



**QUEEN'S
UNIVERSITY
BELFAST**

Exploring perceptions of emotional distress among couples living with Type 2 diabetes and diabetes healthcare providers and considering support needs

Berry, E., Davies, M., & Dempster, M. (2019). Exploring perceptions of emotional distress among couples living with Type 2 diabetes and diabetes healthcare providers and considering support needs. *Diabetic Medicine*. Advance online publication. <https://doi.org/10.1111/dme.14052>

Published in:
Diabetic Medicine

Document Version:
Peer reviewed version

Queen's University Belfast - Research Portal:
[Link to publication record in Queen's University Belfast Research Portal](#)

Publisher rights

© 2019 Diabetes UK. This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

General rights

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact openaccess@qub.ac.uk.

Open Access

This research has been made openly available by Queen's academics and its Open Research team. We would love to hear how access to this research benefits you. – Share your feedback with us: <http://go.qub.ac.uk/oa-feedback>

Full title: Exploring perceptions of emotional distress among couples living with Type 2 diabetes and diabetes healthcare providers and considering support needs

Running title: Emotional adjustment in Type 2 diabetes

Authors names and affiliations:

Berry, Emma¹; *Queen's University Belfast, School of Psychology, Northern Ireland;*
E.Berry@qub.ac.uk

Davies, Mark²; *Clinical Psychology Department, Belfast Health and Social Care Trust,*
Northern Ireland; mark.davies@belfasttrust.hscni.net

Dempster, Martin¹; *Queen's University Belfast, School of Psychology, Northern Ireland;*
m.dempster@qub.ac.uk

Main affiliation and present address: Queen's University Belfast, School of Psychology,
David Keir Building, 18-30 Malone Road, Belfast, Northern Ireland, BT9 5BN

Corresponding Author: Dr Emma Berry; E.Berry@qub.ac.uk

Manuscript word count: 5501

Abstract word count: 249

Conflicts of interest: none to declare

Funding: This study was funded by the Department of Education and Learning as part of a
PhD Studentship

Novelty statement:

- This study is the first to compare the emotional experiences reported by people living with Type 2 diabetes with the perceptions of their partners.
- The study also explores how the experiences and perceptions of couples living with Type 2 diabetes align with the perceptions of diabetes healthcare providers about support needs.
- This study conveys different perspectives of the emotional stresses of diabetes and affirms the importance of considering diverse personal and professional challenges when developing strategies to enhance emotional wellbeing.

Acknowledgements: The authors would like to thank the people with diabetes, partners and diabetes healthcare providers who graciously agreed to take part. We would also like to thank Diabetes UK for their assistance with recruitment.

Abstract

Aims: Emotional distress experienced by people with Type 2 diabetes has been studied previously. The perceptions of their partners and the degree of concordance and discordance, has not been previously addressed. The perceptions of HCPs and how these differ from the perceptions and experiences of couples living with Type 2 diabetes about support needs are also explored.

Methods: A purposive sample of people with Type 2 diabetes and partners were recruited through Diabetes UK media outlets and support groups, and HCPs were recruited through hospital and diabetes education teams. Inductive Thematic Analysis was conducted.

Results: Seven people with Type 2 diabetes and six partners took part in separate semi-structured interviews and seven HCPs took part in focus groups. Themes emerged that described unique psychological struggles for people with Type 2 diabetes: ‘sense of restriction’; ‘disempowered’; ‘accepting diabetes’; and for partners: ‘feeling responsible’ and ‘need for greater involvement’. Common themes across people with Type 2 diabetes, partners and HCPs, highlighted diabetes-related stresses: ‘self-care struggles’ and ‘perceived need for appropriate psychological support’. A key theme among HCPs was ‘perceived professional barriers to psychological support’, which captures concerns related to providing emotional support in clinical practice.

Conclusions: People with Type 2 diabetes, partners, and HCPs share a common understanding of the emotional stresses of living with Type 2 diabetes, however also experience diabetes differently depending on their role and responsibilities. All face barriers that need to be considered to ensure that emotional support in diabetes is meaningful and feasible in routine practice.

Key words: Diabetes Mellitus, Type 2; Social Support; Emotional Adaption; Family; Health Personnel

1. Introduction

How individuals, their partners and family make sense of Type 2 diabetes and the quality of their relationship are important determinants of adjustment and adaptation [1-4]. Conflicting beliefs about diabetes between couples contributes to greater diabetes distress [1,2] and poorer self-care [5]. Conversely, positive relations and shared coping between couples living with Type 2 diabetes can alleviate diabetes distress [6].

Qualitative work [7] has explored adjustment in couples following a diagnosis of Type 2 diabetes and found that couples reported discordant feelings about diabetes, relationship strain and struggles with lifestyle adjustments. Other studies of couples living with Type 2 diabetes have reported similar themes [8,9]. The experience of being a partner or family member of someone with Type 1 diabetes has also been extensively explored [10,11]. Recent qualitative work with couples living with Type 1 compares perspectives of what constitutes diabetes support, revealing some distinctions between how people with Type 1 diabetes and their partners make sense of adequate self-care [12]. The study also suggested that people with Type 1 diabetes are not always aware of the extent to which diabetes affects their partner. However, the extent to which partners are aware of the emotional struggles experienced by people with Type 2 diabetes is less understood.

Quality of communication between people with Type 2 diabetes and their healthcare providers can also have a considerable influence on emotional adjustment [13-16]. People with diabetes and diabetes healthcare providers recognise the importance of a positive patient-provider relationship in enhancing self-care autonomy and having sufficient time during appointments to discuss self-care [17]. Falke and Lawson's qualitative work also captures the importance of tailoring patient-provider relationships to suit the unique needs and preferences of people with diabetes and their spouses [18].

Diabetes healthcare providers recognise the importance of psychosocial support in diabetes care, but in reality the majority feel apprehensive about engaging in conversations about psychological issues [19,20]. A key prerequisite of starting a conversation about the emotional challenges underpinning diabetes self-care is being able to *notice* this in daily practice. Exploring diabetes healthcare providers' experiences and perceptions of diabetes-related stresses as observed in routine clinical practice can provide a better sense of this.

This paper focuses on the extent to which the emotional stresses experienced by individuals with Type 2 diabetes are recognised by partners and diabetes healthcare providers. The study aims to:

1. Compare the emotional experience of people living with Type 2 diabetes with the perceptions of their partners.
2. Explore how the experiences and perceptions of couples living with Type 2 diabetes compare/align with the perceptions of diabetes healthcare providers about support needs.
3. Explore issues around providing psychological support in diabetes care pathways from the perspectives of diabetes healthcare providers.

