Khadijah Bakur et al, 2020;3(2):60–70.
https://doi.org/10.24911/JBCGenetics/183-1596638212

ORIGINAL ARTICLE

Role of religion/spirituality in the context of genetic counseling: health professionals' experiences in an Islamic country

Khadijah Bakur[1,2,3*], Jumana Al-Aama[3,4], Zuhair Alhassnan[5], Helen Brooks[6], Tara Clancy[7], Saud Takroni[8], Fiona Ulph[9]

ABSTRACT

Background: Religion/spirituality plays a vital role in most aspects of Muslims' lives. However, there has been little research on the part of religion/spirituality in health professionals' clinical experience with patients with genetic disorders, including long QT syndrome.

Methods: This qualitative study explored health professionals' views working in Saudi Arabia concerning the role of Islam in their clinical practice. Semi-structured interviews were undertaken with 12 health professionals from two cardiogenetic centers in Saudi Arabia.

Results: The participants included clinical geneticists (4/12), genetic counselor (1/12), molecular geneticists (2/12), cardiologists (3/12), and patient coordinators (2/12). The data were analyzed using thematic analysis, and three main themes were identified: (1) the value attributed to religion/spirituality in the context of genetic counseling, (2) professional and patient-level barriers to formal religious assessment and conversations in the context of genetic counseling, and (3) incorporating religion/spirituality into genetic counseling sessions.

Conclusion: The study sheds light on the advantages of using informal religious language to establish rapport and build trust between patients and health professionals in genetic counseling. It also draws attention to the importance of exploring patients' willingness to discuss religious issues. Participants identified a lack of appropriate training as a significant barrier to attending to patients' religious/spiritual needs during genetic counseling.

Keywords: Islam, religion/spirituality, genetic counseling, Saudi Arabia, long QT syndrome, lived experience.

Introduction

Few studies have investigated the impact of religion/spirituality in genetic counseling (1). Overall, the available evidence suggests that patients vary in the extent to which their decisions and risk perceptions are influenced by their religion/spirituality (1). However, patient's religion/spirituality has been shown to sometimes lead to an aversion to seeking medical advice, affecting their ability to cope with the diagnosis and their subsequent medical decision-making process (2); thus, it is vital to address the religious issues in the patient-clinician relationship (3). Although genetic health professionals understand that religion/spirituality values are significant for many patients, influencing their decision-making and coping processes, there remains limited evidence on health professionals' views regarding the impact of patients' religiosity/spirituality on counseling sessions. Reis et al. (4) conducted a cross-sectional study on members (127/633) of the National Society of Genetic Counselors in the USA to explore genetic counselors' attitudes regarding spiritual assessment and levels of comfort in performing such assessment. An important finding from the study of Reis et al. (4) was that 59% of the participants performed religious assessments during their

Correspondence to: Khadijah Bakur
*School of Biological Science, Faculty of Biology, Medicine, and Health, University of Manchester, United Kingdom, Department of Genetic Medicine, King Abdulaziz University Hospital, Saudi Arabia, Princess Al-Jawhara Centre of Excellence in Research of Hereditary Disorders, King Abdulaziz University, Saudi Arabia.
Email: k.bakur@gmail.com
Full list of author information is available at the end of the article.
Received: 05 August 2020 | **Accepted:** 18 September 2020

clinical consultation, 76.4% due to the patient raising the issue, and 29.9% being discussions concerning the end of life decisions. The genetic counselors cited a lack of time, proper training, and knowledge of how to use the information as barriers to perform spiritual assessment and perceived client discomfort with the subject. This reveals that, in most of the cases, if religion/spirituality assessment was completed, it was patients' led. Findings from Reis et al. (4) suggest that personal spirituality and religious beliefs had a limited impact on the clinical practice of introducing spiritual assessment as a component of genetic counseling sessions among those identified as religious and non-religious. Reis et al. (4) were in line with other studies in the literature supporting the observation that, for most genetic health professionals, religious beliefs did not affect their ability to remain non-directive during genetic counseling sessions (5). However, the other studies have reported genetic counselors, and other genetic professionals are at high risk of experiencing internal conflict (6-8), which can contribute to conflict during counseling sessions. For example, there is a danger that genetic counselors might impose their personal religion/spirituality beliefs onto their patients (9,10).

Moreover, others might struggle to reconcile their faith with their profession, affecting health professionals' professional satisfaction (11). This makes it essential not only to investigate health professionals' experience of the impact of patients' religion/spirituality in the context of genetic counseling but also to investigate the impact of genetic professionals' religion/spirituality on the counseling they deliver. The previous studies showed that health professionals' religiosity/spirituality could impact the genetic counseling sessions, which could affect patients' satisfaction with the quality of the services provided to them. However, those findings should be interpreted with caution, not only because those studies targeted specific populations (e.g., USA population), but also the differences in previous studies could be attributed to many factors. The studies varied in their methodology and employed different measures. Individuals also tend to interpret religiosity and spirituality differently, complicating data gathering, which is considered a limitation of studies that rely on self-reported measures (4,12). Few studies investigated the role of religion/spirituality in health professionals' experience in the Islamic population; those were in contexts other than genetic counseling, e.g., Al-Yousefi (13). This current study aimed to explore the health professionals' experience of the role of patients' religion/spirituality in genetic counseling sessions, particularly concerning medical decisions. It also examined the impact of health professionals' own religion/spirituality on the provision of counseling to such patients, including the interplay between the patient's and the professional's beliefs when providing services to the targeted population. This study is a part of a broader study investigating the role of Islam on the lived experience of Saudi patients with long QT syndrome (LQTS) (the study that examined patients' perspectives is published elsewhere). LQTS, a group of cardiac arrhythmias disorders causing severe cardiac manifestations with sudden death (14), was chosen for this project, as there an increased number of Saudi patients diagnosed with LQTS (15). This led to establishing two cardiogenetic research centers in Saudi Arabia to further investigate the clinical, molecular, and psychological aspects of LQTS, among other cardiogenetic disorders, to provide culturally sensitive diagnostic and preventative counseling services.

