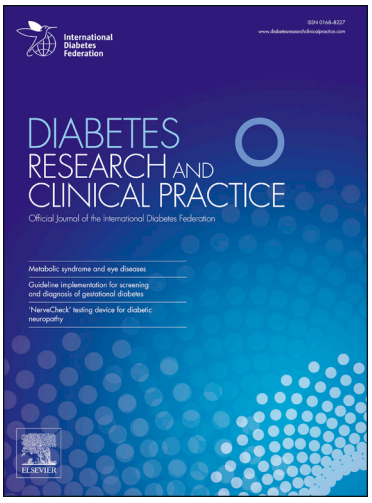

Patients with Diabetes Observing Ramadan: The Experience of Muslims in the United States

Pauline R. Myers, Noordeen Shoqirat, Deborah H. Allen, Latefa Ali Dardas

PII: S0168-8227(18)31562-6
DOI: https://doi.org/10.1016/j.diabres.2018.12.011
Reference: DIAB 7575

To appear in: *Diabetes Research and Clinical Practice*

Received Date: 12 October 2018
Revised Date: 6 December 2018
Accepted Date: 17 December 2018

Please cite this article as: P.R. Myers, N. Shoqirat, D.H. Allen, L. Ali Dardas, Patients with Diabetes Observing Ramadan: The Experience of Muslims in the United States, *Diabetes Research and Clinical Practice* (2019), doi: https://doi.org/10.1016/j.diabres.2018.12.011

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First author:
Pauline R. Myers, MSN, BSN
Duke University Hospital, 2301 Erwin Rd, Durham, NC 27710
Email: pauline.myers@duke.edu

Second Author:
Noordeen Shoqirat, PhD
Associate Professor, Mutah University, Karak, JORDAN
noordeen@mutah.edu.jo

Third author
Deborah H. Allen, PhD, RN, CNS, FNP-BC, AOCNP
Director of Nursing Research & EBP
Duke University Health System, Durham, NC 27710
hutch.allen@duke.edu

Last author (Corresponding):
Latefa Ali Dardas, PhD, PMHN
Assistant Professor, School of Nursing, The University of Jordan, Amman, 11942, Jordan
Email: l.dardas@ju.edu.jo

Abstract

Background and Purpose: Little is known about the experience of Muslims with diabetes while fasting during Ramadan in the United States. Providing quality care for Muslim patients requires being aware of Islamic beliefs and practices, particularly in regard to healthcare ramifications. Therefore, the aims of this study were to (a) explore the beliefs which influence the experience and practices of diabetes management among Muslims in the United States during Ramadan, and (b) explore perspectives of Muslims with diabetes on their experience with healthcare providers providing support during their fasting experience.
Methods: Using an exploratory design, semi-structured interviews were conducted for qualitative analyses. A purposive sample of 14 Muslim patients with diabetes was recruited from mosques located across North Carolina.
Results: Analyses revealed six subthemes on their "feelings" that were inherent to their experiences of managing diabetes while fasting during Ramadan. These were organized into two main themes: 1) having diabetes and fasting during Ramadan and 2) fasting challenges. Having diabetes and fasting during Ramadan focused on the experience of fasting and comprised four "feelings": 1) feeling spiritually connected, 2) feeling socially connected, 3) feeling physically healthy, and 4) feeling religiously obligated. The second theme focused on fasting challenges and included 1) feeling sick and dehydrated, and 2) feeling vulnerable and poorly understood by healthcare providers.
Conclusion: This is the first known study to explore the experience of Muslims with diabetes while fasting during Ramadan in the United States. Our findings offer important insights into how Muslims manage their diabetes while fasting and the missed opportunities for relevant conversations when partnering with healthcare providers during Ramadan. The importance of cultural competency across healthcare systems in the United States cannot be overemphasized. Healthcare providers need to hold conversations embracing shared decision-making to resolve healthcare dilemmas resulting from cultural differences, expand cultural knowledge, and adapt services to meet culturally-unique needs of their patients.

Keywords: Diabetes; Fasting; Muslims, Cultural competency, Ramadan

Introduction

Diabetes is a leading cause of mortality and morbidity, reaching epidemic growth worldwide as approximately 422 million adults are diagnosed with diabetes (WHO, 2016). It is estimated that in the year of 2015 alone, 1.6 million deaths were directly caused by diabetes, and another 2.2 million deaths were attributable to high blood glucose (Almansour, Chaar, & Saini, 2017; Alsafadi, Wilson, & Patel, 2011). Yet, many acute complication related to diabetes may be prevented through proper diabetes care (American Diabetes Association, 2017).

