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Parents' experiences of caring for a young child with type 1 diabetes: a systematic review and synthesis of qualitative evidence

Running title: Parents' experiences of caring for a young child with type 1 diabetes

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Abstract

1

2 **Aims**

3 To synthesise the qualitative evidence on parents' experiences of caring for a child aged ≤8
4 years with type 1 diabetes to identify: the challenges they encounter; their views about support
5 received; ways in which support could be improved; and, directions for future research.

6 **Methods**

7 We searched Medline, EMBASE, CINAHL, PsycINFO and Web of Science databases to
8 identify qualitative studies reporting parents' views and experiences of caring for a child with
9 type 1 diabetes aged ≤8 years. Key analytical themes were identified using thematic synthesis.

10 **Results**

11 Fourteen studies were included. The synthesis resulted in the generation of two overarching
12 themes. *Monopolisation of life* describes the all-encompassing impact diabetes could have on
13 parents due to the constant worry they experienced and the perceived need for vigilance. It
14 describes how parents' caring responsibilities could affect their wellbeing, relationships and
15 finances, and how a lack of trusted sources of childcare and a desire to enable a 'normal'
16 childhood constrained personal choices and activities. However, use of diabetes technologies
17 could lessen some of these burdens. *Experiences of professional and informal support*
18 describes how encounters with healthcare professionals, while generally perceived as helpful,
19 could lead to frustration and anxiety, and how connecting with other parents caring for a child
20 with type 1 diabetes provided valued emotional and practical support.

21 **Conclusions**

22 This synthesis outlines the challenges parents encounter, their views about support received
23 and ways in which support might be improved. It also highlights significant limitations in the

24 current literature and points to important areas for future research, including how
25 sociodemographic factors and use of newer diabetes technologies influence parents' diabetes
26 management practices and experiences.

27 PROSPERO:

28 https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019128710

29

30 Key words: type 1 diabetes; parents; child; qualitative synthesis

31

32 **Background**

33

34 Type 1 diabetes is one of the most common chronic childhood conditions and its incidence is
35 rising worldwide [1], including among pre-school aged children [2]. This condition is now
36 mostly managed using flexible intensive insulin regimens, which involve multiple daily tasks
37 (e.g. regular blood glucose monitoring, carbohydrate counting, calculating and administering
38 insulin) and may present different issues and challenges to conventional regimens based on
39 fixed schedules and insulin doses. For young children (those aged ≤ 8 years), however, most
40 of these tasks are too complex to undertake independently; hence, parents/caregivers
41 typically take on and/or oversee these responsibilities [3]. The physiological, cognitive,
42 behavioural and socio-emotional issues at this developmental stage make diabetes
43 management challenging [4] and clinically recommended blood glucose targets difficult to
44 achieve [5]. Hence, caring for a young child with diabetes can be overwhelming and stressful
45 for parents, and can affect wider family life [6].

46

47 Qualitative studies have explored parents' experiences of caring for a child with type 1
48 diabetes in a range of contexts and situations, such as following diagnosis, using different
49 diabetes management regimens and whilst managing transitions [7-11]. Synthesising bodies
50 of qualitative literature can help clarify understanding of a phenomenon, identify gaps and
51 ambiguities in the existing literature, and inform decision-making by policymakers and
52 healthcare practitioners [12]. However, syntheses of qualitative or mixed-methods research
53 involving parents of young children with type 1 diabetes remain scarce and have generally
54 focused on specific aspects of their experience, such as their psychological reactions to their
55 child's diagnosis [13] or their use of diabetes technologies [14]. To date, no reviews have
56 focused on parents' *everyday* experiences of caring for a young child with type 1 diabetes.
57 This review aims to address this gap. By identifying, examining and synthesising the
58 qualitative evidence on parents' experiences of caring for a young child with type 1 diabetes,

59 we sought to: (1) describe the published evidence base; (2) identify the challenges parents
60 encounter when managing their child's diabetes; (3) explore their views about support
61 received from health professionals and other sources; (4) identify ways in which support could
62 be improved; and (5) identify gaps in the evidence base and directions for future research.

63

64

65 **Methods**

66

67 We followed Thomas and Harden's thematic synthesis approach, which is well suited to
68 reviews focused on individuals' perspectives and experiences [15]. This approach involves a
69 systematic search of relevant literature, quality appraisal of the included studies and three
70 distinct stages of data manipulation: (1) line-by-line coding, (2) organising codes into
71 descriptive themes, and (3) developing analytic themes. Our reporting follows the guidelines
72 for Enhancing Transparency of Reporting the Synthesis of Qualitative Research (ENTREQ)
73 and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [16,17].

74 Details of the protocol for this systematic review and synthesis were registered on

75 PROSPERO

76 (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019128710)

77

78 **Search strategy**

79 We identified papers for inclusion from a systematic search of electronic databases (Medline,
80 EMBASE, CINAHL, PsycINFO and Web of Science). Working with a medical library science
81 professional, we developed a search strategy that drew on existing literature and a
82 combination of Medical Subject Heading (MeSH) terms and keywords relating to our target
83 condition, population and methodology. Our searches were also informed by the SPIDER
84 (Sample, Phenomenon of Interest, Design, Evaluation, Research type) approach to identifying
85 qualitative literature [18] and search terms were tailored to suit each database. We screened

86 the reference lists of included studies and relevant reviews identified by the search to identify
87 further papers for inclusion. We limited our search to papers published from 2002 onwards,
88 as this was the time when flexible intensive insulin regimens began to be widely used as part
89 of routine clinical care [19]. A sample search strategy for Medline database is presented in
90 supplementary figure Fig. S1.

91

92 **Study selection and screening**

93 Our choice of age cut-off at ≤ 8 years was informed by the literature highlighting the high level
94 of parental responsibility for diabetes management tasks in this younger age group [3].
95 Subsequently, increasing maturity and independence sees children assume progressively
96 more responsibility for their own diabetes care; this transition changes parents' role in their
97 child's diabetes management, and thus their experiences, and was outside the scope of this
98 review.