Subjects and Methods

The study aimed to explore health professionals' perspectives concerning the role of religion/spirituality in Saudi patients with LQTS. A qualitative approach was chosen to answer whether or not, why, and when health professionals engage in religious assessment and conversations with their patients in the context of LQTS and how they manage such discussions. The study also aimed to explore the role of health professionals' religion/spirituality when dealing with Muslim patients and explore the influence of patients' religious beliefs on coping skills and medically related decision-making. Semi-structured interviews were implemented as a data collection tool; this method is a flexible and powerful tool for eliciting data, which enables the researcher to investigate individual perspectives in depth (18). As health professionals were expected to have limited time during working hours, the study used face-to-face and telephone interviews to increase the sample size (18). The participants were recruited purposively from all the cardiogenetic clinics in Saudi Arabia, depending on their specialty and experience working with patients diagnosed with LQTS. A purposive sampling was considered to be appropriate because the study targeted health professionals from different backgrounds, namely a heterogeneous population, working at separate cardiogenetic clinics (16), and because the researcher was interested in selecting interviewees who would provide in-depth and appropriate data, due to their experience of the topic in question (17). This approach to the sampling was also used due to the limited number (16) of professionals in the target population working with LQTS patients, as there are currently only two cardioenetic centers in Saudi Arabia. The inclusion criteria consisted of being a health professional with experience of working with patients with LQTS in Saudi Arabia. The participants were required to be fluent in Arabic or English. Religiosity was not an inclusion criterion since many non-Muslim health professionals care for patients with LQTS in Saudi Arabia, and one of the objectives of this study was to explore the interplay between health professionals' and patients' religiosity during genetic counseling sessions. The health professionals, who worked at the cardiogenetic clinic but had no experience of working with patients diagnosed with LQTS, were excluded from the study. The head of each cardiogenetic clinic sent an invitation letter, which included an information sheet, a consent form, and the researcher's contact information, to all eligible participants ($N = 15$). The interested parties ($N = 12$) then

contacted the researcher to learn more about the study and to arrange a time and date for their interview. According to the participants' preference, seven semi-structured interviews were conducted face to face. Five were conducted via telephone because the latter participants had a limited amount of time during their working hours or because they resided outside Saudi Arabia during the study period.

The interview guide (Appendix A) was designed by the main researcher (KB), an experienced Saudi genetic counselor. This researcher was supported by the research team, including an expert in qualitative research, genetic counseling, and public health, who reviewed the interview guide to confirm that the questions were appropriate for addressing the research aims, in line with good practice (18). Furthermore, in line with good practice (18), the local Saudi supervisors reviewed the interview guide to ensure that it reflected the target population's culture. The participants were asked about their specific roles in the cardiogenetic clinic and then reflected on their perspective on religion/spirituality in health. The guide also covered the participants' experiences regarding their patients' religiosity and spirituality. Furthermore, the participants were asked about the discussion of religious issues in their clinical sessions and the impact of their own religion/spirituality on counseling patients with LQTS.

The researcher (KB) conducted the interviews. She explained the aims and objectives of the research to the participants. She informed them of their rights, including that, as volunteers, they were free to withdraw from the study at any time, up to the point at which the data were pseudo-anonymized (2 weeks after the interview). To ensure confidentiality, face-to-face interviews were conducted at secured research clinics in both centers, with participants giving written consent. Telephone interviews were undertaken in secure research cubical at the University of Manchester. The participants were asked to provide verbal consent and be instructed to choose a quiet and private place and be alone during the interview. Each participant was interviewed once, for an average of 30 minutes, as interviews ranged between 15 and 60 minutes. The interviewer used the participants' responses to guide the order of questions and probed further to obtain additional depth and clarity. All interviews were digitally audio recorded. Due to a number of the participants being known to the researcher, KB minimized the risk of coercion by clarifying her role as a researcher in this setting and maintaining the researcher's stance in both her language and attitude. She was also aware of the importance of verifying intended meanings from both parties, to avoid misinterpretations and any inadvertent changes to meaning (19).

All interviews were conducted in English, apart from (as requested by the interviewees) two in Arabic, with all transcribed in the interview's language. The Arabic transcripts were subsequently translated to English by the interviewer, a bilingual, and Saudi, which also ensured familiarity with the participants' culture. A professional translator, who is working independently from the research team, checked the translation to ensure the accuracy of the translation (20). Field notes taken by KB were written in English and transcribed.

KB pseudonymized the data following the guidelines set out by the UK Data Service (Ukdataservice.ac.uk). As the research query was exploratory and experiential, thematic analysis was considered a suitable approach in enabling the researcher to identify the meaningful patterns across the data in a systematic manner (21); this helped to identify shared beliefs and attitudes among health professionals concerning the research aim. The research aimed to explore individual experiences within a contextualism position (22). To ensure a rigorous analysis, the researcher familiarized herself with the data by reading and re-reading the transcripts and making written notes on the individual transcripts and the entire data set to obtain more insight. The notes were shared with the supervisory team to prepare for the initial coding phase (21). During the initial coding, the researcher identified codes relevant to the research objective, reflecting the participants' experiences. After coding the entire data set, the researcher constructed potential themes by reviewing the codes to identify similarities and differences. In this phase, the researcher looked for repeated patterns capturing essential meanings in the data set related to the research question inquiry (21). The identified individual themes were distinctive while being related, relevant, and answering the main research question (21). During the following phase, the researcher and members of the research team with expertise in qualitative research (HB and FU) reviewed the potential themes in relation to the codes. This phase involved relocating codes under different themes, splitting themes, and collapsing other themes together. The second stage of this phase involved reviewing the final themes concerning the complete data set (21). This was followed by defining and naming the themes, with each having a specific focus related to, but not overlapping with, other themes while building on a previous theme.

KB employed an inductive approach in analyzing the data, with the identified codes and themes being data-driven (21). This helped to prioritize the data-based meaning rather than predetermined theories (21). Inductive thematic analysis identified different perspectives and experiences on the role of religion in genetic counseling. The researcher moved between semantic and latent approaches when analyzing the data, which helped to draw broader assumptions underpinning what participants reported (21).

As the research team is a multidisciplinary team, with members from different religious backgrounds, it is thought that the interview guide and analysis process may have been influenced by their experiences drawing on psychological theories.

