Original Article

Considerations for Redirection of Care in Muslim Neonates: Issues and Recommendations

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ABSTRACT

Objectives: To identify and formulate recommendations regarding challenges faced while considering redirection of care (ROC) for Muslim neonates based on experiences of neonatologists frequently encountering such situation
Design: Cross-sectional survey
Setting: Anonymous web-based questionnaire was distributed between August and September 2015
Subjects: Neonatologists practicing in select countries with predominantly Muslim population (Kuwait, Oman, Saudi-Arabia and Egypt)
Intervention: Anonymous web-based questionnaire
Main outcome measure: Challenges toward ROC
Results: A total of 120 neonatologists were requested for the survey, out of which 98 (82%) responded by completing the survey. A total of 36 (36.7%) respondents were against ROC because of the uncertainty of the prognosis (100%), the uncertainty of the religious edicts (Fatwa)(80%), belief that ROC was against Islamic ideals (50%) and fear of legal repercussions (10%). On the other hand, 63.2% (n = 62) were of the opinion that ROC should be offered to neonates with unfavorable prognosis related to extreme prematurity and it's related complications (61%), severe asphyxia (74%), multiple congenital anomalies (80.5%), and genetic syndromes (92%). Training background was significantly associated with neonatologists who considered ROC after adjusting for possible confounders (odds ratio = 3.1; 95% confidence interval: 1.1 to 8.8; P = 0.03). The major religious barriers identified with respect to ROC were the lack of clarity and fear of breaching Islamic ideals. All respondents felt that ethical codes conforming to Islamic and legal standards were urgently required.
Conclusion: ROC consideration for Muslim neonates has many socio-cultural and religious barriers. Comprehensive ethical codes conforming to Islamic and legal standards are required to aid decision-making.

KEYWORDS: Islam, neonatology, social and ethical issues

INTRODUCTION

Advances in perinatal-neonatal medicine in the last few decades have improved the survival of neonates who were previously considered unviable[1,2]. However, the causes for mortality and morbidity have more or less been constant[1,3,4]. Neonatal deaths remain a major contributor to overall pediatric mortality, and they are frequently encountered in neonatal intensive care settings[5]. Neonatal care providers routinely face infants with life-limiting conditions with poor prognosis where they have to make decisions for redirection of care (ROC), *i.e.* either withdrawal or withholding life prolonging treatments[6,7].

Decisions regarding neonatal ROC are overwhelming and irrevocable, often involving significant anxiety and distress for the families and care providers[8]. Recent research has shown that neonatal ROC can have long term psychological implications for the family[9]. These stresses are compounded by cultural and religious differences between the family and care providers. With the increase in international migration and globalization, neonatologists are frequently faced with such issues[10]. Cultural and religious differences in ROC related issues should be respected and addressed in an empathetic manner to avoid potential misunderstandings and grievances[11].

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Islamic theology is centred in Allah's message, revealed by Prophet Muhammad and noted in Quran; it serves as the basis of religious beliefs, attitudes, morals and guidelines for human interaction[12-14]. ROC discussion with Muslim patients therefore necessitates a more considerate approach due to their distinct religious convictions that "Life is an exam and perseverance in face of challenges (including disease and death) would result in salvation (Quran 2:155-57)" and "Any act which leads to human death is a grave sin (Quran 5:32)"[15]. Novel questions posed by medical advances, such as those related to neonatal ROC, require a degree of interpretation and application of Quran by authoritative teachers (Imams). This has led to diverse inferences and continues to be an extremely challenging topic needing awareness and knowledge on the side of neonatal care providers[14].

We sought to assess the challenges faced when considering ROC for Muslim neonates and to formulate recommendations based on the experiences of neonatologists frequently encountering such situations.

SUBJECTS AND METHODS

An anonymous, web-based questionnaire with open-ended questions and descriptive responses was developed covering the following components: demographic variables, knowledge, attitude and practices regarding ROC decision-making, factors impacting ROC decisions and opinions on how ROC decisions should be best approached. ROC was defined as the process of moving from curative to palliative care[16]. Related published studies were also used to identify challenges and recommendations. The investigators individually prepared the questionnaires. The final questionnaire was prepared by incorporating suggestions from all authors. Any differences were debated and all investigators mutually agreed on the final questionnaire. The questionnaire was designed to reach the neonatologists practicing in select countries with a predominantly Muslim population (Kuwait, Oman, Saudi-Arabia and Egypt). These countries are representative of different Islamic sects, hence were carefully selected for generalizable conclusions. The questionnaire was distributed via email between July and September 2015 to the medical directors of neonatal intensive care units in the selected countries. Two email reminders were distributed after the first month of conducting the survey. Informed consent was implied by the submission of a completed survey. Responders were divided into two groups; Group A – those respondents who were against any consideration for ROC, and Group B- those respondents who were open to consider ROC in specific circumstances. The Ministry of Health of Kuwait Clinical Research Ethic Board approved the study.