2. Method

Design:

This qualitative study incorporated semi-structured interviews and focus groups. Ethics approval was obtained from Queen's University Research Ethics Committee and written consent was obtained from participants. The Consolidated criteria for Reporting Qualitative research (COREQ) Checklist informed the final report [21].

Participants:

A purposive sample [22] of adults diagnosed with Type 2 diabetes who currently lived with someone who they regarded as a close person (partner/spouse/family member) was recruited. Other than age, the only other exclusion criterion was lack of capacity to provide informed consent. As the study focused on emotional experience solely through narrative accounts and without presupposition, we did not seek to recruit individuals with specific levels of diabetes distress. People with Type 2 diabetes and their partners were recruited through Diabetes UK online social media platforms (Twitter and Facebook), a Diabetes UK newsletter and Diabetes UK support groups. Individuals were invited to contact the research team if they were interested in participating. A purposive sample of diabetes health care providers (HCPs) from professionally diverse backgrounds (focusing on different roles within diabetes clinical teams) was recruited by approaching a community based diabetes education team and a hospital-based diabetes team. Recruitment continued until no new codes and themes emerged

as agreed by the three authors after iterative reviewing of transcripts and discussion of the codes. Recruitment for focus groups ceased after two professionally diverse groups were completed. Findings from the two focus groups were triangulated and codes and themes were comparable across both focus groups.

Data collection:

Interviews were undertaken in a private location and lasted 30-100 minutes. Both focus groups lasted 60 minutes. Topic guides were developed for the people with Type 2 diabetes and partner interviews (Appendix 1 and 2) and for the HCP focus groups (Appendix 3) from key findings of surveys undertaken by the authors, which investigated relationship and communication conflict among couples living with Type 2 diabetes [1,3]. Pilot interviews were conducted with one person with Type 2 diabetes and one partner to refine the topic guide and interviewer approach. Topic guides for HCP focus groups were based on service issues raised within medical teams but were largely intended to prompt new insights on the topic of emotional support in diabetes. Interviews and focus groups were audio recorded and transcribed verbatim.

Analysis:

Inductive Thematic Analysis was used to interpret interview and focus group data, facilitating analysis which is not bound to a theoretical framework. Analysis followed six phases: transcription and familiarization of the data; preliminary coding; collation of codes and identification of themes; review of themes; confirming and defining themes; reporting key themes [23]. A subtle realist stance [24] was adopted to thematically explore perceptions and experiences of emotional distress in professional or personal contexts. This approach is sensitive and attentive to the meanings that individuals ascribe to make sense of diabetes, while retaining the perspective that a common reality underpins this, which qualitative investigation attempts to capture [24]. Three independent researchers (EB, MDa, MDe) were involved in the iterative analytic process, ensuring that codes and subsequent themes identified remained closely bound and were adequately supported by relevant data extracts. Triangulation of interview and focus group methods, and subsequent comparison of themes, allowed for exploration of the experiences and perceptions of emotional distress from different perspectives.

3. Results

Seven people with Type 2 diabetes and six partners participated in separate interviews (one partner was unable to attend due to ill-health). Seven HCPs actively took part in one of two focus groups (group 1: 4 HCPs; group 2: 3 HCPs). Demographics are summarised in Table 1. Thematic analysis was conducted separately for couples and for HCPs, due to the differing topic schedules and data collection approach; however the themes extracted across all groups are discussed collectively. Figure 1 displays themes extracted for people with Type 2 diabetes, partners, and HCPs, and shared themes. See Appendix 4 for further examples of data extracts in support of the themes and subthemes drawn.

3.1. Themes drawn from interviews with couples

3.1.1. People with Type 2 diabetes themes

Three broad overlapping themes drawn from people with Type 2 diabetes narratives captured experiences of living with Type 2 diabetes, which were not observed in the dialogues with partners or HCPs: sense of restriction; disempowered; and accepting diabetes.

Sense of restriction

Subthemes: physical/somatic; social; occupational

People with Type 2 diabetes often felt that they were no longer able to take part in life in the same way as before being diagnosed due to loss of physical functioning, engagement in social activities, and/or due to reduced occupational capacity. Some people with Type 2 diabetes described a perceived reduction in physical capacity, feeling that their body no longer functioned as it did before diagnosis.

you get down because you can't do certain things, it's like when older people say, oh I used to be able to do this and that, and, I feel like that now, I can't do certain things, and I'm going, this is horrible, I feel like I'm getting old before my time, it's really scary stuff (P5)

Other participants felt that since their diagnosis, they were no longer able to fully engage in common social conventions focused on food. Socialising during parties or family events tended to also revolve around food, and participants felt that they were losing out on the enjoyment of the occasion.

If you're out or at a party or at somewhere... it was our Church's 50th anniversary at the weekend there and the whole place was full of buns and cakes, and puddings and treats, it's very hard. It can be tempting to think that you wish you weren't diabetic, that you could eat them, you know when you remember how you could have. (P7)

A number of people with Type 2 diabetes described how Type 2 diabetes impacted on their capacity to work due to feeling unable to cope with work load/ intensity alongside managing their diabetes. Worries about diabetes-related outcomes such as hypoglycaemia or hyperglycaemia affected concentration at work.

I don't even really understand how I'm still working in an office, because it's astounding the pressure I have to go through every day, to get through my day. And amidst it all I'm going, "am I going too low, going too high?" (P5)

Disempowered

Many people with Type 2 diabetes felt that diabetes was an unwelcome imposition, which they had little control over. Participants reflected on occasions when they felt unable to influence their circumstances (particularly in relation to influencing diabetes related symptoms). There was also a sense of hopelessness as to the extent to which they could impact diabetes outcomes and the trajectory of their illness. This suggested that they felt quite 'stuck' at times.

I remember there was one time I just felt that bad, and I was up in hospital all night with itchy skin, you should've seen me, and see that morning I cried and I cried and I cried, and there were loads of nurses and medics around me and I just says, "I just feel like I've fallen into a big hole and I can't get out of it", I want home, I was like a baby I just wanted home. Eleven weeks in there was enough. And I says oh this is desperate, and I'll never forget it. Talk about a fit of depression. (P6)

There's no way out that's the way I see it, you're stuck with it. When I first found out I had diabetes I tackled it, but I think I was a bit naïve, I didn't think the consequences would be as hard on you. (P5)

Accepting diabetes

Subthemes: passive/reluctant acceptance; reframing the situation

This theme captured the different ways people made sense of their condition, and the degree to which they felt able to integrate diabetes into day to day life. The narratives suggested that some participants found it easier to accept diabetes than others. For example, some people with Type 2 diabetes accepted that diabetes was now a definitive part of their life; but felt that they had *no choice* other than to accept their condition. The narratives conveyed a sense of passivity or resistance toward the reality of having diabetes.

