraq) I would not be alone. I would have my mother, sister, aunts; family around me. This means that if I was tired, they could relieve me; take over".<sup>44</sup></p>	<p>Povlsen 2009<sup>44</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p>Turner 2015<sup>42</sup></p> <p><b>Low</b></p> <p>Boman 2015<sup>47</sup></p> <p>Hinder 2012<sup>46</sup></p>

TABLE 3 (Continued)

Theme and description	Example (primary and secondary constructs)	Papers contributing to this Theme GRADE CERQual level of certainty
<p><b>5 HCP and health service delivery</b></p> <p>Factors impacting on HCP in information provision including challenges in language and communication.</p>	<p>Information from medical records. Most families were described as having limited knowledge and/or compliance, but the records also demonstrated a lack of follow-up on identified problems. For example, one girl was tested and found to have limited knowledge on diabetes, but was not offered re-education; children with fear of injections or known failure to take the prescribed insulin were introduced to a new regimen requiring more daily injections. Some were educated at a level that seemed poorly adjusted to their background, such as being instructed and given a handout in Danish prescribing graduated doses of fast-acting insulin according to blood glucose levels and carbohydrate intake.<sup>45</sup></p> <p>The team expressed obvious frustration to the fact that many immigrant families have difficulties in accepting that diabetes is a 'true' chronic disease and that this influenced their motivation for education and learning: "What they want to know, is when the child will be cured. Some say it every time".<sup>45</sup></p>	<p>Povlsen 2008<sup>45</sup>                      Povlsen 2009<sup>44</sup>                      Sharpe 2021<sup>43</sup>                      Turner 2015<sup>42</sup>  <b>Moderate</b>                      Boman 2015<sup>47</sup></p> <p>Bowman 2017<sup>48</sup>                      Hinder 2012<sup>46</sup>                      Povlsen 2008<sup>45</sup>                      Povlsen 2009<sup>44</sup>                      Sharpe 2021<sup>43</sup>  <b>Moderate</b>                      Boman 2015<sup>47</sup></p>
<p><b>6 Perceptions of the clinical consultation</b></p> <p>CYPD and families' views and experiences of clinical consultations and challenges self- and family/carer management to between appointments.</p>	<p>Too often, participants' behaviour and attitudes have been wrongly characterised by clinicians as a marker of their disengagement from the service. The markers are hardly ever directly discussed by the healthcare team or voluntarily disclosed in clinical appointments by CYPD but loom large over the relationship. Participants said: "At first, I did not really take it [diabetes] that seriously, I suppose, but then when you realise it's going to affect you every day, then I started to take it more seriously" (P9, aged 15, T1). Some parents perceived that the diabetes team provided good help and support, while others felt that the professionals did not really care about them.<sup>45</sup></p>	<p>Boman 2017<sup>48</sup>                      Povlsen 2008<sup>45</sup>                      Sharpe 2021<sup>43</sup>  <b>Moderate</b></p>

(Continues)

TABLE 3 (Continued)

