Improving quality of life for Muslim patients requiring a stoma: A critical review of theological and psychosocial issues

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Abstract

Aim: The impact of a stoma on the health related quality of life (HRQoL) in patients is irrespective of faith. Muslim patients report lower quality of life and spiritual well-being following stoma surgery as compared to others. This critical review aims to improve awareness of Islamic practices and HRQoL outcomes in this cohort of patients amongst healthcare professionals.

Method: An extensive non-systematic search of EMBASE, MEDLINE and Google Scholar was performed for original research articles pertaining to health related quality of life (HRQoL), stoma care and impact on religious practice in Muslim patients. A narrative synthesis of extracted data was performed and presented using basic thematic analysis.

Results: The findings from the 10 original articles, including 954 participants, were identified. Perceptions of cleanliness emerged as a concern to Muslim patients with stomas as it is core to the performance of prayer. Muslim patients with stomas are known to avoid or reduce participation in prayers due to perceived inferior hygiene and fear of leakage. The consensus opinion from Islamic scholars is that they can pray normally, attend mosque and perform the Hajj pilgrimage. Stoma patients may fast in the holy month of Ramadan provided it is medically safe. Evidence suggests religion-specific counselling can reduce the detrimental effect on HRQoL of Muslim patients following stoma-forming surgery and increases engagement in social aspects of life.

Conclusions: It is important for patients, family members and healthcare professionals to understand the practical and religious implications of stomas on these patients for appropriate guidance and counselling.

KEYWORDS
Islam, Muslim, ostomy, quality of life, stoma, surgery

1 | INTRODUCTION

Considering the implications of a medical intervention on an individual’s religion is one of the key components of good medical...
practice.1 Religion and spirituality play important roles in an individuals’ well-being, coping, acceptance of treatment, and post-treatment lifestyle.2,3

With 1.2 billion followers, Islam is the second most widely practiced religion worldwide. The impact of stomas on health related quality of life (HRQoL) in patients is irrespective of faith. However, they may be more problematic for patients of the Islamic faith, given their relatively lower socio-economic background in Western societies, combined with religious obligations to maintain strict hygiene standards for prayers.4

Muslim patients report a significantly lower quality of life and spiritual well-being following stoma surgery as compared to non-Muslims.5,6 This incorporates psychological factors, social isolation, underreporting of complications, sexual dysfunction (leading to breakdown of marital relations) and either have limited or no ability to perform religious practices.6 Awareness of Islamic practices amongst healthcare professionals involved in stoma-forming surgery is limited. This may hinder a fully-informed discussion prior to surgery.7

Healthcare professionals receive little or no training about the complex association between culture, religion, health, and healthcare delivery, including the impact of a stoma on Muslims.6 There is a gap in knowledge of healthcare professionals regarding Islamic religious practices that can be affected by stomas.7 There is also a lack of appropriate understanding by Muslim patients about religious rulings regarding a stoma.8

This article presents a contemporary critical review regarding clinical, religious and patient factors that should be appreciated prior to and following stoma surgery for Muslim patients. To understand the impact of a stoma in the socio-personal life and religious practice of Muslim patients, a brief discussion regarding the foundations of Islam is also provided.

2 | METHODS

An extensive literature search was performed of MEDLINE, PubMed, EMBASE and Google Scholar databases for relevant manuscripts using the terms: (“Muslim” OR “Islam”) AND (“stoma” OR “ostomy”) AND “quality of life” AND “outcomes.” The search was performed from database inception to 1 July 2019. Original research and review were included. Case reports, case series ≤10 patients, abstracts and non-peer reviewed articles were excluded.

Data was extracted regarding study author, study design, study reference, publication year, patient population, validated assessment tool utilized, primary outcome, secondary outcomes (if listed), health related quality of life (HRQoL) outcomes, statistical analysis (univariate, multivariate, P-value), by two independent authors (AB, MJC).

A narrative synthesis of extracted data was performed and presented using basic thematic analysis. In addition to the primary search, a further electronic search pertaining to Islamic scholars’ attitudes and rulings regarding the Muslim religion and stomas was performed to provide context for the readers of this review.

3 | RESULTS

The findings from the 10 original articles, including 954 participants, identified in our extensive search of the literature are summarized in Table 1. The majority of these studies utilized validated questionnaires to assess HRQoL and spiritual well-being of patients who underwent the formation of a stoma. A broad spectrum of stomas underwent appraisal including colostomy, ileostomy and urostomy.