But, well, I suppose you just have to cope with it really and that's it. (P6)

people say to me "If you lose weight it will go away", but you can't lose diabetes even if your blood glucose is controlled. You will always be diabetic, you're damaged in ways, your pancreas is damaged...its getting your head around it all. (P5)

One participant talked about how it can be difficult for people to accept diabetes due to being unaware or unable to comprehend the seriousness the condition.

Sometimes it's like the blinkers are up...if I ignore it maybe it will not be as bad.

Maybe it will go away. (P1)

Other people with Type 2 diabetes found ways to make diabetes easier to inherently accept diabetes. Some participants compared their own situation with others they perceived to be less fortunate or 'worse off', which seemed to help with accepting their own situation.

Another participant found it easier to accept diabetes when they were able to channel this experience into more positive things such as volunteering.

No, I look at it like I could've had a lot worse diagnoses than diabetes, he could have been telling me I've 6 months to live with terminal cancer. (P7)

I have my days, but you know I try not to, because of the things I have to look forward to. Next Thursday I have such and such, I've had days at [name of local venue], spoke at several events and eh, it [volunteering] gives you momentum and something to—it's like Ok I'm diabetic, it's gonna eventually kill me but, you know, you don't sort of dwell on that there, you just go on and see the positive things. (P2)

3.1.2. Partner themes

Partners recognised distress in their loved ones (as described in section 3.1.3), however two themes captured their own personal struggles: feeling responsible and need for greater involvement.

Feeling responsible

This theme captures how a number of partners believed that it was their responsibility to manage their loved one's diabetes. These partners felt concerned that diet or blood glucose targets were being met and felt obliged to ensure that the diabetes regimen was followed.

it's on a daily basis, and I'm having to, I just watch his moods, or if he's tired or- I'm on the ball with it though... I'll recognise things and he's going "don't be silly it's nothing" and I'll be like do your bloods, just check them to be sure. So I'll be on his back about it. The wee devil poking him with a fork—"get your bloods done".

(Partner3)

This strong sense of responsibility seemed to elicit feelings of frustration when their partner with diabetes did not manage diabetes in a healthy way, which they felt unable to influence at times.

I'm doing my best, I mean I don't always have control over what [name of partner with Type 2 diabetes] does. He'll say oh I only eat what you give me. But he doesn't... whenever I go out—I don't really go out in the morning because of his disability. But if I go out, no matter what he always eats something when I go out. And I find that frustrating. (Partner1)

Need for greater involvement

A number of partners felt that they would like to engage more with health services to acquire a greater involvement in diabetes care. The narratives suggested that at times they felt excluded from self-management and from the conversations that their partners with diabetes were having with healthcare providers.

a whole lot of people with diabetes would go off to appointments on their own, and it's like "well what happened?" and they're like "Uh I don't want to have to go through the whole lot"- they'll hand you the leaflets just...so it's just keeping on top of things, so that I know what I'm dealing with. (Partner3)

Partners also expressed a degree of uncertainty as to *how* they could support their partner with diabetes, despite wanting to help. Not having the knowledge of how to help made it difficult to actively support self-care.

I try to help her as much as I can, like when I'm making any food, but it's knowing what she can and can't eat sort of...I guess, you'd love to make her better but you just, carry on with it. (Partner4)

3.1.3. Overlapping person with Type 2 diabetes and partner themes

Self-care struggles

This theme was conveyed by both people with Type 2 and partners, and relates to the demands of diabetes self-care. The majority of people with Type 2 felt that aspects of managing diabetes such as taking medication, adhering to a healthy diet, or blood glucose monitoring, were tedious and overwhelming at times. It was felt that self-management required a lot of adjusting to new routines and planning.

life is totally different, really, because you have to change how you think, where you're going, what you're going to do, what you have with you, what there is to eat... if you're going anywhere you have to have your own wee bag of stuff, you know, you can't just open the cupboard and grab something to take; you have to just think about it first. (P4)

Taking medication and remembering when to take certain tablets was a specific source of frustration alongside diet.

He [partner] writes it all down, so we know what all medication I'm on and my allergies and all. You wouldn't remember it all otherwise. It's my tablets more than anything, they rattle me. (P6)

A number of partners were strongly aware of the pressures and concerns experienced by their loved ones, especially surrounding blood glucose levels and insulin administration. Partners expressed concern with using insulin and felt that lack of time with healthcare providers and inconsistent information contributed to this. Partners shared similar self-care stresses as people with Type 2 diabetes.

at the start her blood sugars where very high, and she would have contacted the nurse a lot. So until she got herself regulated I know she had a lot of worries around that. (Partner6)

he had a really bad high one when he was ill and we just didn't know what to do, we had Lantus, which is a slow acting insulin in the fridge but we didn't know how to use

it we were never instructed in how to use it....that was the most frustrating thing of the whole lot, was trying to work out in your head- what do you do here? (Partner3)

Perceived need for appropriate psychological support

A number of people with Type 2 diabetes and partners acknowledged a gap in non-medical support provision for people affected by Type 2 diabetes. Many people with Type 2 diabetes perceived a lack of emotional support for diabetes from healthcare providers. It was felt that simple interactions inquiring about general wellbeing were often absent in healthcare support.

people don't really ask "how are you?" People just seem to more deal with the practical things...nobody really asks you if there are times when you're actually fed up to the teeth and wish you weren't a diabetic. (P4)

Some people with Type 2 diabetes felt that the support provided by family members was inappropriate. At one extreme, family were seen as being overprotective whereas at the other extreme family were seen as providing little or no support with diabetes.

They're all very aware of my diabetes and watch out for what I'm eating and so on, well almost too much...even the grand children would say "no you're not allowed to eat that!" My family are a bit like the food police and that can be frustrating. (P1)

They haven't got a clue...my sister's kid has got T1, and it's like "Aw you're not as bad off as my children". Like what a cruel thing to say. They maybe think I'm putting it on a bit, I mean they have no idea...so now I just help myself and never let on.

There's no support there, no, not at all. (P5)

Partners conveyed the need for greater peer support from other couples living with Type 2 diabetes which would present an opportunity to talk to and receive help from other partners who were experiencing similar struggles related to diabetes. Such support was viewed as important for partners' emotional wellbeing.

