

# Muslim patients and health disparities in the UK and the US

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This article provides a framework for understanding how Muslim identity, and the current social and political contexts in which it is shaped, affects the health of Muslims in the UK and the US, and the quality of health care they receive. Key medical and public health literature that addresses health concerns related to Muslim communities in the UK and the US is reviewed. Few data exist specific to health disparities for Muslim minorities. However, the article focuses on emerging studies concerning the consequences of “Islamophobia” for the physical and mental health and health care of Muslim families and children. We argue that, despite substantive structural differences in the health care systems of the UK and the US, social structural and political forces play similar roles in the health of Muslim children in both countries. Finally, we call for significant cultural and institutional adjustments in health care settings and further research studies to provide specific data to address health disparities for these growing and diverse populations.

health-promoting practices. This section is based on a content analysis by two authors (LDL, LLB) of references identified from a Boolean search using the terms “islam and muslim” in OVID Medline, published bibliographies related to healthcare for Muslims,<sup>5</sup> and cultural competence resources produced by private, non-profit organisations.<sup>6,7</sup> Second, we discuss emerging research frameworks for examining how Muslim experiences of religious discrimination have negative consequences for the health of, and quality and delivery of care for, Muslim families and their children. Finally, we summarise examples and recommendations for addressing the factors that result in such disparities.

## HEALTH CONCERNS RELATED TO MUSLIM COMMUNITIES

Literature addressing health concerns among minority populations rarely provides data specific to Muslims. US census data do not include religious affiliation. Instead, Muslims are often subsumed under ethnic categories such as “Arab Americans”, “African Americans” and “Asian Americans”, in contrast with “South Asians”, “Asians” and “black and ethnic minority” communities in the UK. However, 2001 UK census data have begun to fill in the picture. Compared to other religious groups, Muslims in the UK have the highest age-standardised rate of reported ill health (13% for males, 16% for females) and disability (24% of females, 21% of males), with widespread poverty and deprivation.<sup>3</sup> Muslims in the US generally have higher socio-economic status than their UK counterparts, although the range is wide.<sup>4</sup> Specific health research data are sparse, and information on Muslim youth even more limited.<sup>8</sup>

Nevertheless, certain health concerns emerge. Epidemiological literature focuses on risk factors for morbidities related to specific Muslim practices. Chief among these is the exposure of pilgrims to infectious diseases, heat and injury during the annual Hajj rites in Mecca.<sup>9,10</sup> Although the government of Saudi Arabia requires proof of vaccinations before granting a Hajj visa, adults and children have contracted influenza at the Hajj<sup>11</sup> and family members may be exposed to infectious diseases such as meningitis from returning pilgrims.<sup>12</sup> Primary care providers may be asked to give pre-travel advice to those planning to take part in the Hajj.

Fasting from food and drink from dawn to dusk during the month of Ramadan may also require health professionals to advise those with specific chronic illnesses, such as diabetes, which is common in some South Asian communities.<sup>13</sup> Fasting may also complicate drug, diet and sleep

Alleged “clashes” between “Islam” and “the West” have burst onto the front pages of English-language newspapers around the world over the past 5 years. Media reports, political rhetoric and legislative action, often citing 9/11 and 7/7, increasingly focus on Muslims as an out-group, promoting negative stereotypes of Muslims and Islam.<sup>1</sup> Yet few sources ask how such attention affects the health of Muslims, many of them children and adolescents, living in Western societies. Moreover, medical and public health literature generally address health concerns of adult Muslims, compounding the systematic neglect of children.<sup>2</sup>

Muslim communities in the UK and the US are historically, culturally, ethnically and linguistically diverse, including immigrants and the native born. Of the 1.6 million Muslims who comprise over half the UK’s non-Christian population, 74% are of Asian ethnic background, with smaller percentages of white British, white ethnic and black African Muslims. In 2001, 34% were under age 16.<sup>3</sup> In the US, of an estimated 6–7 million Muslims, the three largest ethnic subgroups are of South Asian (32%), Arab (26%) and US-born African-American (20%) origin. The US Muslim community is younger than the general American population.<sup>4</sup>

This article will first examine ways in which medical and public health literature address health concerns related to Muslim communities in the UK and the US and, in some cases, link Islam to

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regimens important in the management of other chronic illnesses. For some vulnerable adults, ritual fasting may be associated with temporary dehydration, weight loss, irritability and lack of concentration, although the literature provides contradictory findings (eg, benefits such as improved lipid profiles<sup>14</sup>). Although children are not required to fast until puberty, many begin practicing partial fasts from a young age, making this a potentially important area of inquiry. Paediatricians need to be cognizant of these issues and their potential effect on school performance.

