Introduction

Living with type 1 diabetes mellitus (T1DM) presents myriad challenges in day-to-day life. These include the ongoing monitoring of blood glucose levels and the administration of insulin with the aim to prevent the development of long-term microvascular, macrovascular and neurological complications. In addition, people with T1DM must actively avoid potentially troublesome hypoglycaemic episodes. As a consequence of this disease burden and its complex self-management, the mental health and wellbeing of people living with T1DM also are often affected. For example, the Australian arm of the Management and Impact for Long-term Empowerment and Success (MILES) study found that 28% of people with T1DM lived with severe diabetes-related distress. This distress was focused on feelings of worry and guilt, and uncertainty over whether mood and feelings were related to diabetes. In addition, high rates of self-reported anxiety (27%), self-reported depression (20%) and clinical depression (12%) have also been reported. The association between diabetes and its psychological burden appears to be a vicious cycle. Disease-burden-related emotional distress compounded with comorbid depression has been shown to add further challenges in optimising glycaemic control. There is a need to understand the challenges of T1DM self-management and the circular associations between mental health issues and the difficulty in maintaining glycaemic control. Studies indicate that when people with diabetes are better informed and more motivated, they are likely to experience improved diabetic control and enjoy a higher quality of life, highlighting the need for a comprehensive management approach, including psychological support services.

There are currently two well-established treatments for controlling glycaemic levels: the insulin pump (otherwise known as continuous subcutaneous insulin infusion [CSII]) and the more traditional multiple daily insulin injections (MDII). CSII therapy was first described around 40 years ago and has since been heralded as a superior means to improving glycaemic management with a significant reduction in glycated haemoglobin levels (HbA1c) compared to the alternative therapy, along with fewer severe hypoglycaemic episodes. Several meta-analyses have demonstrated CSII’s ability to optimise diabetic management with a significant reduction in glycated haemoglobin levels (HbA1c) compared to the alternative therapy, along with fewer severe hypoglycaemic episodes. Such convincing evidence combined with improved smaller user-friendly devices has led to an increase in popularity.

Despite these technological advances, few studies have examined the psychosocial outcomes of...
these interventions. There are a small number of quantitative reviews that examine the quality of life of CSII users. One quantitative systematic literature review examined the effect of CSII therapy on quality of life and highlighted the lack of evidence to support any improvement of quality of life when compared to MDII.12 Furthermore, the study concluded that existing research presents conflicting findings due to inconsistent assessment or is flawed due to poor methodology. The authors suggest that this lack of reported benefit of CSII is probably the result of poor research rather than the pump therapy not offering quality of life benefits. A Cochrane review by Misso et al.7 examined the literature on quality of life in CSII users compared to MDII. Two of the studies included in the review used the validated Diabetes Quality of Life Scale and concluded that the MDII group scored lower than the CSII group, representing better quality of life for MDII users.13,14 A further four studies used the validated Diabetes Treatment Satisfaction Questionnaire, of which two included participants under 18 years of age. All four studies reported improved treatment satisfaction among CSII users relative to MDII.15–18 Overall, Misso et al.7 concluded that people using the CSII were more satisfied with their therapy compared with MDII.

These quantitative data are promising, but by gaining a subjective insight into the lives of people living with T1DM, it will be possible to better understand the variety of perceptions about the insulin pump. To this end, we performed a qualitative systematic review of CSII users to explore their attitudes to the use of CSII technology.

Methods

The aim of this study was to systematically review all available research literature addressing the attitudes, experiences and perceptions relating to the physical, psychological and social health of people living with T1DM and using an insulin pump.

The systematic review was registered on a prospective register of systematic reviews (PROSPERO registration no: CRD42016034000).

A comprehensive three-step search methodology, followed by the PRISMA methodology (see Figure 1), was employed.19 The key search terms included: Diabetes Mellitus, Type 1; Insulin Infusion Systems; and Qualitative Research. These terms were used to search for relevant studies on Medline on OVID, PsycInfo on OVID, EMBASE on OVID, CINAHL, and the Cochrane Library.

Identified studies were screened using inclusion and exclusion criteria (detailed in Table 1). Studies that met inclusion criteria were critically analysed using the qualitative research critical appraisal checklist produced by the Critical Appraisal Skills Programme (CASP).20 Each study was then graded using the system proposed by Attree and Milton21 (shown in Appendix 1, available online at www.practicaldiabetes.com).