But it's good to speak to somebody who has experienced diabetes and that sort of thing and you can share your thoughts, you know what I mean? When it's shared, it's halved, you know? (Partner1)

I think like a group thing would be good because then you would be with other people maybe with similar worries and that, other partners would be there. (Partner5)

3.2 Themes drawn from focus groups with HCPs

Self-care struggles

Similar to that of couples, a number of HCPs reflected on the challenges associated with self-care. Specifically, HCPs discussed how not achieving target outcomes often generated feelings of failure, which commonly transpired during conversations with people with Type 2 diabetes at diabetes clinics. Self-blame was a common reaction to self-care struggles and not achieving certain medical ‘targets’.

Control as well, a lot say they really don’t know where to turn anymore; trying their best but not achieving anything—still perceive that they’re failing. (HCP1)

One lady recently came to see me, she has Type 2 diabetes, but she’s not overweight, and she says I don’t overeat, I’m not fat, I manage my diet. She still felt she wasn’t doing something right; she was like “it must be my fault”. (HCP7)

Perceived need for appropriate psychological support

A number of HCPs mentioned how people are often told they have diabetes in a cold and uninformative manner, which was a common grievance among patients during clinics and education groups.

They’ve been in for blood test but they haven’t even been told they have diabetes, and so when they get here they’re very angry... There’s a lot around that, where they’re either not taking it on board when they’ve heard it or they have been confused by mixed messages from other GP’s saying you have or you haven’t it. It’s the inconsistency. (HCP3)

HCPs identified that unmet emotional needs can impose barriers on self-care as people may not be in a healthy frame of mind to absorb instruction and advice, which in turn can impact diabetes medical outcomes. HCPs felt that improving emotional wellbeing may help people to better manage their condition.

If emotionally they are not in the right place they won’t take on any of the key messages, and you would see that time and time again. They’re just really surviving. (HCP4)

addressing those (emotional) issues as well might have ripple effects on the overall management of their condition because they might be able to have a bit more clarity, and focus on things like diet and lifestyle, because their emotional health is being looked after as well. (HCP1)

There was a general perception that greater psychological support is needed for people with Type 2 diabetes; however there was some dissonance as to when best to provide such support across the diabetes trajectory. The majority of HCP felt that it would be better to offer psychological help *after* receiving diabetes education, so that they would have a better understanding of their condition.

You see a transition in people's attitudes after they've been to the whole programme because some are sceptical at the start so maybe that is a better time for an intervention for diabetes distress, because people are maybe more open minded (HCP6)

However other HCPs queried whether this might exclude people who were not attending structured education due to underlying emotional distress. Addressing emotional struggles might support attendance at structured education as individuals have had the opportunity to voice concerns and make sense of their diagnosis.

there might be a lot of people who don't turn up because they're dealing with stuff, so maybe if they could have had a little bit of support at that point...somebody's heard them and they've listened and they've been able to sort things out and they're in a different place. (HCP3)

HCPs recognised that inappropriate family member involvement can be harmful to self-care. Similar to that of people with Type 2 diabetes, HCPs also recognised that inappropriate family member involvement can be harmful to self-care, which often transpired during clinics and phone calls with patients. Family members have often been described as overprotective or not supportive enough with diabetes.

Yeah family doesn't care, they're giving me no support or family keep telling me to take my blood sugars, so you've kind of got the two extremes. Trying too hard or not trying hard enough, yeah we'd get a lot of calls like that. (HCP2)

Perceived professional barriers to psychological support

Subthemes: language and terminology; facilitating psychological support

HCPs raised the issue of using certain emotive language and terminology when supporting individuals with Type 2 diabetes psychological struggles. HCPs mentioned that the term “depression” for instance, has previously elicited some discomfort or anger during structured Type 2 diabetes education groups.

There was another lady who was very resistant, saying “are you telling us we’re all depressed?” (HCP6)

we had a gentleman last week who said “why are you saying all this stuff about depression?” and when I spoke to him afterwards about it he just said “Well you just have to get on with it like don’t you? Like that’s a load of rubbish about depression”. (HCP3)

A number of HCPs felt that a Diabetes Specialist Nurse (DSN) may be best placed to address diabetes-related stresses as they would have a close insight into common struggles. HCPs felt that people with Type 2 diabetes may find it easier to talk to their DSN about emotional issues as they would be more comfortable with them from attending clinics.

They’re very caring, very holistic. And I think also the DSN’s are in contact quite regularly with these patients, particularly insulin treated patients, and they’d be the main point of contact for patients and they’d be also maybe in contact with patients between appointments. So it’s having that rapport. (HCP2)

However, many HCPs were doubtful about their capacity to provide psychological support for people with Type 2 diabetes, which reflected on worries about not having the skills or confidence to address emotional issues. There were specific concerns about providing inappropriate support and getting it ‘wrong’.

But we maybe don’t know how to cope with all that very well ourselves. But it does usually come out a lot during those appointments...you want to fix it and solve it. (HCP5)

Oh I think it would really need to be a specialist, a psychologist, I wouldn't really feel comfortable dealing with those sort of issues...I don't think it would be safe for me to

be trying to give that kind of help—say if I gave out the wrong information. Some of the things that people disclose can be really quite sensitive. (HCP3)

It was also felt that addressing emotional distress was not feasible during clinics or education programmes due to time constraints and felt that a designated time and space was required to address emotional concerns.

It would be impossible time wise for us to squeeze that in, because it's something that's going to take more time than checking a blood pressure. (HCP2)

4. Discussion

This study explores the emotional challenges of living with Type 2 diabetes, from the perspectives of people with Type 2 diabetes and the people who support them personally and professionally. People with Type 2 diabetes, their partners and HCPs talked about the difficulties posed by managing Type 2 diabetes and the importance of emotional support in similar ways. The emotional challenges reported by people with Type 2 diabetes and the perceptions of the partners and of health care providers overlapped but, crucially, also differed according to perspective. All participants recognised the importance of the psychological support and the burden of self-management. People with Type 2 diabetes tended to focus on themes such as restriction, disempowerment and acceptance whilst their partners reported their sense of responsibility and powerlessness.

The emotional challenges of managing diabetes and the lack of adequate emotional support from family and healthcare systems were considered important by people with Type 2 diabetes, their partners, and HCPs alike. This highlights areas of common concern for individuals affected by diabetes personally and those involved in providing diabetes healthcare. In partners, perceived self-care struggles related to the unpredictability of blood glucose levels and the prospect of supporting insulin use resonates with numerous previous studies with partners of people with Type 1 diabetes [10,11]. This affirms the importance of involving partners and other family members in diabetes education and psychosocial support.