Theme and description	Example (primary and secondary constructs)	Papers contributing to this Theme GRADE CERQual level of certainty
<b>7 Perceptions of diabetes and glycaemic control</b>	<p>Views of CYPD and parents on living with diabetes, acceptance of diabetes and treatments for good self- and family/carer management to avoid future consequences.</p> <p>“That’s what I want most; I really wish they could wipe it [the disease] out. That would be the best” (G, 16). They hoped that science would come up with a cure, and some put their faith in God, praying for the disease to disappear. They also declared their unwillingness to talk about their disease in their social network.<sup>47</sup></p> <p>The parents were also anxious about possible social consequences, e.g. that the children would not be able to complete an education and get a good job in the future or, especially for the girls, get married and have healthy children. The latter was most obvious among the Egyptian parents. One of them said: “There’s fear. Will my child develop complicating diseases when she gets older? Will she get married? And, if so, will there be complications in relation to pregnancy and delivery?”<sup>44</sup></p>	<p>Boman 2015<sup>47</sup></p> <p>Boman 2017<sup>48</sup></p> <p>Hinder 2012<sup>46</sup></p> <p>Povlsen 2008<sup>45</sup></p> <p>Povlsen 2009<sup>44</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p>Turner 2015<sup>42</sup></p> <p><b>High</b></p>
<b>8 Perceptions of treatments for diabetes</b>	<p>Views of CYPD and parents’ specific treatments and lifestyle regimen in self- and family/carer management of diabetes such as insulin injection, food restriction and medication adherence.</p> <p>Injecting insulin, measuring blood glucose and making restrictions on food intake were, especially by the immigrants, described as “unnatural” and even as “a punishment”.<sup>44</sup></p> <p>Although participants described benefits of this treatment option, three interviewees commented they would prefer not to be on insulin or liraglutide. Reasons given were being bullied at school and called a “druggie”, associating injections with “serious” illnesses, finding the injections painful, and experiencing weight gain as a side effect of insulin. Weight gain with insulin was viewed as making the diabetes worse. (Type 2 diabetes)<sup>42</sup></p>	<p>Boman 2015<sup>47</sup></p> <p>Povlsen 2008<sup>45</sup></p> <p>Povlsen 2009<sup>44</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p>Turner 2015<sup>42</sup></p> <p><b>Moderate</b></p>
<b>9 Self-perception and identity of the CYPD</b>	<p>Participants’ shared common stories of how their peer groups behave, look and think. Accounts of peer group norms revealed how participants positioned themselves at the centre and/or margins of such norms rather than the actual perceptions and behaviour of their peers. Participants said:</p> <p>“If I was to walk on the street, no one could actually tell that I had diabetes, unless I actually do something ... for example a blood test...” (P7, aged 15, T1).</p> <p>“Now at age 15, I have realised that diabetes does not make me different from anybody else” (P10, aged 15, T1)<sup>43</sup></p>	<p>Boman 2017<sup>48</sup></p> <p>Sharpe 2021<sup>43</sup></p> <p>Turner 2015<sup>42</sup></p> <p><b>Moderate</b></p>



TABLE 3 (Continued)

Theme and description	Example (primary and secondary constructs)	Papers contributing to this Theme GRADE CERQual level of certainty
<p><b>10 Social interaction and peer support</b> CYPD navigating social life and fostering support for self-management of diabetes from peers in social context.</p>	<p>Interviewer And how was it at school with friends and that? Participant I did not really tell them. Unless they saw me doing an injection, I never really let them know ... it was more to keep it quiet so ... they thought I was a bit weird, a bit off. (Participant 9)</p> <p>Interviewer You sound slightly hesitant to tell your friends. Participant I think it's just because the minute you say like, obviously they associate diabetes with like overweight, bad health ... I did not want them sort of knowing all of that side of things. (Participant 11)<sup>42</sup></p>	<p>Boman 2015<sup>47</sup> Povlsen 2009<sup>44</sup> Hinder 2012<sup>46</sup> Sharpe 2021<sup>43</sup> Turner 2015<sup>42</sup></p>
<p><b>11 Taking responsibility for self-management (by CYPD)</b> CYPD negotiations with HCPs and parents in taking/ceding responsibility to self-manage diabetes for self- and family/carer management of diabetes.</p>	<p>I want my mother to know that I can, that I can do it by myself; she does not need to nag all the time. I do understand that all she wants is to take care of me, but she does not need to nag. (G, 18G)<sup>47</sup></p> <p>G5: "I like to do things my way, I want to have the control, and I want to know I'm in control". In one of these consultations, the adolescent was successful in her self-care and the doctor confirmed her autonomy: D4: "Yes, you are old enough now. You can do it by yourself, that's for sure".<sup>48</sup></p>	<p><b>Moderate</b> Boman 2017<sup>48</sup> Hinder 2012<sup>46</sup> Povlsen 2008<sup>45</sup> Povlsen 2009<sup>44</sup> Turner 2015<sup>42</sup> <b>Moderate</b></p>

Note: CYPD child or young person with diabetes.  
Abbreviations: D, Doctor; G, female; HCP, healthcare professional; P, participant; T1, Type 1 diabetes.

their own background or country of origin.<sup>45</sup> Continuing struggles with accepting the condition, shame and stigma and a lack of trust can compromise attempts to support and empower CYPD and families and can make it more difficult for them to receive from their social network.

*Theme 3: Integration of diabetes (into self and daily life)* (this theme was drawn from descriptive themes: perception of diabetes, self-perception and identity, perceptions of diabetes treatments, social interaction and peer support and family support).

Integration of diabetes refers to the extent that having and managing diabetes is incorporated into the daily lives of CYPD and their sense of self. The integration of diabetes is contingent on ameliorating perceived alienation and increasing empowerment in CYPD to enhance their engagement with self- and family/carer management behaviours beyond the clinical consultation. The focus of integration of diabetes into CYPDs' identity is to elicit a sense of competence and volition such that CYPD are armed with skills to successfully negotiate their family and social environment and undertake self-management behaviours whilst embarking on their journey from adolescence to adulthood.