Data extraction initially involved populating an a priori spreadsheet summarising the key characteristics of each included study. This step was validated by an independent reviewer (CO). This systematic review applied a meta-ethnographic approach, based on that described by Noblit and Hare,22 to examine and synthesise summative themes. This method allows for the unusually small qualitative data sets to be combined for a more extensive synthesis.

Results

Sixteen studies met the inclusion criteria (Table 1). Three of these studies were eliminated due to poor methodology as assessed and agreed by two reviewers (DG and CO) independently during the critical appraisal stage. The remaining 13 studies were conducted in the UK (n=7), USA (n=3) and Sweden (n=3). (See Appendix 2, available online at www.practicaldiabetes.com).
The majority of studies were aimed at gaining a broad insight into the subjective experience of living with T1DM and using an insulin pump. However, some had a more specific aim. One study,25 explored the experiences of transitioning from MDII to CSII, while the study of Wilson and colleagues24 sought to gain an appreciation of the communication process between patients and health care professionals (HCPs). Other studies aimed to determine the barriers to improving glycaemic control with CSII,25 the reasons for discontinuing CSII therapy,26 and establishing contextual factors that influence technology use in T1DM.27 Only one study considered newer technologies such as the closed-loop configuration.28 Methodology of the included studies was heterogeneous and included interviews (mainly semi-structured) (n=10), focus groups (n=3) and mixed methods (n=3).

There was inconsistency across studies in reporting demographics, length of CSII experience, and details of analytic strategy. There was significant variation in the ages of study populations (range 12–80 years) and a slight tendency for more female participants.

The meta-ethnographic analysis of the 13 studies used the principles of reciprocal translation by considering first, second and third order constructs to build a line of argument synthesis. This synthesis concluded four closely interlinked major themes, which succinctly encapsulated the psychosocial aspects of living with an insulin pump. These are best considered in two subgroups where the themes are opposed: the disease compared with the pump, and self in contrast to the support team. The disease explores issues that are not directly related to the pump itself but, rather, those pertinent to living with T1DM. These in turn are expressed in two subthemes, namely T1DM self-management and the disease burden. The pump describes the physical presence of the pump itself. Again, two subthemes have also been applied to encapsulate the personal responses of pump use described in the theme self, namely emotional responses and societal awareness. The role of others is explored by the theme support team. The hierarchy of these themes is illustrated in Table 2.

The disease

T1DM self-management. Compared with chronic illnesses where the individual takes a relatively passive role, the key to optimal management of T1DM is largely reliant upon the ability to self-manage the condition. For many users, the pump made self-management easier and increased a sense of accountability. However, Ritholz et al.29 found a difference between those users with a high HbA1c and those with a lower HbA1c. Users with less optimal diabetic control took a more passive approach to self-management. Despite knowing the ‘right thing’ to do, they tested the boundaries of the new-found freedom and flexibility that the pump provided.

There is an expectation among pump users that the therapy will stabilise blood glucose levels, improve HbA1c and reduce the frequency of hypoglycaemic episodes. Unmet expectations can be used as a reason to discontinue CSII therapy.26 Everett et al.25 concluded that although CSII therapy made it easier to achieve glycaemic control, it still required commitment from pump users. They went on to suggest that the challenge of achieving ideal HbA1c levels was hindered by a fear of hypoglycaemia, not wanting to submit to a highly restrictive lifestyle and mistrust of the importance placed on HbA1c results. The latter point is contradicted by other studies, such as Garmo et al.30, that suggested patients were consciously aware of the importance of HbA1c levels because of the correlation with the risk of complications of the disease. These contradictory observations may be understood by examining differences among groups of pump users stratified by their level of diabetic control. Thus, Ritholz et al.29 found that individuals with a low HbA1c perceived the pump as a useful tool in achieving optimal diabetic control but recognised

