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Having diabetes and having to fast: a qualitative study of British Muslims with diabetes

Neesha R. Patel PhD MSc BSc,* Anne Kennedy PhD BSc SRN,† Christian Blickem PhD,‡ Anne Rogers PhD Acss,§ David Reeves PhD¶ and Carolyn Chew-Graham MD FRCGP**

*Research Associate, Trainee Health Psychologist, ‡Research Associate, ¶Reader, Centre for Primary Care, Institute of Population Health, University of Manchester, Manchester, †Senior Research Fellow, Health Services Research, Faculty of Health Sciences, §Professor of Health Systems Implementation, Health Services Research, Faculty of Health Sciences, University of Southampton, Southampton and **Professor of General Practice Research, Primary Care Sciences, Research Institute: Primary Care and Health Sciences, Keele University, Keele, Staffordshire, UK

Correspondence
Neesha R. Patel PhD, MSc, BSc
Research Associate, Trainee Health Psychologist
Primary Care Research Group,
Institute of Population Health
University of Manchester
5th Floor Williamson Building, Oxford Road
Manchester
M13 9PL
UK
E-mail: neesha.patel-2@manchester.ac.uk

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Abstract

Background There are approximately 2.7 million Muslims in the UK, constituting 4.8% of the population. It is estimated that 325 000 UK Muslims have diabetes. Whilst dietary practices of Muslims with diabetes have been explored, little work has described the beliefs and decisions to fast during Ramadan, whereby Muslims with diabetes refrain from eating, drinking and taking medication between sunrise and sunset.

Objective To explore beliefs and experiences of fasting during Ramadan of Muslim respondents with diabetes and their perceptions of the role played by their general practitioner (GP) and/or practice nurse (PN) in supporting them.

Design Qualitative study.

Setting General practices and community groups located in Greater Manchester.

Participants 23 South Asian Muslims.

Methods Semi-structured interviews were conducted as part of the Collaboration of Applied Health Research and Care (CLAHRC) programme, Greater Manchester. Respondents were recruited using random and purposive sampling techniques. Interviews were analysed thematically using a constant comparison approach.

Results Thirteen respondents reported they fasted and altered diabetes medication and diet during Ramadan. The decision to fast was influenced by pressures from the family and the collective social aspect of fasting, and respondents made limited contact with primary care during fasting.

Conclusion Tensions exist between the respondent's personal desire to fast or not fast and their family's opinion on the matter, with a strong reluctance to disclose fasting to GP and/or PN. Future

research needs to explore whether GPs or PNs feel competent enough to support patients who wish to fast.

Introduction

Diabetes affects 2.9 million people in the UK and is six times more common in the South Asian population and four times more common in the Bangladeshi and Pakistani groups than the general UK population. Recent data suggests that there are approximately 2.7 million Muslims in the UK, constituting 4.8% of the population, and 325 000 Muslims have diabetes in the UK.[1,2] Whilst the everyday dietary practices of South Asian people with type 2 diabetes (T2DM) have been investigated,[3] the regularly made decision to fast and the implications for relationships with primary care professionals has not been a topic of research. Ramadan is important for practicing Muslims, as it is one of the five pillars of Islam and the month in which the holy Quran was revealed.[4] During Ramadan, Muslim people only eat two meals per day, once before sunrise (*sehar*) and one after sunset (*iftar*). Ramadan is a time to celebrate with family, friends and the wider community, and for reflecting on their relationship with Allah and fellow people.[4] Consequently a tension exists for many Muslims with diabetes who wish to observe this important religious ritual in accordance with their faith and the competing need to manage their health. Although the Islamic law states that the 'sick' can be exempt from fasting for one or all 30 days[5], the majority of Muslim respondents with diabetes do not perceive themselves as 'sick' and choose to fast.[6,7]