Integration requires family/carers ceding responsibility to enable CYPDs to self-manage their condition. Strategically, this might partly be achieved through parental style such that attitudes expressed within a “consultative” and supportive style may promote empowerment as opposed to a parental style perceived as “reminding”, “nagging”, and “controlling” which can cause frustration and discontent in CYPD. The synthesis also showed that CYPD who had integrated diabetes as part of their self-identity expressed hope that they could further improve

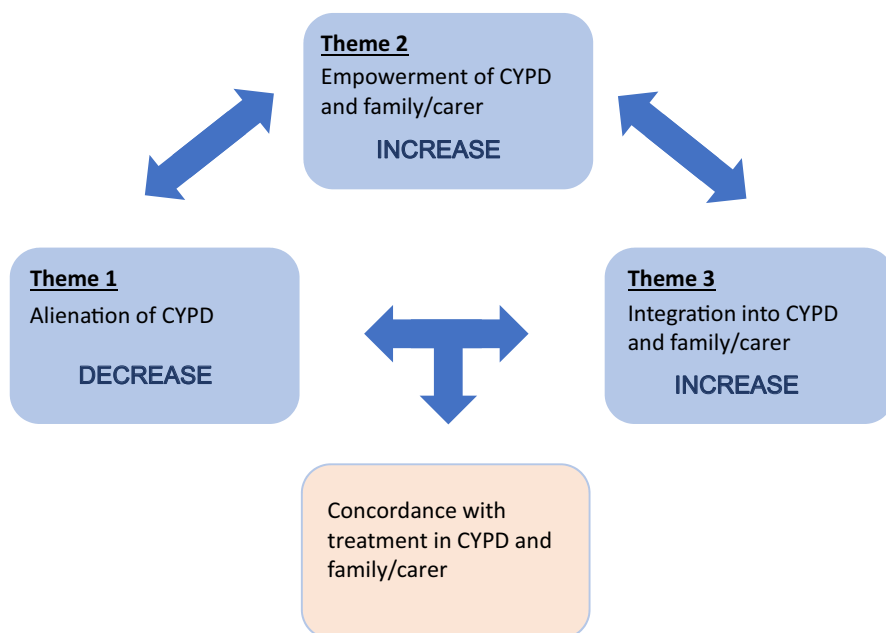
the quality of their self-management.<sup>47</sup> This journey to integration could also be supported by HCPs through broadening the clinical encounter to explore the socio-cultural and emotional factors related to integration as the CYPD negotiates responsibility with both their family/carers and HCPs. Thus, determining the degree to which CYPD integrate diabetes into their self-identity is important to optimise psychological and emotional well-being and elicit the motivation to enact self-management behaviours.

### 3.4 | Concordance and self-management of diabetes

It is proposed that the three analytical themes are interdependent and provide a conceptual framework for understanding the socio-cultural and economic determinants of self- and family/carer management of diabetes. In addition, the themes may be used to explore engagement with the “diabetes discourse” in the clinical encounter to foster greater concordance with treatment. See [Figure 2](#).

## 4 | DISCUSSION

The aim of this qualitative evidence synthesis was to identify existing primary qualitative research exploring the experiences, beliefs, and views of CYPD from underserved communities, their family/carers and those who deliver diabetes healthcare services. The findings have informed the development of three analytical themes. (1) Alienation of CYPD; (2) Empowerment of CYPD and family; (3) Integration of diabetes into daily life. These themes may



**FIGURE 2** From alienation to concordance. How the analytic themes work independently and synergistically to decrease alienation, empower and increase integration to achieve greater concordance in self-family/carer management of diabetes.

serve as a conceptual framework to inform and strengthen communication between CYPD, family/carers and HCPs to foster greater concordance in diabetes care. The desired outcome of concordance is to elicit a trusting relationship in the clinical encounter that supports self-management outside of the clinic environment.