We have presented these findings using the following three themes: (a) impact on quality life, (b) impact on Islamic prayer and religious practice, and (c) impact of pre- and post-operative religious counselling.

3.1 | Foundations of Islam

To understand the impact of a stoma on Muslim patients, an appreciation of the foundations of Islam is required. Briefly, there are five pillars of Islam fundamental to the faith and are essentially required to be observed by all capable and practising Muslims (Table 2).

1. Declaration of faith (Shahada)
2. Obligatory prayers for five times a day
3. Fasting in the month of Ramadan
4. Compulsory alms-giving (Zakat)
5. Pilgrimage to Mecca (Hajj)

During prayers, the devotee must be in a state of ritual purity entered into through physical ablution (Wudhu). This state must be maintained throughout the duration of each prayer (5–10 minutes). Bodily functions including voiding urine, passing flatus or faeces all necessitate re-ablution. Bodily fluids including urine and faeces are considered as impurities if they come into contact with the body surface or clothing.

The very nature of a stoma leads to either the continuous or uncontrolled expulsion of urine, faeces or flatus hence the fear of invalidation of a Muslim’s ritual purity and, as a consequence, their acts of prayer.8

3.2 | Impact on quality of life outcomes

With regard to HRQoL, Holzer and colleagues’ evaluated the influence of geography and education on HRQoL in patients with colorectal cancer with a permanent colostomy.10 This large prospective multi-centre study was based from 13 institutions in 11 countries where patients were evaluated for changes in HRQoL following surgery using a modified American Society of Colon and Rectal Surgery Faecal Incontinence Questionnaire (ASCRS).10 Their study identified a persistently negative impact of a colostomy in patients practising Islam compared to other religions.

Mahjoubi et al12 investigated 155 Muslims with stomes to assess the prevalence of underlying nonpsychotic psychiatric

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| No | Author | Year | Study design | Study size (n) | Study population (n) | Validate assessment tool | Primary outcomes | Secondary outcomes |
|----|--------|------|--------------|---------------|----------------------|-------------------------|------------------|--------------------|
| 1  | Ayik and Cenan⁹ | 2019 | P | 95 | Colostomy (n = 95) | Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) | Adjustment to a stoma and spiritual well-being are the most significant factors affecting HRQoL | The most significant factors affecting quality of life were adjustment to a stoma and spiritual well-being |
| 2  | Holzer et al¹⁰ | 2005 | P | 29 | Colostomy (n = 29) | Modified American Society of Colon and Rectal Surgery Faecal Incontinence Questionnaire (ASCRS) | Persistently low QoL in Muslim patients with a stoma | Age, gender, and educational status did not reveal a statistically significant influence QoL |
| 3  | Miah et al⁸ | 2017 | P | 134 | Urostomy (n = 134) | Non-validated questionnaire | 90% Imams believe it is possible for a Muslim to perform ablution, pray, and enter a mosque with a urinary stoma | 86.6% of Imams stated that refusal of a urinary stoma was not justified by religious teachings |
| 4  | Akgul and Karadag¹¹ | 2016 | R | 105 | Colostomy (n = 61) Ileostomy (n = 89) | Non-validated questionnaire | Participants reported decreasing the frequency of daily and Friday prayers (25.2% colostomy; 22.7% ileostomy) or stopped practicing activities all together (12.0% colostomy; 14.0% ileostomy) | Increased frequency of acts of absolution while reduced acts of fasting occurred. Perceptions of cleanliness, central to performance of salat within the Islamic faith, emerged as a central concern |
| 5  | Cavdar et al³ | 2013 | P | 66 | Colostomy (n = 66) | Non-validated questionnaire | 87.9% of the patients (n = 58) fasted regularly before stoma creation, which decreased to 43.9% (n = 29) after stoma creation | 74.2% of the patients (n = 49) prayed regularly before stoma creation, which decreased to 53% (n = 35) after stoma creation |
| 6  | Mahjoubi et al¹² | 2009 | P | 155 | Colostomy (n = 117) Ileostomy (n = 10) Other (n = 17) | General Health Questionnaire-28 (GHQ-28) | Frequency of psychiatric disorders observed were related to mucosal haemorrhage of the ostomy (P = .03), stomal stenosis (P = .012) | Females’ mean GHQ score was significantly higher than that of males (P = .001) |
| 7  | Celasin et al¹³ | 2011 | P | 93 | Permanent colostomy (n = 50) Sphincter-preserving surgery (n = 43) | Medical Outcomes Study Short Form 36 Health Survey (SF-36) | Post-operative QoL and religious practices of stoma patients were improved who had pre-operative religion specific counselling | Embarrassment scale was worse in permanent colostomy than sphincter preserving cohort (P < .001). Religious worship (praying alone, praying in mosques, fasting during Ramadan and purifying alms) was not significantly different amongst the two groups |