Controversy surrounds the link between high rates of consanguineous marriage, especially among Pakistani immigrant Muslims, and congenital disorders. Although 75% of Pakistani Muslims in the UK marry close relatives, some researchers question the role of consanguinity in adverse birth outcomes, emphasising confounding factors such as economic deprivation and lack of access to health care services.<sup>15 16</sup>

Similarly, the debate about female genital cutting (FGC) is highly politicised, often precluding objective research or nuanced cultural understanding. Few health professionals are familiar with the health issues following these procedures.<sup>17 18</sup> Physicians are prohibited from performing female circumcision in the UK and the US,<sup>19 20</sup> and the practice is rare and discouraged by Islamic leaders in most Muslim countries.<sup>21 22</sup> Nevertheless, it persists among a few African refugee populations.<sup>23</sup> Girls with FGC may be at risk for urinary tract and gynaecological disorders, and may experience social, sexual and psychological consequences. Paediatricians must exercise particular clinical sensitivity in treatment. Further expertise is often needed in caring for these patients when they are giving birth.<sup>24</sup>

Muslims now constitute established minority ethnic groups in Western societies. Economic and social disenfranchisement may compound the burden of chronic disease that Muslim immigrants present on arrival in the US or the UK. Over time, the epidemiological focus has shifted from infectious disease control to chronic disease management, although much of the literature focuses on adults, paying minimal attention to youth illnesses such as asthma.<sup>25</sup> This shift can be traced, in part, to Muslim acculturation to the diet and activity-level patterns of the majority population.<sup>26</sup> Here, immigrant Muslims resemble other immigrant groups suffering the long-term consequences of infectious disease such as liver cirrhosis and liver cancer caused by hepatitis B, gastric ulcer caused by *Helicobacter pylori* and cervical cancer caused by human papillomavirus (HPV).

## ISLAM AND HEALTH PROMOTION PRACTICES

Islamic faith encourages healthy lifestyles, and the family plays a central role in health behaviours. Muslim communities may also share meanings and cultural world views associated with illness and healing.

### Encouraging healthy lifestyles

Muslims frequently differentiate between Islam and “Western religion”, characterising the former as a “comprehensive way of life”. Child-related health benefits of Islamic moral, ethical and ritual practice include Qur’anic prescriptions to breastfeed infants for up to 30 months, promotion of personal hygiene, avoidance of intoxicating substances and extramarital sexual contact, and moderation in both eating and parental discipline of children. Children in Islamic jurisprudence have clear rights to a stable family environment, basic education, freedom from violence or hard labour, preparation for marriage and medical treatment when ill.<sup>27 28</sup>

### Meanings of illness and healing

The physical body has rights, and Muslims are encouraged to seek medical treatment. Illness and health have a spiritual or

“heart” dimension, and illness may be construed as a divine test or an opportunity to purify the soul. Correspondingly, the connection of body and soul places the welfare of the whole person at stake in illness episodes,<sup>29</sup> although pre-pubertal children are not considered accountable for sins: those who die are believed to enter Paradise.

Historically, Muslim physicians played a significant role in preserving, adapting and transmitting Greco-Arabic medicine to Western Europe. Even now, humoral theories emphasising balances of hot-cold and dry-moist oppositions in diet, activity and emotional states coexist with biomedicine. This coexistence becomes relevant when explaining dietary and physical activity changes to parents and children, as when treating diabetes.<sup>30</sup>

Expressing emotional distress in somatic terms is common in Muslim societies from North Africa through South Asia.<sup>31</sup> Mental illness is often highly stigmatised, and Muslims may prefer private coping and religious strategies (eg, prayer) for managing depression and symptoms of schizophrenia.<sup>32</sup> Such messages are conveyed both directly and indirectly to children. Formulating therapeutic interventions in relation to somatic complaints may therefore make it easier for families to discuss problems and accept care.