#### 4.1 | Developing concordance with self-management of diabetes

A key finding is that the “diabetes discourse” may dominate in the clinical encounter and mostly exclude the CYPDs’ subjective experience. A particular point of concern for CYPD during the clinical encounter, is the perceived narrow biomedical focus on glycaemic control without support to achieve it and to integrate the complex behaviours required into different lifestyles, for example seeing CYPD as having lives outside of the diabetes consultation. Indeed, Sharpe et al.<sup>43</sup> suggest that engendering trust in the clinical relationship ought to be prioritised to allow for “honest and frank discussions on lifestyles, behaviour and identity, which are not currently actively taking place in clinical appointments”. However, sometimes CYPD may actively seek positive feedback and reassurance from HCPs. Therefore, such invitations provide an opportunity for the HCP to offer encouragement to sustain and intensify their striving for improvement.<sup>48</sup> Finally, good communication can take place in the clinical encounter without compromising the biomedical aspects, if issues of concern to CYPD and family/carer are also addressed.<sup>48</sup> Even when biomedical aspects are communicated well from the patient perspective, the socio-cultural factors may not be adequately acknowledged and addressed in the consultation and may reinforce feelings of alienation that are grounded in CYPDs’ social and family lives. Some HCPs simply refrained from bringing up certain topics in diabetes education sessions on the assumption that they were not culturally acceptable, despite their relevance to diabetes care.<sup>45</sup> In summary, communication of the biomedical aspects of managing diabetes in the clinical encounter is important but not to the exclusion of, addressing socio-cultural and emotional issues of concern to CYPD and family/carer rather than focusing solely on clinical concerns.

Person-centred care and shared decision-making approaches that promote collaboration between individuals with diabetes and HCPs have the potential to mitigate health inequalities, including the lower uptake of diabetes technology, fewer prescriptions of intensive therapy plans, and worse psychosocial outcomes.<sup>49,50</sup> Furthermore,

making efforts to know the CYPD, to provide opportunities to engage CYPD as active partners in a person-centred approach, have been shown to improve concordance between care provider and patient regarding treatment plans in other illness contexts.<sup>51</sup> It is also suggested that HCPs should address CYPD family/carers’ practical and emotional problems, to minimise conflicts related to diabetes management in order to elicit motivation for self-care as well as promoting clinic attendance.<sup>46</sup>

There were data in the synthesis to suggest that HCPs expressed interest in the families by being “open, curious and not prejudiced” and/or by trying not to go beyond their limits with regard to perceived privacy and/or cultural norms. HCPs also endeavoured to become better acquainted with CYPD in an effort to empower them through empathising with their lives and perspectives and by asking them to describe themselves and link that to their motivation for self-management.<sup>48</sup> Furthermore, other HCP strategies such as normalising feelings of frustration and acknowledging negative emotional responses to having a chronic disease by offering emotional support can help manage crises and enable CYPD come to accept their condition and ongoing management.<sup>46</sup>

Socio-economic factors play a pervasive and persistent role in child health and development.<sup>52</sup> However, it is not clear how ethnicity impacts on childhood diabetes independently of socio-economic status. Such complexity could explain why not all CYPD and family/carers attribute non-adherence with self- and family/carer management to their migrant and ethnic background. For example, Boman et al.<sup>47</sup> suggest that belonging to an underserved community does not necessarily mean that it is the membership in itself that is associated with vulnerability. Language may also be an additional or a stand-alone challenge to communication other than the ethnic/religious background of the CYPDs’ family. Furthermore, it can also be difficult for some CYPD to acknowledge and articulate relevant aspects of their own culture, because they are inherent and/or assimilated since birth or may not be different, with regard to identity and social interaction, to that of peers from non-ethnic backgrounds. It is also known that health inequalities can compromise support seeking from and empowerment of patients from minoritised communities.<sup>26</sup> We were unable to draw directly from the included studies any substantial themes about what CYPD, their carers or the HCP caring for them would like to see in terms of support for self-management as there were no direct first-order constructs on this. In some cases we could infer the type of support that was lacking, but views were not all aligned. For example some parents expressed a lack of trust in the healthcare services while others in the same study found the support to be