HCPs were aware of many of the self-care struggles experienced by people with Type 2 diabetes and recognised the impact this had on self-esteem and diabetes self-efficacy, which echoes that of previous work with healthcare providers [16,19,20]. HCPs also recognised that psychological supporting diabetes services was valuable to support self-management, particularly at the point of diagnosis which aligns with previous work [25]; however there

was a degree of dissonance as to when it would be most helpful to provide such support. Many HCPs felt that a form of psychological support would be of particular value to those who have attended structured diabetes education, but have *persisting* emotional distress. Equally, it was recognised that many people with diabetes do not feel able to attend education groups due to unmet psychological needs. This is supported by previous systematic review work which identified that unmet emotional struggles (fears and avoidance of self-care and diabetes-related symptoms and complications) are a common reason for not attending structured Type 2 diabetes education [26].

The focus groups elicited discussion about the problems surrounding language when discussing emotional wellbeing and issues surrounding the facilitation of psychological support. HCPs reflected on how some people with Type 2 diabetes, during previous education groups or clinics, have felt uncomfortable with the use of terminology associated with mental wellbeing—perhaps due to a lack of understanding or perhaps due to the perceived shame of admitting they are experiencing such issues. Language is a hugely important (and *cost-effective*) tool in fostering empowerment towards self-care [15]. However if used insensitively language and labels can engender shame and stigma [27]. Likewise, evidence suggests that the quality of communication between people with Type 2 diabetes and their healthcare provider is a strong determinant of the nature of the patient-provider relationship—specifically, a relationship built on trust, empathy and encouragement can lead to substantial improvements in diabetes self-care [13].

The focus groups also revealed how many HCPs felt uncertain about whether they could provide emotional support adequately or if they would have the clinical time to do so. Similar concerns have been raised in previous work with diabetes HCP [28,20], highlighting an important challenge within diabetes practice. The question of who should be responsible for delivering emotional support is an important issue in diabetes care. The focus groups demonstrated that diabetes HCPs are familiar with the common emotional stresses reported by people with Type 2 diabetes. Given that emotional distress is, to a greater or lesser degree, experienced by the majority if not everybody diagnosed with type 2 diabetes, it seems reasonable to suggest that emotional support should fall within the bailiwick of everybody who cares about and for people diagnosed with Type 2 diabetes. It is therefore important that diabetes HCPs feel confident enough to be receptive to or to start conversations with their patients about what is most stressful about diabetes, in a way that does not require expert psychological skills and does not demand excessive time during appointments. Psychological

support at a minimum can be facilitated by taking a few moments to ask and listen—to acknowledge a patient’s struggles and to be *present*. This simple approach has demonstrated benefits, as revealed in a randomised controlled trial which showed that an ‘active listening’ intervention which was delivered by a nurse and doctor was *as effective* at reducing emotional distress as a more complex psychological intervention [29]. Motivational Interviewing may benefit people with emotional distress in a similar way [30].

A novel but challenging element of this study was the collective evaluation of interview and focus group findings. The decision to conduct focus groups was partially pragmatic, based on the availability of HCPs. However this approach also facilitated discussion and prompting between individuals of different HCPs about a relatively novel topic. Combining the two approaches for such reasons is common in health research [30]. Still, it is acknowledged that focus group data is largely the product of social exchanges; to include influences of occupation and social hierarchy, while interviews place emphasis greater on personal reflection [31]. Moreover, focus group and interview schedules were not identical which limits the comparability of themes. Interview questions for couples were geared toward specific issues related to the psychological struggles of diabetes, to build on existing knowledge around the topic. Although topic guides were developed, interviews were conducted in an open manner and prompts were extensively used to facilitate discussion and depth of responses. The method for recruiting participants (via a diabetes charity) limits the social representativeness of the sample and it is recognised that participants may have been more active in their diabetes management. However generalizability of findings is not a primary concern of qualitative research.

This study identifies some of the less discernible emotional stresses expressed by people with Type 2 diabetes and the perceptions thereon of their partners. Partners and HCPs recognised some of the common challenges experienced by people with Type 2 diabetes; however the results also capture how diabetes can be perceived quite differently, depending on the perspective taken. This prompts reflection on the importance of constructive communication and openness between couples and between patients and HCPs. This study is a reminder of the importance of considering the needs of individuals who are personally affected by diabetes and those involved in professional diabetes care, to ensure that psychological support is meaningful to people with Type 2 diabetes and their families, but is also acceptable in practice.

References

1. Berry E, Davies M, Dempster M. Managing Type 2 diabetes as a couple : The influence of partners' beliefs on diabetes distress over time. *Diabetes Res Clin Pract* 2018; 141:244–55.
2. White P, Smith SM, Hevey D, O'Dowd T. Understanding Type 2 diabetes: Including the family member's perspective. *Diabetes Educ* 2009; 35(5):810–7.
3. Berry E, Davies M, Dempster M. Illness perception clusters and relationship quality are associated with diabetes distress in adults with Type 2 diabetes. *Psychol Heal Med* 2017; 22(9):1118–26.
4. Dempster M, McCarthy T, Davies M. Psychological adjustment to Type2 diabetes and relationship quality. *Diabet Med* 2011; 28(4):487–92.
5. Searle A, Norman P, Thompson R, Vedhara K. Illness representations among patients with type 2 diabetes and their partners: Relationships with self-management behaviors. *J Psychosom Res* 2007; 63(2):175–84.
6. Franks MM, Sahin ZS, Seidel AJ, Shields CG, Oates SK, Boushey CJ. Table for two: Diabetes distress and diet-related interactions of married patients with diabetes and their spouses. *Fam Syst Heal* 2012; 30(2):154–65.
7. Dellafiore F, Rosa D, Pittella F, Caruso MP, Allemano M, Caruso R. The impact of type 2 diabetes diagnosis on married couples. *J Diabetes Nurs* 2018; 22(2).
8. Trief PM, Sandberg J, Greenberg RP, Graff K, Castronova N, Yoon M, Weinstock RS. Describing support: A qualitative study of couples living with diabetes. *Fam Syst Heal* 2003; 21(1):57.
9. Beverly E, Wray LA, Miller CK. Practice implications of what couples tell us about type 2 diabetes management. *Diabetes Spectr* 2008; 21(1):39–45
10. Messina R, Due-Christensen M, Keller-Senn A, Polek E, Fantini MP, Sturt J. Couples living with type 1 diabetes: An integrative review of the impacts on health and wellbeing. *J Health Psychol* 2018; <https://doi.org/10.1177/1359105318817356>
11. Whittemore R, Delvy R, McCarthy MM. The Experience of Partners of Adults with Type 1 Diabetes: an Integrative Review. *Curr Diab Rep* 2018;18(4).
12. Litchman ML, Wawrzynski SE, Allen NA, Tracy EL, Kelly CS, Helgeson VS, Berg CA. Yours, Mine, and Ours: A Qualitative Analysis of the Impact of Type 1 Diabetes Management in Older Adult Married Couples. *Diabetes Spectr* 2019; <https://doi.org/10.2337/ds18-0057>
13. Polonsky WH, Capehorn M, Belton A, Down S, Alzaid A, Gamerman V, et al. Physician–patient communication at diagnosis of type 2 diabetes and its links to patient

outcomes: New results from the global IntroDia® study. *Diabetes Res Clin Pract* 2017;127:265–74.

