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Being the supporter: an interpretative phenomenological analysis of the role of caregivers in the self-management of type 2 diabetes

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ABSTRACT

Objective: Social support is key in improving the care and self-management of people living with Type 2 Diabetes (T2DM). Despite the benefits of social support, limited research has explored the experiences of family members acting as caregivers for those living with T2DM.

Design: This qualitative study explored the pressures, attitudes, and views of immediate family caregivers supporting a relative's self-management of T2DM.

Methods: Five online semi-structured interviews were conducted with caregivers and analyzed using Interpretative Phenomenological Analysis. Results: This analysis presents two superordinate themes: Values within caregivers and Support for the Supporters. Participants shared stories of coping and resilience in adopting a duty of care to support their family members. However, they also highlighted a lack of support from healthcare professionals, increasing feelings of personal responsibility and loneliness when caring for their family, including further pressures during the UK COVID-19 lockdown periods. Although caregivers do not have T2DM themselves, the burdens of supporting can have detrimental effects on the psychological health of these individuals.

Conclusion: Healthcare professionals should consider the needs of caregivers, specifically improving psychological health and increasing understanding of T2DM, which may also improve health-related outcomes for the person living with T2DM.

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Introduction

Social support is defined as a psychological sense of belonging and acceptance, which increases people's ability to cope better with stressful situations, and often refers to a person's social network, including family and friends (van Dam et al., 2005). The World

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Health Organization (WHO) states that for adequate care provision for chronic health conditions, the individual with type-2 diabetes (T2DM) and their family must play an active role (World Health Organisation, 2002). Therefore, interventions incorporating families into healthcare activities have positively impacted patients' self-management, such as those living with T2DM (Baig et al., 2015; Felix et al., 2019; Withidpanyawong et al., 2019). Overall, evidence suggests that engaging family caregivers in the treatment of patients with T2DM improves self-management effectiveness and the patient's health (Chan et al., 2020; Rajkumar, 2020). Social support has been associated with reduced psychosocial symptomatology, better adaption of beneficial lifestyle activities (Strom & Egede, 2012) and greater glycaemic control (Stopford et al., 2013). However, the type of family member providing support could depict the type of care the person with T2DM receives, specifically married partners often share the same habits and lifestyle and view illness-related distress collectively as 'ours' instead of 'yours' or 'mine', and therefore family members often join together in T2DM management efforts (Seidel et al., 2012). In addition, the quality of care can also be affected by the gender of the supporter; for example, female spouse caregivers, compared to male caregivers, implement specific care in dietary-related support, a key aspect of diabetes management (Sandberg et al., 2006). Observational studies (Albanese et al., 2019) have further shown that women patients with male spouses have reported receiving little overall support. All family members can play a key part in supporting patients to take medicines on time, supervise healthy diets, and encourage physical activity (Gu et al., 2017), and social supporters can buffer the impact of negative psychological consequences related to the disease (Onu et al., 2022; Ramkisson et al., 2017).

Although social support in long-term conditions is increasingly perceived to be a cornerstone to care, these individuals are largely unrecognized members of the healthcare team (Griffin et al., 2012; Nucera, 2016). Furthermore, providing care for extended periods can negatively impact a caregiver's health (Conde-Sala et al., 2010; Figueiredo, 2017; Pearlin et al., 1990). In relation to T2DM, the limited evidence examining the psychological burden of support on caregivers suggests that the effects of caregiving can result in higher rates of depression, poorer quality of life (Anaforoğlu et al., 2012), and increases in stress over time (Costa et al., 2018). Moreover, caregiver stress can be further intensified by factors such as the type of family relationship between the caregiver and person with T2DM, the amount of care the person requires, and the individual's cognitive processes evaluating the condition and coping (Schulz & Eden, 2016). In addition, it is noteworthy that although interventions examining family functioning show promising results, many interventions lack information about how family members support self-management behaviours (Pamungkas et al., 2017). More knowledge is needed to enhance the potential of the social network to improve diabetes-related care (Thirsk & Schick-Makaroff, 2021). To our knowledge, although much qualitative research focuses on the patient's perspective (Fink et al., 2019; Hernandez et al., 2020; van Smoorenburg et al., 2019), there is limited evidence examining in-depth accounts of how those offering social support are supported to assist patients with T2DM and how they are affected by it (Luciani et al., 2021). Thus, to understand these experiences better is to seek an 'insider perspective' (Conrad, 1987) and explore the lived experiences of these individuals. During this project, it was recognized how the current COVID-19 pandemic had affected day-to-day life

(Haleem et al., 2020), and the impact of the UK lockdown and ongoing COVID measures have been widespread, impacting both clinical and psychosocial aspects of those with long-term conditions (Extance, 2020). Further, the social isolation measures used to combat the spread of COVID-19 have reduced many patients' access to social support, with shielding increasing in individuals experiencing general and diabetes-related distress and loneliness. This, in turn, saw a negative effect on disease management (Fisher et al., 2020). Thus, investigating the effects of COVID-19 on social support is imperative for improving the self-management of T2DM as we approach the end of the pandemic and can also provide all-important knowledge on the additional pressure caregivers have experienced during this time.

The present study examined the experiences of family who support people diagnosed with T2DM. The specific aims were to (a) explore the experiences, attitudes, and views of caregivers, (b) examine how families are encouraged to support people with T2DM, and (c) understand any additional pressures or experiences that the COVID-19 pandemic has had on the support they offer.

Methods

Design

Interpretative phenomenology analysis (IPA) is a qualitative approach allowing particularly rigorous explorations of subjective experiences and social conditions (Smith, 1996). IPA views individuals as experts on their own experiences who can offer researchers an understanding of their thoughts, commitments, and feelings, particularly when every day becomes significant (Reid et al., 2005). Moreover, the method has been used to explore the experiences of patients living with T2DM (McKenzie et al., 2016). Thus, IPA was considered the most valuable approach to more deeply understanding the experiences of those supporting individuals with T2DM.

