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## ARTICLE IN PRESS

Primary Care Diabetes xxx (xxxx) xxx



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# **Primary Care Diabetes**

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# The experiences of insulin use among older people with Type 2 diabetes mellitus: A thematic synthesis

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#### ABSTRACT

*Background:* Type 2 diabetes mellitus is common in older people. Managing diabetes in older people can be challenging due to comorbidities and age-related disabilities, particularly in the context of insulin therapy. The purpose of this review is to explore older people's experiences of insulin use and to consider how these experiences might inform healthcare delivery.

*Review methods*: A systematic review with thematic synthesis was conducted and reported in accordance with the PRISMA and ENTREQ statements. MEDLINE, Embase, PsycInfo, CINAHL and Web of Science were searched from 1985 to September 2019 with subsequent updates in December 2019 and June 2022. Included studies were quality appraised, findings tabulated, and results used to inform an integrated thematic synthesis.

Results: Fourteen studies that reported insulin experiences with 274 patients aged 60 years and over were included; nine of the studies were qualitative and five used questionnaires surveys. Seven themes emerged that were grouped into treatment-related factors (physical impact of insulin, physical capacity to administer insulin, insulin self-management behaviours) and person-centred factors (emotional factors, social factors, daily living, and personal knowledge/beliefs). Three analytical themes to guide clinical practice were derived from the data: addressing physical capacity and ability, supporting social and emotional issues and improving interactions with healthcare professionals.

Conclusion: The review indicates issues surrounding the technical aspects of insulin administration, side effects of treatment and reactions to insulin administration are common amongst older people. However, research evidence is limited, and there is an urgent need for empirical, participatory research with older insulin dependent adults with type 2 diabetes.

*Implications for practice:* Healthcare professionals need to ensure that older type 2 diabetes people on insulin are actively involved in their own care, to allow their insulin regimens to be personalised and aligned with their goals and expectations. Tailored educational interventions to reduce treatment hazards and promote physical and psychological wellbeing are also needed for this population.

## 1. Introduction

Insulin is a commonly used therapy in people with Type 2 diabetes mellitus (T2DM) for whom oral agents or lifestyle management are inadequate in reducing hyperglycaemia both in relation to acute osmotic symptoms and diabetes complications [1]. Research suggests a number of challenges for individuals, across various age groups with type 1 (T1DM) or type 2 diabetes, in successfully managing their diabetes and insulin regimen. These include insufficient insulin-related education, lack of support with the administration of insulin, a negative impact on

their social life and fear of hypoglycaemia [2,3].

One in four people living with diabetes are aged > 65 years; and the prevalence among old people continues to rise [4]. Despite the prevalence and complexity of treating older people with diabetes, there is a surprising lack of evidence about how people manage their condition [5]. Older people's diabetes management may be compromised by an increase in comorbidities, age-related disabilities, frailty, and a dependence on the support of others. The use of insulin in older people can be particularly challenging due to their ability to safely manage their blood glucose levels [6,7]. In particular, age-related factors such as reduced

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vision, impaired mobility and dexterity may impact on the ability of an older person to follow their insulin regimens. Management can also be compromised by impaired cognitive function, sensory deficits, and a reliance on others over meal timing [8]. However, it is important that older people can successfully manage insulin use in order to reduce the occurrence of hypoglycaemia which can increase the risk of falls [9–11] and is associated with worse health outcomes [12].

There have been several reviews which have looked at the experiences of insulin treatment in younger adults with type 1 and type 2 diabetes [13–22]. However, no previous reviews have focused on the experiences of older people with type 2 diabetes who are required to insulin. Understanding insulin use in this population is especially important given the different focus of care for many older people, with quality of life and safety being as important as preventing long-term complications [23–26]. Thus, as relatively little is still known about this population, the purpose of this review was to explore older peoples' experiences of managing their insulin. The reviewed aimed to identify and synthesise evidence to better understand the factors affecting their use of insulin and to consider how the information might inform healthcare professionals who support this population.

#### 2. Methods

Thematic synthesis is one of a range of methods available for synthesising diverse sources of evidence [27]. This review employed the approach by Thomas and Harden [28], which involves a systematic search, quality appraisal, extraction of data and a thematic synthesis. The synthesis includes line-by-line coding of primary studies, the development of descriptive themes from initial emergent themes, and finally going beyond the descriptive themes to produce analytical themes.

Although this form of thematic synthesis often refers to the amalgamation of findings from qualitative studies, it has also been used successfully in previous research to integrate both quantitative and qualitative research [27,29]. An initial scope of the literature by the lead author (CL) located very few studies which looked exclusively at the experiences of older adults with insulin management. Given the dearth of empirical research in this area to date, it was therefore considered important to include both quantitative studies which comprised exclusively older adult samples, alongside relevant qualitative studies which whilst rich in detail, often included much smaller numbers of older participants within a mixed age group. The review is reported in accordance with the PRISMA and ENTREQ statements [30,31].

### 2.1. Search strategy

Ovid MEDLINE, Embase, PsycInfo, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Web of Science were searched from 1985 until September 2019 with subsequent updates in December 2019 and June 2022. The search strategy was developed by initially searching the Cochrane Database of Systematic Reviews using the terms 'type 2 diabetes mellitus', 'older people', and 'insulin', to identify appropriate keywords and synonyms. Synonyms were determined for the identified text words and, where appropriate, truncation commands were applied to control for spelling variations of keywords (e.g., old, older). Search term syntax was then customised for each database and separate searches were performed with terms for qualitative research e.g., experiences, interviews. The search strategy for each database is provided as supplementary information (Appendix 1). We also searched electronic theses (EthOs) and Google Scholar.

## 2.2. Inclusion criteria and study selection

Inclusion criteria were qualitative and quantitative studies explicitly documenting insulin-related experiences, and/or older people's perceptions of insulin-treated T2DM, and which were published in the

English language. We focused on studies of people already receiving insulin therapy, and not those on insulin initiation. While we recognise that older people with diabetes are not a homogenous group, for the purpose of this review they were defined as being aged  $\geq 60$  years, to allow for the identification of a broader set of published evidence [32]. Studies that sampled mixed age groups were included if data for people aged 60 and over could be isolated. We excluded studies of people with T1DM, or which sampled people with T1DM, and people with T2DM where Type 2 data could not be isolated. Studies were also excluded if they did not report people's experiences and if participants were not on insulin injections.