When Ramadan falls in the summer and spring (as it does for the 8 years between August 2009 and May 2017) daylight lasts between 17 and 19 h, thus increasing the number of fasting hours. This poses difficulties for Muslims with diabetes that need to eat and take medication regularly to maintain glycaemic control. Short-term risks of fasting include poor diabetes control with ketoacidosis and dehydration[5,8], and longer-term increases in mortality, morbidity and reduced quality of life.[9] Apart from abstaining from food, changes to diabetes regimes during Ramadan include altering medication regimes[10,11], and some patients also make a personal choice to refrain from accessing health services due to their perceptions that health-care professionals (HCPs) have negative views of fasting.[11] More recently, risk stratification has been developed by diabetes clinicians as a strategy to identify patients at high, moderate and low risk with recommendations for intensive structured education programmes for all Muslim patients with diabetes wishing to fast, in order to reduce the risk of dehydration, hyperglycaemic and hypoglycaemic events during Ramadan.[12] Diabetes UK has produced information for patients on managing diabetes safely whilst fasting, together with the implications of fasting for people with diabetes and recommends that patients discuss fasting with their GP (general practitioner) and/or religious teacher(s) (Imams), as Imams often provide support and guidance on fasting in accordance with the Quran.[13,14] In supporting patients to manage diabetes and fast safely, GPs and PNs (practice nurses) need to understand the effect of fasting on the pathology of diabetes[5], as well as the wider impact of religious beliefs relevant to long-term condition management.[15,16] To date, there are no UK national health guidelines, or formal training for GPs and PNs on this topic and the extent to which Muslim patients with diabetes seek medical advice about fasting from their GP or PN is unknown.[17] Although previous research has investigated beliefs about diet and medication in South Asian people with diabetes,[3] fasting during Ramadan and implications for relationships with primary care professionals has not been a topic of research.

Research aims:

1. To explore the beliefs which influence the experience and practices of diabetes management in Muslim people with diabetes during Ramadan.

2. To explore perspectives of Muslim people with diabetes about the role of their GP and/or PN in supporting them to fast during Ramadan.

Methods

This study was conducted as part of The National Institute for Health Research (NIHR) Collaboration of Applied Leadership in Health and Care (CLAHRC) Long-Term Conditions (LTC) programme[18] and ethical approval was granted through this programme of research (Ref: 10/H1008/1 09130). South Asian adults with type 1 (T1DM) or T2DM, living in Greater Manchester were recruited with the assumption that they had beliefs and experiences related to the study aims. Two methods of sampling were used: random sampling of 22 GP registers and purposive sampling to obtain a broader and varied sample of Muslim respondents from community groups (Mosques, Islamic classes and Muslim day centres).

Semi-structured face-to-face interviews were conducted with ($n = 23$) respondents between March 2010 and July 2011. The interviews lasted between 30 and 90 min and were audio recorded with consent. A topic guide was developed to explore a range of beliefs about diabetes management including fasting, diet, self-management resources, medication and social networks. Data collection and analysis was an iterative process with modification of the topic guide as analysis progressed.

A professional interpreter, unattached to the project, provided language support for Urdu-speaking respondents whose first language was not English. One interview was conducted in Hindi by the first author (NP). On occasions where this was requested, members of patient's families sometimes helped with interpretation. In two cases, a diabetes Asian Link Worker was present to provide language support. All respondents were reimbursed for their time.

Principles of grounded theory were used to analyse the data, but, as this study had a priori ideas, we did not use a full-grounded theory approach. Initially, open coding was used to analyse the transcripts and, through comparison of these codes, categories and themes were identified.[19] Thereafter, data were analysed thematically using a constant comparison approach.[20] Themes were developed independently by all authors and then agreed through discussion. Field notes and written memos were used to help develop interpretations during analysis. Data collection was continued until category saturation was achieved in that interviews continued until no new themes emerged from the data.[21] Atlas.ti6 software was used to store and manage the data.[22]

Results

Twenty-three Muslims with diabetes were recruited into the study, 11 were selected from the CLAHRC study sample and a further 12 were purposively sampled from community groups (Table 1). Two respondents who fasted had T1DM and were on insulin. Of the 21 respondents with T2DM, five were on insulin and did not fast. Thirteen who were on oral medication fasted; the remaining three did not fast, suggesting this was due to problems with managing their diabetes. The majority of the sample were migrants from either Pakistan or Bangladesh, whose first language was Urdu.

Data is presented in four main themes: *normalising diabetes, the significance of fasting, pressure to fast and not to fast; and to disclose or not to disclose*. Analysis of the data is presented thematically and respondents are identified by their age and gender with an asterisk to indicate a respondent has been quoted more than once.

Normalizing diabetes

The majority of respondents knew diabetes was more prevalent in the South Asian population. This was either due to living with family members with the condition or being aware of extended family members and people in the community living with the condition.