14. Tanenbaum ML, Kane NS, Kenowitz J, Gonzalez JS. Diabetes distress from the patient's perspective: Qualitative themes and treatment regimen differences among adults with type 2 diabetes. *J Diabetes Complications* 2016; 30(6):1060–8.

15. Cradock S. Positive behavioural change requires clarity, objectivity and support. *Diabet Med* 2017; 34(8):1025–6.

16. Pooley CG, Gerrard C, Hollis S, Morton S, Astbury J. “Oh it's a wonderful practice ... you can talk to them”: A qualitative study of patients' and health professionals' views on the management of type 2 diabetes. *Heal Soc Care Community* 2001; 9(5):318–26.

17. Beverly EA, Ganda OP, Ritholz MD, Lee Y, Brooks KM, Lewis-Schroeder NF, et al. Look who's (not) talking: Diabetic patients' willingness to discuss self-care with physicians. *Diabetes Care* 2012; 35(7):1466–72.

18. Falke SI, Lawson L. Couples with diabetes and health-care providers: A grounded theory of preferential relating. *Heal Expect* 2015;18(6):3136–46.

19. Nichols J, Vallis M, Boutette S, Gall Casey C, Yu CH. A Canadian Cross-Sectional Survey on Psychosocial Supports for Adults Living With Type 1 or 2 Diabetes: Health-Care Providers' Awareness, Capacity and Motivation. *Can J Diabetes* 2018; 42(4):389–394.e2.

20. Graves H, Garrett C, Amiel SA, Ismail K, Winkley K. Psychological skills training to support diabetes self-management: Qualitative assessment of nurses' experiences. *Prim Care Diabetes* 2016;10(5):376–82.

21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Heal Care* 2007;19(6):349–57.

22. Robinson OC, Robinson OC. Qualitative research in psychology sampling in interview-based qualitative research: A theoretical and practical guide. *Qual Res Psychol* 2016;11:25–41.

23. Braun V, Clarke V. *Successful qualitative research: A practical guide for beginners*. London: Sage, 2013.

24. Mays N, Pope C. Assessing quality in qualitative research. *Bmj* 2000; 320:50–2.

25. Peel E, Parry O, Douglas M, Lawton J. Diagnosis of type 2 diabetes: A qualitative analysis of patients' emotional reactions and views about information provision. *Patient Educ Couns* 2004;53(3):269–75.

26. Horigan G, Davies M, Findlay-White F, Chaney D, Coates V. Reasons why patients referred to diabetes education programmes choose not to attend: a systematic review. *Diabet Med* 2016; 34(1):14–26.
27. Lloyd CE, Wilson A, Holt RIG, Whicher C, Kar P, on behalf of the Language Matters Group. Language matters: a UK perspective. *Diabet Med* 2018; 35: 1635–1641.
28. Joensen L, Fisher L, Skinner T, Doherty Y, Willaing I. Integrating psychosocial support into routine diabetes care: perspectives from participants at the Self-management Alliance meeting 2016. *Diabet Med* 2018. <https://doi.org/10.1111/dme.13836>
29. Chew BH, Vos RC, Stellato RK, Ismail M, Rutten GEHM. The effectiveness of an emotion-focused educational programme in reducing diabetes distress in adults with Type 2 diabetes mellitus (VEMOFIT): a cluster randomized controlled trial. *Diabet Med* 2018;35(6):750–9.
30. 1. Sturt J, Dennick K, Hessler D, Hunter BM, Oliver J, Fisher L. Effective interventions for reducing diabetes distress: systematic review and meta-analysis. *Int Diabetes Nurs* 2015;12(2):40–55.
31. Lambert SD, Loiselle CG. Combining individual interviews and focus groups to enhance data richness. *J Adv Nurs* 2008; 62(2):228–37.

Table 1: Characteristics of people with Type 2 diabetes and partners (N=13) and diabetes healthcare providers (HCP) (N=7)

Age of couples (<i>range in years</i>)	42-73
Time since diagnosis (<i>range in years</i>)	0.5-15
Diabetes treatment	
Insulin	1
Medication	4
Diet-only	2
Attend diabetes support groups	
Yes (person with Type 2 diabetes only)	0
Yes (as a couple)	2
No	5
Diabetes Education attendance	
Yes (person with Type 2 diabetes only)	1
Yes (as a couple)	3
No	3
Diabetes Healthcare professions	
Diabetes Specialist Nurse	3
Diabetes Dietician	2
<i>of which were structured diabetes educators*</i>	3*
Consultant Diabetologist	2