Abstracts were screened by the lead author (CL) and papers excluded if they did not meet the inclusion criteria. Full texts were retrieved for the remaining articles and read separately by three authors (CL, GR, AF). Their eligibility and relevance were discussed until consensus was reached. Forward citation tracking of included articles was undertaken by hand and potentially suitable articles were screened for eligibility.

## 2.3. Quality appraisal

Qualitative studies were assessed using the Critical Appraisal Skills Programme qualitative checklist [33]. Quantitative studies were assessed using a checklist devised by Barley et al. [34], based on the STROBE statement [35] and assessment tools reviewed by Sanderson et al. [36]. The CASP checklist included 10 items which appraised the qualitative studies, scored each item (Yes or No) to produce a total possible score of 10. The checklist [34] by Barley et al. included 7 items which appraised the quantitative studies, scored each item (Yes or No) to produce a total score of 7. Critical appraisal of the included studies was undertaken by the lead author (CL) and then was discussed with the co-authors until consensus was reached.

#### 2.4. Data extraction and synthesis

The synthesis was conducted in three stages as recommended by Thomas and Harden [28]. A data extraction template specially designed for the review (appendix 2) was used by the lead author (CL) to extract key methodological detail for each study including the research aim, participant characteristics, data collection analysis methods, results (including direct quotes from the qualitative studies) and conclusions. Extraction forms were checked by co-authors (GR, AF).

Stage 1: Findings from the qualitative studies were examined by the lead author (CL) for concepts and themes illuminating the experience of insulin use in older adults. As the qualitative studies featured mixed age groups, only themes which were supported by quotes or data of older adults were included. Themes were developed inductively. Table 3 provides these initial themes with exemplar quotes. The results from the quantitative studies were firstly tabulated under descriptive headings and then the quantitative findings were turned into qualitative insights to enable easier integration. Table 4 provides details of the results of each of the quantitative findings and the initial themes derived from analysis. This whole process was carried out by the lead author (CL) and reviewed by a second author (GR).

Stage 2: Descriptive themes from the qualitative and quantitative studies were then developed from the initial set of themes established in stage 1, to produce seven integrated themes. This process considered and accommodated areas of commonality and divergence between the qualitative and quantitative research. This process was reviewed by coauthors (GR, AF).

Stage 3: Finally, 'analytical' themes were generated from these integrated themes to further address the aim of this review and identify areas for further research. This process was carried out, led by one author (CL) and subsequently reviewed by co-authors (GR, AF).

#### 3. Results

A total of 8213 records were retrieved after the removal of duplicates, of which 8117 were excluded following title and abstract screening. Full text articles for the remaining 96 records were retrieved and appraised against the study's eligibility criteria. Eighty-two were excluded and 14 were included in the review. Fig. 1 summarises results for each stage of the search strategy.

## 3.1. Study characteristics

Table 1 presents study characteristics. The fourteen studies were published between 1991 and 2021 and included nine qualitative and five quantitative research designs. Qualitative studies were undertaken in Australia [37–39], Malaysia [40,41], Ethiopia [42], China [43], New Zealand [44] and Iraq [45]; and the quantitative research was conducted in Germany [46], United Kingdom [47], United States of America [48], France [49], and the Netherlands [50]. Qualitative studies included data from 71 participants using in-depth and semi-structured interviews. Analytical methods included thematic descriptive approaches and interpretative phenomenological analyses. Quantitative

studies captured data from 203 participants using questionnaire-based interviews except for one, which utilised self-completion questionnaires undertaken as part of a randomised controlled trial (RCT) [48]. These studies provided descriptive and inferential statistics on the experiences of older people using insulin.

#### 3.2. Quality appraisal

Table 2 presents quality ratings for each study. Qualitative studies were appraised as good with positive ratings ranging from 6 to 8 out of a possible 9. No item was rated negatively although some studies did not provide sufficient information to accurately appraise all items. All qualitative studies provided valuable research evidence. For example, consideration was given to the relationship between a study's findings and the wider evidence [40,41], and additional research questions arising from the work were suggested in a number of papers [37,41]. Quantitative studies were also rated as good with positive ratings ranging from 5 to 6 out of a possible 6. Two studies did not adequately control possible biases [49,50] and another two studies were supported by pharmaceutical or medical device companies, which may suggest a conflict of interest [47,48]. With these few caveats, the overall risk of

## Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)

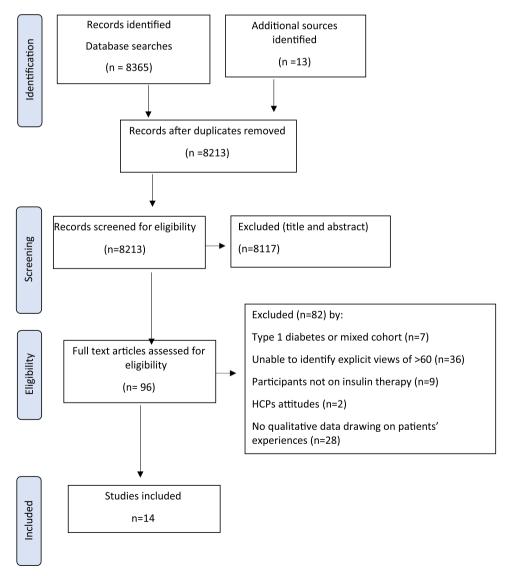


Fig. 1. PRISMA flow diagram of database searches.

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Table 1
Study characteristics.