Table 1 Characteristics of respondents recruited into the study

	Muslim respondents (*n*)
Total	23
Gender	
Male	10
Female	13
Age (mean = 52, SD = 12)	
38–40	5
41–60	13
61–80	5
Recruitment strategy	
GP practices	11
Community groups	12
Diabetes	
Type 1	2
Type 2	21
Respondents reported to fast	13
Type 1	2
Type 2	11
Medication	
Oral	16
Insulin injections	7

> We just put it down to being in the family because my Dad had it [53 year old female, T2DM]

Some respondents minimized the seriousness of the condition and the importance of self-management, with a strong belief that diabetes was an expected and 'normal' part of life for South Asian people.

> It's okay because these days everyone has diabetes [laugh]…If it was like I'd never heard of it, I'd think, oh what's happening, am I going to die… because my immediate family had it, it wasn't that much of a surprise [42 year old male, T1DM]

Respondents also described how they had anticipated and/or expected the diagnosis of diabetes and did not take action to prevent or delay the onset of diabetes. Having family members with diabetes and witnessing them managing their diabetes also seemed to reduce the emotional distress of their own diagnosis.

> Diabetes is in the family, my sister had it, my parents didn't have it but other people in the extended family had it and I knew somewhere along the line it's going to happen. [46 year old female, T2DM]

The significance of fasting

Fasting during Ramadan was reported in terms of people viewing this as a religious duty which should be fulfilled by all Muslims in spite of living with diabetes.

> For Muslim people, it is vital to fast. Yes I am ill but my faith keeps me strong and if I am going to get worse health-wise I am going to get worse no matter what. [43 year old female, T2DM]

Respondents who fasted stated that they felt more energetic and happier during Ramadan, despite abstaining from food and medication for a long period of time.

> At the beginning, I feel weak but then I am okay. It makes me feel mentally and physically strong, very, very strong more lighter [38 year old male, T2DM *]

Some respondents claimed to have better control of their diabetes during the fasting; some relating it back to the strength 'Allah' gives them during Ramadan. The willpower to abstain from food and drink seemed to result in a sense of both positive mental and physical well-being.

> Allah made it for us like that and he helps us, Allah helps us loads, it doesn't make any difference. You feel very fresh, very happy, and very calm [69 year old female, T2DM *]

Respondents often reported how they responded to fasting by altering their medication regime to avoid hypoglycaemia, and typically expressed confidence in their ability to do so.

This often involved missing or taking a lower dose of their diabetes medication.

> Normally, I have to take my tablets once in the morning and once in the evening…if feel my sugar is high or very low then I take one in the morning before breakfast otherwise I just take it at night (43 year old, male, T2DM)

Their confidence in altering their diabetes medication stemmed from their prior experiences of fasting and managing their diabetes.

Very few consulted their GP and/or PN for advice on how to alter their medication.

R I didn't take advice from anyone… I made the decision whether it was okay for me to take the medication…and it worked fine.

I Have you ever talked about fasting with your GP?

R No, there's no need because, as I said, that I have the sense for that so there is no need at present. (43 year old, male, T2DM)

Two male respondents with T1DM on insulin reported that they fasted and had good control of their diabetes whilst fasting.

> I have better control during Ramadan…I know I can manage. I know how to adjust my insulin and how much to eat morning and night I eat once in the morning and then I don't eat anything throughout the day and when it's time to eat my sugar level is usually between 3.6 and 4.2 mmol [38 year old, male, T1DM]

Five respondents with T2DM who had progressed from oral medication to insulin did not fast and perceived fasting as a threat to their diabetes.

> I haven't since I started the insulin but when I was on the metformin I was fine. As soon as I started the insulin, I used to get hypos very quick. That's why I can't really because when you start a fast you're not supposed to break it until sunset. So I just stopped because I knew, I would be not able to last and also they are very long at the moment as well. [43 year old female, T2DM *]

In addition to the religious significance of fasting, some participants described some of the social activities which were a significant part of the fasting ritual.

> We meet each other, we support each other, and you find plates of food are being exchanged in the streets [laugh] from Muslim to non-Muslim… we all eat at the same time…. We all walk to the mosque and open fast there, my husband he likes that. We have lots of visitors I love Ramadan! [45 year old female, T2DM *]

The pressure to fast and not to fast

Respondents, who chose not to fast because of their diabetes, described the tensions between their personal decision not to fast and the pressure they received from their family to fast. As well as reports of guilt and embarrassment for not fasting; respondents described eating their daytime meals in secret or when the family is not in the house.