Sampling and recruitment

Following ethical approval (Liverpool John Moores University; granted 9th Feb 2021), participants were recruited through the general population *via* social media adverts. Participants were eligible if they were over 18 years old and did not have a diagnosis of diabetes (any type) and were supporting or living with someone else diagnosed with T2DM. Participants made direct contact with the researcher *via* email; nine participants initially engaged in online correspondence, and five agreed to follow up and participated in an online interview. We conducted this study on a small homogeneous sample, suitable for Interpretative Phenomenological Analysis (IPA), focusing on the role of caregiving in the immediate family, which included three women and two men. This small sample size aligned with the IPA approach, which aimed to examine these particular participants' experiences in-depth (Pietkiewicz & Smith, 2014).

Table 1 shows the participant's details and relationships with whom they support. Three participants were spouses, and two cared for a parent of those living with T2DM. The years of providing support varied between participants, ranging from two years up to twenty years.

Table 1. Details of participants and relatives for whom they support.

Participant	Gender	Relationship to patient	Years since T2DM diagnosis
Participant 1 (P1)	Female	Wife	20 years
Participant 2 (P2)	Female	Daughter	12 years
Participant 3 (P3)	Male	Son	8 years
Participant 4 (P4)	Female	Wife	2 years
Participant 5 (P5)	Male	Husband	10 years

Materials and data collection

The study employed semi-structured interviews, conducted between March–May 2021 (Smith et al., 2009). The interview questions were inductive and flexible, allowing participants to give detailed recognition of their experiences without the researcher making assumptions. Before the interview, the researcher and participant discussed their participation and the consent process, followed by a general chat about the research aims. This discussion was used to settle the interviewee, normalize the process of participating in an online research interview and build rapport. The interview was structured in three parts: Part one asked participants for general information to understand their position as a caregiver and the person with T2DM whom they supported. Part two explored their attitudes and experiences. For example: ‘How does living/supporting someone with T2DM influence daily living at home?’; ‘Please tell me about your experiences’. Part three asked questions about their role in offering support, what advice they had received, and if COVID-19 had affected the social support they offered. For example: ‘What type of support should be offered to the person with T2DM and for you? Why?’; ‘Do you feel any additional pressures when supporting the individual due to the ongoing COVID-19 pandemic? What has happened?’ Prompts such as ‘How did this make you feel’ and ‘How did you cope’ were used to enhance the richness of the responses throughout. Questions were worded following the participant’s language used, and the flow of the interviews varied, depending on the individual participant’s responses (Alase, 2017). All interviews were conducted online and lasted between 30–40 min. The digital recordings of the interviews were transcribed verbatim, and original names were replaced with pseudonyms.

Analysis

Data were analyzed using IPA (Smith et al., 2009). Initially, the author (JB) read the transcripts multiple times, drawing on her thoughts to gain a reflective engagement with the participant’s accounts. During this process, the researcher made notes relating to anything within the text that seemed significant or interesting. Subsequently, coding for meaning, similarities and differences was highlighted on each transcript, and themes were noted once completed. As IPA follows an idiographic approach (Smith, 2004), each case was considered singularly for themes before moving to another. The themes generated at this stage reflected the researcher’s interpretation and the participant’s original words, and the establishment and reliability of these themes involved the analytical process of abstraction, polarisation, numeration, and function (Smith et al., 2009). Researcher triangulation (Heale & Forbes, 2013) occurred between authors throughout the analysis and during the write-up of this article,

which promoted rigour in the quality of the analysis conducted (Reynolds et al., 2011). This triangulation included critical reflexivity serving as a mini audit (Smith et al., 2009) and enhanced transparency. The corresponding author (LN) was a female Registered Health Psychologist with expertise in qualitative methodology, research interests, and clinical expertise in diabetes. The second author (JB) was a female Health Psychologist in Training with research interests in diabetes and cardiovascular disease and employed as an NHS Well-being Practitioner. The third author (SD) was a female Registered Health Psychologist with research interests and clinical expertise in long-term health conditions.

Finally, themes were reviewed and checked for similarities, discrepancies, and patterns before being reorganized to produce superordinate themes. Within the analytical text, a range of participant quotations are selected to offer a detailed example of a theme or because the extract portrayed the pattern of a recurrent theme across the participants; brackets after quotes indicate the participant as referenced in Table 1. Due to the nature of this qualitative research, in line with legal and ethical approval, participants of this study did not agree for their full transcripts to be shared publicly, so supporting data beyond the sample quotation extracts is not feasible.

Results

This analysis presents two superordinate themes: 1. Values within caregivers, and 2. Support for the Supporters, and five subthemes, bringing together the most crucial data from the participants. Figure 1 depicts how the themes link and inform each other.

Values within caregivers

The overarching theme of 'Values within caregivers' consisted of two subthemes: 1.1 Positive-focused Coping, and 1.2 Duty of Care. These subthemes reflect the researcher's understanding of the participants' inherent strengths and coping strategies, which extend beyond supporting family members with T2DM. Additionally, they encompass participants' relationships with their loved ones and their individual challenges.

Positive-focused coping

A common coping mechanism from all participants was the ability to build resilience through a positive mindset. For example, some participants showed adaptability to their situation, and others avoided discussing negative emotions. Several participants highlighted how the situation could be worse: 'There are worse diseases than diabetes' (P2 F).