Study	Aim	Participants	Data collection	Data analysis	Content summary
Qualitative studies Holmes-Truscott et al. (2016)[37] Australia	To explore the personal impact of insulin therapy, and attitudes towards future insulin intensification	20 adults with T2DM (11 over 60 years on insulin) (43–76 years)	Face to face interviews	Thematic	Physical impact Personal control Emotional well-being Freedom and flexibilities Concerns about others' reactions
Tong et al. (2015)[41] Malaysia	To explore factors influencing poor glycaemic control in people with T2DM using insulin.	17 people (3 over 60 years on insulin) 22–69 years T2DM On insulin At least 3 over 60 years	Semi structured interviews	Thematic	Freedom and flexibility Emotional well-being Physical impact Personal control
Ong et al. (2014)[40] Malaysia	To explore the barriers and facilitators to SMBG, in people with T2DM using insulin.	15 people (6 over 60 years on insulin) 58.7 $\pm$ 14 (23–83) T2DM All on insulin	Semi structured interviews	Thematic	Knowledge Cost of test strips and needles Frustration related to high blood glucose reading Perception that SMBG was only for insulin titration Stigma Fear of needles and pain Inconvenience Unconducive workplace Lack of motivation Lack of knowledge and self-efficacy Experiencing hypoglycaemia symptoms Desire to see the effects of dietary changes Desire to please the physician
Janes et al. (2013) [44] New Zealand	To better understand barriers to glycaemic control from the patient's perspective	15 people (10 over 60 years on insulin) T2DM All on insulin	Semi structured interviews	Interpretative phenomenological analysis	Family motivation Feelings/fears: the emotional/psychological responses to the illness Ideas on causation: the intellectual response to the illness Effects on functioning: the impact of the illness on body and lifestyle Expectations: what the person expects of the provider.
Browne et al. (2013) [38] Australia Bayked et al. (2021) [42] Ethiopia Lv et al. (2021)[43] China Mikhael et al. (2019)[45] Iraq Maneze et al. (2019)[39] Australia	To explore the social experiences of Australian adults living with T2DM, with a particular focus on the perception and experience of diabetes-related stigma. To explore the information needs of type 2 diabetes mellitus patients receiving insulin treatment in North-East Ethiopia. To explore self-care experiences for a chronic disease among empty-nest elderly patients with T2DM in mainland China. To understand the knowledge, behaviours, and barriers of diabetes self-management among Iraqi type 2 diabetes mellitus patients  To explore the information-seeking experiences of patients with type 2 diabetes and how these influenced self-management behaviours	25 adults (1 over 60 years and on insulin) T2DM 24 adults (10 over 60 years on insulin) T2DM All on insulin 15 adults (7 over 60 years on insulin) T2DM 25 adults (9 over 60 years on insulin) T2DM 18 adults (14 over 60 years on insulin) T2DM	Semi structured interview Face to face In-depth interviews Semi structured interview Semi structured interview Semi structured interview Semi structured interview	Thematic Thematic Thematic Thematic Thematic Thematic	Blame and shame Emotional well-being Knowledge Poor compliance with SMBG Poor adherence to medication Knowledge Emotional distress Knowledge Self-management Emotional well-being Inconsistent information Knowledge Lack of education
Quantitative studies Bahrmann et al. (2014)[46] Germany	To determine the extent to which geriatric patients with diabetes mellitus experience psychological insulin resistance	67 (34 over 60 years on insulin) T2DM	Questionnaire based-interview	Statistical	Concerns about others' reactions Physical impact Emotional well-being
Eiser et al. (1997)[47] UK	To determine the impact of conversion to insulin on clinical, social, personal parameters of elderly people	31 people (all over 65 on insulin) T2DM	Questionnaire based-interviews	Descriptive statistics	Physical impact Freedom and flexibility Personal control Emotional well-being
Herman et al. (2005) [48] US	To compare the efficacy, safety, treatment satisfaction and quality of life of continuous subcutaneous insulin infusion	107 people (54 over 60 years on insulin injection) T2DM	Self-completion questionnaire	Statistical	Physical impact Personal control

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Table 1 (continued)

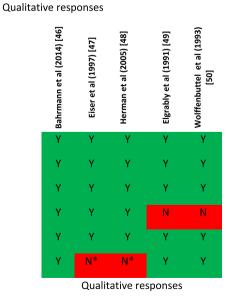
Study	Aim	Participants	Data collection	Data analysis	Content summary	
	(CSII) and multiple daily injection (MDI) in older people					
Elgrably et al. (1991) [49] France	To examine older peoples' management of insulin 2 years after initiating treatment	106 people (58 over 60 on insulin)	Questionnaire based-interviews	Statistical analysis	Freedom (independence) Emotional well-being Knowledge	
Wolffenbuttel et al. (1993)[50] Netherlands	To investigate which possible factors determine the decision for elderly type II diabetes patients to start with insulin therapy	53 people (26 over 60 years on insulin) T2DM	Questionnaire	Statistical analysis	Knowledge Physical impact Personal control Emotional well-being Freedom and flexibilities Concerns about others' reactions	

Table 2
Quality appraisal ratings.

Qualitative appraisals: (CASP, 2013 [33])	Holmes-Truscott et al (2016) [37]	Tong et al (2015) [41]	Ong et al (2014) [40]	Janes et al (2013) [44]	Browne et al (2013) [38]	Xiaoyan Lv et al. (2021) [43]	Maneze et al. (2019) [39]	Ehab Mudher et al. (2019) [45]	Bayked et al. (2021) [42]
Was there a clear statement of the research aims?	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Is a qualitative methodology appropriate?	Υ	Υ	?	Υ	Υ	Υ	Υ	Υ	Υ
Was the research design appropriate to address the research aims?	Υ	Υ	?	Υ	Υ	Υ	Υ	Υ	Υ
Was the recruitment strategy appropriate for the research aims?	Υ	?	?	Υ	Υ	Υ	Υ	Υ	Υ
Was the data collected in a way that addressed the research issue?	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Was the relationship between researcher and participants adequately addressed?	?	Υ	Υ	?	?	Υ	Υ	?	Υ
Have ethical issues been taken into consideration?	?	Υ	Υ	Υ	?	Υ	Υ	Υ	Υ
Was data analysis sufficiently rigorous?	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
Is there a clear statement of findings	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ
How valuable is the research		Qualit	ative re	sponse	S				

## Quantitative appraisals: (Barley et al., 2011 [34])

Was there a clear aim?
Was the selection of the participants appropriate?
Was the measurement of variables appropriate?
Was there appropriate control of bias?
Was the use of statistics appropriate?
Was the study free of conflict of interest?
List any limitations of the study?



Key: Y=yes, ?=can't tell, N = no, \*supported and/or funded by a pharmaceutical or medical device company

bias of the synthesised evidence was considered to be low.

#### 3.3. Findings from qualitative studies

The qualitative studies generated 11 themes relating to the use of insulin in the context of older age: hypoglycaemia, weight gain, physical impact of injecting insulin, self-monitoring blood glucose (SMBG), regulating food to insulin, distress-anxiety-depression, satisfaction and well-being, self-efficacy, stigma and embarrassment, burden and treatment goals, insulin knowledge and cultural beliefs. Table 3 summarises key findings from the qualitative studies with exemplar quotes to show how they were placed into themes.