> Usually when they are playing on their games or something, I will get myself a little snack or sandwich or something and go upstairs and eat. I try and make sure they are not in front of me [laugh] but yeah I would feel guilty. I do feel guilty about it, especially at the beginning I did really sort of….I used to fast from the age of 5 and I have been fasting until I started on the insulin. I just feel like you can't do what you're supposed to do as part of your religion, and I definitely feel guilty. [43 year old female, T2DM *]

There were differences in descriptions of support received from the spouse. For example, a spouse, who was aware of other family members or friends in the wider community who fast and have diabetes, encouraged fasting, despite the respondent's decision not to fast.

> Wife: Yeah but he [husband] doesn't fast now. Our Ramadan is coming up and he can still fast but he for that past 2 years has not been fasting and I don't think it's an option, he should do fasting. He thinks that if he fasts that his sugar will go low but he doesn't want to so…I know they are going back and fasting times are longer but still if a kid can manage he can manage. I mean my dad can manage it, he is diabetic, all the old diabetic people can manage it. [Wife of a 47 year old male, T2DM]

Whereas other spouses were described as discouraging fasting due to concerns about the negative effect of fasting for the respondent and the diabetes. Some respondents felt guilty for not fasting because they had been fasting since childhood in their native countries, yet the support they received from the family seemed to inhibit the feelings of guilt.

> I feel guilty. It's still the inner feeling, like I feel like I'm not doing the right thing by my religion and my beliefs. In our religion, it says that if somebody is on medication, and you're ill, you're not compelled to do it. And my husband convinced me of that and said, 'you're not to blame. And you do need your medication and you do need to eat small amounts [54 year old female, T2DM*]

However, others chose to fast despite being told not to by their family, as respondents did not perceive their diabetes to be at a serious stage.

> My in-laws tell me not to fast, but I don't listen. They think I am diabetic I shouldn't fast but I don't follow that rule because …you know I am not in a high stage and I don't know about this year because it's going to be really long [Annoyed voice] [45 year old female*, T2DM]

To disclose or not to disclose

Respondents described how they were not willing to disclose fasting to their GP and/or PN, mainly because of the fear of being told not to fast. Some respondents described how they refrained from accessing health services or going to see their GP during Ramadan.

> In that month I never go to the doctor – that one month I feel fine [laugh]. If I am not well, I still don't go because they will tell me not to fast. [69 year old female, T2DM *]

For those who did inform their GP, reported that they were advised not to fast. They described how they still continued to fast, either because they felt they were able to control their diabetes or that their GP did not understand the significance of fasting during Ramadan.

> GPs have always said 'don't fast'. I suppose if they are not from that cultural background they won't understand it anyhow. To them it's what you've got to do for your health, but with me when I was on the tablets I felt okay fasting and they were shorter around that time. [43 year old female, T2DM*]

> The doctor used to say not to fast but I never really took that advice, I sort of follow my own pattern…Like I said I do have a lot of control over my…my first consultant knew I fasted…He would talk to me about it and then he got the understanding of it – he was very supportive….I don't think there was enough information available for the professionals to…., so I think I trained him [laugh] [47 year old female, T2DM*]

The reluctance to disclose fasting was not influenced by the ethnicity of the GP. Regardless of whether the GP was Pakistani Muslim or White British, some respondents still perceived their GP to have a lack of expertise to support them effectively during fasting.

> I've not openly told her that I fast, but she knows I am Muslim she should tell me. I can't remember if she has told me anything but maybe she is thinking it's not something that is good for health but as a doctor…She knows but she doesn't say anything [45 year old female, T2DM *]

> I don't bother tell my GP. My doctor never advices anything for Ramadan, even though my doctor is a Muslim doctor himself. I am really surprised about this. I am not very happy about my GP [38 year old male, T2DM *]

Some respondents reported having discussions with the GP and/or PN about fasting in an attempt to seek advice on whether or not they should fast. Most described consultations with their GP and PN as unsatisfactory with no help being offered.

> I've discussed it with my nurse and she said, 'the choice is yours, but you've got your medication. She pointed out that I will have long gaps. I never really know how it's going to affect me… even though I've asked them they say it's my choice [54 year old female, T2DM *]

In these circumstances, it was common for some respondents to make changes to their medication regime without further consulting their GP and/or PN. Respondents seemed to be aware of the potential risks of fasting to their diabetes and described frequently monitoring their blood sugar levels to prevent the onset of hypoglycaemia.