Analysis was done by Stata 14 statistical software (StataCorp. 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP). Descriptive statistics (number and percent) were reported for demographic characteristics and survey responses. Fisher's exact test was used for statistical differences between responses. Logistic regression models were used to assess the variables influencing physician's attitudes. Odds ratios (OR) with 95% confidence intervals (CI) were calculated and p-value of less than 0.05 was considered statistically significant.

RESULTS

A total of 120 neonatologists were invited, out of whom 98 (82%) responded by completing the survey. Of the total 98, 33 (33.7%) respondents were from Oman, 24 (24.5%) from Egypt, 23 (23.5%) from Saudi-Arabia and 18 (18.4%) from Kuwait. Sixty of the respondents (61.2%) were male and 38 (38.8%) were female. A majority of the respondents (n = 56, 57%) were between 35 - 44 years old. Sixty-four of the respondents (65.3%) received their neonatal training in Middle East Asia and the remaining 34 (34.7%) respondents were trained in North America.

On views regarding neonatal ROC, 36 (36.7%) respondents were against any consideration for ROC (Group A) and 62 (63.2%) respondents were open to consider ROC in specific circumstances (Group B). The reasons for opposition to ROC in Group A were related to the uncertainty of prognosis (100%), uncertainty of the religious edicts (Fatwa) (80%), a belief that ROC was against Islamic ideals (50%) and fear of legal repercussions (10%). Respondents in Group B were of the view that allowed ROC for neonates with an unfavourable prognosis related to extreme prematurity and its related complications (61%), severe asphyxia (74%), multiple congenital anomalies (80.5%) and genetic syndromes (92%). The method of choice for ROC was "do not resuscitate", withdrawal of life support and withholding of fluid/ nutrition for 90.5%, 8% and 1.5% of respondents from group B respectively.

Comparative analysis between the two groups showed that North American training was associated significantly with ROC consideration (Group B), 43.5% in group B vs. 20% in group A ($p = 0.013$) (Table 1). On multivariable logistic regression analysis, North American training was significantly associated with neonatologists who considered ROC after adjusting for possible confounders (years of experience and self-rated religious background) (OR = 3.1; 95% CI: 1.1 to 8.8; $p = 0.03$). There were a higher percentage of respondents against ROC from Oman (42.4%) and Saudi Arabia (39.1%) than Egypt (33%) and Kuwait (27.8%), although this trend

Table 1: Baseline characteristics

Characteristics	Disagree with ROC n = 36 (Group A)	Agree with ROC n = 62 (Group B)	p-value
Age (n(%))			0.930
25 - 34	9 (25)	17 (27.4)	
35 - 44	22 (61)	34 (54.8)	
45 - 55	4 (11)	9 (14.5)	
> 55	1 (28)	2 (3.2)	
Gender (n(%))			0.407
Male	21 (58.3)	39 (63)	
Female	15 (41.7)	23 (37)	
Years of experience			0.217
< 5	2 (5.5)	11 (17.7)	
5-10	22 (61)	31 (50)	
> 15	12 (33.5)	20 (32.3)	
Children			0.323
Yes	29 (80)	46 (74)	
No	7 (20)	16 (26)	
Country of residency			0.743
Kuwait	5 (14)	13 (21)	
Oman	14 (39)	19 (30)	
Saudi-Arabia	9 (25)	14 (23)	
Egypt	8 (22)	16 (26)	
Country of neonatal training			0.013
Middle East	29 (80)	35 (56.5)	
North America	7 (20)	27 (43.5)	
Religion is important in medical practice?			0.369
Agree	33 (92)	54 (87)	
Disagree	3 (8)	8 (13)	
Self rated religious background			0.165
Very religious	13 (36)	20 (32)	
Somewhat religious	20 (56)	26 (42)	
Not very religious	1 (2)	3 (5)	
Not religious	2 (6)	13 (21)	
Confidence in leading discussion with families of critically ill infants about their religious or spiritual beliefs?			0.456
Not at all	2 (6)	10 (16)	
Somewhat well	16 (44)	21 (34)	
Reasonably well	14 (39)	23 (37)	
Very well	4 (11)	8 (13)	

was not statistically significant (p = 0.743). Other variables including age, gender, experience, number of children, religious background, and self-reported confidence in ROC-related discussion were not found to be statistically different between the two groups (Table 1).