However, participants found comfort in comparing T2DM to arguably more life-threatening diseases:

It's not like it was stage 4 cancer, so I thought, OK, this is the problem. How are we going to fix it...I mean, it's not terminal cancer. (P3 M)

The words emphasize the participant's bravery towards the situation and strong eagerness to be a good caregiver, and a desire to normalize the condition.

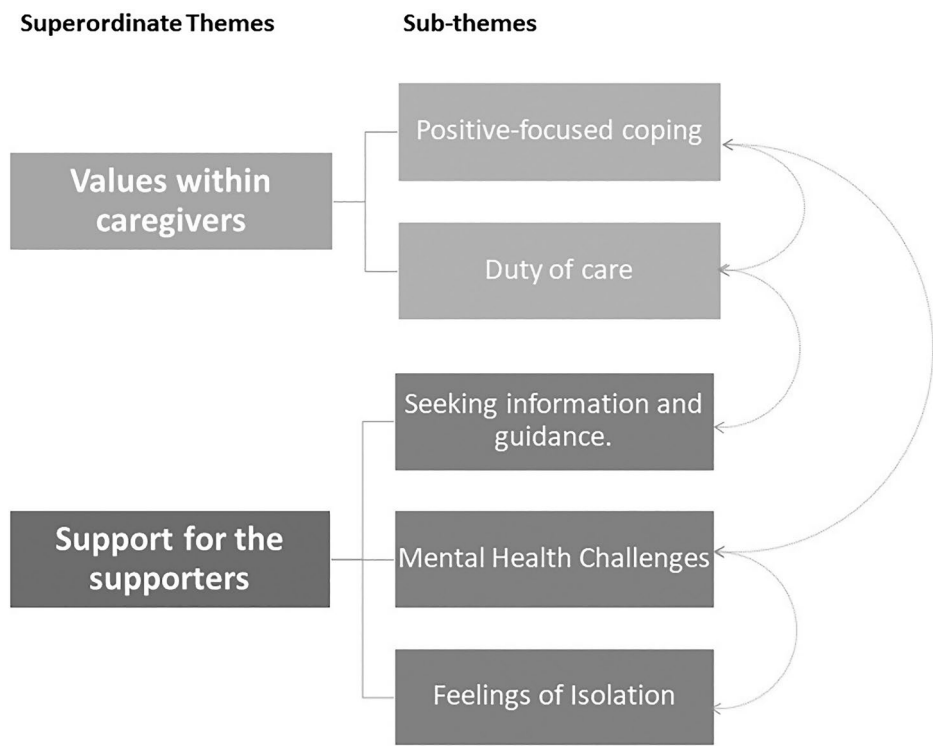


Figure 1. Representation of Thematic Analysis

Further, the participant’s view that diabetes can be fixed reinforces the idea that diabetes is manageable, less severe, and therefore less troublesome than cancer. Interestingly, participant 3 was the most relaxed when it came to discussing caregiving and the challenges it causes, and therefore the repetitive downward comparison to another long-term disease could be his way of justifying his casual attitude, making him feel better about his father’s ill health, and in turn, feel comfortable with the idea of providing support. Nonetheless, their positive attitude shows adaptability and strength towards the situation and highlights the values of compassion and care they have for their loved one.

Participants also maintained their interpretation of T2DM as an opportunity and embraced lifestyle change as a positive experience.

We have not changed anything greatly, just healthier. To be honest, I get him to now eat vegetables *laughs* you would never have heard of that before. We’re just trying to see it as a fresh start, learn from past mistakes, and trying to take it from a positive point of view (P4 F)

The participant has not always lived such a healthy lifestyle, and the apparent ‘fresh start’ indicated T2DM had a real impact and allowed the supporter to view the diagnosis as an opportunity and motivation to change. Moreover, the words ‘get him to now eat vegetables’ emphasize the key role and the participant’s passion for self-management of her husband’s T2DM. Further, the laughter shows the researcher that she feels self-satisfied and happy with the improvements she has made for herself and her husband’s health.

Duty of care

This theme explores how participants perceive their role in supporting their family members with the condition. While all participants showed passion and commitment towards assisting T2DM self-management, it was evident that those participants who supported their marital partner showed a greater sense of responsibility to care:

I don't know, erm almost like it was my responsibility to make him feel better, and if I couldn't, then I failed. It was a hard time, and I feel like I need to be the fixer. He never puts this pressure on me, by the way, I just don't know. Perhaps it's in my nature to be this way; it's what you sign up for in marriage, isn't it (P4 F)

The participant feels responsible for her husband's health and seems to take a natural and, what seems, necessary role. Her use of the words 'failed' and 'fixer' emphasizes her drive to adapt to the situation and suggests that she sometimes feels concerned that she cannot ease her husband's discomfort. Further, her idea of what marriage means is highlighted in the passage; the words 'sign up' emphasize the idea of commitment to being a caregiver and that it is their absolute responsibility to support their spouse. In addition, there was a sense of uncertainty and frustration as the words 'hard time' portray that the participant recognized the challenges encountered in her role as caregiver.

I didn't (laugh); no I mean I did, I had to. There are worst diseases than diabetes. I have to be the strong one to help her through her bad days. It's tough, but I wouldn't have it any other way (P2 F)

The participant found it hard to discuss the negative experiences they experienced and found it necessary to give a positive outlook. Furthermore, the passage gives a real sense that she navigated herself alone by supporting her mother and had grown from the challenge. The participant's emphasis on 'I had to' suggests a personal responsibility towards caring. Furthermore, the choice of language, 'be the strong one' and 'wouldn't have it any other way', also suggests resilience which helps the participant feel efficient and in control of the situation. Additionally, the laughter implies that she needed to make light of the situation, which helps her feel more comfortable speaking about her emotions and highlighting the difficulty.