99

100 We included peer-reviewed papers published in English if they reported: (1) primary research
101 using qualitative methods or mixed-methods studies reporting qualitative data separately; and
102 (2) views and/or experiences of parents and/or caregivers of children with type 1 diabetes ≤ 8
103 years of age. This included studies which also reported the views of parents of older children,
104 but where findings pertaining to those with children aged ≤ 8 years and cutting across age
105 ranges were clearly discernible. We had originally excluded some cross-cutting papers
106 involving only a small number of parents of children in our target age range. However, a later
107 re-evaluation found these studies contributing important cultural and sociodemographic
108 dimensions to the overall analysis, which warranted their inclusion. We excluded papers if
109 they reported: (1) non-primary research; (2) only quantitative research; (3) data that focused
110 exclusively on: parent/caregiver views and/or experiences regarding their child being
111 diagnosed or immediately after diagnosis (which have been reviewed elsewhere [20]); parents
112 of children older than 8 years with type 1 diabetes; and, adults with type 1 diabetes reporting
113 their own experiences of living with type 1 diabetes.

114

115 Search outputs were imported into EndNote X8, then exported, de-duplicated and screened
116 using Covidence systematic review management software (Veritas Health Innovation,
117 Melbourne, Australia). To reduce selection bias, two authors (BK and DR) independently
118 screened the titles and abstracts of identified records and compared and agreed their
119 selections. Full texts were retrieved for any papers that appeared to meet the eligibility criteria.
120 Disagreements on the final selection were minimal and resolved through discussion without
121 need for third-party arbitration.

122

123 **Data extraction and quality assessment**

124 BK extracted the following data from the included studies: author(s); year of publication;
125 country; study aims; sample size; parent and child characteristics; methodology. For each
126 paper, we imported full 'Results' and 'Discussion' sections into NVivo 10 (QRS International,
127 Doncaster, Australia). We extracted quotations and descriptive reporting of parents' accounts
128 from Results sections only when this material could be clearly attributed to parents of children
129 ≤ 8 years of age. No findings (quotations or descriptive material) were extracted which reported
130 the views of parents of children aged > 8 years. In keeping with our aim to identify ways in
131 which support for parents could be improved, we extracted recommendations in Discussion
132 sections proffered by the primary authors. Recommendations made by primary authors were
133 only extracted when these could be clearly attributed to children ≤ 8 years of age, or where
134 these were cross-cutting.

135

136 BK and DR evaluated each study using the CASP (Critical Appraisal Skills Programme) quality
137 appraisal tool for qualitative studies [21]. This tool consists of 10 questions considering
138 different aspects of study validity and the perceived value of each study's contribution. The
139 purpose of this systematic appraisal process was not to exclude studies, but to consider
140 strengths and limitations of the included studies.

141

142 **Data analysis and synthesis**

143 We conducted a 3-stage thematic synthesis informed by Thomas and Harden's thematic
144 synthesis approach [15]. First, findings from included articles relevant to the aims of the review
145 were coded using free codes that remained close to the original meaning in the primary
146 studies. Second, we compared similarities and differences between the free codes before
147 grouping related data segments into descriptive themes. Finally, we considered the patterns
148 and relationships between these themes to develop interpretations beyond the primary data
149 and generate overarching analytical themes. We then used the same process to compare
150 recommendations made in the Discussion sections of selected articles, by comparing
151 similarities and differences to develop descriptive themes, followed by the generation of
152 analytical themes. We ensured that data pertaining to findings and recommendations were
153 kept separate. This was done to distinguish between themes arising directly from participants'
154 data (findings) and the thematic synthesis of recommendations developed by authors in
155 response to their findings. BK independently coded the extracted data and undertook the
156 synthesis. To reduce bias and enhance rigour, the resultant outputs were discussed with two
157 other review authors (DR and JL) to consider any additions or changes and agree on the final
158 analytic themes.

159

160

161 **Results**

162

163 The search identified 2622 unique records (see Fig. 1). Of these, 2466 papers were excluded
164 after titles and abstracts were screened for relevance. Full-text review of the remaining 156
165 studies led to the exclusion of 142 papers that did not meet eligibility criteria. Screening of
166 reference lists of included studies and relevant reviews identified by the search did not identify
167 further papers for inclusion. This resulted in 14 studies being included in the synthesis.

168

169 <Insert Fig. 1 here>

170

171 **Study characteristics**

172 The 14 included papers reported the views and experiences of 274 parents in seven countries:
173 Canada [22], United States [23-27], United Kingdom [28-30], Sweden [31,32], Norway [33],
174 Iran [34] and Palestine [35]. Four papers reported exclusively on the experiences of parents
175 of children aged ≤ 8 years (n=80) [23,25,26,33]. The remaining 10 also included parents of
176 older children and provided insufficient detail to determine the number of parents with children
177 in our target age group. The provision of information about study participants'
178 sociodemographic characteristics varied greatly. Across all studies, the majority of parents
179 were reported as being: married or co-habiting, qualified to higher education level and in
180 employment. Approximately half of papers specified participants' ethnicity and reported this
181 as mostly, or exclusively, white/Caucasian [23-27,29]. All studies employed interviews; one
182 additionally used online focus group discussions. Most studies considered parents' holistic
183 experiences of caring for a young child with type 1 diabetes, with some focusing specifically
184 on the experiences of mothers [23,32,34] and fathers [25,31], respectively. Two papers
185 described parents' everyday experiences of managing their child's condition using insulin
186 pumps [24,29]. Table 1 outlines the key characteristics of the included studies.

187

188 <Insert Table 1 here>

189

190 **Quality assessment**

191 Using the CASP quality appraisal checklist [21], we concluded that all 14 studies had clearly
192 justified and stated research aims, appropriately employed qualitative methodology and
193 provided sufficient information about their data collection processes. However, in some cases
194 it was difficult to determine the rigour of data analysis from the limited information provided.
195 Furthermore, several papers lacked detail regarding their consideration and mitigation of
196 potential researcher influence and ethical issues. In respect of their wider contribution, we

197 rated 10 of the 14 studies as being of good value, three of medium and one of low value. The
198 study rated low value used mixed methods to report on a narrow topic area (parents'
199 perceptions of healthy eating for children with type 1 diabetes) [26]. See supplementary Table
200 S1 for the completed CASP scoresheet.