<table>
<thead>
<tr>
<th>Table 1. Inclusion and exclusion criteria</th>
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<tbody>
<tr>
<td><strong>Inclusion criteria</strong></td>
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<tr>
<td>• Persons diagnosed with type 1 diabetes mellitus (T1DM), regardless of their glycaemic control</td>
</tr>
<tr>
<td>• Use of a portable subcutaneous insulin pump, otherwise known as a CSII system, either in a closed- or open-loop configuration</td>
</tr>
<tr>
<td>• Studies reporting the experiences of insulin pump therapy for managing T1DM from the perspective of the patient</td>
</tr>
<tr>
<td>• Qualitative or mixed-methods study designs</td>
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<tr>
<td>• Studies published after the introduction of CSII from 1978 onwards</td>
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<tr>
<td>• Conference abstracts</td>
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<tr>
<th>Table 2. Hierarchy of major and minor themes of the meta-ethnographic synthesis</th>
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<tbody>
<tr>
<td><strong>Synthesis focus</strong></td>
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<tr>
<td>Life with type 1 diabetes and an insulin pump</td>
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effort is still required. Conversely, they found users with higher HbA1c levels viewed the pump as a sort of ‘magic pill’ which would make their diabetes disappear. These attitudes were found to impact on overall glycaemic control, with more realistic expectations more likely to be realised.

A number of positive experiences were described by pump users, where there was an overall sense of regaining control of their T1DM. Several studies reported on the attainment of near-normal blood glucose ranges which were more stable, particularly in connection with physical activity.\textsuperscript{23,24,29–31} Additionally, pump users perceived a decrease in the frequency and severity of hypoglycaemic episodes and some users felt it easier to recognise the symptoms and treat the episode.\textsuperscript{53}

Ultimately, these benefits were thought to reduce the risk of chronic diabetic complications. These benefits were also reflected in an improved quality of life resulting from knowing that glycaemic control was more stable and there were fewer hypoglycaemic episodes.

‘Earlier it was like a roller coaster. Now it’s so [much] smoother.’\textsuperscript{30}

The disease burden. Living with a chronic illness brings with it myriad challenges in day-to-day life. The disease is unrelenting where self-management requires a constant state of consciousness in regard to a number of factors including dietary intake, physical activity, body weight, record keeping, medications and blood glucose levels on top of the daily tasks and chores that are required to maintain control and manage a chronic illness. This results in a sense of living with restraints and a need for routinisation and meticulous planning.

‘It is hard not ever taking a holiday away from one’s illnesses.’\textsuperscript{32}

In this context, the insulin pump can be viewed in three different ways. For many, the use of CSII therapy provides a key to unleashing the shackles of the disease burden. After having realised greater control of glycaemic levels, users tend to gain a greater sense of control of their lives. The pump enables the removal of ties and limitations leading to increased flexibility and freedom, which ultimately results in greater autonomy over lifestyle choices – for example flexibility regarding diet, a relative ease in altering plans for a day when something unforeseen occurs, and engaging more in spontaneous social situations.

Some studies also examined the change in the way pump users viewed food. Pump therapy brought with it a new-found experience of eating. Food was no longer viewed as a troublesome consumable which ultimately added to the disease burden by altering glycaemic control and required another dose of insulin. Rather, the dietary discipline could be relaxed and food could be enjoyed and easier managed. Other overt benefits that were mentioned include convenience, improved sleep, more energy and increased physical strength. These benefits result in an overall sense of carefree living and facilitating a more relaxed manner to dealing with deviations in normal routine.

For others, the pump merely loosens the shackles, and restraints of the therapy were still burdensome. An additional negative was the cost of CSII therapy, which differs upon the health care jurisdiction in question and availability of funding. The management of T1DM with an insulin pump can also be time consuming.

There is also a small population where the pump does not meaningfully loosen the shackles and results in no overall relief from the disease’s restraints. This group does not realise a greater sense of control over their life but, rather, feel like they are surrendering to a machine. Such individuals typically end up discontinuing CSII therapy or require intensive support from their support team.\textsuperscript{26}

The process of learning about T1DM therapies can assist pump users to minimise the disease burden and achieve optimal self-management of T1DM. Everett \textit{et al}.\textsuperscript{25} provided a unique insight into the learning process of pump users. Initially, people commencing pump therapy felt bombarded with the resources that were provided to them, making the therapy difficult to contemplate and assess. However, learning was an ongoing feature for pump users. Everett \textit{et al}.\textsuperscript{25} described three means of learning which included experimental learning for self-management skills, talking to others, and technology. There are likely to be further advances in the latter method involving improved electronic resources and the emerging development of telehealth.