Participants reported feelings of added pressure, not just with supporting the management of T2DM but in seeing themselves as having to protect their loved one from catching COVID-19:

It kept me awake at night at first, when we didn't understand entirely what COVID was. I thought it was a death sentence (P4 F)

Although it was apparent, there was a strong supportive relationship between caregiver and patient. It was evident that some found it challenging to discuss T2DM as a family:

We don't necessarily sit there and discuss her condition anymore ...it ends in arguments...I think she thinks that it's her condition and her problem, and sometimes I don't say the right thingand then it ends in a row, and things and then other things get thrown in...just other problems...nothing major...so I just don't bring it up (P5 M)

A mismatch in understanding and communication has caused friction between the family members. The use of 'anymore' suggests previous conversations about the self-management of T2DM have not been resolved; it implies that the caregiver wants to support their partner and provide care, but overall the role of having a shared responsibility has not been addressed. Further, the long pauses within the passage emphasize distress over the unwanted barriers between the individual and their spouse.

Support for the supporters

The superordinate theme of 'Support for the supporters' comprised three subthemes: 2.1 Seeking information and guidance, 2.2 Mental Health Challenges, and 2.3 Feelings of Isolation. While participants shared insights into their effective ways of supporting their family members and their inherent caregiving values, they also acknowledged experiencing personal isolation and recognized an amplified requirement for their own support.

Seeking information and guidance

Although participants shared resilience and caregiving abilities, all admitted that they experienced a lack of understanding of the best support for their family member with T2DM. The need for expert guidance was strongly apparent in all interviews, with participants stating they had not received sufficient information about T2DM as a disease, the self-management involved in this, and how to provide support best:

The nurses make me feel that not much else can be done; you know, they seem to run out of ideas (P1 F)

Participants reached out to healthcare providers and, in return, received inadequate information. The words 'not much else can be done' give a sense that the supporter is close to giving up on the healthcare system regarding her husband's health. Further, the passage also suggests that practitioners lack engagement in caregivers' needs and feelings, as the phrase '*run out of ideas*' emphasizes how isolated and alone the individual felt in the caregiving process. The struggle for expert advice is also echoed by Participant 2, who discussed new found practical self-management knowledge, but this information did not come from a professional source:

That information about cutting out her carbs didn't come from her nurse or anything it came from a friend, and she only has, I think....one appointment annually...annually it makes me cross. It's a lifetime condition, and she's only been seen by a professional once a year. (P2 F)

The participant felt angry, and there is a sense that this anger stems from the participant being upset about the apparent disinterest and insufficient information from professional sources. The repetition of 'annually' emphasizes their frustration and perhaps even desperation for practitioners to be more attentive. Most participants described similar frustrations:

Yeah, of course...I don't understand why I didn't. It doesn't make sense. Surely the people you live with who see the condition day in day out need just as much information (P3 M)

Mental health challenges

The psychological stress that comes with managing T2DM was acknowledged, and participants flagged how more support would be helpful for both the person with T2DM and his/her supporter:

The importance of mental health has blown up recently, I am sure you know all about that, but I am not sure if there's a lot for people with diseases who suffer or people like me who look after them and sometimes need some guidance, yeah (P5 M)

Participant 5 expresses uncertainty about whether sufficient support or resources are available specifically for people living with T2DM who suffer from mental health issues or for caregivers like themselves who require guidance and support. Specifically the word 'suffer' implies that both the loved one with T2DM and the caregiver have struggled with the psychological stress of T2DM, and both are at a disadvantage due to insufficient guidance. This lack of support for the psychological stress of T2DM is further reiterated by Participant 1, who expressed that the stress of caregiving resulted in her taking antidepressants periodically over the last 20 years:

We're very lucky that we do get on, but erm, I must admit I've ended up on erm sertraline (P1 F)

This extract also highlights that the caregivers may suffer from psychological comorbidities, suggesting that those in the presence of a patient endure similar negative consequences for long periods.

Feelings of isolation

Although participants acknowledge that they were the ones supporting a family member with T2DM, they were very much alone throughout this process:

The hardest part that affected me was finding the time to actually learn about diabetes on my own. Looking after Mum doesn't affect me at all. She's my mum, but feeling like you're on your own when there is meant to be help out there ...that's where the problem lies. (P2 F)

Participant 2 was committed to offering her mother ongoing support but suggested the extensive time and effort required to understand T2DM has been challenging. The repetitiveness of similar words, such as 'on my own' and 'feeling like you're on your own', emphasizes how isolated the participant felt and suggests the little guidance she received from professional sources.

The impact of COVID-19 on feelings of isolation and emotional distress was also highlighted for participants and their family members:

Well, he keeps getting letters telling him to isolate, and yes, that is really starting to get him down now, and he's not seeing the family. It's difficult as it does affect me. He's been really down because of it all, and of course, I am around it all the time, so seeing him down does affect me. How could it not? It's just all about taking each day as it comes (P1 F)

The passage reinforces the idea that caregivers suffer significantly from the emotional effects of living with and caring for a patient with a disease. The participant's

willingness to admit she has struggled, coupled with the repetition of the words 'affect me', emphasizes that emotions were heightened due to COVID-19 lockdown measures. However, it is interesting to note that the participant finished with the phrase 'taking each day', also reinforcing the idea that she needs to stay positive in order to cope further and perhaps implying that COVID-19 is one of the many hurdles she has faced in caregiving over the last 20 years.