acceptable, and none stated what they actually would like to see.<sup>44</sup>

A recent overview of reviews on supporting self-management for CYPD identified four broad strategies psychoeducation, including many delivered as digital games; psychological counselling to families and children or to adolescents as individuals; self-monitoring using mobile phones and apps; and telehealth, which incorporated self-monitoring with feedback and contact with services, again using apps and websites. The effects of these interventions on healthcare outcomes were mixed, with some studies reporting improvements and others finding the interventions had no effect<sup>17</sup> however none of the reviews included had a focus on children from underserved communities. Evidence from reviews of interventions for adults with diabetes from underserved communities show a positive effect of developing or adapting interventions on healthcare outcomes. Adaptations included use of culturally tailored materials, using community centres, consideration of literacy levels, ethnic foods, and traditional remedies, use of group meetings, smart phone apps, and peer-support.<sup>53–56</sup> In 2010, a review of how culture was addressed for managing diabetes or asthma in children from ethnic minority groups reported the following adaptations: translation of materials into native language of ethnic groups; accommodation of beliefs, myths and practices of ethnic groups; acculturation of interventionists; and adopting a collaborative approach to intervention development with ethnic groups.<sup>19</sup> A review of strategies to deal with food insecurity in families with diabetes, listed new practices to support populations with diabetes management including screening for food insecurity as part of routine care, nutrition counselling and budget management, tailoring of medical management to reduce incidence of hypoglycaemia, involving patients in decision making process, assess coping strategies of patients and referral to community resources related to food and housing, such as affordable grocery stores.<sup>57</sup> Issues encountered by adults from minoritised populations with diabetes and their medical care included the participants' strong adherence to cultural norms, religious beliefs, linguistic diversity, low health literacy levels, different beliefs about health and illness, belief in expert and professional support, low accessibility of culturally appropriate services/information, and low concordance with Western professional advice.<sup>58</sup> Taken together this evidence suggests that for underserved communities diabetes health care could be enhanced with measures to improve communication in clinical encounters, and a power sharing approach could help to achieve concordance.<sup>19,57</sup>

## 4.2 | Culturally informed education and support in and beyond the clinical encounter

This qualitative evidence synthesis suggests that underserved communities are likely to face challenges in the adaptation of diabetes education to their own context and require culturally competent consultations and informed education and support in and beyond the clinical encounter. It is also recognised that CYPD have a greater risk than their peers, living without diabetes, of psychological conditions such as anxiety and depression, and behavioural conditions such as conduct disorders and attention deficit hyperactivity disorder.<sup>59</sup> Therefore, these factors should be given due consideration especially for CYPD from underserved communities.<sup>43,46</sup> This point is emphasised by the UK National Institute for Health and Care Excellence (NICE) guidelines for CYPD which recommend that “children and young people with Type 1 diabetes and their families or carers should be offered emotional support after diagnosis tailored to their emotional, social, cultural and age-dependent needs”.<sup>59</sup> It has been suggested that incorporating an explicit focus on ethnicity is important because ethnic identities have implications for health, independent of other socio-economic factors.<sup>60,61</sup> However, addressing these diverse, socio-economic factors within four 30 to 45 minute-, clinic consultations per year (based on typical UK consultation times) is challenging. There is therefore, a need for more support for HCPs to address socio-cultural factors in clinical consultations. Some HCPs may be reluctant to bring up topics related to ethnicity, culture and socio-economic disadvantage as they may be sensitive and evoke strong emotions. However, training in communication skills, active listening and cultural competence is available. By gaining insight and confidence in navigating and responding to the varied needs of patients, HCPs will influence the way care is given and could have an impact on reducing disparities in healthcare outcomes.

## 4.3 | Limitations of findings

The studies included in this synthesis comprise a range of data collection approaches such as direct observation of consultations and analysis of medical records, which support the adequacy of the findings and are not solely reliant on the quality of a semi-structured interviews. The certainty of the descriptive themes is somewhat supported by the application of GRADE CERQual which demonstrated moderate confidence across most themes. Issues with regard to confidence were mostly around adequacy of data with some themes arising from four or fewer studies.

Following a comprehensive search seven studies met the inclusion criteria and although two research groups contributed to four of these papers each paper from those groups was a distinct piece of research with unique participant samples. Furthermore, some descriptive themes were developed from papers that had limited relevance to our research question, for example the sample in Hinder et al.<sup>46</sup> were aged 5 to 88 and included many adults although data was extracted pertaining only to quotes attributable to CYPD. Turner et al. drew from a broad population with only 4 participants identified from underserved communities.<sup>42,46</sup> This particularly affected the theme of finances where insufficient evidence was found to include it in the analytical themes, the importance to families of adequate financial resources to provide the means to support healthy lifestyles and stable family structures is acknowledged. Therefore, future primary research should include questions relating to financial security and the family budget and such data may need to be included in the future development of the themes as more evidence becomes available.