Results

Of the 15 eligible participants, 12 were interviewed, consisting of three cardiologists, four clinical geneticists; one genetic counselor; two patient coordinators, and two molecular geneticists (see Table I for participants' characteristics). Three eligible participants (molecular geneticists) decided against participation and did not contact the researcher to arrange an interview date.

Apart from the two non-Muslims, all participants considered themselves moderate in their religiosity; where they reported committing to the main religious practices and occasional optional practices. The health professionals shared differing kinds of information with their patients, depending on their specialty and role at the center. However, their speciality exerted some influence on the type and nature of the conversation between themselves and their patients, including religious discussions. Cardiologists had the least cause to have such discussions as they mainly discuss diagnosis and treatment modalities. Simultaneously, clinical geneticists and genetic counselors spend more time discussing recurrence risk, inheritance, prenatal testing, and reproductive options, having a higher chance of involving religion/spirituality in the discussion. The differences between roles contributed to citing some participants more than others in the results below. Since the molecular geneticists had no frequent contact with patients, their interviews gave perspectives on the context, in which services were provided for patients with LQTS. Using thematic analysis, the researcher identified three main themes (Figure 1).

Theme 1: The value attributed to religion/ spirituality in the context of genetic counseling

The participants acknowledged the positive impact of religion/spirituality on their health for both them and their patients. From their perspective, religion/ spirituality generally helped to overcome the difficulties faced by patients and career-related challenges for health professionals.

Religion/spirituality and health: multidimensional relationship

When asked about their general perspective on the relationship between religion/spirituality and health, the majority reported that religion influences health through a psychological pathway. Health professionals reported that the influence is applicable for their patients as well as themselves. "Being religious helps me to undergo hardships including illness of myself or loved ones, it's like the light at the end of the tunnel, it helps us to move on and be stronger through it [illness]" (#6, Female, Clinical Geneticist, Muslim). From their perspective, religion provides individuals with acceptance of their illness, which helps them to feel comfortable and empowered in dealing with their problems with satisfaction. "If you are a believer you will trust your god that he will take care of you, you just need to do your part, what your doctor tells you to do, yah and do what it takes you to be healthy" (#4, Male, Clinical Geneticist, non-Muslim). Nevertheless, participant #9, among other participants, viewed that both religion/spirituality and illness influenced each other. "I think illness makes my faith stronger. With a hardship, one tends to try to find all the help they could get, and the first thing is to ask God as he is our creator, and he can make any hardship disappear" (#9, Female, Patient Coordinator, Muslim). However, participant #11 considered the impact as not being linked to formal religion but rather to being spiritual. "I think it is not specific to religion, but it is more of having belief in something, it is about how the person feels, I mean if they feel empowered and feeling positive about what they believe in then this will help them" (#11, Female,

Table 1. *Participants' characteristics.*

Participant number	Gender	Nationality	Degree	Specialty	Year in practice	Religion
1	Male	Saudi	MSc	Genetic Counselor	4	Muslim
2	Male	Saudi	MD	Clinical geneticist	15	Muslim
3	Male	European	MD, Board certified	Cardiologist	40+	Non-Muslim
4	Male	Indian	MD, Board certified	Clinical geneticist	12	Non-Muslim
5	Male	Saudi	MD, Board certified	Cardiologist	17	Muslim
6	Female	Saudi	MD, Board certified	Clinical geneticist	5	Muslim
7	Female	Saudi	MSc	Molecular geneticist	10	Muslim
8	Female	Jordanian	MSc	Patient coordinator	8	Muslim
9	Female	Saudi	MSc	Patient coordinator	9	Muslim
10	Female	Saudi	MSc	Molecular geneticist	7	Muslim
11	Female	Saudi	MD, MSc	Clinical geneticist	6	Muslim
12	Male	Saudi	MD, Board certified	Cardiologist	25+	Muslim