Discussion

This study explored how family caregivers played a role in providing social support to patients with T2DM and focused on their lived experiences, attitudes, and views in being that supporter. Overall, this research concurs with previous research on the importance of social support in the self-management of T2DM. However, the findings also suggest a deeper meaning, highlighting the impact of disease on family members who act as social supporters. Specifically, although the participants do not suffer from T2DM, they have taken on many of the responsibilities and emotions of the illness. Further, there was a real sense that these individuals were so accustomed to being supportive that they often felt guilty and reluctant to discuss the negative impacts the disease has caused. Previous research on spillover effects found that family members experience emotional and psychological effects from having an ill relative (Wittenberg et al., 2013).

Moreover, whilst other qualitative research broadly focuses on the importance of social support, to our knowledge, the present research is one of the first to use IPA to explore the feelings of social supporters, and the current findings add a closer analysis of the effects of inadequate knowledge. Lack of information and professional guidance was highlighted when participants discussed their insight into the basic requirements of T2DM self-management; they felt that there was a lack of guidance and support regarding the emotional distress associated with living with T2DM. The increase in emotional distress and emphasis on personal responsibility is evidenced by the participants expressing loneliness, worry and stress relating to living with someone with T2DM. The findings further support other long-term conditions studies, which found that constant anxiety about a patient's health can be exhausting for the relatives and result in emotional problems (Garcia-Sanjuan et al., 2019).

This research was conducted during the COVID-19 pandemic, and it was apparent that participants' emotions, perceptions and recognition of T2DM were heightened. In addition to stress, many expressed added pressure, supporting the ongoing self-management requirements and wanting to protect their family member with T2DM from a severe infection linked to COVID-19. The present research is one of the first to explore the feelings of social supporters during the COVID-19 pandemic and builds upon present literature that found that people of risk groups report higher levels of fear and worry due to the virus (Bauerle et al., 2020; Forte et al., 2020; Rajkumar, 2020). Moreover, shielding throughout the COVID-19 pandemic reduced social contact, and the constant fear of becoming infected psychologically impacted the well-being of patients and, in turn, impacted the caregiver's emotional state. Although much research has focused on patients with T2DM (Mukhtar, 2020), there

are few investigations on the effects COVID-19 on caregivers. Thus, the results suggest that further research on the psychological spillover effects the COVID-19 pandemic has had on caregivers is needed.

As one of the first studies to use an in-depth approach to understand the experiences of T2DM social supporters, it was very apparent that the results indicated that caregivers' sense of resilience was an internal protective factor in coping with being a social supporter. Resilience can be defined as the force that drives a person's ability to grow through adversity and upheaval and is also known as the ability to bounce back and overcome challenges (Rutter, 1985). This 'bounce back' mentality was evidenced by participants' need to react positively to the negative and stressful experiences of living with someone with a T2DM diagnosis. Previous evidence on long-term conditions suggests that recognizing positive aspects in the informal care of patients can create a sense of meaning for supporters, allowing individuals to gain satisfaction from it and better adjust to a patient's illness (Semiatin & O'Connor, 2012). In the current study, some participants commended how self-management strategies such as improved diet and exercise positively impacted the patient and the family's health.

Additionally, it was apparent that resilience helped justify the lack of engagement from healthcare professionals, as some felt the need to downplay the severity of diabetes, such as those who repetitively made downward comparisons to cancer. These findings somewhat reflect Festinger's Social Comparison Theory (Festinger, 1954), that individuals make social comparisons when there is unpredictability about an aspect of their life or due to the inadequacy of objective information and thus again reinforces the idea that caregivers need more guidance and instruction. Nevertheless, resilience can be seen as a positive psychological process that reduces the adverse effects of a stressor (Hornor, 2017), and the present study complements the ever-growing body of evidence on resilience in the context of caregiving (Palacio et al., 2020). The findings emphasized the strong relationships between the patient and caregiver, and it was evident that those who offered spousal support showed a stronger duty of care than others (Cash et al., 2019). Nevertheless, it should be noted that those who shared a filial relationship also expressed great care. The present research highlighted that all participants viewed being a caregiver as an obligation, but many seemed to struggle to openly discuss the condition and its impacts as a family. It was evident that disagreements came from confusion and uncertainty as participants spoke about how divergent views on managing T2DM led to family arguments. Previous literature suggests disruptive family behaviour, such as bickering about diet and exercise regimes, are barriers to a patient's effective self-management (Mayberry et al., 2014) and can pose added difficulty for the caregiver (Bertschi et al., 2021).

Alongside these feelings of responsibility in caregiving for family members, many felt let down by the support offered by healthcare staff, potentially enhancing this personal expectation to provide care. Recommendations from the National Institute for Health and Care Excellence (NICE, 2015) state that structured education to adults with T2DM and their family members should be offered at the time of diagnosis and followed by reinforcements and review. However, at no point did these social supporters acknowledge any help to understand their role of being a supporter. All participants illustrated a desperate need for expert guidance. There were frustrations

with the lack of knowledge and guidance provided; despite expressing willingness to attend and engage with the patient's T2DM appointments or social support guidance, most had never been invited or included. These results are somewhat discouraging as it suggests that best practice advice (Felix et al., 2019; Withidpanyawong et al., 2019) highlighting the importance of interventions that encourage family involvement in self-management is not being implemented.

Implications for practice and Future research

Future research needs to understand and consider the impact that T2DM has on families and how adopting a supporter role may impact an individual's health. This research suggests that limited knowledge and skills hinder the quality of social support available and may contribute to increased psychological stress for both the caregiver and the person living with T2DM. The present findings suggest that the spillover of disease can cause those providing support to suffer alone, psychologically. The thoughts, feelings and behaviours of these individuals should be considered by healthcare and support providers not necessarily just as caregivers but also in their well-being and day-to-day life. Clinicians offering support to families should also be aware of caregivers' reluctance to discuss the psychological burden T2DM has on themselves and be reassured that the stress and spillover effects they feel should be accounted for. Diabetes services and health professionals need to review how they include family members within their education, guidance and review appointments, and assess how they align to best practice recommendations regarding family inclusion and facilitating social support (NICE, 2015).