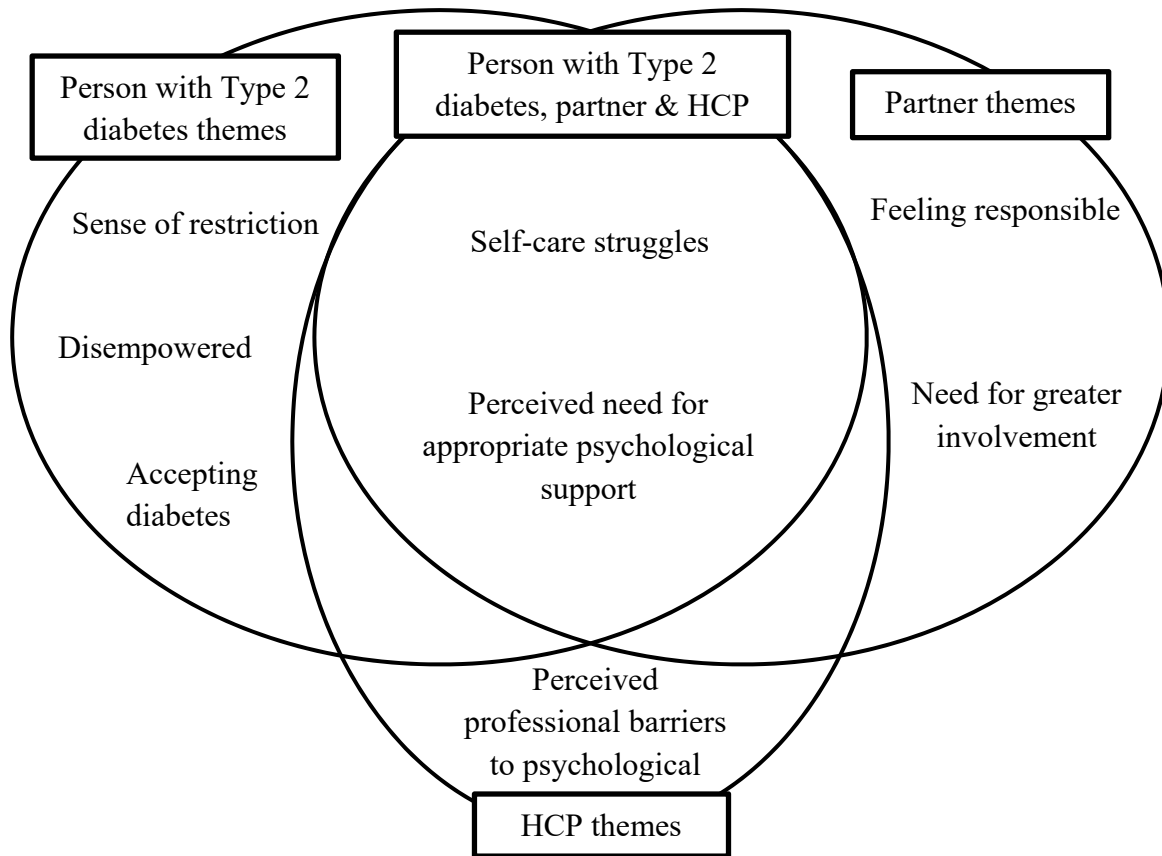


Figure 1: Venn diagram displaying exclusive themes for people with Type 2 diabetes', partners' and diabetes healthcare providers' (HCPs) and shared themes

Appendix 1: People with Type 2 diabetes interview topic guide

1. When were you diagnosed with Type 2 Diabetes? Could I ask you to describe what's it like to live with Type 2 diabetes? (*Follow-up prompts provided where needed/relevant e.g. any previous experience of diabetes? What was your reaction when you were diagnosed?*)
2. I'd like you to think a bit about the emotional impact that diabetes might have on your day to day life (*Follow-up prompts provided where needed/relevant e.g. what do you think the source of this was? would you have ever experienced anything like that before the Diabetes? why might this be?*)
 - Have there been times when you ever felt overwhelmed or burdened by your diabetes?
 - What about in terms of day to day management of diabetes?
 - What about in relation to your experiences with healthcare professionals, doctors, nurses etc.?
 - What about in relation to your experiences with family/ friends?
3. I'm going to ask you some questions about your own thoughts and beliefs about your diabetes (*Follow-up prompts provided where needed/relevant e.g. why is this? what has helped this?*)
 - Would you say you feel able to influence your diabetes? Would you say you have a good understanding of diabetes?
4. I would like to ask you a few questions now about how diabetes might influence your relationship with your partner (*Follow-up prompts provided where needed/relevant e.g. why is this? What has helped/ not helped this?*)
 - Firstly, would you say your partner has a good understanding of your diabetes?
 - Do you feel able to talk about diabetes?
 - Are you able to enjoy time spent together despite diabetes?
 - Would there ever be any conflicts or disagreements about diabetes?
5. Have you ever been to a diabetes support group or education program before? (*Follow-up prompts where needed/relevant e.g. what was that like? What was most helpful/ unhelpful?*)
6. Thinking about the types of things we have already talked about, if we could provide an intervention/program to help individuals with diabetes and their partners cope better emotionally, would you engage? What might you want from this? What would **not** be helpful?

Appendix 2: Partners interview topic guide

1. How did you feel when your partner was first diagnosed with T2D? (*Follow-up prompts were provided where needed/relevant e.g. any previous experience of diabetes? What was your reaction to the diagnosis?*)
2. Do you feel that you have a good understanding of your partner's diabetes? (*Follow-up prompts provided where needed/relevant e.g. why is this? What has helped/ not helped this?*)
3. Do you feel able to help/ support your partner with their diabetes? (*Follow-up prompts provided where needed/relevant e.g. why is this?*)
4. At present, do you think that you play an important role/part in your partner's diabetes? (*Follow-up prompts provided where needed/relevant e.g. why is this?*)?
5. I would like to ask you a few questions now about how diabetes might influence your relationship with your partner (*Follow-up prompts provided where needed/relevant e.g. why is this? What has helped this/ made this difficult?*)
 - Would you talk to your partner about their diabetes?
 - Are there ever any disagreements about diabetes?
 - Does diabetes ever intrude upon you and your partner's ability to enjoy time together?
6. Have you ever been to a diabetes support group/program with your partner before? (*Follow-up prompts where needed/relevant e.g. what was that like? What was most helpful/ unhelpful?*)
7. If we could provide an intervention/ program to help individuals with diabetes and their partners cope better emotionally, would you engage? What might you want from this? What would **not** be helpful?

Appendix 3: Diabetes healthcare providers' focus group topic guide

1. Diabetes distress has been described as emotional stresses caused by diabetes and the demands of self-care. Do you recognise this description? Do you ever come across diabetes distress in day to day practice?
2. Do you think that an intervention/program to reduce diabetes-related emotional distress and help persons with diabetes and their partners' better emotionally adjust to diabetes would be useful? (*Follow-up prompts where needed/ relevant e.g. why is this?*)
3. Thinking about the difficulties you have come across which have been experienced by individuals with diabetes, what could be included in this programme that would be of most benefit to patients and partners?
 - What aspects of living with diabetes might people need support with?
4. Who do you think would be best to facilitate an intervention/programme addressing diabetes distress?
5. How/when might we target people for this type of support?
6. From your knowledge of health care, could you foresee any barriers to providing this type of support? (*Follow-up prompts where needed/ relevant e.g. why might this be? What might help this?*)

Appendix 4: Themes across people with Type 2 diabetes, partners, and healthcare providers with sample codes and additional data extracts