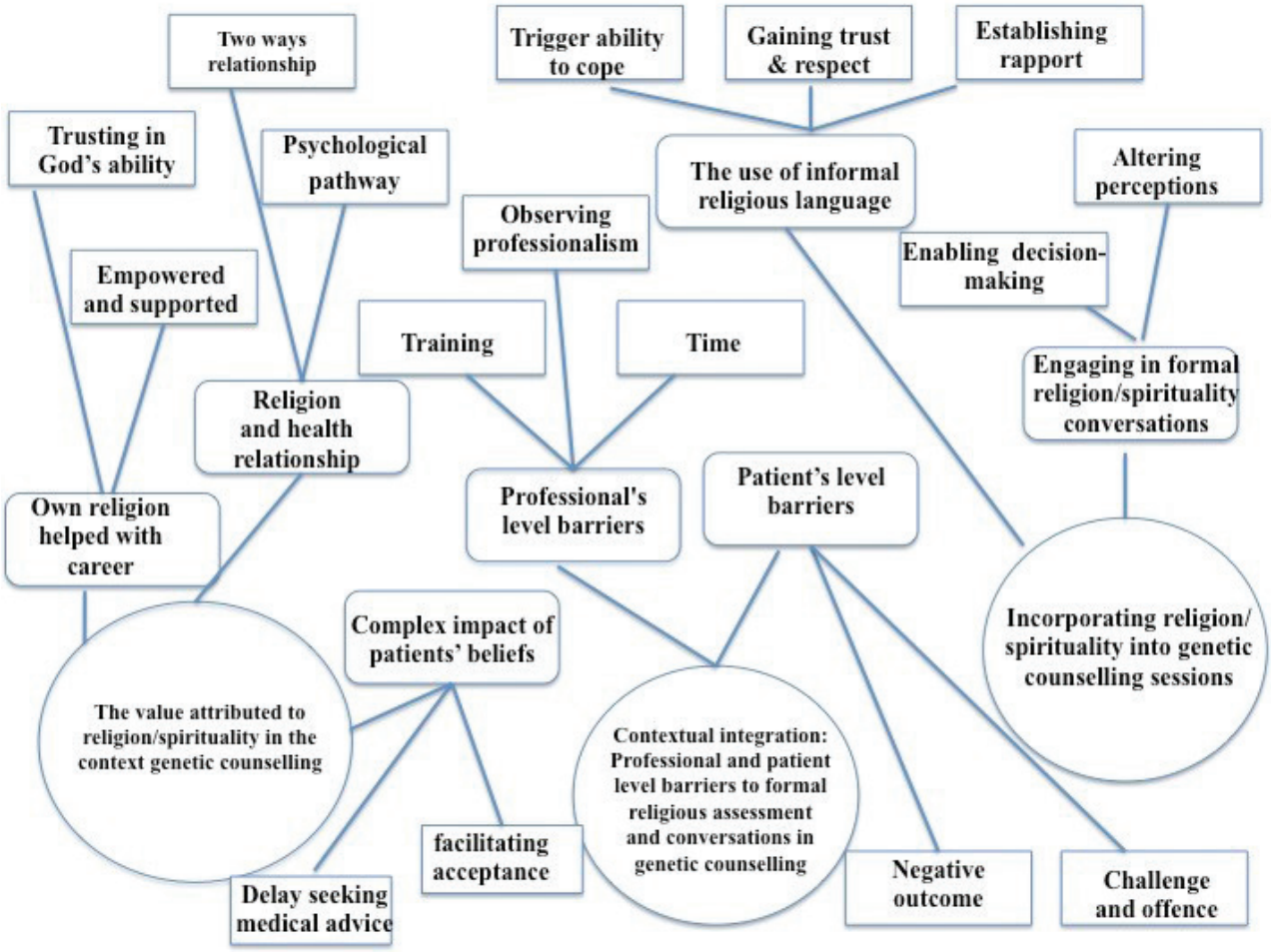

Figure 1. *Thematic analysis map.*

Clinical Geneticist, Muslim). Participant #11 perspective could result from having recently finished her training in a diverse community. Her view was only shared by one of the non-Muslim health professionals.

Health professionals' own religion/spirituality beliefs helped with facing career-related difficulties during counseling sessions

Health professionals reported that as most of the genetic disorders, including LQTS, have no cure, this sometimes makes them feel having less to offer to their patients. However, they reported that their religion/spirituality helped them to overcome feeling helpless during counseling sessions. Apart from one Muslim and one non-Muslim health professionals who claimed that religion/spirituality had no impact on their career, all health professionals in this study claimed that their own religion/spirituality helped them feel empowered, supported, and content during counseling sessions. "Yah, I don't feel inadequate I know there is greater power, yah that's for me, this is how my religion and spirituality helps me in my profession" (#1, Male, Genetic Counselor, Muslim).

Another example of how health professionals' own religion/spirituality helped them with counseling sessions is trusting God's ability to cure patients. "When you believe there is a greater power than science and medicine and everything; that gives you always hope, so even if all the studies said that this child with this diagnosis would never survive, there are miracles and exceptions, I believe in that, that is not false hope" (#11, Female, Clinical Geneticist, Muslim). One of the non-Muslims' health professionals, who had a belief system around spirituality, stated that his own religious/spiritual beliefs had helped him with his career, believing that it strengthened his ability to overcome difficulties and reminded him of the benefits. Thus, although most of the participants in this study were Muslims, these data suggest that the impact is wider than Islam. "My religion always reminds me of why I became a doctor at the first place; this helps me to face any difficulties related to my career" (#4, Male, Clinical Geneticist, non-Muslim).

Complex impact of patients' religious beliefs in the context of genetic counseling

When asked about their experience of the impact of patients' religious beliefs on their lived experience with

LQTS, the participants reported a complex impact. All of the participants emphasized the role of a belief in fate in facilitating acceptance of the diagnosis and coping with sudden death. Muslim and non-Muslim health professionals shared the same views. "It was along the line that they stated that it was their fate that was happening to them, the fate was commonly stated to help them" (#3, Male, Cardiologist, non-Muslim). Participant #12 had experience working with non-Muslim patients during his training abroad a long time ago, and he acknowledged the positive impact of belief in fate on Muslim patients with LQTS. "It is difficult for patients with LQTS to adjust to the idea of being at risk for sudden death, it is even difficult if your child has the risk, but Muslim patients believe in fate, and that helps a lot to cope with the risk of sudden death" (#12, Male, Cardiologist, Muslim). However, despite acknowledging this primarily positive impact of fate, some health professionals raised concerns that misinterpretation of fate could occasionally lead LQTS patients to delay seeking medical advice. "It is rare [negative impact], but sometimes the belief in fate hold patients back from looking for the cause of their symptoms" (#6, Female, Clinical Geneticist, Muslim). A number of interviewees expanded on this potentially negative contribution, and they found it usual for some Muslims to interpret any unexplained problem as fate so not wishing to interfere with God's will. The participants observed that this arose in families experiencing a sudden death without understanding that the disorder caused this. Both Muslim and non-Muslim health professionals shared this view. "You can find families where they have this problem [sudden death], and they cannot figure out an obvious reason to cause that problem, so they think that this is their fate, they accept that and carry on with their life without looking for cause" (#8, Female, Patient Coordinator, Muslim). "They believed this is their fate that their children had a sudden death, so they did not want to interfere with what God wrote for them but when they went to the doctor, and they knew it is the LQTS that caused sudden death then here their fate helped them to accept and adhere to treatment" (#3, Male, Cardiologist, non-Muslim). Although belief in God's power empowered both the patients and most of the health professionals and helped them to overcome problems in the context of genetic counseling, belief in fate was demonstrated to have a complex impact on the patients, as it sometimes caused them to delay seeking medical advice.

Theme 2: Contextual integration: professional and patient-level barriers to formal religious assessment and conversations in the context of genetic counseling

All of the health professionals agreed that the initial religion/spirituality assessments were lacking, due to barriers related to both the patients and the health professionals.

Professional's level barriers

All health professionals in this study acknowledged the importance of attending to patients' religious needs; however; generally, none performed an initial religiosity assessment. "I never performed an initial assessment of religiosity" (#2, Male, Clinical Geneticist, Muslim). The only exception was one geneticist, participant #11, who was trying to hold on to the practice of religious assessment but reported periodic assessment. "I was trained to do this initial assessment; you know we deal there [in a western country where she had her training] with patients from different backgrounds; those patients hold different faiths or even does not have any religious faith" (#11, Female, Clinical Geneticist, Muslim). The participants identified a number of practical barriers to engage in formal religious assessment and conversations. All of the health professionals claimed that a lack of appropriate religious training was a shortcoming of medical training, "As a doctor, we should separate emotions from caring for patients, this is how we were trained" (#3, Male, Cardiologist, non-Muslim).