Strengths and limitations

IPA is unique to other qualitative methodologies in that it is concerned with the particular rather than the universal in an experience. Adopting an idiographic approach facilitated insight into the attitudes and values of T2DM social supporters. In addition, the nature of IPA allowed rich, in-depth explorations of the lived experiences, and uniquely, the present study was one of the first to offer an important understanding of participant perceptions as reflected on during the COVID-19 pandemic. Moreover, the study demonstrated the need to broaden T2DM health management to include the caregiver's needs and further provided valuable results that highlighted the call for interventions to improve education for healthcare professionals and caregivers. The recruitment approach for this research utilized an open call to recruit all caregivers to this study. However, the number of people who came forward to participate was limited only to family members and may indicate the limited acknowledgement that caregivers receive in this role (Griffin et al., 2012; Nucera, 2016). As such, following IPA methodology, this research explored the experiences of a specific homogenous family sample, and this sample only included people of white ethnicity from Northwest England. Hence, the findings may not reflect all caregivers' cultural and demographic diversity. Further, the rapidly changing situation regarding the COVID-19 pandemic may not have been fully captured within a single interview with each participant, so

the fluidity of a carer role may benefit from further longitudinal data. Finally, it is noteworthy that IPA research applies a double hermeneutic perspective and reflects the researcher's understanding and interpretations of the participant's experiences (Smith et al., 2009). The researchers acknowledged their personal and professional experiences offering clinical support, research expertise and their social and cultural context of the role of caregivers for T2DM. For example, one of the authors reported a caregiving role to a family member with T2DM; another author acknowledged her caregiving role to her spouse but not for T2DM. Hence throughout this research methodology and analysis, the researchers engaged in reflective practice and supervisory discussions to acknowledge possible (mis)interpretations of data.

Conclusions

The findings contribute to evidence of the experiences of T2DM social supporters. The detailed and idiographic analysis has provided insight, illuminating some of the challenges supporters face and demonstrating that limited guidance from healthcare professionals can negatively affect the quality of life in both caregiver and patient. The present study found evidence to suggest that more support for caregivers is imperative for the health and well-being of these individuals, and implementing interventions that focus on the needs of caregivers will benefit both the patient and supporter. Moreover, it is recommended that interventions focus on educating and improving communication between practitioner and caregiver. Additionally, the findings support the use of this qualitative methodology in further understanding the needs of family members of patients living with T2DM.

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Author contribution

Lisa Newson: Conceptualization, Methodology, Resources, Recruitment of Participant Strategy, Validation, Formal Analysis, PPI Data Curation, Writing- Original, Writing- Review & Editing, Visualization, Supervision. Jessica Brown: Conceptualisation, Methodology, Recruitment of Participants, Data Curation, Formal Analysis, Writing- Original. Stephanie Dugdale: Formal Analysis, Data Contribution, Supervision, Writing- Review & Editing.

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Data availability Statement

Raw data has been included as evidence *via* extracted quotes from verbatim transcripts as samples of evidence. Full transcript release has not received ethical approval or participant consent.

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References

- Alase, A. (2017). The Interpretative Phenomenological Analysis (IPA): A Guide to a Good Qualitative Research Approach. *International Journal of Education and Literacy Studies*, 5(2), 9. <https://doi.org/10.7575/aiac.ijels.v5n.2p.9>
- Albanese, A. M., Huffman, J. C., Celano, C. M., Malloy, L. M., Wexler, D. J., Freedman, M. E., & Millstein, R. A. (2019). The role of spousal support for dietary adherence among type 2 diabetes patients: A narrative review. *Social Work in Health Care*, 58(3), 304–323. <https://doi.org/10.1080/00981389.2018.1563846>
- Anaforoğlu, İ., Ramazanoğulları, İ., Algün, E., & Kutanis, R. (2012). Depression, anxiety and quality of life of family caregivers of patients with type 2 diabetes. *Medical Principles and Practice*, 21(4), 360–365. <https://doi.org/10.1159/000334622>
- Baig, A. A., Benitez, A., Quinn, M. T., & Burnet, D. L. (2015). Family interventions to improve diabetes outcomes for adults. *Annals of the New York Academy of Sciences*, 1353(1), 89–112. <https://doi.org/10.1111/nyas.12844>
- Bauerle, A., Steinbach, J., Schweda, A., Beckord, J., Hetkamp, M., Weismuller, B., Kohler, H., Musche, V., Dorrie, N., Teufel, M., & Skoda, E. M. (2020). Mental health burden of the COVID-19 outbreak in Germany: Predictors of mental health impairment. *Journal of Primary Care & Community Health*, 11, 2150132720953682. <https://doi.org/10.1177/2150132720953682>
- Bertschi, I. C., Meier, F., & Bodenmann, G. (2021). Disability as an interpersonal experience: A systematic review on dyadic challenges and dyadic coping when one partner has a chronic physical or sensory impairment. *Frontiers in Psychology*, 12, 624609. <https://doi.org/10.3389/fpsyg.2021.624609>
- Cash, B., Warburton, J., & Hodgkin, S. (2019). Expectations of care within marriage for older couples. *Australasian Journal on Ageing*, 38(1), E19–E24. <https://doi.org/10.1111/ajag.12590>
- Chan, C. K. Y., Cockshaw, W., Smith, K., Holmes-Truscott, E., Pouwer, F., & Speight, J. (2020). Social support and self-care outcomes in adults with diabetes: The mediating effects of self-efficacy and diabetes distress. Results of the second diabetes MILES - Australia (MILES-2) study. *Diabetes Research and Clinical Practice*, 166, 108314. <https://doi.org/10.1016/j.diabres.2020.108314>
- Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Vilalta-Franch, J., & Lopez-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies*, 47(10), 1262–1273. <https://doi.org/10.1016/j.ijnurstu.2010.03.001>
- Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care*, 6, 1–31.
- Costa, M. S. A., Machado, J. C., & Pereira, M. G. (2018). Burden changes in caregivers of patients with type 2 diabetes: A longitudinal study. *Journal of Advanced Nursing*, 74(10), 2322–2330. <https://doi.org/10.1111/jan.13728>