### The centrality of family

Authors likewise contrast the importance of the extended family in Muslim societies with the more individually-centred model that often structures clinical practice. Parents and the extended family may be involved in medical decision-making, speaking on behalf of even older youth. Parents also play an important role in modelling positive health behaviours, which can help decrease Muslim adolescent risk behaviours.<sup>33</sup> The possibility of dishonouring one’s family by deviating from sexual norms or gender roles carries great psychological weight. Openly homosexual or sexually active, unmarried Muslim youth and young adults may risk alienating family and community.<sup>16</sup> In some communities, it is acceptable for older adolescents to marry and parent children, with related implications for public health programs for pregnancy prevention.<sup>34</sup> In the UK, young Muslim adults are more likely to be married, and household size is generally larger than those of other religious groups.<sup>3</sup>

### Cultural dimensions of health care for Muslims

Most observant Muslims abide by ritual requirements, along with ethical and legal obligations to self, family and community, as part of healing, childbearing and childrearing. Examples include sensitivities about sexual conduct, the significance of purity and hygiene for the normal performance of daily prayer, and periodic rituals (after the age of “maturity”).<sup>27 28</sup> Health professionals may need to have some familiarity with birth customs,<sup>35</sup> male circumcision,<sup>36</sup> and Islamic ethical positions on pregnancy termination, prenatal screening,<sup>28</sup> disability,<sup>37</sup> end of life care and organ donation.<sup>38–40</sup> Their elaboration lies beyond the scope of this paper.

Segregation of space and activities by gender to prevent potential illicit contact between the sexes leads many Muslim post-pubertal adolescents to prefer same-sex providers, especially for genital examination. Prohibitions against ingesting alcohol and pork products may inhibit acceptance of some medications, although many Islamic authorities indicate that medical “necessity overrides prohibition” in emergency cases. One should therefore consult with parents and/or the patient regarding their preferences.

The branch of medical literature focused on “culturally competent care” has both strengths and limitations. Overly simplified summaries of Islam risk reinforcing stereotypes and prejudices. At its best, however, this literature provides necessary contextual frameworks for understanding Muslim

patients<sup>7</sup> and their views, needs and concerns. It can help the paediatrician recognise that being “Muslim” provides a person with an identity that informs motivations and decisions regarding medical issues. One can formulate a tentative hypothesis while never assuming that a particular patient is like all other patients.

## MARGINALISATION AND HEALTH DISPARITIES

Health disparities among racial and ethnic groups are influenced by the structural (socially or state-sanctioned), institutional and interpersonal aspects of a society and its health care systems.<sup>41–46</sup> A 1997 Runnymede Trust report introduced the term “Islamophobia” to refer to forms of prejudice, exclusion and violence toward Muslims that have risen to new levels over the past 20 years.<sup>47–49</sup> We suggest that “Islamophobia” in the UK and the US contributes to health disparities – “differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist”<sup>50</sup> – among Muslim minorities. Despite obvious differences in the organisation, administration, funding and availability of health care in the UK National Health Service (NHS) and the US healthcare system, we argue that comparable societal forces of marginalisation and “faith-blind” or “religion-blind” health policies challenge the health of Muslim families and their access to culturally appropriate care.

Minority religious identity is rarely separated out analytically in health disparities research. The concepts of “intersectionality” and “differential racialisation”<sup>51 52</sup> – terms developed in the study of racial discrimination – may therefore be useful in understanding how Islamophobia can play a part in health disparities.

“Intersectionality” refers to cases in which individuals or groups experience prejudice toward multiple attributes of their identity. For example, Muslims in the UK and the US are differentiated by race (eg, black, white, Asian) and ethnicity (eg, South Asian, Arab, West African), national origin, social class and immigration status, any of which can result in being the target of social bias. At the same time, they may also experience “Islamophobia”, which both coexists with, and sometimes overrides, these other differences while not eliminating them.

“Differential racialisation” means that each minority or targeted group becomes defined in relation to a given majority group, often in terms of being “more” or “less” similar. These definitions arise out of the needs of the majority group, and may be given legal expression.<sup>51</sup> Because Muslims are often represented as coming from non-white groups, their religious identity becomes directly or indirectly linked with racial identity. Muslims are thereby negatively “racialised” in the current political climate in ways that members of other religious groups usually are not. According to US, UK and EU studies, the events of 9/11 and 7/7 did not create negative attitudes toward Muslims, but, rather, these events increased the potency and open expression of pre-existing biased attitudes.<sup>49 53 54</sup>