The majority of respondents from both groups reported themselves to be religious (92% and 74% from groups A and B respectively). Respondents from both groups believed that ROC discussion and decision-making should involve family members and an authoritative teacher (Imam) (95 and 80% in groups A and B respectively). The major barriers identified with respect to ROC discussion and decision making were the lack of clarity and a fear of breeching Islamic ideals. All respondents felt the need for ethical codes conforming with Islamic and legal standards was urgent.

DISCUSSION

We aimed to identify and formulate recommendations regarding the challenges faced by neonatologists while considering ROC for Muslim neonates. As neonatology has developed rapidly during the last few decades, an increasing number of critically ill neonates receive life support treatment[1-4]. This has led to improved survival, however, fairly large numbers of neonates encounter complications impacting short and long term survival and morbidity[1-4]. ROC has assumed an increasingly important application in neonatology for decreasing pain and suffering for neonates and their families with poor prognosis[6,7,17-19]. Redirection and end of life of care requires comprehensive and compassionate support for optimal coping by the family[20]. The belief, attitudes, knowledge and communication skills of neonatal care providers can greatly influence family

experiences and coping, secondary to redirection and end of life of care[20,21]. Redirection and end of life care needs specialized training for neonatal care providers for comprehensive care and for increasing awareness towards potential errors and omission[22]. Our results confirm that training background has an impact on practice and attitude towards neonatal ROC. We found that North American training was associated significantly with ROC consideration on bivariate ((Group B), 43.5% in group B vs. 20% in group A (p = 0.013) (Table 1)) and multivariate logistic regression analysis (OR = 3.1; 95% CI: 1.1 to 8.8; p = 0.03). This could be attributed to differential exposure and training, and hence is indicative that ROC and end of life care should be incorporated in formal training for better care provision and experiences.

People from Muslim background firmly believe in following Allah's directives as noted in Quran[12-15]. Novel questions posed by medical advances such as those related to neonatal ROC require interpretation and application of Quran by authoritative teachers (Imams), this has led to varied inferences and confusion[14]. In our survey, we found that the majority of respondents from both groups reported themselves to be religious (92% and 74% from Group A and B respectively) and a large number of them (36.7%) were against any consideration for ROC. A significant proportion of those who were open to consideration would consider ROC only for specific diseases. The reasons for reservations against ROC were mainly religious (uncertainty of the religious edicts (80%) and the belief that ROC was against Islamic ideals (50%)). This represents a significant challenge regarding ROC consideration. This finding is in agreement with previous research suggesting that religious and cultural background of the patient and the care-providers impacts ROC decision-making[23-28]. As physicians are considered as having authoritative and decision-making role in Islamic culture, the responsibility of physicians to consider and discuss options for treatment is further pronounced[29]. The major barriers identified with respect to ROC discussion and decision making were lack of clarity and fear of breeching Islamic ideals. All respondents felt that ethical codes confirming with Islamic and legal standards for neonatal ROC were urgently required.

There have been recommendations from previous studies suggesting improved family comfort and better emotional outcomes in neonatal ROC when religious clergy and family members were involved in ROC decision making[21,29-31]. Our study reiterates similar findings: respondents from both groups felt that ROC discussion and decision-making involving family members and authoritative teacher (Imam) was better (95 and 80% in group A and B respectively). Additionally, the presence of Imam may help decrease the feeling of guilt accompanying ROC decision for the family as well as neonatal care providers involved in the decision-making.

Research focusing on issues, challenges and considerations for ROC in Muslim neonates is scant. Our questionnaire-based interview of neonatologists serving in middle-east Asia, who frequently face terminally ill Muslim neonates qualifying for ROC, is precisely targeted to address this issue. Our research highlights key recommendations for ROC in Muslim neonates and would prove helpful to neonatal care practitioners around the world when in such a scenario. The results of this study will help in increasing awareness of the neonatal care providers to better understand and manage the specific issues related to ROC for Muslim neonates. This study is based on interviews from neonatologists from four Islamic countries with adequate number of respondents, increasing the applicability and generalizability of the findings.

Limitations

As with any interview based research, there is a possibility of response bias. Although we asked open-ended questions and sought descriptive answers to minimize the bias, impact of response bias cannot be ascertained or ruled out.

CONCLUSION

ROC consideration for Muslim neonates has many socio-cultural and religious barriers. Neonatal care providers should be sensitive to the unique socio-religious context to better manage the specific issues related to ROC for Muslim neonates. Comprehensive ethical codes conforming Islamic and legal standards are urgently required to aid decision-making.

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Authors' contributions

VS, AA and MA conceptualized & planned the study, drafted the manuscript, did the data collection, revised the manuscript and consented to the final manuscript as submitted.

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Future directions: Development and application of neonatal ROC and end of life protocols specific

for Muslim families should be researched in further detail.

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