However, learning about the complexity of their unique diabetic pattern as well as active experimentation appeared to be the most fruitful method of education, facilitating an ability to overcome some of the burdens of the therapy. This is reflected in a higher level of maturity in young adults with pumps as described by Tullman.\textsuperscript{35}

The pump

Several studies reported the physical presence of the pump as having negative associations, for example visibility of the pump, fashion challenges, discomfort, pain, and intimacy issues. These experiences can be reasons for discontinuing with pump therapy.\textsuperscript{36} Another reported difficulty was associated with travelling.\textsuperscript{26,30} When travelling, pump users are challenged with ensuring adequate consumables and battery life, airport security issues, pump alarms and consciously managing disconnection times. Subsequently, many diabetes associations, such as Diabetes UK, have published magazines and guides to assist people living with diabetes who wish to travel.\textsuperscript{34}

‘The worst part [of wearing an insulin pump] is the appearance.’\textsuperscript{53}

Users’ perceptions of body integrity and the feeling of being constantly connected to technology was an important constraint. Garmo \textit{et al}.\textsuperscript{32} suggested that this physical connection created a feeling of having to submit to CSII therapy. Tullman\textsuperscript{33} linked this to a heightened sense of awareness and the pump’s presence was a constant reminder of the diagnosis of T1DM, and made the diagnosis overly apparent to the outside world.

These realisations in adjusting to the pump’s presence often led to a change in perception of body
Type 1 diabetes and an insulin pump: an iterative review of qualitative literature

Browne 1c-

Self

Emotional responses. The burden of T1DM takes an emotional toll and the use of an insulin pump elicits a variety of emotional responses itself. Mostly, there is a positive psychological response resulting from pump use, with improved mood and a newfound freedom leading to more fun and pleasure in life. Furthermore, users reported fewer mood swings. Users also report a sense of empowerment and relief from feeling in control of their T1DM. This led to greater self-confidence and less uncertainty, and supported further motivation to take active control of their condition. They also felt less guilt about unsuccessful self-care.

'I am a different person – happier.'

While life improvements are reported, pump use is still an inconvenience and stressful in other ways. Users often described a heightened fear of hypoglycaemic episodes resulting in an underlying level of anxiety and creating a potential barrier to achieving ideal glycaemic control. Everett et al. suggested that for CSII therapy to be successful, these fears need to be addressed early so such avoidance strategies aren’t learnt. There was also a fear and constant preparedness in relation to failure of the technology. Many pump users realised the dependency they have on the device and had an awareness of potentially devastating complications should the device fail.

Some users did not experience a feeling of security but, rather, felt vulnerable, including physical, social and emotional vulnerability. However, time and experience led to self-acceptance, where users felt more directly responsible for their self-care. Ritholz et al. reported that users with a lower HbA1c stated that pump use helped them feel more accepting of their diabetes, less ashamed of it and able to speak about it to others for the first time. In contrast, individuals with higher HbA1c levels spoke of being tired of the pump, feeling discouraged and frustrated that the pump did not fix everything. These authors suggested that individuals who experienced a similar reaction when they were first diagnosed with diabetes gained better glycaemic control once on a pump than those who did not. One explanation for this is that recognition of the feelings evoked by pump therapy is important for the adjustment to and continuation of treatment.

The impact of T1DM and pump use on body image is also an important issue, where a constant awareness of dietary intake can turn pathological. There is an established association with eating disorders and T1DM. Tullman explored the effects of pump therapy on body image and its relationship to self-esteem in female emerging adults. Firstly, she found a heightened sense of body awareness. The effects of T1DM and the pump on self-esteem are difficult to define because they are not mutually exclusive. However, it can be concluded that the effect on self-esteem appears to be individualised—some had positive reactions, others negative. Tullman proposed the notion of accepting part of the body is in some way wrong or not working, which has a significantly negative effect on self-esteem. In contrast, others found the diagnosis of T1DM to be a positive influence on their self-esteem, where it was viewed as a defining characteristic.