The participant #11 had, unlike the others, recently finished her training abroad and reported that this had taught her to practice an initial assessment of religiosity. However, she claimed that training did not teach them how to conduct religious conversation properly and how to integrate the information generated from such discussion into the management plan. "We did not train properly in that regard [Dealing and engaging in formal religious conversation], we do not know how to use the information in a clinical context" (#11, Female, Clinical Geneticist, Muslim). Moreover, the time factor was cited as a barrier by the majority of the participants, and limited time in consultations means that medical issues are prioritized. "It is not the right time to be discussing religion in detail with a patient. What is important now is the medical information" (#6, Female, Clinical Geneticist, Muslim). The interview data also suggest that the participants' unwillingness to initiate religious discussions and minimized formal religious conversations originated from other different avenues, such as reserving their image as health professionals at the eye of patients as well as in their own eyes by being professional and focusing only on medical aspects in delivering counseling sessions. "I think we do not want our image as professionals to be affected in front of the patients; we respect the boundaries" (#5, Male, Cardiologist, Muslim). Observing their specific roles as health professionals was another reason for not initiating formal religious conversation. "I never assess patients' religiosity or raise religious conversation; it is not my duty" (#4, Male, Clinical Geneticist, non-Muslim). Moreover, health professionals believe that religion is a personal matter, and they do not have the right to discuss it. "A person's religious practices and beliefs are between them and God" (#6, Female, Clinical Geneticist, Muslim).

Patient's level barriers

All participants reported not engaging in religion/spirituality conversations to avoid accidentally imposing their own religion/spirituality beliefs on patients. An important factor that contributed to their attitude

was that they had been trained not to be directive in counseling sessions. “I don’t share my beliefs, so it does not affect the patient in any way” (#1, Male, Genetic Counselor, Muslim). Moreover, health professionals also reported being very cautious and vigilant to the danger of challenging patients’ religious beliefs during the formal religious conversation, which could result in a negative outcome. “If you challenged someone religious believes you might lose them” (#2, Male, Clinical Geneticist, Muslim). Participant #5 further elaborated on how the doctor-patient relationship could be impacted by challenging a patient’s religious beliefs because Muslim patients see religion as an identity. “When we are in a formal religious conversation, and if by any chance, if I challenged their religious beliefs, they will doubt my religiosity they will think that I am not Muslim, I think they would be so much offended because they will perceive this as not criticizing what they believe, they will think I am criticizing the religion itself, especially those who are conservatively religious” (#5, Male, Cardiologist, Muslim). Some of the barriers to engaging in conversations regarding religion/spirituality can, therefore, be overcome or addressed in a way that facilitates a greater engagement with the matter, when appropriate. Among how this can be achieved is providing proper medical training that focuses on managing religion/spirituality conversations, rather than merely training health professionals to perform an initial religion/spirituality assessment. This could contribute to better patient outcomes in counseling sessions.

Theme 3: Incorporating religion/spirituality into genetic counseling sessions

Although there is currently a lack of religion/spirituality assessment, due to uncertainty regarding how the information obtained from inquiring about patients’ religion/spirituality should be used, the health professionals involved in the present study felt more able to engage in discussions of religion/spirituality in specific contexts, such as addressing a patient’s religious concerns if the patients raised it, or when the discussion involved reproductive issues.

Engaging in formal religion/spirituality conversations

When it comes to proper religious discussion and assessment, all participants generally agreed that it is rare for the patients to raise religious conversations during counseling sessions in the context of LQTS, except in specific circumstances, where religious beliefs were considered to have a contribution. “Discussing reproductive options will spontaneously make the patients to place religious conversation on the table” (#1, Male, Genetic Counselor, Muslim). All health professionals in this study acknowledged the importance of attending to patients’ religious needs; however; all participants reported not usually initiating religious conversations but rather attending to patients’ requirements in that regard. “I prefer to leave it to the patient if they want to discuss any religious beliefs related to their diagnosis or management, or in the case, I feel it is appropriate” (#2, Male, Clinical Geneticist, Muslim). Even when the health professionals considered it appropriate to engage in formal religious discussion, they emphasized the importance of the patients’ responsiveness to enter into a formal religious discussion. “Even if you sense it is appropriate to discuss religious beliefs, it is vitally important to make sure the family is willing to get in religious conversation, I mean as a formal conversation” (#2, Male, Clinical Geneticist, Muslim).

Participants reported their initiating of formal religious conversations to be limited in nature and performed in specific situations; i.e., enabling patients to make decisions regarding invasive procedures or altering their religious beliefs concerning the cause of the disorder. All the Muslim health professionals viewed it as appropriate, in the context of LQTS, to remind patients to perform religious practices (mainly the Estikhara prayer) when making decisions regarding invasive procedures, i.e., implanting an ICD. The Estikhara prayer is a special prayer to find guidance from God for making the best choice. This prayer will not tell the performer exactly what to choose but rather to give inner peace that God will, in all events, dictate the best solution for him/her. Health professionals reflected on the positive impact of the Estikharah prayer on patients’ decision to undergo a procedure. “The only one related thing we do is to ask them to make (Estekharah), and we only do that if we want to implant a defibrillator, but not with medications, this helped them to accept the procedure” (#12, Male, Cardiologist, Muslim).

About preimplantation genetic diagnosis (PGD), the health professionals felt that the impact on the decision-making process came not only from the religious ruling itself but also from the individual’s interpretation. This led them to explain the religious ruling regarding the PGD in a non-directive way, to enable patients to make an informed decision. “When it comes to reproductive option, here where patients’ religious beliefs might be problematic, some of the patients think that PGD is not permissible in Islam, so we have no option but to discuss the religious ruling to clarify these points to them and most of them then agree for prenatal testing or PGD” (#6, Female, Clinical Geneticist, Muslim). Participant #1 outlined the approach taken by healthcare professionals to alter patients’ beliefs regarding the cause of their diagnosis without the risk of challenging their beliefs, particularly in the context of LQTS, in the absence of any obvious pattern of inheritance in the family, where symptoms could be attributed to supernatural forces. “I acknowledged her belief, I had to do that to win her, I acknowledged that evil eye is something cited in religion and I told her that there is scientific explanation too, I also told her that I understand it might be difficult for her as a mother to understand de novo mutations and I tried

my best to answer all her questions" (#1, Male, Genetic Counselor, Muslim).