> I manage very well – I lower my dose of insulin and bring my sugars high and drink orange juice. You've got to have it high to last the whole day,

> and if I started with low sugars I would not survive the day. I would have a hypo. I am very, very careful and I do monitor my sugar very carefully [47 year old female, T2DM*]

Respondents suggested that they would like support and advice, especially from their GP on fasting safely, providing their GP was trained, empathic and understood the significance of Ramadan for Muslims with diabetes.

> Maybe if she said eat this and don't eat this I would find it helpful but I haven't asked and maybe if they had training about Ramadan or if it was a Muslim doctor I would ask. [43 year old female, T2DM*]

Discussion

Summary of main findings

This is the first study in the UK to explore the beliefs and experiences of managing diabetes during fasting in Muslim people with diabetes, and disclosure about fasting to the GP and/or PN. Respondents' decisions to fast encompassed personal, religious and social factors, with a strong reluctance to disclose fasting to the GP due to the fears of being told not to fast, and believing that the GP lacked understanding of the importance of fasting in the Muslim faith. The study findings also inform on how patients who fast alter their diabetes medication independently, and are specifically relevant to HCPs working in primary care and looking after Muslim patients with diabetes.

Comparison with existing literature

The current literature mainly reports on the biomedical implications and risks of fasting, with recommendations for HCPs to be trained to support Muslim people with diabetes wishing to fast,[7,12,23,24] and ensuring that all patients receive a pre-Ramadan medical assessment and structured education before Ramadan.[16] Religious beliefs have been suggested to influence medical decisions and conflict with medical care[25]; however, research on the effects of religious beliefs and behaviours is sparse.[26]

Our study presents the importance of considering patient experiences, especially when forming guidelines on this topic, as some patients do not feel comfortable disclosing fasting to their GP and/or PN. Living with diabetes did not inhibit respondents from fasting, especially those with T2DM on oral medication. Rather respondents believed that god was giving them the strength to fast and manage their diabetes. Two respondents with T1DM fasted, and five with T2DM who were on insulin did not fast due to the difficulty of managing their diabetes. Although small in number, our findings lend some support to the large retrospective epidemiological study of Muslims with diabetes (EPIDAR study) which also found fewer patients on insulin fasted during Ramadan, in comparison with patients on oral medication.[27] Most respondents normalized diabetes as part of life and appreciated the perceived beneficial effect fasting had on their mental and physical well-being. Although Ramadan marks a significant ritual in the Islam religion, it was also a joyful occasion and a time when family and friends came together and engaged in religious and social activities. Being part of a religious group with the support of others has been known to provide people with a sense of identity and achievement.[25] Thus, the psychosocial effects of fasting may reinforce fasting behaviours in this population, especially if there is a lack of information and support available on the risks of fasting to diabetes, as was the case in our study sample. However, respondents who did not fast during Ramadan reported feelings of guilt and shame, resonating with previous research which suggests that non-compliance with group rituals can generate negative emotions for the individual in the group.[28] There are links also to Campbell *et al.*'s notion of 'strategic non-compliance'[29], in that respondents who fasted also reported altering their diabetes regimen independently and often without the consent of their GP and/or PN. Similar to Lawton *et al.*'s study[3] on food practices in South Asian people

with diabetes, our findings suggest that compliance with dietary regimen is not only related to social and cultural factors but religious factors too. Preserving well-being and maintaining a sense of belonging within the family and community appeared to be pertinent during Ramadan.

The finding that respondents, who did not fast, despite family and peer-pressure, suggest that health concerns clearly outweighed the desire to follow social and religious conventions. This resonates with Rotter's (1966) theory of locus of control (LOC), which states that people with an internal LOC believe that the events in their life derive from their own actions, and these people will engage in activities that will improve their situation. People with an external LOC will believe that their life is controlled by external factors (e.g. others, fate)[30]. In our study, those who believed that fasting was a threat to their diabetes did not fast, thus demonstrating a possible internal LOC and greater levels of self-efficacy. In relation to external LOC, those who believed that fasting was not a threat to their health, and/or felt pressured to conform to the family/social group tended to fast. People estimate their chances of success and failures on the basis of their prior experiences of the same event[30,31]; thus, respondents who have fasted for a number of years are likely to fast if they have not encountered any problems or believe they can control their diabetes.