The majority of the observations in this synthesis are from CYPD and families with Type 1 Diabetes. Two the seven studies included CYPD with Type 2 diabetes, Sharpe et al. 2021 included 2/20 children and Turner recruited all 12 respondents with Type 2 diabetes.<sup>42,43</sup> Hinder et al. included 5 children but we do not know which type diabetes.<sup>46</sup> The remaining 4 studies had 49 respondents and all children had Type 1 diabetes.<sup>44,45,47,48</sup> We saw no themes that related specifically to the type of diabetes. It is reasonable to assume that much of the work to engage families and CYPD from underserved communities will be similar irrespective of diabetes type, but there will be differences specific to the management of these different diseases. Further studies could show how clinical services or interventions could incorporate such differences.

Data were also limited with regard to the perspective of the HCPs by including only 4 HCPs and 1 diabetes team, which limit making generalisations about HCP's perceptions. However, one study was based on a phenomenological analysis of video-recordings of 12 paediatrician-CYPD consultations which served to complement CYPD perspectives of the clinical encounter derived from interview data.<sup>48</sup> The majority of the respondents in the synthesis had a diagnosis of Type 1 diabetes and there were a wide range of ethnic minorities represented, but the extent of socio-economic deprivation is less certain. There are also limitations on the extent that underserved communities are affected by access to and effects of the newest technology, such as hybrid closed-loop pumps, which have come out since the papers included in this reviews were published.

#### 4.4 | Future work and management of diabetes in CYPD from underserved communities

The present QES has highlighted that the relationship between health services provided for CYPD from underserved communities in the UK and Europe is an under-researched area. The findings from this QES have informed the design and conduct of ongoing primary qualitative work that aims to explore the management of diabetes in CYPD and family/caregivers from underserved communities and the healthcare professionals who care for them. This primary qualitative research, together with this QES and two systematic reviews will inform the development, in partnership with CYP and their families, of culturally acceptable intervention packages.<sup>17,62,63</sup> These will be based on models of community liaison keyworkers, targeting education and behaviour change, addressing the specific personal, family, cultural and community barriers to optimal glucose control faced by these groups with Type 1 or Type 2 diabetes.

#### 4.5 | Analyst reflexivity statement

AS is a qualitative methodologist with a background in health psychology including self-management of diabetes and practitioner-patient communication. TM has a background in evidence synthesis of quantitative and qualitative data. In acknowledging their respective areas of expertise, the primary analysts have made complementary contributions to data analysis and interpretation of data such that any inherent bias in findings would be balanced by their different theoretical and methodological perspectives.

#### AUTHOR CONTRIBUTIONS

Conception of the review; Sabi Redwood, Aidan Searle, Julian Hamilton-Shield. Design of the review; Theresa H. Moore, Aidan Searle, Sabi Redwood, Julian Hamilton-Shield, Jessica Wheeler. Coordination of the review; Theresa H. Moore, Aidan Searle. Search design and organisation of search results; Sarah Dawson. Selection of studies for inclusion in the review; Theresa H. Moore, Aidan Searle. Collection of data for the review; Theresa H. Moore, Aidan Searle. Assessment of the methods; Theresa H. Moore, Aidan Searle. Development of descriptive themes; Theresa H. Moore, Aidan Searle. Assessment of the certainty in the body of evidence; Theresa H. Moore, Aidan Searle. Development of analytical themes; Aidan Searle, Jessica Wheeler, Theresa H. Moore. Comment on the manuscript; Theresa H. Moore Sabi Redwood IL SG



Julian Hamilton-Shield, Timothy G. Barrett. Writing of the review manuscript; Aidan Searle, Theresa H. Moore.

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## CONFLICT OF INTEREST STATEMENT

None.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available in the medical research literature, within the references of our included studies. These data were derived from the following resources available in the public domain: Boman et al.<sup>47</sup>; <https://journals.sagepub.com/doi/full/10.1177/1049732314549358> Boman et al.<sup>48</sup>; <https://journals.sagepub.com/doi/full/10.1177/2050312117700056> Hinder et al.<sup>46</sup>; <https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-12-83> Povlsen et al.<sup>45</sup>; <https://journals.sagepub.com/doi/10.1177/0017896907086156> Povlsen et al.<sup>44</sup>; <https://onlinelibrary.wiley.com/doi/full/10.1111/j.1471-6712.2008.00644> Sharpe et al.<sup>43</sup>; BMJ Open <https://doi.org/10.1136/bmjopen-2020-046989> Turner et al.<sup>42</sup>; Diabetic Medicine: <https://doi.org/10.1111/dme.12577>.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## APPENDIX

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