201

202 **Synthesis findings**

203 Below, we present two overarching analytical themes resulting from our synthesis,
204 *Monopolisation of life* and *Experiences of professional and informal support*, with each theme
205 comprising several subthemes. Primary authors' recommendations for how parent/caregiver
206 support could be improved in respect of the issues identified are summarised in Table 2 at the
207 end of this section.

208

209 *1. Monopolisation of life*

210

211 Impact on physical, psychological and emotional wellbeing

212 Across the studies, parents noted how the complexities and unpredictability of type 1 diabetes
213 made it a 'very tiring disease' to manage [25]. They described living in a perpetual state of
214 watchfulness [22,23,33] and physical and mental readiness to take action, because '[T]hings
215 may change in minutes' [33]. Consequently, their child's diabetes was permanently present in
216 their minds. As one father explained, 'even if you are not thinking about it [the illness], you are'
217 [25].

218

219 Hypoglycaemia, in particular, was an all-pervasive concern [22,23,28] borne from several
220 considerations: the child being too young to recognise and report low blood glucose ('he
221 doesn't have a clue, because he's just learning to talk' [28]), some children's poor
222 hypoglycaemia awareness [28,29]; and, parents' awareness of the potential deadly
223 consequences of hypoglycaemic events [22,28,32]. Parents' concerns were greatest during
224 the night, when they worried that severe hypoglycaemia might go undetected and threaten

225 their child's safety. To alleviate their fears, they described testing blood glucose regularly
226 throughout the night, leading to exhaustion and chronic sleep deprivation [22,23,33]. Some
227 parents recognised that their actions could be borne from irrational fears, but preferred being
228 hyper-vigilant to having potential future regrets [22,29]. Some, like this mother, also
229 acknowledged that their efforts came at a cost to their own health and wellbeing:

230

231 'I am satisfied in one sense since NN is feeling fine. At the same time, I feel unhappy
232 when I think about not sleeping, feeling anxious and feeling tired and moody all the time.'
233 [32]

234

235 Furthermore, despite their child's young age, many parents already worried about how
236 diabetes would affect his/her life in the future [27,30,34,35]:

237

238 'I am always thinking about his future. I wonder what will happen to his body. Can he be
239 successful in his life? I do not know; the future is unclear.' [34]

240

241 These concerns could be influenced by sociocultural norms and expectations. Parents of
242 young girls in the studies conducted in Iran [34] and Palestine [35] described worrying about
243 their daughter's diabetes harming her chances in marriage, lest she be viewed as less
244 desirable and at risk of passing the condition on to her own children.

245

246 In light of parents' varied and constant concerns, many worried about how their emotions might
247 be perceived by, and affect, the child, because, as this mother explained, 'it's hard not to
248 transfer that worry onto him all the time. I know I don't want him to feel worry not going to
249 places or doing things or that sort of thing' [22]. Consequently, they described deliberate efforts
250 to hide their fears, worries and exhaustion by adopting an 'outward façade' [22,32].
251 Additionally, some mothers reported depression, weight problems, migraines and episodes of
252 hospitalisation, which they linked to the burden of their caring responsibilities [23].

253

254 Impact on relationships

255 Several studies highlighted how caregiving responsibilities not only monopolised parents' own
256 lives, but also affected their relationship with the child [23,30,32,33]. Some parents observed
257 how diabetes had 'come between me and my child, and to me that was kind of a feeling of
258 loss' [33]. Managing their child's condition was described as requiring an atypical level of
259 caregiving input [32], with some mothers likening their experience to caring for a newborn [23].

260

261 Mothers and fathers also described how their relationships with one another had changed as
262 a result of having to 'live with constant attention directed at the diabetes condition' [33].
263 Mothers typically shouldered the main caring responsibilities [23,25,32], with fathers being
264 more willing to be involved in diabetes care when it involved technology [24]. However, fathers
265 still played an important role, especially by providing emotional support and respite to mothers
266 [23,25,32,34]. Some studies indicated potential gender differences in parents' attitudes and
267 approaches to their child's diabetes management, with fathers being more relaxed than
268 mothers in this regard [24,25,32]. This could sometimes lead to conflict between parents, but
269 also encouraged more in-depth communication about how best to manage their child's
270 diabetes [24].

271

272 Impact on personal choices and activities

273 Parents described caring for a child with type 1 diabetes as a full-time job [32,33]. They noted
274 that the unpredictability of the condition required them to constantly plan ahead [33].
275 Accommodating regular clinic appointments required time and flexible employment [25].
276 Having their child looked after in a daycare facility, including nursery or school, did not
277 necessarily provide respite. Indeed, it could create additional work, as parents needed to
278 ensure that staff were educated about their child's specific care needs and make themselves
279 available throughout the day to answer questions or attend the facility as required [33].
280 Moreover, the unpredictability of their child's eating and physical activity while at

281 school/nursery could add to parents' anxieties about their child's safety [28]. Mothers also
282 reported feeling concerned about staff's (in)ability to provide appropriate diabetes care and
283 some chose not to place their child in daycare for that reason [23]. Similarly, many parents felt
284 unable to entrust the care of their child to relatives and others in the community, as they
285 perceived them as largely ignorant about diabetes and/or insufficiently vigilant about its
286 management [22,24,28,32]. Consequently, many mothers curbed personal activities to be
287 available to care for their child [23,28,35]. As one mother explained:

288

289 'I didn't go to many places, because she couldn't be with me and no one else can take
290 care of her but me.' [35]

291

292 These concerns could also affect mothers' employment decisions, with some quitting work or
293 reducing their working hours to allow them to care for their child at home [28]. However, others
294 described how, despite wanting to be stay-at-home caregivers, they needed paid employment
295 to afford their child's diabetes treatment costs [34]. Importantly, this financial strain related to
296 their child's diabetes care was also reported by parents who self-identified as middle- to upper-
297 middle class [27] and were in possession of medical insurance, as this did not always cover
298 all necessary expenses [34,35].