(Continues)
| No | Author          | Year | Study design | Study size (n) | Study population (n) | Validate assessment tool                        | Primary outcomes                                                                 | Secondary outcomes                                                                 |
|----|-----------------|------|--------------|----------------|----------------------|-------------------------------------------------|-----------------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| 8  | Karadag et al¹⁴ | 2003 | R            | 43             | Colostomy (n = 31)   | Digestive Disease QoL Questionnaire 15 (DDQ-15) | HRQoL was significantly better 3 months after dedicated stoma counselling, also improved social engagement | Cumulatively all of the items improved significantly after stoma-therapy, such as getting dressed, bathing, and participating in sports |
| 9  | Kuzu et al¹⁵    | 2002 | R            | 178            | Permanent colostomy (n = 75) Sphincter-preserving surgery (n = 103) | Short Form(SF) - 36 | Scores for all eight subscales of the SF-36 in the abdominoperineal resection group were significantly poorer than those in the sphincter-saving resection and colostomy groups (P < .001) | Social life and work responsibilities were significantly more affected in the colostomy group (P < .001). A significantly greater number of colostomy patients stopped praying daily and fasting during Ramadan (P < .001) |
| 10 | Altuntas et al²⁰| 2013 | P            | 56             | Colostomy (n = 56) | Quality of Life Questionnaire - Cancer 30 (QLQ-C30) (Version 3.0) and QLQ-CR29 | Ramadan fasting had almost no influence on quality of life. Fasting lowered pre-albumin levels (27.6 ± 7.4 vs 21.2 ± 4.4; P = .046) Fasting did not adversely affect other nutritional or global health status variables | 92.9% (n = 13 of patients in the fasting group stated they would feel sad if they were not fasting |

Abbreviations: P, prospective; R, retrospective; HRQoL, health related quality of life.

*Study population are Imams.*
TABLE 2 Summary of the five pillars of Islam

| Pillar                  | Description                                                                 |
|------------------------|-----------------------------------------------------------------------------|
| Faith (Shahada)        | To declare and believe in one God and to accept Prophet Muhammad as the Messenger of God. |
| Prayer                 | Obligatory prayers for five times a day. This also includes Friday early afternoon prayer (Jummah), which needs to be in congregation. |
| Fasting                | Ritual fasting during the Islamic month of Ramadan where physically capable Muslims are required to abstain from food, drink and sexual activity from dawn to dusk. |
| Alms-giving (Zakat)    | This is applicable for a Muslim who possess a certain threshold of wealth for a year. |
| Pilgrimage to Mecca (Hajj) | Every able-bodied Muslim is obliged to make the religious pilgrimage to the Mecca once in their lifetime. |

conditions using a validated instrument (General Health Questionnaire–28 (GHQ)). Their study demonstrated 55.5% of patients (n = 86) were deemed to harbour a psychiatric disorder in comparison to the 10.8% to 16.7% in a similar control population group. In females, the mean GHQ score was significantly higher than that of males (P = .001). Psychiatric disorders were also significantly more prevalent amongst patients with lower educational levels (high school vs tertiary level (P = .001)).

Kuzu et al performed a retrospective cross-sectional cohort study that measured impact on social life and work responsibilities between 178 Muslim patients who either underwent abdominoperineal resection or continent preserving bowel resections for primary rectal carcinoma. Social life and commitment to work responsibilities was also shown to be significantly affected in a negative manner for the sphincter-sacrificing cohort. The authors’ concluded that these issues were likely to be key drivers of psychological morbidity in this faith group.

The group concluded that to improve quality of life in this group of patients, religious issues of a stoma should be discussed during pre-operative counselling, the informed consent process and engagement and counselling with local religious authorities.

3.3 Impact on Islamic prayer and religious practice

Muslim patients with a stoma are significantly more likely to have stopped performing daily prayers (either alone or in a mosque) and fasting during Ramadan. It has been proposed that cessation of these religious practices were likely to be key drivers of psychological morbidity in this faith group.