## 3.4. Findings from quantitative studies

The findings of the quantitative studies identified 11 treatment-related and experiential factors in insulin use: hypoglycaemia, physical impact of injecting insulin, dexterity, vision, accuracy of insulin doses and timing, self-monitoring blood glucose (SMBG), regulating food to insulin, depression, satisfaction and well-being, stigma and embarrassment, insulin knowledge and cultural beliefs. Table 4 summarises key findings from the quantitative studies, along with the topics derived from the quantitative findings.

## 3.5. Integrated themes

The themes from the qualitative and quantitative studies were included in the primary thematic framework. There was considerable overlap and alignment between the data from both sources. The synthesis integrated these themes to form seven descriptive themes across two domains, namely treatment and patient related factors (see Table 5, Domains, themes, and sub-themes). Treatment related domains included: physical impact of insulin, physical capacity to administer insulin, insulin self-management behaviours, and patient related domains included: emotional factors, social factors, daily living, and personal knowledge/beliefs.

Fig. 2 demonstrates how the different types of data were incorporated into a thematic synthesis. Findings from qualitative studies (dotted outline) were linked with themes identified from quantitative studies (solid outline). The integrative themes are presented below with source data from the qualitative studies (with participant comments) and from quantitative surveys (which are identified). Where available, the participant's number, gender and age are provided.

## 3.6. Domain 1: Treatment-related factors

## 3.6.1. Theme 1: Physical impact of insulin

Quantitative research demonstrated a number of physical effects of using insulin for older people. Herman et al. [48] reported for example that 87% of older participants with diabetes reported bruising and bleeding as a result of their insulin injections. Bruising and bleeding, as well as pain, may be accepted by older people as part of the treatment or it may lead to avoidance of insulin injections [37,40,41,44,46–49]. Older people with dexterity difficulties or fear of injections may be more likely to press the insulin harder and cause injury to the injection site [51]. There was little information from qualitative data regarding the impact of physical injury during insulin use. One older participant in a qualitative study however seem to accept it as part of treatment:

Sometimes it might bleed and bruise ... but it's fine. (Holmes-Truscott's et al. [37], #15, female, age 65, Qualitative paper)

Insulin related weight gain and obesity was reported [48] in one quantitative study. However, qualitative research suggested that participants were not always aware of the potential relationship between insulin, food-craving and weight-gain.

**Table 3**To show initial thematic analysis for qualitative study with number of papers and exemplar quotes.

Descriptive theme	Illustrative quote	Reference
Hypoglycaemia	I do have hypos and that was one of the things that alerted me to the fact that I might've	[37]
	gone just a bit too far [with insulin dose].  I take my insulin injection after meals because	[45]
	if I inject it before meals hypoglycemia may	[10]
	occur	F003
	Well, if I follow the specialist (the endocrinologist), which the dietitian said	[39]
	don't because I'd be starving and I'd end on a	
	hypo. Because he didn't want me to have any	
	carbohydrates or anything. Because I live by	
	myself, I can't take chances like that. So I just limit what I take. I know what I can eat, and I	
	do break it at times. But doesn't seem to affect	
Maisht sain	it very much	FOT 41 441
Weight gain	Participants were not always aware of the potential relationship between insulin and	[37,41,44]
	food-craving or weight-gain.	
	Some of the medical profession say no, insulin	[39]
	doesn't put on weight and others say, yes it does.	
Physical impact of	Sometimes it might bleed and bruise but it's	[37]
injecting insulin	fine.	
	I wish there is a program that focus on	[45]
	educating us how to inject insulin with less pain	
	I rotate my insulin injection between arm,	[45]
0.16	thigh and abdomen.	E 403
Self-monitoring blood glucose	"Why is the blood glucose not coming down."  Ahh, that frustration. I pray hundred times, I	[40]
gracosc	pray, pray, pray, [that it] must not be more	
	than this, must not be, still I prick and see "Oh,	
	it is more than that"before that kills me, the	
	mental torture will kill me. Ahh, that's why I just couldn't be bothered [to practice SMBG].	
	The test strips were used up so fast, 50 pieces	[43]
	were gone in a few days. It is pretty expensive	
	to buy strips.	F 403
	I will record blood sugar for a few days if health care providers ask me to do this.	[43]
	Recording is decreased after this period.	
Regulating food to	Every so often I am guilty of breaking out. I	[44]
insulin	sometimes crave a bit of chocolate and I think, oh, bust, I am 72, yes, perhaps, perhaps I will	
	break out. It does not worry me. the thought of	
	death does not worry me. I sort of think, well I	
	am this age now and if the worst comes to the	
	worst, well that is it. That is life and it is over, so I have myself some chocolate.	
	Somebody say one thing, somebody say	[39]
	different thing, I don't care what the people	
	say; I eat what I want to. I don't have much control overeating out with	[43]
	other people. If you adhere to dietary	[43]
	restrictions when eating out, it is considered	
	that you are picky with food and out of tune with others.	
Distress, anxiety,	with others. I thought, oh boy, once you are on that	[44]
depression	[insulin] you have not got far to go. I thought I	2.7.3
	must be on the way out.	F0.003
	I just want to stay on the two [injections] so I'd better work a bit harder.	[37]
	I would like to improve it, but I asked the	[39]
	doctor and he said, can't improve nothing, you	
	stay on that, every three months the same. So,	
Satisfaction and well-	there is no hope. There's no future for diabetes  Qualitative data indicated that satisfaction	[37,38,40,
being	with insulin treatment and well-being	44]
	while on insulin mediated how older	
	people used insulin both positively (e.g.	
	adopting an insulin regimen to control blood glucose) and negatively (e.g.	
		l on next page