- Extance, A. (2020). COVID-19 and long term conditions: What if you have cancer, diabetes, or chronic kidney disease? *BMJ (Clinical Research ed.)*, 368, m1174. <https://doi.org/10.1136/bmj.m1174>
- Felix, H. C., Narcisse, M. R., Long, C. R., English, E., Haggard-Duff, L., Purvis, R. S., & McElfish, P. A. (2019). The effect of family diabetes self-management education on self-care behaviors of marshalllese adults with type 2 diabetes. *American Journal of Health Behavior*, 43(3), 490–497. <https://doi.org/10.5993/AJHB.43.3.4>
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7(2), 117–140. <https://doi.org/10.1177/001872675400700202>
- Figueiredo, D. (2017). Caregiving and carer stress. In N. A. Pachana (Ed.), *Encyclopedia of Geropsychology* (pp. 445–455). Springer. https://doi.org/10.1007/978-981-287-082-7_351
- Fink, A., Fach, E. M., & Schroder, S. L. (2019). Learning to shape life' - a qualitative study on the challenges posed by a diagnosis of diabetes mellitus type 2. *International Journal for Equity in Health*, 18(1), 19. <https://doi.org/10.1186/s12939-019-0924-3>
- Fisher, L., Polonsky, W., Asuni, A., Jolly, Y., & Hessler, D. (2020). The early impact of the COVID-19 pandemic on adults with type 1 or type 2 diabetes: A national cohort study. *Journal of Diabetes and Its Complications*, 34(12), 107748. <https://doi.org/10.1016/j.jdiacomp.2020.107748>
- Forte, G., Favieri, F., Tambelli, R., & Casagrande, M. (2020). COVID-19 pandemic in the italian population: Validation of a post-traumatic stress disorder questionnaire and prevalence of PTSD Symptomatology. *International Journal of Environmental Research and Public Health*, 17(11), 4151. <https://doi.org/10.3390/ijerph17114151>
- Garcia-Sanjuan, S., Lillo-Crespo, M., Cabanero-Martinez, M. J., Richart-Martinez, M., & Sanjuan-Quiles, A. (2019). Experiencing the care of a family member with Crohn's disease: A qualitative study. *BMJ Open*, 9(10), e030625. <https://doi.org/10.1136/bmjopen-2019-030625>
- Griffin, J. M., Friedemann-Sanchez, G., Jensen, A. C., Taylor, B. C., Gravely, A., Clothier, B., Simon, A. B., Bangerter, A., Pickett, T., Thors, C., Ceperich, S., Poole, J., & van Ryn, M. (2012). The invisible side of war: Families caring for US service members with traumatic brain injuries and polytrauma. *Journal of Head Trauma Rehabilitation*, 27(1), 3–13. <https://doi.org/10.1097/HTR.0b013e3182274260>
- Gu, L., Wu, S., Zhao, S., Zhou, H., Zhang, S., Gao, M., Qu, Z., Zhang, W., & Tian, D. (2017). Association of social support and medication adherence in Chinese patients with type 2 diabetes mellitus. *International Journal of Environmental Research and Public Health*, 14(12), 1522. <https://doi.org/10.3390/ijerph14121522>
- Haleem, A., Javaid, M., & Vaishya, R. (2020). Effects of COVID-19 pandemic in daily life. *Current Medicine Research and Practice*, 10(2), 78–79. <https://doi.org/10.1016/j.cmrp.2020.03.011>
- Heale, R., & Forbes, D. (2013). Understanding triangulation in research. *Evidence Based Nursing*, 16(4), 98–98. <https://doi.org/10.1136/eb-2013-101494>
- Hernandez, L., Leutwyler, H., Cataldo, J., Kanaya, A., Swislocki, A., & Chesla, C. (2020). The Lived experience of older adults with type 2 diabetes mellitus and diabetes-related distress. *Journal of Gerontological Nursing*, 46(3), 37–44. <https://doi.org/10.3928/00989134-20200129-05>
- Hornor, G. (2017). Resilience. *Journal of Pediatric Health Care*, 31(3), 384–390. <https://doi.org/10.1016/j.pedhc.2016.09.005>
- Luciani, M., Montali, L., Nicolo, G., Fabrizi, D., Di Mauro, S., & Ausili, D. (2021). Self-care is re-nouncement, routine, and control: The experience of adults with type 2 diabetes mellitus. *Clinical Nursing Research*, 30(6), 892–900. <https://doi.org/10.1177/1054773820969540>
- Mayberry, L. S., Rothman, R. L., & Osborn, C. Y. (2014). Family members' obstructive behaviors appear to be more harmful among adults with type 2 diabetes and limited health literacy. *Journal of Health Communication*, 19(sup2), 132–143. <https://doi.org/10.1080/10810730.2014.938840>
- McKenzie, C., Bennert, K., Kessler, D., & Montgomery, A. (2016). The illness-disease dynamic: psychological wellbeing in type 2 diabetes: an interpretative phenomenological analysis. *The Qualitative Report*, 21(5):. 33–951
- Mukhtar, S. (2020). Psychological health during the coronavirus disease 2019 pandemic outbreak. *International Journal of Social Psychiatry*, 66(5), 512–516. <https://doi.org/10.1177/0020764020925835>