Akgul and Karadag reported a reduction in the frequency of daily and Jummah prayers (25.2% and 22.7%, respectively) with complete cessation of these prayers in (12.0% and 14.0% respectively) in Muslims who have a stoma. Respondents tended to increase the frequency of ablution while reducing acts of fasting. Perceptions of cleanliness is core to the performance of prayer within the Islamic faith. This, therefore, emerged as a central concern amongst the respondents of this study.

Muslim patients with stomas avoid or reduce their participation in congregational prayers due to a fear of perceived inferior hygiene and fear of leakage. Congregational prayers are of particular importance to Muslims as these are rewarded by a factor of 27 in comparison to performing them individually. Cavdar et al reported fasting and daily prayer were significantly reduced in the majority of Muslims with a stoma in comparison to their pre-stoma Islamic practices. Their study discovered that 87.9% and 74.2% of Muslim patients regularly prayed and fasted prior to their stoma formation. This decreased to 53% and 43.9% following stoma formation. A “feeling of uncleanness” was cited by 71% as the main reason for reducing prayer frequency, while 79% of non-fasters described “fear of causing damage to the stoma” as the main reason for not participating in Ramadan fasting.

Spiritual well-being comprises feelings of hope, inner peace, and meaning in life whereas religious well-being involves a feeling of comfort derived from a connection with a divine and eternal higher power. A recent study by Ayik and Cenan has demonstrated a detrimental decrease in spiritual well-being of Muslim patients who underwent the formation of a colostomy or ileostomy. This was measured using the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) where multivariate analysis found spiritual well-being and adjustment to a stoma were significantly related to quality of life.

Kuzu et al performed a retrospective cross-sectional cohort study measuring the impact of Islamic religious worship in terms of prayer and fasting during Ramadan in 178 Muslim patients. The study cohort either underwent curative abdominoperineal resection (n = 75) or continent preserving bowel resections for rectal carcinoma (n = 103). Using the SF-36 survey and a questionnaire, their group demonstrated that Muslims who had undergone sphincter-sacrificing surgery and stoma formation scored a significantly lower score in all eight subscales of the SF-36 in comparison to those who underwent a continence preserving bowel resection. There was a significant number (P < .001) of Muslim patients who stopped praying and performing Ramadan fasts altogether in the sphincter-sacrificing cohort.

3.4 Impact of pre- and post-operative religious counselling

Celasin et al prospectively studied 93 Muslim patients who underwent creation of either a permanent stoma or sphincter-sparing surgery for treatment of their colorectal cancer with the use of various validated health related quality of life questionnaires pre- and post-surgery (Medical Outcomes Study Short Form 36 Health Survey (SF-36)). Participants of this study received ostomy specific education from a stoma therapist familiar with Islamic practices and rulings and religious counselling from an Imam (Islamic spiritual leader) prior to surgery. Health related quality of life did not differ between those
who had a permanent stoma or sphincter-sparing surgery. Religious worship, including praying alone, praying in mosques and fasting during Ramadan, was not significantly different between the groups.

Their study concluded that religion-specific counselling can ameliorate the detrimental HRQoL Muslim patient may have otherwise suffered.

Karadag et al investigated 43 Turkish Muslim patients who previously underwent the formation of colostomy or ileostomy which were all deemed surgically to be well-functioning. This group underwent specialized and dedicated stoma-therapy counselling including the religious and spiritual aspects. The digestive disease QoL questionnaire (DDQ-15) was used to analyse HRQoL. The mean HRQoL score was shown to be significantly higher 3 months after their dedicated stoma counselling. In addition, the patients demonstrated an increased participation in daily and recreational activities following this specialized counselling.

Clinical reassurance can be provided for those with a stoma deemed medically capable of fasting but fear performing this religious act during Ramadan will harm their stoma. Altuntas et al have prospectively demonstrated that there was no decrease in HRQoL between those with an established colostomy (secondary to malignancy) who participated in fasting (15-16 hours) and those who did not. Their study demonstrated that there was no significant deterioration in nutritional and metabolic biochemical parameters (albumin, pre-albumin, BUN, urea, creatinine and cholesterol) or global health status (measured with European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Cancer-30 (QLQ-C30), and Quality of Life Questionnaire-Colorectal Cancer-29 (QLQ-CR29)) variable differences between those colostomy patients who fasted and those who did not.