The public focus on “fundamentalism” and “fanaticism” can reinforce racist attitudes toward Muslim ethnic communities,<sup>37</sup> and NGO and government statistics document the overt rise in reported hate crimes against Muslims.<sup>55–57</sup> Sheridan concludes that religion may supersede race or ethnicity as a determinant of discrimination.<sup>49</sup> While it can be difficult to distinguish racial from religious discrimination, evidence suggests that religion-based bias figures strongly in violence and property crimes, as well as in school bullying.<sup>49</sup> Schools often marginalise Muslim students by omitting, or providing biased misinformation about, Muslim history and contributions to knowledge, and by instituting discriminatory policies (eg, denying Muslim girls

the right to wear a headscarf).<sup>58 59</sup> According to the UK Home Office report on religious discrimination, Muslim organisations registered higher levels of unfair treatment than other religious groups, both in proportion of and frequency of incidents. Problem areas identified included attitudes and behaviour of health care staff, along with institutional policies.<sup>54</sup>

## THE NATURE OF RELIGIOUS DISCRIMINATION

Religious discrimination is difficult to address in health care settings due to the expectation that state-regulated or state-funded institutions are secular, the assumption among health professionals of a strict separation of church and state, and the frequent relegation of religion to the private sphere. Moreover, institutions and policies often take the Protestant or Catholic model for “religious or spiritual needs” to be normative. In Western cultures, for example, religious identity is routinely assumed to be a voluntary and partial identity, rather than the comprehensive world view it is for many Muslims. Viewing “culture” as the more encompassing and significant category also makes it difficult to see “Muslims” as a group, with specific health needs and vulnerabilities. The Race Relations (Amendment) Act of 2000 in the UK, and subsequent human rights legislation guiding the work of the Commission on Racial Equality, protect Sikhs and Jews as “ethnic” minorities, while Muslims, as religious minorities, are unprotected from discrimination in public services.<sup>60</sup> Ironically, the very term “Muslim” is ambiguous in health literature and is often merged with ethnic or racial group identity rather than used to refer to people distinguished by beliefs, practices or affiliations.

Weller and colleagues<sup>48</sup> identify six levels of religious discrimination, each with relevance for health care provision as follows:

- (1) Religious prejudice is an individually held attitude that may result in exclusionary or discriminatory behaviour.
- (2) Religious hatred is a more entrenched attitude that may be used to justify actual violence on ideological grounds.
- (3) Direct religious discrimination involves deliberate unfair treatment and exclusion.
- (4) Indirect religious discrimination results from individuals or groups not taking into account how their routine practices fail to reflect changes in the social and religious fabric of a community.
- (5) Religious disadvantage occurs when only some religious groups have privileged arrangements with state or institutional power and policy, and others do not.
- (6) Institutional “religionism” involves combinations of the other five dimensions. Religious discrimination in health-care operates on all these levels, affecting access and quality of care for Muslim patients.

## HEALTH EFFECTS OF MARGINALISATION

Perceived threats of “the enemy within” contribute to the marginalisation of Muslims by the surrounding society, with consequences for access to care.<sup>61</sup> For example, qualitative studies on the experience of South Asian patients in British health care facilities explore reasons for consistent patient dissatisfaction. Beyond the lack of provisions for religious dietary needs, prayer facilities, inadequate language services and visiting hours, patients routinely struggle to “fit in” to what they perceive to be “an English space”<sup>62</sup> that does not include them.

Ethnic minorities are sometimes viewed as not accessing particular health services because of religiously based explanations for illness or disability – an explanation that attributes the

cause entirely to the family. However, Bywaters and colleagues demonstrate that “institutional and structural racism” also lies behind parents’ poor economic status and lack of access to appropriate services for their children, compounded by the fear of being misunderstood by “out-group professionals”.<sup>37–63</sup> For instance, clinicians who encounter girls who wear headscarves, ask for a same-gender provider or consult with a male relative in making decisions, often incorrectly interpret the girl as oppressed, abused, or “traditional” (understood negatively) in her understanding of sexuality, gender roles and morality. The tendency to pathologise the patient for what is an otherwise understandable response to a social stressor has parallels in failures to understand the behavioural effects in response to racism experienced on a daily basis. As with racism, clinicians need to know that religious discrimination exists, in order to recognise its effects.