299

300 Finally, several studies described how parents were determined not to let diabetes dominate
301 their child's life [22,25,26,28,30,32,33], so that the child could 'have her innocence, to go out
302 and play and feel like a normal child without feeling there is something different with her' [28].
303 To facilitate this 'normality', parents adopted strategies that required even more of their time
304 and effort, such as becoming actively involved in school and social activities (e.g. their child's
305 sports team) to allow the child to participate while ensuring a watchful eye on their glucose
306 needs [25] and temporarily relaxing the child's food regimen and later correcting high blood
307 glucose if necessary [26,28]. Caring for a young child with diabetes also had an all-
308 encompassing impact on wider family life. Some parents reported modifying their own and/or

309 their family's eating practices to make managing mealtimes easier [26]. Bedtimes, leisure
310 activities and holidays were also often adapted to accommodate the child's needs and limited
311 opportunities for spontaneity [32].

312

313 Diabetes technologies: lessening the impact

314 While most studies illustrated the pervasive impact of the child's diabetes on parents' lives,
315 two studies highlighted how using an insulin pump could alleviate some of the stresses and
316 constraints they experienced [24,29]. Although parents reported needing to undertake some
317 additional tasks, such as dealing with occasional mechanical problems [24] or more frequent
318 blood glucose checking [29], they also described how pump use had helped reduce the
319 'slavery of diabetes management' [24] because they no longer needed to administer basal
320 insulin at specific times of day [29], could approach eating and snacking more flexibly due to
321 the ease with which bolus doses could be administered via the pump [24,29], felt less fearful
322 about their child being cared for by others [24,29] and found others more willing to babysit
323 [24]. Parents also reported finding it easier to achieve good blood glucose control using a
324 pump due to the ability to administer smaller (more precise) insulin doses, having fewer
325 variables (e.g. only one type of insulin) to manipulate to manage glucose excursions and the
326 pump's data log and bolus advisor helping to reduce management errors [24,29]. Finally,
327 parents in another study described how using a continuous glucose monitor had helped make
328 treatment decisions easier as it gave them convenient access (via a smart phone app or digital
329 platform such as Nightscout) to real-time blood glucose information and allowed them to
330 review how their child's body responded to different insulin doses throughout the day [27].

331

332 *2. Parents' experiences of professional and informal support*

333

334 Experiences of professional support

335 Parents received their initial education about diabetes management from hospital paediatric
336 diabetes teams. However, they described how sometimes 'one nurse would come in and say

337 do it this way, another would come in and show us a different way' [25], resulting in
338 inconsistencies in the information received. Moreover, parents across several studies
339 considered their initial training inadequate preparation for the daily challenges of caring for a
340 young child with type 1 diabetes [23,25-27,34]. As this father noted:

341

342 'It is like being handed a big city phone book and you have to learn all the names before
343 you go home.' [25]

344

345 While diabetes teams were generally considered a helpful resource, some parents felt that
346 professionals did not always appreciate the complex and dynamic nature of managing
347 diabetes at home [31] and the considerable effort this required [23]. Furthermore, staff not
348 making time to answer questions or calls, avoiding discussion of more holistic issues and
349 offering inaccurate or inconsistent advice could undermine parents' trust in their diabetes team
350 [31]. Some parents described how they felt stressed and anxious in the run-up to clinic
351 appointments for fear of being reprimanded for a (perceived) lack of effort and not meeting
352 blood glucose targets [23,28,32]. This fear also led to some actively withholding information
353 from the diabetes team [23] and was felt even in the absence of any critical comments from
354 staff [32].

355

356 Several studies also highlighted potential conflict between parents' and professionals'
357 diabetes expertise. The fathers in Boman's study described a mismatch between their own
358 personal experiences of caring for a child with diabetes and the general recommendations
359 and goals put forward by the diabetes team [31]. Parents in another study felt that healthcare
360 professionals had unrealistic expectations of what was achievable in terms of their young
361 child's blood glucose control [28]. Indeed, many emphasised how their unique personal
362 understanding of their child's individual needs and their impact on everyday life provided them
363 with insights that extended beyond professionals' focus on glycaemic control [22,28,31]. As
364 this father of a 4-year-old reported:

365

366 'I have a larger backpack than the professionals' knowledge of HbA1c. Yes, it's an
367 individual who is affected, but in everyday life it [the diabetes] controls the whole family's
368 life, and then you have to have more in your backpack than just HbA1c.' [31]

369

370 Relatedly, some parents described how professionals tended to focus exclusively on the
371 needs of the child and failed to acknowledge how some parents may be struggling to cope
372 with the strains of diabetes management in the context of wider family life [32].

373

374 Experiences of informal support

375 Parents described drawing on informal sources to support the management of their child's
376 diabetes. Most often, this involved their spouses/partners [23,25,33] or other family members
377 [23], although their support could be limited due to relatives' poor diabetes knowledge and
378 understanding [32]. While parents craved social contact with other families, their caring
379 responsibilities made them feel different to others and they reported struggling to feel fully
380 present in social situations [33]. Some parents, like this mother, credited support groups with
381 making them feel less isolated and able to vent their frustrations about the challenges of
382 providing diabetes care:

383

384 'I am in a diabetes support group with moms and I find I've learned a lot from what other
385 moms do... I can say, oh my goodness, today is making me crazy and I can't figure it
386 out and diabetes is not fun right now.' [22]

387

388 Moreover, parents considered their peers a vital source of information when professional
389 advice was deemed insufficient [34] or, as this mother explained, difficult to access [27]:

390

391 'Facebook groups were also super helpful, because it was really nice to be able to post
392 a question like, "How do you guys do this, or what should I do about this?" ... because

393 we did have the number to call, but getting hold of the doctor or educator was just a
394 huge pain, and sometimes you don't know if your question is big enough to call the
395 doctor about.' [27]

396

397 < Insert Table 2 here >

398

399 **Discussion**

400 This review is the first to synthesise and describe the findings from qualitative studies, which
401 report parents' everyday experiences of caring for a child aged ≤ 8 years with type 1 diabetes.
402 It highlights the all-encompassing, relentless and enduring nature of parents' care experiences
403 and how their lives are dominated by constant worry, the need to be vigilant and a desire to
404 enable their child to have a 'normal' childhood. Moreover, the synthesis illustrates how
405 caregiving responsibilities could be detrimental to parents' own physical, psychological and
406 emotional well-being, relationships, personal choices and everyday activities. Parents'
407 encounters with healthcare professionals, while generally perceived as helpful, could add to
408 their anxieties and frustrations, as could lack of access to trusted sources of childcare and
409 informal support. Conversely, connecting with other parents who had a child with type 1
410 diabetes constituted an important source of emotional and practical support. The synthesised
411 recommendations by primary authors presented in Table 2 highlight ways in which clinical
412 practice might be adapted to help alleviate parents' care burden, improve their emotional and
413 educational support, and foster more collaborative working between parents and
414 professionals.