Diabetes management requires providers to incorporate a framework of shared decision-making and cultural competence. As diabetes management is directly impacted by food intake, exercise, and medication regulation, variability in these factors as it relates to cultural influence may negatively affect the body's ability to regulate blood glucose levels (Almansour et al., 2017; Hassanein et al., 2017). Therefore, the purpose of this paper is to describe the influence of fasting during Ramadan in Muslims with diabetes and provide considerations relevant to shared decision-making in diabetes care.

Cultural Considerations of Ramadan

Islam is the second largest religion in the world with Muslims comprising 22% of the world population. It is estimated that 3.45 million Muslims are living in the United States, accounting for 1.1% of the total U.S. population (Mohamed, 2018). American Muslims embody a variety of cultural backgrounds making them one of the most racially diverse religious groups in the United States (Younis, 2009). With an increasing presence in Western countries, much of the Western population do not know the beliefs or practices of Islam or how it may impact participation in healthcare management (Harff, 2018, Hassanein et al., 2017; Khattab, Mahmoud, & Shaltout, 2016; Patel, Kennedy, Blickem, Rogers, Reeves, & Chew-Graham, 2015). Ramadan

occurs in the ninth month on the Islamic calendar, lasting 29 to 30 days, and is a time of spiritual reflection involving introspection, communal prayer, and faithful intention for the forgiveness of past sins. Fasting from dawn to sunset acts to cleanse the soul and precludes one from drinking water and or taking oral medications. While Muslims with chronic illnesses are not obligated to observe the practice of fasting, many may discontinue their medications or alter their diabetic treatment plan without having a medical consultation, which may lead to serious complications that include dehydration, hypoglycemia, and diabetic ketoacidosis (Hassanein et al., 2017).

A few studies have reported on the experience of fasting Muslims with diabetes residing in Western, predominately European, countries: Pakistanis in Denmark (Mygind, Kristiansen, Wittrup, & Nørgaard, 2013); Turks in Belgium (Peeters et al., 2015); Moroccans in Spain (Jansà, Diaz, Franch, Vidal, & Gomis, 2010); Somalis in Sweden (Wallin, Löfvander, & Ahlström, 2007), and Algerians in France (Gaborit et al., 2011). A consistent theme across these studies was the lack of cross-cultural understanding and communication between health care providers and their clients, which often leads patients to fasting without notifying or seeking input from the providers. To date, no studies have explored the experience of Muslims with diabetes residing in the United States. Therefore, the aims of this study were to (a) explore the beliefs which influence the experience and practices of diabetes management among Muslims in the United States during Ramadan, and (b) explore perspectives of Muslims with diabetes on their experience with healthcare providers providing support during their fasting experience.

Method

Design

Using an exploratory design, semi-structured interviews were conducted for qualitative analyses. The interview questions provide standardization while permitting flexibility of new

viewpoints to emerge freely through a two way interaction (Aira, Kauhanen, Larivaara, & Rautio, 2003). Moreover, the qualitative method was advantageous for exploring participant knowledge and perception in the context of diabetes and culture (Gillani, Sulaiman, Abdul, & Saad, 2017; Rohan et al., 2013). The study was approved by the local Institutional Review Board.

Setting and sampling

The participants were recruited from 10 local mosques in North Carolina. Leaders in the mosque agreed to advertise the study through announcements, flyers, and emails to Muslims in their community. Interested participants contacted the study PI (PM) to discuss study purpose and procedures and perform eligibility screening. Inclusion criteria were: Muslim faith, aged 18 years or older, diagnosed with diabetes mellitus, and able to speak and read English; those with cognitive impairment were excluded due to informed consent requirements.

Data collection

The PI conducted all of the participant semi-structured interviews using a guide of open-ended items developed from the literature for interview consistency (Almansour et al., 2017; Gillani et al., 2017; Ilkilic & Ertin, 2017; Zainudin et al., 2017). The interviews centered on personal perspectives and beliefs, experiences and practices about fasting and managing diabetes during Ramadan. Using reflective inquiry, the interview specifically sought participant feelings about fasting during Ramadan, missing fasting days, decision-making about fasting, changes to their normal routine, barriers to managing diabetes during Ramadan, and the support received during Ramadan from healthcare providers. All participants were encouraged to consult with friends and family before obtaining consent. The interviews were done in English in a private room provided at the mosque they attended. All interviews were digitally recorded with the

permission of the participants. A summary of the interview was provided to participants to permit additional comments or seek clarification.