Societal awareness. Browne et al. described the existence of stigmatisation and discrimination against Australians living with T1DM, which was largely based on the stigma by association with T2DM, stereotyping and negative social judgement, as well as exclusion and rejection. The impact of societal awareness on people living with T1DM and using an insulin pump is an important theme examined by a number of studies in this review. Ritholz et al. suggested that using an insulin pump lifts the stigma of diabetes. However, others felt that it increased a sense of self-consciousness leading to more thought about their own appearance and outward image as a result of wearing a pump.

You think people can see right through you and tell you have [an insulin pump] or diabetes.”

Garmo et al. juxtaposed this stigmatisation with normalisation. Diabetes may be seen as a defining characteristic of a person’s identity. For some, being subjected to pump therapy is a constant, non-discreet and burdensome label that causes people with T1DM to be frequently reminded of their diagnosis and subsequently feel like an outsider. However, others felt that it symbolised a transition from being ill to being healthy. The pump itself was not thought of as an appendage but as an addition to the human body necessary for survival. It therefore signified normality. This quest for a sense of normality is an important finding. Hood and Duke found that the insulin pump furthered this quest for normality by reducing social vulnerability and learning to accept one’s self.

O’Kane et al. provided a unique perspective by examining pump use with the aim of informing future medical device development. The authors found that there is a large variation in use, which is largely dependent on the individuals’ perceived comfort with the social environment. Thus, some participants routinely took advantage of the ‘dead’ time on public transport, for example, while others preferred to be more private. Variation also existed in participants’ work-life use, where some would be open about their T1DM from the beginning while others preferred to be secretive. Hiding the insulin pump in times of uncertainty—such as in new romantic situations, starting a new job, and when meeting unfamiliar people—was also observed. While hiding the device was a common theme, some individuals saw it as a vehicle for disclosure and felt compelled to tell others they had diabetes because the pump could be seen or heard if an alarm went off.
These findings conclude that every individual’s experience with the insulin pump and its social impact is unique. There was, however, a shared journey to strive for a sense of normality among society and improve societal awareness for T1DM and pump use.

Support team

The concept of a ‘support team’ was synthesised for this review after being discussed in part by many of the included studies. It is evident that people living with T1DM are supported by a comprehensive team including HCPs – such as endocrinologists, general practitioners, nurses, diabetes educators, dietitians and podiatrists – as well as family and friends. However, the value of this support was equivocal and the pump was reported to have varying impacts on these relationships.

There is only an 11-year range in the date of publication of studies. Despite this, older studies tended to focus on a perceived lack of knowledge, training and understanding by HCPs. This was the source of much frustration among users and the subsequent insecurities regarding the lack of feeling supported leads to a sense of vulnerability. This is added to by a perception of difficulty when communicating with HCPs and, alternatively, it was easier to use other resources such as the internet to find answers to any questions one might have. Furthermore, some users felt that HCPs tended to focus on glycaemic control indicators such as HbA1c rather than considering the whole life situation as an indicator for disease control.

In contrast, more recent studies described a collaborative relationship between HCPs and people with T1DM, and that this relationship was valued and proven to produce beneficial changes in diabetic control. One explanation for this finding is the increasing popularity and use of the insulin pump as well as a subsequent increase in the awareness and training that is provided to HCPs. As the insulin pump continues to become more mainstream in T1DM care, it is expected that this collaborative relationship with HCPs will continue to be a feature of the support team.

There are benefits to the family and friends as well; it [really] does touch every aspect in a positive way.”

Relationships with family and friends are equally, if not more important to optimising diabetic care. People with T1DM often seek support from family, friends or other sources such as online social networks and blogs. However, there is an overall perceived lack of social support networks for pump users. These relationships were analysed in a large number of studies, all of which concluded beneficial outcomes as a result of using pump therapy. Initially, close relatives may be frightened or disturbed by the use of an insulin pump, but this then quickly changed to a positive outlook. Barnard and Skinner found that pump users identified an increased quality of life for those close friends and family since commencing CSII therapy. Generally, the use of an insulin pump supports greater autonomy and independence for oneself and family members. Yet these benefits for family members can easily be overlooked. Garmo et al contradicted this notion by describing an increased sense of dependency when commencing pump therapy. They acknowledged that there was freedom in some respects but a new dependency arose from greater involvement of HCPs for pump programming and other technical issues.