415

416 Some parents, particularly mothers, described how they were forced to make decisions about
417 employment based on their child's diabetes care needs and associated expenses.
418 Furthermore, even parents who self-identified as middle-class and were in possession of
419 medical insurance reported experiencing diabetes-related financial strains due to at least

420 some treatment supplies needing to be paid for through personal means. Resonating with
421 these findings, a survey conducted with parents of young children with type 1 diabetes found
422 that having a child with diabetes influenced the employment decisions of 60% of parents
423 (89.5% of them mothers), with nearly one quarter reducing or quitting work and others
424 maintaining employment for financial reasons [36]. Research has also shown that caring for a
425 child with type 1 diabetes was significantly more detrimental to their work and finances
426 compared with parents of children with other or no special healthcare needs [37]. The study
427 samples in our synthesis were skewed towards co-habiting and working parents; hence, our
428 findings raise important questions and concerns about how parents living in low-income
429 countries or on low incomes (including single-parents, who are more likely to report lower
430 incomes and benefit dependency [38]) manage the practical and financial demands of their
431 child's diabetes care.

432

433 Some parents described how using insulin pumps and glucose sensors helped reduce the
434 stresses and constraints diabetes management placed on everyday life. The use of insulin
435 pumps in paediatric populations has risen considerably in recent years [39] and insulin pump
436 therapy is now the recommended method of insulin administration in young children [40].
437 These developments suggest that greater numbers of parents are now using insulin pumps
438 than when some of the included studies were conducted. Research suggests that newer
439 technologies, such as continuous glucose monitors and closed-loop systems, are likely to help
440 further ease the burden of diabetes management. For example, use of continuous glucose
441 monitors may lessen parental anxiety due to the device alerting them to hypo- and
442 hyperglycaemia [41], while those able to monitor their child's glucose data remotely may
443 experience improved sleep and greater lifestyle freedoms [42,43]. Similarly, while user
444 evaluations of closed-loop systems have mainly involved older participant groups with type 1
445 diabetes and/or their parents [44-48], preliminary trials involving very young children suggest

446 that this technology can help parents feel less burdened by diabetes management tasks and
447 facilitate better sleep [49].

448

449 Several parents reported benefitting from the emotional and practical support provided by
450 other parents of children with type 1 diabetes via support groups and online fora. Conversely,
451 while parents were generally appreciative of the support provided by healthcare professionals,
452 some described how this contact could make them feel frustrated and anxious. They also
453 described receiving inadequate diabetes education following their child's diagnosis and
454 conflicting messages from different healthcare professionals. These issues are noteworthy as,
455 arguably, they could be adding to the psychological and emotional burden parents experience.
456 Other studies have described how parents wish for a tailored, collaborative approach to their
457 education and clearer, more sensitive communication from diabetes professionals [50].
458 Moreover, it has been noted that parents feeling anxious during diabetes consultations can
459 affect their ability to concentrate, and thus assimilate, the information provided [51]. As
460 appropriate patient education and communication is critical to achieving positive behaviour
461 change in diabetes management [52], diabetes teams should urgently consider the quality of
462 their communication and parents' emotional needs during clinical encounters. Primary
463 authors' recommendations, such as adopting a collaborative approach to engaging with
464 parents (Table 2), provide a useful starting point for diabetes teams to consider and build
465 upon.

466

467 This review and synthesis was conducted in accordance with established methods for the
468 systematic reviewing, appraising and synthesising of qualitative studies [15,21] and reported
469 according to published guidelines [16,17]. Nevertheless, we acknowledge that syntheses, by
470 their nature, cannot convey the contextual richness of the individual studies upon which they
471 draw. We also recognise that our decision to exclude papers not published in English may
472 have resulted in the final sample containing fewer studies from lower-income countries.
473 However, our reporting is strengthened by the consistency of findings observed across the

474 primary studies, despite these having been conducted in a diversity of countries with different
475 cultures and healthcare systems. We also recognise the potential influence of our unique
476 perspectives as UK-based, non-clinical researchers throughout the analytic process and in
477 the presentation of results.

478

479 The limitations inherent in the primary studies included in this synthesis highlight important
480 considerations for future research. The study samples were biased towards parents who were
481 married or co-habiting, qualified to higher education level, in employment and
482 white/Caucasian. Consequently, the experiences and views presented in this synthesis may
483 not reflect those of other parents caring for a young child with type 1 diabetes. Indeed, while
484 we found good consistency of findings across the studies, they did indicate potentially
485 divergent challenges related to income and cultural norms. Other studies suggest that
486 education, financial status, family make-up and ethnicity may differentially affect parents'
487 ability to manage and cope with diabetes [53,54] and, importantly, influence children's
488 diabetes outcomes [55]. Consequently, it is vital that future research considers the
489 experiences and views of parents of different demographic and socioeconomic backgrounds
490 and those living in low-income countries and settings. Moreover, as parents' experiences, and
491 thus support needs, may be more diverse than the current literature shows, providing more
492 detailed participant data will help practitioners draw more nuanced conclusions from study
493 findings. Finally, given the potential positive impact of newer diabetes technologies, such as
494 closed-loop systems, qualitative studies could explore the experiences of parents caring for
495 very young children with type 1 diabetes using these newer technologies and assess whether,
496 and how, they help address some of the challenges highlighted in this review.

497

498 **Conclusions**

499 The current literature consistently describes caring for a young child with type 1 diabetes as
500 an all-encompassing and relentless undertaking, which can have a detrimental impact on

501 parents' own well-being, relationships, personal choices and everyday activities. However,
502 significant limitations and gaps in this literature mean that parents' experiences may in fact be
503 more diverse than is currently recognised, which could have implications for the support they
504 require from healthcare professionals. In particular, we recommend that future research
505 should explore how sociodemographic factors and use of newer diabetes technologies
506 influence parents' diabetes management practices and experiences of caring for a young child
507 with type 1 diabetes.