#### Table 3 (continued)

Descriptive theme	Illustrative quote	Reference
	skipping doses or discontinuing insulin	
	altogether)	F401
	I often go out for a walk with my friends, or with my spouse. They give me a lot of	[43]
	companionship and encouragement. I think	
	it's hard for me to keep going out for exercise	
	almost every day without their company and	
	supervision; they are important to helping me have the motivation to exercise.	
	He [husband] helps me, helps me to test the	[41]
	blood sugar, helps me to inject insulin at night.	
	I can't do it on my own. I don't have the mood	
	to learn. I often forget to take my medicine and insulin	[43]
	injection, although I have been unwell for a	[43]
	long time. Sometimes I fail to bring an insulin	
	pen with me when I go out.	
	I adjust myself sometimes or express my	[43]
	feelings to my daughter. She blames me all the time. Our children treat us well and always	
	buy us something to eat. Those things are	
	unsuitable for me. The most common thing	
	they say to me is to take my medicine on time	
Stigma and	and to exercise more.  I think the problem was more in corporate life	[38]
embarrassment	I was in a very senior role and I felt the need	[00]
	to hide it from that particular situation.	
	[I am] embarrassed to give needle in public	[44]
Burden and treatment	just like a drug addict. Injecting at the correct time is very difficult	[37]
goals	because the demands on your lifestyle are not	[07]
	regimented [they're] dictated by	
	circumstances, which change every day.	[07]
	That's probably the hardest part, going away, telling the tour directors of two different tours	[37]
	that I needed a fridge in every room making	
	sure you've got letters on the plane	
	Travelling, yes, you wish you didn't have it	
	then I can't take my insulin with me when I go	[45]
	outside my home, since I don't have a	[10]
	refrigerator in my car and I'm afraid that	
	insulin will be damaged when exposed to	
	extreme temperatures during the travel.  It is suffering to have diabetes, you must pay	[43]
	attention to your diet, physical activity, and	[45]
	insulin injection. It is imbalanced compared	
	with the responsibilities other people have	
nsulin knowledge and	They (health professionals) did not properly	[42]
cultural beliefs	educate me on how to inject it (insulin), but let me tell you what I did: I only drew out the	
	plunger, I did not know that the water	
	(insulin) should go down into the needle with	
	itWhat I was injecting before was nothing,	
	not the medicine, because it was not being drawn up into the needleIt was then that	
	someone noticed my mistake and wondered,	
	and I started to draw it correctly and became	
	better then.	F401
	He (a patient with diabetes) should handle and use it (insulin) properly with sufficient	[42]
	information as long as he has diabetes,	
	because it is a matter of life and death.	
	I don't think it improves your health	[37,42]
	When I first started [SMBG], I tried three times a day. Before breakfast, before lunch,	[40]
	before dinner. I feel that it doesn't serve	
	purpose. I practiced this [three times a day]	
	only once. I said to myself, "For what? The	
	blood sugar will surely rise after meals."  That's why I only monitor once every morning	
	now.	
	I blame my GP before because he will ask me	[39]
	to have blood testshe don't tell me	
	anything it's also my fault. I should ask	
	more what's going on	

Table 3 (continued)

Descriptive theme	Illustrative quote	Reference
	I didn't know who to ask, and where to go. Don't know what you have to ask, because you don't know what you don't know	[39]
Self-efficacy	He [husband] helps me, helps me to test the blood sugar, helps me to inject insulin at night. I can't do it on my own. I don't have the mood to learn	[41]

It piles weight on and I said to [my doctor] 'there's something bizarre about this'. (Holmes-Truscott et al. [37] #03, male, age 67, Qualitative paper).

Some older patients described how their experience of weight-gain made them adapt or alter their routines and eating habits to adopt more restrictive food-intake regimen with their insulin treatment [37, 41,44].

## 3.7. Theme 2: Physical capacity to administer insulin

Quantitative studies identified that limitations in physical capacity often made administering insulin challenging for older adults [47–49]. Lack of dexterity led to a reliance on others to administer their insulin. Whilst some required assistance to operate their insulin pen, others were afraid to fill the syringe due to shaky hands and some reported difficulty depressing the insulin pen plunger [48,49]. Indeed, participants who experienced practical difficulties with insulin pen use also reported less satisfaction with insulin and lower wellbeing compared to those who did not experience difficulties [47]. Vision also affected older people's ability to self-inject insulin. Some participants experienced difficulties seeing the amount of insulin injected and needed considerable support [48,49]. Some participants were too nervous to inject themselves for fear of using the wrong dose, whilst performing inaccurate injections were also reported [47]. None of the qualitative studies included older people who reported problems with physical capacity and insulin use.

#### 3.8. Theme 3: Insulin self-management behaviours

Data from the quantitative studies confirmed that older people often had negative experiences and practical difficulties when self-monitoring their blood glucose [46,47,49,50]. Hypoglycaemia was also a problem for older people who used insulin [46–48] including severe hypoglycaemic episodes which sometimes resulted in a coma. In addition, there was evidence that patients and clinicians were not always in agreement as to how best to manage their diabetes. For example, one older study found that patients often did not discuss their target goals with their doctors, and that some participants adopted tighter, inappropriate blood glucose goals than those recommended by their physicians [49].

Qualitative studies considered people's ability to undertake diabetes self-management activities [37,40,41,44]. Some participants reported finding insulin intensification difficult to implement and were concerned they might forget to take additional injections. One of the older participants explained:

It would be a nuisance because I think, I can forget, you know, I get into a routine ... if I had to take more than one it would be the nuisance factor, the inconvenience rather than the actual injections. (Holmes-Truscott et al. [37], #11, male, age 68)

Tong et al. [41] reported participants' fear of making mistakes and not adjusting their insulin dosage appropriately, while other participants reported a lack of self-efficacy in relation to monitoring their blood glucose. An older person in this study explained:

# **Table 4**To show initial thematic analysis for quantitative studies with number of papers,

Author and Reference	Summary of the Findings relevant to insulin treated older people
Bahrmann[46]	Overall, older people had negative attitudes towards insulin whilst those already on insulin to a lesser extent. Fear of hypoglycaemia was low amongst older people, however, they were concerned about been confused
P: 147	with drug addicts. older people's concerns about stigma and the potential association of injecting in public with drug-addiction negative experiences and practical difficulties when selfmonitoring their blood glucose
Eiser[47]	Older people on insulin experienced weight gain, increased frequency of hypoglycaemic episodes. Additionally, difficulties in handling the injection device were common particularly amongst those who live alone. For the total group, 48.4% would recommend the treatment to others, 12.9% would not and the remainder felt it was the doctor's decision. This study highlights the personal costs and benefits associated with conversion to
	insulin. Older people who were not advised on diagnosis (or could not recall being advised) that conversion to insulin might be necessary were more likely to be depressed (68%, n = 21/31) compared with those who did recall being so advised (32%, n = 10/31) Older people who experienced practical difficulties with insulin pen use also reported less
Herman[48]	satisfaction with insulin and lower wellbeing compared to those who did not experience difficulties Some older people believed insulin would make them feel much better than before, only to be disappointed with minimal improvements in their activity levels.  Negative experiences and practical difficulties when selfmonitoring their blood glucose 87% of participants reported bruising and bleeding as a result of insulin injections.  There was an improved satisfaction with treatment in the first four weeks despite the higher occurrence of technical difficulties in the first two months of insulin use. No change in people's experience of treatment flexibility during a 12-month study period Older people's concerns about stigma and the potential association of injecting in public with drug-addiction