The routine experience of overt and indirect prejudice has health effects. Workplace discrimination and “chronic daily hassles”, including insults, can increase risk of common mental disorders.<sup>64</sup> Parental stress may therefore exacerbate the effects of similar experiences Muslim children face in the school setting, such as the increased verbal and physical harassment post-9/11.<sup>65</sup> Arab Muslims in the US experience higher degrees of acculturation stress and related symptoms than do Arab Christians,<sup>66</sup> while post-9/11 abuse correlates with depressive<sup>69</sup> and anxiety symptoms<sup>67</sup> among Muslims. Because published studies focus on adults, the impact of religious discrimination on Muslim youth health has not been adequately explored. The literature on racism and its health consequences may provide a guide.<sup>68</sup>

## CONFRONTING ISLAMOPHOBIA IN THE MEDICAL SETTING

National laws in different European countries now require culturally appropriate and sensitive care for patients.<sup>38</sup> Similar regulations pertain in the US.<sup>69</sup> Many medical and nursing schools and health care facilities in the UK and the US have instituted programs in cultural competence or transcultural health care. Nevertheless, ignorance and indifference persist among health providers, faculty and trainees,<sup>70</sup> and are reflected in the paucity of health literature and research studies involving Muslim youth.

The Muslim Council of Britain and the Council on American-Islamic Relations have produced particularly thoughtful guides to culturally competent care for Muslim patients.<sup>6–7</sup> In practice, one might also ask some of the following kinds of questions about paediatric patient preferences:

- Do you want to be seen in the same room with your siblings/parents?
- Are you fasting today? (If during the month of Ramadan, which is now marked on many European and American calendars). If so, do you wish to defer your vaccines until after your fast?
- Do you have any concerns about the medications we’re discussing?
- Do you want to undress completely, or would you prefer to just lift up your skirt/shirt? (Either way, the patient should be given gowns and covers to ensure that he or she can conceal the body as much as desired).
- How can I help you to be most comfortable during this procedure?

Anything one can do to protect the patient’s modesty – whether male or female – is likely to be appreciated as in, for example, lifting robes or covers as little as one can while performing the examination. Parents will usually be present,

and providers seeing an opposite-sex patient should have a relative or aide of the patient’s sex in the room.

Even simple adjustments may overcome barriers. The use of new hospital gowns that more effectively guard patient modesty have shown significant results.<sup>71</sup> Gatrads’ successful effort to reduce non-attendance rates combined education about religious practices, outreach to religious communities, and practical adjustments for multiple cultural, social and linguistic barriers.<sup>72</sup> Eliminating discrimination and increasing the employment and education of Muslim health care providers and community outreach workers may be one of the most effective ways to reduce health care disparities for Muslims.

Cultural competency literature tends to provide “laundry lists” of cultural traits and practices of particular groups, thereby reinforcing stereotypes. A more helpful alternative is to transform the culture of care provision, so that cultural, religious and individual diversity is genuinely accepted, encouraged and accommodated.<sup>73</sup> The philosophy of “holism” in nursing certainly holds promise in this regard. However, even here, challenges persist. For example, a study of nursing care for hospitalised Pakistani Muslim patients in West Yorkshire indicates that many nurses trained in “holistic care” had difficulty seeing any connection between culture, spirituality and care in relation to Islam. Although thinking of themselves as supporting patient “spirituality”, they had little specific knowledge of Muslim religious life, and thus had difficulty in conceptualising spirituality outside the Western cultural norms of the institution.<sup>74</sup>

The present review is not exhaustive of the literature on health care for Muslim patients. We have outlined major emphases, noted the lack of empirical research directly related to Muslim youth, and suggested a framework for understanding disparities in the burden of disease and access to appropriate services for Muslim paediatric patients. Despite substantive structural differences in the health care systems of the UK and the US, social structural and political forces may play a similar role in the health of Muslim children in both countries.

## CONCLUSION

The transformation of health care culture is an important goal, not only for Muslim patients but for patients of all religious backgrounds. However, as a key case study, health care research needs to focus attention on the specific experiences and health outcomes of Muslim youth, particularly in the current political and social context. Health narratives and the lived experiences of marginalised Muslims must inform culturally appropriate services. Addressing religious discrimination involves action not only in the health sector but also in other sectors of society, including the media, welfare services and legislative reform.<sup>52</sup> Paul Stubbs distinguishes between “ethnic sensitivity” and “anti-racist” approaches to issues of health disparity.<sup>75</sup> Perhaps what is needed is a principled and collaborative “anti-religionism” in the UK and US health systems.

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