The use of informal religious language

The participants distinguished between the use of informal religious language during consultations and formal religious conversations. In explaining the differences, "It is not like we never talk religion, but we do that mainly casually, you know we as Saudi and Muslim; religion is always part of our everyday conversation and patients understand that this is far from being a formal discussion, it is not like in western countries" (#1, Male, Genetic Counselor, Muslim). Participants used informal religious language to help establish a rapport, where like all the Muslim health professionals in this study, participant #5 reflected on the role of informal religious language for gaining patients' trust and respect, as well as establishing rapport and increasing patients' willingness to collaborate with the medical team. Participants reported that to be attributed to the high importance Muslims place on their religion. "If patients noticed you using the [informal] religious language that will help them to trust you more and be open to cooperating with you" (#5, Male, Cardiologist, Muslim). Participants also used informal religious language in the context of LQTS to trigger patients' ability to cope. A typical scenario was when health professionals were about to deliver unfavorable news. "Like in the clinic when the patient starts to cry I usually remind them that this is something from God and this helps them so much I can see the impact" (#9, Female, Patient Coordinator, Muslim). Furthermore, health professionals employed informal religious language to help explain a diagnosis when patients failed to understand the scientific explanation behind the disorder. As it is difficult for some patients to understand genetics, they get relieved by the religious explanation, for example, reminding them that God created them and that their disease is from God. Failing to understand the diagnosis could have a negative impact on the patients' coping mechanism. The participants used this approach because the Saudi patients place importance on religion. "When we discuss scientific facts for patients especially with genetics, it is like something that is not real for them it's like an imaginary thing to them, so in this case, I usually try to link to their religious beliefs because this is something that they believe in and they feel it is something tangible for them, and this helps them to understand and cope better" (#1, Male, Genetic Counselor, Muslim). The health professionals working in the context of LQTS distinguished between the use of informal religious language and formal religious conversations. Religion/spirituality conversations primarily sought to enable the patients to make decisions regarding invasive procedures or to alter patients' religious beliefs regarding the cause of the disorder.

Discussion

This study explored health professionals' perspectives concerning the role of religion/spirituality in the context of LQTS. It identified the fact that health professionals dealing with Saudi patients with LQTS generally have a positive experience of the role of religion in the context of genetic counseling. This research, therefore, supported the previous studies involving Muslim populations and confirmed that health professionals view religion as an essential coping strategy for helping Muslim patients to accept their diagnosis (13) and to enhance their psychological well-being (23). However, this study identified the fact that the misunderstanding, or misinterpretation, of religious rulings or beliefs, can be challenging and can cause patients to avoid taking medically related decisions that are in their best medical interest. The impact of this misinterpretation of religious rulings, particularly concerning PGD, was reported among Saudi patients with genetic disorders (24).

The failure to initiate religion/spirituality assessments identified by the current study concurred with the findings of other studies conducted in the context of genetic counseling (11,4), as well as among Saudi health professionals in clinical settings, other than genetic counseling (13). The lack of such assessment, due to uncertainty of what to do with the information obtained from inquiring about patients' religiosity, while feeling more able to address a patient's religious concerns if the patient raised the subject, was also a concern reported by genetic health professionals in the previous literature (11,4). The health professionals involved in the current study distinguished between engaging in formal religious discussion and employing informal religious language to support Muslim patients during consultations. The study found that the use of informal religious language built trust. It strengthened doctor-patient relationships and communication, concurring with the findings of other studies that investigated the factors affecting the relationship between health professionals and their patients in the Saudi and Islamic context. For example, in their cross-sectional quantitative study, Al Ali and Elzubair (25) provided evidence that using informal religious language as part of the culture, among other factors, significantly improved the communication skills of physicians and contributed to better patient outcomes.

In terms of formal religion/spirituality discussions, the participant in the present study reported that informal engagement discussion of religion/spirituality was rare and that there was a preference to limit such conversations to specific issues. Moreover, the current study identified that such practice sought to enable patients to make decisions regarding invasive procedures or to alter their religious beliefs concerning the cause of the disorder. Limiting religion/spirituality discussion to specific issues is a common practice among health professionals, in the context of genetic counseling (4). The current study also observed that patients rarely raised formal

religious discussions in the clinic and discussions that did occur primarily concerned prenatal testing and PGD. This resonated with the study conducted in the United States by Curlin et al. (26), in which only a small number of physicians reported that patients mentioned religion during a consultation in a general clinical context. On the contrary, Al-Yousefi (13) conducted a quantitative study that investigated the role of religion in the attitudes of physicians in Saudi Arabia and found that the majority reported that patients mentioned religion in their clinical consultations. Al-Yousefi (13) identified the differences between her study and that of Curlin's et al. (26) as relating to the specific differences between Saudi Muslims and American patients. However, Al-Yousefi's (13) claim does not explain the difference in her study and the current study regarding the frequency of the patients raising religious issues in the clinic. A possible reason could be the fail of Al-Yousefi's (13) study to differentiate between the formal and informal use of religious language, resulting in a lack of clarity concerning content counted as referring to religious issues. Al-Yousefi's (13) findings can be misinterpreted as the majority of the patients in Saudi Arabia are willing to discuss the religious problems during clinical consultations formally.

The barriers to discuss religion/spirituality cited by participants in this study were in line with the other studies in the literature, including (1) risk of imposing own views causing offense (27) or challenging patients' beliefs unintentionally, leading to a serious negative impact on patient care (28); (2) time constraints (13,29), where the medical discussion took priority if only limited time available (4); (3) feeling unequipped (4); and (4) lack of appropriate training (4,13,26). Concerns regarding the appropriate training highlight the importance of investigating medical training programs. This was supported by Kub et al. (30). They concluded that it is routine for many hospitals to enquire about patients' religious affiliation on admission, but that this may not provide an adequate understanding of how to fulfil patients' spiritual needs.