Discussion

The limited number of studies featured in this review highlights a need for more qualitative research in this field, particularly in the Australian context. To date, CSII therapy has been proven to be a revolutionary means of treating T1DM. Additionally, there are some exciting developments for this technology in the pipeline, including continuous glucose monitoring technology, but these future technological advancements must fully consider the psychosocial impact.

From the research available, it is evident that every individual’s experience with an insulin pump is unique but the themes concluded in this review highlight the key areas where the insulin pump has a significant impact. All HCPs need to be challenged to look at the person as a whole and not just focus on the figures. This review also provides evidence that clinicians must give patients realistic expectations of pump therapy, advocate for greater societal awareness and realise that a one-size-fits-all approach is not adequate. It is envisaged that this qualitative synthesis will aid in the education of HCPs and provide a basis for psychological support services in the T1DM health care setting.

Limitations

In this review, only published articles which were originally written in English were included and, consequently, it is acknowledged that particular cultural findings may be missed.

Throughout the screening process, the reviewers also identified a number of studies which focused on the psychosocial aspects of the continuous glucose monitoring in a closed-loop configuration rather than the insulin pump itself. These studies were not included.

A meta-ethnographic approach is largely dependent on the quality of the included primary research. An attempt to overcome this issue was made through an a priori decision to implement a relatively strict critical appraisal process which eliminated those studies that did not meet certain quality metrics. However, if, for example, the original researchers conducted only superficial analyses, the validity of their conclusions will affect this review’s findings. Any conclusions from this meta-ethnography thus are limited by other researchers’ interpretations. Additionally, all reviewers agreed that the critical appraisal process was largely dependent on the quality of the written report rather than the methodology of the study itself. Therefore, it is also possible that the studies that reached the quality assessment stage may have had a sound study design yet were not communicated in a clear way that was adequately reflected in the CASP checklist. These articles were subsequently excluded from the review.
Conclusion
The main purpose of this review was to gain a meaningful insight into the lives of people living with T1DM and using an insulin pump. Our qualitative synthesis determined a number of themes including: the role of the pump in loosening the shackles or burden of T1DM from a physical, social and emotional perspective; the importance of a support team and self-management in achieving optimal diabetic control; and users striving for a sense of normality, realised both from within themselves and from others. These notions should be at the forefront for all HCPs involved in the care of people living with T1DM and using an insulin pump, in order to provide a holistic approach to their care and optimise their management. Additionally, we encourage further qualitative research to better inform HCPs and patients.

Acknowledgements
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Declaration of interests
There are no conflicts of interest declared.

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20. CASP Qualitative Checklist: 10 questions to help make you sense of qualitative research [online article]. 2013. Available from www.casp-uk.net/ [accessed 10/02/2016].
23. Saarinen T, et al. Insulin pump therapy is perceived as liberating, but to many it can imply a sense of the diabetes made visible. Eur Diabetes Nursing 2014;11:38–42.
### Appendix 1. Appraisal grading, using the system proposed by Attree and Milton²¹

<table>
<thead>
<tr>
<th>Grade</th>
<th>Description</th>
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<tbody>
<tr>
<td>Grade A</td>
<td>No or few flaws</td>
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<tr>
<td>Grade B</td>
<td>Some flaws: unlikely to affect the validity of the study</td>
</tr>
<tr>
<td>Grade C</td>
<td>Considerable flaws: study still of some value</td>
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<tr>
<td>Grade D</td>
<td>Significant flaws that threaten the validity of the whole study</td>
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### Summary of key characteristics of the 13 included studies.