The principal findings of this review are Muslim patients who undergo stoma formation are likely to have a poorer post-operative HRQoL compared to other patients of other faith. In addition, stoma formation may negatively impact on Islamic prayer and religious practice. Further, pre-operative counselling with a stoma therapist and an awareness of Imams views of stomas may help improve post-operative HRQoL and assist in maintaining religious practice (Figure 1).

4.1 Medical guidance for healthcare professionals

Physical morbidities and psychosocial effects of stoma impacts HRQoL in patients irrespective of faith base. It has been shown that these can be more problematic for patients of the Islamic faith. Muslims with an ostomy, and especially elderly, socially deprived or persons with lower educational levels, may require a more focused follow-up to assess general well-being and coping after stoma surgery. Therefore, health status and coping after stoma formation should be followed in a tailored manner for this cohort of patients.

It is important for surgeons, family physicians and stoma nurse specialists to understand and recognize religion specific concerns that they may encounter with Muslim patients requiring an ostomy. These educational issues could also be potentially highlighted and addressed at an undergraduate level. Studies have shown that the time and effort dedicated to prepare the patients for the surgery were very useful, particularly in helping them to overcome the pre-existing worries and anxieties.

Muslims living with an ostomy may face personal and religious isolation. This can be within their community and include refusal of entry into places of worship. Findings from this review showed that, inclusion of family members and religious leaders in pre-operative discussions may improve HRQoL. Hence, community education of Muslim patients living with an ostomy, in collaboration with faith institutions, hospital-based spiritual leaders, and medical staff can have significant and sustained benefits following stoma surgery. Discussing life after surgery, coping mechanisms, and ways to maintain religious observance with fellow Muslims with an ostomy may also be helpful.

FIGURE 1 Health professional's summary of impact of stoma, Islamic leaders’ views and clinician advice to patients on stoma formation. HRQoL, health related quality of life
4.2 Religious guidance for healthcare professionals & patients

Scholars of Islamic jurisprudence derive opinions from the Quran and the teachings of the prophet Mohammed to guide Muslims when new situations arise such as a stoma. In Islam a fatwa is a non-binding legal opinion or advisory ruling given by Islamic scholars on questions submitted to them by individuals, courts, non-governmental organizations or governments. Two slightly different fatwas are in existence regarding Muslim patients with stomas. However, crucially the consensus opinion is that they can pray normally, attend mosque and perform the Haj pilgrimage.

Wudhu (ablution before prayer) must be performed before each prayer. If a stoma functions during prayer then a person with a stoma can continue praying as they have no control over this. At the onset of a new prayer the individual is required to perform the ablution again. This Fatwa was released by The International Ostomy Association alongside its regional associations – European Ostomy Association Asia South Pacific Ostomy Association and Ostomy Associations of Americas.

“Fiqh” is an Arabic word linguistically translated to “to know; to understand; full comprehension of subject.” A prominent Fiqh council in the UK have stated that a person who is required to wear a stoma bag and who has impurities which constantly exit from the body such as stool, urine or flatus are regarded as being in the ruling of someone in the UK have stated that a person who is required to wear a stoma bag and who has impurities which constantly exit from the body such as stool, urine or flatus are regarded as being in the ruling of someone in the ruling of someone wearing a cast, bandage or dressing for an injury. Wudhu remains valid for a person wearing a bandage even if the bandage contains blood or exudate within it. Thus, wudhu will remain valid for these patients as long as the contents do not exit the stoma bag. However, when the stoma contents do exit the bag then the wudhu would be invalidated.

It is not prohibited for a person with a stoma bag to enter a mosque or to perform Tawaf (circumambulation of the Kaba during Hajj), on the condition that they are sure that they will not soil the mosque and there is no unpleasant odour which could inconvenience other worshippers.

With regards to fasting in the holy month of Ramadan, stoma patients may fast on the condition that they are not medically advised not to do so. It is important for patients, patients’ family members and healthcare professionals to understand and appreciate the practical and religious implications of stoma care before Islamic guidance can be delivered.

5 Conclusion

A holistic approach is required when counselling Muslim patients who require stoma-forming surgery to improve their post-operative HRQoL and maintain their participation in religious and spiritual aspects of life.

It is important for patients, patients’ family members and healthcare professionals to understand and appreciate the practical and religious implications of stoma care before Islamic guidance can be delivered.

Religious issues should also be addressed with close dialogue and engagement with Islamic-faith leaders via healthcare-based Muslim chaplains or locally approved Islamic religious authorities.

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CONFLICTS OF INTEREST

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