- NICE. (2015). *Type 2 diabetes in adults: Management, Guidance*.
- Nucera, A. (2016). An invisible and essential role for the community: The caregiver. *International Journal of Stroke*, 11, 293.
- Onu, D. U., Ifeagwazi, C. M., & Prince, O. A. (2022). Social support buffers the impacts of Diabetes distress on health-related quality of life among type 2 diabetic patients. *Journal of Health Psychology*, 27(10), 2305–2317. <https://doi.org/10.1177/1359105320980821>
- Palacio, G. C., Krikorian, A., Gomez-Romero, M. J., & Limonero, J. T. (2020). Resilience in Caregivers: A Systematic Review. *American Journal of Hospice and Palliative Medicine*®, 37(8), 648–658. <https://doi.org/10.1177/1049909119893977>
- Pamungkas, R. A., Chamroonsawasdi, K., & Vatanasomboon, P. (2017). A Systematic Review: Family Support Integrated with Diabetes Self-Management among Uncontrolled Type II Diabetes Mellitus Patients. *Behav Sci (Basel)*, 7(4), 62. <https://doi.org/10.3390/bs7030062>
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583–594. <https://doi.org/10.1093/geront/30.5.583>
- Pietkiewicz, I. S., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Czasopismo Psychologiczne Psychological Journal*, 20(1), 14 <https://doi.org/10.14691/cppj.20.1.7>
- Rajkumar, R. P. (2020). COVID-19 and mental health: A review of the existing literature. *Asian Journal of Psychiatry*, 52, 102066. <https://doi.org/10.1016/j.jap.2020.102066>
- Ramkisson, S., Pillay, B. J., & Sibanda, W. (2017). Social support and coping in adults with type 2 diabetes. *African Journal of Primary Health Care & Family Medicine*, 9(1), e1–e8. <https://doi.org/10.4102/phcfm.v9i1.1405>
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *The Psychologist*, 18, 20–23.
- Reynolds, J., Kizito, J., Ezumah, N., Mangesho, P., Allen, E., & Chandler, C. (2011). Quality assurance of qualitative research: A review of the discourse. *Health Research Policy and Systems*, 9(1), 43. <https://doi.org/10.1186/1478-4505-9-43>
- Rutter, M. (1985). Resilience in the face of adversity. Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry: The Journal of Mental Science*, 147, 598–611. <https://doi.org/10.1192/bjp.147.6.598>
- Sandberg, J., Trief, P. M., Greenberg, R. P., Graff, K., & Weinstock, R. S. (2006). He Said, She Said: The Impact of Gender on Spousal Support in Diabetes Management. *Journal of Couple & Relationship Therapy*, 5(2), 23–42. https://doi.org/10.1300/J398v05n02_02
- Schulz, R., & Eden, J. National Academies of Sciences, Engineering, and Medicine. (2016). *Family caregiving roles and impacts. (Families caring for an aging America*. National Academies Press.
- Seidel, A. J., Franks, M. M., Stephens, M. A., & Rook, K. S. (2012). Spouse control and type 2 diabetes management: Moderating effects of dyadic expectations for spouse involvement. *Family Relations*, 61(4), 698–709. <https://doi.org/10.1111/j.1741-3729.2012.00719.x>
- Semiatin, A. M., & O'Connor, M. K. (2012). The relationship between self-efficacy and positive aspects of caregiving in Alzheimer's disease caregivers. *Aging & Mental Health*, 16(6), 683–688. <https://doi.org/10.1080/13607863.2011.651437>
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology & Health*, 11(2), 261–271. <https://doi.org/10.1080/08870449608400256>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39–54.
- Smith, J. A., Flower, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis. Theory, Method and Research*. SAGE.
- Stopford, R., Winkley, K., & Ismail, K. (2013). Social support and glycemic control in type 2 diabetes: A systematic review of observational studies. *Patient Education and Counseling*, 93(3), 549–558. <https://doi.org/10.1016/j.pec.2013.08.016>
- Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. *Current Diabetes Reports*, 12(6), 769–781. <https://doi.org/10.1007/s11892-012-0317-0>

- Thirsk, L. M., & Schick-Makaroff, K. (2021). Family interventions for adults living with type 2 diabetes mellitus: A qualitative meta-synthesis. *Patient Education and Counseling*, 104(12), 2890–2899. <https://doi.org/10.1016/j.pec.2021.04.037>
- van Dam, H. A., van der Horst, F. G., Knoop, L., Ryckman, R. M., Crebolder, H. F., & van den Borne, B. H. (2005). Social support in diabetes: A systematic review of controlled intervention studies. *Patient Education and Counseling*, 59(1), 1–12. <https://doi.org/10.1016/j.pec.2004.11.001>
- van Smoorenburg, A. N., Hertroijs, D. F. L., Dekkers, T., Elissen, A. M. J., & Melles, M. (2019). Patients' perspective on self-management: Type 2 diabetes in daily life. *BMC Health Services Research*, 19(1), 605. <https://doi.org/10.1186/s12913-019-4384-7>
- Withidpanyawong, U., Lerkiatbundit, S., & Saengcharoen, W. (2019). Family-based intervention by pharmacists for type 2 diabetes: A randomized controlled trial. *Patient Education and Counseling*, 102(1), 85–92. <https://doi.org/10.1016/j.pec.2018.08.015>
- Wittenberg, E., Saada, A., & Prosser, L. A. (2013). How illness affects family members: A qualitative interview survey. *The Patient*, 6(4), 257–268. <https://doi.org/10.1007/s40271-013-0030-3>
- World Health Organisation. (2002). *Adherence to long-term therapies*. Evidence for action.