Data Analysis

All interviews were digitally recorded, transcribed verbatim and thematically analyzed using NVivo 11™ (QSR International, Australia). Following the fourteenth interview, saturation had been achieved as no new concepts and ideas were emerging. Using constant comparative analysis, thematic analyses aimed at identifying commonalities and patterns of experience in the participants' narratives. Transcripts were read initially several times by the full research team to develop a sense of the experience under investigation (Speziale, Streubert, & Carpenter, 2011). Two researchers (NS & LD) examined each transcript and coded separately to extract significant statements and concepts for each specific experience and perception. Subsequently, all related codes were grouped together to create themes and subthemes. This form of analysis requires cross comparisons among all themes and clustering of elements to confirm, revise, and explore the overall story to reach full team agreement (Holloway & Galvin, 2016) .

Trustworthiness

Trustworthiness of data was established using a variety of processes (Speziale et al., 2011). First, credibility was addressed by ensuring that participant narratives reflected the themes that our research team heard from their stories through member checking processes (Korstjens & Moser, 2018). Specifically, our PI asked participants to examine the transcripts and then verify the themes the team found as an accurate reflection of their actual words and expressions. Dependability was maximized by involving two qualitative researchers who independently performed the steps of transcript coding. The codes were then used to form

subthemes and themes by the full research team. Thus, all themes and subthemes were validated by each member of the research team (n=4) throughout the whole comparative analysis process. Finally, our team has provided a detailed account for our readers of data collection and analysis processes in which to promote applicability of our findings to similar populations in similar settings (Holloway & Galvin, 2016).

Results

Participants Profile

The study included 14 participants (9 men and 5 women) living in Eastern United States but originating from a variety of geographical areas including countries in North America and Asia. The mean age was 51 years, ranging from 43 to 75 years. All participants had type 2 diabetes. Interview durations ranged from 33 to 115 minutes.

Themes

Analyses revealed six subthemes on their "feelings" that were inherent to their experiences of managing diabetes while fasting during Ramadan (Table 1). These were organized into two main themes: 1) having diabetes and fasting during Ramadan and 2) fasting challenges. Having diabetes and fasting during Ramadan focused on the experience of fasting and comprised four "feelings": 1) feeling spiritually connected, 2) feeling socially connected, 3) feeling physically healthy, and 4) feeling religiously obligated. The second theme focused on fasting challenges and included two "feelings": 1) feeling sick and dehydrated, and 2) feeling vulnerable and poorly understood by healthcare providers. These are detailed by reinforcing extracts from the participants.

Theme One: Having Diabetes and Fasting During Ramadan

Subtheme one: feeling spiritually connected

Spiritual connection prevailed throughout the interviews, particularly in response to their experiences with diabetes while fasting during Ramadan. The cluster of elements identified within spiritual connections include: the state of obtaining a spiritually-enriching feeling with Allah and a spiritual connection to people who are suffering. Despite the feeling of hunger during fasting, remembering people who have nothing to eat led to better coping. These spiritual connections are illustrated by these excerpts:

"When I fast Ramadan, I feel like having gotten more spiritual with Allah as I wanted and get that type of spiritual connection… it really is a state of spiritually enriching feeling."

"[I] felt the spiritual connection to the people who are suffering and because that was what my reason to fast. I feel so helpless that I felt fasting would be my way to purge and through fasting connect with the suffering and connect with what it feels like to not be able to eat. You feel the hunger but feeling with sufferers give you tolerance …."

Subtheme two: feeling socially connected

Another emanating "feeling" was that of being socially connected. Some participants (n=4) focused on how fasting with diabetes made them socially close. Further analysis identified two social connections. First, participants felt that their families were more caring and concerned about their health status given the complexity of maintaining normoglycemia while fasting. This emotional aspect of caring offered some participants a sense of closeness:

"I mean I really felt closer to my family, they all kept saying, "Are you sure you're OK?" "Are you sure __". For them it was __ to know that I was not in any way in discomfort".

The second social connection was in relation to their work environment.

"It wasn't just me, but even the effect of my co-workers who all were like "Oh, God no." Because I made an announcement, "Guys I'm going to fast and you know what, it's going to go further than that. I cannot be angry. I cannot be critical. And they're like, "But you're not going to be any fun". Everybody was more respectful and supportive."

These excerpts exemplify an overall positive impact of fasting with diabetes on the social aspect of health. However, an expression such as *"But you're not going to be any fun*" raises concerns about support from work colleagues for fasting Muslims and a lack of understanding their commitment to their religious practice.