508

509 **List of Abbreviations**

510 ENTREQ: Enhancing Transparency of Reporting the Synthesis of Qualitative Research.

511 PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

512 MeSH: Medical Subject Heading.

513 SPIDER: Sample, Phenomenon of Interest, Design, Evaluation, Research type.

514 CASP: Critical Appraisal Skills Programme.

515

516

517 **Declarations**

518 **Ethics approval and consent to participate**

519 Not applicable.

520

521 **Consent for publication**

522 Not applicable.

523

524 **Availability of data and materials**

525 Not applicable.

526

527 **Competing interests**

528 RH reports having received speaker honoraria from Eli Lilly and Novo Nordisk, serving on
529 advisory panels for Eli Lilly and Novo Nordisk; receiving license fees from BBraun and
530 Medtronic; having served as a consultant to BBraun, patents and patent applications related
531 to closed-loop insulin delivery, and director at CamDiab. BK, JL, CB and DR have no
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540

541 **Authors' contributions**

542 All authors (BK, JL, CB, RH and DR) contributed to the design of this review. BK and DR
543 conducted the literature search, screening and quality assessment. BK extracted and coded
544 the data, analysed the data with input from DR and JL, and drafted the initial manuscript. All
545 authors (BK, JL, CB, RH and DR) critically reviewed and approved the final manuscript.

546

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550

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Table 1: Characteristics of studies included in the qualitative synthesis

Reference	Country	Study aim	Parent characteristics	Child characteristics	Method	Data analysis
Boman et al, 2013 [31]	Sweden	To explore and discuss how fathers involved in caring for a child with T1D experience support from paediatric diabetes teams in everyday life.	n=11 (all fathers) Age: 37-51 years Cohabiting with mother: n=7 Higher education: n=5	n=11 (≤ 8 yo n=6) Age: 4-16 years Diabetes duration: 2-8 years	Online focus group discussion (n=6 fathers); semi-structured interviews (n=8 fathers) (mix of phone and face-to-face); both (n=3 fathers)	Constructivist grounded theory analysis
Elissa et al, 2017 [35]	Palestine	To explore the experiences of daily life in children with T1D and their parents living in the West Bank in Palestine	n=10 (6 mothers) Age mothers: 28-49 years Age fathers: 32-42 years Cohabiting: all Higher education: n=3 In employment: n=4 (fathers) Rural or camp living: n=4	n=10 Age: 8-16 years Diabetes duration: <5 years (n=3); 1-5 years (n=4); >5 years (n=3)	Face-to-face interviews	Qualitative content analysis as per Graneheim & Lundman (2004)
Iversen et al, 2018 [33]	Norway	To explore the lived experience of being mothers and fathers of a young child with T1D aged 1-7 who had had the diagnosis for at least 1 year.	n=15 (8 mothers) Age mothers: 26-40 years (m=30) Age fathers: 29-46 (m=38) Cohabiting: 7 couples, 1 single mother In employment: all	n=8 Age: 1-7 years Age at diagnosis: 1-5 years Diabetes duration: 1-6 years MDI (pen): n=1 CSII: n=7	In-depth face-to-face interviews (one by telephone)	Interpretative phenomenological methodology as described by Van Manen
Khandan et al, 2018 [34]	Iran	To explore the experiences of mothers with diabetic children after the transfer of caring role	n=11 (all mothers) Age: 30-48 years Cohabiting: n=9 Higher education: n=8 In employment: n=5	n=11 Age: 7-14 years (≤ 8 yo n=3) Diabetes duration: 12-96 months	Semi-structured and open-ended face-to-face interviews	Analysis as per Colaizzi
Lawton et al, 2015 [28]	UK	To explore the difficulties parents encounter in trying to achieve clinically recommended blood glucose levels.	n=54 (38 mothers) Age all parents: 25-51 years (m=40.6 \pm 6.1) Cohabiting: 70% Higher education: 27.8% In employment: 68.5%	n=41 Age: 2-12 years (m=8.4 \pm 2.5) Age at diagnosis: 3-10 years (m=5.2 \pm 2.1) Diabetes duration: 1-11 years (m=4.1 \pm 2.9) CSII: 31.7%	In-depth face-to-face interviews	General theoretical and procedural direction taken from Grounded Theory research

Reference	Country	Study aim	Parent characteristics	Child characteristics	Method	Data analysis
Lindström et al, 2017 [32]	Sweden	To experience how mothers experiencing burnout describe mothering a child with diabetes, with special focus on their need for control and self-esteem.	n=21 (all mothers) Age: 31-50 years (m=41) Cohabiting: 85.7% Higher education: 71.5% In employment: 90.4%	n=22 Age: 3-17 years (m=10.7) Diabetes duration: 1.5-15 years (m=5.3) CSII: 77%	Semi-structured, face-to-face interviews	Inductive content analysis
Marshall et al, 2009 [30]	UK	To explore and describe the experiences of children and their parents living with T1D from diagnosis onwards	n=11 (10 mothers) Ethnicity: Asian, Eastern European, Jamaican, Irish, English backgrounds	n=10 (≤8yo n=4) Age: 4-17 years Diabetes duration: 10 months – 8 years	Conversational interviews	Van Manen's phenomenological approach to thematic coding
Patton et al, 2016 [26]	US	To describe parents' perceptions of healthful eating for T1D in families of young children and identify factors related to parents' dietary management in young children.	n=23 (21 mothers) Age all parents: 27-49 years (m=35.7 ± 5.1) Married: 83% Higher education: 87%	n=not specified Age: 2-6.9 years (m=4.6 ± 1.3) Ethnicity: 78% non-hispanic white, 13% hispanic, 9% black Diabetes duration: m=2.0 ± 1.5 years CSII: 87%	Semi-structured, face-to-face interviews	Guided by a grounded theory approach
Perez et al, 2018 [27]	US	To explore how parents negotiate the uncertainty surrounding T1D	n=29 (mother/father not specified) Age all parents: 33-50 (m=44) Ethnicity: all Caucasian/white Married: n=28 (97%) In full-time employment: n=18 (stay-at-home: n=11) Most identified household income as middle to upper-middle class	n=30 Age: 2-17 years (m=10.9) Age at diagnosis: 13 months - 13 years (m=6.5 years) Diabetes duration: 4 months - 10 years (m=4.39)	Interviews (by phone n=26)	Thematic analysis as per Braun & Clarke (2006)
Rankin et al, 2015 [29]	UK	To explore parents' experiences of using an insulin pump to manage their child's diabetes, including their views about the benefits and challenges for themselves and their child.	n=19 (13 mothers) Age all parents: 34-44 years (m=40.1 ± 3.7) Ethnicity: all white British Married or cohabiting: n=18 Higher education: n=9 In employment: n=12	n=14 Age: 3-12 years (m=8.4 ± 2.8) Age at diagnosis: 1-6 years (m=3.8 ± 2.1) Length of time on pump: 1-4 years (m=2.2 ± 1.2)	Face-to-face interviews	Thematic analysis using the method of constant comparison