The study is one of the first to contribute to an understanding of the perspective of health professionals regarding the role of religion in the context of LQTS in Saudi Arabia. A strength of the study was recruiting participants from all possible sites. As most of the studies investigated the role of religion/spirituality in the context of genetic counseling from health professionals' perspective focused on genetic health professionals, an added strength of the current study was investigating diverse perspectives as this study involved cardiologists and patient coordinators. Moreover, the interviewer was able to generate in-depth data through phone interviews similar to face-to-face interviews. This supports the literature arguing the benefits of phone interviews in qualitative research. However, due to the small sample size, the findings from this study may not be transferable to the broader Saudi and Islamic population. In addition, all the Muslim health professionals in this study were Sunni, and therefore, it should be considered that those from different Islamic sects might differ in their beliefs and attitudes. The cardiogenetic clinic in this current study is only every month basis. Therefore, due to this study being dependent on participants' interviews, it was not possible to determine the extent to which their accounts were influenced by hindsight. Thus, the use of non-participant observation might have been beneficial to explore the issues identified in the study in more depth and real-time. Furthermore, the time restraints of the health professionals, mainly the cardiologists, resulted in the interviews being relatively short (i.e., one lasted only 15 minutes), which may also impact on the depth of the interview and richness of the resulting data. It should also be noted that the researcher is a genetic counselor, who has worked at one of the centers, in which the participants were recruited, and who were therefore known to her. Although all measures were taken to prevent the risk of coercion, this is still considered a potential limitation to the study. The current study suggests that health professionals can draw on the belief in fate as an essential principle and a pillar of Islam when dealing with Muslim patients, thereby assisting Muslims confronting the risk of sudden death. The health professionals in the current study emphasized the importance of ensuring patient willingness to engage in formal religious conversation, particularly as the everyday use of religious language can be erroneously taken as readiness to engage in formal discussion. Findings also highlighted the importance of educating patients regarding the religious rulings impacting on medical management, so enabling patients to make informed decisions while avoiding bias. Although this was a sophisticated skill, it did not contribute to a negative impact. Moreover, this study emphasized the need for a critical evaluation of the training curricula concerning dealing with religious issues in clinical consultations. This includes the international collaboration of medical professionals and religious scholars from different faiths to design appropriate training programs for the assessment and management of religious issues in clinical practice. Similarly, national training programs should integrate religious training into their initial plans to help medical students in dealing with specific religious issues in clinical settings.

Conclusion

The participants of this study found that the use of informal religious language provided their patients with psychological support, which forms an essential aspect of holistic care. The study noted that this provision was not specific to the context of genetic counseling in Saudi Arabia (25). The health professionals showed respect toward patients' religiosity. They strove to commit to the best medical practice and holistic patient care, being willing to attend, whenever appropriate, to the religious and spiritual needs of patients. This study also revealed that health professionals working in Saudi Arabia in the context of cardiogenetics experienced religion/

spirituality discussions taking place during consultations as a means of facilitating interactions with patients rather than as part of an initial assessment or history taking.

Furthermore, the health professionals in this study cited professional's and patient's level barriers to engaging in formal religion/spirituality assessment and conversations drawing attention to avoid imposing their religious beliefs to prevent driving patients away from effective medical treatment and any consequent risk to health. The study emphasized the value of exploring patients' perspectives on the role of health professionals' religion/spirituality in the context of genetic counseling as well as exploring patients' attitudes regarding religion/spirituality assessment and conversations. The attitudes of Muslim genetic health professionals regarding religion/spirituality and health when dealing with non-Muslim patients in Saudi Arabia are also worth exploring, to identify any further related challenges.

List of Abbreviations

LQTS	Long QT syndrome
PGD	Preimplantation genetic diagnosis

Funding

None.

Declaration of conflicting interests

The authors of this article have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

Ethical approval

The Ethics Committee approved this study at the Unit of Biomedical Ethics, King Abdulaziz University (ref 494-16: dated Jan 1, 2017); 2) the Research Ethics Committee at King Faisal Specialist Hospital and Research Centre (ref C30/576/39: dated May 21, 2018); and the University Research Ethics Committee at the University of Manchester (ref 2018-5666-7916: dated Dec 20, 2018).

Consent for publication

Informed consent was obtained from the participants.

Author details

Khadijah Bakur[1,2,3], Jumana Al-Aama[3,4], Zuhair Alhassnan[5], Helen Brooks[6], Tara Clancy[7], Saud Takroni[8], Fiona Ulph[9]

1. School of Biological Science, Faculty of Biology, Medicine and Health, University of Manchester, United Kingdom
2. Department of Genetic Medicine, King Abdulaziz University Hospital, Saudi Arabia
3. Princess Al-Jawhara Centre of Excellence in Research of Hereditary Disorders, King Abdulaziz University, Saudi Arabia
4. Department of Genetic Medicine, Faculty of Medicine, King Abdulaziz University, Saudi Arabia
5. Department of Medical Genetics, King Faisal Specialist Hospital and Research Center College of Medicine, Alfaisal University, Saudi Arabia
6. Institute of Population Health Sciences, University of Liverpool, United Kingdom
7. Manchester Centre for Genomic Medicine, St. Mary's Hospital, Manchester, United Kingdom
8. Department of Medical Genetics, King Faisal Specialist Hospital & Research Center, Saudi Arabia
9. Division of Psychology and Mental Health, Faculty of Biology, Medicine, and Health, Manchester Academic Health Science Centre, University of Manchester, United Kingdom