Participant group	Themes & subthemes	Sample Codes	Data Extracts
<p>People with Type 2 diabetes</p>	<p>Sense of restriction</p> <ul style="list-style-type: none"> - Physical/somatic - Social - Occupational <p>Disempowered</p> <p>Accepting diabetes</p> <ul style="list-style-type: none"> - Passive/ resistant acceptance - Reframing the situation 	<p>Diabetes symptoms can limit functional capacity</p> <p>Less able to engage in social life/ social activities</p> <p>Feel less able to engage with work</p> <p>Feeling unable to influence circumstance</p> <p>No choice but to live with diabetes</p> <p>Finding ways to live with/make sense of diabetes</p>	<ul style="list-style-type: none"> - But it's very difficult, you know, you've got a health problem but it also affects your mental health as well. Sometimes I'll get very fed up and I'll maybe just stay in bed all day, just cause' you generally just feel tired, and it's probably mentally tired rather than physically tired. (P2) - There are loads of things like the birthday buns, and I'm starting to say no now because it's just getting too much every time—there's like a wee breakfast club on...I just go no, and go have my Weetabix. There's a bit of a difference going on in cheering your life up isn't there? (P5) - I don't even really understand how I'm still working in an office, because it's astounding the pressure I have to go through every day, to get through my day. And all along I'm going, "am I going too low, going too high?" (P5) - It's a time bomb—you can have Type 2 diabetes before you even have symptoms so the damage is already done before you even know. (P7) - I just get on with it to tell you the truth. At the end of the day, if you've got it, you've got it...I think along with the rest of the health problems I just take it in my stride to tell you the truth. I do get a bit upset sometimes about it, but nothing much really—just "what has to be has to be" and that's it really. (P3) - I try and think of people who are very, very ill in hospital and would love to eat something, and I'd say to myself well now there people who wouldn't mind having a sensible salad sandwich and they don't even have that choice. Sometimes you need to give yourself a bit of a jolt. (P4)
<p>Partners</p>	<p>Feeling responsible</p>	<p>Responsible for partners diabetes self-care</p>	<ul style="list-style-type: none"> - I'm very methodological about it, but it would take you to do it, you go into the doctor and trying to remember things, when you took things and everything. It's like when you asked when she was diagnosed, you'd need to have it written down. Well, I think it's always at the back of your mind, the

	Need for greater involvement	Want to know how to help; feel unable to help	<p>diabetes. You don't want the sugars going haywire. (Partner6)</p> <ul style="list-style-type: none"> - I'm not demanding everyone flock around me—all I want is someone to come along to explain things... Everything that flies through your head cause' you've maybe seen it on the TV or some diabetes people losing legs and stuff like this here and all this goes through your head. (Partner6)
All participants	Self-care struggles	Struggles with medication	<ul style="list-style-type: none"> - I handed the tablets back and said they aren't doing me any good- making me feel sick. I was taking a lot of blood pressure tablets, and tablets for my diabetes, and taking tablets to counteract the tablets, and you get into this cycle, and at one stage I was taking 13 tablets a day. (P2) <p style="text-align: center;">***</p>
		Partners' recognise the challenges of insulin use	<ul style="list-style-type: none"> - first time we went to the nurse, she saw us very quickly, she didn't have much time. And she handed us this testing kit—didn't even open it. (Partner1) <p style="text-align: center;">***</p>
		HCPs' recognise the emotional impact of self-care	<ul style="list-style-type: none"> - You find that with weight also sometimes if they've been doing everything they can do but are still stuck. (HCP2)
	Perceived need for appropriate psychological support	People with Type 2 diabetes feel that non-medical support from HCP is sometimes lacking	<ul style="list-style-type: none"> - Your kinda left on your own, like I just get on with it now, but I see your man now every 6 months now, just in between, but if there's anything wrong well you can always just go down to the doctor or the nurse or something, you know? But nobody is really that interested to be honest with you, I mean I find that. You know, that's there, just go and do that and go on like, don't come back, you know what I mean? Not really asking properly how ya are. (P6)
		People with Type 2 diabetes feel that family support is sometimes absent	<ul style="list-style-type: none"> - My partner wouldn't really have a good understanding of my diabetes, no, but you see he has a lot of other health complications to deal with. (P7) <p style="text-align: center;">***</p>
		Partners need greater psychological support	<ul style="list-style-type: none"> - If you could talk to someone, even on the phone and for them to be like yeah well this is how we would deal with that and couple's groups getting together and just discussing how they're getting on with it and dealing with things day to day would be very beneficial. Somewhere you can get things off your

	<p>HCP recognise the need for psychological support from people working in healthcare</p> <p>HCP recognise the benefits of psychological support</p> <p>Psychological support would be appropriate post-education</p> <p>Emotional distress may prevent diabetes education attendance</p> <p>HCP recognise the need for psychological support from family</p>	<p>chest and so on. (Partner3)</p> <p>***</p> <ul style="list-style-type: none"> - It's usually around the anger about believing they have it, and the way they have been informed they have it because how that information has been passed onto them if they are not in the right frame of mind to deal with it can really affect them. (HCP4) - the main thing is having the opportunity to talk to someone who is non-judgemental and who is not a family member...When they come to our clinic they can be afraid that we are going to scold them for not having good enough blood sugars—so just the opportunity to talk to somebody. (HCP7) - they've so much information to take it at the time they're diagnosed. So post-education probably. (HCP7) - But then you're going back to the high level of DNA [did not attend] there, there people who are probably emotionally distressed. (HCP4) - I think maybe if family could be involved more it would help, sometimes they listen to their family better, and that's someone they trust. (HCP5)
<p>Healthcare providers</p>	<p>Perceived professional barriers to psychological support</p> <ul style="list-style-type: none"> - Language and terminology - Facilitating psychological support 	<p>Issues with terminology associated with mental health</p> <p>Diabetes Specialist Nurses have relevant interpersonal skills and insights to address psychological issues</p> <ul style="list-style-type: none"> - It's their own health beliefs, and everyone is so individual, how they've been brought up, and some will bury their head in the sand and they'll say well I'll not admit to that because that's admitting failure. (HCP4) - Perhaps with the type of distress you are talking about then it would be the Type 2 diabetes educators who would need to deliver this intervention, along with the appropriate training for that intervention. They would be wearing the two different hats so to speak—so as a diabetes specialist and educator but also for the emotional distress, the worries and so on that come up for people. (HCP4)

	<p>Perceived lack of skills/confidence to address psychological issues</p> <p>No time to address diabetes distress</p>	<ul style="list-style-type: none"> - I would have thought it would have been a psychologist or a counsellor of some sort, someone who had training, whereas if you'd thrown me into that I wouldn't have a clue what to say, definitely. So I think you need someone with a bit of training or something behind you surely. (HCP1) - we do usually bring it up at the beginning [during DESMOND] and then thread it through the programme, but getting time to actually address it in detail, and then when things come up is limited, you're restricted to a degree . But we do see it sometimes when one person opens up then what happens is sort of a ripple effect where everybody does, and there isn't really time to support that sometimes. But it's such an important aspect of diabetes. (HCP3)
--	--	--