<table>
<thead>
<tr>
<th>Study</th>
<th>Primary focus</th>
<th>Recruitment</th>
<th>Sample size</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Key themes</th>
<th>Appraisal grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnard &amp; Skinner (2007)</td>
<td>To elicit experience in order to discover the therapy’s benefits, downsides and effect on quality of life</td>
<td>Opportunistic following a targeted mailout based on a database</td>
<td>n=80</td>
<td>Brief phone interview</td>
<td>Iterative process where data were reduced to meaningful constructs, then themes emerged</td>
<td>Key positive themes: control vs controlled; freedom; independence; family effects; flexibility; benefits; reduction in hypoglycaemic episodes/severity; comparison with previous insulin regimen; convenience; effects on quality of life. Key negative themes: device and skin visibility issues; cost; health care professional (HCP) advice and breakdown</td>
<td>Grade C</td>
</tr>
<tr>
<td>Barnard et al. (2015)</td>
<td>To explore the psychosocial experiences of closed-loop technology</td>
<td>Recruitment from 3 centres in the UK</td>
<td>n=24</td>
<td>Mixed methods: psychosocial questionnaire and semi-structured telephone interview</td>
<td>Content and thematic analysis</td>
<td>Key positive themes: reassurance and peace of mind; general positivity; better sleep; improved blood glucose; improved blood glucose control overnight leading to improved daytime control. Key negative themes: alarms beeping frequently; technical/usability difficulties; night-time hypoglycaemic episodes; increased frequency of hypoglycaemic episodes on closed-loop; device is too big</td>
<td>Grade A</td>
</tr>
<tr>
<td>Everett et al. (2010)</td>
<td>To determine why some people maintain their HbA1c level above that advised by their HCP</td>
<td>Written invitation to eligible patients on a local registry</td>
<td>n=17</td>
<td>1-hr semi-structured focus groups</td>
<td>Consolidation of emerging themes between authors, verified for accuracy by participants</td>
<td>Fear of hypoglycaemic episodes and feeling safe; hard work; restrictions; mistrust of HbA1c; learning from experience, others and technology</td>
<td>Grade C</td>
</tr>
<tr>
<td>Garmo et al. (2004)</td>
<td>To describe the experiences when changing from MDII to CSII and to study the effects of changing on metabolic control</td>
<td>Invitation to all people who changed from MDII to CSII at a single clinic</td>
<td>n=23 (only 4 were interviewed)</td>
<td>Mixed methods study: DTSQ, HbA1c and 30–40 min semi-structured interview</td>
<td>Content analysis</td>
<td>HbA1c and variation in glucose levels; management of insulin; a sense of freedom; a sense of restraint</td>
<td>Grade B</td>
</tr>
<tr>
<td>Garmo et al. (2013)</td>
<td>To describe the experiences of insulin pump therapy after &gt;5 years’ use</td>
<td>Invitation to all people who changed from MDII to CSII at a single clinic</td>
<td>n=16</td>
<td>40–50 min interview using a narrative approach</td>
<td>Content analysis</td>
<td>A shackle and a lifeline; subjected vs empowered; dependent vs autonomous; vulnerable vs strengthened; routinised vs flexible; burdened vs relieved; stigmatised vs normalised</td>
<td>Grade A</td>
</tr>
<tr>
<td>Hayes et al. (2011)</td>
<td>To examine why people with T1DM choose to discontinue CSII</td>
<td>Purposive sample from a single site</td>
<td>n=5</td>
<td>Semi-structured interview</td>
<td>Hermeneutic phenomenology</td>
<td>Challenges of wearing the pump (time consuming, visibility, managing on the beach, discomfort and skin irritations, intimacy issues); lack of control over the pump, body and health (technical failures, failing off and disconnecting, doubting technology); expectations vs reality (participants’ expectations, comparing the pump with previous insulin regimen, HCPs’ expectations, life pressures)</td>
<td>Grade A</td>
</tr>
<tr>
<td>Hood &amp; Duke (2015)</td>
<td>To investigate the meaning of CSII therapy during the period of emerging adulthood</td>
<td>Purposive sample after mailout in 2 USA states</td>
<td>n=9</td>
<td>Semi-structured interview and authors’ reflective journal</td>
<td>Hermeneutic phenomenology</td>
<td>Seeking control; becoming responsible; staying connected; accepting me</td>
<td>Grade A</td>
</tr>
</tbody>
</table>

Appendix 2. Summary of key characteristics of the 13 included studies. (Continued on next page)
## Type 1 diabetes and an insulin pump: an iterative review of qualitative literature