Subtheme three: feeling physically healthy

Six participants described how fasting during Ramadan played a vital role in shaping their physical health. For instance, they perceived having better control over their body weight as the number of meals permitted during Ramadan is limited. This in turn contributed to better management of glucose levels.

" ...I was taking frequent meals, it actually affects my weight but when its Ramadan, I take just two meals .. before the sun rise and after sunset so I feel that I have control on my diet"

"Each time I check the sugar reading during Ramadan, it is the same. Thus, I can do it. So, I feel more energetic during Ramadan to be very frank. And I feel good that I have control on my diet."

Subtheme four: feeling religiously obligated: fasting without asking

Decisions to fast by those with diabetes revealed some divisive views and misunderstandings. While participants acknowledged that they are not obligated to fast as the Islamic religion permits ill Muslims a dispensation from doing so, half of the participants (n=7) felt obligated to fast regardless of their health status. Further, they perceived this to be non-negotiable as they would fast without asking others, including healthcare providers. This belief seemed to be based on misinterpretations of certain verses from the Quran.

"…I am taking Metformin medicine and sometimes become hypoglycemic ...But I continue fasting the holy month…[the decision] it is out of the question "

"even if I am unwell …We do not discuss the decision of fasting Ramadan. It's like obligation. We don't discuss that you really need to fast or not fast "

Theme Two: Fasting Challenges

Despite the perceived advantages about fasting, two challenges to fasting were expressed: 1) feeling sick and dehydrated, and 2) feeling vulnerable and poorly understood by healthcare providers.

Subtheme one: feeling sick and dehydrated

A majority of participants (n=9) described feeling sick and dehydrated while fasting. This was mainly due to the duration of fasting and its effects on blood sugar levels as elaborated below.

" my biggest concern was that I was dehydrated because I felt like there was a connection between dehydration and my blood sugar as well. The more dehydrated, the higher my blood sugar…I've never seemed to drink enough. You've only got a few

hours before you start all over again. I mean I should stay up all night. So I tried drinking as soon as the fast would break and just keep going."

Concerns and uncertainty over their health seemed to continue throughout the month of Ramadan. However, some participants expressed their inability to cope with specific symptoms, such as dehydration. The statement *"I mean I should stay up all night. So I tried drinking as soon as the fast would break and just keep going"* demonstrates why hydration management should be discussed with the healthcare provider as over-hydration can lead to the life-threatening condition of hyponatremia. Food choices during Ramadan often include overconsumption of foods with a high glycemic index which negatively impacts diabetes management.

Subtheme two: Feeling vulnerable and poorly understood by healthcare providers

Every participant (n=14) expressed their vulnerability as non-Muslim physicians lack accurate knowledge on Muslim traditions, particularly those that influence healthcare management such as fasting during Ramadan. As expected, participants described how Muslim doctors were very supportive of the needs of patients with diabetes who fast during Ramadan.

"I had to explain it to her [non-Muslim doctor] the details of fasting. I explained to her what Ramadan is, the details and what is required for me. She normally gives me some support, cause I tell her that I do take my medicine as a main concern"

"And I can tell you a Muslim doctor almost 100% will say not to fast. Because she knows or he knows that we don't have to fast. A non-Muslim doctor doesn't know better. So he can't decide whether to fast or not".

Their perception of vulnerability was illustrated by participants withholding vital information from their healthcare providers. This might restrict some from expressing their experiences and concerns about how to fast with diabetes.

"I think Muslims in general are trying not to raise their profile especially. We feel very vulnerable and so communication with health providers they have to make the first. They have to be the ones to reach out to Muslim diabetic population or many of the chronic illness issues".

Overall, participants stressed the importance of increasing cultural awareness of all healthcare providers regarding Muslim practices so that essential shared decision-making about diabetes and fasting can be addressed.

Discussion

This qualitative study describes the beliefs and practices of fasting Muslims with diabetes residing in a Western country. Our results contribute uniquely to current knowledge by addressing Muslim experiences specifically in the United States.

In our study, fasting during Ramadan was found to be a positive experience for Muslims with diabetes. Fasting provided opportunities to feel compassion for those who are underprivileged; build a sense of self-control and will-power; improve their ability to resist temptations for over-eating; and develop a greater sense of humility, spirituality, and social involvement. These results are consistent with previous international studies reporting perceived benefits of fasting despite having diabetes (Hassanein et al., 2017; Ilkilic & Ertin, 2017; Patel, Kennedy, Blickem, Rogers, Reeves, & Chew-Graham, 2015).