Reference	Country	Study aim	Parent characteristics	Child characteristics	Method	Data analysis
Sullivan-Bolyai et al, 2003 [23]	US	To provide a detailed description of day-to-day management experiences of mothers raising young children under 4 years with T1D.	n=28 (all mothers) Age: m=33 ±5.24 years Ethnicity: 89% white Married: 86% Education: m=15 ± 2.5 years Not working outside of home: n=15	n=28 Age: m=2.9 ± 0.6 years Diabetes duration: m=1.25 ± 0.7 years	Face-to-face interviews	Naturalistic inquiry
Sullivan-Bolyai et al, 2004 [24]	US	To describe the experiences of parents managing the T1D of their young children using an insulin pump.	n=21 (14 mothers) Age all parents: m=38 ± 3 years Ethnicity: all Caucasian Married: n=20 Education: m=16 ± 2 years	n=16 Age: 2-11 years (m=7 ± 2 years) Length of time on pump: 3-36 months (m=16 ± 11)	In-depth, face-to-face interviews	Qualitative content analysis as described by Sandelowski
Sullivan-Bolyai et al, 2006 [25]	US	To describe fathers' experiences in parenting and managing the care of their young children's day-to-day diabetes regimen.	n=14 (all fathers) Age: m=36 ± 2 years Ethnicity: all white Married: all Education: m=16 ± 2 years In employment: all	n=15 Age: 2-8 years (m=5 ± 2) Diabetes duration: 2 weeks – 3 years (m=1.4 ± 0.8 months)	Face-to-face interviews	Qualitative content analysis
Watt, 2017 [22]	Canada	To explore the emotion work of doing worry that parents engage in when caring for their children with diabetes.	n=7 (5 mothers) Age all parents: 34-53 years (m=44) All 2-parent, middle class families Education: all higher education	n=not specified Age: 18 years or younger Age at diagnosis: 9 months – 14 years	In-depth interviews in the context of institutional ethnography (not clear if face-to-face or phone)	Analysis guided by Smith's (2005) conception of work and analytic questions suggested by IE scholars (McCoy, 2006)

Table 2. Primary authors' recommendations to improve parent/caregiver support in relation to each analytical theme

<p>1. Monopolisation of life</p>
<p>To help reduce the detrimental impact on parents' psychological and emotional wellbeing, the primary authors recommended that healthcare professionals could: ascertain and address issues related to hypoglycaemia concerns, lapses in confidence and sleep [23]; and, provide encouragement and support by acknowledging the unpredictability of diabetes and treatment outcomes [22]. More general recommendations included professionals needing to familiarise themselves with the symptoms of burnout [32], and helping parents address any harmful emotions related to their caregiving situation [33]. This could involve: teaching parents strategies to manage negative feelings about the child being 'different' because of diabetes [26]; and, assessing and encouraging parental self-care, including helping to identify sources of respite [23]. Finally, to help reduce anxieties related to social stigma and gendered impacts, primary authors recommended that healthcare professionals seek to improve public awareness and understanding of type 1 diabetes [27,34,35].</p> <p>To help relieve the care burden on mothers and encourage fathers' involvement, primary authors recommended that professionals should, from the outset, set the expectation that (where possible) both parents attend clinic consultations [28] and that, for respite and emergency purposes, both should be involved in their child's diabetes management [25]. This recommendation could be supported by working with parents to develop a 'division of labour' plan [23].</p> <p>To alleviate parents' concerns regarding potentially inappropriate diabetes management in daycare settings (e.g. nurseries, schools, playgroups), primary authors recommended that healthcare professionals should help educate staff on safe management practices [23] and, where possible, broaden their outreach work in these settings to increase the number of people available to support the child's diabetes management [28].</p> <p>To address potential financial pressures related to the child's diabetes treatment, primary authors recommended that healthcare professionals should provide parents with financial guidance about all aspects of diabetes management [27] and offer referral to charitable organisations where appropriate [34].</p>
<p>2. Parents' experiences of professional and informal support</p>
<p>To address parents' concerns regarding their diabetes management education and avoid mixed messages, primary authors recommended that healthcare professionals should develop and follow an agreed-upon teaching plan; this should include the option of booster sessions, which revisit information and techniques taught at the time of diagnosis [25] and take into consideration individuals' differing speeds of learning and developing confidence [24].</p> <p>To alleviate potential tensions between parents' and professionals' views regarding diabetes management, primary authors recommended that healthcare professionals should educate parents on their specific clinical perspective [28], while also using parents' knowledge regarding their unique family situation and the child's individual needs to inform treatment decisions [28,31].</p>