<table>
<thead>
<tr>
<th>Study</th>
<th>Primary focus</th>
<th>Recruitment</th>
<th>Sample size</th>
<th>Data collection</th>
<th>Data analysis</th>
<th>Key themes</th>
<th>Appraisal grading</th>
</tr>
</thead>
<tbody>
<tr>
<td>O’Kane et al. (2015)UK</td>
<td>To examine contextual factors that influence technology use</td>
<td>Variety of methods including posters, flyers, online public forums, email lists, social media, snowball sampling</td>
<td>n=41</td>
<td>Multi-method approach including contextual interviews in social settings, a diary study and observation of technology use</td>
<td>Thematic analysis, where emergent themes were contextualised according to Goffman’s metaphor for presentation of self</td>
<td>Wide variation in ‘normal use’; uncertainty in social situations can lead to hiding; showing off to people can achieve a purpose</td>
<td>Grade B</td>
</tr>
<tr>
<td>Ritholz et al. (2007)USA</td>
<td>To identify psychosocial issues related to diabetes, approaches to self-care, self-perceptions, and social interactions</td>
<td>Purposive sample after mailout to 120 patients of a diabetes centre based on their HbA1c level</td>
<td>n=30</td>
<td>90 min semi-structured focus group</td>
<td>Content analysis with triangulation</td>
<td>Diabetes self-care (active engagement, convenience, decreased hypoglycaemic episodes, discipline when eating, fear of technology, still a lot of work, necessary evil, resistance to record keeping, passivity, total freedom); emotional reactions (more accepting of diabetes, feeling normal, frustration, lifts stigma of diabetes, negativity, reminiscent of initial diagnosis, return of hunger, tired of pumping, vehicle for disclosing diabetes to others); body image/social acceptance (feeling different, fashion challenge, increased self-consciousness, like a pager)</td>
<td>Grade A</td>
</tr>
<tr>
<td>Saarinen et al. (2014)Sweden</td>
<td>To describe the experience of transitioning from MDI to CSII</td>
<td>Targeted mailout based on patients at a single hospital</td>
<td>n=11</td>
<td>90 min focus group</td>
<td>Content analysis</td>
<td>Life and health (more flexible meals, obstacle during exercise, better glucose and easier control, reduced treatment concerns); involvement of others (closest relatives may initially be frightened or disturbed, increased curiosity and interest from others); technology dependence (need for continuous technology support, constant preparedness for failure, need to be continuously linked with technology, pump eventually becoming a natural part of the body)</td>
<td>Grade B</td>
</tr>
<tr>
<td>Todres et al. (2010)UK</td>
<td>To provide insight into the changes that may be experienced by patients embarking on CSII therapy</td>
<td>Purposive sampling from a specialist diabetes centre</td>
<td>n=4</td>
<td>2 phases: (i) Biographic narrative interview (ii) Theme-focused follow-up interview</td>
<td>5-stage descriptive phenomenological analysis</td>
<td>The challenge of adjusting to pump technology; changes in relationships with health professionals; realising a greater sense of control, both in terms of insulin levels and of life in general; learning something significant about their own diabetic pattern; expanding into some activity of life which they previously could not have engaged in; the significance of diabetes pump technology for those close to the patient in their personal lives</td>
<td>Grade B</td>
</tr>
<tr>
<td>Tullman (2013)USA</td>
<td>To explore experiences of female adolescents living with T1DM and wearing an insulin pump</td>
<td>Flyers posted online targeting a limited geographical area</td>
<td>n=12</td>
<td>Semi-structured interview</td>
<td>Phenomenological analysis</td>
<td>Increased level of maturity; increased awareness of one’s body; increased concern over body weight and relationship with food; positive reflection on increased flexibility in daily lives; increased perceived control over one’s diabetes; struggles with relationships and self-esteem; lack of societal awareness</td>
<td>Grade B</td>
</tr>
<tr>
<td>Wilson (2008)UK</td>
<td>To explore the communication process with HCPs</td>
<td>Random sampling of a nation-wide database</td>
<td>n=78 (only 25 were interviewed)</td>
<td>Mixed methods study: questionnaire and telephone interview</td>
<td>Preliminary thematic analysis followed by systematic analysis</td>
<td>Experience lacking amongst HCPs; difficulty accessing pump services and information; lack of support; feeling misunderstood; role of personal motivation; treatment technology achieved intensive self-management</td>
<td>Grade C</td>
</tr>
</tbody>
</table>

Appendix 2. Summary of key characteristics of the 13 included studies. (Continued from previous page)