Hypoglycaemia Stigma and embarrassment Self-monitoring blood glucose

Themes

Hypoglycaemia Depression Satisfaction and well-being Insulin knowledge and cultural beliefs Self-monitoring blood glucose

Physical impact of injecting insulin Satisfaction and well-being Stigma and embarrassment

Table 4 (continued)

Author and Reference	Summary of the Findings relevant to insulin treated older people	Themes
Elgrably[49]	Participants reported experiences of severe hypoglycaemic episodes including coma. Some participants adopted tighter blood glucose goals than recommended by their physicians.  Dexterity mediated older people's reliance on others to administer their insulin. Some required assistance to operate their insulin pen, others were afraid to fill the syringe due to shaky hands and some reported difficulty depressing the insulin pen plunger.  Poor vision also affected older people's ability to self-inject insulin.  Some participants experienced difficulties seeing the amount of insulin injected and needed considerable support. Others did not attempt to fill the syringe because of poor vision and required assistance from others. After two years on insulin, more people (74% vs 21%, p < 0.001) ate at least three times a day less likely to travel for up to two years after insulin initiation.  Negative attitudes were also expressed by participants towards available educational methods e.g. booklets, courses, consultations, engagement with other patients negative experiences and practical	Hypoglycaemia Dexterity Vision Regulating food to insulin Insulin knowledge and cultural beliefs Self- monitoring blood glucose
Wolffenbuttel [50]	difficulties when self-monitoring their blood glucose Older people felt that strict injection times and diet associated with insulin treatment restricted their normal daily life. Older people expressed concerns about stigma and the potential association of injecting in public with drug-addiction Older people using insulin therapy were more knowledgeable than those treated with oral medications regarding the harmful effect of high blood glucose in the development of diabetic complications Older people reported negative experiences and practical difficulties when self-monitoring their blood glucose	Accuracy of insulin doses and timing Stigma and embarrassment Insulin knowledge and cultural beliefs Self-monitoring blood glucose

He [husband] helps me, helps me to test the blood sugar, helps me to inject insulin at night. I can't do it on my own. I don't have the mood to learn. (Tong et al. [41], #12, female, age 71)

Some quantitative studies identified that participants altered food intake, meal timings, and eating habits to avoid hypoglycaemia [46,48]. Whilst managing in this way may not be unique to older adults, there were examples in the qualitative literature where participants age and time of life directly affected their persistence with dietary regulation. One participant for example, used their advance age to reclaim some autonomy by actively breaking the rules:

**Table 5**Integration: Domains, themes and sub-themes.

Domain	Theme	Sub-themes
1. Treatment- related factors	1. Physical impact of insulin	Side effects of treatment (hypoglycaemia, weight gain)     Reaction to insulin administration (bruising, bleeding, pain)
	Physical capacity to administer insulin     Insulin self-management	Insulin administration challenges (dexterity, vision, accuracy)     Self-monitoring blood glucose (SMBG)
	behaviours	Regulating Food to insulin
2. Patient-related factors	4. Emotional factors	<ul><li>Distress/anxiety/depression</li><li>Satisfaction/wellbeing</li><li>Self-efficacy</li></ul>
	5. Social factors	Stigma     Embarrassment
	6. Daily living	Burden (need to carry, limit activities)
		<ul> <li>Treatment goals</li> </ul>
	7. Personal knowledge/	<ul> <li>Insulin Knowledge</li> </ul>
	beliefs	<ul> <li>Cultural beliefs</li> </ul>

Every so often I am guilty of breaking out. I sometimes crave a bit of chocolate and I think, oh, bust, I am 72, yes, perhaps, perhaps I will break out. It does not worry me. the thought of death does not worry me. I sort of think, well I am this age now and if the worst comes to the worst, well that is it. That is life and it is over, so I have myself some chocolate. (Janes et al. [44], #5, age 72).

#### 3.9. Domain 2: Patient-related factors

#### 3.9.1. Theme 4: Emotional factors

The impact of insulin on satisfaction and wellbeing was apparent in the quantitative findings [47,48]. One study identified that older people who were not advised on diagnosis (or could not recall being advised) that conversion to insulin might be necessary were more likely to be depressed (68%, n=21/31) than those who did recall being so advised (32%, n=10/31) [47]. Encouragingly however, participants in the Herman et al. [48] study reported improved satisfaction with treatment in the first four weeks despite the higher occurrence of technical difficulties when initiating insulin use.

Qualitative data also suggested that people, including older adults, used insulin both in a positive way (e.g., adopting an insulin regimen to control blood glucose) but also in a negative way (e.g., skipping doses or discontinuing insulin altogether) [37,38,40,44]. The qualitative studies also detailed positive and negative emotional reactions to insulin influencing participants' insulin-related behaviours [37,38,40,44]. Although negative feelings were common across age groups, one older person described how unmotivated they felt to manage their diabetes after perceiving themselves as failing:

"Why is the blood glucose not coming down." Ahh, that frustration. I pray hundred times, I pray, pray, pray, [that it] must not be more than this, must not be, still I prick and see "Oh, it is more than that"... before that kills me, the mental torture will kill me. Ahh, that's why I just couldn't be bothered ....(Ong et al. [40], female, age 61)

Another older participant felt that she had failed when insulin intensification was being considered by her physician, seeing this as a reflection of her inability to manage her diabetes:

I just want to stay on the two [injections] ... so I'd better work a bit harder. (Holmes-Truscott et al. [15], #15, female, age 65)

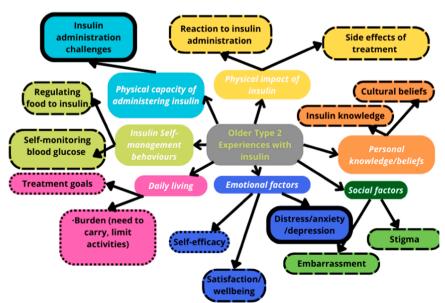
## 3.10. Theme 5: Social factors

Quantitative studies described older peoples' concerns about stigma and the potential association of injecting with drug-addiction [46,48,50]. Participants experienced embarrassment when injecting insulin in public. Some avoided injecting outside the home except when absolutely necessary and looked for private locations and tried to be discreet.