Fig. 1. PRISMA flow chart of study selection process

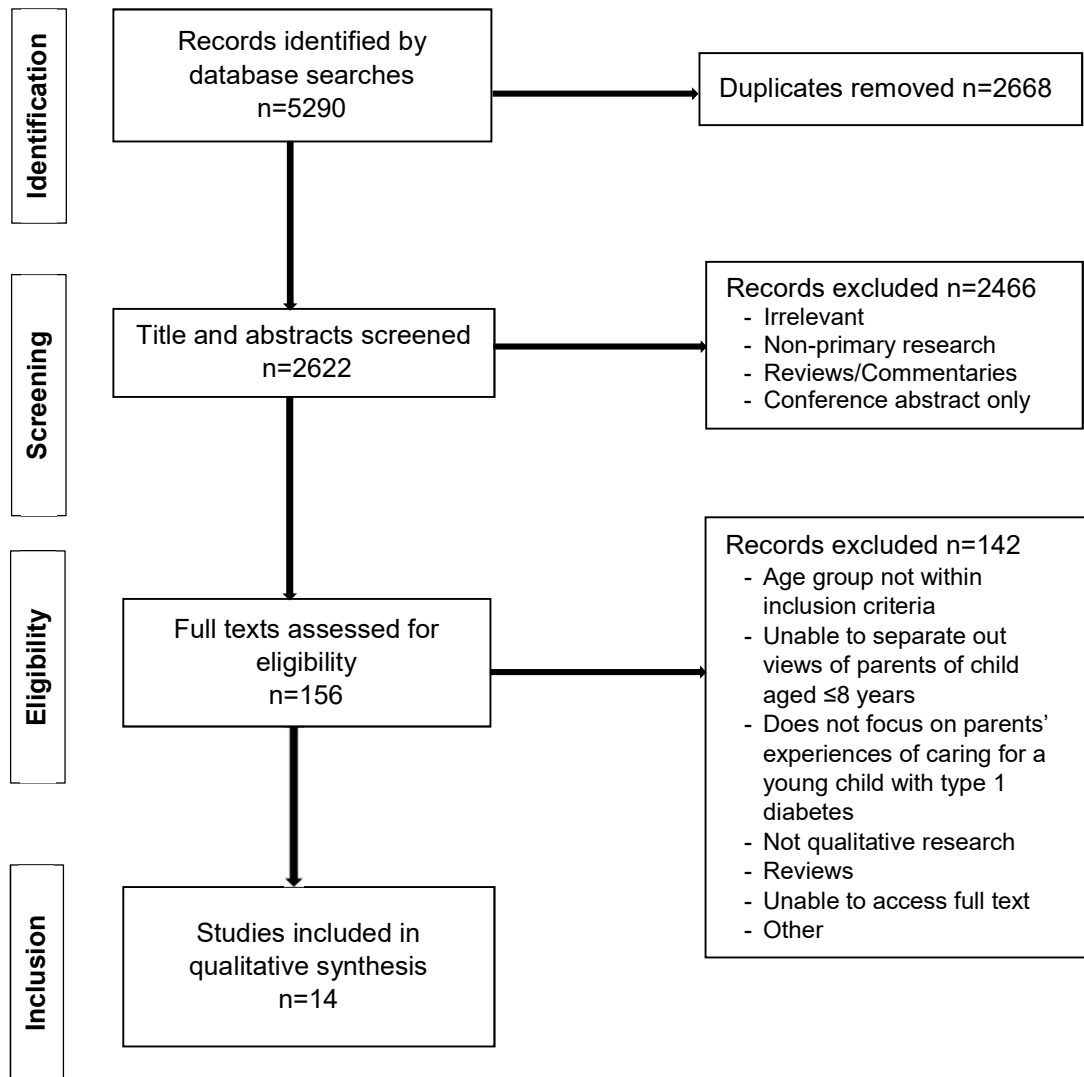


Table S1. CASP quality appraisal scoresheet

Study reference	Clear statement of aims?	Qualitative methodology appropriate?	Research design appropriate?	Recruitment strategy appropriate?	Data collection approach appropriate?	Researcher-participant relationship considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is this research?
Boman et al, 2013	Y	Y	Y	Y	Y	Y	Y	Y	Y	G
Elissa et al, 2017	Y	Y	Y	Y	Y	CT	Y	Y	Y	G
Iversen et al, 2018	Y	Y	Y	Y	Y	CT	Y	Y	Y	M
Khandan et al, 2018	Y	Y	Y	Y	Y	Y	Y	Y	Y	G
Lawton et al, 2015	Y	Y	Y	Y	Y	Y	Y	CT	Y	G
Lindstrom et al, 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	G
Marshall et al, 2009	Y	Y	Y	CT	Y	Y	Y	Y	Y	M
Patton et al, 2016	Y	Y	Y	Y	Y	CT	CT	CT	Y	L
Perez et al, 2018	Y	Y	Y	Y	Y	CT	CT	Y	Y	G
Rankin et al, 2015	Y	Y	Y	Y	Y	CT	Y	Y	Y	G
Sullivan-Bolyai et al, 2003	Y	Y	Y	Y	Y	CT	Y	Y	Y	G
Sullivan-Bolyai et al, 2004	Y	Y	Y	Y	Y	CT	CT	Y	Y	G
Sullivan-Bolyai et al, 2006	Y	Y	Y	Y	Y	CT	CT	Y	Y	G
Watt, 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	M

Scoring: Y=Yes; CT=Cannot tell; G=Good; M=Medium; L=Low

Fig. S1. Exemplar search strategy from Medline database

1. exp Diabetes Mellitus, Type 1/
2. (IDDM or T1DM or T1D).mp.
3. ("insulin\$ depend\$" or "insulin?depend\$ or insulin-depend\$").mp.
4. ("typ? 1 diabet*" or "typ? I diabet*" or "typ?1 diabet\$" or "typ?I diabet\$" or "auto?immune diabet\$").mp.
5. ((juvenile\$ or child\$) adj2 diabet\$).mp.
6. 1 or 2 or 3 or 4 or 5
7. exp Parents/
8. (parent\$ or mother\$ or father\$ or caregiver\$ or care\$giver\$ or mum\$ or dad\$ or carer\$ or guardian\$).mp.
9. 7 or 8
10. 6 and 9
11. exp Qualitative Research/
12. (qualitative\$ or ethnograph\$ or experience\$ or interview\$ or focus group\$ or phenomenol\$ or observation\$ or perception\$ or view\$ or (grounded adj theory) or (framework adj analysis) or (thematic adj analysis) or (constant adj comparison)).mp.
13. 11 or 12
14. 10 and 13
15. limit 14 to (english language and yr="2002-Current")