Our findings also imply that people in general are balancing the health risks against the negative emotions associated with not fasting and depending upon their condition and circumstances are coming to different decisions about fasting. Yet, the disappointment amongst some respondents regarding the lack of support from the health services for fasting suggests that respondents may welcome support and information from their GP and/or PN pre-Ramadan. However, disclosing fasting to the GP and/or PN needs to be addressed, in that, patients need to know they can discuss fasting openly in consultations. The negative emotions attributed to those not being able to fast during Ramadan also needs to be addressed so that patients do not feel guilty for not being able to fast.

Strengths and limitations of the study

Recruitment took place in several areas of Greater Manchester to target an adult population from various traditions, backgrounds and age groups to increase sample variety. Most respondents were from deprived communities, whose first language was not English, and some were illiterate in their native language. Despite using a combination of recruitment methods, it can be argued that this sample may not sufficiently reflect patients with T1DM, and the more-educated sections of the South Asian community. However, T2DM remains a significant problem in South Asian people from lower socioeconomic backgrounds, as well as the Muslim populations[32] and warrants research. A professional interpreter, a diabetes Asian Link Worker from the Muslim community, and the respondents' family members facilitated some of the interviews. This may have influenced the data in that the interviewees' responses may not have been captured accurately, as the interpreters may have found it easier to summarise the respondents' answers to the questions asked, rather than interpret each answer in verbatim.[33]

The analysis was undertaken in a multidisciplinary team (Trainee Health Psychologist, Health Service researchers and a Primary Care Clinician), which increases trustworthiness of the analysis.[34] The interview guide contained a range of topics related to diabetes management, and fasting was one of a number of topics explored.

Implications for clinical practice and future research

The impact of religious beliefs on the management of diabetes is complex. The reality is that many Muslim patients with diabetes will fast, despite experiencing difficulties of abstaining from food and medication. The lack of discussion with GP and/or PN means that patients

are doing this unsupported. There may be an opportunity for GPs and/or PNs to harness and work with these patients, by asking them if they intend to fast, and if they need information (e.g. on diet and medication) to ensure that they fast safely.

Despite recommendations for GPs to provide Ramadan-focused patient education[4,16,27,35], it is unclear if this is happening in practice[4,27] and whether the 'sporadic' written information on fasting and diabetes for both patients and GPs[36,37] has been fully integrated into primary care. Notwithstanding recommendations for undergraduate medical curricula to include training and education for HCPs on religion, spirituality, medicine and health[38], few higher education providers have responded to this gap in education.[39,40] Research into the effects of religion and managing long-term conditions is also sparse.[41]

It is important that GPs and PNs are aware of patients who fast during Ramadan, as non-adherence to the daily diabetes regime may result in more Muslim patients suffering the risks and complications associated with diabetes[16], leading to poor quality of life and increased use of NHS health services.[42]

The current delivery of diabetes care in primary care has a biomedical focus with the Quality and Outcomes Framework (QOF) being at the forefront.[43] Recent concerns about how well self-management support for long-term conditions (e.g. diabetes) is actually embedded and integrated into primary care[44–47] also raises concerns for the potential barrier QOF may present to the embedding of culturally sensitive care into primary care. To sustain change and improve clinical communication, HCPs need to feel confident to consult on fasting and be equipped with skills to initiate discussion and support patients from multicultural communities.[48] However, in the current design of services, this may add a layer of complexity to the routine diabetes care already in place, especially since pre-Ramadan medical assessments and structured education is not part of QOF. Furthermore, if patients remain reluctant to disclose fasting in consultation, the challenge for health-care professionals to support Muslim patients wishing to fast, despite receiving training will also remain. Forming collaborations and seeking advice from religious teachers (Imams) on improving communication for fasting and diabetes management in primary care could be another way forward but this also needs further research.

Conclusion

Fasting during Ramadan is an important ritual in the Islam religion, with a highly important social significance as well. In addition to the biomedical literature on this topic, patients' experiences need to be taken into consideration when forming guidelines due to the wider issues related to diabetes management and fasting. Tensions often exist between the patient and their family on the decision to fast. The reluctance to disclose fasting to GPs or PNs has potentially serious consequences for diabetes control and future health. GPs and PNs need to ask patients if they intend to fast, and if they need information about how to fast safely. Although GPs and PNs may benefit from training and skills providing culturally sensitive care, patients also need to feel that they can discuss fasting openly in consultation. Future research into experiences of GPs and PNs in supporting Muslim patients with diabetes during fasting is required to identify gaps in service provision, and to ensure patients from multicultural communities receive the care they need to manage their long-term condition(s).

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Conflict of interests

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Ethics approval

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