Qualitative studies also demonstrated that people experienced stigma and embarrassment associated with insulin use [37,38,44]. Whilst these feelings were expressed across all age groups, older adults certainly felt this acutely:

I think the problem was more in corporate life ... I was in a very senior role and I felt the need to hide it from that particular situation. (Browne et al. [38], #24, female, age 68)

Another older person explained how there were concerned at being mistaken for an illicit drug user:



Key: solid outline= quantitative, dotted outline=qualitative, dashed outline=quantitative and qualitative

Fig. 2. Relationship between themes and integrated themes.

[I am] embarrassed to give needle in public ... just like a drug addict. (Janes et al., [44], #12, female, age 64)

#### 3.11. Theme 6: Daily living

Quantitative research demonstrated the impact of insulin use on older peoples' daily living [46,48–50]. Some participants were less likely to travel for up to two years after insulin initiation [49], and indicated that the strict injection times and diet associated with insulin treatment restricted their normal daily life [50]. When compared with insulin naive individuals, however, some older people reported that insulin treatment provided greater freedom and more flexibility of timing with meals than tablets [50]. Similarly, participants in the Bahrmann et al. [46] study reported fewer concerns regarding flexibility with insulin compared with insulin-naïve participants, and Herman et al. [48] reported no change in people's experience of treatment flexibility during a 12-month study period.

However, there was evidence from qualitative studies which suggested that insulin treatment could have a negative impact on peoples' ability to act spontaneously e.g., going out for dinner, going to bed early or eating when they wanted to. An older participant related how insulin injections were burdensome, requiring increased daily structure and routine:

Injecting at the correct time is very difficult because the demands on your lifestyle are not regimented ... [they're] dictated by circumstances, which change every day. (Holmes-Truscott et al. [37], #08, male, age 68)

People also experienced logistical difficulties when traveling [37], including difficulty transporting insulin supplies; needing refrigeration; carrying enough insulin to last a trip; obtaining travel insurance, and letters from doctors for airports or travel insurance; driving licensing; and travelling only to places where healthcare and medications are accessible in case of emergency. One older person explained how being insulin dependent complicated travelling for work:

That's probably the hardest part, going away, telling the tour directors of two different tours that I needed a fridge in every room ... making sure you've got letters on the plane ... Travelling, yes, you wish you didn't have it then. (Holmes-Truscott et al. [37], #15, female, age 65).

## 3.12. Theme 7: Personal knowledge/beliefs

Quantitative studies highlighted that people were often disappointed with the minimal improvements that occurred in their activity levels after commencing insulin treatment [47]. However, older people using insulin therapy were more knowledgeable than those treated with oral medications regarding the harmful effect of high blood glucose in the development of diabetes complications [50]. This could be explained with a longer duration of the disease and exposure to more educational opportunities such as interactions with healthcare professionals [49]. Interestingly, over half of participants in one study felt that hospitalisation was the most effective way to provide them with the knowledge required to manage their insulin, even more than available educational methods e.g. booklets, courses, consultations, engagement with other patients [49].

Despite a reasonable level of knowledge about diabetes among insulin users shown by quantitative studies, there was evidence in qualitative studies that some patients had negative beliefs and unhelpful attitudes towards insulin usage. For example, one older participant expressed disbelief about the broader beneficial impact of insulin on his health:

*I don't think it improves your health*. (Holmes-Truscott et al. [37], #09, male, age 75)

Others believed that insulin initiation was the 'end of the road' for

them and a sign of their diabetes condition deteriorating. One questioned the value of frequent monitoring of blood glucose levels, feeling that it was unlikely to make any difference to his diabetic outcomes:

When I first started [SMBG], I tried three times a day. Before breakfast, before lunch, before dinner. I feel that it doesn't serve purpose. I practiced this [three times a day] only once. I said to myself, "For what? The blood sugar will surely rise after meals." That's why I only monitor once every morning now. (Ong et al. [40], #13, male, age 62)

## 4. Analytical themes

Three analytical themes were generated from the seven descriptive themes. In the context of this review, these analytical themes indicated areas for potential intervention in supporting older people in using insulin effectively and safely.

## 1. Addressing physical capacity and ability

Age-related deterioration in vision and dexterity may impact older people's ability to administer insulin appropriately. Reduced vision and an associated inability to dial the right dose of insulin can lead to the administration of incorrect insulin doses and subsequent hypoglycaemia. Older people commonly have to rely on another person (family member, nurse) to administer their insulin, or they skip insulin injection and dose titration to avoid hypoglycaemia. Assessing physical capacity and identifying the need for support systems as part of care planning processes is essential for successful implementation of insulin treatment in this population.

#### 2. Supporting social and emotional issues

Older people experience numerous social and emotional factors that present barriers to insulin utilisation. The perception that insulin use represents the 'the end of the road' is likely to be due to inadequate forewarning by healthcare providers that insulin may be inevitable at a certain stage. However, such thoughts cause older people to experience anxiety, depression and distress. Injecting insulin in the presence of others, can also lead to stigma and embarrassment, which can ultimately compromise insulin regimens. Older people can be empowered to overcome these barriers, and their treatment optimised, if their beliefs are understood, and their confidence levels are considered during the care planning process. There was also some evidence that the need to regulate food intake may negatively affect an older person's quality of life, disrupting their daily routines and sense of control, and leading to emotionally fuelled dietary transgressions. The possible impact of insulin treatment on an older person's quality of life and any ameliorative steps that can be taken are important considerations.

## 4.1. Improving interactions with healthcare professionals

Poor information exchange between clinicians and patients may lead to errors and misunderstandings. This was illustrated by participants' lack of knowledge of potential issues with insulin-treatment in older age, and their adoption of tighter blood glucose goals than recommended by their physicians, leading to a greater susceptibility to hypoglycaemia. There was evidence of a lack of appropriate conversations between clinicians and older people at the point of insulin initiation, and an absence of mutual agreement on treatment goals and continuous support for insulin management.