References

1. White MT. Making sense of genetic uncertainty: the role of religion and spirituality. Am J Med Genet C Semin Med Genet 2009; 151(1):68–76. https://doi.org/10.1002/ajmg.c.30196
2. Kinney AY, Emery G, Dudley WN, Croyle RT. Screening behaviors among African American women at high risk for breast cancer: do beliefs about God matter?. Oncol Nurs Forum 2002; 29(5):835–43. https://doi.org/10.1188/02.ONF.835-843
3. Curlin FA, Moschovis PP. Is religious devotion relevant to the doctor-patient relationship?. J Fam Pract 2004; 53(8):632–40.
4. Reis LM, Baumiller R, Scrivener W, Yager G, Warren NS. Spiritual assessment in genetic counseling. J Genet Couns 2007; 16(1):41–52. https://doi.org/10.1007/s10897-006-9041-8
5. Wyatt A, Best RG, Vincent V, Edwards J. Religious convictions in genetic counseling: a survey of genetic counselors. J Genet Couns 1996; 5(4):236–7.
6. Bower MA, Veach PM, Bartels DM, LeRoy BS. A survey of genetic counselors' strategies for addressing ethical and professional challenges in practice. J Genet Couns 2002; 11(3):163–86. https://doi.org/10.1023/A:1015275022199
7. Cragun RT, Woltanski AR, Myers MF, Cragun DL. Genetic counselors' religiosity & spirituality: are genetic counselors different from the general population?. J Genet Couns 2009; 18(6):551. https://doi.org/10.1007/s10897-009-9241-0
8. Pencarinha DF, Bell NK, Edwards JG, Best RG. Ethical issues in genetic counseling: a comparison of MS counselor and medical geneticist perspectives. J Genet Couns 1992; 1(1):19–30. https://doi.org/10.1007/BF00960081
9. Burke MT, Miranti JG. Ethical and spiritual values in counseling, Vol. 1. Alexandria, VA: American Association for Counseling and Development;. 1992. p 126.
10. Kelly Jr EW. The role of religion and spirituality in counselor education: a national survey. Couns Educ Supervision 1994; 33(4):227–37. https://doi.org/10.1002/j.1556-6978.1994.tb00290.x
11. Geller G, Micco E, Silver RJ, Kolodner K, Bernhardt BA. The role and impact of personal faith and religion among genetic service providers. Am J Med Genet C Semin Med Genet 2009; 151C(1):31–40. https://doi.org/10.1002/ajmg.c.30193
12. Zinnbauer BJ, Pargament KI, Cole B, Rye MS, Butter EM, Belavich TG, et al. Religion and spirituality: unfuzzying the fuzzy. J Sci Study Relig 1997: 549–64. https://doi.org/10.2307/1387689

13. Al-Yousefi NA. Observations of Muslim physicians regarding the influence of religion on health and their clinical approach. J Relig Health 2012; 51(2):269–80. https://doi.org/10.1007/s10943-012-9567-z
14. Wallace E, Howard L, Liu M, O'Brien T, Ward D, Shen S, et al. Long QT syndrome: genetics and future perspective. Pediatr Cardiol 2019; 22:1–2.
15. Al-Hassnan ZN, Al-Fayyadh M, Al-Ghamdi B, Shafquat A, Mallawi Y, Al-Hadeq F, et al. Clinical profile and mutation spectrum of long QT syndrome in Saudi Arabia: the impact of consanguinity. Heart Rhythm 2017; 14(8):1191–9. https://doi.org/10.1016/j.hrthm.2017.04.028
16. Etikan I, Musa SA, Alkassim RS. Comparison of convenience sampling and purposive sampling. Am J Theor Appl Stat 2016; 5(1):1–4. https://doi.org/10.11648/j.ajtas.20160501.11
17. Onwuegbuzie AJ, Leech NL. A call for qualitative power analyses. Qual Quant 2007; 41(1):105–21. https://doi.org/10.1007/s11135-005-1098-1
18. Rabionet SE. How I learned to design and conduct semi-structured interviews: an ongoing and continuous journey. Qual Rep 2011; 16(2):563–6.
19. Hayman B, Wilkes L, Jackson D, Halcomb E. Story-sharing as a method of data collection in qualitative research. J Clin Nurs 2012; 21(1-2):285–7. https://doi.org/10.1111/j.1365-2702.2011.04002.x
20. Brislin RW. Back-translation for cross-cultural research. J Cross Cult Psychol 1970; 1(3):185–216. https://doi.org/10.1177/135910457000100301
21. Braun V, Clarke V, Hayfield N, Terry G. Thematic analysis. Handb Res Methods Health Soc Sci 2019: 843–60. https://doi.org/10.1007/978-981-10-5251-4_103
22. Madill A, Jordan A, Shirley C. Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. Br J Psychol 2000; 91(1):1–20. https://doi.org/10.1348/000712600161646
23. Momtaz YA, Hamid TA, Yahaya N. The role of religiosity on relationship between chronic health problems and psychological well-being among Malay Muslim older persons. Res J Med Sci 2009; 3(6):188–93.
24. Alkuraya FS, Kilani RA. Attitude of Saudi families affected with hemoglobinopathies towards prenatal screening and abortion and the influence of religious ruling (Fatwa). Prenat Diagn 2001; 21(6):448–51. https://doi.org/10.1002/pd.76
25. Al Ali AA, Elzubair AG. Establishing rapport: physicians' practice and attendees' satisfaction at a primary health care center, Dammam, Saudi Arabia, 2013. J Family Community Med 2016; 23(1):12. https://doi.org/10.4103/2230-8229.172224
26. Curlin FA, Roach CJ, Gorawara-Bhat R, Lantos JD, Chin MH. How are religion and spirituality related to health? A study of physicians' perspectives. South Med J 2005; 98(8):761–6. https://doi.org/10.1097/01.SMJ.0000163299.94352.A8
27. Braun UK, Ford ME, Beyth RJ, McCullough LB. The physician's professional role in end-of-life decision-making: voices of racially and ethnically diverse physicians. Patient Educ Couns 2010; 80(1):3–9. https://doi.org/10.1016/j.pec.2009.10.018
28. Phelps AC, Lauderdale KE, Alcorn S, Dillinger J, Balboni MT, Van Wert M, et al. Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists, and oncology nurses. J Clin Oncol 2012; 30(20):2538. https://doi.org/10.1200/JCO.2011.40.3766
29. Grant E, Murray SA, Kendall M, Boyd K, Tilley S, Ryan D. Spiritual issues and needs: perspectives from patients with advanced cancer and nonmalignant disease. A qualitative study. Palliat Support Care 2004; 2(4):371–8. https://doi.org/10.1017/S1478951504040490
30. Kub JE, Nolan MT, Hughes MT, Terry PB, Sulmasy DP, Astrow A, et al. Religious importance and practices of patients with a life-threatening illness: implications for screening protocols. Appl Nurs Res 2003; 16(3):196–200. https://doi.org/10.1016/S0897-1897(03)00041-7