However, while the value of fasting during Ramadan was recognized among our participants, the issue of "fasting without asking" raises some concerns. Our Muslim participants felt religiously obligated to fast regardless of their health status and risk for experiencing potential diabetic complications. These findings suggest that this choice was based on misunderstanding Quran and Islamic teachings, which clearly exempt unwell Muslims from

fasting. On the other hand, some participants did not fast for health reasons. These divisive decisions highlight the need to help Muslim patients with diabetes engage in conversations with healthcare providers so that shared decision-making occurs.

Fasting during Ramadan is an individual choice which should be supported by healthcare providers to ensure safe fasting (Ali, Adams, Hossain, Sutin, & Han, 2016). While healthcare providers should guide their Muslim patients with diabetes in evidence-based practices to manage their health during fasting, they need to listen to their patient's experiences and beliefs to make fully informed decisions. Participants who felt religiously obligated to fast expressed their need for different healthcare guidance than those who choose not to fast for health reasons. These results suggest that the use of a standardized caring approach might not be applicable and effective for all patients.

Finally, the vulnerability described by our participants with non-Muslim healthcare providers lacking appropriate knowledge about fasting during Ramadan coupled with patients' feelings of vulnerability in the United States seems an important issue to consider. Their vulnerability negatively impacts informed decision-making about fasting unless participants feel comfortable communicating and consulting with their healthcare providers. Furthermore, many participants reported that they currently prefer making the decision to fast and change their medical routines without the input of healthcare providers. This perception relates to healthcare provider's lack of knowledge about Ramadan or from previous frustrating relationships with providers not supporting their religious practices. The lack of providers' knowledge about Ramadan did at times interfere with patients receiving the needed education. Feelings of being religiously vulnerable might alienate patients from healthcare services and minimize health knowledge seeking behaviors (Amer & Bagasra, 2013; Padela & Raza, 2014). Therefore,

healthcare providers in the United States and other Western countries need to pay great attention to Muslim patients who might feel vulnerable and stigmatized if they verbalize their concerns and needs. Allowing Muslim patients to make their own decision regarding fasting is crucial for self-empowerment, however, they need to be provided the tools to make healthy decisions. Hassanein et al. (2017) has recently published international guidelines aimed to increase healthcare provider knowledge on diabetes and Ramadan fasting and promote shared decision-making on diabetes management during this Muslim tradition.

Limitations

One study limitation pertains to the conduction of the semi-structured interviews by a non-Muslim interviewer as this may affect the trust or honest-reporting of perceptions by participants. However, care was taken to provide a safe unbiased environment for participants to share their perceptions and experiences. Further, using a non-Muslim interviewer kept participants from assuming that the interviewer had knowledge about Ramadan and Muslim practices and prompted participants to further elaborate on their experiences. Lastly, the emerging theme of participant vulnerabilities within religious obligations suggest that interviewing bias was minimized. Other limitations are: all participants were diagnosed with type 2 diabetes and all were required to speak, read, and write English. This may limit generalizability to other Muslim populations given the variation in the treatment regimens, level of education, and language interpretation. Therefore, additional research driven by the themes identified in this study in varying Muslim populations are warranted.

Conclusions

This is the first known study to explore and describe the experience of Muslims with diabetes while fasting during Ramadan in the United States. These findings offer important

insights into how Muslims manage diabetes while fasting and missed opportunities within healthcare practices. The importance of cultural competency across healthcare systems in the United States cannot be overemphasized. Healthcare providers need to hold conversations embracing shared decision-making to resolve healthcare dilemmas resulting from cultural differences, expand cultural knowledge, and adapt services to meet culturally-unique needs of their patients.

Acknowledgment: NA

Conflict of Interest Statement: No conflict of interest has been declared by the authors.

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Table 1: Thematic analyses on the experience of fasting Ramadan (n=14)

Themes	**Subthemes**	**Meanings**
Having diabetes and fasting during Ramadan	Feeling spiritually connected	*"…a state of spiritually enriching feeling"*
		.."spiritual connection to the people who are suffering"
	Feeling socially connected	*"..I was really felt closer to my family"*
	Feeling physically healthy	*".. I feel that I have control on my diet"*
	Feeling religiously obligated: "fasting without asking"	*"We do not discuss the decision of fasting"*
Fasting challenges	- Feeling sick and dehydrated	*"I felt like there was a connection between dehydration and my blood sugar as well"*
	- Feeling vulnerable and poorly understood by healthcare providers	*"…I had to explain it to her [non Muslim doctor[the details of fasting.."*
		"We feel very vulnerable and so communication with health providers they have to make the first"