#### 5. Discussion

The presented synthesis has provided some novel insights into the complex range of factors that impact on older people's experiences of insulin treatment. While a previous review reported similar issues in a younger population of people with diabetes [22], this review has

identified additional difficulties encountered by older individuals. Insulin usage presents challenges to any age group [13–17,19]. Indeed, chronological age may be an inaccurate measure of self-efficacy, as it is largely the degree of frailty as well as comorbidities and functional ability which have the greatest impact on the capacity to manage insulin [52]. However, older individuals with a long duration of diabetes are more likely to suffer from complications including renal impairment, visual deficits, and neuropathy [53]. These all create difficulties for older people and their ability to self-manage insulin. In addition, whilst insulin treatment can lead to unfavourable side effects such as hypoglycaemia and weight gain in any population [54], older people with type 2 diabetes are more prone to suffer from hypoglycaemia [55], experience hypoglycaemia-associated hospitalisation and also mortality [56,57].

Three analytical themes from the synthesis indicate areas for potential intervention to improve care delivery. The first theme refers to addressing physical capacity and ability in older adults with type 2 diabetes who use insulin. This review found evidence of challenges regarding cognition, dexterity and visual acuity which are unique to older adults. Therefore, assessment should establish the ability of an older individual to self-manage insulin independently, or whether the assistance of a nurse or carer is required. It is important that older people are fully supported by their healthcare professionals to ensure that insulin regimens are adequately explained, that leaflets and medical labelling are acceptable to older people in terms of the size of print and readability, and that insulin delivery devices, bottles and vials are appropriate for use by people with reduced dexterity. In the past 20 years we have witnessed the transition from administering insulin syringes to pens which has improved the safety of insulin administration amongst older individuals with dexterity and visual impairment [58, 59]. While newer innovations such as continuous glucose monitoring can potentially ease anxiety and provide peace of mind in insulin dependent people [60-62], it is important to ensure that such advances empower older adults, rather than generating anxiety over technical issues or promoting a hypervigilance of glucose levels.

The second theme refers to supporting the social and emotional issues that insulin can bring in this population. Whilst experiencing negative emotions which create barriers to efficient insulin selfmanagement are common in all age groups [60,61] for older adults particularly, there can be a feeling of resignation and lack of motivation to manage their diabetes effectively. Older adults are also likely to find it more challenging to address diet and exercise habits which may have become ingrained over the years [62]. Unfortunately, the impact of poor management, such as weight gain and hypoglycaemia can increase the health burden for older adults who are already coping with multi-morbidity [53]. For all these reasons, it is important for healthcare professionals to be alert to the older person's emotional response to the initiation of insulin treatment and to provide appropriate motivational and psychological support. In addition, it is important also that older adults' views on injecting in public are addressed [41] and practical advice is provided to find ways of minimising their embarrassment whilst encouraging optimal management outside the home.

The third theme relates to improving collaboration between people with diabetes and clinical staff. It is paramount that healthcare professionals talk about treatment goals from the outset with people, and that these are regularly discussed and adapted as people's health changes. In particular, the patient needs to be involved in discussion over what is desired in terms of avoiding long-term complications, set against quality-of-life concerns, the complexity of polypharmacy and the risks of hypoglycaemia that can result from tighter control [1,63]. The specialist diabetes nurse is a key ally to helping older adults make these initial decisions and adaptations in conjunction with their medical professionals. Where possible, continuity in terms of having access to the same healthcare professional over time will help build trust among older people. This will ensure that insulin regimens are personalised, and compatible with both their cultural and spiritual values, health goals

and lifestyle.

#### 5.1. Research implications

In addition, this review found a dearth of research which has focused on older people's use of insulin. New studies are desperately needed to examine the impact of management practices in different countries on patient's self-efficacy and quality of life. Participatory research with older people, healthcare professionals and carers will better enable the development of new supportive interventions for older people who use insulin. It is important to work towards providing a stronger patient voice for this population who are often neglected in clinical studies [64, 65]. Knowing how best to revise existing insulin education programmes to ensure that they address both the needs of the older person and any carers who may be supporting them will be a key outcome of future research.

#### 6. Limitations

The lack of studies focusing exclusively on older people's experience of insulin was an important limiting factor in the research. This review used both qualitative and quantitative studies to maximise the data available to answer the review questions and to provide greater confidence in the findings. Whilst it is acknowledged that methodological differences can have an impact on the findings derived from different types of study design, it was still possible to synthesise both quantitative and qualitative data that clearly addressed the specific research questions of this review

Although a number of the quantitative studies comprised samples of exclusively older adults, which is why they were included in this review, none of the qualitative literature focused solely on this population. This necessitated using data from mixed-age samples from qualitative research. Older people were always part of the group that provided their experiences. Whilst only quotes from older people were used to support the narrative account in the results, it was sometimes impossible from the qualitative data to determine whether reported challenges were unique to older people. It is likely that some experiences such as failing eyesight or dexterity issues will be felt most acutely by older people, whilst emotional reactions to certain lifestyle changes will be shared by people of all age groups who use insulin. This underlines the importance of conducting more empirical research with this older age group. However, for the purpose of supporting older adults most effectively in a clinical setting, it is still necessary to document the experiences that they may share with younger patients, alongside those which are limited to their older age group.

An additional limitation is that the review included studies dating back to 1991 when insulin regimens and technology differed from those available today. However, whilst some of the technological advances have made insulin delivery easier and more reliable, many of the hazards and challenges of insulin management remain salient. In addition, as these technologies are not yet routinely used internationally to manage glucose levels in older people with type 2 diabetes, their impact was not evident even within the most recent studies retrieved. Although there was no explicit evidence of bias, some of the studies included were also supported by insulin-related companies which may have introduced bias into their reporting of the data [47,48]. This could be due to a conflict of interest between producing good science and seeking results that might be used to support their products. Finally, the review was restricted to studies written in the English language, and thus the review may have missed key papers in other languages, failing to capture culturally specific issues regarding managing insulin in older adults. Despite this, there was a diverse range of countries represented in the studies included, and thus international differences in the management of older patients with diabetes will have been reflected in the experience data.

#### 7. Conclusion

Insulin use in older people with T2DM is often suboptimal and associated with various age-specific challenges and risks. The findings of this review provide evidence that the technical aspects of insulin administration, as well as other physical factors such as the side effects of treatment and reactions to insulin administration, may be accentuated amongst older people. This review reveals the need for better education and support to facilitate successful management of glycaemia and promote personal wellbeing. This support should be personalised, based on an assessment of each individual's risks and potential benefits, and compatible with their beliefs, lifestyle, and psychological attitudes towards insulin.

## **Conflicts of interest**

Chaya Langerman, Angus Forbes, and Glenn Robert have no conflicts of interest related to the contents of this manuscript.

#### Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.pcd.2022.08.008.

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